

(Re)constructing Myself: the
process of transition to
motherhood for women with a
disability

Dr Denise Lawler
Feb' 2013

TABLE OF CONTENTS

GLOSSARY OF TERMS AND ACRONYMS	10
CHAPTER 1 CONTEXT AND BACKGROUND TO THE STUDY.....	12
1.1 INTRODUCTION.....	12
1.2 BACKGROUND AND CONTEXT TO THIS STUDY.....	13
1.3 GENESIS OF THE STUDY.....	14
CHAPTER 2 DISABILITY POLICY IN IRELAND	18
2.1 INTRODUCTION	18
2.2 DEFINING DISABILITY	18
2.3 THE STATUS OF PEOPLE WITH A DISABILITY IN IRISH SOCIETY	19
2.4 MODELS OF DISABILITY	20
2.4.1 <i>Biomedical construction of disability</i>	21
2.4.2 <i>Biopsychosocial construction of disability</i>	24
2.4.3 <i>Alternative constructions of disability</i>	25
2.5 CURRENT DISABILITY POLICY IN IRELAND	27
2.5.1 <i>The World Health Organisation’s classification of disability</i>	27
2.5.1.1 <i>International Classification of Impairment, Disabilities and Handicaps</i>	28
2.5.1.2 <i>International Classification of Functioning, Disability and Health</i>	29
2.5.1.3 <i>The Universal Declaration of Human Rights</i>	30
2.5.2 <i>The development of a National Disability Strategy</i>	31
2.5.2.1 <i>Disability Act (2005)</i>	31
2.5.3 <i>Disability legislation at European and United Nations level</i>	32
2.6 THE INTERSECT BETWEEN DISABILITY AND THE SELF	34
2.7 CONCLUSION	36
CHAPTER 3 THE SELF, IDENTITY AND SYMBOLIC INTERACTIONISM	38
3.1 INTRODUCTION	38
3.2 DEFINING SELF AND IDENTITY	39
3.2.1 <i>Defining identity</i>	39
3.2.1.1 <i>Sameness, uniqueness and the formation of identity</i>	40
3.2.2. <i>Defining self</i>	41
3.2.2.1 <i>Different representations of the self</i>	42
3.3 SYMBOLIC INTERACTIONISM, THE SELF AND IDENTITY	43
3.3.1 <i>The interacting self</i>	44

3.3.1.1	<i>The phases of the interacting self</i>	44
3.3.1.2	<i>The role of symbols in the interacting self</i>	48
3.3.1.3	<i>Role taking and role making abilities of the interacting self</i>	49
3.3.2	<i>The empirical self</i>	50
3.3.2.1	<i>Multiple roles assumed by the self</i>	51
3.3.3	<i>The looking glass self</i>	53
3.3.3.1	<i>The role of emotions in the looking glass self</i>	53
3.3.4	<i>Reflexivity and the construction of the self</i>	54
3.4	STRUCTURAL SYMBOLIC INTERACTIONISM	54
3.5	THE PERFORMATIVE ASPECT OF THE SELF	56
3.5.1	<i>Gender identity and performance</i>	60
3.6	CONCLUSION	63
CHAPTER 4 THEORIES ON TRANSITION TO MOTHERHOOD		64
4.1	INTRODUCTION	64
4.2	DEFINING TRANSITION	64
4.3	DEFINING MOTHERING	65
4.4	DEFINING MOTHERHOOD	66
4.4.1	<i>Ideologies of motherhood</i>	67
4.5	MOTHERHOOD: A LIFE CHANGING EVENT	68
4.5.1	<i>Difficulty in transitioning: crisis and dysphoria</i>	69
4.6	MATERNAL ROLE ATTAINMENT AND ADAPTATION TO MOTHERHOOD	71
4.6.1	<i>Motherhood and maternal role attainment</i>	71
4.6.2	<i>Motherhood and maternal adjustment</i>	73
4.7	DEVELOPING AND CONSTRUCTING MEANING ABOUT MOTHERHOOD	76
4.8	THE SELF, IDENTITY AND TRANSITION TO MOTHERHOOD	78
4.9	MOTHERHOOD AND WOMEN WITH A DISABILITY	86
4.10	CONTEXTUALISING THIS STUDY	87
4.11	CONCLUSION	88
CHAPTER 5 PHILOSOPHICAL AND METHODOLOGICAL UNDERPINNINGS OF THE STUDY		89
5.1	INTRODUCTION	89
5.2	PHILOSOPHICAL POSITIONING – EPISTEMOLOGY AND ONTOLOGY	91
5.2.1	<i>Knowing and the production of knowledge</i>	91
5.2.2	<i>Objectivism and interpretivism</i>	93
5.2.3	<i>Carper’s ways of knowing</i>	94
5.3	THE EMERGENCE OF QUALITATIVE RESEARCH	95

5.4 IDENTIFYING MY EPISTEMOLOGICAL POSITION.....	97
5.4.1 <i>Constructionism</i>	97
5.5 A QUESTION OF BEING – CLARIFYING MY ONTOLOGICAL POSITION.....	100
5.5.1 <i>Relativism</i>	100
5.5.2 <i>Realism</i>	101
5.6 SYMBOLIC INTERACTIONIST AS A THEORETICAL PERSPECTIVE	102
5.6.1 <i>Relating symbolic interactionism to this study</i>	105
5.7 METHODOLOGICAL POSITIONING - CHOOSING AN APPROPRIATE METHODOLOGY	106
5.7.1 <i>The origins of grounded theory</i>	106
5.7.2 <i>Strauss and Corbin’s approach to grounded theory</i>	107
5.8 THEORETICAL SENSITIVITY IN A GROUNDED THEORY STUDY	113
5.9 THEORETICAL SAMPLING IN A GROUNDED THEORY STUDY.....	114
5.10 THE CONSTANT COMPARATIVE METHOD OF ANALYSIS	116
5.11 POSITIONING ONESELF IN THE STUDY	116
5.12 GENDER AND DISABILITY: ISSUES OF CONCERN IN THE CONDUCT OF THE STUDY.....	119
5.13 ACHIEVING QUALITY	120
5.13.1 <i>Fitness</i>	121
5.13.2 <i>Understanding/work</i>	122
5.13.3 <i>Relevance</i>	122
5.13.4 <i>Modifiability</i>	123
5.14 SUMMARY	123
CHAPTER 6 CONDUCTING THE RESEARCH	124
6.1 INTRODUCTION	124
6.2 GENESIS OF THE STUDY	124
6.3 RESEARCH PURPOSE	125
6.4 RESEARCH AIM.....	126
6.5 RESEARCH QUESTIONS GUIDING THIS STUDY	126
6.6 RECRUITMENT OF WOMEN WITH A DISABILITY	127
6.6.1 <i>Challenges encountered when recruiting women with a disability</i>	129
6.6.2 <i>Sampling and eligibility criteria</i>	130
6.6.3 <i>Ethical considerations</i>	131
6.6.3.1 <i>Obtaining informed consent</i>	132
6.6.3.2 <i>Ensuring confidentiality</i>	132
6.6.3.3 <i>Protecting women contributing to the study</i>	133
6.6.3.4 <i>Equity, mutual respect, dignity and reciprocity during the interview process</i>	134

6.6.3.5	<i>The issue of power during the interview process</i>	135
6.6.3.6	<i>Protecting oneself as a researcher</i>	136
6.7	COLLECTING THE DATA	137
6.7.1	<i>Researcher's role in interviewing</i>	138
6.7.2	<i>The importance of using an appropriate means of communication</i>	138
6.7.3	<i>Involvement of a third party in the interview process</i>	139
6.7.4	<i>Reflexivity during the procedure of data collection</i>	140
6.7.5	<i>Journeying through the different phases of interviewing</i>	141
6.7.5.1	<i>The pre-interview phase: social and structural context of the interview</i>	141
6.7.5.2	<i>The immersion phase – getting to hear the women's experiences</i>	142
6.7.5.3	<i>The emergence phase – ending the interview</i>	145
6.7.6	<i>Dilemmas encountered during data collection</i>	145
6.8	DATA MANAGEMENT	146
6.9	ANALYSING THE DATA	147
6.9.1	<i>Open coding</i>	148
6.9.2	<i>Axial coding</i>	149
6.9.3	<i>Selective coding</i>	151
6.10	MEMOING	152
6.11	SUMMARY	153
CHAPTER 7 'RE(CONSTRUCTING) MYSELF': THE PROCESS OF TRANSITION TO MOTHERHOOD FOR WOMEN WITH A DISABILITY		154
7.1	INTRODUCTION TO AND PRESENTATION OF FINDINGS	154
7.2	DEMOGRAPHIC PROFILE OF THE TWENTY-TWO WOMEN WHO CONTRIBUTED TO THE STUDY	157
7.3	HAVING A SENSE OF SELF	159
7.3.1	<i>Introduction</i>	159
7.4	CONSTRUCTING THE SELF AND AN ASSUMPTIVE WORLD	166
7.4.1	<i>Creating a sense of sameness and inclusiveness</i>	167
7.4.2	<i>Disability as a defining entity of the self</i>	170
7.4.2.1	<i>Questioning the notion of normality</i>	171
7.4.3	<i>Disability a non-defining entity of the self</i>	173
7.4.3.1	<i>Concealing disability from others</i>	174
7.4.3.2	<i>Visibility of one's disability</i>	175
7.5	PLANNING TO BECOME A MOTHER: A NORMAL LIFE TRAJECTORY	177
7.5.1	<i>Acknowledging the woman's sexuality</i>	178
7.6	THE PROCESS OF CONFIRMING THE PREGNANCY	179

7.6.1. <i>Technical issues encountered when confirming pregnancy</i>	179
7.6.2 <i>Social issues encountered when confirming pregnancy</i>	180
7.7 PERSONAL KNOWLEDGE AND EXPECTATIONS OF MOTHERHOOD.....	181
7.7.1 <i>Role modelling</i>	182
7.7.2 <i>Increasing one’s knowledge base</i>	184
7.7.3 <i>Sourcing information on motherhood</i>	185
7.8 PREPARING FOR MOTHERHOOD	185
7.8.1 <i>Gaining access to maternity units</i>	186
7.8.2 <i>Interactions with caregivers</i>	188
7.8.2.1 <i>Communicating with caregivers</i>	191
7.8.3 <i>Biomedical approach to care</i>	192
7.8.4 <i>Screening for disability in the unborn baby</i>	194
7.9 SUMMARY OF ‘HAVING A SENSE OF SELF’	196
CHAPTER 8 MAKING MEANING OF THE SELF AS A MOTHER.....	199
8.1 INTRODUCTION	199
8.2 ENGAGING IN AND DOING THE ACTIVITIES OF MOTHERING.....	202
8.2.1 <i>Interactions with caregivers</i>	202
8.2.2 <i>Having to prove oneself to caregivers: undermining one’s sense of agency</i>	203
8.2.3 <i>Taking on the responsibility associated with motherhood</i>	205
8.2.3.1 <i>Taking responsibility for the social development of child(ren)</i>	206
8.2.3.2 <i>Feeling unprepared for the doing of mothering</i>	208
8.2.4 <i>Establishing a relationship and connection with their child(ren)</i>	209
8.2.5 <i>Ensuring protection and safety of child(ren)</i>	210
8.2.6 <i>Realising one’s strengths and abilities</i>	211
8.2.7 <i>Overcoming challenges encountered when doing mothering</i>	213
8.2.8 <i>Ability to mother undermined by others</i>	214
8.2.9 <i>Sustaining elements of pre-motherhood self while doing mothering</i>	215
8.3 SUMMARY OF ‘MAKING MEANING OF THE SELF AS A MOTHER’	216
CHAPTER 9 REFORMING THE SELF AS A MOTHER.....	219
9.1 INTRODUCTION	219
9.2 LETTING GO OF ONE’S PRE-MOTHERHOOD SELF.....	220
9.2.1 <i>Modifying one’s lifestyle</i>	222
9.2.2 <i>Reprioritising one’s life and professional goals</i>	223
9.2.3 <i>Relinquishing the occupational self</i>	224
9.2.4 <i>Creating, maintaining and reconfiguring relationships</i>	228

9.2.4.1 <i>Relationship with partner</i>	229
9.2.4.2 <i>Relationship with other family members</i>	230
9.2.4.3 <i>Relationship with friends</i>	231
9.3 BEING A MOTHER: A LIFE CHANGING EVENT.....	233
9.4 LOOKING TO THE FUTURE	235
9.4.1. <i>Introducing diversity into son or daughter’s life</i>	235
9.5 SUMMARY OF ‘REFORMING THE SELF AS A MOTHER’	238
CHAPTER 10 DISCUSSION	244
10.1 INTRODUCTION	244
10.2 SITUATING THE SUBSTANTIVE THEORY WITHIN THE FRAMEWORK OF EXTANT THEORIES ON THE TRANSITION TO MOTHERHOOD	245
10.3 THE RELATIONSHIP OF THE PROCESS OF TRANSITION TO MOTHERHOOD TO THE SELF	250
10.3.1 <i>Coping with the disruption to one’s assumptive world</i>	253
10.3.2 <i>Constructing meaning about the self as a mother</i>	255
10.3.3 <i>Reforming the self as a mother</i>	257
10.3.4 <i>The importance of letting go</i>	257
10.4 THE IMPORTANCE OF SYMBOLIC INTERACTIONS WITH OTHERS LOCATED IN ONE’S SOCIAL WORLD	259
10.4.1 <i>Experiencing stigma</i>	260
10.4.2 <i>Assuming a state of helplessness when interacting with others</i>	261
10.4.3 <i>Reconfiguration of relationships with others</i>	264
10.5 DOES THE NATURE OF ONE’S DISABILITY INFORM THE CONSTRUCTION OF A SENSE OF SELF?	265
10.6 UNIQUE CONTRIBUTION OF THESIS TO EXISTING KNOWLEDGE ON TRANSITION TO MOTHERHOOD	267
10.7 REFLECTIONS ON THE USE OF GROUNDED THEORY AS A METHODOLOGY	267
10.8 CONCLUSION	270
CHAPTER 11 RECOMMENDATIONS	272
11.1 INSTITUTIONAL AND PROFESSIONAL RECOMMENDATIONS FROM THIS RESEARCH	272
11.2 RECOMMENDATIONS FOR PRACTICE	274
11.3 RECOMMENDATIONS FOR MIDWIFERY EDUCATION	275
11.4 RECOMMENDATIONS FOR FUTURE RESEARCH	275
11.6 LIMITATIONS OF THE STUDY	276
11.7 DISSEMINATION	277
11.8 CONCLUSION	277
REFERENCES.....	279
APPENDICES.....	300
APPENDIX 1 MEMBERS OF THE MULTIDISCIPLINARY TEAM	301

APPENDIX 2 EXPLANATORY NOTE ON INDIVIDUAL AND COLLECTIVE SELF.....	302
APPENDIX 3 DIAGRAMMATIC REPRESENTATION OF CONDITIONAL MATRIX	303
APPENDIX 4 TABLE OF LITERATURE REVIEWED ON THE TRANSITION TO MOTHERHOOD.....	304
APPENDIX 4A SEARCH TERMS USED IN THE STUDY.....	304
APPENDIX 4B TABLE OF LITERATURE REVIEWED ON THE TRANSITION TO MOTHERHOOD	304
APPENDIX 5 LIST OF VOLUNTARY AGENCIES CONTACTED DURING THE CONDUCT OF STUDY	305
APPENDIX 6 POSTER FOR FIRST PHASE OF THE STUDY	306
APPENDIX 7 INFORMATION LEAFLET FOR WOMEN EXPRESSING AN INTEREST IN PHASE ONE.....	307
OF THE STUDY.....	307
APPENDIX 8 PARTICIPANT INFORMATION AND CONSENT FORMS FOR PHASE ONE AND TWO OF THE STUDY ..	308
APPENDIX 8A LETTER TO WOMEN MEETING INCLUSION CRITERIA FOR THE FIRST PHASE OF THE STUDY (N=54).....	308
APPENDIX 8B CONSENT FORM TO CONTACT THE WOMEN WHO EXPRESS AN INTEREST IN PARTICIPATING IN THE FIRST PHASE OF STUDY (N=54)	308
APPENDIX 8C LETTER TO WOMEN EXPRESSING A WILLINGNESS TO PARTICIPATE IN FACE TO FACE INTERVIEWS IN THE FIRST PHASE OF THE STUDY (N=54)	308
APPENDIX 8D INFORMATION BOOKLET FOR WOMEN PARTICIPATING IN THE FIRST PHASE OF THE STUDY (N=54).....	308
APPENDIX 8E PRE-INTERVIEW PARTICIPANT CONSENT FORM FOR THE FIRST PHASE OF THE STUDY (N=54)	308
APPENDIX 8F RECRUITMENT LETTER TO WOMEN PARTICIPATING IN THE SECOND PHASE OF THE STUDY (N=22).....	308
APPENDIX 8G CONSENT FORM TO CONTACT THE WOMEN WHO EXPRESS AN INTEREST IN PARTICIPATING IN THE SECOND PHASE OF THE STUDY (N=22)	308
APPENDIX 8H PRE-INTERVIEW PARTICIPANT CONSENT FORM FOR THE SECOND PHASE OF THE STUDY (N=22)	308
APPENDIX 9 ETHICAL APPROVAL TO CONDUCT STUDY	309
APPENDIX 10 LONE WORKER POLICY	310
APPENDIX 11 DEMOGRAPHIC DETAILS OF TWENTY TWO WOMEN WHO CONTRIBUTED TO THE STUDY	311
APPENDIX 12 INTERVIEW GUIDE FOR PHASE ONE AND TWO OF THE STUDY	312
APPENDIX 12A INTERVIEW SCHEDULE FOR INDIVIDUAL INTERVIEWS IN THE FIRST PHASE OF THE STUDY (N=54)	312
APPENDIX 12B INTERVIEW SCHEDULE FOR INDIVIDUAL INTERVIEWS IN THE SECOND PHASE OF THE STUDY (N=22)	312
APPENDIX 13 DIAGRAMMATIC REPRESENTATION OF DATA ANALYSIS AND COLLECTION PROCESS.....	313
APPENDIX 14 DIAGRAMMATIC REPRESENTATION OF THE HELIX MODEL.....	314
APPENDIX 15 EXEMPLAR OF MEMO	315

APPENDIX 16 NATIONAL AND INTERNATIONAL PRESENTATIONS 316
APPENDIX 17 PUBLICATIONS TO DATE..... 317

Glossary of Terms and Acronyms

Adaptation	A process whereby a woman activates and engages various behaviours to help her adjust and adapt to the reality of having a baby and the requirements of motherhood. The process initiates emotional, social, psychological and physical changes.
Adjustment	The act of adjusting, adapting to the position of and role of mother.
AMP	Advanced Midwife Practitioner.
Assumptions	A cognitive construction, a belief that orientate an individual and their lifeworld providing meaning, reality, control and purpose.
Assumptive world	A world populated with abstract, global assumptions that ground, secure or direct the course of an individual's life, providing meaning and purpose.
Attainment	Something (role of mother) attained, a personal acquirement, achievement.
CCA	Constant, comparative analysis.
CMS	Clinical Midwife Specialist.
Disability	A 'substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment' (Disability Act, 2005:p6).
DPI	Disabled People's International Organisation.
EU	European Union.
G.P.	General Practitioner.
ICF	The International Classification of Functioning, Disability and Health.
ICIDH	The International Classification of Impairment, Disabilities and Handicaps.
Identity	the array of meanings that define who a individual is when: (i) that individual assumes a specific role in society, (ii) claims specific traits that identify them as a unique individual or (iii) claims membership of a particular group (Burke and Stets 2009), a socially recognised position, recognised by the individual and others through the social relations they form, engage and interact in.
Meaning	The ability to identify new goals and purpose when an individual experiences an event that disrupt their assumptive world.
Modify	To change to some extent the form or qualities of the self; alter partially; amend.
Motherhood	A complex socially prescribed state that has the potential to fundamentally change a woman's life and assumptive world.
Mothering	A biological practice, a practice that requires the woman to take responsibility for the baby/child(ren).
Mother	The status, function or authority a woman has as a parent.
NALA	National Adult Literacy Agency.
NCBI	National Council for the Blind.
NDA	National Disability Authority.
NWCI	National Women's Council of Ireland.
Reconfigure	To change the shape or formation of something; remodel; restructure.
Reforming	To amend the self by change of form.
Reconstructing	To cognitively re-create something from given or available information.

Glossary of Terms and Acronyms continued

Self	An organised set of intrinsic processes that confers an ability to consider, observe and evaluate itself, to take account, to plan and to construct itself as an object that can be modified in different situations (Smith et al. 2001, Burke and Stets 2009).
Transition	A 'Process of change in life's developmental stages, or alteration in health or social circumstances' (Kralik et al. 2006p:322).
TTM	Transition to motherhood.
UK	United Kingdom.
UN	United Nations.
UPIAS	Union of Physically Impaired Against Segregation.
USA	United States of America.
WHO	World Health Organisation.
WPD	Woman with a physical disability whereby physical disability is defined as a decrement in functioning due to a physical health condition e.g. multiple sclerosis, paralysis or loss of one or more limbs.
WHI	Woman with a hearing impairment whose hearing is affected to an extent that renders the understanding of speech through the ear alone, with or without a hearing aid, difficult or impossible.
WVI	Women with a visual impairment, where according to the Irish legal definition - "best corrected vision must be equal to or less than 6/60 in the better eye or field of vision must be limited to the extent that the widest diameter of vision subtends an angle not greater than 20 degrees".
WWD	Women with a physical disability or sensory impairment.

Chapter 1 Context and Background to the Study

1.1 Introduction

In contemporary western society, becoming a mother is considered a normative developmental experience (Weaver and Usher 1997, Faber 2000), a norm of femininity (Weaver and Usher 1997, Malacrida 2009), a status women are expected to aspire to (Oakley 1980). Theoretically women with a disability should, during their transition to motherhood, experience the same level of care, attention and support as non-disabled women but, presently in Ireland, despite the presence of legislation enshrining the fundamental rights of these women the evidence suggests this is not the case¹ (Begley et al. 2010, Walsh-Gallagher et al. 2012). This chapter presents the background and context of this grounded theory study. It describes how the area of interest and research question evolved from a qualitative descriptive study commissioned by two statutory agencies, the National Disability Authority (NDA)² in conjunction with the National Women's Council of Ireland (NWCi).³ The purpose of that study was to explore the emic experiences of women with a disability when accessing the publicly-funded maternity services in Ireland during pregnancy, childbirth and early motherhood. The findings illustrate how, just like non-disabled women, women with a disability aspire and expect to become mothers but when this aspiration is realised their experience of becoming a mother and being a mother is marred by patriarchal, negative attitudes that disrupt the woman's assumptions regarding the self as a woman with a disability, the self as a mother, their assumptive world and could, potentially, interrupt their transition to motherhood.

¹ This includes legislation such as the National Disability Strategy (2004), Disability Act (2005), Equality Act 2000; 2004.

² National Disability Authority is an independent statutory agency, established in 1999 to inform and advise the Minister for Justice, Equality and Law Reform (Ireland) about issues regarding disability of persons that may affect policy and practice in Ireland.

³ The National Women's Council of Ireland is a public body that promotes women's rights and women's equality in Ireland.

1.2 Background and context to this study

In 2010, a total of 75,600 (ESRI 2011, 2012) Irish women became mothers.⁴ When compared to 2009 statistics, this number represents a slight decrease but nonetheless Ireland continues to record the highest number of births in the European Union (Eurostat 2012). Just like any other women in Irish society, women with a disability⁵ have similar desires and expectations regarding motherhood (Kallianes and Rubenfeld 1997, Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Faber 2000, Grue and Tafjord-Laérum 2002, McKeever et al. 2003, Prilleltensky 2003, McFarlene 2004, McKay-Moffat and Cunningham 2006, Smeltzer 2007, Malacrida 2009, Begley et al. 2010). Becoming a mother is, for many of these women, a symbolic act providing them with a sense of normality; it signifies a capturing of a gender or recapturing of a lost gender, where motherhood and the social status of mother, and not their disability becomes their defining characteristic (Kallianes and Rubenfeld 1997, Grue and Tafjord-Laérum 2002, Prilleltensky 2003, Prilleltensky 2004a, Lee and Oh 2005, Walsh-Gallagher et al. 2012).

Negotiating motherhood can be challenging for any woman but it is especially so for women with a disability, primarily because of the challenges⁶ these women encounter in the public domain (Malacrida 2009, Begley et al. 2010). Their decision to become a mother is often met with scepticism from non-disabled persons.⁷ Furthermore, when they do become mothers their ability to be a good, competent and responsible mother is continually scrutinised (Harris and Bamford 2001, Grue and Tafjord-Laérum 2002, Prilleltensky 2003, Prilleltensky 2004a). They are often depicted as unfit, incompetent and irresponsible mothers (Kallianes and Rubenfeld 1997, Thomas 1997, McKeever et al. 2003, Smeltzer 2007, Begley et al. 2010, Walsh-Gallagher et al. 2012). Afraid of being judged, women with a disability may go to great lengths to present themselves as capable, competent, confident and responsible mothers while simultaneously harbouring a persistent fear that if they do not meet societal norms and expectations of what constitutes a good mother they could lose custody of their child(ren)

⁴ Ireland recorded the highest birth rate in the European Union, 16.8 per 1000 compared to an average of 10.7 in other European countries (Eurostat 2012). At the time of writing this thesis these figures were the latest ones published on the Irish birth rate. At this present time, the number of births to women with a disability is unknown, national statistics do not specifically record the number of births to this cohort. The ESRI Perinatal Statistics Report 2011 is not, at time of submitting this thesis, available.

⁵ For the purpose of this study, the term 'a woman with a disability' refers to a woman with a physical disability or sensory impairment.

⁶ This refers to the attitudinal, structural, physical and communicational challenges women with a disability experienced when accessing maternity care and from others located in their social environment.

⁷ Non-disabled person refers to those individuals without a disability or impairment.

(Kallianes and Rubenfeld 1997, Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Grue and Tafjord-Laérum 2002, Malacrdia 2007, Begley et al. 2010, Walsh-Gallagher et al. 2012).

1.3 Genesis of the study

The area of interest and research question for this study evolved from the findings of a qualitative descriptive study commissioned in November 2007 by two statutory agencies, the NDA in conjunction with the NWCI. I was part of a multidisciplinary team⁸ that applied, through an open tender process, to conduct the study. Once successful, I became the research assistant for the physical disability and sensory impairment strands. My motivation for becoming involved in that study was twofold: (i) the context, the maternity services, was an area I had worked in for 15 years and (ii) the sample, women with disabilities, stimulated my interest in diverse groups. Fifty-four women with either a physical disability (n=18) or sensory impairment (n=36) were interviewed within the physical and sensory strands of the study. The women were interviewed either during pregnancy (n=14), within the first 6 months postnatally⁹ (n=20) or within 1-2 years postnatally (n=20). Data were collected using individual interviews and were analysed using the constant comparative method of analysis¹⁰ (Glaser and Strauss 1967).¹¹ The women's descriptions of the challenges and facilitators encountered when accessing the publicly-funded Irish health services during pregnancy, childbirth and early motherhood were presented under five themes: acceptability,¹² accessibility,¹³ availability,¹⁴ accommodation,¹⁵ and affordability¹⁶ (Begley et al. 2010). The study, commissioned by the NDA and NWCI, was phase one of my doctoral study. Data from that commissioned study specifically, the data informing the themes of accessibility and acceptability, informed the having a sense of self phase, the first phase of the theoretical model that

⁸ See Appendix 1 for members of the team.

⁹ This refers to the period after the birth of the baby.

¹⁰ The computer software package Nvivo 8 was used to assist in managing the data. Demographic data were analysed using the statistical package SPSS

¹¹ Glaser B. G. & Strauss A. (1967) *Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL, Aldine Publishing Co.

¹² Acceptability describes the interpersonal relationships established with the health professionals and the interactions that occurred therein when women with a disability accessed maternity and health services.

¹³ Accessibility refers to the ability of women with a disability to access the maternity and health services; it addresses physical access, access to goods, equipment, and information.

¹⁴ Availability refers to the extent and type of maternity and health services available to address the specific needs of women with a disability.

¹⁵ Accommodation refers to the organisation of resources to accommodate women with a disability when accessing the maternity and health services.

¹⁶ Affordability refers to how affordable the maternity and health services are for women with a disability.

evolved from my doctoral study. Having a sense of self details the effect the woman's environment and her interactions with others, specifically, caregivers had on: (i) the pre-motherhood self, and on the woman's assumptions of the self as a woman with a disability, (ii) the anticipated assumptions of the self as a mother and (iii) on the woman's pre-motherhood lifeworld.

Evidence from phase one (the NDA and NWCI commissioned study) suggested that before becoming a mother, women with a disability were compelled to negotiate a self within a society where others, primarily non-disabled individuals, often perceived them as asexual, different and dependent, somebody to be pitied, a liability (Kallianes and Rubenfeld 1997, Thomas 1998, Grue and Tafjord-Laérum 2002, Walsh-Gallagher et al. 2012). Furthermore, the concept of women with a disability being a mother was considered, by many people without a disability, to be aberrant. So, when the personal goal of becoming a mother is realised by women with a disability, women are required to renegotiate an already negotiated self. The data from the commissioned study (NDA and NWCI study) tenuously suggested that this renegotiation, occurring as it did during the woman's transition to motherhood, was influenced by others located in the woman's social environment but how and to what extent is unknown.

The theme of 'Acceptability' described the relationship established and interaction that ensued between the women and caregivers engaged in the provision of maternity care during pregnancy, childbirth and early motherhood. The findings demonstrated how a minority of women formed a positive relationship with caregivers while the majority created a negative one. Those who had a positive experience attributed this to: (i) the attributes and characteristics of the caregivers encountered,¹⁷ (ii) the continuity of carer policy implemented in the majority of maternity units, (iii) caregivers being sensitive to the woman's individual needs, and (iv) flexibility when implementing policies or procedures governing the provision of care (Begley et al. 2010). Conversely, those who had a negative experience described the caregivers as paternalistic, patronising and judgemental, insensitive and indifferent to the women's specific needs. They perceived the caregivers to be constantly observing, watching and scrutinising how they attended to the physical, social, emotional, cognitive and psychological needs of their baby. Consequently, the women felt insecure in their ability to mother and were apprehensive and fearful about losing custody of their baby. The women detailed the challenges encountered while doing the physical and sensory aspects of mothering but once these challenges were

¹⁷ This was captured in the use of terms such as 'really, really good, very helpful, fantastic, wonderful, lovely, very, very compassionate and comforting' (Begley et al. 2010:p121).

successfully overcome, the women experienced a sense of pride and achievement (Thomas 1997, Thomas and Curtis 1997, Faber 2000, Malacrida 2009, Begley et al. 2010).

The process of negotiating a self while becoming a mother appears complex but a substantive review of the literature revealed that there is a paucity of empirical evidence regarding the experiences of women with a disability and their transition to motherhood, and even less on the relationship of the process involved in the transition to motherhood and the self. Therefore, a study exploring the process involved in the transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self is required to contribute and extend the current body of knowledge relating to disability, self and the transition to motherhood. The purpose of the present grounded theory study was to develop a conceptual understanding of the transition to motherhood from the perspective and experiences of these women through the production of knowledge grounded in their experiences. It is anticipated that the findings will contribute to the development of a conceptual framework that will advance understanding on the phenomenon and will support and assist caregivers in their clinical practice when facilitating women with a disability in their transition to motherhood.

While this thesis is presented in separate chapters, when read consecutively these chapters contextualise the study, they detail how the study was conducted, how the data were conceptualised and the significance and implications of the substantive theory that emerged. Chapter two details how disability is conceptualised within the confines of the medical or social model of disability, while chapters three and four, present a sample of the theories relating to the self and the transition to motherhood respectively. Concepts from these chapters informed the coding paradigm,¹⁸ a tool employed when collecting and coding data. Chapter five describes the philosophical underpinnings of the study; it presents the epistemological, ontological and methodological positions that guided the development of the theoretical model of '(Re)constructing Myself'. Symbolic interactionism, with its emphasises on social interaction and its recognition of how individuals establish and share meaning that evolves from the reciprocal interactions of individuals (Prasad 1993, Benzies and Allen 2001), resonates with my ontological position, how I perceive the self to be constructed and reverberates with the purpose of this study. Therefore, it was the theoretical perspective that guided interpretation of the data during the data collection and analytical phases of the study. Informed by constructionism,

¹⁸ This coding paradigm is also known or referred to as a paradigm model but in this grounded theory study is will be referred to as a coding paradigm.

symbolic interactionism is predominantly associated with an interpretative paradigm and a qualitative approach. Accordingly, the study was conducted within an interpretative paradigm, using a qualitative methodology underpinned epistemologically and ontologically by constructionism and realism respectively. Methodologically, Strauss and Corbin's approach to grounded theory was consistent with the aim of the study. This approach ensured that the conduct of the study was systematic and rigorous. Chapter six details how the study was conducted and the iterative processes engaged in the construction of the substantive theory that emerged. The remaining four chapters (chapters 7-10) present and discuss the substantive theory of '(Re)constructing Myself'. The recommendations arising from the study and the substantive theory are presented in the concluding chapter. In the following chapter, chapter two, I discuss the current disability policy and the status of women with a disability in contemporary Irish society, and detail how the medical model of disability continues to inform their status.

Chapter 2 Disability Policy in Ireland

2.1 Introduction

Historically, people with a disability experienced discriminatory and ostracising societal practices and were treated as a minority group (Scotch and Schriener 1997). In this configuration these individuals were subjected to negative stereotyping and were continually cast as incompetent and dependent (Scotch and Schriener 1997). Such stereotyping augments the sense of discrimination that people with a disability feel and consequently limit the individual's ability to participate fully in society as an autonomous agent attempting to achieve their full potential (Hahn 1985, Bogdan and Taylor 1987, Hahn 1988, Allen and Allen 1995, NDA 2007a). All too often, segregation and sterilisation were strategies implemented by a paternalistic society, and these were perceived as an adequate way to address the complex issues associated with the reproductive issues of people with a disability. This chapter will examine the theoretical underpinnings that informed such practices. It will detail how, in Ireland, pre the mid 1990s the medical model was the dominant model informing and shaping the scant disability policies and how, in more recent years, as the social model of disability gained prominence, disability policy was reshaped accordingly. Before proceeding to discuss the various models of disability and Ireland's disability policy it would be remiss not to define disability.

2.2 Defining disability

Disability is a relative concept defined within the context of how it is used (Raman and Levi 2002). Traditionally, disability was defined within a physiological, functionalist perspective and was classified according to individual pathology and associated deficits, abnormalities and functional limitations. It was perceived to be a failing of the individual, a personal tragedy (Barnes and Mercer 2010). The term was applied when the individual was unable to fulfill normative, socially constructed roles and expectations, like those associated with motherhood (McMillan Boyles et al. 2008). But over the last fifty years people with a disability have refuted this functionalist conceptualisation. Consequently, the concept was deconstructed and definitions relating to it have been modified, altered and reconfigured. The current definitions, that emerge from two differing theorisations, the medical and

social models, are constructs of modern society, responses to economic, attitudinal and political variables (McMillan Boyles et al. 2008, Barnes and Mercer 2010). The definition of disability guiding this study was the one adopted from the Disability Act (2005) whereby disability is defined as a ‘substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment’ (Disability Act, 2005:p6).¹⁹

2.3 The status of people with a disability in Irish society

All citizens residing in a sovereign, democratic state, regardless of their ability or disability, are afforded fundamental human rights, such as the right to equality. These rights are respected, protected and enshrined in national and international law (Begley et al. 2009a). However, until recently, Ireland’s record in relation to the advancement of the rights of people with a disability was appalling. The recent developments in disability policy and equality legislation have generated change, but the shift towards the recognition of the rights of people with a disability, residing in Ireland, is nascent. The recognition of the rights of these individuals was influenced internationally, principally by the World Health Organisation (WHO), through Ireland’s membership of the European Union (EU) and the Irish government’s commitment to implement United Nation (UN) conventions protecting and promoting the rights of people with a disability. Since their development and inception the EU and UN charters have promoted and advanced the development of disability specific legislation and policies within the states that have ratified them, Ireland included. Essentially, these instruments were the impetus that ascertain what the rights of people with a disability were, ensuring that they are realised at a national and international level (Begley et al. 2009a). In the past decade, although the pace of introduction was protracted, Ireland has introduced and implemented legislation and other initiatives to advance the fundamental rights of people with a disability, these include; the Equal Status Act (2000; 2004),²⁰ the European Year for People with Disabilities (2003), the Education for Persons with Special Education Needs Act (2004),²¹ the National Disability Strategy (2004)²² and the Disability Act (2005). The enactment

¹⁹ The Disability Act (2005) can be accessed in full at [http://www.oireachtas.ie/disability act 2005.pdf](http://www.oireachtas.ie/disability%20act%202005.pdf).

²⁰ See Equal Status Act (2000) and Equality Act (2004) Available: <http://www.irishstatutebook.ie/2000/en/pub0008/index.html>. and [http://www.equality.ie/equality act 2004.pdf](http://www.equality.ie/equality%20act%202004.pdf).

²¹ The full Act can be viewed at: <http://www.oireachtas.ie/documents/bills28/acts/2004/A3004.pdf>.

²² The full version of the Disability Strategy (2004) is available at: http://www.justice.ie/en/JELR/Pages/Policy_in_Ireland.

of these statutory instruments generated a monumental shift in the pervasive practice of institutionalising and segregating people with a disability, a practice that was primarily influenced and framed by the biomedical model of disability.

2.4 Models of disability

Four models of disability are discussed in the literature - the moral, medical, rehabilitation and social. The models are frames of reference that influence the views and perceptions of disability. These models primarily conceptualise disability in two distinctive and divergent ways; (i) the functionalist, biomedical or individual perspective that focuses primarily on how an individual's impairment results in the person feeling inadequate and different from the norm or (ii) the biopsychosocial perspective that is concerned with identifying and decreasing the social and physical barriers an individual encounters when trying to participate in mainstream society. The latter conceptualisation gained momentum in the latter part of the last century and coincides with the beginning of the disability movement, a movement that asserts that modernity has supported the casting of people with a disability in a role determined by non-disabled individuals and consequently imprisons, confines and excludes people with a disability from participating and/or achieving the many privileged and powerful roles in society, including that of mother (Oliver 1990). The disability movement had a specific goal, the emancipation of people with a disability from social oppression and exclusion (Oliver 1990) and to some degree the movement were successful in politicising the social and physical struggles these people experience while attempting to conform to the dominant, non-disabled values and practices of modern society. Although, over time alternative frameworks (Swain and French 2000, Tate and Pledger 2003, Patston 2007) have evolved the functionalist biomedical model and the biopsychosocial model remain the dominant models that continue to influence how people with a disability are perceived and understood. The fundamental differences and similarities of the biomedical and biopsychosocial models are discussed in detail below. While the social model is reportedly the model that has influenced the development of disability policy in Ireland, especially the Disability Act (2005), which is the core pillar of the National Disability Strategy, empirical evidence would suggest that the medical model is still the prominent paradigm influencing Irish society's attitudes towards people with a disability (NDA 2002, 2007a, 2007b, 2011).

2.4.1 Biomedical construction of disability

In the medical and nursing literature, disability is principally described from a physiological, functionalist perspective, framed within a linear medical and rehabilitative model. Disability is conceptualised as a limitation in occupational and social functioning resulting from a chronic illness or disease or a functional limitation of the individual (Lutz and Bowers 2003, Barnes and Mercer 2007, McMillan Boyles et al. 2008, Barnes and Mercer 2010). Two models, the moral model and medical model, evolved from this perspective. The moral model of disability conceptualises disability as a consequence of shame and sin; historically it is the oldest model attempting to explain disability but today its use is less prevalent. Nonetheless policies informed by this model continued into the present century whereby people with a disability were often hidden from general society, usually in large institutions and their everyday life regimented and disciplined. The emotional and psychological consequences of such actions were far reaching. Segregation instilled a sense of exclusion and ostracisation, it engendered a sense of guilt and self-hatred, people experienced a loss of self-identity, autonomy and control (Lee 2007).

The idea that disability was a consequence of sin and that those afflicted by it were weak minded engendered a belief that such people should not become parents for fear they would taint society with imperfect individuals (Hubbard et al. 2001). The notion of a perfect individual emanated from the eugenic movement. This movement and associated philosophy surfaced in the 19th and 20th centuries, and throughout history there are well documented examples of where this philosophy has been taken to extremes, for example, (i) the actions of racial cleansing demonstrated by the Nazi movement and (ii) the Swedish policy of conducting hysterectomies on women with a disability. Sadly, empirical evidence would suggest that this philosophy still prevails today. When accessing contemporary maternity care, women with a disability unlike their non-disabled counterparts, are often asked about their intention to continue with or terminate their pregnancy (Begley et al. 2009b, 2010, Walsh-Gallagher et al. 2012).

The medical model²³ of disability coincided with the emergence of the eugenic movement and associated philosophy. This model emanated from the disease model adopted by the medical fraternity, it defines a person with a disability as an individual who, because of their physical or mental disability

²³ This model is also known as the individual model of disability.

are 'less than whole' (Dartington et al. 1981:p126), an individual who cannot fulfil social roles and obligations or is not permitted by society to function in their social roles (Myers 1965, Barnes and Mercer 2007). Almost five decades after the introduction of this model, disability continues to be defined using similar descriptors, as: (i) a limitation in the performance of certain roles and tasks that society expects individuals to do, (ii) an ill fit between the individual's capabilities and the demands of the environment (Brandt and Pope 1997), (iii) 'the condition of being unable to perform a task or function because of physical or mental impairment, something that disables; handicaps, a lack of necessary intellect, strength' (Trevvy 2000:p444). In essence, the medical model suggests that disability is pathological, resulting from a physiological impairment due to a disease or injury process. Consequently, people with a disability are perceived to be unable to function and perform socially constructed roles and responsibilities, they are considered different and dysfunctional, someone to be pitied, someone who requires intervention(s) so as to ameliorate the deficit related to their disability (Brandt and Pope 1997, Barnes and Mercer 2007, McMillan Boyles et al. 2008, Barnes and Mercer 2010). The experiences of women with a disability accessing maternity care (Begley et al. 2009b, 2010) illustrate how conceptualising disability under the umbrella of dysfunction and deviance predisposes these women to stigma, scrutiny and discrimination (Lee 2007, Begley et al. 2009b, 2010).

The rehabilitation model is considered to be an extension of the medical model. The model evolved from the sociological domain of functionalism (Parsons 1951) and is based on the principle that the social world exists as one entity or system comprised of interrelated functional units (Lutz and Bowers 2003). If the system is to function effectively all parts must realise their potential. Any deviation from this principle will render the relationship (one's ability) unstable and the larger system (the individual) will fail to function appropriately (Lutz and Bowers 2003). Like the medical model, the rehabilitation model conceptualised disability as a deficiency of the individual, it pathologised disability, perceiving it as a problem of the individual that can only be addressed through rehabilitation. The model does not consider people with a disability to be autonomous, independent individuals, it beholds that caregivers are responsible for fixing, curing and caring for people and where possible returning them to full functional ability. The individual, in turn, is required to cooperate with caregivers and comply with rehabilitative interventions²⁴ in order to gain some degree of normality (Safilios-Rothschild 1990, Barnes and Mercer 2007).

²⁴ These included services such as surgery, therapy, counselling or other services to compensate for or address the deficiencies caused by their disability.

The rehabilitation model gained momentum after World War II with the rehabilitation of disabled veterans into society. Before World War II, people with a disability were cared for in large institutions where they generally resided until their death, they received no treatment or rehabilitation. This trend began to change after World War II. A key agent in this change was the German born neurologist, Sir Ludwig Guttmann. Guttmann established the National Spinal Injuries Centre at Stoke Mandeville Hospital in Buckinghamshire. This centre was the first specialist unit in the UK specialising in the treatment of spinal injuries. Guttmann believed that sport and exercise were an essential therapy for people with spinal injuries (military personnel) helping them to build physical strength, agility and self-respect. He was instrumental in the development of the Paralympic movement and the Paralympic games. In the last 60 years, this multicultural event has grown from a small competition between British and Dutch athletes on the lawns of Stoke Mandeville Hospital in Buckinghamshire (in 1948) to the more recent games hosted by London (August 2012) where 4,200 Paralympic athletes from 150 countries, participated in twenty different sports. These games were credited with having a positive effect, albeit a momentary interlude, on how people with a disability are perceived and valued in modern society (Beresford 2012).

The descriptions portrayed by women with a disability of the situational, attitudinal and communicational obstacles encountered when accessing maternity care (Bogdan and Taylor 1987, Hahn 1988, Allen and Allen 1995, Barnes and Mercer 2007, NDA 2007a, Begley et al. 2010, Walsh-Gallagher et al. 2012) demonstrate how the reductionist, medical model of disability continues to inform modern maternity care. Moreover, caregivers, engaged in the provision of care tend to perceive the woman's disability as a sickness that threatens her competence in normal role performance. Women with a disability are perceived to be at a disadvantage, to be different and their ability to live independent, autonomous lives are often questioned (Begley et al. 2010, Walsh-Gallagher et al. 2012). Consequently, they are subjected to exclusionary, discriminatory and segregating practices (Bogdan and Taylor 1987, Hahn 1988, Allen and Allen 1995, Barnes and Mercer 2007, NDA 2007a, Begley et al. 2010). These women are rarely viewed as autonomous agents, rather they are constructed as dependent entities; in need of care and sympathy, someone to be pitied (Shakespeare 1996, Watson 1998, Shakespeare 2002, Watson 2002, Massie 2006, Shakespeare 2006, Barnes and Mercer 2007, Begley et al. 2010). Caregivers' interactions with women with a disability are often marred by patronising, paternalistic, unsupportive, insensitive, arrogant and unfriendly behaviours, and the language used by them, when interacting with women with a disability, can be stigmatising, insulting, derogatory and offensive (Lee 2007, Begley et al. 2010, Jackson 2011, Kritzinger 2011). Caregivers fail to recognise the women's abilities choosing instead

to continually question their ability to be good, competent, responsible mothers (Kallianes and Rubinfeld 1997, Thomas 1997, Thomas and Curtis 1997, Thomas 1998, McKay-Mofatt and Rotheram 2007, Smeltzer 2007, Begley et al. 2010).

In the last few decades, people with a disability have challenged and rejected the medical and rehabilitation models principally because they: (i) prioritised impairment over the individual, (ii) viewed people with a disability as somehow lacking and (iii) failed to recognise the salient role played by the environment in disadvantaging people with a disability (Bickenbach et al. 1999). While people with a disability acknowledge that medical intervention is, at times, required they argue that realistically, an individual's disability may never be ameliorated so others need to recognise that they are quite capable of adapting to and integrating the necessary modifications to enable them to fully participate in mainstream society (Safilios-Rothschild 1990, Barnes and Mercer 2007). As the challenges to the medical model accumulated and intensified, an alternative approach to disability, the social model, began to emerge. This model challenges the assumption that disability equates to infirmity or ill health rather is considers disability as an aspect of the individual's life and rejects the contention that people with a disability are inherently defective. It presents disability as an outcome of the interaction between the individual and society, and asserts that society constructs obstacles that impact on the individual's ability to function and fulfill socially prescribed roles and responsibilities. Essentially, it is society and the individual's environment that determines whether or not the individual's disability becomes a deficit (Lollar and Crews 2003, Michailakis 2003, Dewsbury et al. 2004).

2.4.2 Biopsychosocial construction of disability

The origins of the social model can be traced to the Union of Physically Impaired Against Segregation (UPIAS), an organisation of people with a disability in the United Kingdom who, through their personal experiences, concluded that disability evolved from social oppression (UPIAS 1979). The model reflects the central tenets of a social constructionist perspective of disability, a perspective that developed from two main strands - the United Kingdom (UK) strand and the United States of America (USA) strand. Heavily influenced by the theories of Marx and Engels, proponents of the UK strand consider disability to originate from a particular social ideology and structure. While proponents of the USA strand consider disability to be an outcome of contemporary society.

The social model contextualises the individual's impairment in terms of their personal experiences of living with a disability (McMillan Boyles et al. 2008).²⁵ Drawing on a realist philosophy the model suggests that there is no casual relationship between impairment and disability rather disability is conceptualised as a construct of society (Tighe 2001, McClimens 2005). It does not consider disability to be a variant of an individual's pathology or psychology; it conceives it to be an outcome of oppressive and discriminatory social obstacles. Unlike previous models, the social model differentiates between impairment and disability (Lollar and Crews 2003). Impairment is considered to be a medically defined condition while disability is presented as a process influenced and created by the interaction of social and economic variables. The model proposes that it is not the individual's intrinsic pathology that renders them disabled but the social and environmental obstacles encountered by them that are disabling (Finkelstein 1993). Society, the actions and attitudes of its members are integral variables that encumber people with a disability (Asch 1998, Hull 1998).

Postmodern social theorists (Crow 1996, Swain and French 2000, Shakespeare and Watson 2001) have criticised the social model, attributing its weakness to its Marxist/materialist foundations (Thomas 2004). While acknowledging that the social model partially explains the social oppression experienced by people with a disability, some of its critics claim: (i) it fails to conceptualise disability (Shakespeare 2006), (ii) there are gaps in the explanation proposed in the model (Oliver 1996), (iii) the model is over-simplistic (Pinder 1996) and (iv) as an explanatory model, the model is incomplete (Bury 1996). These critics have called for the development of an alternative model of disability.

2.4.3 Alternative constructions of disability

Looking beyond the social model, Shakespeare and Watson (2001) propose its abandonment and draw on an increasing number of criticisms from the feminist and postmodernist perspectives to advance their thesis. Feminists and postmodernists (Crow 1996, Wendell 1996, Corker and French 1999, Swain and French 2000) reject the idea of a conceptual separation of impairment and disability advanced in the social model. They refute the claim that disability is generated from society and not

²⁵ The introduction of social model into the theoretical debate has resulted in euphemistic and imprecise terms such as 'cripple', 'retarded', 'handicap', 'unfortunate' and descriptions such as 'deformed', 'disfigured', 'confined to wheelchairs', 'tragic victims' or 'suffering from a specific infliction' to be rejected and replaced with more exact, and considerate terms like 'people with a disability' or 'people with a learning disability' (Watson 1998, Spruill 1999, Barnes and Mercer 2007).

impairment, arguing instead that impairment has a significant role in causing disability. Furthermore, they assert the body and embodied states are relevant to the experience of being disabled:

'People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial. The British social model approach, because it 'over-eggs the pudding', risks discrediting the entire dish' (Shakespeare and Watson 2001:p17).

Shakespeare and Watson (2001) define disability as 'a complex dialectic of biological, psychological, cultural, and socio-political factors which cannot be extricated except with imprecision' (Shakespeare and Watson 2001:p21), they understand disability to mean restriction of activity where restrictions are caused both by impairment, chronic illness and social obstacles. Moreover, Shakespeare and Watson (2001) suggest that any new theory on disability should recognise and acknowledge that every individual is, to some degree, impaired (Shakespeare and Watson 2001) and this assumption should act as a springboard for dismantling socially constructed divisions between disabled and non-disabled individuals (Thomas 2004).

More recently, Tom Shakespeare's critique of the social model (Shakespeare and Watson 2001, Shakespeare 2006) has ignited theoretical and academic debate and has attracted some negative reviews from some disability activists. Shakespeare, who has a physical disability, contests the partisan nature of the social model; he claims that the model regionalises the issues and interests unique and pertinent to the disabled population. Shakespeare's rejection of the social model is founded on a number of other critical points, he: (i) rejects the Marxist ideological foundation of the model and argues that such ideology is outdated and inappropriate for consideration of contemporary issues, (ii) challenges the divisions generated between the medical and social models and (iii) claims the model fails to recognise and acknowledge the significance of impairment on an individual's life and (iv) how removing social obstacles will not necessarily ameliorate an individual's disability. Shakespeare suggests that activists were so subsumed by the social model that they adopted a unilateral perspective to disability that clouded their conceptualisation of the concept and prevented them from considering other theories.

Shakespeare advocates for a more holistic approach to defining and conceptualising disability. He suggests that disability occurs when there is an interaction between the individual and social factors. This supposition juxtaposes both the medical and social models of disability and the new interactional paradigm constructs disability as a relationship between the individual (intrinsic) and structural

(extrinsic) factors. Intrinsic factors include: (i) the nature and severity of an individual's disability and (ii) the individual's attitudes to it, their personality, attributes and abilities. Extrinsic factors comprise of: (i) the attitudes, perceptions and reactions of others to the individual's disability, (ii) how enabling or disabling the individual's environment is and (iii) the wider social and cultural issues pertaining to disability. Evidently disability is not considered to be a sole consequence of external disabling variables nor is it explained in terms of the individual's impairment and limitations; rather disability emerges from an interplay between an individual's impairment and their environment (Shakespeare 2006). This interactional approach is similar to the relational model advocated by Thomas (1999). The relational model, an amended version of the social model, developed from the qualitative research conducted by Carol Thomas, in the late 1990s, on women with a disability (Thomas 1997, 1998). In addition to the dualistic conception of impairment and disability advanced in the social model, the relational model incorporates the effects of impairment and recognises the psycho-emotional effects of disability. Thomas (2004) avows that disability be explained in a relational context, defined and understood in terms of oppression rather than societal barriers to activity (Thomas 2004).

2.5 Current Disability Policy in Ireland

Currently, Irish disability policy is informed and shaped by international conventions and frameworks devised by the World Health Organisation, the United Nations and the European Union. The objective of this policy would appear to be the removal of physical, attitudinal and social barriers so as to achieve inclusion and full participation of people with a disability in mainstream Irish society. This objective signifies the shift that has occurred around disability policy in Ireland over the last two decades, it is no longer principally informed by the medical model of disability; more recent policies reflect the influence of the social model of disability.

2.5.1 The World Health Organisation's classification of disability

Over the past twenty five years, two conceptual frameworks, the International Classification of Impairment, Disabilities and Handicaps (ICIDH) and the International Classification of Functioning, Disability and Health (ICF), were devised by the World Health Organisation in conjunction with

sociologist Saad Nagi, the purpose being to define, describe and conceptualise disability. Nagi considered disability as a relational concept, one that represented the individual's inability or restriction to perform socially defined roles within society (Jette 1994). The influence of this perception is reflected in the two conceptual frameworks. The frameworks marry the intrinsic and extrinsic factors that cause people to be disabled, unwittingly they reflect the interactional paradigm advocated by Shakespeare (Shakespeare 2006) some five years after the inception of the ICF (see section 2.4.3).

2.5.1.1 International Classification of Impairment, Disabilities and Handicaps

The International Classification of Impairment, Disabilities and Handicaps (ICIDH) was devised in 1980, in response to criticisms that the World Health Organisation's approach to disability ignored the social factors that accentuate the limitations and experiences of people with a disability. Since its inception the framework has contributed to the development of a common language to define disability. Essentially, at the level of impairment and disability the ICIDH recognised and acknowledged the fundamental role social variables play in the disablement of an individual. Described as a 'three tiered hierarchical structural model of disablement' (Ueda and Okawa 2003:p596), the framework defined disability as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being' (WHO 1993:p29). The ICIDH framework considered impairment to be a necessary precondition to disability and proceeded to define impairment as 'any loss or abnormality of psychological, physiological, or anatomical structure or function' (WHO 1993:p28), a temporary or permanent impediment that can be observed and measured, something that can adversely affect the individual's range of activities and may disadvantage the individual by limiting one's independence and social integration.

A year after the publication of the ICIDH framework, the Disabled People's International organisation (DPI) presented an alternative definition for the terms 'impairment' and 'disability.' Referring to more or less the same domain of functional limitations referred to in the ICIDH framework, the DPI defined impairment as a functional limitation within the individual caused by a physical, psychological or sensory source. While disability, was defined as the loss or limitation of opportunities to participate equally in society, perpetrated by physical and social barriers. In essence, people with a disability were considered as individuals with impairments who experience disability as a consequence of socially constructed restrictions that limit opportunity and equal participation and marginalise, and discriminate against such individuals.

Critics of the ICIDH framework (Barnes and Mercer 2007, Jett 1994, Oliver 1990, 1996) observed how, despite its claim to consider social variables, the provisions of the framework were similar to the medical model of disability and how the concepts of functional limitation and disability were not clearly differentiated (Jette 1994, Barnes and Mercer 2007). The critics: (i) refuted the notion that an individual's disability was an inherent characteristic of the individual, (ii) rejected the assumption that people with a disability wanted to achieve a sense of normality (Oliver 1996) and (iii) were dismayed that the framework never considered the individual's strengths, capabilities or personal experiences of disability (Jette 1994, Oliver 1990, 1996). Moreover, the terminology used in the framework was considered disingenuous, because of the charitable and degrading connotations associated with it, the use of the term handicap was an anathema to many people with a disability (Oliver 1990). These condemnations succeeded in diminishing the value and integrity of the framework. The framework was subsequently revised and a new conceptual framework emerged.

2.5.1.2 International Classification of Functioning, Disability and Health

In the late 1990s, the WHO began revising the ICIDH framework, this revision was augmented by the criticism directed at the ICIDH and the recognition that although the medical and social models of disability were incongruent, each had strengths that if integrated into one framework could provide the frame for a more holistic definition and description of disability. During the revision process disability groups from around the world were consulted. Subsequently a new classification system emerged - the International Classification of Functioning, Disability and Health (ICF)²⁶ (WHO 2001). Accordingly disability was defined and described within the context of health and functioning but it was not restricted to any defined limit of functioning (Leonardi et al. 2006). More importantly, the framework acknowledged that the environment was an influencing variable that assisted or hindered the individual's participation in activities and society in general.²⁷ Its development and introduction symbolised a paradigm shift from the biomedical model towards an integrative biopsychosocial model of disability (Brandt and Pope 1997, WHO 2001, Ustun et al. 2003, Bruyere et al. 2005, Barnes and

²⁶ The entire provisions of this classification framework can be read in its totality at WHO (1993) ICIDH: International Classification Of Impairments, Disabilities And Handicap. Available: <http://www.who.int/classifications/icf/en>.

²⁷ When compared with its predecessor (ICIDH), the ICF has similar components; it retained the body function and impairment duality, and also retained the personal activity limitations, it considered disability from a societal participation component, and included an environmental component (Lollar and Crews 2003, Leonardi et al. 2006).

Mercer 2010) nevertheless despite its strengths, the framework was criticised for failing to take account of the personal dimension of disability (Ueda and Okawa 2003).

2.5.1.3 The Universal Declaration of Human Rights

The United Nations' Universal Declaration of Human Rights (UN 1948, 1971, 1975) was one of the most important international instruments devised to promote and protect the fundamental human rights of all individuals. Since its inception, in 1948, the charter has been subjected to a number of revisions. Subsequent amendments have led to the inclusion of declarations in respect to people with a disability. Specific instruments, recognising and charting the rights of people with a disability were subsequently developed, they include: (i) the UN Standard Rules on Equalization of Opportunities for People with Disabilities (UN 1993)²⁸ and (ii) the UN Convention on the Rights of People with Disabilities (UN 2006).²⁹ Following the publication of the UN Standard Rules on the Equalization of Opportunities for People with Disabilities (1993), the Irish government established a taskforce, the Commission on the Rights of People with Disabilities,³⁰ whose fundamental aim was to explore and document the experiences of individuals living in Ireland with a disability. The taskforce employed a multi-method approach to collecting data including: written submissions, consultations, interviews and focus groups with people with a disability. Given the opportunity to have their voice heard participants, people with a disability expressed how they felt excluded from all aspects of society – economical, social and political. They called for equality and the opportunity to fully participate in society. The Commission's conclusions were significant for women with a disability, their report was the first report to acknowledge that these women were generally perceived to be asexual and how they were marginalised and discriminated on the basis of their gender and disability. Based on three guiding principles - equality, maximising participation and enabling independence, and choice - the Commission recommended that people with a disability be afforded the opportunity to fully participate in Irish society, which included respecting their decision to become parents (Begley et al. 2009a).³¹ But sadly, almost two decades after the

²⁸ The entire provisions of this charter can be read in its totality at UN (2000) Available: http://www.who.int/disabilities/policies/standard_rules/en/index.html.

²⁹ The entire provisions of this charter can be read in its totality at UN (2006) Available: <http://www.un.org.disabilities/convention/conventionfull.html>.

³⁰ The full text of this report can be accessed from Government of Ireland (1996) A Strategy for Equality: The Report of the Commission on the Status of People with Disabilities, The Stationery Office: Dublin.

³¹ The Commission also recommended the establishment of an independent statutory body, who would advise the Irish government on disability issues. Subsequently, the National Disability Authority was established in 2000. This Authority was
Footnote continued on next page.

publication of the Commission's report, empirical evidence suggests that when women with a disability access maternity care they, despite evidence to the contrary, continue to be perceived as asexual and are marginalised and discriminated against (Begley et al. 2010, Walsh-Gallagher et al. 2012).

2.5.2 The development of a National Disability Strategy

Another significant development that contributed to the shift in disability policy in Ireland was the development of a National Disability Strategy. The National Disability Strategy, developed in 2004, is a programme of coordinated action across a number of governmental departments that has a specific purpose, the inclusion of people with a disability in mainstream society (Begley et al. 2009a). With its foundations of equality (Equality Act, 2000; 2004) and disability legislation (Disability Act, 2005), the Strategy has four components: (i) the Disability Act (2005); (ii) the Education for Persons with Special Education Needs Act (2004); (iii) the Citizens Information Act (2007)³² and (iv) the formulation of sectoral plans from six governmental departments including: health, communication, environment, employment, social welfare and transport, on the measures they will enact to ensure the inclusion of people with a disability. Structures and provisions are currently in place to oversee the implementation of the National Disability Strategy and to date; various governments have, in their respective plans for government, committed to implementing the strategy in its entirety. The core legislative component of the National Disability Strategy is the Disability Act (2005).

2.5.2.1 Disability Act (2005)

In Ireland, the Disability Act (2005), together with other legislative statutes evoking the principles of equality and non-discrimination³³ afford people with a disability, the right to participate equally and fully in Irish society. The definition of disability adopted in the Act was the definition

established within the provisions of the National Disability Act (1999). The core functions of the National Disability Authority are - (a) provide policy advice to Irish government and public bodies, (b) to assist the Minister with responsibility for disability in the co-ordination and development of policy relating to people with a disability, (c) to commission and undertake disability research and (d) to advise on standards and guidelines relating to services for people with a disability. Since its establishment this agency has co-ordinated and informed the formulation of disability policy and was instrumental in the development of a national strategy on disability.

³² To see the Act in its totality see: [http://www.oireachtas.ie/citizens information act 2007.pdf](http://www.oireachtas.ie/citizens%20information%20act%202007.pdf).

³³ See Equal Status Act (2000) and Equality Act (2004) Available: <http://www.irishstatutebook.ie/2000/en/pub0008/index.html> and [http://www.equality.ie/equality act 2004.pdf](http://www.equality.ie/equality%20act%202004.pdf).

advanced by the ICF framework whereby disability was defined as a ‘substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment’ (Disability Act, 2005:p6). The Disability Act has seven parts.³⁴ Part two (Sections 8-10) establishes that people with a disability are entitled to an impartial, independent assessment of needs. The Act also sets out how these assessments should be conducted, the individuals responsible for conducting the assessments and the redress measures available if an individual considers the outcome of their assessment to be unfair, unjust and unsatisfactory. However, to date, this component of the Act has only been enacted for persons aged 0-5 years therefore this provision of the Act cannot be enacted by women with a disability when accessing maternity care. Part three of the Act however does set out a legal obligation on public bodies, including the twenty-two maternity units in Ireland, to provide integrated and accessible services for people with a disability. Nevertheless despite these provisions, in contemporary Ireland, women with a disability continue to experience difficulty in accessing appropriate maternity services and care (Begley et al. 2010).

2.5.3 Disability legislation at European and United Nations level

In addition to national disability legislation and policy, the Irish government are also guided by disability policies and legislative instruments developed at European Union (EU 2006) and United Nations (UN 2006) level. The first EU policy for people with a disability was advanced at the 1992 conference of EU ministers. At their second conference, in May 2003, the EU ministers adopted the Malaga Ministerial Declaration on People with Disabilities, the provisions of which became the pillars of future disability policy for all EU member states, including Ireland. The overarching aims of both conferences were: (i) the desire to improve the quality of life for people with a disability and (ii) the elimination of all forms of discrimination against people with a disability. Post the 2003 conference, the Council of Europe, formulated a European Disability Action Plan (2005-2016),³⁵ this plan was a

³⁴ Part 1 outlines the definitions enshrined in the Act, Part 2 pertains to assessment of needs and sets out a mechanism for redress, Part 3 is concerned with access to buildings and services and the sectoral plans of various governmental departments, Part 4 considers genetic testing, Part 5 pertains to public service employment and Part 6 is concerned with the establishment of a Centre for Excellence in Universal Design. The Disability Act can be accessed in its totality at: <http://oireachtas.ie/disabilityact2005.pdf>.

³⁵ See: Council of Europe (2006) European Disability Action Plan (2006-2015), Available: http://www.coe.int/t/e/social_cohesion/socsp/Rec_2006_5%20Disability%20Action%20Plan.pdf.

framework to be used by policy makers in member states when designing, implementing and evaluating disability policies (EU 2006). The plan, consisting of fifteen action points, advocates for equal opportunities for people with a disability throughout all EU member states. Various provisions of the plan also set out how member states should ensure all people with a disability have equal access to health services, including gynaecological and maternity services. The plan also highlights the importance of disability training and awareness for all people engaged in the provision of services for people with a disability (EU 2006). Ireland has also ratified the UN Convention for the Rights of People with Disabilities (UN 2006). This statutory instrument requires signatory states to take appropriate action to ensure that people with a disability are afforded the same range, quality and standard of healthcare as non-disabled people. It prescribes that people with a disability should have equal access to the structural environment, that appropriate methods of communication for all people with a disability are implemented and that all relevant information be provided in accessible, and appropriate formats (UN 2006).

Nonetheless despite the existence of these statutory instruments, a recent review of national and international policies governing the provision of maternity care for women with a disability (Begley et al. 2009a)³⁶ highlighted the lack of professional or statutory policies relating to the provision of maternity care for women with a disability. The review revealed that, with the exception of the UK, none of the countries reviewed, had definitive policies or guidelines (professional or statutory) guiding the provision of care for these women. Recommendations contained in other Irish health policies and strategies³⁷ and specific disability legislation (Disability Act, 2005) refers to the need to treat people with a disability equally and in a non-discriminatory way. Furthermore, the two regulatory professional bodies (An Bord Altranais and the Medical Council of Ireland) and the two bodies responsible for medical education in Ireland (Irish College of General Practitioners and the Royal College of Physicians of Ireland) do not, at this point in time, provide guidance on the provision of maternity care for women with a disability. Additionally a survey of the nineteen publicly-funded Irish maternity units revealed that only one of the nineteen units had a written guideline governing the provision of care for women with a disability during pregnancy, childbirth and early motherhood. When reviewed, the scope of this guideline was limited, it referred to the provision of antenatal education for women with a disability

³⁶ The countries included in the review were United Kingdom encompassing Scotland, England and Wales, Sweden, Norway, Denmark, Netherlands, Canada, Australia, New Zealand and the United States of America (USA).

³⁷ This include the National Health Strategy: Shaping a Healthier Future (DOH 1994), A Plan for Women's Health (DOH 1997), Quality and Fairness: A Health System for You (DOHC 2001a), Primary Care: A New Direction (DOHC 2001b), The National Women's Strategy 2007-2016 and the National Intercultural Health Strategy 2007-2012 (HSE 2008).

(Begley et al. 2009a). The definitive lack of national and local policies and guidelines governing the provision of maternity care for women with a disability would suggest that in this regard the provision of maternity care for these women is more reactive than proactive (Begley et al., 2009).

2.6 The intersect between disability and the self

As an autonomous agent, a person with a disability, may or may not choose to claim an identity that incorporates their disability (Watson 2002, Shakespeare 2006). Individuals who consider disability as a positive, defining entity of the self, tend to reject the negative implications associated with the medical model of disability and respond by focusing on the exclusionary and unjust social obstacles that disable individuals (Shakespeare 1996). While some may question the notion of normality and the concept of a normal body, others may reject physicality as an 'essential, biological determinant of the self' (Watson 2002:p524), their disability and the associated limitations are part of their everyday experiences, a part of the self and their self-identity. Their awareness of self is formulated on the notion of what they feel themselves to be, not how others perceive them nor is it informed by discourse or power (Watson 2002). They reject the classification of helplessness and dependency, and assert the notion of subjectivity. Conversely, people with a disability may also choose not to recognise disability as a defining entity of the self. Those who experience oppressive social relations are more likely to reject their disability and are liable to develop a negative sense of self (Shakespeare 1996, Moore 1998).

Watson (2002) and Shakespeare (2006), in their discussions on disability and the self, do not discuss how the nature or severity of an individual's disability may or, may not impact on their acceptance of their disability and how this relates to the self. One theorist that does, Moore (1998) is convinced that the nature and manifestation of one's disability impacts on the individual's acceptance of their disability and on one's self-esteem and self-image (Moore 1998). Therefore, assuming this assertion is valid; it is likely that those with a congenital disability are more likely to accept and integrate their disability and consider it a positive entity of the self while those with an acquired disability are more inclined to reject their disability (Moore 1998, Kralik and Telford 2005b).

Undoubtedly, the acquisition of a disability disrupts the individual's biography; their assumptions about the self and assumptive world consequently, the individual may experience difficulty adjusting to an altered (revised) self, a self with a disability. The construct of an assumptive world was

first introduced by Colin Parkes (1971). The concept is founded on the perception that readily accessible assumptions, mainly cognitive in nature and constructed in childhood, constitute an individual's assumptive world (Janoff-Bulman 1992, Parkes 1971, 1975, Neimeyer 2010). These assumptions provide individuals with a sense of meaning, reality, control and purpose that when disrupted, the level of disruption experienced by the individual will depend on the nature and extent of the disruption. Minor events may not threaten the individual's assumptive world so the resulting disruption may be minimal. However, some events, like the acquisition of a disability, may have a profound affect on the individual's deeply held beliefs about the self. In this instance, the individual will be required to make meaning of their experiences, once achieved they form new assumptions that will form the bases of a revised self and assumptive world. Post the acquisition of a disability, an individual is required to construct a revised self, a self that will reside in a society that considers individuals to be functional, independent, capable, and able to engage in social reciprocity (Lindgren 2004, Barnes and Mercer 2007, NDA 2007a). The newly revised self may or may not be perceived to be separate from the old self or it may consist of entities of the old self that are compatible with the new self (Murphy 1990, Wendell 1996, Lindgren 2004). Alternatively, the individual may perceive their acquired disability as a threat to their existing self (Lindgren 2004) and they may instigate measures to defend and protect their pre-disability self. When an individual's biological or functional make-up does not permit the development of a self that incorporates their acquired disability they may perceive the self as less of a person, as a burden on others and on society, subsequently a negative sense of self may ensue (Moore 1998, Watson 1998). Engaging and interacting with other people with a disability, either through voluntary agencies or opportunistic interactions may facilitate in the dismantling of stereotypical negative perceptions of the self. Seeing how other people with a disability can live innovative, creative and valued lives may help dispel stereotypical myths and beliefs around dependency, vulnerability and helplessness. This engagement and interaction provides individuals with a narrative from which they produce a biography where the self reflexively creates an identity (Watson 1998, Giddens 2009).

The individual's difficulty in accepting a disability may also be influenced by the perceptions of non-disabled individuals located in their social environment. An individual's self-evaluation and self-image are dependent on the impression gained from significant others (Moore 1998). Stigma and discrimination, generated by others, mainly non-disabled members of society, create obstacles and challenges to participation for people with a disability, and may impede the process of adjusting and adapting to living with a disability. Negative attitudes and behaviours towards people with a disability, reflecting embedded patriarchal prejudices, formulated from negative, myths and stereotypes, continue

to be a major challenge experienced by people with a disability (Voh 1993, Shapiro 2000, Begley et al. 2010). Such attitudes and behaviours impact significantly on an individual's acceptance of their disability and construction of the self (Shakespeare 1996, Moore 1998, Watson 2002), and on the full acceptance, integration and participation of people with a disability in mainstream society (Olkin and Howson 1994, Antonak and Livneh 2000, NDA 2007a). Over the past decade the National Disability Authority, conducted three surveys in Ireland, exploring public attitudes towards people with a disability (NDA 2002, 2007a, 2007b, 2011). Emulating international trends, the more recent survey illustrated how attitudes towards people with a disability are changing for the better (NDA 2007a, 2007b, 2011). The surveys highlighted the clear relationship between the formulation of attitudes towards people with a disability and the personal experience of disability (NDA 2007a). Personal contact and close relationships with people with a disability reduce negative attitudes, behaviours and prejudice from others in society (NDA 2007a). The media also play a significant role in reflecting, defining and shaping others' attitudes of and thinking about people with a disability (Longmore 1986, Susman 1994, Briant et al. 2011). In a study conducted in the UK, Briant et al (2011) examined how the print media's reporting of disability influenced public attitudes of people with a disability. Their analysis revealed how, in the last five years, accounts of the personal experiences of living with a disability have decreased while articles relating to disability benefit fraud have increased. Moreover, there was a shift in the way people with a disability were perceived and described, instead of using euphemisms and imprecise terms such as 'cripple', 'retarded', 'handicap' (Spruill 1999, Barnes and Mercer 2007), people were described using pejorative descriptors like 'scrounger, cheat and skiver' (Briant et al. 2011:p6). The use of such terms corresponded with an increase in the perception that people with a disability were deceptive and undeserving of social welfare benefits (Briant et al. 2011). It is perceptions like these, created, sustained and altered in the course of everyday life that influence how people with a disability are considered and experienced in contemporary society.

2.7 Conclusion

This chapter has described how since the mid 1990s, numerous international statutory instruments advocating equality, non-discrimination and the fundamental human rights of people with a disability have been enacted in Irish society. The different and divergent models on disability were also discussed. Presently the social model of disability serves as the reference point for many people with a

disability and national and international policy makers. The main objective of the social model was to shift the emphasis of disability away from the individual and to situate it in the confines of society and the individual's environment (Lutz and Bowers 2003). It emphasises the influential role an individual's environment has on their disability, recognising how the individual's environment can hinder or help their ability to function in society (Lollar and Crews 2003). Disability is not defined in relation to physiological or cognitive measures; it uses terms such as 'barriers' (attitudinal, environmental) and 'a disabling society,' to firmly situate the root of the disability outside the individual and within society (McMillan Boyles et al. 2008). Removing such barriers will counteract the disadvantage experienced by people with a disability (Lutz and Bowers 2003). The chapter also identified the existence of a statutory framework affording fundamental rights to people with a disability residing in contemporary Ireland, but the evidence demonstrates how, despite this framework, women with a disability continue to be treated differently when accessing maternity services and care. The chapter concluded with a discussion on how the nature of an individual's disability and the attitudes and actions of others significantly impact on how one integrates disability and the self. A sample of key theories pertaining to self and identity are discussed in greater detail in the following chapter.

Chapter 3 The Self, Identity and Symbolic Interactionism

'We live in a world where identity matters. It matters both as a concept, theoretically and as a contested fact of contemporary political life' (Gilroy 1997:p301).

3.1 Introduction

In the past two decades qualitative inquiry has gained prominence³⁸ and qualitative studies with their focus on subjective meaning have provided a greater understanding of social realities (Denzin and Lincoln 2005) (see 5.4, chapter 5). Occurring alongside this proliferation of qualitative studies was a discursive surge around the concept of self and self-identity (Ashmore and Jussim 1997, Hall 2000). Premodernity, individuals were considered to be unique, in character and potential, which may or may not be realised, attributes of the self were understood to be relatively fixed and individuals were perceived to have assumed a passive role in the construction of their biographies. Conversely, postmodernity was synonymous with a shift towards the valuing of individuality whereby the self was no longer perceived as a passive entity, determined by external influences (Giddens, 2009). Individuals no longer depended on established traditional norms to inform the self, their self-identity and role in society, they became participative contributors in the construction of their own biographies.³⁹ The purpose of this study was to: (i) explore the process involved in the transition to motherhood, from the perspective and experiences of women with a disability, and (ii) the relationship of that process to the self. It was concerned with exploring how symbolic interactions with others and an individual's environment influence the construction of the self as a mother with a disability. Symbolic interactionism was the theoretical perspective that guided this study accordingly it was the different conceptualisations of the self advanced by traditional symbolic interactionists⁴⁰ that provided an understanding of how the self is constructed. These conceptualisations, presented in this chapter, informed the coding paradigm (see Table 5.2, chapter 5), the analytical tool used when collecting and coding the data. While other conceptualisations of the self were considered, for example, the sociological conceptualisation proposed by Anthony Giddens (1938-present) and the psychoanalytical conceptualisation proposed by Sigmund

³⁸ For a detailed explanation on the eight historical moments see Denzin and Lincoln (2005) pg. 14-21.

³⁹ The concern with the self was not unique to the post-globalisation era however, the type of self, and the use of reflexivity and external expertise to achieve this, were (Bailey 1999a).

⁴⁰ This chapter focuses on the work of George Herbert Mead, William James, Charles Horton Cooley and Herbert Blumer.

Freud (1856-1939), it was the conceptualisations of the self advanced by symbolic interactionists' that were congruent with the purpose of this study. Before describing these conceptualisations, the chapter will begin by defining the concepts of self and identity.

3.2 Defining self and identity

Sourcing a precise definition on self and identity proved difficult. Some suggest that the concepts are 'large, amorphous, and changing phenomena that defy hard and fast definitions' (Ashmore and Jussim 1997:p5), while others suggest the concepts are related and interconnected (Kralik and Telford 2010). At their core, both have a number of associated concepts including, self-awareness and reflexivity, but despite this commonality the concepts of identity and self are, as evident by the diverse ways they have been used throughout different discourses, fundamentally different (Ashmore and Jussim 1997).

3.2.1 Defining identity

Identity is defined as the array of meanings that define who an individual is when: (i) that individual assumes a specific role in society, (ii) claims specific traits that identify them as a unique individual or (iii) claims membership of a particular group (Burke and Stets 2009). Individuals exist within the context of a social structure, they define themselves according to others, either individuals or a group, consequently, their identity evolves from their relationship with others and the community they reside in (Woodward 2004, Burke and Stets 2009). So, identity is a combination of how an individual sees themselves and is seen by others, a socially recognised position, recognised by the individual and others through the social relations they form, engage and interact in.

The interrelationship between structure and agency is critical in the construction of an identity, both are weaved together intricately, one can impact on the other (Woodward 2004). Structure refers to the external factors, outside an individual's control that are deeply entrenched in contemporary society, they include cultural and the economical factors (Woodward, 2004). While agency is an intrinsic

feature referring to the degree of control an individual exerts over who they are.⁴¹ Notably when women with a disability access maternity services they encounter multiple structural challenges in the form of environmental, attitudinal and communicational challenges that impede their agency and result in them feeling vulnerable and demeaned (Kallianes and Rubenfeld 1997, Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Faber 2000, Grue and Tafjord-Laérum 2002, McKeever et al. 2003, Prilleltensky 2003, McFarlene 2004, McKay-Moffat and Cunningham 2006, Smeltzer 2007, Malacrida 2009, Begley et al. 2010, Walsh-Gallagher et al. 2012).

3.2.1.1 Sameness, uniqueness and the formation of identity

The construction of an identity is also dependent upon the degree of self-awareness an individual has and the individual's ability to engage in an ongoing partial and contextual process of identification⁴² (Woodward 1997, 2004, Lawler 2008, Giddens 2009). Developed over time, self-awareness requires the individual to actively engage in a role or process to develop, choose and adopt a specific identity. For example, a woman who wishes to take on a maternal identity will plan to become pregnant and have a baby. Self-awareness emerges when the individual can distinguish between the two phases of the self ('I' and 'Me', see 3.3.1) - and retain the ability to distance themselves from the demands of society. This sense of distancing demonstrates that each individual can react and respond to social interactions and relations in a unique manner. Individuals are informed by the attitudes of others but it is up to the individual to decide if such attitudes are relevant and whether or not these are assimilated or excluded into their sense of self. Noting how the term 'identity' was derived from the Latin term *idem*, which means 'same', Lawler (2008) remarks how individuals share common characteristics with others⁴³ while retaining a uniqueness that differentiates them. It is through this sense of sameness and uniqueness that an individual develops an understanding of the self (Smith et al. 2001, Lawler 2008). However, there can be a discrepancy in how the individual and others perceives her/himself. This discrepancy can be at a private level, personal level (within the context of family and/or friends) or at a more public, global level (Woodward 2004).

⁴¹ An individual's sense of agency can be limited by structural and pathological factors, such as the ageing process, altered or impaired bodily images and/or diminishing illness. Material and social factors include education, poverty, negative prejudicial attitudes and/or infrastructural barriers.

⁴² Identification is defined as a process where the individual assumes characteristics or patterns of behaviours of others.

⁴³ Such as humans, women, white, Irish.

The sense of sameness is epitomised in *'Stepford Wives'*, a satirical novel, about stereotypical American housewives penned by Ira Levin (1972). The novel and subsequent cinematic depiction depict how beautiful, independent, autonomous women become subservient entities complying with the normative behaviours of the social world they find themselves located in. Situated in a world that espouses the conventional role of the woman, the women are positioned in the home where they are expected to passively enact normative behaviours associated with the roles of wife and mother. Any sense of autonomy or agency these women had before locating the self in this social world is relinquished. All are expected to act, behave and perform from the same script that determines the scripted behaviours of how a wife and mother should act; in this life of wifely and motherly servitude there is no latitude for distinctiveness.

Conversely, the concept of uniqueness refers to the specificity of the individual, the 'essence' or core of the individual that may be more profound and authentic than the self portrayed to the external world (Lawler 2008:p5), an aspect of the self not created by one's social environment. This idea of a core, true, inner, deeper, authentic self, untouched by the social environment, has gained momentum throughout the sociological discourse. Nevertheless, Norbert Elias (1994) questioned the taken-for-granted belief that individuals are bounding and self-limiting entities, and that the true, inner self remains untouched by the individual's social world. Elias (1994) agreed with the supposition that a true, inner self exists⁴⁴ but he claimed that the self displayed by the individual is the one informed and constructed through influences in their social world, there is no demarcation between the inner and outer self (Elias 1994).

3.2.2. Defining self

Similar to identity, defining self is a complex process as it is difficult to convey what the self is and how it may function (Onorato and Turner 2001). The self is defined as an organised set of intrinsic processes that: (i) confers an ability to consider, observe and evaluate itself, (ii) to take account, to plan and to construct (and reconstruct) itself, (iii) an entity that can be modified in different situations (Smith et al. 2001, Burke and Stets 2009), (iv) an individual composed of mind and body, character and personality, (v) an entity that can adjust to the setting they are located in. In his iconic work, Mead

⁴⁴ Elias (1994) contends that a true, inner self was a construct of civilisation, a consequence of Western culture occurring around the time of the Renaissance.

(1934) theorised that the self originates in and evolves from an individual's mind, as the mind interacts with its environment to sustain the individual. American philosopher George Herbert Mead (1934) claimed that the apparatus that controls an individual's response to their environment is the mind. An individual develops a state of mind through their ability to identify meanings and to indicate these to the self and others. It characterises the individual's consciousness of her/his own identity. The individual can, as an autonomous agent, choose what aspects of the self they want to present to others and what aspects they want to disguise. It is the self presented to others that informs and influences the creation of perceptions about the individual and these perceptions are then internalised by the individual to form an understanding of the self (Kralik and Telford 2010).

3.2.2.1 Different representations of the self

Individuals, in their overall scheme of self-understanding, incorporate three elementary self-representations; the 'individual self', the 'relational self' and the 'collective self' (Sedikides and Brewer 2001:p1). All three representations are social in origin, coexisting in each individual and are conceptualised as 'an integrated system in which interplay, integration and interdependence are the modus operandi' (Deaux and Perkins 2001:p300, Sedikides and Brewer 2001).⁴⁵ The first representation, the individual self, is attained by the mere fact that the individual is different and distinct from others; this form of self representation is dependent on the act of comparing oneself to others to determine one's sameness or difference. Apparently, this need to compare oneself to others is inspired by the need to protect and enhance oneself psychologically (Sedikides and Brewer 2001) The individual's unique constellation of characteristics renders them similar or dissimilar to others, this differentiates the individual within their social context (see Appendix 2). The second representation, the relational self, comes into existence as part of a unit, defined by the system of relationships the individual resides in, it is created through one's interactions with and the appraisals of others within and outside the familial structure (Sedikides and Brewer 2001). The third self representation, the collective self, is realised when an individual includes themselves in a social group. The collective self is not a personal self; it is a shared social identity, the individual's sense of self is stimulated by the 'psychological reality' of the social group, this has an important but informal role in the maintenance of an individual's self-concept and the

⁴⁵ This study was informed by the symbolic interactionist's perspective of the self therefore a discussion of the psychoanalyst's perspective of the self was not included in this thesis however, the author is aware that such perspectives exist.

change generated therein (see Appendix 2).

While acknowledging the existence of the other two representations, this study was concerned with the relational self, pre-motherhood and as a mother. The relational self comes into existence as part of a unit, defined by the system of relationships the individual resides in, it is created through one's interactions with and the appraisals of others within and outside the familial structure (Sedikides and Brewer 2001). These relationships extend and expand the self whereby individuals assimilate and integrate the perspectives, resources and identities of others, especially significant others (Aron and McLaughlin-Volpe 2001). The relational self is motivated by the desire and need to belong. This sense of belonging is an essential and powerful motivating factor, exemplified by the individual's willingness to form relationships and their reluctance to dissolve relationships with others even when the purpose of some relationships are fulfilled (Tice and Baumeister 2001).

3.3 Symbolic interactionism, the self and identity

The concepts of self and identity have been explored by academics from many disciplines including sociologists, psychoanalysts and philosophers (Elliott 2010). At the turn of the 20th century theorists steeped in the philosophy of pragmatism and symbolic interactionism stressed the relational and social nature of the self (Onorato and Turner 2001). This conceptualisation challenged the prevailing assumption that the self was an intrapsychic, cognitive structure devoid of emotion. Consequently, a compilation of ideas concerning the composition and function of the self and self-identities emerged, donating a perspective that focuses on the relational and social nature of the self, this perspective was symbolic interaction.⁴⁶ This section begins with the founder of symbolic interactionism George Herbert Mead's (1863-1931) conceptualisation of the self, the interacting self.

⁴⁶ Herbert Blumer (1900-1987) coined the term symbolic interactionism, his ideas and interpretations of American philosopher George Herbert Mead's work on the construction of the self led to the development of a strand of symbolic interactionism referred to as traditional symbolic interactionism. Other contributors to this branch of philosophy include William James and Charles Cooley.

3.3.1 The interacting self

George Herbert Mead (1863-1931) stressed the need to examine and explore the impact interpersonal interactions with others and the wider society have on the construction of the self. Mead considered the self, to be an interactive, cognitive entity, an 'interacting self' (Mead (1934), cited by Holstein and Gubrium 2000:p27). Although widely cited in the literature as the founder of traditional symbolic interactionism, Mead did not perceive himself to be a symbolic interactionist; he described himself as a philosopher or social psychologist. His influences included philosophy, psychology and sociology. Drawing on these influences he developed a theory explaining how the self emerges from a social context, through social engagement and interaction with others. Mead's theory of *Mind, Self and Society* (Mead 1934), published by his students after his demise, demonstrated how concerned he was with the processes and structures that linked the self with the external perceptions of others. He rejected the psychological view that the self was an isolated, independent entity that could develop in isolation rather, he conceptualised the self in functional terms, emphasising the activities by which the self is constructed and expressed (Deaux and Perkins 2001). Mead proposed that the mind and self were not pre-existent entities but that both emerged through language and one's interactions with others. Individuals were, for Mead, self-conscious beings with the capacity to imagine, reflect on and visualise how others perceive them and to carry that image with them. He claimed that individuals respond to each other on the basis of the meaning inherent in the gestures demonstrated and displayed by others. These gestures are symbolic; they have the capacity to alter communication, moving it from an instinctive, automatic process to an interpretative practice. The self is constructed through these symbolic engagements and interactions with others. Accordingly, the self cannot be disconnected from others, it cannot be considered in isolation outside the realm of the individual's social world (Elliott 2010).

3.3.1.1 The phases of the interacting self

Mead described the self as consisting of two phases and used personal pronouns - 'I' and 'Me,' - to describe the phases. These phases represent the connection between perception and behaviour that is guided by the individual's mind; they continually alternate as the individual engages in ongoing behaviour. The 'I' represents the phase where an individual responds as an acting subject to objects or

others in their social world (Hewitt 2007). It is the un-socialised self, a compilation of the individual's character, needs and desires, the agent-actor that initiates behaviours under the direction and control of the 'Me', in order to produce desired consequences. The 'I' is the individual's unique needs and desires that distinguish them from others. It provides momentum, spontaneity, impulsiveness and innovative responses to others, injecting creativity and originality into social processes (Hewitt 2007, Elliott 2010). The 'I' is continually acting while the 'Me' continually perceives but both phases are necessary if the individual is to maintain a relationship with others in their social world. The 'Me' refers to the socialised element of the self; it comprises of the internalised attitudes of others, embodies meaning, understanding and experience. It is reflexive,⁴⁷ originating in the practice of role taking where the individual perceives the world from the perspective of the other. It is the controlling and restraining aspect of the 'Me' that provides direction for the behaviour an individual takes.

The significance of the 'I' and 'Me' elements becomes clear when situated within the framework of an act, especially one that involves interacting with others. An act is initiated when the individual's adjustment to a particular situation is interrupted, impulsively; the individual is motivated by the disturbance in some way. Subsequently, the action or behaviour the individual was engaged in at that point in time is disturbed and the 'I' directs the individual's attention and behaviour toward the new stimulus. The individual becomes aware of their environment and the objects situated within it and it is these stimuli that one's actions are directed towards. The individual becomes aware of their initial, impulsive response to the stimulus and this awareness sets actions in motion. The awareness of their initial response to the stimulus heralds the 'Me' element of the self. The continuous alternating of the two phases is manifested when the 'I' is activated in response to a situation and the object therein whilst momentarily the responses becomes part of the past and is therefore part of the 'Me'. The 'I' initiates the act that comes under the direction, control and guidance of the 'Me'. Situated in the individual's recent memory this response is then available to the individual as an object of reflection. Subsequently, an image of the self is generated and the individual as an 'I' responds to this image (Hewitt 2007). This process is exemplified by the actions of women with a disability when addressing the attitudinal challenges encountered when accessing maternity care, faced with attitudes that perceived them to be helpless and dependent, women may choose, while availing of care, to adopt a sick role, the behaviours and actions associated with this role was ingrained in their psychic, from their previous experiences of accessing medical care as a child with a disability, where their care was influenced mainly

⁴⁷ The 'Me' it has the capacity to take account of itself as an object, distinct from others, one that has its meaning and position in the environs of others.

by the medical model of disability.

This iterative configuration of 'I' and 'Me', of spontaneity, impulse and reflection is the means by which individuals achieve control over their behaviour. The 'I' phase is outside the individual's control, the individual is not aware of how they are going to respond until they begin to act therefore, their behaviour can only be controlled after the 'I' is activated. The process of constructing the self is further informed by the internal conversations an individual engages in when trying to decide between what it is they want to do and what it is others want them to do. In the internal dialogue that ensues the 'I' and 'Me' alternate and the individual imagines the various connotations that could accompany their various responses. Likewise, when an individual is overwhelmed by a particular situation the 'I' and 'Me' phases equip the individual with the capacity to respond and act, the 'I' is activated to respond to the particular situation and their awareness of the immediate response(s) signals the 'Me'. The responses are then situated in the individual's memory and are available to them reflectively. The information obtained reflectively enables the individual to construct their own biography, moving it from one that is socially constructed to one that is constantly self produced (Giddens 2009). Furthermore, the impulse to act, the imagined responses to this act, the imagined alternative actions and the final resolution of the internal dialogue that results in a specific course of action, demonstrates how the self is a process created and recreated through social interaction with and the appraisals of others (Hewitt 2007).

Tension exists between the 'I' and 'Me' phases. This tension is generated by the individual's capacity to exercise control over their behaviour, which is dependent on the individual's ability to inhibit their initial, impulsive response to a situation. But on occasion, the impulse can be so powerful that the individual initiates actions before they can assert control over them. As the 'Me' emanates from the individual's imagination of how others perceive them the perceptions of others can be misinterpreted and cues that could help in the formation of an appropriate action could be overlooked. Additionally, individuals retain the capacity to act according to their self interests so, in a specific situation they may decide to enact alternative, sometimes unacceptable, actions and behaviours (Hewitt 2007).

When individuals experience a life changing psychosocial event, like becoming a mother, they engage and embrace the opportunities and threats that accompany the event (Giddens 2009). Giddens uses marriage and divorce as an exemplar of a transitional event formulating a crisis of the self. He suggests that the termination of a marriage is accompanied inevitably with pain, a sense of loss and mourning however he also suggests that some individuals take positive measures to deal with divorce and the associated marriage breakdown. An emotional engagement of the self is activated, considering

and projecting the past, the opportunities lost and contemplating the future with its alternative possibilities requires the individual to experiment with a transformed sense of self. Individuals gain a new understanding and perception of the self; they develop and mature emotionally as they experience a renewal of the self. As the individual advance through the marital separation, they are effectively engaging in an open project, sketching over the past, considering the future and dealing with complex issues associated with the separation. Engaging in interpersonal relationships after a marital separation may be marred with anxiety, apprehension, risks and opportunity. For Giddens the relation between society and the self is not static, it is fluid and dependent on the individual negotiating, changing and developing. Throughout his writings Giddens does not refer to motherhood but this can be equally considered as major transition or life changing event that potentially could cause a crisis of the self. Contemporary social practices shape events of the future, if as Giddens suggests the relationship between the self, society and reflexivity is a dynamic one overturning conventional ways of being then theoretically, the construction of an identity is a constant and continual process which requiring the active participation of the individual, recognising and acknowledging individual agency.

During the transitional process of becoming a mother the woman may feel overwhelmed and may respond by activating the 'I' phase of the self. Once activated, the 'I' formulates and integrates strategies to cope with motherhood. These strategies may manifest as either problem or emotional focused coping strategies (Lazarus and Folkman 1984). When coping with a stressful event, if the individual is intent on managing the event, they tend to employ problem focused strategies including, taking direct action, seeking information, turning to others for help and assistance (Keil 2004). Through the enactment of these strategies the individual attempts to gain control over the event. Conversely emotional focused coping strategies - resigned acceptance, emotional release, and avoidance - are employed when the individual appraises the event as one that is unchangeable so they either accept or avoid the consequences that accompany it.

Expanding Mead's theory, Herbert Blumer (1900-1987) questioned how the self attached meaning to experiences⁴⁸ (Elliott 2010). Blumer reiterated the idea that symbols mediate interaction, for him they facilitated the establishment of meaning (Blumer 1998). Everything in an individual's social life refers to the self and is assigned meaning by self-interpretation, symbols are not just stimuli for action, they are symptomatic of the self (Blumer 1998). Accordingly, while the individual engages in a continual

⁴⁸ Blumer suggested that individuals interpret and define their actions together with the actions of others.

process of monitoring and interpreting the multiple identities they have assumed or intend to assume, they construct and develop actions and behaviours (Elliott 2010). It is through this process of interpretation that the individual demonstrates competence of self to others located in their social world.

3.3.1.2 The role of symbols in the interacting self

'Symbols and representations are important in the production of identities'.

(Woodward, 2004:p12)

Mead's theory revolves around the notion of symbolic interaction, an interaction informed by a variety of symbols. The variety of symbols an individual draws from is informed by the culture they reside in, these symbols can be linguistic, behavioural, pictorial and gesticulational (Woodward, 2004). Symbols become significant when the responses and images stimulated by them are similar to those produced by other individuals who encounter the same symbol. An individual, through behaviours, appearance and social relations symbolises, the sort of individual they want others to think they are. How an individual speaks, the clothes they wear, the behaviours they exhibit all offer important information about the self (Williamson 1986). For example, in contemporary Western society, mothers will purposively change their physical appearance and demeanour to portray an image that corresponds with the societal perceptions of a good, responsible mother (Bailey 1999a). These perceptions are informed and influenced by the hegemonic ideologies of motherhood (discussed in detail in chapter 4).

Individuals engage and interact with each other through meaningful symbols, the core symbol being, linguistic. During the process of becoming a mother, women with a disability interact with many individuals. Empirical evidence reveals how when engaging and interacting with others, especially caregivers, women with a disability encounter affirming and non-affirming attitudes regarding their decision to become a mother and their ability to fulfil the socially prescribed responsibilities and tasks of mothering (Begley et al. 2010). Such attitudes inform and influence the behaviours and actions of others. Affirming attitudes generate encouraging behaviours that engender a sense of worth, belonging, achievement and fulfillment. However, attitudes reflecting embedded prejudices, fashioned from negative myths and stereotypes create prejudicial and patriarchal behaviours, and are generally accompanied by derogatory and insensitive comments that affect the women's self-confidence, self-

esteem, self-efficacy and self-belief, and cause them to question their ability to be a good, competent, responsible mother (Shapiro 2000, Begley et al. 2010). Moreover, when the interactions are marred by negative attitudes, these attitudes are stigmatising, offensive and derogatory (Begley et al. 2010). Accordingly, women with a disability experience a diminished sense of agency and when support for their claimed identity as a mother is not forthcoming, negative emotions evolve.

3.3.1.3 Role taking and role making abilities of the interacting self

Mead suggested that, in any given social situation⁴⁹ individuals imaginatively take the role⁵⁰ of others. By doing so the individual enacts real and imagined behaviour associated with a specific role that others in turn, evaluate, confirm or refute. When roles are enacted they become a dimension of the self (Hewitt 2007). Symbolic interactionists define role 'as a perspective from which conduct is constructed' (Hewitt 2007:p64), an indefinite perspective from which an individual can act. They propose that individuals have the practical and creative capacity to initiate appropriate actions for any given situation. This proposition is founded on three core tenets: (i) 'individuals cognitively structure situations into roles, (ii) a role is a compilation of ideas and principles about what to do in a situation and (iii) individuals use roles as a resource for interaction in social situations' (Hewitt 2007:p63). The proposition suggests that women with a disability have the capacity to define any given social situation; they can determine who is present and what will occur, thereafter they cognitively structure the situation in terms of roles. Once the situation is defined for example, as a familial situation, the individuals involved in it become known and are named, for example, mother and child, the assigned name will reflect the roles taken - mother, son or daughter. Accordingly, to ensure their behaviour and actions are consistent with the role of mother the women employ an organised set of behaviours consistent with that role. While the role of mother does not come with a list of things that a mother should do, assumptions regarding how mothers and children relate to and act towards one another do exist. Having an overall

⁴⁹ Social situations have two composite elements, a conventional dimension encompassing the cultural components that individuals endeavour to meet in a specific social situation and an idiosyncratic dimension referring to the unique interpretation that an individual brings to the situation (McCall and Simmons 1978) For example, the conventional dimension of a maternal identity may entail meanings such as carer and provider, while others such as friendship, may be introduced by a mother, this represents the idiosyncratic dimension.

⁵⁰ Role refers to the constellation of rights, duties and obligations, the set of expectations associated with a particular social position that guide an individual's attitudes and behaviours, providing structure, meaning and organisation to the self and the position the individual is located in (Hewitt 2007, Burke and Stets 2009).

sense of the situation and how various roles are assigned to the different individuals in that situation provide the women with an understanding about the role of mother.

Conversely, role making is the process whereby individuals construct behaviours and actions that fit with a given situation; these are consistent with the individual's role and interconnect with the behaviours and actions of others. The two processes of role taking and role making are interlinked; an individual cannot construct a role without occupying the perspective of the other and considering the self from that perspective (Hewitt 2007). This ability to take the role of others demonstrates how the self is a cognitive not an emotional entity, a fact Mead was cognisant of; his cognitive conceptualisation of the self does not make reference to the individual's emotional responses. Nevertheless, he does not completely overlook the emotional aspect of the self; he contemplates how emotions serve as a signal to others to act in a particular manner, a manner prescribed by society.

3.3.2 The empirical self

Predating Mead's 'interacting self' American pragmatist William James (1890-1950), advanced the notion of an 'empirical self' (James (1961), cited by Holstein and Gubrium 2000:p23). James proposed that the self did not originate from a purely metaphysical realm but was derived from the interactive processes between the individual and their social environment (Holstein and Gubrium 2000). James grounded the self in the empirical world and his discussions of the self began with the self as experienced by him and others in everyday life - 'the self of daily awareness that is formed in reflection upon itself' (Holstein and Gubrium 2000:p22). James used similar personal pronouns to Mead, the 'I' and 'Me', to distinguish between the subjective and objective self. 'I' being the subjective self, the agent of the experience, the thinker and 'Me', the objective self, the individual's thoughts.⁵¹ The 'Me' comprises of a multiplicity of selves that evolve from the multiple roles the individual occupies.

⁵¹ The 'I' was the changing state of an individual's life experiences and consciousness, while 'Me' was variable, at times individuals could perceive their thoughts to be an essential part of them while at other times to be detached and external to them. These thoughts play an important role in behaviour, they signify how behaviour is a social, biological and instinctive act (Onorato and Turner 2001).

3.3.2.1 Multiple roles assumed by the self

In modern society, individuals occupy multiple roles simultaneously, for example, mother, wife, daughter, student and friend, these are a composite of the self. Juggling these multiple roles can generate tension and cause the individual to experience a sense of conflict. So, to offset this sense of conflict, the roles are arranged in a hierarchical structure (McCall and Simmons 1978). This hierarchy represents how individuals perceive themselves, it represents the internalised needs of the self, the higher a specific role, the more important and prominent it is to the self. So, for those women for whom being a mother is central, their maternal self takes precedence over other roles and entities of the self. A number of external⁵² and internal⁵³ factors influence the prominence given to a specific role. These include the support received when occupying a specific role and the level of reward - intrinsic and extrinsic - gained from assuming that role. The greater the support for a specific role, the higher the prominence afforded to it. Prominence is also influenced by the individual's commitment to a specific role, if through the maternal self, the woman's self-esteem is heightened and she experiences positive feelings, then the role of mother and her maternal self will be given precedence over other entities of the self. Self-esteem has three components, self-efficacy, referring to an individual's sense of competency; self-worth representing a sense of being, value and worthiness and self-authenticity signifying that the individual is being their true self. Individuals achieve a heightened sense of self-efficacy when they behave in ways that are consistent with the meanings and expectations of a specific role. However, even if an individual's level of achievements are high, this may not necessarily translate into a high level of self-esteem. If the individual's aspirations were higher than their achievements, the imbalance created by this discrepancy results in the individual focusing on the aspirations that were not achieved rather than those that were and subsequently this engenders a sense of incompetence. A higher level of aspirations engenders a perception that the individual is unable to meet their anticipated goals accordingly, they experience a low level of self-esteem. Alternatively, if the individual's aspirations are modest and their achievements are modest, the individual may experience a heightened level of self-esteem. Self-esteem acts as an internal barometer of belongingness (Tice and Baumeister 2001), if the individual feels socially accepted one's self-esteem increases but similarly it decreases if the individual considers themselves socially rejected.

⁵² Extrinsic rewards gained from assuming an identity may include monetary reward and the prestige obtained from others when claiming a specific identity.

⁵³ Intrinsic factors include the sense of gratification an individual may experience when performing a specific role.

The performance of any role is dependent on the negotiation that occurs with others in a specific situation. Each individual involved in the interaction will have a view on how their role relates to the role of the other. They will enact behaviours that interrelate with each other. To avoid conflict, a degree of co-ordination is required between the individuals but if conflict was to occur both need to engage in a process of negotiation and compromise to ensure the interaction is cordial. If others do not support the individual's role performance in a given situation, this could threaten the self. Consequently, the individual will experience negative emotions and a decreased self-esteem but to offset the negative emotions felt the individual, as an autonomous agent, can enact counter-mechanisms (McCall and Simmons 1978:p92). There are several counter-mechanisms an individual can invoke to avoid upset when dealing with negative feelings when their prominent identity is not confirmed or supported by others. The measures result in the individual either withdrawing from the interaction, or they may blame others in the interaction for not supporting their prominent identity, resorting to criticising and penalising them for their lack of support. The individual could also compensate for the lack of support by switching identities so that the focus is diverted to an alternative identity or they may choose to concentrate on the cues that support the chosen identity and remain oblivious to the cues that do not. Moreover, the individual may misinterpret cues; they may interpret the cues exhibited by others during the interaction as supporting their identity whereas in reality they are unsupportive.

When engaging and interacting with caregivers involved in the provision of maternity care women with a disability do experience conflict between how they perceive themselves and how others perceive them (Begley et al. 2010, Walsh-Gallagher et al. 2012). These women want to be treated like any other woman accessing maternity care but all too often their disability takes precedence over their pregnancy or their role as a mother. It becomes their defining characteristic consequently, the women are perceived as a liability, dependent on others, in need of care and assistance (Thomas 1998, Begley et al. 2010, Walsh-Gallagher et al. 2012). Some women internalise this perception and subsequently adopt a different persona, the independent, autonomous woman is replaced by a passive, submissive individual who feels helpless, belittled, humiliated and dependent, one who questions her own decision to become a mother and her ability to competently care for her baby (Begley et al. 2010). The enactment of such emotions and feelings signify how the self is a cognitive and emotional entity. While Mead's conceptualisation did not take account of the emotional aspect of the self, Charles Horton Cooley's conceptualisation did.

3.3.3 The looking glass self

Charles Horton Cooley's (1902-1922) conceptualised the self as an emotional entity and used the metaphor 'looking glass self' (Cooley (1964), cited by Holstein and Gubrium 2000:p24) to describe how the self and significant others were inextricably linked, and how emotions arose when interacting with others (Onorato and Turner 2001, Burke and Stets 2009). For him the self emerged from their subjective interpretation of how others perceived and evaluated their personal characteristics and behaviours. Essentially, the 'looking glass' self is a public self accessible to others through social engagement and interaction consisting of the reflected views of others. Cooley suggests that the self has three principal components: (i) the ability to imagine how an individual appears to others, (ii) the ability to image how others may judge the individual on their appearance and (iii) the capacity to possess a range of positive and negative feelings, like pride or mortification. Cooley's conceptualisation, illustrates the emotional and contractive nature of the self, it signals how individuals are defined in terms of their similarities and differences to others and identifies how individuals see themselves reflected in the interaction of others, it is through this reflected appraisal that individuals gain an understanding of who they are. Accordingly, the individual's self-views can be confirmed, shared or rejected by others, to the extent that if one's self-views are not shared or verified this may cause an emotional upset that manifest in negative emotions.

3.3.3.1 The role of emotions in the looking glass self

Emotions refer to the feelings individuals experience in a given situation, they are the physiological and meaningful responses generated in social interaction and are essential in the role making process (Cooley 1964, Hewitt 2007, Burke and Stets 2009). Emotions originate from and are regulated through the individual's participation and interactions with others, arising as individuals attempt to complete individual and social acts, like being a mother. Individuals possess four primary emotions - fear, anger, depression and happiness - that are established universally, evolutionarily and biologically (Kemper (1987), cited by Hewitt 2007). These primary emotions are supplemented with a multiplicity of secondary emotions including love, pride, guilt, shame, hate, jealousy, gratitude, wonder, awe and hope. How the secondary emotions are experienced and expressed are dependent on social expectations. Emotional expression is part of role performance. If the role assumed by the individual is

verified by others, it is normal for them to experience feelings of elation and satisfaction however, if unverified, they may experience frustration and anger. Thereafter the individual will invoke counter-measures to address the negative emotions. By doing so, they may employ measures that would reassert the self. The more salient the role, the more likely an individual is to engage various coping strategies to manage negative and unpleasant emotions associated with the non-verification of their role.

3.3.4 Reflexivity and the construction of the self

Central to the symbolic interactionists' theory of the self is the concept of reflexivity. Reflexivity is defined as 'a self-defining process that depends upon the monitoring of and reflection upon, psychological and social information about possible trajectories of life' (Elliott 2010:p45). As discussed previously, the self is constructed through the individual's capacity to: (i) continually examine; structure and restructure social interactions and practices and (ii) through the reflexive arranging of self narratives and an individual's ability to negotiate, and reflect on an ever increasing range of diverse lifestyle choices. The information obtained from this reflexive process constitutes what it is the individual can do and how they do it. In essence, the individual creates their own biography, marking a shift from a socially constructed biography to one that is constantly self-produced. Individuals can draw on a number of resources to inform the reflexive process and to create a suitable environment to address existential issues and provide social stability. These resources include discursive consciousness of the circumstances of their actions and practical consciousness⁵⁴ incorporated in everyday activities. Practical consciousness helps to bracket anxieties that materialise when the individual becomes disorientated and lose their sense of reality.

3.4 Structural symbolic interactionism

An alternative version of symbolic interactionism, structural symbolic interactionism, contrasts with the traditional version of symbolic interactionism outlined previously. Structural symbolic

⁵⁴ Practical consciousness is the taken for granted qualities that individuals exhibit when dealing with the tasks of everyday life, comprising of a cognitive and emotional dimension, when implied they protect the individual's ontology.

interactionists consider the role of social structure rather than social interaction in the construction of the self. Although there are many differences between both approaches, there are important commonalities. Traditional and structural symbolic interactionists agree that: (i) social behaviour is best understood by examining how an individual defines and interprets themselves, others and the situation in which they are located and (ii) individuals act on the basis of the meanings things hold for them. However, despite these commonalities, there are fundamental differences between the two approaches; these are based on two central points, (i) the role of social structure in the understanding of the self and social behaviour, and (ii) the use of theory to explain social processes (see Table 3.1).

One of the main differences between these varying positions is the role structure plays in the formation of the self. Structural symbolic interactionists are concerned with how social structure affects the self and the behaviour enacted by individuals. Structural symbolic interactionists claim that society is stable, durable and is reflected in the patterned behaviour within and between individuals. Social order is pre-existent; the individual is born into a society that is ongoing and organised and through the process of socialisation and learning from others they become accustomed to social order. There are groups, networks, communities and institutions within society that inform the self, these play a fundamental part in shaping the individual's goals but the individual, as an autonomous agent, orientates its behaviour to meet these goals. When an individual attempts to attain these goals, social structure can offer possibilities or can limit the individual's behaviour. Each social situation has a status hierarchy, a set of norms that shape and inform the interactions that occur therein. Structures can impose constraints on an individual's agency but they can also provide resources and opportunities so that the individual can overcome such constraints. If the individual's goals are consistent with social structural arrangements this is reinforcing for the individual. Conversely, if the goal is in opposition to social structural arrangements the interaction could be disrupted, existing structures destabilised and the individual prevented from attaining their goals. Individuals do have the capacity to change social structure and reorientate their behaviour so that new patterns of behaviour can emerge. But, outcomes are not completely organised by the individual's actions or that of others, social structures persists, they can intrude and impact on the interaction and constrain the individual's actions (Burke and Stets 2009).

Just like traditional symbolic interactionists, structural symbolic interactionists contend that individuals are comprised of multiple selves organised within a hierarchical structure. They propose that the meaning of roles are shared among individuals, for example, in contemporary society a maternal role includes meanings of caring, nurturing and protecting, most women would agree with these meanings and behave accordingly (Burke and Stets 2009). Moreover, structural symbolic interactionists consider

society to be composed of a pattern of relationships and interactions that are different but organised. Essentially, individuals exist within a system of social relationships; they enact roles to maintain their position in that relationship, each role has a corresponding identity whereby identities are the individual's internalised role expectations.

3.5 The performative aspect of the self

The notion of a performative self was advanced by the Canadian sociologist Erving Goffman (1922-1982) and the North American feminist post-structuralist philosopher Judith Butler (1956-present). Goffman was considered the 'most brilliant and innovative sociological observer of daily life, social interaction and the production of self' (Elliott 2010:p37). Goffman's comprehensive analyses of social interactions lead him to conclude that the self is socially constructed through interactions with others and the social structure in which individuals are located. He emphasised the performative aspect of the self, suggesting that individuals presents themselves to others through the roles they enact, the self therefore is a product of the scene that is played out. When classifying individuals, Goffman classified the self as a moral, autonomous agent, created socially, an agent who acts according to the situation they are situated in. Goffman's theory contributed to the understanding of the self in a number of ways: (i) the self was considered to be defined according to the situation the individual was positioned in, (ii) the self was not a fixed, stable entity, it was socially constructed, (iii) individuals perform to an audience and its during this performance information about the self can be given off intentionally or unintentionally (Elliott 2010).

Goffman perceived the social interactions where individuals perform an identity as sacred processes, with meanings that extend beyond the individual and provide a sense of social belonging and involvement. Using the theatre, with its front and back stage components, as a metaphor he conceptualised life, daily activities and social interaction. This theorisation of a front and back stage performance explains how, when in the public domain, an individual adorns a mask that hides the inner, true self whereas in the private domain, this mask is unveiled to reveal the inner, true self (Doniger 2005). In the public domain, individuals are aware of their audience and like actors, they perform to that audience, this performance is scripted from a manuscript informed by the various discourses around the specific role(s) an individual assumes. Saliently, although the specific role(s) are scripted and mapped

Table 3.1 Commonality and Differences between Traditional and Structural Symbolic Interactionism

Commonality & Differences	Traditional Symbolic Interactionism	Structural Symbolic Interactionism
Commonality	<p>Symbolic interactionists from both branches agree that social behaviour is best understood by examining how an individual defines and interprets themselves, others and the situation they are located in. Capturing and identifying meaning that the individual attributes to their surrounding through the exploration and examination of their subjective world will provide some explanation and understanding of their reality and their behaviour because as symbolic interactionist would attest individuals act on the basis of the meanings things hold for them.</p>	
Differences	<ul style="list-style-type: none"> • Social structure is always in a state of flux – created and recreated through the interpretation, definitions and actions of an individual in a situation - individuals identify relevant things that need to be taken into account, they act and their actions are informed by others in the attainment of their goals • The individual defines the situation anyway they wish but society is considered to be in a state of flux, outcomes are determined by negotiation but there is no overarching structure 	<ul style="list-style-type: none"> • Society is stable, durable, reflected in patterned behaviour within and between individuals • It is pre-existent to the individual, the individual is born into a society that is ongoing and organised and learn social order through the process of socialisation and learning from others • Within society there are groups, networks, communities and institutions that influence the individual and informs their identity and sense of self – they shape individual goals
Role of social structure	<ul style="list-style-type: none"> • If social structure does exist it is only temporary that comes into play when the individual interacts with others but dissipates when the interaction ends 	<ul style="list-style-type: none"> • Social structure can offer possibilities and can limit an individual’s behaviour – the individual, as an autonomous agent, orientates their behaviour to individually held goals • Individuals can create social structures; they emerge from the individual’s actions, those actions are patterned through interactions over time. Individuals have the capacity to change social structure and reorientating social behaviour with the emergence of new patterns of behaviour • Social structures can be inhibiting or facilitative – each situation has a status hierarchy, a set of norms that shape and inform interaction. Structures can impose constraints on the agency of individual but also provide resources and opportunity so that individual can overcome constraints. If individual goals are consistent with social structural arrangements they are reinforcing for the individual and structures where the interactions occur. Conversely, if the goal is in opposition to social structural arrangements the interaction may be disrupted, existing structure will be destabilised and the individual prevented from obtaining their goals • Outcomes are not completely organised by their own actions or that of others, social structures persists, can intrude and impact on interaction, and constrain individual’s actions

Table 3.2 Commonality and Differences between Traditional and Structural Symbolic Interactionism cont'd

Commonality & Differences

The role of theory

Traditional Symbolic Interactionism

- Informed by Blumer's assumption that theory cannot be created or one cannot use a priori theory to explain social behaviour because it is impossible to predict social behaviour
- No constancy or stability – individuals constantly construct and reconstruct meanings and interpretations of themselves, others and the interaction, co-ordinated behaviour is produced and reproduced and social structure emerges from the situation rather than define and influence the situation
- State of flux makes it impossible for researchers to measure concepts or ideas, no stable reference point
- Sensitising concepts provide some direction regarding what and where to explore when researching social behaviour but noting that these can change as the individual's meanings and behaviours change according to the situation they are located in
- Difficult to import a priori theory because each situation is unique so concepts developed from other studies may be inadequate
- Focus of traditional symbolic interactionism is describing and understanding

Structural Symbolic Interactionism

- Structural symbolic interaction concerned with developing and testing predictive explanations of human conduct
- There is enough stability to generate meaningful data that is reliable and valid and allows for the development of and testing of hypotheses, theory can be developed - concepts can be measured; prediction about the self behaviour and interaction can be developed and tested, theory emerge that can be tested and further developed

(Burke and Stets 2009:p33-37).

out the individual, as a moral autonomous agent, brings their own expectations and interpretations to the assumed role(s). The individual also maintains a degree of control over the situation because the information that is presented may not be a true reflection of them. The performance is achieved through appearance, speech, behaviours and actions, if the individual is to convince others of their authenticity, their actions need to be conscious and explicit and their appearance, behaviours, gestures, and attire appropriate for the role being performed. At times, the performance may occlude the inner, true self, while at other times it may inadvertently give off more information than the individual intended (Woodward, 2004). Moreover when an individual assumes a role they behave in a 'relatively regularised manner' (Lawler 2008:p109), engaging the repertoire of behaviours associated with that role, constantly repeating the behaviours to the extent that they become habitual. These behaviours provide a visual cue to others of the assumed role and because the behaviour is context dependent individuals behave differently in different situations. This ability to change according to the context and situation, signal a distinction between the sacred and profane self (Goffman 1990). The sacred self referring to the inner, true self and the profane self being the less, true self, a self influenced by the individual's social environment.

Context and situation 'frame' social interactions (Lawler 2008:p111), meaningful frameworks that define the setting and organises personal experiences. One such framing system is gender. Gender results in the formation of a sense of self founded on the difference between female and male accordingly, a woman will integrate the role(s), of housewife, wife and mother when constructing a sense of self. This construction is informed by role play and role modelling, practices females engage in from early childhood (Oakley 1974). Examples of this can be found in Ann Oakley's work *'The Sociology of Housework'* (Oakley 1974), or the television series *'The Good Wife'* where despite being autonomous agents, women perceive the socially prescribed roles of housewife, wife and mother as integral to their own biography. Their biography alters according to these roles, being a wife and mother takes precedence. The commitment of the majority of women to the conventional roles of housewife, wife and mothering are not just a consequence of the woman's location within certain economic or social structures, but are a reflection of how young girls are engendered into the role of housewife through role play from a young age, and then later as the young girl matures, her mother becomes her role model, with the woman imitating their mother's housework behaviour (Oakley 1974). If an individual's behaviour is inconsistent with the role they are occupying, the social order is disrupted.

3.5.1 Gender identity and performance

Recent contributors to the debate on the self and identity have recognised the importance and role gender plays in the construction of the self (Butler 1996, Brook 1999, Evans 2003). Like Goffman, Judith Butler questioned the notion of an essential, true self, her conceptualisation of the self destabilised the perception of a 'coherent, unified, stable sexual identity' (Lawler 2008:p104). While Goffman and Butler share some commonalities they differ on others aspects. Both consider the self and self-identity as: (i) something achieved by the individual, (ii) something performed, (iii) a process dependent on collective and social activities. While Goffman used a theatrical metaphor to analyse social interaction Butler was more concerned with the unconscious process at play when an individual is performing a gender identity, for example, when women perform being a mother. Butler questioned why society created gendered differences, she considered gender as an unnecessary frame imposed on an already existing entity of the self, that being sex,⁵⁵ an entity that can only be changed through corporeal transformation. Conversely, a gendered self is constituted within a historical, social, moral political and material context and embodied activities (Butler 1996, Miller 2005). From the moment of birth, the individual is assigned a gender and throughout their life they usually engage in socially determined behaviours and norms consistent with that gender. This gendered behaviour is repeated daily with the individual actively participating in the gendering process. In essence, the individual interpellates or 'hails' (Lawler 2008:p115) their gender. When an individual constructs an identity, Althusser describes this process as interpellation (Althusser 1971). In a sense the individual is first recruited to a specific identity and constructs symbols or representations that conform to that identity. The process refers to how an individual feels that the identity they construct is the right one for them. The process involves three stages: (i) recognition, (ii) examination and reflection, and (iii) realisation. One recognises the role, contemplates how this may be applicable to them and than, if deemed applicable, assumes the role. A case in point is advertising campaigns. The process links the individual with the social and this can occur consciously or unconsciously. Of course, an individual can choose to change their gender. However, it is impossible, socially and legally, to be agender.

For many women, their gendered self manifests and is affirmed when they decide to become a mother. Caring for others and having responsibility for others are highly gendered activities but when one's pathological features are not in keeping with the norm, for example, women with a disability, then

⁵⁵ That being a boy or girl.

doubt about their ability to perform gender activities, such as doing mothering, come to the fore and they are perceived as asexual (Tilley 1998, NWCI 2006, Piotrowski and Snell 2007, Begley et al. 2010). Moreover, women with a disability who do become mothers are often categorised as different and their ability to mother scrutinised (Begley et al. 2010, Walsh-Gallagher et al. 2012). The label of difference is frequently accompanied by a desire by others, primarily non-disabled individuals, to get women with a disability to conform to what society considers the norm. Furthermore, the interaction with others is often tainted by stigma. Stigma is realised when others' attitudes 'reduce the bearer from a whole and usual individual to a tainted, discounted one' (Goffman 1963:p3). The resulting discriminatory behaviour can vary from staring and patronising comments to contempt and open hostility, all behaviours commonly experienced by women with a disability when accessing contemporary maternity care (Begley et al. 2009b, Barnes and Mercer 2010, Begley et al. 2010).

Goffman (1963) argues that stigma can be explained by the concept of deviance whereby there is a deviation from prevalent norms but he does not consider deviance as an inherited characteristic of the individual rather it is others who perceive the act or attributes of the individual to be negatively different. Although Goffman is interested in all types of stigma he frequently refers to the experiences of people with a disability to develop his assumptions. He distinguishes between the discredited, the individual with a visible disability and the discreditable, those with a disability that is not immediately visible. For individuals with a visible disability, managing stigma entails managing the tension that exists in social relationships in order to recover a sense of status. Alternatively, they may autonomously choose to use the disability in a beneficial way, or use it in way so as to excuse them from doing certain activities. Conversely, individuals whose disability is not immediately visible engage specific emotional focused coping strategies – passing,⁵⁶ covering⁵⁷ and withdrawal⁵⁸ (Goffman 1963:p48)- to manage the information imparted to others and to offset the potential of being stigmatised. As the previous chapter highlighted an individual's integrating and acceptance into mainstream society is also dependent on the aetiology of their disability. Those with a congenital disability will, from childhood, be aware that others may perceive them as different and most will assume and embrace a disability identity from an early age. In contrast, individuals with an acquired disability may be more reluctant to claim a disability

⁵⁶ In passing the individual may decide not to disclose their disability choosing instead to hide the impact it has on them.

⁵⁷ Covering is the process whereby the individual may buffer the self by disengaging from the perpetrator of the actions that are stigmatising; in essence, they cover/protect the self from stigma.

⁵⁸ Withdrawal occurs when the individual consciously withdraws from social interactions with others, primarily non-disabled individuals.

identify because their pre-disability perceptions may be based on the perceptions inferred by the hegemonic medical model of disability (Barnes and Mercer 2010).

When addressing the needs of women with a disability, maternity services need to be flexible and innovative but the evidence would suggest this is not the case. Women with a disability encounter a multiplicity of challenges including, structural, communicational, informational and attitudinal challenges (Kallianes and Rubinfeld 1997, Thomas and Curtis 1997, Thomas 1998, Prilleltensky 2003, McKay-Mofatt and Rotheram 2007, Smeltzer 2007, Begley et al. 2009b, 2010, Walsh-Gallagher et al. 2012). They are often stigmatised and categorised as different, their disability is perceived as a problem accordingly they are classified as a high risk and the care provided medicalised. In Ireland and throughout the western world, when women access the maternity services, the provision of care therein, both midwifery and obstetrical, is dominated by the medical model of childbirth, which is associated with the active management of labour philosophy (O'Driscoll et al. 1993, Oakley 1993, Murphy-Lawless 1998, Kennedy 2002). The medical model perceives pregnancy as a pathological state so on entering this structure, the women, especially those with a disability, their pregnancy and imminent birth is situated and categorised within a framework of risk. Women are not considered from a holistic perspective, as an entity comprising of physical, social, emotional dimensions, but rather, as a problem to be solved. The medical model does not always recognise or afford credence to the psychological implications of labour and childbirth, that for many women, is a significant, scared and spiritual event (Bergum 1989, Mauger 1998, Parratt 2002). For the majority of women who traverse this 'patriarchal world of medicine' (Kennedy 2002:p16), the birth of their baby occurs in a male dominated environment, consequently the woman's sense of power, control, autonomy and agency is eroded. The medical model of childbirth annexed the role of birth attendants, traditionally an area of female authority and knowledge, by instituting control over maternity care and others including midwives. In essence this action of discrediting women's traditional knowledge rendered women dependent on male experts (Rich 1977, Oakley 1993, Glenn et al. 1994). In this configuration, women become passive bystanders in the birthing process and this passivity and dependency instigates a disconnect between the woman's body and her labour (Rich 1977). This disconnect contributes to an increased risk of intervention, such as forceps or caesarean section; such interventions diminish the woman's sense of self and causes difficulties with her transition to motherhood (Green et al. 1990, Kitzinger 1992, Fisher et al. 1997, Parratt 2002). For woman with a physical disability, childbirth interventions may also precipitate a sense of failure, as the need for intervention accentuates the woman's limited physicality. Moreover, the women consider caregivers to be experts conferring an understanding of motherhood

that contributes to their formation of a maternal self so, if caregivers perceive them as deviant, dependent and a liability this may engender scepticism regarding their ability to mother, to nurture, to love and care for their baby. Unfortunately, as the following chapter details, the literature in regard to the experiences of women with a disability and the their transition to motherhood is limited so, if maternity care is to be truly woman-centred for these women, an exploration of their experiences is required so that a conceptual framework can be developed and implemented by caregivers engaged in the provision of maternity care.

3.6 Conclusion

This chapter outlined how the self is a cognitive and emotional entity. An entity constructed through an individual's interactions with and the appraisals of others, one that comprises of three representations: the individual self, the relational self and the collective self. The chapter outlined the symbolic interactionists' conceptualisation of the self and described how concepts from the interacting self, the empirical self and looking glass self informed the coding paradigm, an analytical tool used during data collection and analysis. The importance of reflexivity in the construction of the self and one's biography, and how individuals assume multiple roles and identities that are configured within a hierarchical structure where internal and external factors influence the prominence given to a specific role was also discussed. This chapter also detailed how the self is performative whereby individuals have a true, inner self that is only revealed in the private domain and a profane self in the public domain. Motherhood and the transition to motherhood provides researchers with an opportunity to study and look beyond the actual mothering of a baby. This study explored how women with a disability formed and sustained a maternal self through reflexive action, how the self altered according to the situation the women were located in and how motherhood instigated a reconstruction of the self. Chapter 4 will illustrate how only a few studies relating to the transition to motherhood have explored the relationship of the process to the self and relatively few have explored the process from the perspective and experiences of women with a disability.

Chapter 4 Theories on Transition to Motherhood

4.1 Introduction

In contemporary western society, women are defined by their relationship with motherhood (Oakley 1980, Phoenix 1991, Phoenix et al. 1991, Richardson 1993, Letherby 1994, McMahon 1995, Miller 2000a), whether they become mothers or not, motherhood is 'central to the way women are defined by others and their perceptions of themselves' (Phoenix et al. 1991:p13). Adrienne Rich's seminal work '*Of Woman Born*' (Rich 1977) and feminist research conducted thereafter have focused primarily on the empowering and oppressive nature of motherhood (O'Reilly 2010). Whereas sociologists like Ann Oakley (Oakley 1979, 1980) were more concerned with exploring the women's personal experiences of being a mother and the impact society may have on shaping their experiences. While nurse researchers like Rubin (1967a, 1967b, 1975, 1984) and Mercer (1981, 1985, 1986, 2004, 2006) were more interested in exploring the process involved in adjusting to the role of mother. To date, many of the studies that have explored the process of transition to motherhood have done so from the perspective and experiences of non-disabled mothers, mainly first time mothers, few have examined the phenomenon from the perspective and experiences of women with a disability or explored the relationship of the process to the self. This chapter will present the dominant theories that prevail in regard to the transition to motherhood, concepts from these theorisations informed the coding paradigm used in the process of data collection and analysis, it begins by defining the key concepts of transition, mothering and motherhood (see Appendix 4 for search terms used to search the vast amount of literature on this topic and the databases searched).

4.2 Defining transition

Life consists of a series of transitions that are an integral part of an individual's development. Becoming a mother is one such transition. The term transition describes the 'process of change in life's developmental stages, or alteration in health or social circumstances rather than people's responses to change' (Kralik et al. 2006p:322). It denotes the psychological processes of adaptation, reorientation and

transformation that individuals engage in when adapting and incorporating a change in their life. The transition involved in becoming a mother is an intricate one, one that encompasses physical, emotional, psychological and social changes (Oakley 1979, Phoenix et al. 1991, Pridham and Chang 1992, Sethi 1995, Barclay et al. 1997, Smith 1999, Bailey 1999a, Miller 2000a, Redwood 2007, Urwin 2007, Thomson et al. 2011). Managing the transition involves a conscious and unconscious reorganisation of the self (Barclay et al. 1997, Smith 1999, Bailey 1999a, Miller 2000a, Urwin 2007), the change and disruption that ensues can affect the woman's assumptions of the self and their assumptive world⁵⁹ (Oakley 1980, Bailey 1999a, Miller 2000a, Kralik et al. 2006).

4.3 Defining mothering

Mothering is defined as a biological practice, a practice that requires the woman to take responsibility for the infant's growth, development and maturation (Ruddick 1980), a practice 'socially circumscribed and regulated by norms, contemporary discourses and legal requirements that affect what counts as appropriate practice and what the good mother should be' (Urwin 2007:p242). Psychoanalysts define mothering as a 'product of behavioural conformity and individual intention' (Chodorow 1978:p31). Their 'functional-cum-bio-evolutionary' (Chodorow 1978:p17) definition of mothering emerged from an amalgam of functionalist theories relating to the hunter-gatherer societies and the evolution of man. These theories contend that the masculine traits such as aggression, strength and agility render the man more suitable for hunting while the caring, nurturing traits inherent to women fit with the role of childrearing. This division of labour, originally considered essential for hunter-gatherer survival, became ingrained in the human psychic and consequently became a norm of modern society. In essence, mothering became a gendered activity; characteristics associated with it, such as nurturing and caring, sensitivity and responsiveness, were portrayed as innate feminine characteristics. Contemporarily, women continue to be defined according to these characteristics and are continually located within the relational institution of the family. The personal experience of being a mother is incorporated into feminists' definition of mothering, they define the concept as the 'women's lived experiences of childrearing, as women both conform to and/or resist the patriarchal institution of motherhood and its oppressive ideology' (O'Reilly 2010:p2). They contend that mothering is a product of

⁵⁹ Assumptive world refers to the core assumptions of beliefs that ground, secure, stabilise and orientate the individual, providing purpose and meaning to their life.

role training and role identification (Ruddick 1980), a practice that requires the woman to take on additional responsibilities, one that induces numerous changes, including changes in the self and relationships, all of which require considerable adjustment (Kennedy 2002).

4.4 Defining motherhood

While mothering refers to the practices and personal experiences associated with motherhood and being a mother, alternatively motherhood is defined as a complex socially prescribed state, a state that has the potential to fundamentally change a woman's life and assumptive world (Oakley 1980, O'Reilly 2010), a change that can cause disequilibrium in a woman's life; requiring the woman to redefine and restructure the self and her assumptive world (Burley 2003). It emanates from a complex matrix of biological, psychological, social, environmental and political factors. Motherhood is associated with joy and happiness, the activation and enhancement of social bonds and a fortification of one's self-concept but it can also be frustrating, demanding and shrouded in conflict (Gittins 1993, Bailey 1999a, Nomaguchi and Milkie 2003). Psychoanalysts consider motherhood as essential for the fulfillment of women; emphasising how it is a developmental milestone, an opportunity for growth and transformation, representing a transformation at two levels: (i) transformation at an individual level and (ii) the transformation and development of a family unit (Chodorow 1978). Sigmund Freud (1856-1939), challenged the idea of a unified, rational individual. He considered the unconscious mind to be a reservoir of repressed thoughts and feelings that may emerge at any point in the person's life, including the period around becoming a mother, and these can influence the choices the woman makes in her life. Freud proposed that women's psychology originates from the recognition, from a very young age of genital difference between male and female. This he termed penis envy, and he postulated that through the Oedipus complex a female child begins to feel jealousy towards their father for the love and attention he receives from her mother. The female child attributes this affection or love to be associated with the fact that her father has a penis and her mother does not, so her father is perceived in a valuable way. Accordingly to avoid rivalry, for the mother, sons will identify with their father. On realising that they do not possess a penis, girls will develop ambivalent feelings towards their mother while instigating heterosexual attachments with their fathers. Subsequently the woman develops a gendered identity informed by the intervening presence of their father.

4.4.1 Ideologies of motherhood

Twenty-two years ago, Rothman (1989) suggested that ideologies of motherhood were interwoven with ideologies of patriarchy, technology and capitalism (Rothman 1989). This interconnect continues to be relevant today. The current ideologies that shape individual expectations of motherhood are pervasive, compelling and powerful (Glenn et al. 1994, Miller 2000a). These pervasive ideologies are founded on the assumption that reproduction is a biological function of each woman and women are destined to become mothers (Miller 2000a). Situating women within the biological setting of motherhood denies women an identity outside of mothering (Miller 2000a). Moreover, the ubiquitous constructs of a good, ideal mother or intensive mothering constitute and position mothers as 'ever available, ever nurturing providers of active, involved and expert mothering' (Malacrida 2009:p99). Good, ideal mothers are idealised as infinite, natural caregivers who are 'required to be all things to their children, immediately available strong role models, endlessly nurturant and child focused' (Malacrida 2009:p101). This construct of a good, ideal mother is used as the benchmark by which all mothers, regardless of ability, are appraised in modern society.

Ideologies are influenced by public and political changes (Hartrick 1997, Miller 2000b, Malacrida 2009). These changes also redefine societal expectations of and responsibilities associated with motherhood (Phoenix et al. 1991, Miller 2000a) but despite numerous challenges⁶⁰ the ideology of a good, ideal mother remains the backdrop against which contemporary mothers are appraised. Consequently, mothers, with or without a disability, afraid of being perceived as bad mothers, are reluctant to discuss the difficulties associated with being a mother so, motherhood 'retains its sacred aura' (Miller 2000a:p12). Nevertheless it must be recognised that for some mothers, motherhood can be filled with inconsistency, apprehension and uncertainty (Ball 1994, Maushart 1999, Cusk 2001, Brown 2010), and the experience of being a mother may not always resonate with the idealised, romanticised perceptions of it (Rich 1977, Oakley 1980, Phoenix et al. 1991, Barclay et al. 1997, Bailey 1999a, 1999b, Miller 2000a, Nelson 2003, McCourt 2007).

Feminists and sociologists have attempted to unsettle the idealised, romanticised perceptions of motherhood and to provide a more realistic conceptualisation of what it means to be a mother. Nancy Chodorow (1978) in her seminal work entitled *The Reproduction of Motherhood: Psychoanalysis and the*

⁶⁰ These challenges, predominately from a feminist domain combined with changes to the way in which women are perceived in society and the introduction of legislation and policies advancing their rights, amongst others, to education and employment have had some effect on the ideologies surrounding motherhood but the configuration of a good, ideal mother still prevails.

Sociology of Gender, illustrated how a pattern of female mothering evolved from one's experiences of being mothered by women. She claimed that a woman's orientation towards nurturance and care and the development of a female identity was directly related to the woman's identification with and attachment to her mother particularly during childhood. Chodorow concluded that if expectations around motherhood were to change, men must participate more in the parenting process and such participation will correct the gender imbalance of nurturing and caring (Chodorow 1978). The concepts of nurturing and caring also surfaced in Sara Ruddick's work. In *'Maternal Thinking'* (Ruddick 1989), Ruddick attempted to explain why mothers feel compelled to nurture and protect their child(ren). Unlike Chodorow, she argues that the woman's need to nurture and protect her young is not biologically determined or gender related but rather it's a higher cognitive process that evolve from constant maternal practice (Ruddick 1980). Some (Phoenix et al. 1991, Miller 2000a) have criticised Chodorow and Ruddick for accepting the *status quo* and not challenging the biological determined role of motherhood and for failing to recognise that there are different and varied experiences of motherhood.

4.5 Motherhood: a life changing event

Becoming a mother is described as a life changing event, an event that generates change in regard to the woman's role, responsibilities and status in society (Oakley 1980), a transition that encompasses physical, psychological, emotional and social changes. These changes significantly affect the self and the woman's assumptive world, for some, the experience may be fulfilling and transformative while for others the experience can be disruptive and the changes that ensues may be stressful and distressing. Early in the 20th century, the positivist rationalist Van Gennep (1960) constructed motherhood as a rite of passage, a passage whereby the woman exchanges one social status for another. This exchange occurs in three phases: (i) the separation phase, (ii) the transitional phase and (iii) the reincorporation phase. In the first phase, the woman becomes disconnected from her former social positioning. In the second phase, the transitional phase, the woman is between socially recognised states, she is neither in her former state, nor is she a mother but she is in transition. This phase is often accompanied by feelings of confusion and alienation, and the woman may find herself in a state of limbo. It is during this phase that the woman's appearance changes and behaviour alters as she becomes a mother in waiting. The third and final phase, the reincorporation phase, occurs after the

birth of the baby, whereby the woman assumes an altered social state and status; she is now a mother with different responsibilities and priorities than the pre-motherhood self.

4.5.1 Difficulty in transitioning: crisis and dysphoria

Even the most positive life events, like becoming a mother; can cause a psychological crisis, disrupting the self and the woman's assumptive world (Parkes 1971, Oakley 1980, Janoff-Bulman 1992, Rogan et al. 1997, Brown 2010, O'Reilly 2010). Fifty years ago, LeMasters was the first to describe motherhood as a crisis (LeMasters 1957, Dyer 1963, Hobbs 1965). This description was reaffirmed by some (Dyer 1963) and refuted by others (Hobbs 1965, Rossi 1968, Oakley 1980). These qualitative studies were conducted in a time when qualitative inquiry was trying to gain credibility within the research and scientific community. Despite advocating the notion of subjectivity, the studies conducted in this period tended to adapt a positivist epistemological standpoint subscribing to the idea of absolute objectivity. LeMasters (1957) used a non-probability sample of 46 couples to measure the emotions experienced by first time parents.⁶¹ When adjusting to parenthood, eighty three percent (83%) of the couples interviewed described experiencing extensive or severe crisis. Dyer (1963) repeated the study six years later, using a smaller non-probability sample of 32 couples.⁶² The findings revealed that parents experienced a decrease in the degree of crisis encountered, sixty-six percent (66%) of couples reported experiencing a moderate or extensive crisis. The level of crisis experienced was dependent on a number of variables including: (i) the nature of the couple's relationship and state of marriage at the time of the birth of their baby, (ii) the couples' preparedness for marriage and family, (iii) the couples' marital adjustment after the baby was born and (iv) other social and situational variables including, the number of years married, if the pregnancy was planned or unplanned and the age of the child when the study was conducted. The relationship between motherhood and crisis was also reaffirmed in later studies (Hobbs 1965, 1968, Hobbs and Cole 1976, Hobbs and Wimbish 1977) but in these studies the level of crisis experienced was less severe. Methodological issues⁶³ could account for the disparity in the level of

⁶¹ LeMasters used unstructured interviews to collect data from a non-probability sample of 46 urban middle class, married Caucasian couples within the first five years after the birth of their baby.

⁶² Dyer (1963) used a smaller non-probability sample of 32 middle class couples whose baby was less than two years old. The extent to which becoming a parent represented a crisis for each couple was measured using a Likert scale that was developed using technical literature from the domains of marriage and family. This literature theorised that the birth of a first child had a disruptive effect on the family and on marital relationships.

⁶³ In Hobb's (1965) qualitative study, the sample was randomly selected and greater in number (53 couples) than the two previous studies (LeMasters 1957, Dyer 1963) and the couples were interviewed at an earlier interval, when their baby was less
Footnote continued on next page.

crisis experienced in the different studies. A less serious psychological adjustment associated with the transition to motherhood is dysphoria. Dysphoria is a term used to describe the distressed mood some parents experience as they manage their transition to parenthood. In a longitudinal study conducted over a three-year period, Morse et al (2000) examined couples' moods and adjustments during their transition to parenthood. A total of 327 couples expecting their first baby were interviewed in order to measure the level of distressed mood at four different intervals pre and post parenthood: at 24 weeks gestation, 36 weeks gestation, at 1 month and 4 months postnatally. The number of women experiencing distressed mood varied with 19.5% at 24 weeks gestation, 21.6% at 36 weeks gestation to a level of 14.9% at 4 months postnatally. The findings suggest that stressed mood in mid pregnancy correlates with a younger age profile and with a lack of support (Morse et al. 2000).

Over the last three decades research exploring the women's experiences of motherhood has escalated. The studies⁶⁴ can be categorised into two broad disciplines: psychology and sociology. The psychological studies consider motherhood from the perspective of maternal infant attachment. While the sociological studies are concerned with exploring and examining the women's personal experiences of adjusting and adapting to motherhood (Rubin 1967a, 1967b, Mercer 1985, 1986, 2004). In her seminal work '*Women Confined: Towards a Sociology of Childbirth*' sociologist Ann Oakley (1980) alluded to the relationship between motherhood and the woman's assumptive world but did not explore or develop the correlation between them.⁶⁵ More recently researchers have started to explore the phenomenon from an identity development perspective (Rubin 1984, McMahon 1995, Sethi 1995, Smith 1999, Bailey 1999a, Miller 2000a, Yeates 2004, Hilfinger-Messias and DeJoseph 2007) (see appendix 4a and 4b, an outline of the studies reviewed).

than 10 weeks old, compared to 5 years (LeMasters 1957) and 2 years (Dyer 1963). Questionnaires were administered to 53 white, urban couples after the birth of their first baby. The age ranges of the couples varied; mothers were aged between 16-36 years (mean 21.5 years) and fathers were 18-38 years (mean 24.5 years). The most significant methodological issue was the timing of Hobb's research. In his study the couples were interviewed during the first 10 weeks after the birth, this 'honeymoon phase' (Hobbs 1965:p371) was characterised by a feeling of elation, a feeling that could have obscured the participants' true experience.

⁶⁴ These studies are predominately from Ireland, the United Kingdom (UK) and the United States of America (USA).

⁶⁵ The relationship between both will be discussed in the penultimate chapter of this thesis, chapter 10.

4.6 Maternal role attainment and adaptation to motherhood

Earlier theories on the transition to motherhood (Rubin 1967a, 1967b, Mercer 1985) used the term 'maternal role attainment' to explain the process of adjustment and adaptation involved in becoming a mother. However, studies⁶⁶ conducted later were concerned with the static implication of this term, many felt that the term, maternal role attainment, did not reflect the continuous process at play when becoming a mother (McBride and Shore 2001, Mercer 2004). So, the term was replaced with 'becoming a mother' (Koniak-Griffin et al. 2006), a term that was thought to reflect the continuous, expanding and evolving process of change and adaptation occurring in the self and the woman's assumptive world as she becomes a mother (Koniak-Griffin et al. 2006).

There is a consensus among the various theories that to manage the transition involved in becoming a mother the woman needs to embark on a process of adaptation, a process whereby she activates and engages various behaviours to help her adjust and adapt to the reality of having a baby and the requirements of motherhood. This process of adaptation initiates emotional, social, psychological and physical changes (Rubin 1967a, 1967b, Oakley 1980, Pistrang 1984, Barclay et al. 1997, Nelson 2003, Choi et al. 2005, Hilfinger-Messias and DeJoseph 2007). It is frequently conceptualised as causing a loss of self and personal identity that manifests in a loss of autonomy and independence, loss of personal freedom, loss of appearance, loss of sexuality, loss of social attachment and engagement, and loss of occupational self (Rubin 1967a, 1967b, Oakley 1980, Pistrang 1984, Baker 1989, Cowan and Cowan 1995, Barclay et al. 1997, Lewis and Nicholson 1998, Marshall et al. 2007, Darvill et al. 2010).

4.6.1 Motherhood and maternal role attainment

Over four decades ago, Rubin (1967a; 1967b) developed a theory that described the behaviours a woman enacts while creating a maternal self and an understanding of what it means to be a mother (Rubin 1967a, 1967b). Rubin theorised that women, during their transition to motherhood, progress through four stages of development whereby they: (i) seek and ensure safe passage of their baby, (ii)

⁶⁶ These studies were mainly qualitative and reflect the changes that occurred epistemologically through the different phases of qualitative inquiry in the 20th century.

reorganise relationships, (iii) construct a new identity, and (iv) acquire a higher level of maturity. The first two developmental stages were concerned with a safe and successful outcome to the pregnancy and birth, and continues as the baby is welcomed, accepted, supported and nurtured by significant others. The third and fourth stages were realised when the mother bonded with the baby. The four stages and their three associated themes of (i) the taking in process, (ii) the self-system theory and (iii) the active process of operations, describe the practices and processes women employ while adjusting and adapting to motherhood. The 'taking in' process facilitates in the generation of an understanding of what it means to be a mother. The self-system describes how the woman images motherhood; within this theme image is not just a physical dimension, there are three interrelated dimensions: ideal image, self image and body image. Ideal image is concerned with the ability to endure for the love of another person, endure referring to any social, physical, psychological or emotional endeavour. Self image refers to how the woman envisages herself in the present, in the here and now, and not in relation to her former experiences that comprise her self image. Body image implies a focus on physical image but, in this instance, it refers to the woman's ability to function as a mother. The woman's sense of self-esteem and role attainment was dependent on fulfilling this ability. The third theme, active process of operations, incorporates the active processes involved in becoming a mother. It consists of five levels, mimicry, role play, fantasy, introjection/ projection and grief. By engaging in the practice of mimicry, the woman emulates what being a mother may actually feel like. The woman actively seeks out and establishes relationships with others, who are parents, to ascertain if she would be able to cope with and manage motherhood. These relationships are fundamental for the reflexive project of the self. The woman also seeks information from other mothers, including her own mother (Oakley 1974), accumulates and stores this information, both positive and negative, within her psychic realm so that it can be referenced when she eventually becomes a mother (Giddens 2009).

Through the unconscious psychic process of introjection the woman incorporates the information received from the practice of mimicry into her psychic realm so as to ascertain if this corresponds with her own expectations of the self as a mother. This is the most significant aspect of Rubin's theory. Prior to this, the woman attended to childcare in a manner that reflected the actions of family and friends; now she must decide if such ways are amenable for her. Applying her own experience and philosophy she may accept or reject the ways of others. In engaging in and deciding on the actions of others, the woman is actually associating with the role of mother. There is an acceptance and realisation that motherhood is not something that happens to others; rather it is a status and role applicable to her. The woman then considers the observed behaviours, deliberates on how applicable

these behaviours are to her, retains the behaviours she considers appropriate while rejecting the inappropriate ones. An image of the self as a mother is constructed. The construction of a maternal self is assisted by the process of letting go whereby the woman renounces roles and aspects of her life that she considers incompatible with motherhood. This process of letting go is an aspect of and may be accompanied by anticipatory mourning,⁶⁷ a construct that encompasses the woman's reactions to the loss of a known self (pre-motherhood) and details her efforts to cope with and readjust to this loss (Rando 1986, Mercer 2004).

Almost 12 years after the development of Rubin's theory, an American nurse researcher explored the various tasks new mothers had to accomplish so as to competently fulfil the responsibilities associated with being a mother (Mercer 1981, 1985, 1986). Using questionnaires and semi-structured interviews,⁶⁸ Mercer captured the experiences of 294 women, ranging in age from 19 to 42 years and concluded that during the process of adaptation to motherhood a woman traverses four stages of development: anticipatory, formal, informal and personal (Mercer 1981, 1985, 1986). Essentially as these stages are traversed the woman advances from having an awareness of the expectations of her role, to being influenced and directed by others, including role models, to developing her own unique behaviours, until finally, developing confidence and competence in her own ability to mother.

4.6.2 Motherhood and maternal adjustment

Sixteen years after Mercer's seminal work a qualitative, grounded theory study conducted by Australian midwife researchers (Barclay et al. 1997) collected information regarding the personal experience of becoming a mother from nine antenatal focus groups composed of 55 first time mothers ranging in age from 23 to 39 years. They concluded that the process of adaptation to motherhood is not a four stage process (Rubin 1967a, 1967b, Mercer 1985) but rather a six stage process.⁶⁹ The first stage is characterised by the woman becoming accustomed to the life changes accompanying motherhood.

⁶⁷ Anticipatory mourning is a concept normally associated with the loss of a loved one and the associated mourning that accompanies such loss. Its constituents may have some resonance for women transitioning motherhood, in that the concept includes 'the process of mourning, coping, interaction, planning and psychological reorganisation that are stimulated and begun in part response to a loss...and the recognition of associated losses in the past, present and future' (Rando 1986:p24), these are similar to the processes women negotiate and incorporate when transitioning to motherhood.

⁶⁸ Mercer described maternal role attainment as a 'process in which the mother achieves competence in the role and integrates the mothering behaviours into an established role set, so that she is comfortable with her identity as a mother' (Mercer 1985:p198).

⁶⁹ The six stages were categorised as: (i) realising, (ii) unreadiness, (iii) being drained, (iv) aloneness, (v) loss and (vi) working it out.

The impact of these changes becomes obvious in the early postnatal period where there is often a mismatch between the reality of becoming a mother and the woman's expectations of motherhood.⁷⁰ The second stage describes how, despite attending antenatal classes, women feel ill prepared for motherhood and how they resort to using a number of resources, beyond caregivers, to prepare for the role of mother. The third stage depicts the enormous demands: physical, psychological, emotional and social that accompany motherhood, and the resultant sense of being 'emptied out' (Barclay et al. 1997:p722) that women experience. These demands affect the process of adaptation and impact on the woman's psychological adjustment to mothering, affecting her level of confidence and sense of being. They can engender negative feelings, like a sense of loneliness that is exacerbated when an effective support network is inaccessible to the woman. The penultimate stage of Barclay et al's (1997) theory represents the loss of control a woman may experience in regard to the self and self-identity.⁷¹ However, the sense of loss is often counterbalanced by the many gains associated with motherhood, including enjoyment of the experience. In the final stage the authors theorised how women develop new skills and gain confidence in their maternal role and how personal resilience and assertiveness, trusting one's own judgement and feelings rather than the opinions of others, were key variables that could help women in their adaptation to motherhood (Barclay et al. 1997, Rogan et al. 1997).⁷² Unlike Rubin (1984), Barclay et al (1997) suggest that the transitional process is not restricted or bound to a specific timeframe. They agree that it is possible that some women complete the transition to motherhood by, as Rubin (1984) suggests the end of the first month following the birth of the baby but similar to Mercer (1986) they concede that it could take twelve months.

Barclay et al (1997) also suggested that the transition to motherhood initiates a reconstruction of the self, but because this fact remains unrecognised, women remain unprepared for the psychic crisis that accompanies the process (Rich 1977, Barclay et al. 1997, Rogan et al. 1997). Contemporary antenatal education classes that purport to prepare women for motherhood do nothing to dispel this sense of unpreparedness; in fact, they may contribute to this sense. Although they vary in approach, antenatal education classes, tend to focus primarily on birth issues to the disadvantage of issues relating to motherhood, moreover few classes are accessible and appropriate for women with a disability

⁷⁰ For some women, narrating their birth experiences facilitated in the actualisation of the reality of becoming a mother; once told, women could move forward in the transition process.

⁷¹ Loss is a temporal concept relating to time with one's partner, friends and herself, loss of freedom, independence and control.

⁷² Barclay et al (1997) theorised that several subjective and contextual factors inform and influence a woman's experience of motherhood, including: (i) the nature of the baby, (ii) the mother's reactions and interactions to her baby's behaviour, (iii) previous experience with others' babies and (iv) the support network and nature of support available to new mothers (Barclay et al. 1997).

(Conine et al. 1986, Nolan 1997, Nolan and Hicks 1997, Blackford et al. 2000, Begley et al. 2009b, 2010). There is a suggestion that instead of empowering and supporting women to be assertive in expressing their birth wishes, antenatal education classes focus primarily on educating women to comply and accept the services and care provided, care that is currently dominated by the medical model of childbirth (Kennedy 2002, Gagnon and Sandall 2009). In Barclay et al's (1997) theoretical framework, the woman's confidence takes precedence over attaining mastery over the skills associated with the act of mothering; they suggest that as the woman's enjoyment of motherhood increases so too does her self-esteem and sense of self-worth. This often coincides with the baby being less demanding, settling and sleeping better and being more responsive and interactive. Agreeing with others (Smith 1999, Nelson 2003, Redwood 2007), the authors recommend the development of a more realistic programme of preparation for the transition to motherhood, suggesting that the prevailing emphasis on labour and delivery be counterbalanced with a sufficient and adequate focus on motherhood (Redwood 2007). Furthermore, if women are to realise the magnitude of the change associated with becoming a mother, caregivers must be equipped with knowledge of these changes and the relationship of the process on the self and one's self-identity.

Ten years after Barclay et al's study, Flakowicz (2007) used a case study approach to explore the impact becoming a mother had on the identity of a Caucasian, middle-class woman living in London and the psychological adjustments the woman engaged in during the process of becoming a mother for the first time. The findings revealed that becoming a mother and the process of mothering can cause an imbalance in the woman's psych organisation while providing an opportunity for the achievement and reintegration of a more mature self (Flakowicz 2007). Flakowicz (2007) theorised that when a woman becomes a mother for the first time she experiences a series of losses in regard to the self. This sense of loss evolves from the idealised image some women have pre-motherhood and when in reality, this image is not realised, when they become a mother, a sense of loss ensues. This sense of loss is compounded by a feeling of conflict that arises from the mismatch between the woman's needs and the baby's needs, and the sense of vulnerability and helplessness that ensues when a woman perceives herself as being incapable of effectively meeting her baby's needs.⁷³ The woman's self-awareness and self-belief is enhanced once she learns to cope with the perceived sense of loss. Consequently, the woman becomes more confident and her sense of self is enhanced and a sense of equilibrium regained.

⁷³ External variables contribute to this sense of loss and conflict, including: a difficult birth, difficulty in dealing with the ambivalence associated with motherhood and the difficulties related to caring for an infant.

The notion that in becoming a mother, a woman experiences a sense of loss and loneliness is further illustrated by the findings of a longitudinal, qualitative study, conducted in the UK. Urwin (2007) used observation and interviews to explore the impact becoming a mother had on the identity of twenty first time mothers. The women were recruited from a number of settings, mainly community based settings, for example, community midwives or G.P. practices.⁷⁴ The findings revealed that a woman, when dealing with the physical and psychological disruption associated with the process of adjusting to motherhood, experiences an 'existential loneliness' (Urwin 2007:p248) that emanates from a sense of depersonalisation and confusion that is especially acute in the early motherhood period. The sense of depersonalisation engenders a sense of loss that for some women could manifest as depression.

4.7 Developing and constructing meaning about motherhood

Twelve years ago Miller (2000a) used a snowballing technique⁷⁵ to recruit women (n=17) to a longitudinal qualitative study, conducted in the UK, to explore how women develop and construct meaning from the process of transition to motherhood. The majority of women were recruited from 'informal networks' (Miller 2000a:p314) and the mean age was 30 years.⁷⁶ In this study Miller (2000a) incorporated the woman's personal account of mothering; an account she felt would contest and contradict hegemonic theories on mothering. Post analysis Miller (2000a) concluded that becoming a mother was a confusing and risky process; she noted how women negotiate the process through public expectations and assumptions, and personal experiences. Miller (2000a) suggests that during the process of becoming a mother, women are confronted with a myriad of narratives - meta-narratives, public narratives and individual narratives - consisting of culturally embedded, professional and informal expectations of motherhood. Because a woman's personal experiences of motherhood is positioned at the interface of these narratives many feel unable to voice the difficulties and concerns encountered during their transition to motherhood but with the passage of time and reflexivity a shift in the

⁷⁴ Interviews were conducted on three occasions - during pregnancy, in and at the end of their baby's first year. Six of the twenty women consented to let their interactions with their baby be observed on a weekly basis for the baby's first year of life.

⁷⁵ Snowballing is a method of recruitment where one participant nominates another potential participant who meets the inclusion criteria for the study.

⁷⁶ Once recruited, the women were interviewed antenatally and postnatally. A total of 49 semi-structured interviews were conducted, the first between 7-8 months of pregnancy, the second at 6-8 weeks postnatally and the third interviews at 8-9 months postnatally. In addition to semi-structured interviews, 15 of the 17 participating women completed a short postal questionnaire. The constant comparative method of analysis was used to analyse the data.

perception of self occurs, and this facilitates a reordering of the woman's experiences and a regaining of a sense of agency and control whereby the woman becomes independent and confident in her own abilities to mother, and only then does she feel that she can discuss and disclose the difficulties she encountered⁷⁷ (Miller 2002).

Miller (2000a, 2003) highlighted how at the beginning of the process of transition to motherhood, women are dependent on caregivers for support and guidance but as they negotiate the process this changes and there is a shift towards a dependence on other mothers until the woman eventually becomes more competent, self-reliant and confident in her own abilities to mother (Miller 2003). A reliance on the prevailing professional discourse on motherhood, a discourse informed by the ideology of good, intensive mothering, induces: (i) uncertainty in new mothers, (ii) decreases the woman's self-confidence, (iii) increases dependence and over-reliance on caregivers and (iv) undermines the woman's ability to make informed choice and decisions, and develop confidence in her own abilities. Echoing the sentiments of previous research (Barclay et al. 1997, Smith 1999, Nelson 2003),⁷⁸ Miller suggests that currently, when women are preparing for motherhood, there is too much emphasis on the labour and birth processes and not enough on the issues relating to motherhood (Miller 2000a; 2000b; 2003).

Nelson (2003) concurs with the studies mentioned previously (Barclay et al. 1997, Miller 2000a; 2000b; 2003, Nelson 2003, Smith 1999) that suggest expectant and new mothers are insufficiently prepared for the reality of motherhood. On completion of a meta-synthesis comprising of nine qualitative studies,⁷⁹ Nelson (2003) identified five thematic categories: 'commitment', 'daily life', 'relationships', 'work' and 'self' (Nelson 2003:p471-475), that traverse the antenatal and postnatal periods, and support the contention that the process of transition to motherhood disrupts the woman's world and psyche organisation. The meta-synthesis revealed how the transition to motherhood comprises of two processes - the primary process of 'engagement and the secondary process of 'growth and transformation' (Nelson 2003:p467) - that affect the self. During pregnancy, women consider their ability to be a good mother by reflecting on and contemplating their own experiences of being mothered. Women who categorise their experiences of being mothered as insufficient may, because of

⁷⁷ This generally occurred around 8-9 months following the birth of the baby.

⁷⁸ Many of the women interviewed by Miller articulated how becoming a mother did not come naturally to them and the early postnatal period was often confusing and unsettling. Asking for help was perceived to be too risky; it was akin to admitting their inability to be a good, natural, ideal mother.

⁷⁹ The nine studies included in the meta-synthesis originated from North America or Australia. Four were published, and five were unpublished doctoral dissertations. Four adopted a grounded theory methodology and five a phenomenological or hermeneutical method of exploration.

the lack of positive role modelling, feel unprepared for their mothering role (Barlow and Cairns 1997). Realising that this experience may have a significant and detrimental impact on her ability to mother, the woman may engage a number of strategies to come to terms with and try to understand her childhood experiences. The woman may embark on a process of retrieving, where she actively seeks out memories of her mother's demonstration of love for her. In some cases, the pregnancy and subsequent birth may provide a new insight into their own mother's behaviour consequently any sense of resentment felt by the woman, towards her mother, may be diffused and a sense of empathy may evolve (Barlow and Cairns 1997). This meta-synthesis on transition to motherhood also revealed how, when becoming a mother, a number of changes, positive and negative, occurs in the self. The positive changes include being more tolerant, more empathetic and sensitive towards others, especially other parents and children, while loss of self and self-identity is a negative change. Conflicting emotions accompany these changes, women feel intense love, joy, happiness and pride but these are often offset by feelings of uncertainty, fear, frustration, distress, loneliness, guilt, insecurity and shock. Reverberating the recommendation from previous studies (Redwood 2007, Smith 1999) Nelson (2003) also recommended that realistic discussions on the transition to motherhood occur antenatally when the woman is preparing for motherhood.⁸⁰

4.8 The self, identity and transition to motherhood

When a woman becomes a mother, especially for the first time, the self and self-identity changes instantly, she enters a unique and new psychic arrangement that influences the organisation of subsequent behaviours and actions (Nicholson 1998, Stern 2006, Flakowicz 2007, Redwood 2007). The process of transition to motherhood and subsequent adaptation requires the woman to construct an altered self (Richardson 1993). Some of these changes may be anticipated and planned for pre-motherhood, while others may be unforeseen. This reorganisation of the self is a normal process that all mothers consciously experience, it is forged by events in the early motherhood period and is inferred through the woman's relationship with her baby, a relationship wherein she is required to reappraise all

⁸⁰ Nelson's meta-synthesis has limitations, despite a number of studies being available it did not consider the impact the transition to motherhood has on the woman's sense of self and identity. The meta-synthesis was limited and lacked diversity. Research pertaining to teenage pregnancy, significant maternal mental or physical illness, drug addiction, incarceration, adoption, lesbian mothers, mothers with a disability, infant illness or prematurity were not included in the review.

aspects of the self including the roles she occupies as a mother (Stern 1995, Stern et al. 1998). Pre-motherhood, all women occupy an identity as a daughter, this identity forms a large part of their representational world but with the birth of their own baby their identity shifts from one of a daughter to one of a mother so the woman's social identity alters to include that of mother (Stern 1995).

Using a grounded theory approach Sethi (1995) explored the experiences of the transition to motherhood of nineteen Canadian women.⁸¹ Once analysis was completed the author concluded that during the process of becoming a mother women experience a transformation of the self and a new re-altered self emerges through a four stage process - 'giving of self', 'redefining self', 'redefining relationships' and 'redefining personal goals' (Sethi 1995:p236) - whereby after the birth of her baby, the woman embarks on a process of discovery. The categories and subcategories that emerged in Sethi's study captured the multidimensional aspects of the process of becoming a mother and provided the content for the emergence of a core category that demonstrated the transition, contradictions; tensions and transformations women engaged in when becoming a mother. A theoretical model, comprising of four spirals, representing the relationship between the core category and the four categories was developed. The first spiral encapsulated the woman's birth experiences; the second was comprised of the contradictions, tensions and resolutions associated with becoming a first time mother, the third spiral represented the transformation that occurred within the self during the process of becoming a mother and the fourth spiral was concerned with the emergence of a new re-altered self, as a mother.

Sethi (1995) suggests the process of discovery that women embark upon when becoming a mother is time consuming, it is a process that deflects from other aspects of the self and significantly impacts on the woman's personal needs, relationships with others and occupational self. During this period the woman forfeits her own needs in order to meet the needs and requirements of their newborn baby. The woman realises the extent of responsibility associated with being a mother, she makes significant changes to the self and her world to accommodate this sense of responsibility. This realisation stimulates a change in the internal reference system and results in the transformation of the self. Being a mother is the catalyst that causes the woman to reassess and rethink her life and implement changes in order to incorporate motherhood into her biography. The subsequent changes

⁸¹ The sample of 19 women comprised of 12 primiparous women, three multiparous women and four narratives, located in the non-fictional literature. The author justifies the inclusion of multiparous women in the sample as a means to compare and determine if there were differences in the experiences of primiparous and multiparous mothers. Unstructured interviews were conducted with the 15 women during the first three months after the birth of their first baby. Each woman was interviewed twice; the first interview was conducted at two or three weeks postpartum and the second at 10-12 weeks postpartum. Supplementing the data generated from these interviews were field notes and the four non-fictional narratives of first time mothers.

impact on the woman's relationships with others and on her priorities and life plans. Notably, although the women that participated in Sethi's (1995) study reported being happy with their new maternal self they also reported experiencing a loss that manifested in a loss of autonomy, freedom and the ability to predict incidences in their lives. Although the findings of this Sethi's study appear trustworthy the method of sampling casts uncertainties and reservations on the conclusions drawn. The origins of the narrative from the non-fictional literature are unclear and go unreferenced.

This suggestion that motherhood induces a change in the self and a woman's lifeworld was also advanced by McMahan (1995). Using a grounded theory approach and in-depth interviews over a twelve month period with a purposive sample of 59 mothers McMahan (1995) investigated the social processes that shaped Canadian women's experiences of first time motherhood. The sample was composed of a diverse social group of middle class and working class women. The mean age of the middle class women was 35 years and working class was 27 years. The study concluded that a woman's maternal self is a product of her experience and conformity with a gender role. Accordingly motherhood was considered to be a critical event contributing to the reconstruction and transformation of the self, an 'emotionally structured rite of passage in the transformation of a female identity' (McMahan 1995:p274).

Three years after Sethi and McMahan's studies, Smith (1999) conducted a qualitative study using four case studies to explore the effect the process of transition may have on the development of an identity. Using interpretative phenomenological analysis, the study focused on identity and the process of identity change. Four British women, aged between 25 and 29 years, expecting their first baby, were interviewed during pregnancy and postnatally.⁸² The resulting 'theory of a relational self' (Smith 1999:p424) provides an insight into how women prepare psychologically for motherhood. Women begin the process of adjustment to a new state of being during pregnancy. During this adjustment, women engage in a process of self reflection or questioning. The woman's focus and concerns shift from the public domain, that generally comprises of work and a wider social context, to concentrating and focusing on her private domain, focusing on what is happening to herself and the personal world of family. Introspection occurs, albeit insidiously, because at this point the woman is closely involved with significant others. This contact with significant others informs the woman's

⁸² The interviews occurred at three, six and nine months prenatally and five months postnatally. In addition to interviews women kept a diary during pregnancy where they recorded their feelings and thoughts related to the topics discussed in the first interview. Smith's objective was to devise a theoretical model, to explain how women's sense of identity is transformed during the transition to motherhood.

perceptions of herself and may assist the woman to discern and discover her role as a mother. Pregnancy provides an opportunity to develop and grow or can be a period of regression and disorganisation. It affords the woman the opportunity to invoke her future maternal identity.

Understandably, as the woman's pregnancy nears an end, her thoughts and emphasis shift to the impending birth. Women tend to be ambivalent about birth; they may be impatient, experience anxiety and tension emanating from concerns regarding their preparedness for the process. Once the baby is born, a process of adjustment occurs as the woman adjusts to the presence of her baby. Attention and focus turn to her own life and this period marks a significant shift in the woman's perception of the self. Smith (1999) concluded that the increased interpersonal contact with significant others, before and after the birth, facilitates a growing awareness of the self during the transition to motherhood.⁸³

In the same year as Smith's study, Bailey (1999a, 1999b) employed discourse analysis to analyse the content of semi-structured interviews conducted with 30 women in the last trimester of their first pregnancy. This study was concerned with the discursive construction of self during motherhood. The women were aged between 25 and 38 years and all resided in the Bristol region of England. Six themes emerged from the process of analysis: (i) self identity and mothering identity, (ii) the body and self, (iii) the working person, (iv) practices of the self, (v) the relational sense of self and (vi) the experiences of space and time. These themes provide women with an opportunity to change as they negotiate the process of adaptation to motherhood. Bailey described how, when a woman becomes a mother, she experiences a 'refraction of the self' (Bailey 1999b:p338) where vibrant aspects of her character, concealed pre-motherhood, come to the fore.

Some of the women interviewed by Bailey refuted the traditional notions of motherhood and rejected the notion that their lives would change, while others considered pregnancy to be a defining period in their lives whereby in anticipation of becoming a mother the self was significantly altered. The findings populating the first theme 'self identity and mothering identity' demonstrate how becoming a mother increases a woman's sense of self-worth and elevates a woman's status to an adult state where she behaves in a more responsible, less egocentric manner. As the woman negotiates the shift in

⁸³ There are limitations to Smith's theory, its application is limited it is only applicable to those women with similar demographic characteristics to those who participated in his study. Further theoretical development is necessary to extend or expand the theory, and to examine the applicability of the theory for other women engaged in the transition to motherhood.

identity to a maternal identity, she may experience apprehension and uncertainty about the impact being a mother may have on her previous, pre-motherhood self.

The second theme 'the body and the self' revealed how the physical changes accompanying pregnancy act as physical marker that signify the psychological changes that occur as the women engages with the process involved in the transition to motherhood. Women use the physical changes of pregnancy as a reference point to remind them about the impending changes that are about to occur in the self. As the physical signs of pregnancy become apparent, others begin to treat the woman differently; this affects her sense of relationship with her body, her sense of sexuality and fertility come to the fore and, as the pregnancy progresses, she embraces a new gendered identity. But as the pregnancy progresses the woman's body becomes 'public property' (Bailey 1999b:p340) and some may experience a loss of control inferred by the actions of others who touch, pat and comment on the woman's burgeoning abdomen. For some, the actions of others instil a sense of invasion, a sense that some women resent.

The third theme, 'the working person,' explains how, for those women that are in employment, pregnancy becomes an indicator that a change in priorities outside of their working environment is necessary. This theme demonstrates how a woman's occupational self is an important entity of the pre-motherhood self and how some women may experience apprehension about the changes that may occur in their occupational self once they become a mother. Women may have reservations about the respective value others place on their work and their role of mother. Nonetheless, for some women, returning to work can be an important feature in the construction of a maternal self.

The fourth theme, 'practices of the self,' describe how, during pregnancy, women engage in or withdraw from a range of activities, including engaging in antenatal classes and other lifestyle practices.⁸⁴ Women become conscious of the need to alter and change their lifestyle, their appearance and their behaviour as they 'practised their pregnant selves' (Bailey 1999b:p343). Depending on the woman's pre-motherhood lifestyle, these changes can be either minor or radical. Additionally, in preparation for motherhood, women tend to source large volumes of information and read around the topic. The process of transition to motherhood also increases the importance of relationships for many women. The valorising of relationships that occur was captured in the penultimate theme of Bailey's theory of 'the relational sense of self'. During the woman's transition to motherhood, various

⁸⁴ Lifestyle practices include yoga and exercise classes.

relationships especially those with their partners and own mothers are re-altered, often strengthened. The imminent arrival of a new generation may bring a sense of permanence to relationships, especially in the woman/partner relationship, a sense that may be lacking pre-motherhood. Friendships with non-parent friends tend to dissipate and women are more inclined to develop friendships with other expectant mothers and parents. Essentially, women experience a reconstruction of intimacy in some relationships, specifically with partners and their own mothers but the relationship with others, such as friends, are fractured, to what degree depends on whether or not the friends are parents.

The final theme of Bailey's theory 'experience of space and time' encapsulates how the woman's conceptualisation of time and space alter during pregnancy. Long-term planning becomes an essential requisite of being a mother and the private domain of home and family, become prominent. Bailey's (1999a, 1999b) theory also establishes how for those women who wanted to do so, pregnancy offers them an opportunity to change,⁸⁵ it also affords women the right to reject and be non-compliant with the dominant societal perceptions of what constitutes beauty and it confers a right to feel vulnerable and dependable, a state that some women, especially those with a disability, may be reluctant to portray pre-motherhood.

Bailey's (1999a, 1999b) theory provides us with a vast amount of information pertaining to the changes both experienced and perceived while women engage in the process of transition to motherhood. The author, however, only captured the women's experiences and anticipations during pregnancy, as the women prepared for motherhood, not postnatally, where arguably experiences are more realistic, acute and accurate. Narratives constructed during pregnancy can be anticipatory, tentatively produced and narrated cautiously, as women navigate a mass of public expectations and assumptions, and their own personal experiences (Miller 2000a). Despite this limitation concepts from Bailey's (1999a, 1999b) theory together with concepts from the symbolic interactionists' conceptualisations of the self (discussed in chapter 3) informed the coding paradigm (see Table 5.2, chapter 5), the analytical tool used during the data collection and analysis phases of the present study.

Five years after the development of Bailey's (1999a, 1999b) theory, Yeates (2004) conducted a qualitative study in the UK, using a narrative approach to explore the process of reorganising one's identity when becoming a mother for the first time. Six first-time mothers, aged between 21 and 34 years were interviewed and their narratives were analysed to provide an explanation of the intra-

⁸⁵ For example if the woman is unhappy in her occupation motherhood provides her with the opportunity to make changes.

psychic process involved in the transition to motherhood. The study was informed by the psychoanalytic theories of identity and Stern's (1998) motherhood constellation framework. The study concluded that women develop a maternal identity and confidence through adjusting to the changes associated with motherhood and that motherhood induces change and transformation in the self. A woman's adjustment to motherhood is a very public act whereby she enacts behaviours that infer she is a good, competent mother while actively seeking the positive appraisals of others and while also harbouring a fear of being judged and labelled as a bad mother. Yeates (2000) further theorised that the support matrices available to the woman also influence the change experienced in her identity. Although Yeates (2004) was one of a small number of researchers who specifically explored the effect the process of transition to motherhood may have on the self and the woman's self-identity, the study's small sample size is a limitation that limits the applicability of the study.

Almost a decade after Bailey's (1999a, 1999b) theory, Darvill et al (2010) conducted a grounded theory study exploring the transition to motherhood for first time mothers living in the UK.⁸⁶ The findings indicate that the transition to motherhood is not just a postnatal phenomenon rather, it occurs across the continuum of pregnancy, birth and motherhood. Unlike Rubin (1967a: 1967b) and Mercer (1984) who respectively suggest that the process of transition terminates at the end of the neo-maternal month, or twelve months postnatally, Darvill et al (2010) did not commit to a specific timeline, suggesting instead that the process is not complete until the mother regains some control over her internal and external environments. Reiterating the findings of other qualitative studies (Rubin 1967a, 1967b, Barclay et al. 1997, Lewis and Nicholson 1998, Marshall et al. 2007), loss emerged as a central concept in Darvill et al's (2010) study. In this instance, loss related to the loss of control the woman experienced in relation to her body in early pregnancy as the signs and symptoms, sometimes debilitating symptoms of pregnancy, took hold. The personal experience of nausea, vomiting and extreme tiredness may be much greater than the woman ever anticipated and this may instil a sense of loss of control over their corporeal functioning. Contributing to this lack of control is the sense that in pregnancy the woman may feel more vulnerable to physical injury and the need to protect her unborn

⁸⁶ Qualitative interviews were conducted over a six-month period with 13 mothers aged between 17 and 39 years. Nine women were employed in full time employment while 4 women did not work outside the home. The educational accomplishment of the women varied, ranging from not completing formal schooling to attaining a doctoral degree. The interviews occurred between 6 and 15 weeks after the birth of their first baby. In keeping with a grounded theory methodology, the women's narratives were analysed using the constant comparative method of analysis and a core category entitled 'altering self concept' emerged (Darvill et al. 2010:p4). The core category was populated with three subcategories: control, support and forming a family.

baby.⁸⁷ The findings of Darvill et al's (2010) study also highlighted how support is an important variable in the transition to motherhood. Three different sources of support, own mother, partner and peers, inform and influence the process of transition, they provide a sense of normality for the woman's feelings and experiences and instil a sense of confidence and competence.⁸⁸

Chapter three (see 3.3.3.1, chapter 3) explains how Western thinking of and theorising about identity and the self revolves around an understanding of the paradoxical fusion of sameness and difference. Earle (2000) used a Strauss and Corbin approach to grounded theory to explore how pregnant women maintain a sense of uniqueness while simultaneously experiencing a sense of similarity to other pregnant women when accessing community based antenatal care in the UK. In-depth interviews were used to capture the experiences of nineteen primigravida Caucasian women aged between 19-30 years, recruited from community based antenatal clinics.⁸⁹ The findings demonstrate how, through the process of social interactions with others, women generate a sense of uniqueness and similarity. The sense of similarity provides the woman with a frame of reference and helps her to determine if her experiences are normal. While this sense of similarity is an essential element in the construction of the woman's identity so too is a sense of uniqueness but the development of a sense of personal uniqueness is dependent on the nature of the relationship between the woman and the caregivers she encounters, and the institutional policies encountered when women access maternity services.

⁸⁷ The loss of control experienced by participants in Darvill et al's (2010) study abated in mid and late pregnancy as the physical symptoms of early pregnancy began to decrease but it could surface again in the postnatal period. The physical changes of pregnancy and the associated change in self-image signal a shift in focus from the woman's needs to the needs of their unborn baby, thus demonstrating that the transition to being a mother begins in early pregnancy.

⁸⁸ Darvill et al (2010) did not comment on how the timeframe in which the interviews were conducted may have impacted on the need for support and sense of insecurity felt by the women. The women were interviewed between 6-15 weeks postnatally, a period where major physiological, psychological, emotional, cognitive and social adjustments were occurring so it would seem reasonable that during the process of adjustment, women would experience a sense of insecurity and would require additional support at this time.

⁸⁹ Amongst the sample, there was a broad diversity in relation to age and occupation. Each woman was interviewed three times, twice during pregnancy, between 6-14 weeks and within the last trimester of their pregnancy, and once postnatally, between 6-14 weeks after the birth of the baby. The constant comparative method of analysis revealed how women constructed a sense of identity through the process of social interactions with others, especially community midwives and through this process they generated a sense of uniqueness and similarity to others.

4.9 Motherhood and women with a disability

The process of becoming a mother is contoured differently and is dependent on a woman's ability (Thomson et al. 2011). Society often questions and doubts that women with a disability can mother adequately. Historically, society's disapproval of mothers with a disability was manifested in negative attitudes, scepticism and prejudicial assumptions regarding the woman's inadequacy to nurture and care for their child(ren). Literature regarding the transition to motherhood from the perspective and experiences of women with a disability is limited. Some studies, mainly qualitative, originating from Canada, Australia, America and the UK, are available but these tend to focus on the issue of accessibility, profiling the challenges that women with a disability encounter while accessing maternity services, attaining a maternal role and fulfilling the requirements of that role (Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Prilleltensky 2003, Prilleltensky 2004a, Lee and Oh 2005, McKay-Moffat and Cunningham 2006, McKay-Mofatt and Rotheram 2007, Smeltzer 2007, Begley et al. 2009b, 2010, Walsh-Gallagher et al. 2012). Little is known about the experiences of women with a disability and their transition to motherhood and even less about the relationship of this process to the self. Furthermore, contemporary theories on the transition to motherhood were developed from the perspective and experiences of non-disabled women, although there is some diversity among the study populations (for example, women over 35 years (Carolan 2005), lesbian mothers (DiLapi 1989, Wilton and Kaufmann 2001, Spidsberg 2007), adoptive mothers (Fontenot 2007), teenage mothers (Arthur et al. 2007), imprisoned mothers (Shamai and Kochal 2008), African American women (Sawyer 1999), to date, few studies have included women with a disability.

One study (Malacrida 2009) that did explore the experiences of women with a disability (n=43) used a narrative inquiry, to explore how women with a disability reconcile the demands of ideal mothering with the reality of being a woman with a disability. As previously discussed, in western society, the ideal mother is conceptualised as a mother who: (i) mothers instinctively and (ii) who is continually available to care for her baby in a selfless and seamless way. Meeting and adhering to the tenets of ideal mothering can be a challenge for any woman, but even more for women with a disability because these women engage in mothering with fewer resources and greater obstacles than non-disabled mothers. Malacrida (2009) conducted semi-structured interviews with Canadian mothers (n=43). The participants had a range of impairments including multiple sclerosis, spinal cord injuries, mental health issues, cognitive and developmental disabilities and sensory impairments. The study explored the contradictions and tensions experienced by these mothers in their performance of ideal

motherhood. It examined how women with a disability accomplish motherhood in ways that undermine or contest the perceptions of others. The study's findings indicate how, in compliance with the provisions of ideal motherhood, women with a disability employ extraordinary measures to appear competent and capable. Conscious of how others might perceive them and judge them in relation to how they mother these women engage in 'over conscious mothering' (Malacrida 2009:p106). Having an awareness of the norms of ideal mothering may cause some of them to hide aspects of the self and only reveal aspects that fit with the norm.

Although the majority of women who participated in Malacrida's (2009) study acknowledged that performing and adhering to the norms of ideal motherhood was difficult, almost 25% considered their disability to have enhanced their mothering abilities and practices. The women drew on their experiences of having a disability and incorporated their coping and adaptive strategies to negotiate, and to creatively and effectively execute the normative practices associated with the concept of ideal motherhood. Surprisingly, none of the mothers refused, challenged or resisted the premise of ideal mothering nor did they find the construct to be arduous or repressive. As a mother, women with a disability claim a gendered identity, a post-motherhood identity they share with other mothers. However, despite this sense of a shared identity, mothers with a disability encounter intrinsic and extrinsic challenges when attempting to engage and perform ideal mothering. These challenges are not only situated within the woman's body but are created and exacerbated by social policies and institutional practices (Thomas and Curtis 1997, McKay-Mofatt and Rotheram 2007, Smeltzer 2007, Malacrida 2009, Begley et al. 2009b, 2010).

4.10 Contextualising this study

In previous studies exploring the transition to motherhood, the sample generally consisted of white middle class mothers, mainly because researchers were reliant on samples of opportunity (Phoenix 1991). Minority and diverse groups were frequently omitted. While, in more recent times, this anomaly has been addressed for some diverse groups, for women with a disability, their experiences remain under-researched. Consequently, the experiences of these women remain unheard so it is unclear if current theories on transition to motherhood are applicable and appropriate to these women. Most of the extant theories on transition to motherhood use attainment, adjustment and adaptation to describe how women manage the transition, few have explored how the process of change involved in

becoming a mother impacts on the self. The information gained from this grounded theory study exploring the process involved in the transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self will supplement extant theories on the phenomenon. The research seeks to unveil the experiences of women with a disability; a view heretofore undocumented and to delve deeper and more broadly into the topic of transition to motherhood, verifying, modifying and contributing to extant theories that are predominantly from the perspective and experiences of non-disabled women. Furthermore, the findings will provide a conceptual framework explaining how women with a disability embody the existential changes implicit in the role of mother.

4.11 Conclusion

Motherhood emanates from a complex matrix of biological, psychological, social, environmental and political factors. Current theories relating to transition to motherhood provide an understanding of maternal adjustment and role attainment from the perspective and experiences of non-disabled women (the experiences of 1083 non-disabled women form the basis of these theories). Some reference is made to the impact becoming a mother may have on the self and one's identity with the majority of theorists contending that the process of transition to motherhood infers a loss of self and self-identity. Women experience loss in all dimensions of the self including loss of freedom, independence and control over their physical self, psychological and emotional thoughts and feelings. There is no consensus on how long the process of transition to motherhood should take some suggest that the transition is complete within the first postnatal month while others suggest a period of twelve months. The small number of studies that did explore the effect the process of transition to motherhood may have on the self and the woman's self-identity suggest that, during the process, women experience some form of transformation but whether or not this is the same for women with a disability is unclear. This grounded theory study is concerned with exploring and documenting the experiences of women with a disability, the findings will contribute to, modify and/or extend existing theories on transition to motherhood and provide a conceptual framework that can be used as a point of reference for caregivers as they counsel, assist and facilitate the transition to motherhood for women with a disability.

Chapter 5 Philosophical and Methodological Underpinnings of the Study

5.1 Introduction

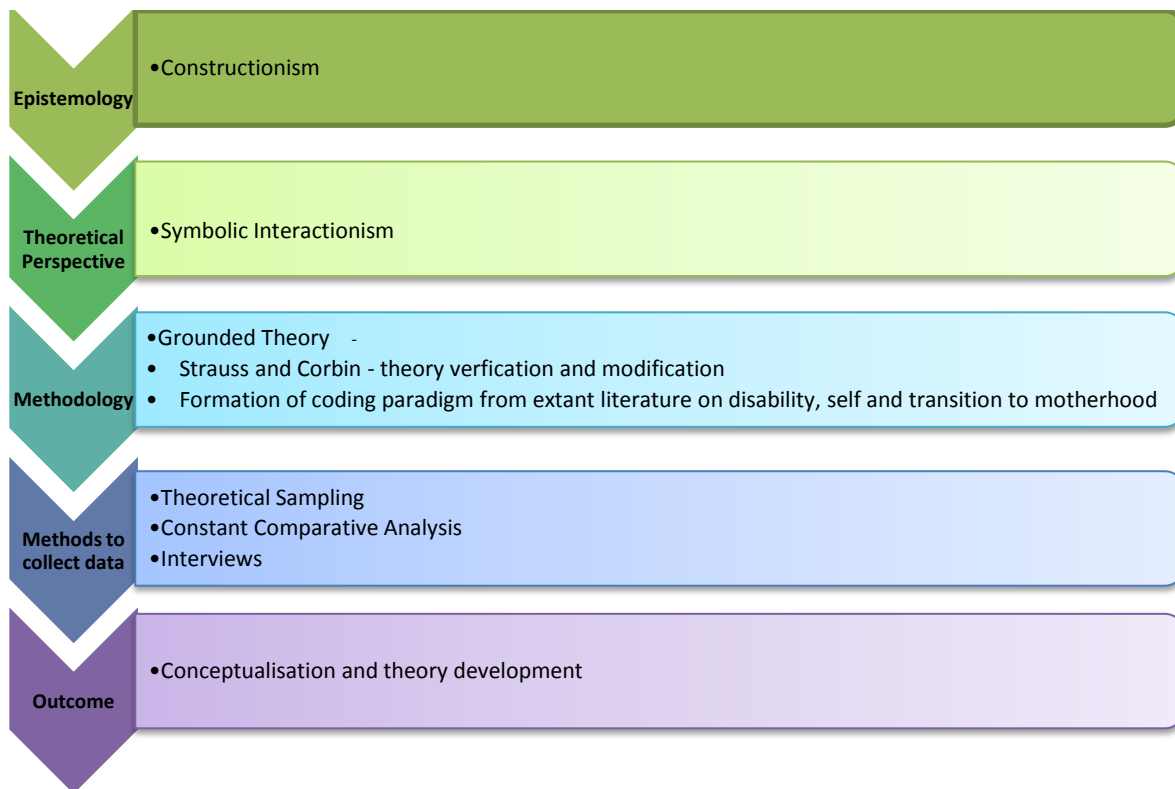
Over the past 25 years, significance has been placed on the importance of clarifying the philosophical and methodological underpinnings informing the conduct of a research study (Guba and Lincoln 1994, Creswell et al. 2007). Emphasis was also placed on evaluating the congruence of these underpinnings with the researcher's own philosophical perspectives. This chapter details the philosophical and methodological assumptions that underpinned this grounded theory study. The study was conducted under the umbrella of interpretivism. Epistemologically, it was informed by constructionism and ontologically critical realism, and the data were interpreted through the lens of symbolic interactionism. Methodologically, the study was conducted using a grounded theory approach specifically, the logico-deductive approach of Strauss and Corbin (Corbin and Strauss 2008) (see Figure 5.1). Many qualitative research studies seek to describe and explore a particular phenomenon, but this grounded theory study differed, it goes beyond mere description and exploration; it seeks to explicate the process involved in the transition to motherhood and generate new knowledge from the perspective and experiences of women with a disability, moving it from the particular to the general (Birks and Mills 2011). Moreover, it is anticipated that the information gained from this study will verify, modify and contribute to existing theories on disability, identity and especially the transition to motherhood.

As detailed in chapter 4, a review of the theoretical literature on transition to motherhood revealed that information on the process of transition to motherhood from the perspective and experiences of women with a disability is limited. The current body of literature on the subject is mainly from the perspective and experiences of non-disabled women, so it was critical that the experiences of women with a disability were explored within the context of extant theories on disability, self and transition to motherhood. Exploring their experiences has established the extent to which the experiences of these women are consistent or at variance with non-disabled women. Through my involvement in the descriptive qualitative study commissioned by the National Disability Authority and National Women's Council of Ireland (see chapter 1),⁹⁰ I was familiar with the literature around disability

⁹⁰ The context and background of this study was discussed in detail in chapter 1.

and less so around the transition to motherhood, it was impossible therefore to claim a tabula rasa.⁹¹ A tabula rasa is a necessary requisite for those who use a Glaserian approach (Glaser and Strauss 1967) to grounded theory. Alternatively Strauss and Corbin argue that at the outset of the study, the researcher needs to be familiar with the extant literature because it is from here that the concepts emerge to inform the coding paradigm (Strauss and Corbin 1990, Corbin and Strauss 2008). Moreover, Strauss and Corbin’s approach to grounded theory, allowing as it does for the verification or modification of existing assumptions on a specific phenomenon was consistent with the purpose of this study, the purpose being to verify or modify existing theoretical assumptions on the process of transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self, a perspective that was unheard heretofore⁹².

Figure 5.1 Epistemology, theoretical perspectives, methodology and methods that structure this research



(Modified from Crotty 2007).

⁹¹ Tabula rasa refers to the absence of preconceived ideas or predetermined goals.

⁹² Belenky et al. (1997) use the metaphor deaf and dumb to vividly capture woman’s salient experiences of feeling silenced and unheard. The term dumb captured women’s experiences of feeling unheard and voiceless. Consequently, the silent women feel disconnected, detached, removed and isolated from a world infused with ‘rumour and innuendo’.

5.2 Philosophical positioning – epistemology and ontology

The purpose of this study was to generate new knowledge regarding the process of transition to motherhood and the relationship of that process to the self from the perspective of those who experience it. This knowledge contributes to the existing body of knowledge on disability, self and transition to motherhood.

5.2.1 Knowing and the production of knowledge

This endeavour to produce knowledge emulates the actions of key protagonists charged with influencing the production of knowledge and the intellectual revolution that occurred in the late 15th and early 16th centuries. These protagonists originated from four European countries, Poland, Italy, England and France (Oakley 2000). The knowledge that emerged from the teachings of Polish merchant Nicholas Copernicus (1473-1543) and Italian, physicist, mathematician, astronomer and philosopher Galileo Galilei (1564-1642) was influenced by the doctrines of astronomy and theology.

In the late 15th, Nicholas Copernicus (1473-1543) a Polish merchant was fascinated by astronomy. His knowledge regarding the universe was informed by two ancient Greek astronomers, Aristotle and Ptolemy. Aristotle's assumption on logic was, at that time, considered the most comprehensive approach to knowledge construction, so much so, it dominated the European academic field and was taught in major European universities. Aristotle's championed the use of human sense and rationale to understand Christian teaching and revelations about the universe. Copernicus challenged the hegemonic theological doctrine regarding the organisation of the cosmos. Although his theory regarding the earth spinning on its own axis, around the sun was revolutionary, the methods used to create this theory - experience, observation and demonstration - were considered anti-empirical. Aristotle's approach to scientific inquiry was rejected by the founder of modern science, Italian, physicist, mathematician, astronomer and philosopher Galileo Galilei (1564-1642). Galileo favoured Copernicus' method of producing knowledge; he believed that experience and demonstration should take precedence over philosophical or theological doctrines. Predictably, the Aristotelian academic community were unhappy with Galileo. His approach to knowledge production did not concur with the

dominant biblical interpretations; his work threatened the norm of Christian teaching so, it was censored and he, condemned for heresy.

Reason and rationality entered the equation in the early 16th century through the teachings of English scientist Francis Bacon (1561-1626) and the teachings of French mathematician, and father of modern philosophy Rene Descartes (1596-1650). Questioning and speculating on the nature of reality, Bacon (1561-1626) suggested that knowledge was derived from experience, and that a deductive method of inquiry was better positioned to use rationale to generate theory. Reasoning and rationality are concepts associated with the Enlightenment period, a period characterised by autonomous thinking, where factual truth was sought through human reason and logic using observation, experimentation and comparison. Descartes (1596-1650) proposed that knowledge emerged from the self and the world experienced by that self. This is the main premise of Cartesian philosophy, which emerged in the early 17th century. Central to this premise was the theory that individuals were composed of two distinct and different entities, the mind and body. The mind being the thinking entity, and the body, the corporeal entity, although related, the interaction between the two is inexplicable. The German philosopher Immanuel Kant (1724-1804) attempted to resolve the dispute between empiricism and rationalism, by concluding that experience was subjective and processed by reason. Thereafter methodology became a prominent actor in the production of knowledge through the teachings of Auguste Comte (1798-1857) but, as evident in the creationists' rejection of Darwin's theory on evolution, the influence of philosophical and theological doctrine continued into the 20th century. Charles Darwin's (1809-1882) work '*On the Origin of Species*', is considered to be the foundation of evolutionary biology. Darwin theorised that through a process of natural selection, populations evolved over the course of generations, but this hypothesis was rejected by creationists who believed that humanity, life, the Earth, and the universe were created by a supernatural being, the Abrahamic God.⁹³ The creationists were so resolute in their belief they fought for and successfully got the teaching of evolution banned in public schools in the United States. However, this action was legally contested and the decision was subsequently reversed. In the case of *Daniel v. Waters* (1975) the judge ruled that teaching creationism in public schools contravened the Establishment Clause of the First Amendment in the US, In the case of *Edwards v. Aguillard* (1987) the judge ruled that creation science similarly contravened the constitution, consequently all references to "creation" in school textbooks in the US were changed to refer to

⁹³ Abrahamic God - a conception of God, found in the Judaism, Christianity and Islamic religions doctrine, God is conceived as an eternal, all-powerful entity, the creator of the universe.

intelligent design, which was subsequently claimed to be a new scientific theory but in the *Kitzmiller v. Dover* (2005) case the judge concluded that intelligent design was not science and that it contravened the constitutional restriction on teaching religion in public school science classes.

Auguste Comte (1798-1857) is considered to be the architect of positivism. With its quantitative, mathematical foundation, his philosophy informs modern positivism, which is based on the premise that knowledge is generated through scientific means. However, this premise was unhinged by the work of Max Weber (1864-1920), Emile Durkheim (1858-1917), and the anti-positivist revolution that accentuated the differences between the natural and social sciences. Post-positivists acknowledge the existence of an external reality but question the ability to fully capture all representations of the world; they question the notion of absolute objectivity and the predicative capability of a positivist approach. This questioning of positivism heralded the beginning of the 'paradigm war' (Oakley 2000:p23), a war predicated on the struggle to gain legitimacy for knowledge created from non-scientific research, one that resulted in the emergence of two different paradigms - objectivism and interpretivism.

5.2.2 Objectivism and interpretivism

The paradigm war was predicated on the conflicting beliefs around the production of knowledge and the authenticity of that knowledge. American historian and philosopher Thomas Kuhn (1922-1996) is credited with the emergence of the term paradigm. Convinced that scientific research approaches were not sufficient to address questions posed by sociologists Kuhn developed a universally recognised set of standards that researchers could refer to (Oakley 2000). The term paradigm is defined as: (i) a 'shared belief system that influence the kinds of knowledge researchers seek and how they interpret the evidence they collect' (Morgan 2007:p50), (ii) a set of 'basic beliefs that deals with ultimate or first principles' (Guba and Lincoln 1994:p107), (iii) a framework employed when contemplating research design, analysis and researcher involvement (Patton 1982), (iv) a set of worldviews encapsulating beliefs around the nature of knowledge and reality (Schwandt, 1989). In essence, a paradigm represents an individual's understanding of the world, its nature, their positioning in it, its component parts and the mass of potential relationships therein.

Much of the research conducted in the last century was underpinned by the philosophical assumptions of science. Proponents of the scientific approach subscribe to an objectivist standpoint, believing that things exist objectively and are independent of individual experience and perception

(Gillett 2004).⁹⁴ This belief is ideal for natural sciences but conflicts with and is contested in humanities. Objectivists consider facts to be located in a value neutral world that when studied reveal a single absolute reality. They use approaches that employ large populations, measurement and statistical analysis as a means to predict and control a particular phenomenon. When employed to study the social world, the knowledge that emerges from such studies can be, through indisputable acceptable principles, used to regulate and control society (Smith 1998, Burr 2003).

While objectivists search for an objective social reality, constant across time and setting, one that can be observed, tested and measured, social scientists, steeped in interpretivism, claim that scientific research is inappropriate for the examination and exploration of complex, dynamic situations (Lincoln and Cannella 2004, Lalor 2007). Interpretativists⁹⁵ perceive facts of the world to be a complex 'impenetrable kaleidoscope' (Oakley 2000:p24) of socially constructed meaning. They perceive knowledge and truth to be created, not discovered; the world is known through an individual's interpretations of it, 'truth is arrived at not by seeking correspondence, but by seeking consensus; not by looking for a perfect match, but by finding a reasonable fit; not by assuming detachment but by assuming commitment. Truth, therefore, is relative rather than absolute; it depends upon time and place, purpose and interests' (Pratt 1998:p23).

5.2.3 Carper's ways of knowing

This discussion on the production of knowledge would be incomplete without reference to Barbara Carper's (1978) seminal work on ways of knowing within the nursing profession. Prior to 1978, before the publication of Carper's work, the vast amount of knowledge generated by nurse researchers was empirical. These researchers knew how to be objective; how to control extraneous variables and how to discard divergent experiences, they never referred to the philosophical underpinnings of the methods used to explore phenomena. Moving beyond empirics, Carper encouraged nurses to consider knowledge from three alternative perspectives - aesthetics, personal and ethics. Subsequently, four

⁹⁴ Essentially, the knower is separated from the known and knowledge of the world is gained from a value neutral perspective.

⁹⁵ Early orientations toward interpretive approaches can be found in Weber's account of 'verstehen' - of subjective meaning and interpretive understanding and in the works of the traditional symbolic interactionists George Mead (1863-1931), John Dewey (1859-1952) and Herbert Blumer (1900-1987).

interconnected patterns of knowing, distinguishable according to their meaning emerged – empiric,⁹⁶ aesthetic,⁹⁷ personal and ethical.⁹⁸ The four patterns of knowing are interconnected, no pattern has precedent over another, nor does knowledge of one pattern require the rejection or neglect of the other three. Nevertheless, an understanding of each pattern is essential in order that there is congruence between the pattern of knowing and its epistemological objectives. The patterns of knowing (i) provide a comprehensive and systematic approach to thinking and learning about personal experiences, (ii) have advanced nursing knowledge, (iii) have increased awareness of the complexity and diversity of such knowledge, and (iv) were instrumental in the developments of Johns' (1995) framework on reflective practice (Johns 1995).⁹⁹ While Carper's work is significant, the strengths are numerous and the impact it has had on the nursing profession is vast nonetheless, the fundamental patterns of knowing was a product of its time and contemporaneously it has been subjected too much criticisms. One such critic is that the patterns of knowing are not, as Carper maintains, a process as to how one comes to know, instead the four patterns are depicted as end products and the epistemological question of how does a person come to know if the knowledge is empiric, aesthetic, personal and/or ethical remains unanswered.

5.3 The emergence of qualitative research

Qualitative research gained credibility with the paradigm shift towards interpretativism. Its historical development, from the beginning of the 20th century to the present day, is mapped out in eight phases. It was over this time that qualitative studies significantly contributed, both conceptually and theoretically to the social sciences, providing a greater understanding of social realities (Denzin and Lincoln 2005). Denzin and Lincoln (2005) define the different phases of development of qualitative inquiry as the 'eight historical moments in qualitative study' where multiple theoretical paradigms developed and evolved at different periods, each with their own epistemological perspectives and

⁹⁶ Empiric is defined as knowledge systematically organised into theories that describe, explain and predict phenomena relating to the discipline of nursing.

⁹⁷ Aesthetic knowing refers to the objective, factual or generalisable knowledge that is attained through experience, subjective expression and acquaintance. Analysis and interpretation of aesthetic ways of knowing have resulted in the development of diverse theories that links aesthetics with personal experience, intuition, gestalt, nursing skills and action.

⁹⁸ To see the characteristics of each pattern of knowing in more detail see Carper (1978).

⁹⁹ Reflective practice is an important tool for midwifery, where midwives learn from reflecting on their own professional practice, it's important for professional development and improvement, its use is advocated by many (Schon 1983, Gibbs 1988, Johns 1995, Rolfe et al. 2001, Kolb and Kolb 2005).

methodologies designed to obtain the truth and advance knowledge. The first two stages - the traditional phase (1900-1950) and the modernist (or golden age) phase (1950-1970) - were associated with a positivist epistemological standpoint and subscribed to the notion of absolute objectivity. It was during this phase that the importance of interpretive study, using systematic methods originating from the Chicago school of interactionism, transpired. This created a unique tradition in qualitative research that challenged the traditional epistemological and ontological perspectives. Grounded theory also emerged at this time. The third phase, blurred genres (1970-1986), was allied with the post-positivist epistemological perspective. Here, the central principle of objectivity remained but the notion of absolute objectivity was questioned. Post positivists recognised that the researcher cannot remain impartial or detached from that which is known. Within this phase researchers had access to a variety of paradigms, methods and strategies to inform and be implemented in their inquiries. Epistemologically, constructivism also gained momentum in this phase, especially in the realm of education and Strauss and Corbin (1990) published their modified version of grounded theory at this time. The fourth phase, the crisis of representations phase (1986-1990) was dominated by the concept of reflexivity. It accentuated the struggle researchers experienced when trying to position themselves reflexively in their texts, here; the emphasis was placed on issues of gender, class and ethnicity. The postmodern phase (1990-1995), was the fifth moment, characterised by the rejection of any particular theory or method. The remaining three phases - the post-experimental study phase (1995-2000), the methodologically contested phase (2000-2004) and the fractured future phase (2005-present), were all 'concerned with confronting the backlash associated with the evidence based social movement' (Denzin and Lincoln 2005:p3).

Qualitative studies have reshaped the nature of knowledge in a more egalitarian way (Oakley 2000). However, despite these developments and the publication of seminal texts like *Awareness of Dying* (Glaser & Strauss, 1967) and *'The Social Construction of Reality'* (Berger and Luckmann 1966) it took some time for qualitative research to emerge as a distinctive method of inquiry within the health arena (Sandelowski 2004). Undoubtedly, the objectivist's critique that it was unscientific and invalid contributed to this delay. Objectivists demoted qualitative approaches to a subordinate, inferior status, a status realised by many qualitative researchers who experience difficulties when trying to: (i) attain funding for qualitative studies, (ii) get qualitative studies published, or (iii) have the findings considered credible by practitioners and policy makers (Morse et al. 2002, Sandelowski 2002, 2004).

5.4 Identifying my epistemological position

When choosing the most appropriate methodology to conduct a research study, the researcher must consider their epistemological and ontological positions because it is these elements together with the research question and aim that inform the choice of methodology. In using grounded theory, I was not restricted to a particular lens; different epistemological perspectives could be employed depending on my ontological perspective. Epistemology is a branch of philosophy that is concerned with identifying how knowledge of reality is gained (White 2004). It considers the nature and forms of knowledge, and reflects the relationship between the knower and what is known (Guba and Lincoln 1994, Norton 1999). The objectivist belief that 'truth and meaning resides in their objects independently of any consciousness' (Crotty, 1998:p42) was at variance with my epistemological belief rather, I consider an individual's consciousness and self-consciousness as integral processes in the production of knowledge. I do not perceive or consider an individual's capacity to exercise agency and make meaning of life events, as a confounding variable to be controlled during the research process. Rather, it is this action of making meaning to explicate the basic social process involved in the transition to motherhood and the relationship of this process to the self that lay at the centre of this study. I believe there is fusion between the knower and what is known. The aim of this study was to understand the process of transition to motherhood from the perspective and through the personal experiences¹⁰⁰ of women with a disability consequently, this study was conducted from an interpretativist perspective and the epistemological position was one of constructionism.

5.4.1 Constructionism

Throughout the methodological literature the terms constructionism and constructivism are used interchangeably (Crotty 1998) but while both are sociological theories concerned with explaining how social phenomena are developed in a social context, the two have different philosophical assumptions. Constructionism is defined as 'the view that all knowledge and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between

¹⁰⁰ Accordingly, the knowledge arising from this study was pragmatic, context dependent, value-laden and action oriented, contributing to extant theories relating to identity, disability and transition to motherhood.

human beings and their world, and developed and transmitted within an essentially social context' (Crotty 1998:p42). Crotty (1998) distinguishes between the terms constructionism and constructivism; the former referring to where the social dimension of meaning is the focus and the latter on the meaning making ability of the individual. Constructivists consider objective knowledge and truth as emerging from one's perspective and emphasises is on the 'instrumental and practical function of theory construction and knowing' (Schwandt 2003) In the technical literature the terms are used interchangeably and inconsistently. As this study is concerned with understanding the experiences of women with a disability I will adopt the term constructionism as it reflects the unique experiences, which are shaped by the social processes and collective endeavours, of becoming a mother for women with a disability. This will capture the wide spectrum of factors that influence the construction of meaning and actions relating to becoming a mother for women with a disability.

Rooted in sociology, constructionism became prominent with the publication of Berger and Luckmann's (1966) *'The Social Construction of Reality'*. In this seminal text, the authors suggested that when individuals interact with each other they do so on the understanding that their respective perceptions of reality are related, and as they act upon this understanding their knowledge of reality is reinforced. It also highlights how individuals and groups may have different and unique perceptions of reality (McElwain et al. 2009). Some authors contend that constructionism mirrors intentionality,¹⁰¹ the premise being that when human consciousness becomes aware of, familiar with and directed towards an object, that object is shaped by consciousness (Crotty 1998, Williams 2005). Essentially, intentionality highlights the interaction between the subject and object so, women with a disability are just not passive observers of their world, they actively engage in it and meaning¹⁰² evolves from their engagement, interaction and interpretations of the realities in that world.

Constructionism unifies individuals and their social environment, it contends that: (i) the relationship between the individual and society is dyadic and (ii) individuals are born into a social structure where they encounter, solicited and unsolicited, significant others who inform their socialisation. It is these others, through their perceptions of the individual and their definition of the situation that infer an objective reality, so effectively each individual is born into an 'objective social structure and objective social world' (Berger and Luckmann 1991:p151), to be responded to. While

¹⁰¹ Intentionality is a phenomenological notion abstracted from Scholastic philosophy and endorsed by the founding phenomenologist Husserl, it donates that consciousness is always intentional so people act intentionally.

¹⁰² Meaning is a necessary requisite for purposeful action to occur in the social world, without it action would be 'directionless and arbitrary' (White 2004:p9).

some infer an objective reality, significant others mediate and modify the individual's social world by selecting aspects that are meaningful to them, resonating with their own organic idiosyncrasies and their position in the social structure. Situated in this context, individuals construct their social world, one that is taken as a form of objective reality to be acted upon but they are also bond by this social world. The process involves three phases, externalisation,¹⁰³ objectification¹⁰⁴ and internalisation.¹⁰⁵

While constructionists assert that all understanding and meaning is constructed and shaped by social processes and collective endeavours constructionists,¹⁰⁶ are concerned with the cognitive meaning making ability of individuals, they claim that each individual interprets and experiences the world differently and constructs understanding and meaning accordingly (Appleton and King 1997, Crotty 1998, Burr 2003). The interactions with the twenty-two women who contributed to this study provided access to multiple views of reality regarding their transition to motherhood. Employing a constructivist approach would only have served to limit the construction of their experiences to an individual endeavour. It would have prevented the capturing of shared meaning and would have negated the inter-subjective, social, historical, political and cultural influences that inform the creation of meaning. Moreover, constructionism mirrored my beliefs about how knowledge is produced and meaning established, I reject the assumption that there is an objective meaning waiting to be discovered rather, I consider the individual as a whole and I acknowledge that women with a disability are born into, embedded in and engage in a world that is socially and culturally explicit, time and context bound (Nightingale and Cromby 1999). This social setting provides the women with symbols that provide the structures by which they interpret meaning. Therefore, meaning is not static; it is constantly constructed from the women's experiences as they engage with a world that is continuously changing.

Burr (2003) constructs constructionism in two ways – one that focuses on the micro structures of language used in social interactions and one that is concerned with the macro linguistic and social structures that encase social and psychological life. At a micro structural level, multiple realities of equal importance emerge through social engagement and interaction. While in a macro structural

¹⁰³ Externalisation involves the attachment of meaning to objects and turning them into signs and symbols (Berger and Luckmann 1991).

¹⁰⁴ Objects can be used by others as signs with externalised meanings (Berger and Luckmann 1991).

¹⁰⁵ Internalisation refers to the socialisation that occurs as a result of acquired meaning, passed on and experienced as if the world is a pre-given and fixed (Berger and Luckmann 1991).

¹⁰⁶ The growth of contemporary constructivist theory is thought to have originated from the work of two early 20th century prominent psychologists; Jean Piaget (1896-1980) a Swiss child psychologist and Russian psychologist and philosopher Lev Vygotsky (1896-1934). Some twenty years before Vygotsky's work American psychologist and philosopher John Dewey incorporated similar theoretical perspectives in his work on educational reform. The theories were devised to contest behaviourism, the dominant science of the time that was founded on an objectivist epistemology.

configuration realities are informed and influenced by the constructive power of language that is associated with social structures, social interactions and institutional practices. Burr (2003) suggests that these two forms are not mutually exclusive because the context of constructed meanings and the configurations and practices from which they occur must be considered. In both structures discourse is critical, discourse being the micro processes that are manifested in the use of language. Chapter 2, and 4 illustrated how our understanding and representations of disability and mothers are determined by medical and sociological discourses (Burr 2003) For example, the medical model of disability represents disability as a pathological process, inherent in the individual while the social model of disability conceptualise it within a sociological domain, external to the person and correlate it with the discriminatory actions of society. Methodologically, my constructionist positioning and the grounded theory approach of theoretical sampling combined with the constant comparative method of analysis introduced a hermeneutic¹⁰⁷ and dialectic logic¹⁰⁸ into the research process.

5.5 A question of being – clarifying my ontological position

While epistemology is concerned with the structure and dependability of knowledge (Silva and Sorrell 1995), ontology is concerned with ‘the nature of existence and with the structure of reality’ (Crotty, 1998:p10). Constructionists protest against any permanent, homogeneous standards by which truth can be generally known (Denzin and Lincoln 2005). They claim individuals produce and reproduce reality, so multiple constructions of reality exist (Norton 1999). Ontologically, the aim is not to reproduce reality, but to represent it from a number of perspectives where all are considered to be equally true and valid (Hammersley 1992). The two prominent ontological perspectives are relativism and realism.

5.5.1 Relativism

Relativism is an ontological position frequently associated with constructivism (Burr 2003, Parton 2003). This ontological perspective does not deny the possibility of a material world rather it

¹⁰⁷ Hermeneutical logic refers to the art and skill of understanding and interpreting actions, statements, outcomes and institutions.

¹⁰⁸ Dialectic logic is concerned with searching for convergent and divergent thinking about the phenomena being explored.

encompasses an ability to know such a world and to question that world. Consequently, the knowledge produced from a study that is ontologically relativist, is relative to the researcher, the context and the participants who take part. Relativists contend there is no absolute truth rather truth has a relative personal value according to how the individual perceive and interpret it. Individuals construct meaning from their personal experiences, so in any given setting different sets of relative, tentative and changeable meanings are constituted and uncovered (Guba and Lincoln 1994, Crotty 1998). The information that emerges from this ontological position is transactional, personal and influenced by temporal, historical and cultural factors (Guba & Lincoln, 1994).

5.5.2 Realism

Conversely, realism is frequently aligned with an objectivist epistemological standpoint, a standpoint espoused by Glaser, one of the original architects of grounded theory. Realists perceive the world to be ordered and independent of individual perceptions with an observable reliability that provides an explanation of a phenomenon, one that Glaser alleges can be obtained in a smash and grab approach (Glaser and Strauss 1967).¹⁰⁹ Others contend that ontologically, a modified realist perspective - subtle realism - is a perspective that occupies the middle ground between relativism and realism and is compatible with a constructionist epistemological position (Hammersley 1992, Crotty 1998, Nightingale and Cromby 1999, 2002). The knowledge generated from a study informed by this ontological perspective would be part realist (what is constructed is real) and part relativist (it is situated and produced in a given social setting). But another perspective of realism, critical realism and its associated principles of intransitivity,¹¹⁰ transfactuality¹¹¹ and stratification¹¹² (Williams 1999) resonate with my ontological beliefs. Ontologically, I believe that it is possible to acquire knowledge about the external world as it really is, independently of the human mind or subjectivity and I refute the belief that the external world is as it is perceived. I recognise and understand perception to be a function of the human mind and that individuals can only acquire knowledge of their world by critically reflecting on the

¹⁰⁹ A smash and grab approach refers to an approach where the researcher directs data collection in order to clarify and validate the relationships between emerging categories (Glaser and Strauss 1967).

¹¹⁰ Intransitivity refers to an action or state that is specific to women with a disability.

¹¹¹ Transfactuality refers to the factual incidents applicable to the transition to motherhood and other processes for women with a disability.

¹¹² Stratification refers to the hierarchical or vertical division of society based on rank and class impacting on women with a disability.

perception of that world. I understand that for women with a disability their social world contains a range of diverse systems, each with their own distinctive structures and it is because of this that the outcome of the process of transition to motherhood cannot be predicted but tendencies associated with the phenomenon can be. Consequently, the understanding and explanation that arises on the phenomenon is an understanding of these tendencies (Houston 2001). Moreover, I do not consider women with a disability as passive agents in their social worlds, rather, they are independent agents, who actively transform their social world, and who are transformed by it. I recognise that there is one reality however imperfectly captured. I believe this reality is independent of individual thought or impression and is composed of three levels: (i) the empirical level, (ii) the actual level and (iii) the real level (Houston 2001).¹¹³ I remain open to the possibility of distorted perceptions and recognise that because of the 'flawed human intellectual mechanisms and the fundamentally intractable nature of the phenomena' (Guba and Lincoln 1994:p110), the reality captured is partial. As a critical realist, I recognise that women with a disability have certain knowledge claims about the social world they reside in and this ontological perspective allows for a conceptualisation of the reality that will inform synthesis.

5.6 Symbolic interactionist as a theoretical perspective

While constructionism accounts for my epistemological positioning and critical realism my ontological standpoint, the theoretical perspective through which the data were interpreted was symbolic interactionism. In Chapter 3, I discussed the self from the perspective of symbolic interactionism but here I discuss symbolic interactionism from a methodological perspective. Symbolic interactionism is one of several theoretical schools of thought associated with the social sciences. Informed by social constructionism, it is predominantly associated with an interpretive paradigm and qualitative methodology (Prasad 1993, Kendall 1999). It emerged from two prominent schools of thought, the Iowa school and Chicago school.¹¹⁴ It was the Chicago school of thought, specifically, the

¹¹³ The (i) the empirical level consists of experienced events, (ii) the actual level consists of all events regardless of them being experienced or not and (iii) the real level consists of the measures that generate events.

¹¹⁴ Manford Kuhn influenced the Iowa school. Influenced by positivism, this school advocated a structured method to symbolic interactionism, its purpose was to develop an explanation of collective social behaviour that can be predicted and tested using empirical methods. Moreover, Kuhn questioned the Chicago school's assumptions of the situated self, claiming that the self and its related attributes was an outcome of social roles and understanding of human behaviour was only achieved when a third party observed such behaviour. While differences exist amongst the two schools, there is a consensus on the following points: (a) individuals are objects, not subjects and (b) the self evolves through social relations and interactions.

work of Mead and Blumer that informed the theoretical perspective of this study. Theoretically, symbolic interactionism resonated with my beliefs regarding objectivism: (i) objectivism is normative, evaluative and traditionalist thus it is unable to account for social change, (ii) objectivism presents a more logical, ordered analysis of social life (iii) objectivism relegates individuals to maintaining a homeostatic, systematic, constant and conformist society (Kendall 1999). Symbolic interactionists regard society as an adaptable and dynamic process of activity and reciprocation of interactions whereby human interactions create and share meaning. Objects and events have no intrinsic meaning rather symbolic interactionists consider meaning to be assigned by individuals in the course of everyday social interaction and are very conscious of the dynamic and dialectical relationship of meaning and action (Prasad 1993). Individuals are perceived to act according to how they interpret their social world, human behaviour is not intrinsic but learned through how others act towards the person. Blumer (1998) explains how meanings are derived from social processes: 'Symbolic interactionism...does regard meaning as emanating from the intrinsic makeup of the thing, nor does it see meaning as arising through psychological elements between people. The meaning of a thing for a person grows out of the ways in which other peoples act toward the person with regard to the thing. Their actions operate to define the thing for the person; thus, symbolic interactionism sees meaning as social products formed through activities of people interacting' (Blumer 1998:p5).

Rooted in pragmatism, symbolic interactionism reflects the influence of American philosophers Pierce, Dewey, James and Mead. Charles Pierce (1839-1914), the father of pragmatism, questioned the notion of validity and certainty afforded to scientific knowledge. He believed that science was tentative; moreover as a pragmatist, he suggested that in order for something to have meaning, individuals must be able to relate to it, it must relate to the individual's actual or observed experiences. Fellow pragmatist and anti-dualist philosopher George Mead is considered to be the 'intellectual ancestor' (Hewitt 2007:p6), of symbolic interactionism. Mead lectured at the University of Chicago on the mind, self and society and his theory on the mind directly and indirectly shaped the work and teachings of many symbolic interactionists including Herbert Blumer. Mead refined the concepts of mind and self, describing the self as something that was in the process of evolution. For him, human mind originated in society, it 'resulted from the exchange of social acts' (Benzies and Allen 2001:p543), mind and conduct were interlinked. Chapter 3, (see 3.3.1, chapter 3) detailed how Mead conceptualised the self using two phases, the spontaneous 'I' and the socially established 'Me'. To recapitulate, 'I' refers to the impulsive behaviours of individuals while the 'Me' represents the behaviours informed by the expectation of others and assumed by the individual. The self emerges from the process of interaction between the

two phases. It is continually reconstructed through the engagement and interactions with others. It is the contentions about the 'I' and 'Me' that set Mead and his contemporary behavioural theorists apart. Behaviourists contend that human behaviour can be explained by directly observing one's behaviour and environmental events associated with such behaviour (Dingwall 2001, Hewitt 2007) Conversely, symbolic interactionists suggest that to understand an individual's overt and covert behaviour the behaviour must be defined, interpreted and assigned meaning (Benzies and Allen 2001) For behaviourists, behaviour is learned, they relinquish any contention that one's mind has input contending instead that conduct is not what people think they are doing but what they are observed to be doing and how they are rewarded for the same. One's mind is therefore irrelevant because it cannot be observed. Mead refuted this assumption; he proposed that the mind was crucial for the explanation of conduct. Although this central tenet of behaviourism still influences modern psychology (Fine 1993), the theoretical contention of socially constructed meaning resides in social interactionism.

Mead published little on symbolic interactionism but after his death his lecture notes were interpreted and synthesised into a theoretical perspective by his student, Herbert Blumer. Blumer is described as the 'arbitor' (Fine 1993:p64) for what symbolic interactionism really means. Blumer's approach to symbolic interactionism, with its three principles pertaining to meaning, linguistics and thinking, highlighted the interpretive process involved in the construction of meaning as experienced by the individual. The theoretical underpinnings of symbolic interactionism helped me understand how, each woman with a disability is capable of responding to her social world and her ability to respond is informed and created by specific environmental conditions and the woman's inherent characteristics. Each woman has the cognitive ability to think reflectively and she employs this in everyday activities to create linguistic symbols¹¹⁵ that provide meaning. The meaning is temporal, evolving over time as surroundings change, alterations occur and new constructs develop, it is tentative not absolute (Benzies and Allen 2001). It is through this process of making meaning that women in this study actively shape their own future.

As a theoretical perspective, symbolic interactionism has its critics, criticism has been directed towards its: (i) conceptual ambiguity, (ii) perceived lack or absence of consideration of the individual's emotions, unconsciousness of human behaviour and social structure (Meltzer et al. 1975, Benzies and Allen 2001), and (iii) how its applicability is limited by its failure to consider the larger social structures

¹¹⁵ Linguistic symbols are the verbal and non verbal sounds or physical gestures, that have significant meaning for the individuals (Belenky et al. 1997, Berg 1998).

and to focus on the specific (Meltzer et al. 1975, Benzies and Allen 2001). Attempting to address some of these criticisms Maines (1988) and Snow (2001), argued that the perceived neglect of larger social structures results from a limited reading and understanding of symbolic interactionism and an over reliance on Blumer's work (Maines 1988, Snow 2001). Snow (2001) proposed an extension and broadening of symbolic interactionism to include four broad principles, interactive determination,¹¹⁶ symbolisation,¹¹⁷ emergence¹¹⁸ and human agency.¹¹⁹ The resulting focus on the complexity of social phenomenon permits generalisability and although this does not result in a general understanding of the phenomenon being explored, the resulting theory is modifiable. This attribute resonates with the aim of grounded theory where, through a process of abstraction a theory of a basic social process is generated, which with subsequent investigation and exploration is modifiable.

5.6.1 Relating symbolic interactionism to this study

The aim of this study was to focus on the individual and the context in order to gain a deeper understanding of the process involved in the transition to motherhood for women with a disability in order to contribute to and extend existing theories regarding disability, self and more specifically transition to motherhood. As a theoretical perspective, symbolic interactionism, offered a way to understand the symbolic processes involved in the transition. It was a perspective, from which I could explore and examine multiple meanings about the women's transition to motherhood and proceed to understand how these meanings were interpreted, assigned and crystallised. At a micro level it facilitated an exploration of how others¹²⁰ informed the process. At a macro level it facilitated an exploration of how temporal, historical and cultural variables influenced and informed the process. The emphasis was on social processes, social structure and social interactions.

¹¹⁶ Interactive determination requires that consideration be afforded to the interactional contexts or relationships in which women with a disability are embedded.

¹¹⁷ Symbolisation emphasises the process through which situations, individuals and groups adopt a particular meaning and the extent to which symbols and meaning are conveyed.

¹¹⁸ Emergence refers to the aspects of social life that are routine and where change can occur.

¹¹⁹ Human agency refers to the active, wilful character of women with a disability and considers biological, structural and cultural factors as predispositions or constraints on action not determinants of actions (Snow 2001).

¹²⁰ Specifically, caregivers and significant others, such as partners and family members, and friends.

5.7 Methodological positioning - choosing an appropriate methodology

During their transition to motherhood, women engage in a process so, grounded theory with its focus on process and meaning was deemed the most appropriate method for this study (Kennedy and Lingard 2006:p103, Buckley and Waring 2009). Moreover, grounded theory is particularly suitable for exploring areas where there is minimal knowledge on a phenomenon or when a new perspective on the phenomenon is required. While, as chapters 2, 3 and 4 demonstrate, there is an anthology of theories regarding disability, self and transition to motherhood, this does not dispel the need for further research and theory generation. The existing extant theories regarding the transition to motherhood are primarily from the perspective and experiences of non-disabled women, so further research from the perspective and experiences of women with a disability was needed. The knowledge constructed from this study will enable caregivers, specifically midwives; obstetricians, paediatricians, general practitioners, public health nurses and social workers, and policy makers to understand better the experiences of women with a disability and how the process of transition to motherhood relates to the self, a relationship that heretofore was relatively unexplored and unexplained.

5.7.1 The origins of grounded theory

Originating in the second developmental phase, *'the modernist phase'* (1950-1970), of qualitative research, grounded theory was developed by two sociologists, Barney Glaser and Anselm Strauss, and was publicised in their classic text *'The Discovery of Grounded Theory'* (Glaser and Strauss 1967). This text was published at a time of reappraisal and renewal in conventional sociological discourse, this renewal was driven by social constructionists and critics of quantitative approaches to research (Noerager Stern 2009). The emergence of grounded theory was heralded as a revolution within the domain of qualitative research (Maijala et al. 2004). With it, Glaser and Strauss, (i) assigned the task of theory generation to qualitative data, (ii) provided a firm and valid base for qualitative research and (iii) demonstrated to positivistic sociologists that there was an alternative, legitimate way to approach data (Noerager Stern 2009).

The theoretical and methodological roots of grounded theory originated from two schools, the Chicago school of qualitative research and the Columbia school of quantitative research. In its original

format, the method rejects the realm of the influential logical-deductive methods of inquiry. With its multiplicity of epistemological and ontological positions, grounded theory provides researchers with a systematic way to generate a substantive, middle range or formal theory to explain interactions that manifest in patterns of consistent behaviours between individuals where there are numerous conceptual relationships, stated as propositions and presented in a discursive structure (Waring 1995). Naming these latent patterns is pivotal in order to portray 'the reality of social interactions and its structural context' (Glaser and Strauss 1967:p32) and to develop a theoretical explanation about a basic social process (Waring 1995, Benoliel 1996, Kennedy and Lingard 2006).

5.7.2 Strauss and Corbin's approach to grounded theory

American sociologists Paul Felix Lazarsfeld (1901-1976) and Robert King Merton (1910-2003) are credited with influencing Barney Glaser's educational, professional and academic growth. Lazarsfeld was one of the major figures of 20th century; he founded the Columbia University's Bureau of Applied Social Research. It was his inductive quantitative analytical thinking that influenced Glaser. Glaser also studied theory construction with another influential figure, Merton who emphasised the processes of theoretical coding and theorising. Merton favoured middle-range theories, suggesting that such theories began with clearly defined aspects of social phenomena not with broad, abstract entities such as society as a whole and championed the notion theories are constructed through the relationship of substantive concepts and theoretical codes. Merton claimed that individuals assume one role and one status, where status is rooted in social structure with a whole set of expected behaviours attached to it. Pragmatist and symbolic interactionist George Herbert Mead (1863-1931) is credited with influencing Anselm Strauss's growth as an academic.¹²¹ After the original publication of the grounded theory method in 1967, Glaser and Strauss disagreed on how the method should be applied and the spilt that ensued between the sociologists resulted in the emergence of two different approaches to grounded theory - the Glaserian approach (also referred to as classical grounded theory) and Strauss and Corbin approach (Stern 1995). Much is written in the methodological literature about the dispute between Glaser and Strauss and the differences between their respective approaches to grounded theory (Charmaz 2000, Clarke 2003, Cutcliffe 2005, Mills et al. 2007, Morse 2009, Noerager Stern 2009). While the ultimate aim

¹²¹ Prior to his collaboration with Glaser, Strauss was instrumental in the advancement of social constructionism. Strauss is attributed with introducing a form of hypothetico-deductivism to grounded theory.

of both approaches remains theory generation, the approaches differ on a number of elements, principally: (i) the epistemological and ontological underpinnings informing each approach, (ii) the formulation of research questions, (iii) the processes employed during data collection and analysis, (iv) the use of literature and how a substantive theory is generated from data, and (v) the procedures used to verify the resultant theory (see Table 5.1).

Table 5.1 Differences between Glaserian and Strauss and Corbin approach

	Glaserian Grounded Theory	Strauss and Corbin Grounded Theory
Aim	Theory generation	Theory verification and modification
Era of development	Modernist phase	Blurred genres phase
Epistemological underpinnings	Post-positivism Objectivism	Interpretativism Subjectivism Symbolic interactionism
Ontological	Realism	Relativism/ Realism
Method of inquiry	Inductive	Logical-deductive
Theoretical sensitivity	Tabula rasa Reflexivity	Enter field with questions Reflexivity
Literature Review	At end of research	At any phase of research
Sampling	Theoretical sampling	Open, relational and variational, discriminate
Constant comparative method of analysis	Substantive and theoretical	Open, axial and selective Use of Paradigm model Use of a Conditional matrix

Strauss and Corbin’s approach to grounded theory evolved from the collaboration between Anselm Strauss and Juliet Corbin. This approach offers more procedural guidance on the different forms of sampling and through the introduction of two analytical tools, the coding paradigm (also referred to as a paradigm model) and conditional matrix, it is credited with extending and developing the analytical process of grounded theory (Strauss and Corbin 1990, Corbin and Strauss 2008, Buckley and Waring 2009). Glaser however, argued that Strauss and Corbin’s approach to grounded theory was positivist in nature and that it was more concerned with conceptual description and verification rather than theory generation. This assertion was refuted by Strauss and Corbin and proponents of their approach, they contend that this approach is post-positivist (Annells 1997a, Heath and Cowley 2004) and is firmly rooted in a symbolic interactionism and pragmatism (Corbin 2009).

Pragmatism began to take hold in the first three decades of the last century, offering a new philosophy that asserted how knowledge was created through the actions and interactions of self reflective individuals (Mead 1934, James 1961, Crotty 1998, Dingwall 2001, Hewitt 2007) Pragmatism

embodies a number of key assumptions: the first assumption, considers truth as temporal; what an individual knows at any given moment is true but this is open to examination and critique, it could be judged untrue at a later stage. Secondly, pragmatism assumes knowledge accumulates and provides the foundations for progression of thought and society. Thirdly, pragmatists use knowledge to instigate action and interaction that in turn produces more knowledge. Pragmatists regard the experiences of those involved in a study as integral and imperative and subscribe to the idea that regardless of who creates the understanding of reality; be it the individual or group, this understanding is generated from an inherited, socialised perspective. These assumptions resonated with my own philosophical positioning.

The central difference between the Glaserian and Strauss and Corbin approaches to grounded theory is the degree to which the resultant theory emerges from the data freely and unimpeded or the extent to which predetermined insights are applied on it. The Glaserian approach allows the theory to emerge liberally and inductively during the process of analysis (Glaser and Strauss 1967). Conversely, the Strauss and Corbin approach places less emphasis on the notion of emergence (Glaser 1992). Strauss and Corbin (2008) believe that all actions or interactions are entrenched in a set of conditions. Their approach to grounded theory is cognisant of the structural, contextual, interactional and symbolic factors that affect individuals (Corbin and Strauss 2008) and that an understanding of these factors can be achieved through the use of a coding paradigm, a tool used during data collection and analysis specifically when coding the data during the axial coding phase. The coding paradigm used in this study was informed by concepts from the extant literature on disability; identity and the transition to motherhood (see Table 5.2). Through the processes of: (i) inductive and deductive thinking, (ii) questioning the data and (iii) making comparisons, it facilitated the systematic thinking about the data and provided an opportunity to understand and explain the process involved in the transition to motherhood rather than just describe it. Once the links between the data were made and the categories emerged, and their properties determined the conditional matrix¹²² ensured that the greater contextual issues¹²³ relative to the phenomenon were considered (Strauss and Corbin 1990).

Glaser disagreed with the use of these analytical tools; he considered them as apparatuses that forced the data in a particular direction, the outcome being a conceptual description of the

¹²² See Appendix 3, a diagrammatic representation of conditional matrix.

¹²³ The contextual issues include historical, political and economical issues.

phenomenon rather than a theory.¹²⁴ He claimed that Strauss and Corbin's approach to grounded theory and the use of a coding paradigm, did not comply with the logic of emergence and theory generation but was more concerned with theory verification. Glaser believed that theory generation should occur through a process of induction where the researcher integrates a ground up approach, by entering the field with no perceived propositions therefore remaining open and flexible, so that the resultant substantive theory evolves from the data. Once the initial data is analysed, a provisional hypothesis is generated and empirical verification occurs through further data collection and analysis. The quality of the resultant theory is evaluated by determining how well it fits with the data, how well it explains and interprets the context from which it originated, how relevant it is to this context and how it can be modified in relation to a changing social context (Williams 2005). Despite their philosophical and procedural differences, both approaches (Glaserian and Strauss and Corbin) to grounded theory share common fundamental principles that guide the conduct of a study using either approach, these include: (i) the need for theoretical sensitivity, (ii) theoretical sampling, (iii) the process of constant comparative analysis, (iv) theoretical memoing, (v) the identification of a core category and (vi) the principle of theoretical saturation.¹²⁵

Strauss and Corbin's approach to grounded theory fitted with the purpose of this study. The study set out to explore women's experiences of their transition to motherhood and the relationship of the process to the self. The aim was to contribute to and extend existing theories on the phenomenon by developing a comprehensive understanding of women's experiences and a substantive grounded theory concerning the social process involved in the transition. Initially I entered the research field with a sensitising question that emerged from the National Disability Authority study (Begley et al. 2010), this was then developed into grounded question(s), a grounded hypothesis developed from the data and this hypothesis was, through the process of theoretical sampling, tested against subsequent data.¹²⁶ The twenty-two women who participated in this study (n=10, with a physical disability and n=12 with a sensory impairment) also contributed to the study, commissioned by the National Disability Authority

¹²⁴ Glaser claimed that the coding paradigm advanced by Strauss and Corbin was a variation of one of the possible eighteen theoretical coding families previously proposed by him.

¹²⁵ How these are implemented vary according to the grounded theory approach. Since its foundation, grounded theory has been adapted and extended for use across a variety of different perspectives, most notably, Strauss and Corbin grounded theory, dimensional analysis, situational analysis, constructivist grounded theory and feminist grounded.

¹²⁶ Findings from the National Disability Authority study (Begley et al. 2010) revealed that when accessing the publicly-funded maternity services, women with a disability encountered discriminatory and stigmatising actions and behaviours that impacted on their self-esteem and self-confidence and caused them to question their ability to care for their baby (Begley et al. 2010). This finding generated a desire to explore the process of transition to motherhood from the perspective and experiences of women with a disability. Specifically, I was interested in exploring how the woman's interactions with others informed that transition and the relationship of the process on the self.

Table 5.2 Coding paradigm: the process of transition to motherhood and the relationship of the process to the self for non-disabled women

Phenomenon – the process of transition to motherhood and the relationship of the process to the self for non-disabled women	
Context	<p><u>Social self:</u> – produced within familial and extra-familial social settings, family especially mother highly significant.</p> <ul style="list-style-type: none"> - social experiences – relationships and interactions with others - autonomous, self-conscious women with a capacity to imagine, reflect on and see how others perceive them - woman’s sense of self pre-motherhood <p><u>Dominant discourse:</u></p> <ul style="list-style-type: none"> - interactive and looking glass self, and discourse of good, intensive mothering - policies re maternity care, mothering and childcare – medicalisation of childbirth, child protection guidelines <p><u>Expectations:</u> assumptions and perceptions of pregnancy and motherhood = motherhood a process – crisis, rite of passage</p> <p><u>Motherhood:</u></p> <ul style="list-style-type: none"> - nature of pregnancy – planned or unplanned - entails responsibility and culpability for child development and growth - mothers interpellated within discourse of responsibility through government policies in child health clinics via development checks etc. - mother subjected to this information and regulate behaviour accordingly – if unsuccessful punitive measures can be taken e.g. losing custody - becoming a mother is confusing and risky , prevailing discourse re good, intensive motherhood generates uncertainty in mother, increases dependence and over reliance on professionals, undermines woman’s ability to develop confidence and make decisions
Causal Conditions	<p>First pregnancy or subsequent pregnancy, commitment to motherhood, similarities and differences to others</p>
Actions, Interactions, Strategies	<p>Woman thinks, reflects, acts, adjusts and changes own perceptions and behaviours in responses to that of others in their social environment</p> <p>Woman presents self to others in the roles she enacts and through speech, behaviours and actions, her actions are conscious and explicit</p> <p>Woman assumes various roles that accumulate and solidify to form a sense of self</p> <p><u>Pre-motherhood:</u> - period of regression and disorganisation or opportunity to develop and grow,</p> <p>Taking in process – tries to understand what it means to be a mother</p> <ul style="list-style-type: none"> - Mimicry - Role play and fantasy - ability to visualise self as mother parallels with subsequent adaptation to motherhood - Self system theory – focus on image: ideal image, body image and self image <p><u>Post-motherhood:</u> - once baby born process of adjustment begins, attention turns to own life, shift in priorities and perception of self, awareness of personal identity, initial few months post birth period of intense change and adjustment</p> <ul style="list-style-type: none"> - engagement with motherhood – committing to motherhood, experiencing, interacting, engaging and actively caring for baby facilitate growth and transformation of mother, not all women experience growth and transformation - growth and transformation – internalising self as mother and experiencing lived reality of motherhood facilitate transformation of self, introspection and self evaluation <p>Introjection</p> <ul style="list-style-type: none"> - taking responsibility, relinquishing pre-motherhood behaviours, alter appearance, redefine and reorganise relationships with others, reflect on priorities, embrace gendered identity, engage in activities that are relevant for pregnancy and motherhood, more aware of difference between private and public domain - engage in practice of letting go, seeking information and develop different (new) skills - desire to display competency and ability in managing and coping <p>Positive appraisal of others important, being perceived as a good mother important, feared being judged as bad mother</p> <p>Misfit between reality and the ideology of motherhood - generates a conflict between women’s experiences and views held therefore they experience a dissolution of previous sense of self resulting in a lowering of one’s self-esteem</p> <p>Measures taken to comply with provisions of ideal motherhood</p>

Table 5.2 Coding paradigm: the process of transition to motherhood and the relationship of the process to the self for non-disabled women cont'd

Consequences	<p>Develops a sense of self, generates perceptions and behaviours in response to environment and relationships with others in that environment.</p> <p>Motherhood creates a crisis, rite of passage, life changing event, defining event, turning point in woman's life, normal crisis in woman's psychological development significant changes in personality & self</p> <p>Motherhood opportunity to change for those who wanted to change:</p> <ul style="list-style-type: none"> - continuity of self - a refracted self - construction of new identity - emergence of new or altered (refraction) or transformed self, a moral, autonomous agent, inner, true self can be revealed or masked - the giving of self, redefining the self, redefining relationships and redefining personal goals - psychic reorganisation of self occurs involves reappraisal of all aspect of the woman's life and of the primary roles she occupies including the roles of woman, mother, wife, partner, daughter, friend, daughter in law, career, her role in the family, in society, legal status, herself as a person with responsibility for another - altered sense of relationship with body & re-organise relationships with others - positive and negative changes <ul style="list-style-type: none"> - empathetic and sensitive towards others - increased patience - greater understanding of love - personality traits not obvious pre motherhood come to the fore - experience a sense of loss – women experience a series of multiple losses (birth of first baby) in regard to her sense of self, this sense of loss evolves from the idealised image some mothers have before the birth of the baby and when in reality, this image is not realised, a sense of loss ensues - conflicting emotions and conflicts - feelings & emotions - development of positive or negative emotions: <ul style="list-style-type: none"> o elevated status to adulthood, sense of maturity, confident and competent in maternal role , self worth o sense of sameness, sense of similarity provides a frame of reference for women and helps them to determine if their experiences are normal o sense of depersonalisation, confusion and loneliness, stress and anxiety, apprehension, uncertainty about impact maternal identity would have on pre-mother identity, loneliness, especially acute in the early postpartum period - emanated from a sense of depersonalisation and confusion that occurred in this period. This depersonalisation process engendered a sense of loss and for some women this intensified and manifested as depression - motherhood challenging
Intervening Conditions	<p>Personality type – ability to deal with change and associated emotional changes</p> <p>Support matrix , availability of resources and support</p> <p>Nature of interpersonal relationship with others – baby, partner, family, friends, health professionals, others</p> <p>Appraisal of others</p> <p>Security and stability – relational and occupational, positioning and importance of occupation in sense of self</p> <p>Expectations of self as mother – realistic or idealistic , birth experience</p> <p>Nature of information available and received, previous experience of motherhood</p> <p>Ability to draw on coping skills, range of adaptive strategies available to woman</p>

KEY:

Phenomenon - the specification of a category – what is the data referring to, what are the actions/interactions about

Context - specific set of properties that pertain to a phenomenon – the locations of events or incidents pertaining to the phenomenon with a dimensional range, represents the particular set of conditions within which the action/interactional strategies occur

Causal Conditions - events, incidents, happenings that lead to the occurrence or development of a phenomenon

Actions/interactions/strategies - strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions

Consequences - outcomes or results of action and interaction

Intervening Conditions - the structural conditions bearing on action/interactions/strategies that pertain to a phenomenon, they facilitate or constrain the strategies taken within a specific context

[Content in blue colour donates concepts associated with the transition to motherhood specifically relating to non-disabled women](#), remaining content in black colour donates concepts common to non-disabled women and women with a disability

and National Women's Council of Ireland, which explored the publicly-funded health services for women with disabilities during pregnancy, childbirth and early motherhood (Begley et al 2009a, 2009b, 2010).

5.8 Theoretical sensitivity in a grounded theory study

The term theoretical sensitivity is synonymous with grounded theory. It is defined as a personal quality of the researcher (Strauss and Corbin 1990). Individuals accumulate past experiences and bring them to each context and interaction; additionally they also formulate new experiences in new contexts, including the research setting. Therefore; as the researcher, I critically reflected on my behaviour during the research process while also observing the behaviours and interactions of the women who contributed to the study. I identified my preconceptions and approached the research with as few a prior assumptions and predetermined ideas as possible. However, I truly believe that a complete abandonment of all a prior assumptions and preconceptions was impossible and unrealistic, no researcher enters the research setting with a *tabula rasa*, some pre-existing concepts, especially if the subject area has being widely researched remain. Having contributed to the National Disability Authority study I had some knowledge of the literature on disability and from a professional perspective I had some knowledge of the theories relating to transition to motherhood¹²⁷ therefore I could not claim a *tabula rasa*. Saliently Strauss and Corbin's (1990) approach to grounded theory acknowledges this fact; they argue that it is unrealistic to expect a researcher to do so. Their logico-deductive approach to grounded theory permitted the integration of existing knowledge while exploring the phenomenon from the perspective and experiences of women with a disability.

Conversely, the Glaserian approach emphasises the need for the researcher to be sufficiently theoretically sensitive in order to conceptualise and formulate a theory as it materialises, untainted from the data. In this instance sensitivity is achieved by leaving the literature review until after the substantive theory has emerged. Apparently, doing so prevents the researcher from being contaminated, constrained, inhibited, or impeded in the discovery of categories that are relevant, fit and

¹²⁷ The National Disability Authority study had three objectives, to conduct comprehensive reviews into: (i) the barriers and facilitators experienced by women with disabilities when accessing maternity services during pregnancy, childbirth and early motherhood, (ii) the local, national and international policies that govern the procedure and practice in service provision during pregnancy, childbirth and early motherhood and (iii) to conduct a qualitative study into the experiences of women with disabilities accessing the publicly-funded maternity services in Ireland.

workable. Glaser argued that a literature review conducted at the outset of the study forces the data into a preconceived model, preventing the researcher from remaining open to emergence. Nevertheless, having some knowledge of the literature from the outset of this study did not impede, inhibit or constrain my interpretation of the data rather; it bestowed a specific understanding of the relevant concepts pertaining to disability, self and transition to motherhood albeit from a non-disabled perspective. I was conscious however that this awareness of the literature could affect my interpretations and subsequent disclosure of the genuine concerns of women with a disability. I knew I needed to remain sensitive to the interpretations and meanings provided by these women so, to ensure this occurred I adopted and implemented Heshusius's concept of 'participatory consciousness' (Heshusius 1994:p17), whereby I engaged in a process of temporarily letting go of all preoccupations, this was achieved through the maintenance of a reflective diary and regular supervisory and peer support meetings (Piantanida et al. 2004). These measures and the use of the coding paradigm during data collection and analysis ensured that the core concern to emerge truly reflected the concerns of the women who contributed to this study.

5.9 Theoretical sampling in a grounded theory study

This study employed a sampling strategy unique to grounded theory, theoretical sampling. The sampling process was deductive, based on the categories that emerged from the coding process. Questions pertaining to the categories determined where data would be collected (Strauss and Corbin 1990, Glaser 1998, Corbin and Strauss 2008). The purpose was to discover concepts relevant to the emerging theory, their properties and dimensions. Theoretical sampling (i) focused and delimited the process of data collection and analysis, (ii) it circumvented me from collecting the same data over and over again and (iii) it directed me to new data sources that increased the scope and depth of the emerging theory that accounted for the main concern being resolved by women with a disability during their transition to motherhood.

In accordance with a Strauss and Corbin approach, in this study, sampling occurred concurrently with data analysis. Three types of sampling - open, relational or variational and discriminate - were employed during the three different phases of coding - open, axial and selective. Sampling during the first phase of analysis took the form of open sampling. The purpose was to uncover as many potential

relevant categories, and their related properties and dimensions, as possible. Open sampling was flexible, purposeful and systematical, as data were collected I remained open to all possible sources of information (Draucker et al. 2007).

Theoretical sampling during the second phase of analysis, took the form of relational and variational sampling. Here, the aim was to gather data to uncover and validate the relationships between categories in order to maximise differences at a dimensional level (Waring 1995, Draucker et al. 2007). During this phase theoretical sampling was more focused, it was more purposeful or systematical and the interviews conducted with the women became increasingly semi-structured in nature. Here, classical grounded theorists would use a smash and grab¹²⁸ approach to data collection but I felt this strategy was inappropriate it would have impacted on the rapport established with the women and on the quality of data obtained during our interactions.

Sampling in the third phase of analysis was discriminative, the purpose here was verification whereby data were collected to verify the emerging theory and to further develop categories that had not been saturated. Theory verification involved 'looking for evidence in the data to verify statements of relationships while also looking for instances of when they might not hold up' (Corbin and Strauss, 2001:p109). Here, I sampled new women, literature and/or revisited the women where I suspected the necessary verificational data could be collected (Waring 1995, Draucker et al. 2007). During this process, I was aware that new data that did not fit with the story line or the relationships found in the data, could potentially surface, when this occurred I examined the instances to determine: (i) if it was a cognitive error that lead to inaccurate conceptualisation or (ii) if it was an example of a variation. Categories were considered theoretically saturated when: (i) no more relevant or new data regarding the category emerged, (ii) each category had been linked with the coding paradigm, (iii) each element was provided for including, variation and process, and (iv) the relationships between categories were well established and validated (Waring 1995).

Glaser disagreed with Strauss and Corbin's three pronged approach to theoretical sampling he accused the authors of using conventional sampling not theoretical sampling. He argued that open, relational or variational and discriminate sampling fractured the concept of theoretical sampling and offered no methodological strength (Glaser 1992). Glaser accused Strauss of being less concerned with discovery through induction and emergence but more focused on finding his theory in the data so that it

¹²⁸ In a smash and grab approach the researcher would direct the collection of data in order to clarify the properties of categories and to validate the relationships between categories (Noerager Stern 2009).

could be tested. In fact, Glaser claimed that Strauss and Corbin had completely deviated from the original concept of grounded theory and had created another methodology, one that was more concerned with conceptual description. The findings of this study refute this claim. A new, alternative substantive theory regarding the process involved in the transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self emerged from this study, providing caregivers with a new perspective of the phenomenon, one based on meaning reconstruction, a perspective not considered heretofore.

5.10 The constant comparative method of analysis

Strauss and Corbin's approach to grounded theory, just like the classical Glaserian approach, promotes the use of the constant comparative method of analysis. This method of analysis allows for interpretations of hypothesis to be continuously verified (Glaser 1998). As previously discussed (see section 5.9, chapter 5), Strauss and Corbin promote a three stage process - open, axial and selective - to coding the data and an intricate form of theoretical sampling - open, relational or variational and discriminate - to support each phase of coding (Annells 1997a). Their approach to analysis is dialectical, where empirical data is used to generate and verify theory, where consistencies and inconsistencies in the emerging theory are sought and rationally discussed through the use of a coding paradigm, memos and comparison to other data (Annells 1997a). Their method of analysis introduces order, structure and meaning to the data (Waring 1995, Corbin and Strauss 2008). The process of analysis is discussed in greater detail in the following chapter (see 6.9, chapter 6). The substantive theory to emerge from this study will provide caregivers with a conceptual framework that they can use when assisting and facilitating women with a disability in their transition to motherhood (Annells 1997a).

5.11 Positioning oneself in the study

In the present era, grounded theory does not operate in a vacuum nor is it removed from the influences of postmodernism (Annells 1997b), therefore postmodern concerns regarding representation and legitimation needed to be considered during the conduct of this grounded theory study. This study

employed a Strauss and Corbin approach to discover the meanings, women with a disability, assigned to the transition to motherhood and the actions/interactions/emotions expressed in response to this process (Corbin 2009). It also considered the impact other structures had on the context from which the empirical data were obtained. While empirical data remains the primary source for generating theory, Strauss and Corbin concede that there are other sensitising sources that allow the data to be considered in a wider context, including: (i) the technical and non technical literature and (ii) personal experience. Furthermore, they consider the reality explored by social studies to be relative, a product of interpretation, constructed through the transactional process between the data and the researcher (Annells 1997a) but researchers are social beings with experiences, assumptions, ideas and perceptions that contribute to their interpretation and understanding of observed social processes (Heath and Cowley 2004). Strauss and Corbin's approach to grounded theory accept and perceive these aspects to be beneficial to the development of theory, provided that, they do not obscure what is significant in the data. Nonetheless, during the conduct of a grounded theory study the researcher is obliged to reflect and consider how their involvement may influence the iterative process of data collection, analysis and interpretation.

Objectivists ignore the situatedness of the researcher but interpretivists do not (Davies and Dodd 2002, Piantanida et al. 2004, Dowling 2006). In this study I did not want to distance myself from the women who contributed to it. As previously discussed, I did not enter the field of study with a *tabula rasa*, free from preconceived ideas. To the research process, I brought knowledge of the extant literature on disability, self and the transition to motherhood, my disciplinary perspective, my own philosophies and biography (McCann and Clark 2004a, 2004b). My attributes, the characteristics of the women who contributed to the study, the reason why and conditions under which we came together all contributed to the type, quality and volume of information exchanged between us, and informed how I interpreted the women's experiences in order to develop a deeper understanding of the process involved in the transition to motherhood from their perspective and experiences (Hall and Callery 2001, Dowling 2006).

Reflexivity was an integral component of this study. Finding a precise definition for this concept was difficult (Colbourne and Sque 2004) nevertheless I perceived it as a process whereby I continuously critiqued and appraised how my experiences and assumptions influenced the various stages of the

research process. Aware that my a priori assumptions¹²⁹ could potentially impact on my interpretation of the data I engaged in the process of critical reflection to ensure that I remained true to the data and my assumptions did not influence the interpretative process. Arising in the 'crisis of representation' (1986-1990) phase of qualitative research development (Chesney 2001, Denzin and Lincoln 2005, Gubrium and Koro-Ljungberg 2005), critical reflection is defined as a process: (i) of examining how factors affect and alter a study (Finlay 2002, McCabe and Holmes 2009), (ii) of critically reflecting on the self as researcher, (iii) a conscious experiencing of the self (Chesney 2001, Malterud 2001, Denzin and Lincoln 2005), (iv) a process where the researcher demonstrates an awareness of and appropriately reacts to the relationship and interaction between them and the participants in the study (Ramazanoglu and Holland 2002), (v) a way of 'critically inspecting the entire research process' (Schwandt 2001:p224). The practice of critical reflection strengthened the interpretive power of this grounded theory study (Thorne 1997) and provided the opportunity to consider and articulate how my perceptions and understandings influenced the interpretation of the data. I maintained a high degree of reflexivity throughout the study, this was achieved through various means, including an examination of any preconceptions I held as a midwife, as a qualitative researcher and as a non-disabled woman who at the time of data collection and analysis was not a mother. During the data collection phase, I maintained field notes and immediately after the interview concluded I recorded my thoughts and feelings regarding the interview, these allowed me to continually review how I engaged and interacted with the women. I also kept a reflective journal where I recorded my thoughts, feelings, concerns and reflections about decisions taken during data collection and analysis. Theoretical and conceptual memos were also recorded during the process of open, axial and selective coding (see 6.9.1, 6.9.2, 6.9.3, chapter 6). Doing so allowed me to examine how I approached the process of data collection and analysis, specifically, my interpersonal and communicational skills and my ability to be empathic and sensitive to: (i) the specific needs and experiences of each woman, (ii) the issues of trust and power that surfaced during data collection and the interview process, and (iii) the degree to which I may or may not have influenced the data collected or (iv) how my pre-existing assumptions informed my interpretations of the data. This process of critical reflection increased my awareness of the influence I had on the study. It allowed me to critically examine my role in the process of data collection and analysis, whether my interpretations

¹²⁹ These assumptions emerged as a result of my involvement in the National Disability Authority study. They included the perception that women with a disability are not vulnerable individuals but rather that their sense of agency is eroded by the caregivers encountered when accessing maternity care. It is the attitudes and behaviours of these caregivers, rather than the woman's disability that renders the woman helpless. I was not sure if this was the case during the process of becoming a mother and so to ensure this perception did not cloud my interpretation of the data I continually asked questions of the data. The process of questioning the data was reflected in the various memos and entries in my reflective diary.

truly captured the core concern of women with a disability and extend to which my knowledge of the extant literature informed the interpretative process.

5.12 Gender and disability: issues of concern in the conduct of the study

The process of data collection, involved me, a woman, interviewing women. The issue of a woman researcher interviewing women participants surfaced in my review of the feminist literature on interviewing (Oakley 1981, Holstein and Gubrium 2003, Reinharz and Chase 2003). Women researchers who interview women during the course of a research study are obliged to 'assist, remain in touch with and otherwise revise the more passive, distant interviewing stance recommended by conventional research methodology' (Reinharz and Chase 2003:p80). I was not concerned about interviewing women but I was concerned that I, a non-disabled woman, would be interviewing women with a disability. I thought that this issue, rather than gender, would have a greater affect on my relationship and interactions with the women (see below, diary entry regarding an incident that occurred with one woman in a wheelchair).

16th February 2008 (diary entry)

'Just left interview with Natasha [women with a physical disability], something phenomenal happened and I cannot explain it. Like other interviews, when offered a cup of tea or coffee, I was only too delighted to accept as this was greatly welcomed and pre-interview it gave me an opportunity to get to know Natasha a little more before I started the recorder. I took a seat in the room just adjacent to the kitchen, and was getting myself organised when I heard the clattering of pottery coming towards me. It was Natasha with a tray on her lap with two cups of tea, a jug of milk, some sugar and biscuits. My initial instinct was to jump up and take the tray from her lap and carry it for her. I was thinking of the consequences, thinking of safety, what if the tray fell?, it would certainly burn and cause untold damage but I could not move, my legs were rooted to the ground, they were fixed, I wanted to move but couldn't, and just then Natasha was in front of me putting the tray on the table beside us. I didn't think anything of it until I listened to my post interview comments, recorded immediately after the interview, there I realised being rooted to the ground was a blessing, if I had got up and taken the tray away the damage caused by my action would be more far reaching than any caused by the cups falling, I would have intruded on the woman's personal space, trampled on her sense of autonomy and independence, rendered her dependent and this would have certainly impacted on our relationship and the exchange of information during the interview'.

However these concerns were futile, the women embraced me for who I was, my physical or sensory abilities were of no concern to them, in fact in some cases the relationship that developed

between us extended beyond the life of the study, we became friends and our friendship continued after the study concluded.¹³⁰

5.13 Achieving quality

If the outcomes of any study are to be considered credible, the quality of the study warrants consideration. Some authors call on qualitative researchers to seriously consider what it is that constitutes a rigorous, high-quality qualitative study (Thorne and Darbyshire 2005). Whether or not the quality of a grounded theory study can be evaluated using a complex permutation of criteria has been the topic of considerable debate. On one side of the debate is the declaration that qualitative research should establish objectivity, validity and reliability. On the other side, there is the suggestion that these concepts be adjusted so that they fit more appropriately with the different permutations of qualitative approaches, like grounded theory. Nevertheless, despite this debate, consensus regarding the criteria to judge the quality of qualitative studies remains elusive.

Quality in a grounded theory study is dependent on a number of elements: 'researcher expertise, methodological congruence and procedural precision' (Mills et al. 2007:p33), adherence to or non-compliance with these elements will influence the potential value and integrity of the resulting theory. In their earlier writings Strauss and Corbin (1990) did not identify specific standards to evaluate quality, deferring instead to those proposed by other qualitative researchers, including: validity, reliability, efficiency and sensitivity (Sandelowski 1986, 1993, 2004) but in their later writings they do advocate the use of a framework with ten criteria, that include the evaluation of: fitness, applicability, concepts, contextualisation of concepts, logic, depth, variation, creativity, sensitivity and evidence of memos (Corbin and Strauss 2008). Classical grounded theorists use a framework consisting of four criteria: fitness, understanding, generality, control (Cutcliffe 2005). This study was guided by the four criteria - fit, understanding/work; relevance and modifiability - advanced by Glaser and Strauss (1967) (see Table 5.3).

¹³⁰ Some women invited me to family events, for example, birthdays and christenings of subsequent babies. One woman asked to become involved in a support group she was establishing for parents with a physical disability and also invited me to act as a midwifery advisor to a non-voluntary organisation that she was employed in.

Table 5.3 Criteria for evaluating quality of a grounded theory study

Criteria	Indicator
Fitness	The theory must closely fit the substantive area in which it will be used
Understanding/work	The theory must be readily understandable by people concerned with this area
Relevance	The theory must be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area, not to just a specific type of situation
Modifiability	The theory must allow the user partial control over the structure and process of daily situations as they change through time

(Glaser 1992, Glaser and Strauss 1967).

5.13.1 Fitness

Fitness refers to how the theoretical categories fit and resonate with the data and how the theory fits with the substantive area in which it will be used. This study gathered rich in-depth data from twenty-two women with a disability. Women from a variety of social backgrounds and different geographical locations were recruited. The nature of disability and extent of physical or sensory difficulties also varied. I developed a close relationship with the women, principally because of our interactions on the National Disability Authority Study; consequently the women recounted their experiences in a frank, open and honest manner often revealing very intimate and emotional experiences. The constant comparative method of analysis forced me to continuously review and test the interpretive assumptions made during the process of analysis as data were moved from the descriptive to the conceptual. As concepts were identified and named, they were theoretically sampled for in the existing data, through further data collection, and in the extant literature to ensure they fitted with the emerging pattern. This process helped to confirm that the name assigned to the concept was appropriate and that it adequately captured the description of the concept. The iterative nature of data collection and analysis allowed me to continually check that the concepts genuinely reflected the data. Incidents that did not fit with the pattern were checked to determine if they were anomalies that arose from a cognitive error when conceptualising or if they were a variant of the theory. In this instance the theory was adapted to incorporate the variation (Corbin and Strauss 2008). As the categories and subcategories emerged and their properties and dimensions grew they were continually integrated into the theoretical structure to deepen the theory until all categories were saturated. Alternative suppositions were considered and deliberated on through the open and active process of memoing, thus heightening my level of interpretation, abstraction and subsequent conceptualisation. The verification of the relationships between each category and subcategories was reflected in memos; these memos captured my attempts to associate each element to the coding paradigm. The complexity of the memos increased as my theoretical sensitivity increased, they became less descriptive, more

abstract and conceptual. Throughout the data collection and analysis process, I examined and explored the effect I may have had on the process and this was documented and continually reviewed in my reflective diary. Bias was exposed and accounted for. In addition I reflected on the relationship established with the women, this afforded me the opportunity to address issues of power and trust that emerged during the research process, especially during the data collection phase.

5.13.2 Understanding/work

This criterion describes how the theory should provide data organised in a practical way that explains the substantive area to which it relates, explaining, predicting and interpreting what is happening. In order for this standard to be fulfilled the reader must consider the applicability and meaningfulness of the theory to women with a disability. Adapting a systematic approach to theory generation should ensure that the resultant theory is applicable and workable. The theory should provide a conceptual perspective that is relevant and salient to women with a disability and others, such as caregivers, who may use it as a conceptual framework to better understand, the meaning and experiences of the process involved in the transition to motherhood and the relationship of the process to the self. But the content of this framework is variable because the theory is only one possible representation of women's experiences and actions, knowledge is not certain or fixed, it is subject to change and modification as other perspectives and experiences of the phenomenon are possible, the theory is relative to a particular context and demographic, that being, mothers with a physical disability or sensory impairment, therefore, it may not be applicable to other women such as those with an intellectual disability, mental health issues or non-disabled women. Further theory development would be necessary in this instance.

5.13.3 Relevance

If the resulting theory fits and works it has achieved relevance. The resulting theory should be general enough so that it can be applied in various contexts. What matters to women with a disability must come to the fore and is conceptualised. Therefore, a grounded theory study should disclose new knowledge that when conceptualised is useful to those who it claims to address. This can be achieved in a number of ways: (i) ensure that the concerns of women with a disability remain central in the research

process, (ii) ensure that the main concerns of women with a disability emerge without obstruction or impediment so that the conceptualised social processes are relevant to the lives of women with a disability, (iii) ensure that during data analysis the emerging concepts reflect the data set and are not imposed from pre-existing theories rather, the extant literature can be used to verify the fit of the substantive theory, or the substantive theory can be used to modify and, or extend the extant theories. Discussing the emerging theory with women who contributed to this study helped to determine the relevance of the emerging theory to their lives and experiences. While doing so, I recognised that others may not identify with the theoretical components of the theory because the theory is a reflection of my conceptualisation and interpretation of the women's narratives.

5.13.4 Modifiability

The resulting theory should be modifiable in response to conditional changes and, or the acquisition of further data. This criterion is realised with the continual development and improvement of both the credibility and applicability of the resulting theory. The resulting theory was, through the processes of constant comparative analysis and theoretical sampling, modified throughout its development and construction. However, as new data emerges in the substantive areas of disability, self and the transition to motherhood further modification will occur.

5.14 Summary

This chapter presented the philosophical and methodological considerations pertinent to this grounded theory study. A constructionist-interpretive approach provided the opportunity to examine and explore the labyrinth of experiences of women with a disability as they engaged in and interacted with their social worlds during their transition to motherhood. The aim was to understand and reconstruct the multiple constructed realities these women held (Guba and Lincoln 1994). The constructions provide those who contributed to the study with an explanation and sense of meaning regarding their experiences. In the following chapter, I discuss how I implemented the Strauss and Corbin approach to grounded theory in order to explore and conceptualise the experiences of women with a disability and to develop the substantive theory of '(Re)constructing Myself' presented in chapters 7, 8 and 9.

Chapter 6 Conducting the research

6.1 Introduction

In chapter five I detailed the theoretical and methodological underpinnings of this study but this chapter is concerned with how this grounded theory study was conducted; it provides a brief description of how the study was conceived, its purpose and the process of data collection and analysis. It also outlines the dilemmas encountered in the field during data collection and the strategies implemented to address these dilemmas. Appropriately, the chapter opens by defining the context in which the area of interest and the research question was generated and developed. Before describing this context I would like to recapitulate on the definition of disability that guided the study. The definition was adopted from the Disability Act (2005), it defines disability as ‘a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the Irish State or to participate in social or cultural life in the Irish State by reason of an enduring physical, sensory, mental health or intellectual impairment’ (Disability Act, 2005:p6).¹³¹

6.2 Genesis of the study

In Chapter 1, I outlined how I became involved in a multidisciplinary research study exploring the strengths and weakness of the publicly-funded Irish maternity services for women with disabilities¹³² during pregnancy, childbirth and early motherhood (Begley et al. 2009a, Begley et al. 2009b, 2010). In that study, in addition to interviewing women with mental health difficulties or intellectual disabilities, fifty-four women with either a physical disability (n=18) or sensory impairment (n=36), were interviewed during either pregnancy (n=14), within the first 6 months postpartum (n=20) or between 1-2 years postpartum (n=20). The area of interest for this grounded theory study evolved from the findings of that study. The findings tentatively implied that the interpersonal relationships established with others, especially caregivers, located in the women’s social world affected the process of their transition to

¹³¹ The Disability Act (2005) can be accessed in full at [http://www.oireachtas.ie/disability act 2005.pdf](http://www.oireachtas.ie/disability%20act%202005.pdf).

¹³² All too often women with a disability are described as vulnerable but vulnerable or marginalised is not a term I would use to describe women with a disability.

motherhood and sense of self but how and to what degree was not clear.

Chapter 4 illustrated how the transition to motherhood is a time of great physical and psychological preparation and adjustment for all women, regardless of ability or disability (Smith 1994, 1999, Bailey 1999a). Essentially, the process involves an adjustment from a known self, to an unknown self. Pre-motherhood, women with a disability had to construct a self and live in a society that perceived them to be different and dependent (Moore 1998, Barnes and Mercer 2010, Kralik and Telford 2010). Within this context, the women constructed a self; a self that did or did not incorporate their disability and all had to implement various coping strategies as they learned to live with their disability. Where necessary, their physical environment was adapted to accommodate their specific needs and in this environment the women were independent, autonomous individuals. However, during the process of becoming a mother, women with a disability are catapulted into a situation that requires them to renegotiate an already negotiated self. They, like non-disabled women are required to deal with the physical and psychological requirements of motherhood but unlike non-disabled women they have to negotiate these changes within the confines of their abilities. Combined with this they also have to access maternity services that are predominately structured for non-disabled women and have to manage assumptions regarding their ability to mother, while configuring a maternal self and adapting their assumptive world to incorporate motherhood.

6.3 Research purpose

This study was designed to contribute to the knowledge base underpinning the transition to motherhood and to explore the relationship of the process to the self for women with a disability. As previously identified, there is very little research exploring the experiences of women with a disability in this regard. The extant literature around this topic is predominantly from the perspective and experiences of non-disabled women. Exploring and conceptualising the experiences of women with a disability will provide an in-depth understanding of the transition to motherhood from their perspective and experiences. Belenky et al. (1997) claim that women have a distinctive way of being, knowing, thinking and feeling, they view and know the world from five different knowledge sources:¹³³ silence, received knowledge, subjective knowledge, procedural knowledge and constructed knowledge (Belenky

¹³³ For a more detailed composition of each perspective see Belenky et al. (1997).

et al. 1997). This study was concerned with the women's subjective knowledge, a knowledge that emanated from their personal experiences. The findings will modify and/or contribute to the existing substantive theories pertaining to disability, self and transition to motherhood. The intention is to enhance and expand current understanding of the phenomenon by developing a conceptual framework, grounded in meaning constructed from the perspective and experiences of women with a disability. It is also anticipated that this study will, by making meaningful recommendations, inform midwifery practice, social and maternity care policy.

6.4 Research aims

The aims of this study were: (i) to explore and understand and (ii) to construct a substantive theory that explains the process involved in the transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self.

6.5 Research questions guiding this study

This study set out to explore:

1. the women's experiences of becoming a mother,
2. the women's experiences of becoming a mother with a disability,
3. if and how the process of becoming a mother influenced the women and their sense of self,
4. if and how interpersonal relationships created with others during pregnancy, childbirth and early motherhood facilitated or inhibited the construction of a sense of self.

6.6 Recruitment of women with a disability

Women who participated in this study were recruited from the cohort of fifty-four women¹³⁴ who participated in the National Disability Authority study (Begley et al. 2010). Once ethical approval was granted from the Faculty of Health Science, Trinity College Dublin, and the three study sites (3 large publicly-funded maternity units), initial access to these fifty-four women was gained via a number of routes which included contact with individual women with a disability; through gatekeepers working in the publicly-funded maternity units and resources workers in voluntary agencies; a national advertising campaign, using the specialist magazines and newsletters of voluntary agencies e.g. the Spinal Injury Ireland, National Council for the Blind of Ireland, Irish Wheelchair Association, the National Association of Deaf and others. See Appendix 5 - list of voluntary and non voluntary agencies. Recruitment to the National Disability Authority study was a two phased process, spanning ten months. The first phase in the recruitment process lasted six months, it commenced in March 2008 with a national media campaign. The aim was to maximise the possibility of recruitment by establishing a trusting relationship with gatekeepers and resource officers working in the three study sites and voluntary agencies. A letter of introduction was sent to all gatekeepers and resource officers requesting a meeting. The purpose being to (i) outline the study, (ii) devise a mechanism to disseminate study information to women with a disability, (iii) afford the gatekeeper, and resource officers, an opportunity to pose any questions they may have about the study and (iv) to provide clarification on any issues regarding the study.

Disseminating information about the study involved: (a) displaying posters in strategic positions in the three study sites, community health centres, general practitioner's offices and voluntary agencies, (b) publishing information regarding the study in the newsletters, print and electronic versions, of the voluntary agencies and (c) sending information packs to all gatekeepers and resource officers for distribution to any woman who met the inclusion criteria. The contents of the information pack included a letter of invitation, information leaflet outlining the study, a consent form that the woman was asked to complete and return to me signifying their intention to participate in the study. The information leaflet set out the aims of the study, the method of data collection, the time commitment involved if the woman agreed to participate in the study and that (i) participation was entirely voluntary, (ii) the woman's anonymity would be protected and (iii) the woman could withdraw from the study at any time.

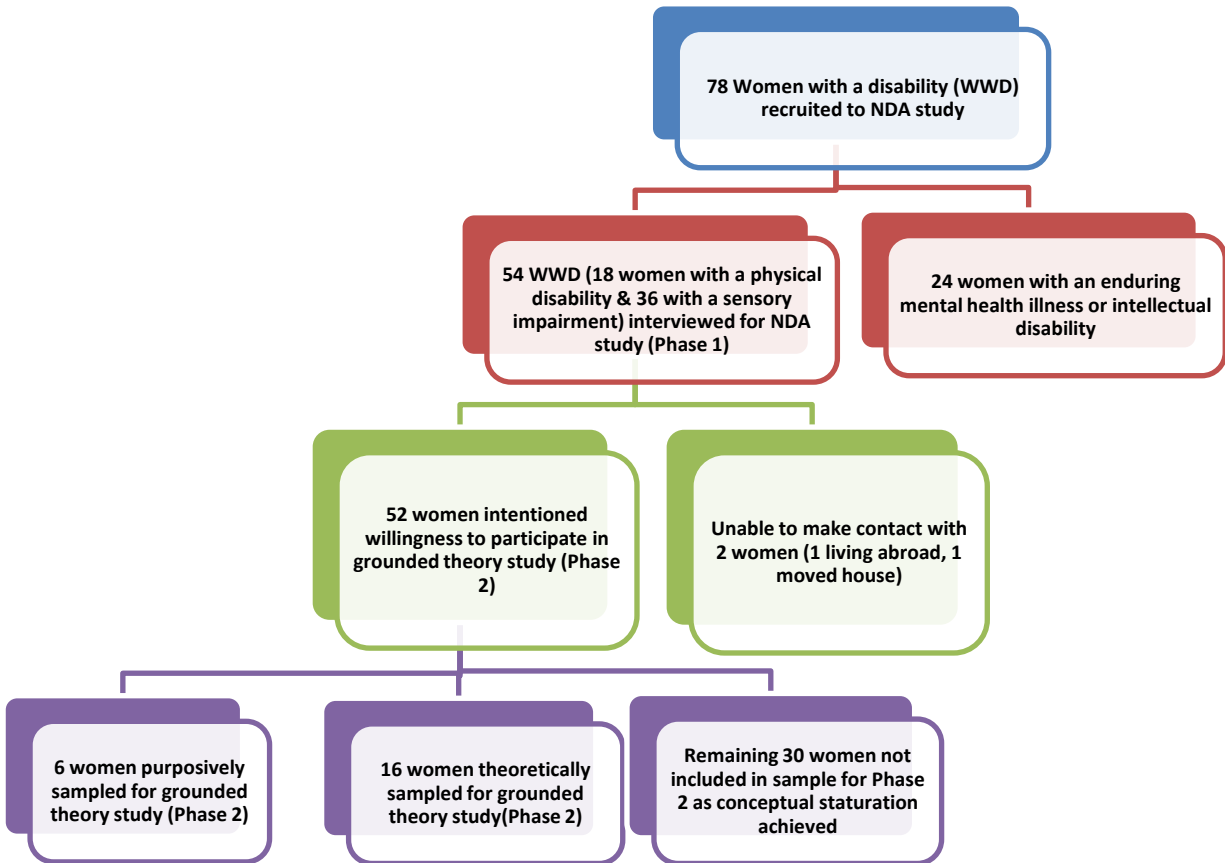
¹³⁴ During the planning stage of the National Disability Authority study the population of women with a disability could not be readily delineated, few comprehensive databases or censuses existed on this population.

At the outset of the study, the information leaflet and consent form were reviewed by the National Adult Literacy Agency (NALA) and the National Council for the Blind (NCBI) to ensure the language therein was appropriate, and that the content and level of detail was suitable for women with a disability. The information leaflet (see Appendix 7) was available in alternative formats e.g. audio, Braille and easy-read format. On receipt of the completed consent form, I telephoned, texted or emailed the woman, this provided her with an opportunity to ask any questions. If after that the woman consented (verbally and/or written) to participate in a one to one interview, arrangements were made to meet at a time and venue convenient for her. The response rate over this phase was less than anticipated (n=4). The second phase of recruitment commenced in October 2008 and lasted four months. Print and electronic versions of the study information were redistributed to the gatekeepers and resource officers in the voluntary agencies. This phase yielded the most responses, with fifty women recruited.

Once the NDA study was completed, a letter of thanks was sent to all fifty-four women who had contributed to that study. This letter set out where the three reports (Begley et al. 2009a, Begley et al. 2009b, 2010) that evolved from the study could be accessed; it also outlined the purpose of this grounded theory study and invited the women to consider participating. Included in the letter was an information sheet explaining the purpose and conduct of the study and a consent form that the women were requested to complete if they wished to contribute to the study. The letter, information leaflet and consent form were available in different formats - audio, Braille and easy-read format, all were reviewed by the National Adult Literacy Agency (NALA) and the National Council for the Blind (NCBI) to ensure the language therein was appropriate, and that the content and level of detail was suitable for women with a disability. If the women expressed a willingness to partake in the study, they were asked to return the consent form in a stamped self-addressed envelope or to contact me via email, text or telephone.¹³⁵ Once their intention to contribute was received, the women were initially purposively sampled (n=6: physical disability (n=2), visual impairment (n=2) and hearing impairment (n=2)) and thereafter theoretical sampling was invoked (see Figure 6.1 diagram outlining recruitment process).

¹³⁵ See Appendix 8.

Figure 6.1 Diagram indicating process of recruitment of women with a disability to the study



6.6.1 Challenges encountered when recruiting women with a disability

No real or obtrusive challenges were experienced during the recruiting and sampling phases. However, the length of time it took to recruit the women was surprising. The initial recruitment of the fifty-four women spanned 10 months, the critical element here was the establishment of a trusting relationship with the gatekeepers and resource officers located in the three study sites and voluntary agencies. As previously discussed in chapter 5 (see 5.12, chapter 5), at the outset of the study I was concerned that I did not have a disability and I was worried that this could pose difficulty during both the recruitment and interview phases. Theoretically, women could have felt aggrieved that a non-disabled person was exploring their experiences with little emic understanding of the actual challenges encountered by them on a daily basis but this concern never materialised during the conduct of the

study. However, a concern that did materialise, especially for women with a hearing impairment, was how the women's anonymity and confidentiality would be maintained. In Ireland the deaf community is small and close knit so understandably women with a hearing impairment were concerned that when the study was published their identity could be easily deciphered accordingly all the women who contributed to the study were reassured that their anonymity and confidentiality would be maintained through the use of pseudonyms of their choosing.¹³⁶

6.6.2 Sampling and eligibility criteria

A total of twenty-two women with a disability were interviewed for this grounded theory study. In accordance with a Strauss and Corbin approach the sampling method employed was theoretical sampling - open, relational or variational and discriminate sampling (see 5.9, chapter 5). During the process of open sampling six women with a disability were purposively sampled. The women (physical disability (n=2), visual impairment (n=2), hearing impairment (n=2)) were purposively chosen to gain the maximum amount of data needed to uncover the potential categories and their properties and dimensions to elucidate the phenomenon. As the concepts and categories began to emerge, open sampling was replaced by relational or variational sampling. Here, the purpose was to collect data to unearth and validate the relationships between categories. Once validated, discriminate sampling occurred, the purpose being to collect data to verify the emerging theory and to further develop the categories that were not saturated (Draucker et al. 2007).

The defining characteristics for women with a physical disability or sensory impairment were:

- (a) Women with a visual impairment, according to the Irish legal definition - "best corrected vision must be equal to or less than 6/60 in the better eye or field of vision must be limited to the extent that the widest diameter of vision subtends an angle not greater than 20 degrees",
- (b) Women with a hearing impairment - whose hearing is affected to an extent that renders the understanding of speech through the ear alone, with or without a hearing aid, difficult or impossible,

¹³⁶ Meeting with key people in the deaf community to discuss the study was also invaluable; it greatly assisted in the recruitment of women with a hearing impairment.

- (c) Women with a physical disability - a decrement in functioning due to a physical health condition, for example, multiple sclerosis, paralysis or loss of one or more limbs.

Inclusion criteria: Women who face ability challenges as above and had given birth in the past four years.

Exclusion criteria: Women who, by virtue of mental or physical distress were considered to be unable to give informed consent on the day of the interview.

6.6.3 Ethical considerations

As the researcher, it was my responsibility to ensure that this grounded theory study was ethically rigorous. The key ethical principles of respect for each woman's autonomy,¹³⁷ beneficence, nonmaleficence,¹³⁸ justice,¹³⁹ veracity,¹⁴⁰ fidelity¹⁴¹ and confidentiality were, as recommended by An Bord Altranais,¹⁴² used as a framework to guide the conduct of this study (ABA 2007). Measures implemented to ensure these principles were adhered to included: (i) obtaining informed consent and (ii) ensuring anonymity and confidentiality. Ethical approval to conduct the study was gained from the Faculty of Health Sciences, Trinity College Dublin and the three study sites (publicly-funded maternity units) (see Appendix 9).

¹³⁷ Respect for each woman's autonomy was demonstrated by considering each of the twenty-two women who contributed to the study was treated as an independent agent with the capacity to make choices for herself.

¹³⁸ Beneficence refers to the intention to do good whilst nonmaleficence refers to the intention to do no harm; this was exemplified in the desire to ensure the study would benefit women with a disability and positively contribute to the process of transition to motherhood.

¹³⁹ Justice refers to how each woman who partook in the study was treated fairly and equitable throughout all stages of the research process.

¹⁴⁰ Adhering to the principle of veracity, I ensured that each woman who contributed to the study was told the truth about the study and there was no deception, all aspects of the study were explained and every effort was made to ensure that the woman understood the implications throughout the study.

¹⁴¹ The principle of fidelity is synonymous with the concept of trust. The relationship established with the twenty-two women who contributed to the study was based on trust therefore it was my responsibility to ensure they were protected and had an understanding of the potential risks associated with their participation in the study.

¹⁴² An Bord Altranais refers to the Nursing Board, the regulatory body for the nursing and midwifery professions in Ireland.

6.6.3.1 Obtaining informed consent

An information sheet relating to this study on women's transition to motherhood was included with the letter of invitation sent to the fifty-four women who participated in the National Disability Authority study and if a woman was interested in contributing to this study she was asked to complete and return a written consent form giving me permission to contact her (see Appendix 8). The consent form was returned in a stamped self-addressed envelope or if they wanted to, the women intoned their willingness to contribute to this study by telephoning or emailing me, or sending me a text message. The women's consent (written or verbal) was also obtained and recorded at the beginning of the interview. Consent to contact the woman again, if required, was also sought at the end of the interview.

6.6.3.2 Ensuring confidentiality

Confidentiality was maintained through the act of anonymising all data using a pseudonym of the woman's choosing. The chosen pseudonym was applied to all recordings and transcripts. All data were stored as per the Data Protection Act (1988; 2003):

- they were anonymised (with woman's chosen name),
- stored separately from master list of names and contact details,
- all hardcopies of data were stored securely in a locked filing cabinet in my office at home or in Trinity College Dublin,
- all electronic data were stored and accessible only by using alphanumeric passwords known only to me,
- all laptops and PCs were firewalled with antiviral software,
- the transcriber who transcribed the data signed a confidentiality form and adhered to the provisions of the Data Protection Act (1988; 2003).

6.6.3.3 Protecting women contributing to the study

At the outset of the study how the women would react or respond in terms of the level of upset they may or may not experience while recounting her experiences could not be anticipated. During the interview process the women were free to disclose or discuss personal information as they so wished. I observed them for obvious or obscure signs of discomfort and distress, for example, tears, facial grimaces, frowning and closed body language. If the women exhibited any of these signs I did not probe sensitive issues. All the women were advised that they could stop, take a break, restart or discontinue the interview at any point. Additionally the technique of 'grounding' was implemented (see section 6.7.5.3, chapter 6) at the end of each interview. This technique was used to reinstate a sense of reality and normality, and to re-orientate the women back into their daily routine. To help achieve this I remained with the women until they felt sufficiently able to return to the activities planned for the remainder of the day. If required, there was a mechanism in place to refer the woman to a counsellor, but this action was not required by any of the women interviewed. When recounting their experiences some women did, at intervals during the interview, get upset and tearful. These emotions were triggered when recalling negative aspects of their experiences, for example, when the women felt undermined by others but this sense of upset was fleeting; it dissipated as the women recounted their own strengths and achievements as a mother. To increase my awareness and sensitivity of issues around disability, before beginning this study, I completed a disability awareness and training programme, I found this and my previous involvement in other studies¹⁴³ where I interviewed women on sensitive topics to be invaluable, undoubtedly this experience enhanced my interactions with women with a disability.

During the planning phase of the interview, strategies were put in place to enhance the security and safety of women with a disability, especially those with a sensory impairment. On the day of interview, I telephoned (more suitable for women with a visual impairment) or texted (more suitable for women with a hearing impairment) the woman to confirm the interview was still occurring as planned. When I was near the woman's house I then telephoned or texted to inform her I was on route and would be knocking on the door shortly. Women with a visual impairment used voice recognition as a method to confirm my identity or if a companion was in the house, with the woman's permission, I showed them my identification card. As a lone researcher I too needed to implement measures that

¹⁴³ Specifically the NDA study (Begley et al. 2010) and a study exploring the lived experiences of postnatal depression (Lawler and Sinclair 2003).

protected me so, during the interviewing process I implemented the provisions contained in a lone worker policy.¹⁴⁴

6.6.3.4 Equity, mutual respect, dignity and reciprocity during the interview process

At a very superficial level an interview can be an unremarkable interaction between individuals; however, sometimes it may be an extraordinary experience for some interviewees and, or interviewers. Interviews are not neutral, context-free tools. For some women, giving voice to their experiences may be a liberating encounter (Reinharz and Chase 2003). In this study the women were keen to express their gratitude at the opportunity to recall and recount their experiences; many remarked how their experiences as women with a disability were frequently disregarded. Consequently, they candidly and generously spoke about their personal experiences of the transition to motherhood.

Before I interviewed the women about their experiences, I was intent on establishing a rapport based on equity, mutual respect and dignity so to achieve this I implemented the following measures: (i) I was conscious of the impact my dress code could have on my interaction with the women. Dressing formally was inappropriate, it would convey a sense of authority and imply that there was a hierarchical relationship between us, additionally, it would impede the sense of equity I sought to achieve (Dearnley 2005). So, to minimise the women's sense of discomfort I adopted a causal but smart dress code, (ii) based on my observations of the women's level of literacy and how they articulated their experiences I also altered the language I used during our interactions. The women were interviewed twice but it was during the second interview that the importance of having a relationship based on trust, equity and reciprocity became clear. The interaction that occurred in that interview was less formal, friendlier and more conversational in approach; the women were more open and willing to share, and discuss their personal experiences. The information that emerged was more intense and profound but I was also conscious that where there was reciprocity there was always the potential that women would disclose or discuss experiences, feelings and thoughts that they may later regret (Gubrium and Koro-Ljungberg 2005, Clarke 2006). Accordingly at the end of each interview each woman was given the opportunity to clarify any issues or to identify content they did not want included in the write up of the study. None of the women asked for any content to be withdrawn.

¹⁴⁴ See Appendix 10.

Self-disclosure was also an important ingredient in my interactions with the women. It helped to create a friendly, trusting, empathetic and sensitive rapport between us (Stanley and Wise 1993, Gubrium and Koro-Ljungberg 2005) and to establish a sense of equality (Gubrium and Koro-Ljungberg 2005, Dickson-Swift et al. 2006). If the women asked personal questions, for example, whether I was a mother or not, I willingly and openly disclosed such information but I was concerned that the closeness and friendship that ensued could cause me to lose sight of my role as a researcher (Johnson and Macleod-Clarke 2003). I was also concerned that this intimate relationship could have enticed the women to disclose more information than they originally intended (Corbin and Morse 2003). Despite these concerns, setting boundaries around rapport, friendship and intimacy was an impossible task, especially considering I was asking women to divulge personal and sensitive information relating to their experiences of their transition to motherhood (Duncombe and Jessop 2002). Building a good rapport and earning the trust of each woman helped convey my respect for them and demonstrated that I had a genuine interest in their experiences (Clarke 2006). Allowing the woman to determine the direction of the interview and the sensitive employment of laddered questions also helped in the disclosure of very personal, sometimes emotional experiences (Price 2002) (see section 6.7.5.2, chapter 6).

6.6.3.5 The issue of power during the interview process

Adopting a constructionist approach, I was conscious that each woman came to the interview assuming a particular identity and that their responses would be in keeping with their own constructions of the self, and that our interaction would be central to the construction of meaning (Gubrium and Koro-Ljungberg 2005). Throughout our interactions I considered the woman to be a partner, not a subject to be studied. I assumed a receptive role rather than an assertive one (Wengraf 2001, Gubrium and Koro-Ljungberg 2005), I positioned myself as a reflective learner, wanting to learn about the women's experiences so as to inform the provision of midwifery care for women with a disability (Corbin and Morse 2003, Manderson et al. 2006). The women were given the opportunity to retain a sense of power and control over our interaction, and what and how much information they disclosed, and the degree to which they wished to explore upsetting experiences (Donalek 2005). However, the idea of gaining complete equity in our interaction was a misnomer. For example, when walking alongside a woman who is a wheelchair user, I became acutely aware of the possibility that there was an asymmetry of power between us. When interacting with this woman I wanted to demonstrate attentive listening, interest

and understanding but I was concerned that the difference in our physicality would affect the woman's perception of me and sense of control between us (see extract from reflective diary below).

12th Feb 2008 Reflection after the interview with [name]

'I have just finished the interview with [name, women with physical disability, wheelchair user], good interview but something phenomenal happened, [name] answered the front door and almost immediately I was struck by the fact I was a non-disabled woman, standing upright, towering over [name] while she was sitting in her wheelchair, she invited me in and while walking alongside her down the hall and talking with her, I felt as if I was looking down on her, I was really uncomfortable and wondered was this the asymmetry of power I had read about, if so I felt an overwhelming sense of guilt, responsibility that I had some hand, act or part in instigating this asymmetry, after all I was a guest in [name's] house, she was telling me her personal experiences'.

During the interviews, although I did not intentionally exert power or control over the interview process, there was always a subtle sense that there was an imbalance of power between the women and I (Chesney 2001, Corbin and Morse 2003, Gubrium and Koro-Ljungberg 2005). A number of factors contributed to this, including: (i) regardless of reciprocity, the interview was not a conversation between equals I controlled the focus, content and fluidity of the interview and our interactions, (ii) the questioning was one directional, the interview became the instrument that provided me with descriptions, narratives and text to interpret and then report on from a particular research perspective. An awareness of this potential imbalance of power did inform the process of critical reflection, I reflected on the role such power may have had on the interactions that occurred between the women and I, and on the subsequent interpretation of the data and production of knowledge.

6.6.3.6 Protecting oneself as a researcher

Conducting qualitative research can be very demanding on the researcher (Corbin & Morse, 2003). The course of the interaction cannot be predicted at the outset. The process of data collection and analysis can be emotionally exhilarating and exhausting as women share their intimate experiences, feelings and emotions. Just like the women who contributed to this study, I also needed a support mechanism that I could access during the lifetime of the study (Parnis et al. 2005). This included: (i) the use of field notes and a reflective diary, (ii) regular meetings with my supervisory team and peer

support, (iii) memoing and reflecting in my reflective diary and (iv) attending the monthly research support and education meetings in my affiliated school.

Field notes, recorded immediately after the interview ended, captured my immediate feelings and emotions pertaining to the interaction and information that was shared by the women, and the time between interviews was used to process the event and information. Regular meetings with my supervisory team afforded me the opportunity to discuss and confront any enduring emotions retained from interviews. Memoing and critical reflection aided conceptualisation and helped to ground me during the research process, these tools captured how my everyday life intertwined with the research study. Attending the monthly research support and education meeting was invaluable; they provided an avenue of support and companionship as I met and engaged with people at different stages in their research journey.

6.7 Collecting the data

In this study individual interviews were the tool used to obtain an understanding of women's experiences but social scientists have used this method to collect data for centuries (Kvale and Brinkmann 2009). Interviews are described as a cultivation of conversational skills that many individuals, by virtue of being able to pose questions, already retain (Kvale and Brinkmann 2009), they are inherently intersubjective, interactional and reflexive (Denzin 2001), yielding knowledge that is '*contextual, linguistic, narrative and pragmatic*' (Kvale and Brinkmann, 2009:p18). All twenty-two women¹⁴⁵ who contributed to this study consented to be interviewed twice. It was anticipated that each interview would take approximately one hour but in keeping with the nature of a qualitative study the length of each one varied from woman to woman (Kvale and Brinkmann 2009). All interviews were, with the woman's consent, digitally recorded. If recording the interview was disconcerting for any of the women, their concerns and fears were identified and addressed at the beginning of the interview process.

¹⁴⁵ For further particulars regarding the women see Appendix 11.

6.7.1 Researcher's role in interviewing

During data collection, the nature of disclosure was dependent on: (i) the social interaction between the women and I, (ii) my skills of interviewing, (iii) the openness of the women and (iv) my subjective judgment to pose suitable questions at the appropriate time. In constructionist terms I became the research instrument, my integrity - knowledge, experience, honesty, fairness and trustworthiness - was crucial to the interaction, disclosure of information and development of knowledge.¹⁴⁶ Developing the practical skills of interviewing was, for me, context and content bound (Kvale and Brinkmann 2009). Theoretical information on interviewing was obtained from the many texts available on qualitative interviewing but the act of interviewing remained an abstract theoretical puzzle until I actually went into the field to collect data. Good interviewing technique was certainly more than just the application of principles, it included an ability to make a judgment on what to ask, or not to ask; when and how to probe or not to probe in an ethically sensitive way (Kvale and Brinkmann 2009). Sensitivity and empathy was something that the women responded well to, consequently the disclosure of information was spontaneous and fluid.

6.7.2 The importance of using an appropriate means of communication

Throughout my interactions with the women both verbal and non verbal methods of communication were used. The use of non-verbal cues, such as nodding, was inappropriate when communicating with the six women with a visual impairment so in that instance emphasis was placed on paralinguistic cues such as intonation, inflection of one's voice and ensuring adequate time was given to the women when responding. Demonstrating attentive listening was difficult when non-verbal cues were redundant, so I consciously integrated phrases such as ye, ah, umh, OK to demonstrate attentive listening. Equally for the six women with a hearing impairment, verbal cues were inappropriate so emphasis was placed on the non-verbal cues to demonstrate that active, attentive listening was occurring. This usually took the form of exaggerated nodding and maintaining eye to eye contact. At the

¹⁴⁶ A theoretical and conceptual understanding of the phenomenon obtained from a review of the extant literature, identified whether the information that emerged was new, its scientific contribution and how it could be integrated with existing knowledge.

outset of the interview a mechanism of gaining the woman's attention was negotiated,¹⁴⁷ so that I could seek clarification on any aspect of the women's experiences.

13th June 2008 Reflections post interview with [name]

'Finished interview with [name], first woman with a visual impairment, I didn't really appreciate the value of verbal communication skills until now, positioned myself opposite woman to maintain eye contact, nodded and smiled at various points in response to some elements of the woman's experiences but I'm not sure why because these visual cues were irrelevant, the woman couldn't see them, I should have agreed a way to get her attention before we started the interview because, although I was giving off non-verbal cues, the woman didn't see these and I ended up interrupting her mid flow on some occasions, which is totally disrespectful. Need to make arrangements re: same in next interviews.¹⁴⁸

6.7.3 Involvement of a third party in the interview process

When a sign language interpreter was employed to facilitate communication between a deaf woman and I the interpersonal relationship became a tripartite one. With the introduction of this third party, spontaneity diminished. This was not related to any individual or individual's roles within the interaction rather, it occurred because the time interval needed for the exchange of information was much longer. I would pose the question while looking at the woman but I knew unless she could lip read she did not understand what I was saying so, the interpreter translated the questions and then, in turn, translated the woman's responses. Although this was time consuming, the data collected was rich, valuable and in-depth but the length of time it took to collect the data was increased greatly, the duration was usually three hours. This was a concern especially in regard to the woman's level of concentration and fatigue. So, regular comfort breaks were taken to help maintain focus and comfort but although necessary, these breaks disrupted the flow of interaction; they prolonged the length of the interview and impinged on the woman's plans for the remainder of the day.

Establishing an empathetic, trusting relationship through a sign language interpreter was extraordinary. In the instances where a sign language interpreter was used, the information that emerged was as rich and in-depth as any interaction without an interpreter but I am not convinced that

¹⁴⁷ At the outset of the interview the women suggested that to gain their attention I would touch the woman's arm, knock on the table/chair or wave.

¹⁴⁸ As a result of this interview, in subsequent interviews with women with a visual impairment, I used (sometimes over-emphasised) verbal cues to demonstrate attentive listening and at the outset of the interview, I always agreed on a way of gaining the woman's attention.

the relationship I established with the woman facilitated the disclosure of such rich information. I believe the women wanted their experiences to be heard and documented and it was this desire that motivated them to contribute to this study. So, the quality of the relationship established between us was secondary to this motivation. At times I felt like an observer, looking on as the relationship between the interpreter and the woman evolved and flourished. Despite all my attempts to do so, it was the interpreter who maintained the eye to eye contact therefore it was only natural that the woman would look at the person signing and not the person posing the questions. My sense of detachment intensified as the relationship between the woman and the interpreter deepened and often I wondered how did the woman perceive me? Was I merely the person posing the questions in a cold and formulated manner, was the interpreter perceived as the empathetic, sensitive one?

26th June 2008 Reflections after interview with [name]

‘Completed interview with [name], sign language interpreter was present for the first time, interpreter and I met before the interview to plan how the interaction would play out, it was good to meet because the interpreter advised me not to be distracted by her [interpreter], to always look at the woman when asking questions and listening to her replies so I was very conscious that I needed to maintain eye contact but despite this I felt I didn’t really get to bond with the woman, yes I asked the questions and listened for the replies, yes I sat directly opposite the woman, maintained eye contact, nodded, smiled, but I got the sense I was only posing the questions, the woman maintained eye contact with the interpreter for most of the time, the relationship was there not with me, I wonder will this be similar in other interviews.’¹⁴⁹

6.7.4 Reflexivity during the procedure of data collection

During data collection I continually reflected and considered how I may have influenced the interview process. The interviews presented an abundance of oral text but the women’s behaviour and non-verbal cues exhibited during the actual interview were also observed and recorded, this provided context for the experiences that were unfolding. Field notes were transcribed during the process and time was set aside at the end of each interview to record my immediate thoughts on the interaction that occurred and to reflect on what emerged. These notes provided context when analysing the transcribed text. It also afforded me the opportunity to review my technique as an interviewer.

¹⁴⁹ Despite having an awareness of the impact of a sign language interpreter on my interactions with deaf women, the feelings felt in this interview was experienced in subsequent interviews with this cohort.

6.7.5 Journeying through the different phases of interviewing

Qualitative interviewing can be emotive (Kvale 1998, Corbin and Morse 2003, Manderson et al. 2006, Kvale and Brinkmann 2009) and for me the journey was certainly steeped with emotions of varying intensity. I adopted a constructionist approach to interviewing so; detachment was not a critical criterion. At the beginning of the study I was very enthusiastic and committed; as it evolved, I became immersed in conceptual and theoretical issues and, once the interviews commenced, the emotions and anxieties associated with interviewing came to the fore. My anxiety emanated primarily from the fact that I perceived myself as a novice interviewer required to adhere to the traditional objective principles of interviewing but it was impossible to remain objective when interacting with women, especially when asking them to recall and recount sensitive and personal information regarding a very intimate and private event but I did not perceive this lack of detachment as a limitation. By being emotionally involved I was empathetic towards the women and their experiences. A sense of solidarity and identification ensued; the relationship established between us was warm and friendly, and the disclosure concerning their experiences was open and candid consequently invaluable information was gained.

6.7.5.1 The pre-interview phase: social and structural context of the interview

The pre-interview phase commenced once the women's intention to participate was received by post, email, text or telephone. On receipt of this intention, I telephoned or texted the woman to explain the study, discuss the ethical provisions of confidentiality and answer any questions the woman had. Once the woman consented to be interviewed a date, time and venue was agreed. The time spent on this preliminary contact was crucial because it set the foundations for our subsequent interaction. A similar format was followed when arranging the second interview. I was aware that the social and structural context of where the interviews were set and conducted could impinge on the interaction and disclosure that occurred therein (Manderson et al. 2006) so several principles guided the conduct of the interview: (i) the women needed to feel comfortable in their environment, (ii) the venue needed to be private, (iii) the atmosphere informal and (iv) furniture arranged in a manner that facilitated conversation and eliminated any sense that I had all the control and power (Sin 2003, Donalek 2005, Gubrium and Koro-Ljungberg 2005). The majority of women chose to be interviewed in their own home. This venue was very appropriate because their home was adapted for their use, so access to and within

the environment was not an issue. Childcare tended to dominate when and where the interviews were conducted, so for many, having the interview in their home eliminated this variable. The women were comfortable in their homes, this combined with the friendly, informal, respectful relationship established between us set the scene for women to recall, recount and disclose their personal experiences in an open and uninhibited manner (Corbin and Morse 2003).

Women, especially those with a sensory impairment were asked to identify the most appropriate space to conduct the interview, this helped keep the interaction woman-centred and provided them with a sense of control (Moore 2002, Gubrium and Koro-Ljungberg 2005). Inevitably the woman chose a space that was comfortable where the light was sufficient and glare minimal. This was a very important consideration for those with a hearing impairment especially, if lip reading was their primary method of communication. In this instance, I needed to position myself sufficiently to ensure the woman could lip read effectively. If sign language was the woman's primary mode of communication, the services of a sign language interpreter was engaged. Again, in this instance care was taken not to impede the woman's line of sight or occlude the interpreter when signing.

Understandably, the women wanted to get to know me before they freely disclosed sensitive information about their experiences and their feelings so, the first few minutes of the interview, the pre-interview phase, were important (Dickson-Swift et al. 2006). To diffuse the women's anxieties and encourage them to open up when recounting their experiences I needed to establish a trusting relationship (Taylor and Bogdan 1998). When I first arrived to the woman's house, before the interview commenced I tended to be offered, and accepted, a cup of coffee or tea. It was during this time, that a degree of comfort was achieved and a sense of trust began to evolve. This, without doubt, was the most decisive period of the interview where the tone of the interview was set and the foundations of reciprocity established (Corbin and Morse 2003).

6.7.5.2 The immersion phase – getting to hear the women's experiences

The pre-interview phase was followed by the interview phase but the movement between the two phases was discernable by the woman's actions and responses (Corbin and Morse 2003). Here, the women began to disclose their experiences but, until a sense of trust was established between us, the disclosure was staggered (Corbin and Morse 2003). More in-depth information began to unfold as the sense of trust increased and the women became completely immersed in the interview process. The

immersion phase was dominated by an honest and fruitful disclosure of experiences. In the second interview, because of our previous relationship, this phase occurred more spontaneously.

Strauss and Corbin do not specify whether unstructured or structured interviews should be carried out (Buckley and Waring 2009). The initial interviews that occurred with the six women who were purposively sampled were unstructured but once the concepts and categories began to emerge from analysis, a more structured approach was adopted to uncover, validate and verify the relationships between categories. At the outset of the study, a flexible interview guide¹⁵⁰ was developed using concepts identified from the literature review. Initially it was used, if necessary, to prompt the women but as analysis proceeded, the interview guide was implemented more readily to explore and validate a specific category and to verify the relationships between categories. As analysis progressed, the interview guide was amended accordingly, its use was flexible, the interview was led by the nature of the women's responses so if, while recounting her experiences the woman introduced a new experience, the interview guide was suspended temporarily and this new experience was explored in more depth. If this experience was relevant the interview guide was amended to allow for further exploration of the experience in subsequent interviews.

Qualitative interviewing requires some degree of probing into women's private lives and thoughts. Although the interview approach was conversational, where necessary, I did probe to encourage the woman to articulate the meaning of her experiences however the number of times probing was used was minimal. Learning to probe or not to probe was as much a skill as it was a judgment and I developed an almost intuitive sense of when to or when not to probe. It is difficult to articulate how this intuitive sense evolved; it was mainly informed by the woman's verbal and non-verbal cues and behaviours. During the interview I carefully observed the woman's body language for any cues that indicated any degree of discomfort with the questions being posed and the flow of conversation. If the woman appeared comfortable, if her body language was open and responses relaxed, I did probe if the meaning was not clear but if the woman appeared uncomfortable I stopped the interview and provided support. When the woman felt more comfortable, their permission and consent to continue was obtained and the interview was resumed by moving to a less anxiety provoking aspect of her experience (Donalek 2005). Some of the women did cry while recalling and recounting their experiences but when asked if they would like me to stop the interview, all said no that it helped to talk, two of the women described how talking about their experience was 'liberating' (Emily PAd) and

¹⁵⁰ See Appendix 12 interview guide.

'healing' (Helen PAd). At the end of each interview any interpretations and hypothesis were presented to the woman and were verified, falsified or refined (Kvale and Brinkmann 2009).

I was mindful of the potential intrusiveness that occurs when interviewing others so, I adopted and implemented a laddering approach to questioning (Price 2002). Using this technique my aim was to discover how the woman's thoughts, beliefs and actions correlated with one another. Designed to provide direction on the use of probing in qualitative interviews, Price (2002) professed that the integration of this laddering technique would yield richer data than a traditional ad hoc approach to interviewing. I used three levels of questions: (i) questions inviting descriptions of or about actions; these tended to be less intrusive or invasive and were frequently used at the beginning and end phase of the interview, (ii) knowledge questions, these were invasive questions that challenged the woman to review how she reasoned and deconstructed her experiences, these questions opened up several lines of enquiry about the woman's experiences and (iii) personal philosophical questions pertaining to the woman's beliefs, values and feelings, these were the most invasive questions (Price 2002). The interview process, consequently, yielded a mass of rich in-depth data that captured the women's emic views and their personal experiences of transition to motherhood, and the relationship of the process to the self (Kvale and Brinkmann, 2009). Some women were more pensive and thoughtful than others; some chose to disclose and reveal more of their thoughts, feelings and actions or as the excerpt from my reflective journal illustrates, some chose simply to answer the questions posed in a very factual and contained manner (Corbin and Morse 2003).

24th July 2008 Reflections post interview with [name]

'Just finished the interview with [woman's name] (women with MS) it was a strange one, unlike other women, it was very business like, there was no welcome extended, baby was asleep in another room. So [name] was anxious to get started, probably because she knew baby would wake up at a certain time, from the very beginning I got the impression that it was a purposive interaction, that I was there to get certain information, pleasantries were exchanged but there was no warmth exhibited, [name] answered the questions asked but didn't deviate from the point, first impressions is the interview was very focused, lead by me, which in any other circumstance would be good but I don't feel I've captured the woman's true experience, I didn't get to the nub of it. Not sure if it was our personalities, or maybe it was because I was a midwife, but the interaction was very cold and distant.'¹⁵¹

¹⁵¹ While I obtained valuable information about the woman's experiences of becoming a mother, my relationship with this woman, unlike those with some of the other women who participated in the study, did not extend beyond the life of the study.

6.7.5.3 The emergence phase – ending the interview

As the interviews drew to a natural conclusion, they entered the emergence phase. Here, the interview moved to a less intense emotional level. Surprisingly some women, despite having recounted very personal and emotional experiences, queried the value of the information they had disclosed. Others talked about how the experience was enlightening or enriching and how they enjoyed talking about their experiences with an attentive listener. They gained a new insight or perspective into their experiences and in a sense unburdened themselves of their feelings and emotions (Peel et al. 2006). At the end of each interview I applied the psychological technique of 'grounding' whereby if towards the end of the interview the women were talking about an experience that was upsetting I would try to lighten the tone by asking a more positive question or moving to a more positive aspect of their experience. I always concluded the interview with something positive or humorous because I knew that leaving the interview abruptly could potentially leave the woman feeling rejected and mistreated (Corbin and Morse 2003). As the interview came to a close, each woman was asked about the interview process and conduct. They were asked to comment on the fact that I did not have a disability and that I was not a mother and whether this had influenced the interview process or the disclosure of information. None of the women considered these as an issue; they were more concerned with my interpersonal and communicational skills. The women were also asked to comment on their interview experience and to make suggestions regarding the process, conduct and content that could potentially enhance subsequent interviews. All twenty-two women were complementary of the approach used when interviewing them and the interpersonal skills I employed during our interactions.

6.7.6 Dilemmas encountered during data collection

Interviewing was an interactive process that involved the development of close interpersonal relationships with women with a disability. A constructionist approach to interviewing was implemented so, I experienced some level of emotional involvement. Some researchers struggle with the notion of developing a friendly, trusting and empathetic rapport (Dickson-Swift et al., 2006). Setting professional boundaries and not crossing or merging those boundaries are often strategies established to manage the challenges of qualitative interviewing but managing those boundaries can be difficult. In this study I found trying to prevent the blurring of boundaries as a woman, midwife and researcher very difficult, as the women recounted their experiences, particularly their negative ones I was affected, personally and

professionally, by their narratives. I employed a variety of strategies to help make sense of my experiences and feelings, these included, recording the impact the women's narratives may have had on me and discussing the specific issues with my supervisors.

How to manage and prevent a research interview from transgressing into a counselling session was another challenge encountered during the interview process (Liamputtong Rice and Ezzy 1999). Empathy and attentive listening were important attributes enacted during the process of interviewing but these are also fundamental elements of any counselling session so, a research interview could tentatively mirror a therapeutic interview (Dickson-Swift et al. 2006, Kvale and Brinkmann 2009). Trying to steer the interview from becoming a therapeutic interview was challenging and this was a technique I had no training or skills in. Entering the field with little or no experience in this regard was anxiety provoking. As the number of interviews increased so too did my awareness of the delicate line between the research interview and therapeutic interview. As this awareness intensified I became more observant for the cues that indicated the interview was steering towards a therapeutic one. If the interview progressed in this direction, I did not stop the flow of conversation; I listened to the woman's comments and descriptions and if necessary I would encourage the woman to talk to a counsellor. A referral mechanism was available to all women who participated in the study but none of the women interviewed required this.

6.8 Data management

In this grounded theory study I decided not to use a qualitative data analysis software programme to manage the data. I did complete a one day training session on the practical application and use of Nvivo 8. I obtained the license for the package and I did use the software programme on the National Disability Authority study. However, despite using it previously and being aware of the many well documented benefits of the programme, I chose not to use it in this study. A number of factors informed this decision: (i) I found it took a considerable amount of time to insert the raw data into the programme and the time spent inserting and labelling the data deflected from the process of interpretation, (ii) although it was relatively straightforward to construct and work with the tree node structure I found this structure fragmented the data furthermore, (iii) at any given time only a small amount of text was available to view on screen, effectively removing the data from its context, I did not

want to do this because in order to have an outline of the process and to capture meaning, I needed to see the content before and after the particular segment of text and (iv) the structuring of the tree nodes gave weight to elements that appeared frequently but frequency was not relevant, as the elements that appeared frequently were not always the issue of concern for women with a disability. While there are a variety of qualitative data analysis programmes to assist in the management of data, fragmentation of data that occurs with these programmes makes it difficult to link relationships between the woman's experiences and across several women's experiences. It is because of this I chose to manage the data manually, as described in the following sections.

6.9 Analysing the data

Analysis is a dynamic process of 'examining something in order to find out what it is and how it works' (Corbin & Strauss 2008:p46). In a grounded theory study, the purpose of analysis is to develop concepts that create a set of categories that when combined generate a theory (Waring 1995). The constant comparative method of analysis was applied to understand the process involved in the transition to motherhood, from the perspective and experiences of women with a disability, it brought order, structure and meaning to the data (Waring 1995, Corbin and Strauss 2008). The process involved coding, which is an active process of generating codes where empirical data is transformed into theoretical constructs relating to the social process being explored (Birks and Mills 2011), a 'process of breaking down, examining, comparing, conceptualising and categorising data' (Strauss and Corbin 1990:p61), and putting it back together in a new way. While the two different approaches to grounded theory define coding in a similar way, the process of coding is different in each approach. Glaserian grounded theorists apply two types of coding, open (substantive) and selective (theoretical) while Strauss and Corbin's approach is more formulaic, they utilise three types of coding - open, axial and selective - to create theoretical constructs and produce end products (Kendall 1999).

In this study, analysis and coding commenced after the first interview. A professional transcriber who upheld the principle of confidentiality transcribed all interviews. When transcribed each interview was simultaneously read and the sound file listened to, to: (i) verify the accuracy of the transcription, (ii) address any discrepancies that may have arisen during transcription and (iii) create a general view of the interview. Once the transcript was deemed to be an accurate account of the interview, coding of the

data began. The physical disability data and the sensory impairment data were analysed independently but the emerging categories were examined for areas that complemented and/or contradicted each other.¹⁵² During the coding process I used the Helix Model (Waring 1995),¹⁵³ an invaluable tool that ensured my approach was systematic and robust.

6.9.1 Open coding

Open coding was the first phase of analysis. In open coding the data were broken down, examined, compared, conceptualised and categorised so that the data could be interpreted, and concepts and categories¹⁵⁴ selected. The transcript of the interview was read and re-read, and all interview passages depicting interaction regarding the process involved in the transition to motherhood and the relationship of the process to the self were underlined to gain a preliminary understanding of the phenomenon. The events, ideas and incidents that occurred in each paragraph were assigned a name in the form of a code. The text was read again and the highlighted sections were further delineated, lower level concepts describing the antecedents relevant to the phenomenon, actions/strategies/interactions or consequences of the phenomenon were labelled, and then conceptualised to form higher level concepts that formed the categories which captured the underlying patterns within the data (Glaser 1998, Birks and Mills 2011). These concepts were labelled using language from the data and this took the form of a 'gerund or 'in vivo' code (Birks and Mills 2011:p93). The categories that emerged were multi-dimensional, consisting of a number of subcategories. Once created, the properties¹⁵⁵ and dimensions of these categories were identified (see Figure 6.2), these helped to recognise and identify the relationship between categories so that a core category, explaining the phenomenon, could be developed. The flexibility implicit in open sampling, the sampling strategy that paralleled open coding, facilitated the unearthing of as many potentially relevant categories, their properties and dimensions, as possible.¹⁵⁶ During open coding my thoughts about the data were

¹⁵² See Appendix 13, a diagrammatic representation of the process of data collection and analysis.

¹⁵³ See Appendix 14, a diagrammatic representation of the Helix Model. The model incorporates coding, theoretical sampling memos, and logical and integrative diagrams. It is spiral in shape and its trajectory is downwards towards a specific focus that represents the resultant theory. The resultant theory becomes denser as the researcher progresses through the different stages of the coding.

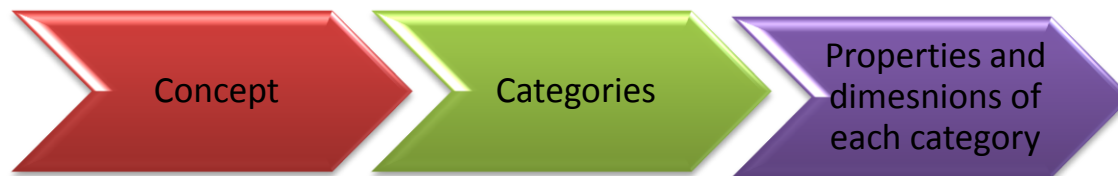
¹⁵⁴ A category is defined as a cluster of coded data reflecting a type of concept (Norton, 1999).

¹⁵⁵ Properties are the conceptual attributes of a category, at a lower level than a category (Norton, 1999).

¹⁵⁶ Open sampling was characterised by the purposive sampling of women with a disability, the aim being to gain the maximum amount of data to create potential categories, their properties and dimensions.

captured in the form of code memos, theoretical memos and operational memos (Strauss and Corbin 1990). Code memos¹⁵⁷ captured my thoughts and feelings when coding the data initially, while theoretical memos¹⁵⁸ extended the code memos. These memos were vast and descriptive and needed further verification, which was achieved during the remaining coding processes of axial and selective coding. The memos fulfilled their purpose; they caused me to question the categories to emerge during open coding, which helped to increase my theoretical sensitivity and more importantly, these memos informed the drafting of operational memos¹⁵⁹ that directed further sampling.

Figure 6.2 The relationship between concepts, categories and the properties and dimensions of each category



6.9.2 Axial coding

Strauss and Corbin integrated an additional coding step to the analytical process, axial coding. Once the categories and subcategories that emerged in open coding were sufficiently reinforced by data from subsequent interviews I moved to the axial coding phase. The process of open and axial coding was not linear, I moved between the two forms of coding (Waring 1995). During axial coding, the data were reconstructed in different ways through the linking of categories and subcategories. This linkage was achieved by inductive and deductive thinking, and by the use of a coding paradigm (see 5.7.2, chapter 5). Essentially, the coding paradigm enabled me to systematically think about and question how the

¹⁵⁷ Code memos - refer to memos containing the actual products of the three types of coding, such as conceptual labels, paradigm features and indications of process (Strauss and Corbin, 1990:p197).

¹⁵⁸ Theoretical notes - these are theoretically sensitising and summarising memos, formed from inductive or deductive thinking about relevant categories, their properties, dimensions, relationships, variations, processes, and conditional matrix (Strauss and Corbin, 1990:p197).

¹⁵⁹ Operational notes - are memos that direct sampling, questions, possible comparisons, leads to follow up on, and so forth (Strauss and Corbin, 1990:p197).

categories and subcategories were related (Strauss and Corbin 1990, Corbin and Strauss 2008). It enabled a clearer focus to be achieved consequently, the phenomenon could be explained not just described (Strauss and Corbin 1990, Corbin and Strauss 2008).

Glaserian grounded theorists contest the use of a coding paradigm, the core argument being that it suppresses the emergence of a theory; they claim it forces the data into pre-existing theoretical assumptions. However, Strauss and Corbin defend its use, claiming it helps researchers to construct complex and meaningful grounded theory. In this study, I found that by dimensionalising and describing the categories I developed a deeper description, understanding and an appreciation of the women's experiences (Strauss and Corbin 1990, Kendall 1999, Corbin and Strauss 2008). This deeper understanding facilitated the development of appropriate, practical recommendations to enhance the provision of midwifery care for women with a disability and assist midwives to facilitate the process of transition to motherhood for these women. Theoretical sampling during axial coding took the form of relational or variational sampling, here, data were collected to uncover and validate the relationship between categories and subcategories. The memos recorded during this phase captured my attempts to associate each aspect of the data to the coding paradigm. The complexity of the code and theoretical memos intensified as my theoretical sensitivity increased. Operational notes provided guidance on what categories to focus on when conducting further sampling or to explore suppositions generated and requiring verification in subsequent interviews. During axial coding, I also employed visual tools in the form of diagrams to assist in the mapping of the relationships between categories and subcategories. Two types of diagrams were employed, logical and integrative diagrams; logical diagrams demonstrated the logical relationship between categories and subcategories, while integrative diagrams were used to incorporate threads of the emerging theory and to demonstrate conceptual links (Buckley and Waring 2009). These diagrams were initially simplistic in nature but became more complex as analysis advanced. As a visual person, these diagrams were invaluable, with them I could visualise the relationship between categories and this was very useful during the coding process especially when conceptualisation appeared to plateau. I also found the diagrams to be a valuable tool when communicating and explaining my ideas to others.

6.9.3 Selective coding

The final phase of coding - selective coding, integrated the categories developed during open and axial coding, and refined the developing theory. Here, the core category was selected and all other categories were integrated into that core category. The core category provided an explanation for the most variations of the central phenomenon of concern for women with a disability. To assist in the identification of the core category I implemented the guidelines set out by Strauss and Corbin (1990), these included:

- (i) the explication of a story line, achieved through the recording and documenting of thoughts, using an existing or creating a new category that becomes the core category, that is abstract enough to consume all described in the story and determine the properties and dimensions of the core category,
- (ii) relate the additional categories around the core category using the coding paradigm,
- (iii) relate categories at the dimensional level,
- (iv) validate the relationship against the data,
- (v) fill in categories that require further development or refinement.

Explicating a story line involved the selecting of or generating a category that described the story of the phenomenon, none of the existing categories satisfied this criterion so a new category was created - (Re)constructing Myself - this encapsulated all other categories. Existing categories were then matched to relevant portions of the coding paradigm. The relationships between categories were further defined. Once developed, the theory was compared to other extant theories relating to disability, self and transition to motherhood, to validate or highlight inconsistencies or differences in the understanding of the phenomenon. The theoretical sampling employed in this phase of coding was discriminate, the data were collected to verify the theory and to develop the categories that were not well saturated. If at this point new data not fitting with the story line emerged, this information was examined to determine if it was an issue related to conceptualisation or if it was an instance of a variation. The memos drafted during this coding phase were more complex and deeper, reflecting the evolving theory and the diagrams guided and kept the nature of the relationship between the categories clear, the memos and diagrams were a great aid when writing up the theory.

6.10 Memoing

During the research process, memos were used to record my thoughts, ideas and thinking. I used them to develop ideas, they were a means of continuously integrating interpretation into the constant comparative method of analysis (Piantanida et al. 2004). The coding process facilitated the exploration of how women with a disability created meaning of their personal experiences and memoing captured my internal processes of meaning making (Piantanida et al. 2004). Code, theoretical and operational memos advanced the analytical process and facilitated the conceptual development of the concepts identified in the data. Memoing took the form of personal diarising, free from the constraints of the necessity to be grammatically correct; the process allowed me to be creative about the data. Memos kept track of what was emerging from the data; they moved the data forward by analytically dissecting and developing the codes to form conceptual categories. Thereafter each category was assigned a meaning and the relationship between categories determined. Memos assisted in the development of the relationship between the core category, the subcategories and their respective dimensions and properties. The memos recorded during open coding were quite descriptive but as analysis advanced their complexity increased. The process of memoing was incessant, occurring at any time or place. Each memo was titled and dated and remained open and active until the study ended.

Figure 6.3 Types of memos used in open coding¹⁶⁰

(Strauss and Corbin 1990)



¹⁶⁰ See Appendix 15 exemplar of memo.

6.11 Summary

This chapter detailed how this grounded theory study was conducted. Strauss and Corbin's approach to grounded theory provided a framework within which to explore and examine the process involved in the transition to motherhood from the perspective and experiences of women with a disability and to explore the relationship of the process to the self. This chapter outlined the method used to collect data and discussed how the constant comparative method of analysis facilitated the interpretation of women's experiences, the findings of which are presented in the following three chapters. The challenges encountered when interviewing women with a disability, particularly those with a sensory impairment were highlighted but these were not insurmountable, they were, with some forward planning, overcome. The substantive grounded theory that evolved from the process of analysis is presented in the following three chapters.

Chapter 7 'Re(constructing) Myself': the process of transition to motherhood for women with a disability

7.1 Introduction to and presentation of findings

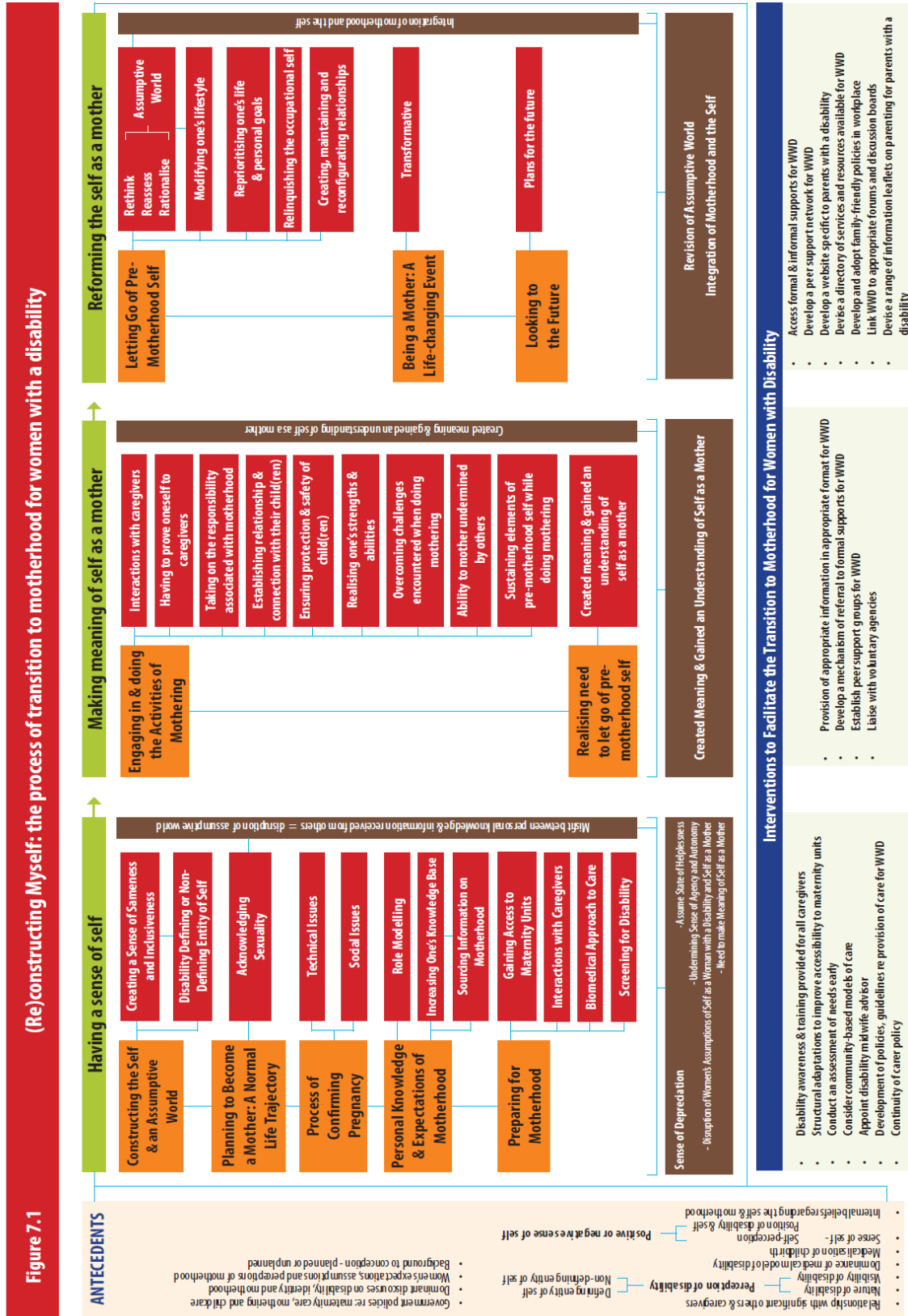
Becoming a mother is an experience that marks an important personal, biological and sociological transition in a woman's life. In asserting their right to become a mother, women with a disability have to overcome many personal, institutional and societal challenges but research exploring their personal experience of the transition to motherhood and the relationship of the process to the self¹⁶¹ is limited. The limited amount of research undertaken in this area focuses on the challenges encountered by women with a disability when accessing maternity services and care (Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Prilleltensky 2003, McKay-Moffat and Cunningham 2006, McKay-Mofatt and Rotheram 2007, Smeltzer 2007, Begley et al. 2009b, 2010, Walsh-Gallagher et al. 2012) or, on women's experiences of mothering with a disability (Prilleltensky 2003, Prilleltensky 2004a, 2004b, Malacrida 2009). In Chapter 4, I discussed how the technical literature pertaining to the transition to motherhood (LeMasters 1957, Dyer 1963, Rubin 1967a, 1967b, Oakley 1980, Mercer 1985, Ball 1994, McMahon 1995, Sethi 1995, Barclay et al. 1997, Smith 1999, Bailey 1999a, 1999b, Earle 2000, Lawler 2000, Nelson 2003, Prilleltensky 2003, Mercer 2004, Yeates 2004, Miller 2005, Stern 2006, Flakowicz 2007, Urwin 2007, Malacrida 2009, Darvill et al. 2010) was predominantly from the perspective and experiences of non-disabled women. The appropriateness and applicability of these varying extant theories in describing the experiences of women with a disability have not been explored.¹⁶² The twenty-two women with a disability, who contributed to this study, provided valuable data regarding their personal experiences of their transition to motherhood and the relationship of the process to the self. Some accounts exemplify the women's resilience particularly when managing the negative prejudicial attitudes of others located in their social world.

¹⁶¹ To recapitulate, this study was guided by the following definitions of self and identity. The self is defined as an organised set of intrinsic possesses that confers an ability to consider, observe and evaluate itself, to take account, to plan and to construct itself as an object that can be modified in different situations (Smith et al. 2001, Burke and Stets 2009). The self originates in and evolves from an individual's mind, as the mind interacts with its environment to sustain the individual. While identity is defined as the array of meanings that define who an individual is when: (i) that individual assumes a specific role in society, (ii) claims specific traits that identify them as a unique individual or (iii) claims membership of a particular group (Burke and Stets 2009). It is a combination of how an individual sees themselves and is seen by others, a socially recognised position, recognised by the individual and others through the social relations they form, engage and interact in.

¹⁶² Furthermore, only a small number of studies have investigated the effect becoming a mother had on the self.

Chapter 4 illustrates how becoming a mother, is an event that has the potential to change the self, each woman's experience of the transition to motherhood is very subjective and although each of the twenty-two women who contributed to this study made a unique contribution, the grounded theory approach used in the study facilitated the exploration and interpretation of women's experiences of the basic psychosocial process involved in the transition to motherhood. '(Re)constructing Myself' represents the core category that explains the process of transition to motherhood for women with a disability and the relationship of the process to the self. Three theoretical codes emerged: '*Having a sense of self*', '*Making meaning of the self as a mother*' and '*Reforming the self as a mother*', these denote how through the process involved in the transition to motherhood, women with a disability, reconstruct the self and their assumptive world so as to incorporate motherhood. The three theoretical codes represent the different phases of the process. The first phase represents the pre-motherhood self while the second and third phases represent how the women engaged in a process of making meaning so as to gain an understanding of the self as a mother with a disability, and how, having made meaning they reconstructed the self and their assumptive world to incorporate motherhood. The duration of each phase differed from one woman to another and progression through the process was not linear, women moved back and forth through the phases, especially the second and third phases. This movement was influenced by the information received from others and whether or not it corresponded with the woman's own assumptions of the self as a woman with a disability and the self as a mother. Nonetheless the process explains a common pattern of behaviours that can be easily observed. The data presented in this chapter and the following two chapters explain how women with a disability reform the self and their assumptive world to so as to incorporate motherhood. Figure 9.3 presents a diagrammatic representation of the theoretical model explicating the process involved in the transition to motherhood for women with a disability. A summary of the theoretical model to emerge from the study is presented diagrammatically in Figure 7.1. The remainder of this chapter presents the demographic details of the women who contributed to this study (see Table 7.1) and provides a description of the first theoretical code 'Having a Sense of Self'.

Figure 7.1 Diagrammatic representation of Summary of theory



7.2 Demographic profile of the twenty-two women who contributed to the study

A total of twenty-two women with a disability contributed to this study. Ten women had a physical disability, six women had a visual impairment and six women had a hearing impairment, and all agreed to be interviewed twice. In-depth interviews¹⁶³ were conducted over a two-year period. The nature and visibility of the woman's disability varied. Eighteen women had a congenital disability and four had an acquired disability. The majority of women (n=17) were aged between 32-40 years (mean=34.86 years, SD=4.268, range 26-44 years). A more detailed description of the demographic profile and characteristics of all twenty-two women are presented in Table 7.1.

¹⁶³ Initially the interviews were exploratory but as the concepts began to emerge and as the theory began to take shape the interviews took on a different purpose, that of confirming the categories and emerging theory.

Table 7.1 Demographic profile and characteristics of 22 women who contributed to the study

No	Site	Disability	Nature of Disability	Age	Parity	SEG	Status	Gestational Interview	Postnatal Interview	Assistive Aids used	Mode of delivery	Typology	Code
1	4	Physical (d)	Acquired	32	Mother of 2	5	B	N/A	6/12 & 1.5yrs	None	Spontaneous Vertex Delivery (SVD)	Ad	Aine PAd
2	2	Physical (c)	Acquired	34	New mother	7	B	N/A	1 & 2 yrs	None	SVD	Ad	Helen PAd
3	2	Physical (b)	Congenital	40	New mother	1 F/T	A	N/A	6/12 & 2yrs	Wheelchair	C/ Section	CD	Natasha PCD
4	3	Physical (d)	Congenital	38	New mother	1 F/T	B	N/A	6/12 & 2yrs	Wheelchair	C/Section	CD	Selina PCD
5	4	Physical (b)	Congenital	28	New mother	1 F/T	B	32 weeks	1.5 yrs	Walking sticks	C/Section	CD	Louise PCD
6	2	Physical (c)	Acquired	36	Mother of 2	5	B	N/A	3/12 & 1.5 yrs	None	C/Section & SVD	Ad	Emily PAd
7	1	Physical (b)	Congenital	26	Mother of 2	5	A	N/A	3/12 & 2.5 yrs	Walking sticks	Forceps	Cd	Kim PCd
8	2	Physical (d)	Congenital	40	Mother of 2	1 F/T	B	N/A	2 & 4 yrs	Wheelchair	Vacuum & SVD	CD	Sinead PCD
9	2	Physical (c)	Acquired	39	Mother of 3	5	B	28 weeks	1.5 yrs	Walking sticks	SVD	Ad	MSK PAd
10	3	Physical (b)	Congenital	44	New mother	1 F/T	B	N/A	14 wks	Wheelchair	C/Section	CD	Olive PCD
11	4	Hearing (e)	Congenital	34	Mother of 2	5	B	28 weeks	1 yr	Hearing aid (HA) & lip reading (LR)	SVD	Cd	Christine HCd
12	3	Hearing (e)	Congenital	31	New mother	1 F/T	B	30 weeks	9 months	HA & LR & Sign language	SVD	CD	Maggie HCD
13	2	Hearing (e)	Congenital	34	Mother of 2	5	B	N/A	6/12 & 2 yrs	HA & LR	C/Section x 2	Cd	Kerrie HCd
14	2	Hearing (e)	Congenital	36	Mother of 3	1 F/T	B	31 weeks	16 months	Sign language	SVD	CD	Evelyn HCD
15	3	Hearing (f)	Congenital	36	Mother of 2	5	B	N/A	1 & 3 yrs	HA & LR	SVD	Cd	Jackie HCd
16	2	Hearing (f)	Congenital	38	Mother of 3	5	B	N/A	6/12 & 1.5 yrs	HA & LR	SVD	Cd	Sharon HCd
17	2	Vision (g)	Congenital	30	New mother	4	A co-hab	32 weeks	15 months	Guide dog	SVD	CD	Birte VCD
18	2	Vision (g)	Congenital	33	Mother of 2	1 F/T	A co-hab	34 weeks	2 yrs	Guide dog	SVD	CD	Lorna VCD
19	2	Vision (h)	Congenital	32	New mother	1 F/T	B	N/A	3 wks & 2.5 yrs	Glasses	SVD	CD	Sara VCD
20	3	Vision (g)	Congenital	36	New mother	1 F/T	B	N/A	9 months	Guide dog	SVD	CD	Anne VCD
21	2	Vision (h)	Congenital	32	New mother	4	A co-hab	29 weeks	1.5 yrs	None	SVD	CD	Aoife VCD
22	4	Vision (g)	Congenital	38	Mother of 2	1 F/T	B	N/A	2 & 4 yrs	Guide dog	SVD	CD	Betty VCD

Recruitment site 1=Hospital site, 2=Voluntary agency, 3=Snowballing, 4=Advertising. **Disability** a=Spina bifida, b=Cerebral palsy, c=Multiple Sclerosis, d=Other, e=Deaf, f=Partially deaf, g=Blind, h=Partially sighted. **SEG** 1=Working for payment or profit, 2=Looking for a regular job, 3=Unemployed, 4=Student, 5=Looking after home/family, 6=Retired from employment, 7=Unable to work due to permanent sickness and disability, 8=Other (Source Central Statistics Office, 2011). **Status** A=Single, B=Married, C=Re-married (following widowhood), D=Re-married (following divorce/annulment), E=Separated, F=Divorced, G=Widowed (Source Central Statistics Office, 2011). **Typology** CD=women with a congenital disability where disability was considered a defining trait of the self, Cd=women with a congenital disability where the disability was not considered a defining trait, AD=women with an acquired disability where disability was considered a defining trait of the self, Ad=women with an acquired disability where disability was not considered a defining

7.3 Having a sense of self

7.3.1 Introduction

Having a sense of self represents the first phase of the process involved in the transition to motherhood for women with a disability. Data for this phase emerged from the first interviews conducted with the women¹⁶⁴ while data for the second and third phases evolved from the second interviews (sections 6.7 and 6.9, chapter 6 details the process of data collection and analysis). This phase is the only phase of the process relating to the pre-motherhood period whereas the remaining two phases are concerned with the period after the birth of the baby. The categories, their properties and dimensions constituting this theoretical code represent the pre-motherhood self and the abstract, global assumptions that ground, secure and direct the self and structure the woman's assumptive world. It reveals how, like non-disabled women, the twenty-two women with a disability had planned for and aspired to become a mother, in fact this aspiration was a fundamental assumption populating their assumptive world. During this phase the women established positive or negative perceptions of motherhood and an innate belief that they would be a good, competent, confident, responsible mother. 'Having a sense of self' demonstrates how the self was constructed through symbolic relationships and interactions with others in the women's social world (Mead 1934, Cooley 1964, Blumer 1998), the role models they choose to emulate, life experiences and their interpretation of those lived experiences.¹⁶⁵ Consequently, the women created a positive,¹⁶⁶ neutral¹⁶⁷ or negative¹⁶⁸ sense of self.

The Strauss and Corbin approach to grounded theory used in this study allowed for a review of the technical literature before the process of data collection (Strauss and Corbin 1990, Corbin and Strauss 2008). Concepts from this literature informed the coding paradigm (see Table 5.2, chapter 5 and

¹⁶⁴ Data for this phase emerged from the first interviews conducted with the women; these interviews also provided the data for a study commissioned by the National Disability Authority (Begley et al. 2010). A total of 54 women with a physical disability or sensory impairment were interviewed, the purpose was to explore the strengths and weaknesses of the publicly-funded maternity services for women with a disability during pregnancy, childbirth and early motherhood. Twenty two of these women were interviewed again during the second phase of interviewing; the purpose here was to explore the women's experience of transition to motherhood and the relationship of the process on the self.

¹⁶⁵ Lived experience refers to the woman's personal, subjective experiences.

¹⁶⁶ The woman describes the self in a positive way, using nouns such as self-esteem, self-worth, self-respect, self-fulfilled and a sense of belonging.

¹⁶⁷ The woman neither describes the self in a positive or negative way. Aspects of it are positive and aspects are negative but neither configuration is given prominence by the woman.

¹⁶⁸ The woman describes the self in a negative way; using phrases like feeling insignificant, experiencing a feeling of diminished self-esteem and a sense of otherness, this negativity is either explicit or implicit in her description of the self.

section 6.9.2, chapter 6). Therefore I had some knowledge of the more recent theories on the transition to motherhood albeit from the perspective and experiences of non-disabled women. So, as I proceeded to collect data I queried how these theories applied to, and indeed, if they were appropriate and applicable to women with a disability, and if the experiences of these women were similar or dissimilar to non-disabled women. As analysis progressed, it became clear that while some aspects of the experiences of these women resonated with those of non-disabled women (see Table 7.2), others did not therefore new concepts pertaining to the transition to motherhood from the perspective and experiences of women with a disability began to materialise. Accordingly, during analysis, in addition to implementing the coding paradigm I also theoretically sampled the literature so as to develop the different concepts that were emerging. As a tentative conceptual framework began to materialise, where necessary, additional literature was sampled and reviewed to clarify and modify the concepts or social process uncovered. In this instance, the constructs of assumptive world (Parkes 1971, Janoff-Bulman 1992), a belief in a just world (Lerner 1980) and learned helplessness (Peterson et al. 1995) were essential when formulating an understanding of the psychosocial process occurring as women with a disability became mothers. When the women experienced a discrepancy between their assumptions of the self and the information received from others located in their social world, the misfit that ensued disrupted the women's assumptive world. Once disrupted, the women had to instigate a variety of coping strategies to manage and cope with the disruption in order for the transition process to occur (see Figure 7.2 diagrammatic representation of this phase, phase I Having a Sense of Self).

Table 7.2 Coding paradigm: ‘Re(constructing) Myself’: the process of transition to motherhood for women with a disability (WWD)

Phenomenon – Re(constructing) Myself: the process of transition to motherhood for women with a disability (WWD)	
Context	<p><u>Social self:</u> – produced within familial and extra-familial social settings, family especially mother highly significant.</p> <ul style="list-style-type: none"> - social experiences – relationships and interactions with others - autonomous, self-conscious women with a capacity to imagine, reflect on and see how others perceive them - woman’s sense of self pre-motherhood <p><u>Dominant discourse:</u></p> <ul style="list-style-type: none"> - medical model of disability, interactive and looking glass self, and discourse of good, intensive mothering - policies re maternity care, mothering and childcare – medicalisation of childbirth, child protection guidelines <p><u>Expectations:</u> assumptions and perceptions of pregnancy and motherhood = motherhood a process, rite of passage, life changing event</p> <ul style="list-style-type: none"> - internal beliefs regarding the self in the role of mother <p><u>Disability:</u></p> <ul style="list-style-type: none"> - nature and visibility of disability – congenital/acquired - visibility - use assistive aids or not <p><u>Motherhood:</u></p> <ul style="list-style-type: none"> - nature of pregnancy – planned or unplanned - entails responsibility and culpability for child development and growth - mothers interpellated within discourse of responsibility through government policies in child health clinics via development checks etc. - mother subjected to this information and regulate behaviour accordingly – if unsuccessful punitive measures can be taken e.g. losing custody - prevailing discourse re good, intensive motherhood generates uncertainty in mother, increases dependence and over reliance on professionals, undermines woman’s ability to develop confidence and make decisions
Causal Conditions	<p>Commitment to motherhood, similarities and differences to others</p> <p>Woman’s sense of self pre-motherhood</p> <ul style="list-style-type: none"> - sense of connectedness and belonging - sense of sameness and inclusiveness - acknowledgeing sexuality <p>Disability as a core or non-core element of self</p> <ul style="list-style-type: none"> - acceptance of disability - taking on disability identity - visibility of disability - immersion into disability community - questioning normality <p>Occupational identity core identity pre-motherhood</p> <p>Process of confirming pregnancy – technical and social issues</p> <p>Expectations of motherhood</p> <ul style="list-style-type: none"> - personal knowledge and expectations relating to self as a mother - role modelling <p>WWD - responses to their pregnancy varied - opposition and scepticism to delight</p> <ul style="list-style-type: none"> - sexuality not recognised, was denied or undermined by family and society - maintaining control over own reproduction important - motherhood a viable option - influence of traditional gender roles

Table 7.2 Coding paradigm: ‘Re(constructing) Myself’: the process of transition to motherhood for women with a disability (WWD) cont’d

Actions, Interactions, Strategies	<p>Woman thinks, reflects, acts, adjusts and changes own perceptions and behaviours in responses to that of others in their social environment</p> <p>Woman presents self to others in the roles she enacts and through speech, behaviours and actions, her actions are conscious and explicit</p> <p>Woman assumes various roles that accumulate and solidify to form the self</p> <p>Pre-motherhood: - opportunity to develop and grow</p> <p>Taking in process – tries to understand what it means to be a mother</p> <ul style="list-style-type: none"> - mimicry - role play and fantasy - ability to visualise self as mother parallels with subsequent adaptation to motherhood - self system theory – focus on image: ideal image, body image and self image, presenting maternal self to others <p>Post-motherhood: - once baby born process of adjustment begins, attention turns to own life, shift in priorities and perception of self, awareness of personal identity, initial few months post birth period of intense change and adjustment</p> <ul style="list-style-type: none"> - engagement with motherhood – committing to motherhood, experiencing, interacting, engaging and actively caring for baby facilitate growth and transformation of mother, not all women experience growth and transformation - growth and transformation – internalising self as mother and experiencing lived reality of motherhood facilitate transformation of self, introspection and self evaluation <p>Introjection</p> <ul style="list-style-type: none"> - taking responsibility, relinquishing pre-motherhood behaviours, alter appearance, redefine and reorganise relationships with others, reflect on priorities, embrace gendered identity, engage in activities that are relevant for pregnancy and motherhood, more aware of difference between private and public domain, may hide aspects of self - engage in process of letting go - seeking information - develop different (new) skills - desire to display competency and ability in managing and coping <p>Positive appraisal of others important, being perceived as a good mother important, feared being judged as bad mother</p> <ul style="list-style-type: none"> - WWD - needs and level of formal support varied, influenced by woman’s disability - WWD experience a myriad of stresses and challenges when accessing services - lack of adequately funded resources a major challenge for WWD - impacts on their parenting abilities - formal supports are: <ul style="list-style-type: none"> o invasive, disruptive and impact on bond between mother and baby o facilitative and helpful <p>At beginning of transition mothers with a disability depend on expert advice and information but as transition progresses this changes and they develop confidence in own abilities</p> <p>WWD –</p> <ul style="list-style-type: none"> - conscious of how others may perceive them and judge them in relation to mothering - engage in over conscious mothering in public and private domain - hide facets of self revealing only aspects that fit with norm and tailor practices of mothering in a manner that is less stigmatising <p>Misfit between reality and the ideology of motherhood - generates a conflict between women’s experiences and views held therefore they experience a dissolution of previous sense of self resulting in a lowering of one’s self-esteem</p> <p>Measures taken to comply with provisions of ideal motherhood</p> <p>Engaging with maternity services</p> <ul style="list-style-type: none"> - biomedical approach to care - gaining access to maternity units - navigating and negotiating internal environment of maternity units - medicalisation of pregnancy and childbirth - Interacting and communicating with health professionals
--	--

Table 7.2 Coding paradigm: ‘Re(constructing) Myself’: the process of transition to motherhood for women with a disability cont’d

<p>Actions, Interactions, Strategies cont’d</p>	<p>Engaging in the activities of mothering cont’d</p> <ul style="list-style-type: none"> - having to prove oneself - social development of child(ren) - establishing a relationship and connection with their child(ren) - ensuring the child(ren)’s protection and safety - feeling unprepared - realising one’s strengths and limitations - overcoming the challenges of doing mothering - doing mothering in the public domain - sustaining aspects of the pre-motherhood self - desire to display competency and ability to manage and cope <p>Reforming the self</p> <ul style="list-style-type: none"> - Letting go <ul style="list-style-type: none"> o relinquish pre-motherhood behaviours o alter appearance o redefine and reorganise relationships with others o reflect on priorities o embrace gendered identity
<p>Consequences</p>	<p>Develops a sense of self, generates perceptions and behaviours in response to environment and relationships with others in that environment</p> <p>Motherhood a rite of passage, life changing event, defining event, turning point in woman’s life, normal crisis in woman’s psychological development significant changes in personality & self</p> <p>Motherhood opportunity to change for those who wanted to change:</p> <ul style="list-style-type: none"> - psychic reorganisation of self occurs involves reappraisal of all aspect of the woman’s life and of the primary roles she occupies including the roles of woman, mother, wife, partner, daughter, friend, daughter in law, career, her role in the family, in society, legal status, herself as a person with responsibility for another - altered sense of relationship with body & re-organise relationships others - positive and negative changes <ul style="list-style-type: none"> - empathetic and sensitive towards others - increased patience - greater understanding of love - personality traits not obvious pre motherhood come to the fore - experience a sense of loss – women experiences a series of multiple losses (post first baby) in regard to their sense of self, this sense of loss evolves from the idealised image some mothers have before the birth of the baby and when in reality, this image is not realised, a sense of loss ensues - conflicting emotions and conflicts - sense of fulfilment - development/retention of positive sense of self - static – no effect on sense of self – motherhood added dimension but sense of self same as pre-motherhood - altered assumptions of self, alter assumptive world - feelings & emotions - development of positive or negative emotions: <ul style="list-style-type: none"> o elevated status to adulthood, sense of maturity o confident and competent in maternal role, self worth o sense of sameness, sense of similarity provides a frame of reference for women and helps them to determine if their experiences are normal, o sense of shared identity with other mothers, claim to sexual and gendered identity

Table 7.2 Coding paradigm: 'Re(constructing) Myself': the process of transition to motherhood for women with a disability (WWD) cont'd

Consequences cont'd	<ul style="list-style-type: none"> ○ sense of depersonalisation, confusion and loneliness, loneliness, especially acute in the early postpartum period, it emanated from a sense of depersonalisation and confusion that occurred in this period ○ stress and anxiety <p>- motherhood challenging – for WWD challenges situated within the woman and society</p>
Intervening Conditions	<p>Integration/disassociation of disability into sense of self</p> <p>Personality type – ability to deal with change and associated emotional changes</p> <p>Support matrix, availability of resources and support</p> <p>Nature of interpersonal relationship with others – baby, partner, family, friends, health professionals, others</p> <p>Attitudes and perceptions of others</p> <p>Appraisal of others</p> <p>Security and stability – relational and occupational, positioning and importance of occupation in sense of self</p> <p>Expectations of self as mother – realistic or idealistic</p> <p>Nature of information available and received</p> <p>Previous experience of motherhood</p> <p>Ability to draw on coping skills, range of adaptive strategies available to woman</p>

KEY:

Phenomenon - the specification of a category – what is the data referring to, what are the actions/interactions about

Context - specific set of properties that pertain to a phenomenon – the locations of events or incidents pertaining to the phenomenon with a dimensional range, represents the particular set of conditions within which the action/interactional strategies occur

Causal Conditions - events, incidents, happenings that lead to the occurrence or development of a phenomenon

Actions/interactions/strategies - strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions

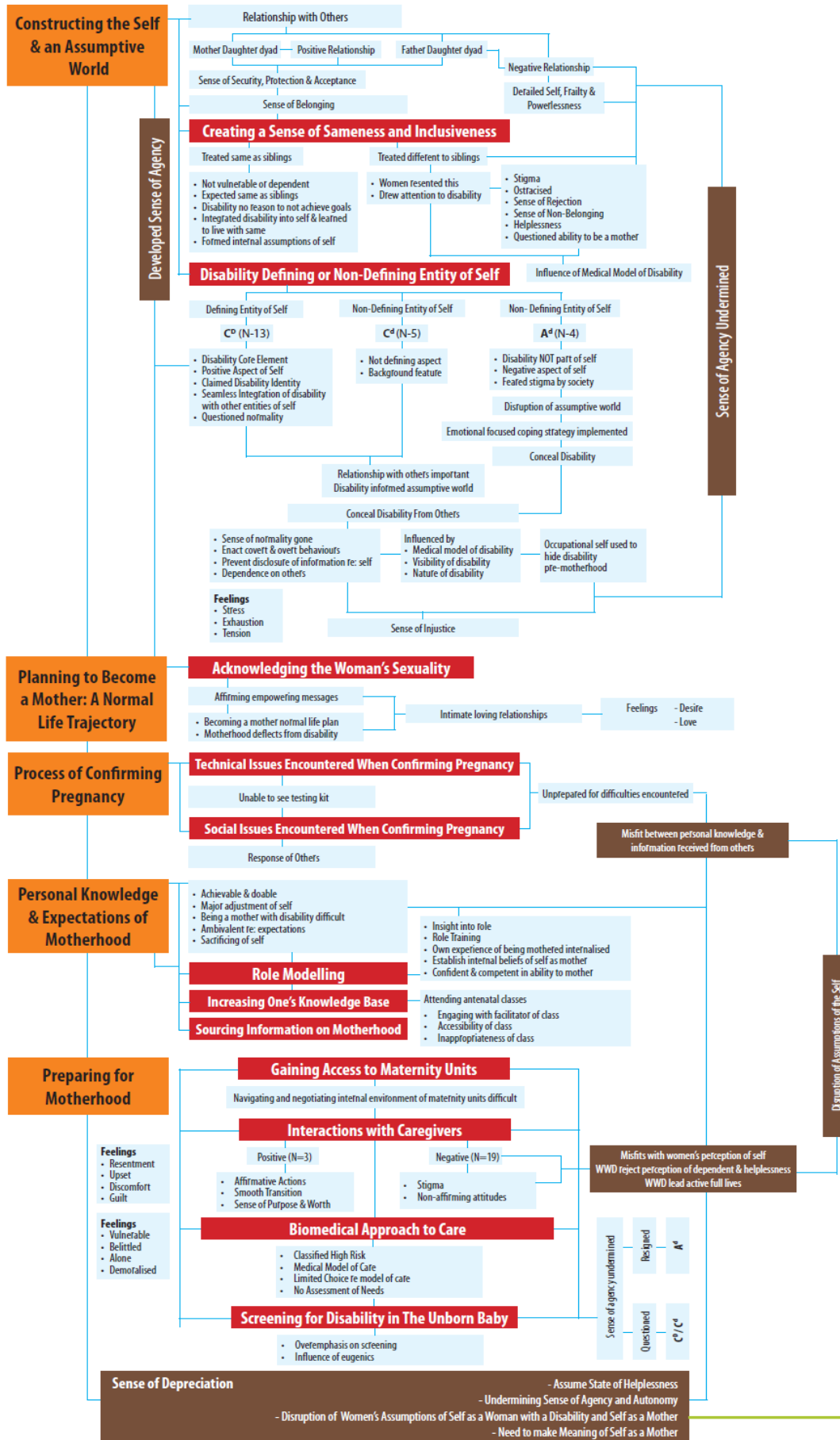
Consequences - outcomes or results of action and interaction

Intervening Conditions - the structural conditions bearing on action/interactions/strategies that pertain to a phenomenon, they facilitate or constrain the strategies taken within a specific context

Content in red colour donates concepts associated with the transition to motherhood specifically relating to women with a disability, remaining content in black colour donates concepts common to women with a disability and non-disabled women

Figure 7.2

Having a Sense of Self



7.4. Constructing the self and an assumptive world

The data revealed how, just as symbolic interactionists suggest (as discussed in section 3.4, chapter 3), the self was fashioned, through interpersonal interactions with and appraisal of others within a familial and extra-familial context (Lawler 2000). From a very early age, the attitudes and behaviours of significant others and others to whom the women felt an attachment were influential in the dynamic process of forming the self and the establishment of abstract, global assumptions that provided meaning to and purpose in the women's life. These assumptions resided at the core of the women's psyche, providing them with the necessary information to navigate their life course autonomously, serving as a guide and filter for their life experiences.¹⁶⁹ Their relationship with significant others instilled a sense of security, protection, and acceptance, and a sense of belonging that manifested in feelings of connectedness and relatedness to others. This sense of belonging provided the women with a sense of place and purpose, and was instrumental in the creation of a positive understanding of the self. It enabled the women to function at a physical, psychological, emotional, cognitive and spiritual level.

'I had a large family, they [parents, siblings] all helped me to become the person I am.' (Christine HCD)

'I've been very fortunate; I've had a beautiful family, I am the person I am because of them.' (Evelyn HCD)

All twenty-two women who contributed to this study grew up in a family where the division of labour was based on the traditional role of parenting.¹⁷⁰ The women internalised aspects of the relationship with their parents, especially their mother. This mother-daughter relationship was significantly meaningful in the creation of an understanding of the self. The women's experiences of being mothered instilled, in them, (i) a desire to become a mother, (ii) an expectation that this goal could be realised and (iii) an assumption that they would be good, competent, responsible mothers¹⁷¹.

'My mother was always there for us, my dad was out working...it was my mother who shaped the person I became and the goals I set in my life, including being a mother.' (Birte VCD)

¹⁶⁹ If these assumptions are ever disrupted it is essential that the woman activates and implements appropriate coping strategies to cope and manage the disruption so as to minimise the effect on the self and her assumptive world.

¹⁷⁰ Whereby their mother remained at home and assumed the prime responsibility of caring for and nurturing the children while their father assumed the role of provider.

¹⁷¹ For the remaining four women (Louise, Helen, Emily and Anne), their relationship with their respective mothers were not considered to have influenced their decision to become a mother.

'I'd a great childhood, I know it defined me, my mother was great, she shaped who I am and encouraged me to achieve everything I wanted including becoming a mother.' (Natasha PCD)

Fathers had a role to play too, albeit a different one. One woman described how it was her relationship with her father that influenced, and still does to the present day, the formation of an independent, autonomous self and a belief that she could and would achieve all her life goals, including being a mother.

'My father is a very important influence in my life...he taught me that no matter what be independent and if you have a problem figure it out. There are other ways of overcoming things that was his attitude and it stuck and still does to this day. I know that I will have to rely on certain people for certain things but he insisted I be independent, to do things the way I want to and don't depend on anyone else.' (Kim PCd)

But when, as evident in Helen's account, the self was derailed by her relationship with significant others, specifically her father, a sense of frailty and powerlessness ensued. This sense of frailty and powerlessness impacted negatively on the self however when she became a mother Helen's self perception changed for the positive.¹⁷²

'I have some negative traits in my personality, I'm quite aware of them but I think they were pointed out by my dad a lot when I was growing up, he found them hard to live with and I thought I must be a horrible person...but being a mother has helped me realise my positive traits.' (Helen PAd)

7.4.1 Creating a sense of sameness and inclusiveness

Parents were also instrumental in the creation of a sense of sameness and inclusiveness and this accentuated or subverted the women's sense of belonging. Seventeen of the eighteen women with a congenital disability¹⁷³ described how their parents accepted their disability¹⁷⁴ and never considered the woman as different, vulnerable or dependent. The women's parents treated them the same as their

¹⁷² It was only after becoming a mother did Helen could correlate the negative sense of self with her relationship with her father.

¹⁷³ Sara, a women with a congenital visual impairment spoke about how her parents, especially her father had difficulty accepting her disability and how they treated her different to her siblings.

¹⁷⁴ I used the word differences instead of limitations to describe the deficits associated with the woman's physical disability or sensory impairment because at no time during the interviews did the majority of women (18 with congenital disability) refer to their physical or sensory deficiencies as limitations or deficits so, to do so in this and the following two chapters would be disingenuous to the women who contributed to this study.

non-disabled siblings, they did not 'wrap them in cotton wool' (Kerri HCd). Allowances were rarely made for the women's physical or sensory differences. Consequently, the women never considered their disability as an impediment rather it was regarded as an entity of the self, albeit a defining or non-defining entity that informed their assumptive world.

'The same things were expected of me really as of the others [siblings].' (Louise PCD)

'My mam always treated me like one of her other children.' (Lorna VCD)

All seventeen women welcomed and appreciated the sense of sameness, inclusiveness and equality promoted and evoked by their parents; it was a means of building character.

'I felt one hundred percent included in my family, equal and involved, it shaped who I am.' (Evelyn HCD)

'I would have grown up in a very mainstream type home, the term disability didn't occur and as a result...I wouldn't have seen myself as disabled.' (Sara VCD)

The women were encouraged to be independent and self-sufficient. Parents had an unrelenting sense of confidence in their daughters' abilities, they never doubted or questioned the women's ability to achieve their anticipated life goals, including becoming a mother. Parents' unrelenting sense of confidence in their daughter's abilities was evident in the high expectations they had regarding social and academic achievements. Three women with a sensory impairment, two with a hearing impairment and one with a visual impairment, were educated in a specific school e.g. school for the deaf or blind while the remaining nineteen women, on the insistence of their parents, went to mainstream schools. The parents who insisted and fought for their daughter's right to receive formal education in a mainstream school were steadfast in their belief that this would, from a young age, help their daughter integrate fully into society and subsequently become resilient to the negative attitudes and associated stigma that they would experience from some members of society. Louise, a woman with a congenital physical disability, described how her parent's active encouragement to pursue a third level education reinforced a sense of independence, self-worth and self-belief. Two other women with a congenital physical disability (Natasha and Olive) described how the self-belief engendered by their parents contributed to their sporting prowess, at both national and international level. The sense of sameness and equality instilled by the women's parents positively contributed to: (i) the formation and

understanding of the self, (ii) the development of a positive belief in the self and (iii) the formation of a sense of independence, determination and resilience.¹⁷⁵

'The attitude from my parents, from an expectation point of view and from a responsibility and independence point of view was well if you don't do it yourself nobody else is going to do it for you.' (Natasha PCD)

Conversely Sara's, Helen's, MSK's, Aine's and Emily's parents had difficulty accepting their daughter's disability; they considered it 'an embarrassment' (Emily PAD). The sense of rejection that ensued eroded the women's sense of belonging. It engendered a sense of vulnerability that dissipated over time, as the women got older and more confident with living with a disability but re-emerged again when the women experienced (i) the patriarchal, negative attitudes of caregivers engaged in the provision of maternity care and (ii) difficulties negotiating the built environment when preparing for motherhood. This sense of vulnerability contributed to a feeling of helplessness (discussed further in chapter 8).

'My father couldn't accept it [disability]...he had difficulty accepting it and if I ever asked him for help, he would say no, do it yourself....I think he was just embarrassed.' (Sara VCD)

'...sickness in our family was always something that you wouldn't do, my father had a saying, if you were sick, you've no moral fibre, so sickness was just something you didn't entertain.' (Emily PAD)

Natasha and Kerrie spoke of how their parents were influenced by caregivers to disregard their own knowledge and expertise regarding their daughter's disability in favour of professional knowledge (Prilleltensky 2003, Prilleltensky 2004a), a knowledge generally underpinned by the medical model of disability. The medical model pathologised the woman's disability, considering it a digression from the normative standard of health, something that interfered with and impeded the woman's ability to function and perform socially constructed roles and responsibilities, like becoming a mother (Myers 1965, Brandt and Pope 1997, Chatterji et al. 1999, Amundson and Tresky 2007, Barnes and Mercer 2007, McMillan Boyles et al. 2008, Barnes and Mercer 2010). Embracing the medical model of disability, the caregivers supported the use of interventions. In a benevolent way, Natasha and Kerrie's parents were

¹⁷⁵ In the one instance, where parents treated their daughter with a congenital visual impairment (Anne) different to her siblings, the woman resented it and attributed such actions as a means of drawing attention to her visual differences consequently, especially while in the public domain, she felt that others, mainly non-disabled people labelled, stigmatised and ostracised her. Moreover, Anne felt these discriminatory practices impeded her sense of agency and autonomy, and affected her ability to participate fully in a society that advocated the inclusion of all (Hahn 1985, Bogdan and Taylor 1987, Hahn 1988, Allen and Allen 1995, NDA 2007a). But these experiences, however negative at the time, equipped Anne with the strategies to cope effectively with and manage the negative attitudes encountered as she prepared for and became a mother.

consumed with the desire to treat, correct and cure their daughter's physical or sensory differences. Consequently in an attempt to ameliorate their disability, the women were exposed to insensitive, invasive treatments, like intensive surgery and physiotherapy. The information inferred by such behaviours and actions affected the women, to what extent, depended on whether or not the women deemed their disability to be a defining or non-defining entity of the self.¹⁷⁶

'It was amazing that I was even able to stand up, should have never been even standing up I was told. My mother invested an awful lot of time and patience with me as regards operations and all that sort of stuff, she was influenced by the professionals to do this and fix it [disability] and to get it right, get that operation done and to do this and get that, physio and whatever and that wasn't her decision necessarily, she was very much influenced by the professionals saying fix this disability, this can be fixed.' (Natasha PCD)

'At my parent's insistence, I went to a lot of speech therapy sessions and learned how to speak. So they [my parents] gave me a voice.' (Kerrie HCD)

7.4.2 Disability as a defining entity of the self

The narratives of the eighteen women with a congenital disability suggest that these women had integrated their disability into the self and assumptive world, albeit to differing degrees. It was either a defining or non-defining entity of the self. Thirteen¹⁷⁷ of the eighteen women described their disability as a defining entity of the self,¹⁷⁸ a 'defining trait' (Natasha PCD). These thirteen women claimed a disability identity (Watson 1998, 2002, Shakespeare 2006) whereby (i) they considered their disability to be a positive element of the self, (ii) they associated with other people with a disability and (iii) they seamlessly integrated their disability with other entities of the self, like gender, race and sexual orientation (Onken and Slaten 2000, Weeber 2004).¹⁷⁹ Disability was part of their biography, they described themselves as a 'disabled person' (Selina PCD), as a 'blind woman' (Anne VCD) or as a 'deaf woman' (Evelyn HCD).

¹⁷⁶ Natasha considered her physical disability to be a defining entity of the self so she deeply resented the notion of trying to fix her disability while Kerrie considered her hearing impairment to be a non-defining entity of the self so she perceived the actions of her parents as being a positive one, as giving her a voice in a predominantly hearing world.

¹⁷⁷ Six of these women had a visual impairment, two a hearing impairment and five a physical disability.

¹⁷⁸ This is represented in the codes assigned to the women who contributed to the study as CD – women with a congenital disability where disability was considered a defining entity of the self.

¹⁷⁹ The thirteen women with a congenital disability, who considered their disability as a defining entity of the self, were more likely to be actively involved in the disability community. Doing so facilitated the development of a disability identity and the dismantling of pervasive negative, stereotypical perceptions encountered in the wider society. It reinforced the affirming behaviours of significant others and instilled a belief that they could live innovative, creative and valued lives, and could, despite having a disability, achieve their projected life plans, including becoming a mother.

'My disability is part of my identity; I took on an identity of someone with a disability and linked more with other people with disabilities.' (Aoife VCD)

'I'm a disabled person, it's who I am, it's [disability] part of me.' (Selina PCD)

The remaining five women with a congenital disability perceived their disability to be an entity of the self but a non-defining entity.¹⁸⁰

'It [hearing impairment] doesn't define me, it's part of me but it's not a major part of me.' (Kerrie HCD)

'I can't get away from the fact that I am disabled, I have a disability but I am an individual and I have feelings and a personality and all that stuff behind this disorder... it's not me it's just one part of who I am.' (Kim PCd)

Regardless of whether one's disability was a defining or non-defining entity of the self, all eighteen women with a congenital disability shared one commonality, disability was part of their biography, part of their everyday experiences, a normal characteristic of the self, an entity that informed their assumptive world and life course.¹⁸¹

7.4.2.1 Questioning the notion of normality

Sixteen of the eighteen women with a congenital disability¹⁸² subscribed to and embodied the doctrine enshrined in the social model of disability. This social model of disability challenges and contrasts significantly with the biomedical perspective by contextualising a person's impairment in terms of the person's experiences of living with a disability (McMillan Boyles et al. 2008) Drawing on a realist philosophy it suggests that there is no casual relationship between impairment and disability rather disability is conceptualised as a construct of society and such a construct is the result of multiple factors within society (Tighe 2001, McClimens 2005). Disability is not related to a variant of the human pathology or psychology but is manifested as an outcome of social barriers that are oppressive and discriminatory. The women identified how the negative attitudes, discriminatory practices, physical and

¹⁸⁰ This is represented in the codes assigned to the women who contributed to the study as Cd – women with a congenital disability where disability was not considered a defining entity of the self.

¹⁸¹ So, any information received from others in their social environment, such as caregivers that disputed this assumption would likely cause a disruption of the woman's assumptive world. Once disrupted the woman needed to activate coping strategies to cope and manage the disruption in order to minimise the effect on the self and one's assumptive world.

¹⁸² The remaining two women with a congenital disability did not express or intimate the model they subscribed to.

institutional impediments experienced in their social world disrupted their assumptions of the self and hindered their ability to function independently (Oliver 1990, Finkelstein 1993, Oliver 1996, Asch 1998, Hull 1998, Tighe 2001, Lollar and Crews 2003, Lutz and Bowers 2003, McClimens 2005, McMillan Boyles et al. 2008).

'It is society that puts the barriers in my way, it's not my impairment, and my impairment is no one's business but my own, if people have a problem with that, well they're the ones with the problem, not me.' (Selina PCD)

'Coming up against blocks and institutional barriers and prejudice...I think coming up against that adversity, realising the barriers are there from just pure lack of perspective or knowledge or experience, it's not psychological, it's a sheer lack of insight and lack of knowledge and experience of it [disability].' (Aoife VCD)

'Naivety, or ignorance, that's the main hurdle in my life, I didn't fall from the planet Zog, I'm not the first person with a disability, I don't mind people being inquisitive but don't treat me like I'm something foreign, I am like any other normal girl; like any other normal person.' (Kim PCd)

Moreover, some of these women questioned the concept of normality and the constituents of a normal body. They perceived themselves to be 'like anyone else' (Kim PCd) and rejected the notion that one's physicality, visual or auditory ability should be a determinant of the individual.

'I was pretty much like anyone else, disability never really got in my way.' (Kim PCd)

'I should be treated the same as everybody else...just because I have a hearing impairment shouldn't mean I'm any different than anyone else.' (Kerrie HCd)

The eighteen women with a congenital disability tended to be more positive, more self-aware and had a greater level of self-belief. Their narratives, unlike the narratives of the four women with an acquired disability, did not reflect a sense of injustice that they and not others had a disability; their disability was an integral entity of the self informing their assumptive world.

'I'm a very positive person, I'm very content...I could beat myself up, I could feel sorry for myself but it's not going to change the fact that I've got this [visual impairment]...you just get on with life and you don't ask 'why me' and you don't say 'what if', it just is you. I think you cope because you accept it, I mean you can kick against it but it's a waste of time, it's a waste of energy.' (Sara VCD)

7.4.3 Disability a non-defining entity of the self

Conversely the four women with an acquired disability did not consider their disability to be a part of the self,¹⁸³ the acquisition of a disability disrupted the woman's biography, their assumptions of the self and their assumptive world.

'I think it's [disability] a crutch, it is a struggle or rather I have a cross to bear. I pretend it's not there I feel vulnerable with it, I think if it became my defining characteristic that would destroy me, it would become a label I wear.' (Emily PAd)

Consistent with Lerner's theory of a belief in a just world (Lerner 1980), post-diagnosis three of the four women, Helen, MSK and Emily, questioned why they had acquired a physical disability. Acquiring a disability violated the women's assumption that they had control over their life. All three were, at the time of first interview, in a state of 'total denial' (Helen PAd), to the extent that one woman (MSK) was hoping the caregivers would make contact to tell her the diagnosis was a mistake. Denial was a defence mechanism, an emotional focused coping strategy (Lazarus and Folkman 1984) that aided in the cognitive avoidance of the reality of having to live with a progressive disabling condition.

'Up until even recently...I was waiting for the call to say they [caregivers] made a mistake...you very much deny it [disability] to yourself...you try carrying on your life as normal but you're very much in denial.' (MSK PAd)

The acquisition of a disability shattered the women's assumptions about their pre-disability self (Janoff-Bulman 1992). Once shattered, the women needed to make meaning of their experiences, once gained, this meaning contributed to the formulation of new assumptions about the self, assumptions that incorporated their experiences of living with a disability. Cognitively, physically and emotionally they needed to adapt to a different way of living in a society that predominantly expects individuals to be functional and independent (Lindgren 2004, Barnes and Mercer 2007, NDA 2007a). However, their newly revised assumptions considered their disability as a 'cross to bear' (Emily PAd), a non-defining¹⁸⁴

¹⁸³ This is represented in the codes assigned to the women who contributed to the study as Ad – women with an acquired disability where disability was not considered a defining entity of the self.

¹⁸⁴ Accordingly the typology that emerged from this study for women with a disability was: for women with a congenital disability where their disability was considered to be a defining entity of the self (CD), for women with a congenital disability where their disability was considered to be a non-defining entity of the self (Cd), for women with an acquired disability where their disability was considered to be a defining entity of the self (AD) and for women with an acquired disability where their disability was considered to be a non-defining entity of the self (Ad).

entity of the self. The four women internalised their own and other's perceptions of people with a disability,¹⁸⁵ they assumed a spoiled identity, an identity that was informed and tainted by the stigmatising reactions of others (Goffman 1963). Assuming such an identity the women experienced a diminution of their self-worth and sense of autonomy.¹⁸⁶ To offset the fear of being stigmatised and labelled the four women intentionally concealed their disability (Malacrida 2009), particularly when in the public domain, but this emotional-focused coping strategy was not always effective.¹⁸⁷

'I was afraid of what others thought, I think the goal that was in my head was to hide my disability for as long as I could.' (Helen PAd)

7.4.3.1 Concealing disability from others

To prevent the disclosure of any intentional or unintentional information regarding their disability, Aine, Helen, MSK and Emily enacted covert or overt behaviours, like overcompensation at work or using a 'handbag to shield a weak arm' (Aine PAd).

'I wanted to push myself, I would put in the longer hours and do the extra work and make sure nobody saw that I was doing that maybe to make up for my limitations.' (Aoife VCD)

The desire to conceal one's disability took precedence over all other things. Concealing their disability helped portray a sense of normality but such actions had far reaching physical and psychological consequences especially for Helen who was willing to live a life full of 'tension and anxiety' (Helen PAd), who 'sacrificed everything' (Helen PAd) to the extent that her pre-motherhood life was a 'hollow vacuous one' (Helen PAd). In an attempt to hide her disability Emily described how, when diagnosed with Multiple Sclerosis, she felt she needed to move away from the area she resided in. She felt that moving away would help her deal with, process and accept the diagnosis. She anticipated that living in an environment where people knew her pre-diagnosis, would result in their post-diagnosis interaction being marred with pity and sympathy. So, she decided to move to another county, where people did not know her pre-disability, where she could start afresh and where, with its picturesque landscape she

¹⁸⁵ These perceptions were informed by the medical model of disability.

¹⁸⁶ Pre-disability the four women categorised people with a disability as dependent and helpless so, predictably post-disability when the women willingly assumed a state of helplessness while interacting with caregivers it did not disrupt the woman's assumptions of the self, helplessness was an assumption populating their assumptive world.

¹⁸⁷ Chapters eight and nine will demonstrate how, when interacting with caregivers during the process of doing mothering the women's fear of being stigmatised became a reality.

could, over time, learn to accept and internalise her diagnosis. The move symbolised a reinvention of a new self. Following the move she established new relationships and decided to discuss her disability openly but when others saw her disability first and failed to acknowledge the existence of a person behind the disability, Emily was devastated and decided to move back to her original county of residence, where she chose to hide her disability from others. The non-affirming attitudes of others and the general tendency to recognise the woman's disability as her defining trait further exemplifies how the medical model of disability remains the pervasive model informing the perceptions and attitudes of others in contemporary society (Myers 1965, Brandt and Pope 1997, Chatterji et al. 1999, Amundson and Tresky 2007, Barnes and Mercer 2007, McMillan Boyles et al. 2008, Barnes and Mercer 2010).

7.4.3.2 Visibility of one's disability

Success in concealing one's disability was determined by the visibility of the woman's disability, all four women who wanted to conceal their disability had an invisible disability, none used assistive aids, essentially what could not be seen by others could be easily hidden.

'...the goal that was in my head was to hide my MS for as long as I could, so nobody saw it.' (Helen PAd)

The remaining eighteen women¹⁸⁸ did use visible, assistive aids such as wheelchairs, walking sticks, hearing aids or guide dogs. The women remarked how the use of such aids acted as a marker for disability and how their differences were always apparent and never inconspicuous to the external world. They never experienced the anonymity the four women who did not use aids¹⁸⁹ were afforded.¹⁹⁰

'I have a very visible physical disability, when people think of disability they think of me, this person in the chair...so people's perceptions of disability is actually hinged on what they can see. The wheelchair or the crutches are a marker of disability because you can't hide it.' (Olivia PCD)

'It's quite obvious I'm a disabled person, I'm sitting in a wheelchair, so I suppose it has to be part of my identity, there's no point in denying reality.' (Selina PCD)

¹⁸⁸ Seven women had a physical disability, six a hearing impairment and five a visual impairment. Sign language, although not an assistive aid, was included in this number because sign language when in use is a very visible display of a person's hearing impairment.

¹⁸⁹ This consists of three women with a physical disability and one with a visual impairment.

¹⁹⁰ Thirteen of the eighteen women considered their disability to be a defining entity of the self so they, unlike the six who considered it to be a non-defining entity, did not seek anonymity rather they assumed a disability identity.

'I find that the dog labels you, and people, they talk down to you as a result. People don't see me, they see a blind person, I'm seen as abnormal because I am blind, it's because my disability is more prominent.' (Lorna VCD)

The use of assistive aids was associated with a greater level of social devaluation.

'I'd be going out with my friends and I'd be all dolled up and I might be the only person there with a physical disability...I'd be all quite confident and I'd be sitting down having a drink and the crutches would be on the ground, others wouldn't see them initially. Others would be chatting me up, talking away and they wouldn't realise I had a disability and then suddenly I have to go to the toilet and then the whole dynamic changes because I've a disability.' (Olivia PCD)

While assistive aids were symbols of disability, they also acted as an 'ice breaker' (Aoife VCD), initiating interactions with others.

'A guide dog, is a very visual symbol of having a disability, I suppose it's a more acceptable face of blindness.' (Anne VCD)

'People are more likely to try and engage with you with a dog than they are with a cane...people who've never come across a person with visual impairment can be a bit nervous about how to approach you and I think the dog does break the ice.' (Aoife VCD)

However the woman's visual impairment was accentuated when the guide dog misbehaved in public.

'If he [guide dog] works well and smoothly then being visually impaired is not an issue, if he is acting the maggot...or is a nuisance it's very much an issue.' (Birte VCD)

Evidently, from their early childhood, all twenty-two women developed a set of 'strongly held set of assumptions about the world and the self which is confidently maintained and used as a means of recognising, planning and acting' (Parkes 1975:p132). These assumptions were based on the understanding that the world was benevolent, meaningful and the self worthy¹⁹¹ (Janoff-Bulman 1992). When these assumptions are challenged, the level of disruption experienced depends on the nature and extent of the event causing the disruption. Minor disruptions may not threaten the woman's

¹⁹¹ In her theory of loss of assumptive world Janoff-Bulman (1992) suggested that there are three value beliefs: the world is benevolent (relates to people and events, to one's world and future events), the world is meaningful (refers to the relationship between the person and what happens to them, this relationship is characterised by justice and control. Justice - good, decent, moral person deserve good things to happen, positive outcome. Control - implies a person can control or influence what happens to them) and a belief in self-worthy (self-worth is centred on the belief that one is essentially good, decent and moral in character and effective in one's actions).

assumptions of the self so when encountered they are managed relatively easily but some psychosocial events, like the acquisition of a disability or the transition to motherhood, can have a profound effect on the woman's deeply held assumptions and can challenge, derange and shatter the woman's assumptive world (Janoff-Bulman 1992). Managing the disruption that may ensue is a complex process, a process that involves the woman making meaning of the disruption whereby this meaning is used to establish new assumptions that rebuild a new, viable assumptive world. Having a sense of self represents how relationships with significant others facilitated the developed of a set of fundamental assumptions about the self as a woman with a disability; these assumptions populated the women's assumptive world pre-motherhood. The relationships enhanced the women's self-esteem and provided all but two women with an acquired disability (Helen and Emily) with a sense of self-worth, inferred a sense of coherence, trust; security and self-confidence. Subsequently, like non-disabled women, the women set life plans, which included becoming a mother, plans they anticipated would be realised.¹⁹² Their sense of unity, security and self-confidence instilled a self-belief that they would be good, confident, competent, responsible mothers.

7.5 Planning to become a mother: a normal life trajectory

Pre-motherhood, seventeen of the women were married and five were single but in long term relationships,¹⁹³ this demographic establishes how the women were capable of, and successful in, forging and developing intimate, loving relationships. The data challenges the prevailing perception that women with a disability are asexual (Prilleltensky 2004b, Begley et al. 2009b, 2010). They, like non-disabled women, experienced feelings of desire and love, sought sexual gratification and planned to become mothers (Anderson and Kitchin 2000, Prilleltensky 2004a, 2004b).

'I was in a long term relationship and still am...we travelled, we've done the whole coming in at three, four, five in the morning, we had our house and started talking about having children.' (Lorna VCD)

¹⁹² Helen and Emily, both with an acquired physical disability, credit their mother as having an influence on the development of their sense of self, but both had a fractured relationship with their father so their sense of self-worth, coherence, trust security and self-confidence developed insidiously, as a result of their life experiences. Pre-disability neither of these women had planned to become mothers but when they received the diagnosis of their disabling condition both re-evaluated their life and subsequently decided becoming a mother was a core priority.

¹⁹³ At the time of first interview all five were cohabiting with their partner but at the time of second interview two had separated and they subsequently described their status as single.

'[Husband's name] and I met about seven years ago and we got married four years ago and there was always going to be kids in the future.' (Maggie HCD)

For the four women with an acquired physical disability becoming a mother became a priority after they were diagnosed. They anticipated that motherhood would reinstate a state of normality and sense of belonging, something that had eluded them since diagnosis.

'...it [disability] signalled a shift from how I thought about life and about myself. I started thinking this isn't the only show in town [work]...but I didn't feel like I had another role that I could legitimately step down to but motherhood helped me do that.' (Helen PAd)

'After being diagnosed [with disability] I wanted a child...obviously because of the disability [husband's name] wasn't too keen on the idea but I got pregnant straight away.' (Aine PAd)

All twenty-two women expected motherhood to be a life changing event, an event that they would successfully adapt to, cope with and manage. Their desire to be a mother was shaped by the attitudes of significant others who either acknowledged or ignored the woman's sexuality.

7.5.1 Acknowledging the woman's sexuality

The majority of women who contributed to this study were exposed to numerous empowering and affirming messages regarding their sexuality, from their parents, mainly their mother. The majority of women discussed how their parents: (i) acknowledged their sexuality, (ii) fostered the notion of a healthy sexual identity and (iii) were aware of the possibility that their daughter would engage in intimate relationships. Consequently, similar to non-disabled women (Oakley 1980, Barclay et al. 1997, Miller 2005, Flakowicz 2007, Darvill et al. 2010), women with a disability envisaged, assumed and expected that some day, they would become mothers, this assumption was part of their normal life trajectory, a 'rite of passage' (van Gennep 1960, Di Matteo et al. 1993, McMahon 1995), a desirable life goal (Glaser and Strauss 2010), a goal they expected to achieve.

'...my parents encouraged me to live and experience life; they encouraged me to want the same as anyone else, including being a mother.' (Kerrie HCD)

7.6 The process of confirming the pregnancy

Once their plan to become a mother was realised, the women embarked on a process of confirming their pregnancy and preparing for motherhood. Therein they encountered difficulties accessing the built environment and caregivers whose attitudes towards people with a disability were informed principally by the medical model of disability. These encounters subverted the women's sense of agency and autonomy and disrupted the woman's assumptions regarding the self as a woman with a disability and the self as a mother. Eight women described feeling unprepared for the difficulties encountered during the process of confirming their pregnancy. None of the women had anticipated the technical¹⁹⁴ and social difficulties¹⁹⁵ encountered. While all twenty-two women experienced probable signs of early pregnancy the first definitive sign was a positive pregnancy test.

7.6.1. Technical issues encountered when confirming pregnancy

Four of the six women with a visual impairment described how the opportunity to confirm their pregnancy within the privacy and protection of their own home was not an option available to them. They could not see the indicator panel on the pregnancy testing kit so they relied on others to convey the result. This sense of dependence on others impacted on the woman's sense of agency, autonomy and control. It caused the women to consider how they would fulfil the responsibilities associated with mothering.

'I got my husband to buy a pregnancy test because it's impossible to do because I'd have to go in to a pharmacy or somewhere and ask somebody would they be able to give me one...I had to ask my husband to read it for me, there's no way as an individual I can do that alone, it's such an invasion of your privacy, so right from the very beginning, I needed somebody to tell me if I was pregnant.' (Betty VCD)

¹⁹⁴ The technical challenges refer to the difficulties encountered with the use of pregnancy testing kits; they apply to women with a visual impairment only.

¹⁹⁵ Social challenges refer to the perceptions and attitudes encountered when disclosing the news of their pregnancy and impending motherhood to others within their social environment. Evidence to support this can be found in section 7.6.2.

The women's dependency on others moved a very personal experience into the public domain, an unexpected shift that imbued a sense of intrusion and invasion of one's privacy.¹⁹⁶

'I had a feeling I was pregnant, I bought a pregnancy test and ideally what I would have liked to do was do the test myself in the privacy of my own home and then maybe take him [partner] out to dinner and tell him that it was positive but I couldn't do that because my sight prohibited me from doing it.' (Lorna VCD)

7.6.2 Social issues encountered when confirming pregnancy

Technical issues were not the only challenges encountered by women when confirming their pregnancy. When women shared the news of their pregnancy with others, the response reciprocated was not always the one anticipated. Similar to the women who participated in Prilleltensky's (2004a, 2004b) study, some were positive while others were unconstructive, unenthusiastic, unhelpful and unsupportive. Significant others and caregivers, who acknowledged the woman's sexuality tended to respond more positively.

'...people reacted very positively when I was pregnant, I thought they were just going to say 'oh my god what have you done?' but everyone was absolutely thrilled.' (Louise PCd)

Less positive responses were demonstrated by those who chose not to acknowledge the woman's sexuality, choosing instead, to view the woman as an asexual being (Prilleltensky 2004b, Begley et al. 2009b, 2010).¹⁹⁷

'I got very sick and my local GP was treating me for gastro-enteritis, he didn't think to ask was I pregnant...I took a pregnancy test and it came out positive.' (Kim PCd)

¹⁹⁶ The degree of the woman's visual impairment and the use, or not, of assistive aids impacted on the level of intrusion and invasion of one's privacy. Using an aid, like a magnifying glass, helped maintain a sense of independence and afforded some women the opportunity to retain control over when and to whom they would disclose the news of their pregnancy.

¹⁹⁷ This perception became a reality for Kim, a woman with a congenital physical disability, who was diagnosed with gastro-enteritis, although she displayed the probable signs of pregnancy including nausea and vomiting, tiredness and fatigue. This pejorative misconception has prevailed for decades so much so that in Ireland the reproductive rights of women with a disability remain excluded from statutory legislative instruments concerning women's health (Shakespeare 1996, Kallianes and Rubinfeld 1997, Tilley 1998, Kaplan 2000, Miller 2000a, Shakespeare 2002, Prilleltensky 2004a, Miller 2005, NWCI 2006, Piotrowski and Snell 2007, NDA 2007a, 2007b, Begley et al. 2009b).

Family, friends and caregivers were concerned about the impact being a mother may have on the woman's physical health.

'...she [obstetrician] said you could never be allowed to have a child, it's too dangerous.' (Selina PCD)

'...funnily enough a lot of people raised their eyebrows when they hear I'm pregnant again, nothing is said but you kind of have that feeling, I'm fairly intuitive, so I think people think we're crazy, that we're going to have a second baby, they're saying 'how are they going to cope, how are they going to manage?' but it's our decision to have a second baby, why should we restrict ourselves to only having one child just because oh we might not be able to do this or won't be able to do that, we've coped with the first baby.' (Louise PCD)

While others, unaware of the woman's abilities and potential, questioned her ability to be a mother.

'There were a lot of questions [from the caregivers] on 'how are you going to look after this baby?' and 'how are you going to do this and that?' (Betty VCD)

Unsurprisingly, the negativity generated by the response of and information imparted by others regarding the woman's pregnancy caused nine of the women to question their own assumptions regarding their ability to be a good, competent, confident and responsible mother.

7.7 Personal knowledge and expectations of motherhood

All twenty-two women had some knowledge of the responsibilities associated with motherhood.¹⁹⁸ This knowledge was created and shaped through the woman's interactions with others, namely female relatives who were mothers, and by sourcing knowledge from and beyond caregivers. All the women anticipated motherhood would be achievable and doable; none anticipated that their pregnancy would be classified as high risk, as was the case when they accessed maternity care. Just like non-disabled women, the majority of women (n=18) described how they felt excited and looked forward to becoming a mother and how this new status was, for them, the beginning of a major adjustment of the self (Oakley 1980, Barclay et al. 1997, Smith 1999, Bailey 1999a, Earle 2000, Yeates 2004, Flakowicz 2007, Urwin 2007, Darvill et al. 2010), a positive life changing event.

¹⁹⁸ The primigravida women (n=3) who contributed to the study did not, unlike the multigravida women (n=19), have the reflexive capacity or resources associated with previous experience so their expectations were based on an idealised, romanticised notion of motherhood (Miller 2005).

'Pregnancy was the beginning of a major adjustment, I started seeing that there was more to life than just my disability and job and that another role was about to happen, I wasn't going to be the same person anymore, it was just the beginning of a huge adjustment in who I felt I was.' (Helen PAd)

Others (n=4) were more pragmatic, they anticipated that being a mother with a disability would be difficult but they were willing to ask for help and would accept any familial or extra-familial support offered. Notwithstanding these anticipated difficulties, the women expected to be treated like any other woman assuming the role of mother; they did not consider their disability would hinder their mothering abilities. So, when their interactions with others cast doubt on this assumption it disrupted the women's assumptions regarding the self as a mother.

'I was under no illusion as to how difficult it [motherhood] was going to be but I had every faith in myself, if I couldn't do it I'd tell people but I should be treated the same as everybody else.' (Kerrie HCd)

A small number of women (n=5) were uncertain about what to expect from motherhood. They had some concerns about how their disability would impact on their mothering abilities.¹⁹⁹

'I'd no real expectations of motherhood, I always said if I have the feeling of love, a fire inside me then I'll do alright. I didn't know what to expect. I knew it was going to be very tiring, I knew it was going to be immensely rewarding, I knew all these things but until you become a mother you know nothing.' (Louise PCD)

'I was looking forward to it [motherhood], I was a bit concerned about the practical things to do with my visual impairment and how was I going to cope with anything from changing nappies to feeding, I was worried about how will I know what baby needs and that I mightn't be able to see the little subtle cues.' (Anne VCD)

7.7.1 Role modelling

Some of the women, while anticipating motherhood, imaginatively engaged in the role of mother and contemplated the self from that standpoint (Rubin 1967a, 1967b, Smith 1999). Imagining the self in this

¹⁹⁹ For Emily, a woman with Multiple Sclerosis, her anxiety about her ability to cope with and manage the physical requirements of mothering manifested in panic attacks. Resonating with the idea that motherhood was associated with a loss of self and self-identity (Oakley 1980, Sethi 1995, Barclay et al. 1997, Nelson 2003, Flakowicz 2007, Urwin 2007, Darvill et al. 2010). Helen, a woman with an acquired physical disability, associated motherhood with a sacrificing of the self whereby sacrificing was considered as the practice of giving up all aspects of the self, for the sake of one's baby but her personal experience of mothering changed this perception.

role enhanced the woman's personal knowledge²⁰⁰ but as Louise's account illustrates, their expectations did not always resonate with their personal experience of being a mother.

'I looked after my younger siblings and that gave me a huge sense of self-esteem growing up because it was something I could do and I could do it really well, I think from very early on, I always wanted to be a mother, that sense of something, I think it's [being a mother] an amazing special thing to do in your life and I feel my life wouldn't have been complete without that.' (Aoife VCD)

'I kind of had an idea of the basics of what needs to be done, because my own sisters and brothers had kids so I knew that baby has to be fed, has to be changed, had to sleep, you've to do this, you've to do that; however, I didn't realise the amount of work that's involved with them [children], because when you're only getting a glimpse into somebody else's life you don't really know how much is actually involved in being a mother.' (Louise PCD)

The women's comments (n=14) affirmed how the desire to become a mother was an outcome of role training (McMahon 1995). From early childhood, these women received signals and symbols that situated them in a nurturing, caring, mothering role. As a child they, like other young girls, were given dolls to play with and were encouraged to role play at being a mother. They were inundated with images and perceptions promoting mothering, notwithstanding from a non-disabled perspective. Moreover, the women described how they considered their mother and other female relatives to be role models.

'...being a mother is more important than any other role in my life, this was something I learned as a child from my mother and other female relatives...my mother, she was always there for us, we [her children] were her priority that is how I perceived motherhood to be.' (Aine PAd)

'My parents were very big role models, especially my mother, as a young girl I knew I wanted to be a mother just like her someday'. (Kerrie HCD)

The women's narratives epitomised how their own experiences of being mothered influenced and informed how they planned to mother their baby (Prilleltensky 2004b). All the women's (n=22) mothers adopted a traditional approach to parenting where they were defined according to their role of mother and wife.²⁰¹ By identifying with their mother, the women developed a sense of what mothering involved

²⁰⁰ Aoife, Louise and Kerrie described how caring for younger siblings or nieces and nephews provided an insight into the role and responsibilities associated with being a mother.

²⁰¹ This practice is representative of the dominant policy in Ireland in 1970s whereby when women married they relinquished their career and occupation in order to remain at home to fulfill the roles of wife and mother. None of the women's mothers worked outside the home, they assumed the primary role of childcare and childrearing while their father assumed the role of provider. This sexual division of labour exemplified the dominant ideology of the time, motherhood was perceived to be biologically determined and created in relation to a patriarchal society, and where it was assumed that the 'good mother' *Footnote continued on next page.*

and the responsibilities associated with that role. They internalised representations of their mother's characteristics and the care provided by her to the extent that pre-motherhood the majority of women (n=16) expected that being a mother would, like their own mother, become their defining characteristic. Two women, Lorna and Helen articulated how their mother motivated and inspired them to achieve and fulfil their life goals even though their goals were different to the ones attained by their mother. These women's experiences of being mothered created, in them, a determination to mother differently. Role modelling and role training shaped the nature of the women's personal experiences regarding motherhood but when a misfit occurred between this knowledge and the knowledge received from others, namely caregivers, the women experienced a disruption to their assumptions about the self as a mother.

'My mother would be the person that holds all our family together, because even though my dad was working, myself and my brothers would always go to my mother because she was always there. To me that's what being a mother is all about, I wanted that for myself.' (Kerrie HCd)

7.7.2 Increasing one's knowledge base

Similar to their non-disabled counterparts, in their quest to understand motherhood and the effect this process may have on one's life, the majority of women (n=18) attended antenatal classes. The remaining four, two with a physical disability and two with a sensory impairment, did not attend classes because they: (i) chose not to, (ii) were unaware of the classes, (iii) the classes were inaccessible or (iv) they gave birth earlier than expected and their antenatal education classes were scheduled to take place later in pregnancy. By attending antenatal classes the women expected that their self-belief regarding their ability to mother would be reinforced. However, this expectation was not always realised because of the difficulties encountered in accessing the classes, the inappropriateness of the information received and the women's desire to hide their disability from the facilitator of and others attending the class.

'I wasn't impressed [with antenatal classes], the content wasn't relevant to me but I wasn't 'going to stand up and say 'hi, I'm really worried about dropping the baby' or I wasn't going to disclose that I had MS.' (Helen PAd)

'They [antenatal classes] were a joke. I went to one; they weren't geared for me at all. They really weren't. First of all they were in a real old part of the building that wasn't accessible...I got nothing out of it I have to say...I wasn't given any information that I thought 'oh yeah that's really helpful'. All I came out with was 'oh my god what am I letting myself in for'.' (Natasha PCD)

would stay at home and devote herself to the role of childrearing and housework (Oakley 1979, 1980).

'I was concerned about the video because there was no sub-titles on them, at the lecture for parents your listening to a couple of the consultants and the midwives giving a lecture on the reproductive bits and how to care for the baby and all that type of stuff and I found that really difficult to follow because obviously I couldn't hear the person talking over the video. I was so far back [in the class]; there was a lot of people up front so I didn't really follow it one hundred percent. I found I had to speak to my mum and friends and family members who had had babies but it shouldn't really have to be that way.' (Kerrie HCd)

7.7.3 Sourcing information on motherhood

The women sourced information beyond caregivers but the information sourced was not always appropriate or evidence-based so the potential to be misinformed was substantial. Some women recognised this and were apprehensive, while others did not.

'I found an Australian website...it was very, very good, I found that really, really helpful because it gave me the information that I wanted and it went through all sorts of things like abnormalities and stuff...it's good to have access to the information...but the site was a bit awkward to access...it wasn't designed particularly well to use with the screen reader [computerised programme to help people with a visual impairment to read]...I also found talking to a few blind parents really helpful...overall the maternity services provided the least helpful information.' (Betty VCD)

'I contacted [name of voluntary agency] and I asked for any books they had...I was quite apprehensive because what if this isn't the same information as what the hospital are providing.' (Lorna VCD)

7.8 Preparing for motherhood

Once their pregnancy was confirmed the women then began to prepare for motherhood whereby they were required to: (i) access maternity services and care and (ii) engage with caregivers involved in the provision of maternity care. It was during their preparation for motherhood that the majority of women (n=19) experienced a discrepancy between their assumptions of the self and the information received from others. This discrepancy disrupted the women's assumptive world, which once disrupted had to be managed.

7.8.1 Gaining access to maternity units

Reiterating the findings of other studies, the women described experiencing great difficulty in gaining access to maternity units, in making and keeping appointments, and in negotiating the internal structures of maternity units (Goodman 1994, Nosek et al. 1995, Campion 1997, Thomas and Curtis 1997, Welner 1997, Grabois et al. 1999, Anderson and Kitchin 2000, Nosek et al. 2001, DeJong et al. 2002, Smeltzer 2007, Begley et al. 2009b, 2010). Many women encountered difficulty in getting to the maternity unit for scheduled and unscheduled appointments.²⁰² In one case, when Kim missed her antenatal appointment, she received a call from the maternity unit questioning her behaviour, the inference being that she was irresponsible. When the women were unable to access accessible public transport, they had no other recourse but to consider alternatives including, taking a taxi or depending on others to transport them to the maternity units. For some, especially for the women in receipt of state benefits, taking a taxi was often an expense they could not afford. For others the sense of dependency on others had an adverse affect on their sense of self. Whilst those who could drive, encountered great difficulties in sourcing appropriate parking close to the main entrance of the maternity unit. All too often, the designated parking area was occupied by other vehicles that did not display a disability sign. Some units were quite old and the main entrance doors were narrow and not automated, some women had to negotiate steps and the uneven topography at the entrance to the units. Newer builds were more accessible for the women because they were compliant with Part M of the building regulations devised by the Department of Environment and Local Government (1997: 2000) that stipulates that all new buildings should be accessible for all.

'Transport was a difficult thing...buses were quite difficult, with schedules and things, I often missed appointments...when I didn't turn up for the appointment, I was kind of confronted with phone calls saying 'well why haven't you turned up and what is going on here and you've missed this appointment again, you know we can't keep re-scheduling'.' (Kim PCd)

The majority of general practitioners and maternity units did not have the facilities to text women with a hearing impairment, so these women relied on hearing relatives to, on their behalf, communicate with

²⁰² Some women with a disability could not drive independently so they were reliant on public transport to get to their appointments. But, despite the Department of Transport's policy that all public transport be universally accessible by 2015, not all public buses or taxis were accessible for women with a disability. The service was often infrequent, unreliable and the women had to wait for long periods before suitable transport arrived. This presented great difficulty for the women when trying to attend for scheduled antenatal appointments. When the women tried to reschedule appointments that were more realistic and achievable for them, some maternity units were unaccommodating.

the maternity units. This encroached on the women's sense of independence and their fundamental right to privacy and confidentiality.

'My husband would ring [the maternity services]; but it would have been nice to have a phone number that you can text.' (Kerrie HCd)

'I got a letter that said you need an appointment for fetal assessment so I got someone to ring for me which means again your privacy is completely compromised.' (Evelyn HCD)

Several women, specifically those with a physical disability encountered great difficulty in navigating the internal environment. Their difficulty was exacerbated when they were unaccompanied; the women relied on the goodwill of people working in the unit, other women and/or the relatives of other women accessing maternity care.

'I'm not dependent by nature but because the maternity unit is unfamiliar territory I have to be dependent on someone.' (Anne VCD)

'...it was very degrading asking for help, that was quite upsetting for me, because I don't like having to depend on people, I never did depend on people, so it was kind of a new thing for me and I didn't like it to be honest, even though I knew it had to be done, it often upset me.' (Kim PCd)

The inaccessible, obstructive reception areas, ineffective use of appropriate signage, insufficient lighting, use of fixed, non-adjustable equipment and lack of wheelchair accessible bathrooms compounded the women's difficulties, increased their sense of dependence on others²⁰³ and impacted on the woman's sense of independence, dignity, privacy and self-worth.

'Early in my pregnancy I had a number of appointments for early scans in the EPAU [early pregnancy assessment unit] and that had a couple of steps down to it, that was a bit of a struggle, my husband got me up and down in the wheelchair, he pulled me and the chair up and down the steps...I was annoyed, I thought in this day and age there's no need for that.' (Selina PCd)

'I'd go to the security guard at the desk and ask that person and sometimes they would point to signs and I kind of go 'well could you just tell me, I can't see the sign'.' (Aoife VCD)

²⁰³ High reception desks and the use of Perspex screens created great difficulty for the women who used wheelchairs and those with a sensory impairment, when interacting with administrative staff and caregivers. Women with a sensory impairment also experienced great difficulty when attending for scheduled appointments. When attending for appointments, the maternity units used two different systems to call women for their consultations, one was a number based system and the other, a name calling system. Women with a visual impairment felt excluded when a number based system was used; they could not see their number while a name calling system excluded women with a hearing impairment, as they could not hear their named being called. The use of these systems resulted in the women having to depend on others to signal when it was their turn and often, they ended up waiting for very long periods to be assessed.

None of the women had an assessment of need conducted so care was not based on the woman's specific needs. This accentuated the woman's differences, and heightened her sense of dependence on others.

'There was no assessment done...you can't make an assumption about anybody and you certainly can't when it comes to a disabled person because their bodies have particular things that relate to the physicality of having the disability and are not the same as another woman.' (Olivia PCD)

7.8.2 Interactions with caregivers

Despite evidence suggesting that attitudes towards people with a disability in Ireland are changing (NDA 2002, 2007a, 2007b, 2011) and the introduction of legislation and policies²⁰⁴ advancing the rights of people with a disability residing in Ireland, the women's accounts revealed how, similar to international experiences, when interacting with caregivers, they were exposed to a myriad of negative, stereotypical, prejudicial, 'patronising' (Christine HCD), 'arrogant' (Louise PCD) attitudes and derogatory, and discriminating practices (Nosek et al. 1995, Shakespeare 1996, Kallianes and Rubinfeld 1997, Tilley 1998, Nosek et al. 2001, RCN 2007). These negative, patriarchal attitudes heightened the woman's sense of vulnerability, sense of insecurity, isolation and marginalisation (Welner 1997, Schopp et al. 2002, McGuinness 2006, Begley et al. 2009b, 2010). The reconstructions also revealed how these women continue to be labelled, stereotyped, stigmatised and perceived as being dependent, in need of sympathy and pity (Lipson and Rogers 2000, Clark 2002, Prilleltensky 2003, RCN 2007), a perception that was incongruent with the women's perceptions of the self.

'I felt really belittled, I felt labelled, pathologised, criticised, they [caregivers] insisted on sticking labels on us, just because I am deaf...my self esteem decreased, sometimes you kind of feel like just giving up and just surrendering, but I'm very determined not to do that and I have a strong sense of self-worth and determination about not letting them [caregivers] win and not submitting to that kind of dynamic.' (Evelyn HCD)

'They [caregivers] were complimenting me and saying how marvellous I was, how brilliant I was because I was blind...quite patronising.' (Lorna VCD)

The women used adjectives such as sociable, independent, resilient, positive and assertive to describe their perceptions of the pre-motherhood self. Their narratives illustrate how, just like non-disabled women, the women lead very full and active lives.

²⁰⁴ Such as the National Disability Strategy (2004), Disability Act (2005), Equality Act 2000; 2004 (see chapter two).

'Before motherhood, I was a reckless party animal...I used to party a lot and go out and drink and have a great time...I wanted to be involved in everything; I didn't want to miss anything. I was a very socially active person.' (Kerrie HCD)

'I've always been a very independent person...a planner, an organiser...I can be stubborn, I'm very strong willed, always have been, like my mum, a very strong willed woman, and she raised me to be very strong willed and independent .' (Selina PCD)

Selena, Sinead, Lorna and Olive's resilience, self-belief, self-confidence and sense of worth insulated them from the negative attitudes exhibited by others.

'I wouldn't have given them [others] that much credit of having an influence on my life, they're not as important as all that.' (Selina PCD)

'They [caregivers] were complimenting me and saying how marvellous I was...quite patronising, how brilliant I was because I was blind...I was lapping it up and in the back of my mind I was like 'eejits'.' (Lorna VCD)

But, the remaining eighteen women were less resilient; they internalised the negative attitudes exhibited by others. Consequently, they felt vulnerable in a society that classified and labelled them as different and deviant.

'I was vulnerable, I was trying to please society, trying to fit in.' (Evelyn HCD)

'I felt very vulnerable, having it [hearing impairment] made me different so people treated me different, they assumed I could do nothing.' (Christine HCD)

They felt different, 'grotesque and unhuman' (Betty VCD), 'degraded, demeaned' (Evelyn HCD) and 'belittled' (Natasha PCD). Consequently the women exhibited a range of emotional reactions including; (i) a diminution of their self-worth, self-esteem, agency and autonomy, (ii) self-doubt about her ability to mother, (iii) anger and (iv) frustration.

'I had difficulty with patronising attitudes...it's just subtle attitudes from people, you hear people saying this pregnant woman with a guide dog, there's almost a kind of horror and it kind of makes you feel kind of grotesque and unhuman.' (Betty VCD)

'I felt that they [caregivers] looked at me like as if I was incapable of making decisions...the attitude of we're going to talk about you in front of you, not with you.' (Kerrie HCD)

Caregivers pathologised the woman's disability; it took precedence over and overshadowed her imminent role as mother.

'...they [midwives] never saw or didn't want to know the woman behind the disability, the disability was more important.' (Jackie HCd)

Three women, Maggie, Sara and Sharon, did not encounter negative attitudes or derogatory behaviours. They encountered warm, caring and compassionate caregivers who acknowledged the woman's individuality and ability to mother, who looked beyond the disability and treated the woman exactly the same as any other woman, disabled or non-disabled, accessing maternity care. The women appreciated the sense of inclusion, equity and individualism afforded by such kind and understanding caregivers.²⁰⁵

'The attitudes were all very positive; the GP doesn't make any issue of me being blind.' (Birte VCD)

When as evident in Helen's account, the caregivers acknowledged the woman's disability and recognised her role as expectant mother, and provided practical advice in an empathetic, non-judgmental manner this instilled, a sense of purpose self-worth and positivity.

'I found her [midwife] very kind and very unfazed by my medical history, I thought she was going to start, 'oh, goodness me', but she was really unfazed, I came out feeling not so bad and she was very kind to me, like she said 'women are very hard on themselves, especially mothers, if you can't manage breast feeding because of tiredness because of your MS, don't be beating yourself up about it, you do whatever it takes to get you through', and I thought that was very nice of her, it wasn't done in a condescending way, she was supportive and kind and I suppose there would have been the potential there for me to think 'oh no, I'm failing him [baby]' but I think she helped me feel that doing my best by him was important but me being in good physical shape for him was good as well.' (Helen PAd)

Clearly, the initial reactions of caregivers shaped the subsequent nature of the relationship between the women and caregivers. Empathy, sensitivity, understanding, support and belief in the woman's ability to mother were key attributes that rendered the interactions positive conversely when such attributes were absent the experiences were more negative. Positive interactions reinforced the women's sense of confidence that they would be good, competent, responsible mothers and assisted in the smooth transition to motherhood. While negative interactions had an adverse affect.

²⁰⁵ The positivity engendered by these interactions were, in part, facilitated by the continuity of carer policy in place in some units, this contributed to the development of a trusting and unprejudiced relationship between the woman and the caregivers.

7.8.2.1 Communicating with caregivers

In addition to experiencing dispiriting, non-affirming attitudes, the majority of women with a sensory impairment encountered immense difficulty when communicating with caregivers, this supports the finding that 47% of people with a hearing impairment experience moderate to severe difficulty when communicating with caregivers (CSO 2008). Verbal and written communication was the primary mode of communication employed by caregivers but these modes of communication was totally unsuitable and ineffective for women who could not hear the spoken word, or for women who could not see the written word, they rendered the women voiceless. Some caregivers were skilled in the use of non-verbal gestures and were aware of the need to position the self appropriately in order that the women who lip read could do so without impediments. However, others were unaware of the need to face the woman with a hearing impairment or if in use, to remove surgical masks when communicating with women.

'The doctor was dismissive and rude, he didn't want to speak to us he was too nervous. They [caregivers] were reluctant to talk to you and give you information, he'd come over and I'd say what's happening, what's going on, and I'd try and get it out of him...[but] there were parents on the other side of the ward and he made the effort to speak to them.' (Christine HCD)

Evelyn, a deaf woman who uses sign language as her primary mode of communication, encountered resistance when she tried to get the maternity service providers to arrange a sign language interpreter.²⁰⁶ Family and friends were asked to interpret and this had a profound effect on Evelyn's right to privacy and confidentiality. Moreover, when a third person was involved in the interaction, the caregivers tended to communicate with that person, which excluded Evelyn from the process. This significantly impacted on the woman's, (i) sense of independence and agency, (ii) ability to obtain information, (iii) ability to make informed decisions and (iv) provide informed consent. The resulting sense of disempowerment was incongruent with the sense of empowerment Evelyn felt before interacting with caregivers.

'I would go to the [maternity unit] with my mam or husband; I always had somebody with me but they [midwives] talked to them but they weren't the pregnant one I was.' (Evelyn HCD)

²⁰⁶ One woman was advised that if a sign language interpreter was employed she would have to incur the cost.

Kerrie's sense of empowerment, self-esteem and self-value were replenished when her father (a hearing person) intervened and effectively gave her a voice but this action accentuated her vulnerability and impressionability.

'...my dad had enough, he asked me 'would it be ok if I had a chat with the consultant' and I said 'by all means if you want to have a chat with the doctor go ahead.' So my dad said to him [doctor] 'can I speak with you outside' and the doctor said 'well I'm not going to break any confidentiality', my dad said 'it's nothing to do with confidentiality, I just want to explain about her deafness, how she expects to be treated' because he said 'I'm listening to her getting upset and she's stressed about everything', so he said 'ok.' So they stepped outside and came back in and he [doctor] was like a different person, he came in with a smile on his face and made sure he was looking at me and he instructed his team that I had particular needs.' (Kerrie HCd)

Similarly, for six women with a visual impairment the lack of information in appropriate formats, for example, Braille, audio or pictorial, rendered them powerless and impacted on their ability to make informed choices or provide informed consent. It also increased their dependence on others and impacted upon their right to privacy and confidentiality, they relied on others to read and convey the content of any written information received. Laura's powerful narrative captures her sense of dependence on her partner and illustrates how her reliance on him deprived her of her right to have ownership over her personal experience of becoming a mother.

'There was a whole load of information, booklets, leaflets, pamphlets, the whole lot, all in print and I nearly cried, I did, there was tears coming into my eyes, there was a lump in my throat. My partner said 'look I'll read it to you' but I mean who wants to be sitting there with their partner going on about breast feeding and different types of labour and everything, it was something I wanted to read for myself as a woman, it wasn't going to happen to him, none of these changes were happening to him, the only changes that were happening to him were emotional and psychological changes but physically they were all going to happen to me and he was 'ah you'll be grand', he read bits of it and I got bored with him reading, although he was the best in the world, he'd no problem reading it, he was like 'ah do you really want to know about all this' and I was 'yeah I do, it's my first pregnancy, I want to know what's going to happen to me'.' (Lorna VCD)

7.8.3 Biomedical approach to care

Caregivers pathologised and contextualised the woman's disability within a biomedical functionalist framework,²⁰⁷ which resulted in the categorisation of women as high risk. The concept of risk is

²⁰⁷ Situated in this framework disability is perceived as a functional limitation of the individual, a limitation in occupational and social functioning resulting from a chronic illness or disease (Lutz and Bowers 2003, Barnes and Mercer 2007, McMillan Boyles
Footnote continued on next page.

juxtaposed with the biomedical approach to care, an approach that has become dominant in Ireland over the last half a century (Miller 2000a, Kennedy 2002, Miller 2003, O'Connor 2006, Devane et al. 2007) but as Aine's accounts demonstrates this classification did not resonate with the women's assumptions of the self.

'I went for my first meeting and here's me thinking oh I'm getting the scan done and the minute I walked in it was like how long have you had this [disability] and it was just this man [obstetrician], he did not understand why I was pregnant, I just came out and I was like what have I done...I came out crying...I was taken aback, I was thinking 'oh no what have I done, am I going to die?' (Aine PAD)

Exercising and asserting her sense of agency and autonomy, Betty, a woman with a visual impairment, planned to have a home birth. She felt that this environment would be the most suitable for her, one she was familiar with, felt in control of, comfortable and secure in. She feared that in a hospital setting she would be disorientated and this engendered a sense of vulnerability, anxiety and stress. As her pregnancy was uneventful, Betty assumed that her plan to have a home birth would be supported by the caregivers involved in the provision of care; however, when she discussed her plans with her general practitioner, the response received was unexpected. Her general practitioner was unreceptive to the idea of a home birth and threatened to withdraw care if the woman proceeded with this plan. The women felt forced and 'shoehorned' (Betty VCD) into using hospital based services. Exerting her sense of agency and autonomy even more, Betty tried to access midwifery managed services to offset the medicalised approach to care so dominant in a hospital environment but unfortunately the midwifery managed services did not extend to her geographic area. This lack of choice around the model of care impacted negatively on the self, it eroded Betty's sense of agency and autonomy and generated a sense of disempowerment.

A high risk classification exposed the women to regular monitoring and prenatal screening for anomalies but these normative practices undermined the women's sense of agency as they; (i) became dependent on caregivers and valorised the knowledge they espoused, (ii) were receptive and accepting of the knowledge advocated by caregivers, (iii) were willing to accept their risk classification and accompanying medicalisation of care, and how through such practices their sense of control, autonomy and power were undermined and a sense of helplessness ensued. The extent to which the women's sense of agency, autonomy and control were subverted depended on the woman's resilience. Women with a

et al. 2008, Barnes and Mercer 2010).

congenital disability, especially those who considered their disability to be a defining entity of the self (n=13), experienced a greater erosion of these attributes. They resented being classified within a risk framework because it contravened their fundamental assumption that the basis of their disability was socially constructed. So, there was a discrepancy between the women's assumptions of the self and the public narrative of women with a disability (Miller 2005). Conversely, women with an acquired disability were more accepting of and conforming to the biomedical approach to care. This is perhaps partly due to the fact that their disability was diagnosed within a similar medical framework and that pre-disability, their philosophy regarding people with a disability resonated with the medical model's conceptualisation that such individuals were dysfunctional, different, dependent and helpless.²⁰⁸

7.8.4 Screening for disability in the unborn baby

Routine ultrasound is a normal and integral part of hospital based antenatal care, a prenatal screening and diagnostic tool used to confirm pregnancy and to screen for abnormality in the unborn baby. Like other pregnant women, all twenty-two women with a disability had this procedure and most of them willingly accepted the practice. Maggie and Birte derived 'great reassurance and comfort' (Maggie HCD) when the ultrasound revealed that their baby did not have a disability.

'They [sonographer] just described what they were seeing...that description was quite enlightening...so I actually, never thought I was missing anything; because, when we had the detailed scan she said...it all looks fine, when I heard that I was relieved.' (Birte VCD)

However, Betty and Evelyn did not welcome the emphasis on screening²⁰⁹ or the difficulties encountered when having the procedure.²¹⁰ These difficulties were compounded when (i) the 'ultrasound equipment was too small and the images generated were inaccessible' (Anne VCD), (ii) by an

²⁰⁸ This high risk classification effectively excluded women with a disability from availing of different models of care, such as community based models that offered an alternative to the medical model. A community based model of care refers to the midwifery managed or midwifery led care that is administered in the woman's home or locality.

²⁰⁹ Women with a congenital disability because of the nature of their disability were unlike those with an acquired disability exposed to frequent requests from the caregivers to have an ultrasound scan(s) to confirm or out-rule the presence of a disability in their unborn baby.

²¹⁰ Some with a physical disability were unable to negotiate 'fixed, unadjustable scanning beds' (Kim PCd), those with a sensory impairment experienced difficulty in seeing the images on the screen or hearing the results being conveyed by the sonographer.

unsuitably lit environment,²¹¹ or (iii) by the tendency of sonographers to discuss the results amongst themselves, effectively excluding the woman.

'I didn't like the woman doing the scan, I did tell her I was hard of hearing and I said to her would you please explain things in detail and she wasn't a bit helpful...I thought she was a snotty yoke, she was just there and I said 'sorry can you repeat that' and my husband kept saying 'sorry my wife didn't hear you', ok she goes, 'right then I'll explain again', it was a big deal that she had to explain it to me, I wasn't happy with that. She turned around the machine alright, eventually, and showed me the pictures but I could hear her sighing and huffing and puffing and I could see the expression on her face, it's like oh your bothering me like and I was very upset over that and I was so annoyed too but I never complained, I should have complained.' (Jackie HCD)

For some (n=5), the over-emphasis on prenatal screening generated a great deal of resentment, upset and discomfort and instilled a sense of guilt that they could possibly be responsible for bestowing a disability on their unborn baby.

'Practically all of them [caregivers] asked me about my sight...how much can you see and all that kind of stuff...they asked me about the condition being in the family...we said it's a 50/50 chance [of baby developing the condition] and one person asked me would I consider pre implantation screening. Pre-implantation screening, warning bells were going off in my head, is that legal...and I got really, really upset and really insulted by that, it suggests that being blind is something so horrific and so horrible that you'd be willing to abort a child...to me being blind is like having red hair and being tall...to suggest that you wouldn't want to have anything to do with it [baby], I felt really, really upset...its abnormal in my family to be able to see, only my mum and my sister can see, my dad and my brothers can't...and they've all got on with their lives, especially now there's so much available for blind people, there's no reason why blind people can't have a normal, very fulfilled life.' (Betty VCD)

The emphasis on prenatal screening represents how the eugenic philosophy²¹² and the medical model of disability continue to dominate and influence the attitudes and practices of caregivers engaged in the provision of contemporary maternity care. It also affirms how some caregivers equate having a disability with a tragedy, an assumption that has long been decried by people with a disability who live full, active, meaningful, fulfilling and enjoyable lives (Prilleltensky 2004a, 2004b).²¹³

²¹¹ 2d ultrasound has to be conducted in a darkened room in order to see the images but this fact was never explained to any of the women with a visual impairment (n=6) who contributed to this study.

²¹² The core premise of this ideology, advanced by Francis Galton in the 1920s, is that no life is perceived to be better than a life with a disability.

²¹³ Although termination of pregnancy was not explicitly discussed, two women with a congenital disability, Kim with a physical disability and Betty with a visual impairment, recalled how they were asked about their intentions if their unborn baby had a disability.

'The first question he [general practitioner] asked me did I want to keep it [baby].' (Kim PCd)

The combination of patriarchal attitudes, the influence of the biomedical model of care and the medical model of disability, and the use of technology all undermined the women's sense of agency and autonomy, and confidence in their abilities to mother, they engendered a sense of depreciation, none of which corresponded with the women's assumptions of the self. The sense of depreciation did not, as Urwin (2007) conceptualises, engender a sense of loss that intensified and manifested as depression rather it caused many of the women to enact a cognitive coping strategy that saw them relinquish control and power to caregivers and assume a state of helplessness whereby they became compliant, passive recipients of care. The theory of learned helplessness (Seligman 1975, Peterson et al. 1995:p300) provided the theoretical underpinnings that explained why, when engaging with caregivers, women with a disability willingly assumed a state of helplessness. When invoked, this emotional focused coping strategy helped the women maintain a sense of control over their experiences.

7.9 Summary of 'Having a Sense of Self'

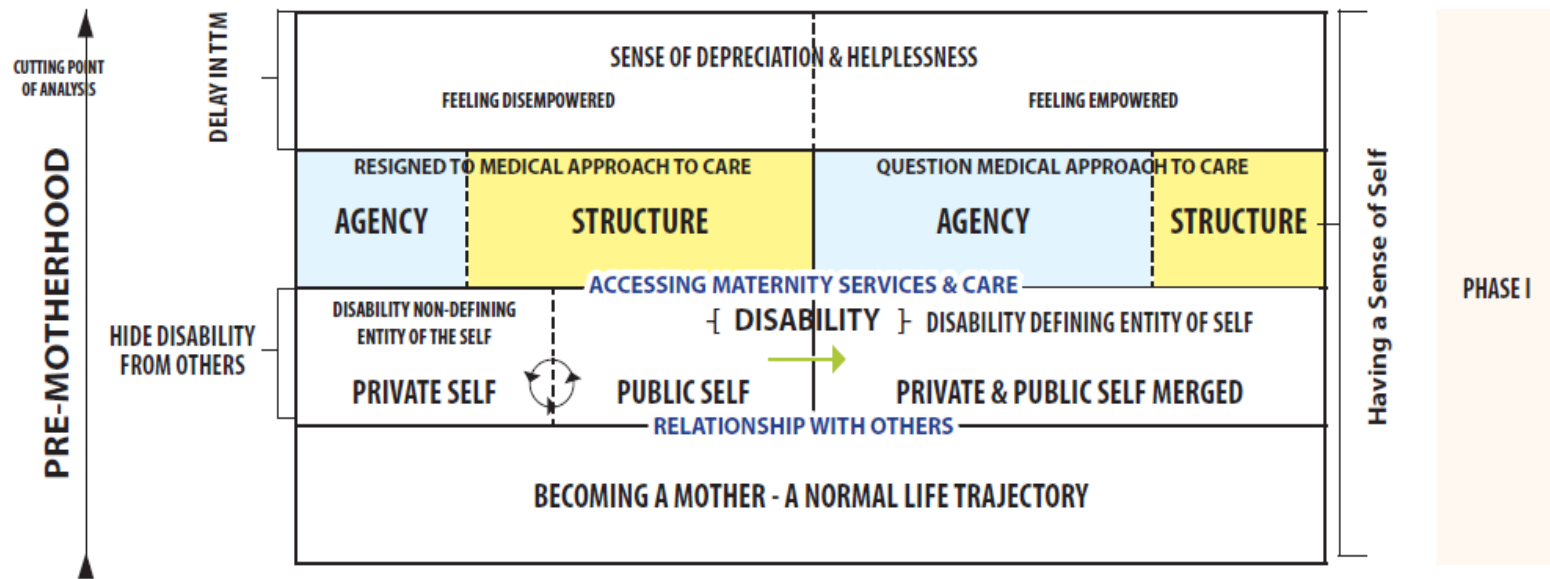
Having a sense of self exemplified how the relationship with significant others, and the social setting that women with a disability were located in, were instrumental in the construction of the pre-motherhood self, and the establishment of a set of assumptions that created an assumption that the women would be good, competent, responsible, confident mothers. These relationships meaningfully contributed to the women's sense of belonging and influenced how the women incorporated disability into the self. The eighteen women with a congenital disability positively amalgamated their disability and the self. They considered their disability to be an entity of the self, one that informed and shaped their assumptions about the self and their assumptive world. Moreover, the affirming actions and behaviours of significant others helped to instil a sense of agency, self-worth and self-determination. There was no differentiation between self in the public or private domains. Furthermore, becoming a mother was a normal life plan, something the eighteen women had planned for and expected to achieve.

Conversely, the four women with an acquired physical disability experienced difficulty in assimilating their disability into the pre-motherhood self. This difficulty manifested in the women's

intentional attempt to conceal their disability from others, a fate easily achieved as they did not use assistive aids to ameliorate their physical difficulties. Consequently the self portrayed in the public domain was different to the self portrayed in the private domain. The acquisition of a disability was inconsistent with the women's assumptions and worldview. The women had to resolve this inconsistency; they had to revise their assumptions of the self and their assumptive world so as to create new assumptions that integrated disability. This involved a process of rationalising and reorganising their life plans and life goals. Consequently the plan to become a mother became a priority. The women imagined that being a mother would afford them the opportunity to portray an alternative self to others, a self where their disability did not take precedence.

All twenty-two women expected the act of becoming a mother to be a turning point in their life; they believed that they, despite their disability, would be good, competent, confident, responsible mothers however, the women's interactions with caregivers engaged in the provision of maternity care and the environmental challenges encountered when availing of maternity services significantly unhinged this and other assumptions of the self. For the majority of women (n=19) the misfit between their assumptions of the self and others assumption of them significantly impacted on the women's sense of agency. The women felt disempowered and a sense of depreciation and helplessness prevailed. Once their assumptions were disrupted the women had to enact a variety of coping strategies to make meaning of the self as a mother, a mother with a disability so that they could eventually reform the self and their assumptive world in order to incorporate motherhood. The actions they took to create this meaning are discussed in greater detail in the following chapter 'Making meaning of the self as a mother'. For the remaining three women, their encounters with caregivers were more positive, the information received correlated with their assumptions of the self, they experienced minimal disruption to their assumptive world and their sense of empowerment remained intact. Nevertheless they did experience a degree of helplessness, albeit to a lesser extent than the other nineteen women, that required them to make meaning of their experiences so as to reform the self and assumptive world to incorporate motherhood (see Figure 7.3 diagrammatic representation of this phase, phase I Having a Sense of Self). Transition to the next phase of the model, the making meaning phase is represented by the birth of the baby and the willingness of the women to engage with motherhood and take responsibility for mothering. While for some this process was delayed, principally due to the interactions with caregivers and the subversion of their sense of agency, all twenty-two women willingly assumed responsibility and enacted strategies that facilitated the doing of mothering.

Figure 7.3
Diagrammatic Representation of Phase I - Having a Sense of Self



Chapter 8 Making Meaning of the Self as a Mother

8.1 Introduction

The following two chapters are different in format to the last chapter as the cutting point of analysis commences with the birth of the baby and the woman's discharge from hospital. This study and the constructionist approach used therein facilitated the development of an understanding of the process involved in the transition to motherhood and the relationship of this process to the self from the perspective and experiences of women with a disability. This phase represents the women's accounts of trying to make meaning of the self as a mother when their views of the self in this role were corroborated (n=3) or disrupted (n=19) by information received from others, particularly caregivers engaged in the provision of maternity care. Progression from phase one to phase two is represented temporally as being associated with the birth of the baby.

The first phase illustrated how during the process of transition to motherhood nineteen women experienced a disruption in their assumptions regarding the self as a woman with a disability and the self as a mother whereby medical knowledge was valorised over all other forms of knowledge including personal knowledge. Once disrupted a crisis of meaning was induced at a deep cognitive and emotional level and existing meaning and understanding of the self disintegrated. To manage the disruption the women needed to implement a variety of coping²¹⁴ strategies so that they could make meaning and gain an understanding of the self as a mother, once gained they (re)constructed the self and their assumptive world. Making meaning represents the problem and focused coping strategies (Landman 2002) invoked by the women that caused them to: (i) review their assumptions of the self, (ii) reorient the self, (iii) recognise what was happening to the self, (iv) restructure their way of viewing the self and their assumptive world, (v) establish new assumptions of the self as a mother with a disability and (vi) develop a plan of action that provides for the integration of motherhood and self, as a woman with a disability.

²¹⁴ Coping refers to the women's 'constantly changing cognitive and behavioural efforts [enacted by women] to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman 1984:p141).

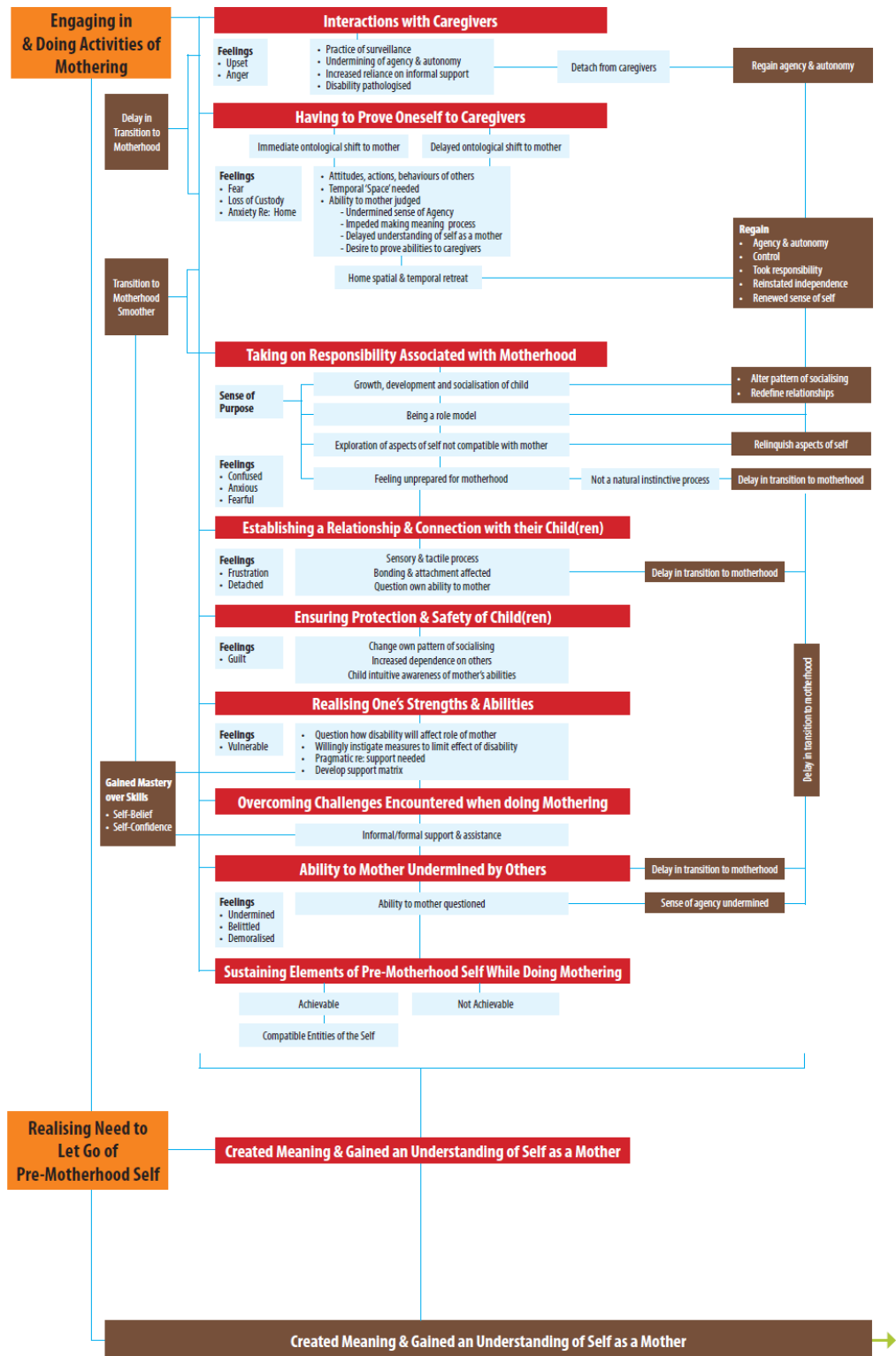
Psychologically, the birth of the baby is a marker for this phase. Maggie, Sara and Sharon's transition through this phase was seamless, the information gained during their preparation for motherhood correlated with their assumptions of the self and this together with their immediate ontological shift to motherhood facilitated smooth progress to the next phase. So, this phase was, for these three women, relatively short-lived. Immediately after the birth of their baby their focus moved to gaining control over their experiences and to reforming the self and their assumptive world so as to include motherhood. While for the remaining nineteen, it was more complex, the discrepancy they experienced between their assumptions of the self and the information received from others, mainly caregivers, caused a delay in their ontological shift to motherhood. While the ontological shift to motherhood can and does vary, regardless of the delay, if adaptation to motherhood is to occur for women with a disability, this shift is vital.

The pace at which the women progressed through this phase of the model varied; it was influenced by the challenges women encountered when doing mothering.²¹⁵ For some like Maggie, Sara and Sharon, the challenges were minor and easily overcome. So, their progression through the phase was relatively easy and prompt while others (n=19) encountered significant challenges that affected the making meaning process, consequently their understanding of the self as a mother with a disability was delayed and progression through the phase was much slower, more convoluted. A specific timeframe for this phase cannot be determined because the length of time it took for women to progress through the phase was not quantified but progression to the next phase was recognised when women spoke about the need to: (i) let go of some or all aspects of the pre-motherhood self and (ii) to reform the self and assumptive world so as to facilitate the integration of motherhood. Although the pace of progression varied from woman to woman, all twenty-two women did create meaning regarding the self as a mother with a disability, which once attained facilitated progression to the next phase (see Figure 8.1 diagrammatic representation of this phase, phase II Making Meaning of the Self as a Mother).

²¹⁵ Doing mothering refers to the physical, physiological, cognitive, emotional and social activities associated with mothering.

Figure 8.1

Making Meaning of Self as a Mother



8.2 Engaging in and doing the activities of mothering

All twenty-two women who contributed to this study gave birth in a publicly-funded maternity unit. The length of time women spent in hospital after the birth varied from a couple of days to a week.²¹⁶ During this period, the women's reliance on expert knowledge continued but in comparison to the pre-motherhood phase, the women perceived the caregivers to be less engaging in the early motherhood period.

8.2.1 Interactions with caregivers

Postnatally, caregivers were more inclined to engage in the practice of surveillance; a practice, no doubt, informed by the requirement to adhere to legislation regarding the safety and protection of the baby²¹⁷ but one that nevertheless (i) influenced the nature of the relationship between them and the women, (ii) undermined the women's sense of agency and autonomy, and (iii) caused some women to question their ability to be a good, competent, responsible mother. With minimal assistance and support from caregivers the women relied on their informal support network²¹⁸ to provide the much needed physical, psychological, emotional and social assistance and support. Their reliance on informal support caused the women to contemplate and rethink their relationships with others in their social world.

'There was a bit of 'oh now she's disabled, let's see if she can do this'...the nurses were going around showing the others [mothers] how to bath their babies but because [partner's name] was there with me pretty much all the time, it was more 'ah well she's all right, she's looked after, she doesn't need us, we don't have to worry about her, we'll throw an eye over to her now and again that's all we have to do'.' (Natasha PCD)

Similar to their pre-motherhood experiences, the women's disability took precedence in the early motherhood period. Caregivers continued to overemphasise and 'pathologise' (Evelyn HCD) the

²¹⁶ The length of time women spent in hospital after the birth depended on the mode of delivery and on the woman's ability to prove to caregivers that she could confidently and competently complete the physical tasks associated with being a mother, it varied from a couple of days to a week.

²¹⁷ Caregivers were guided by provisions within the Child First: National Guidelines For The Protection And Welfare Of Children (2004) and the more recent edition of the guideline, the Child First: National Guidelines For The Protection And Welfare Of Children (2011), which decrees that people working with children have a statutory duty to comply with the provisions enshrined in the guideline.

²¹⁸ This support network comprised of their partner and family members.

woman's disability and were overly concerned with screening the baby²¹⁹ for abnormality much to the determinant of the woman's experience of mothering. These actions reinforced the assumption that having a disability 'wasn't normal' (Maggie HCD), a deduction many of the women rejected²²⁰ but nevertheless found upsetting. In Evelyn's case,²²¹ the caregivers were quite open in showing their sense of relief when her son's hearing test confirmed that he did not have a hearing impairment. This action infuriated Evelyn because she considered her hearing impairment to be a defining entity of the self. To manage the situation Evelyn decided to distance the self from caregivers, in so doing, she regained a sense of agency and autonomy, and the process of making meaning of the self as a mother began.

'The attitude [of caregivers] was just appalling, I felt like they were blaming me, I felt like it was really all my fault, hearing or not this is what everyone wanted to know and then you have to keep having all these hearing tests and I didn't want to do that, I don't want to put my child through that. I remember, when the child did have a hearing test the attitude of the professional staff was 'oh, that's great, the child is hearing, thank god, thank god, thank god, your child isn't deaf', I was like, excuse me, 'I'm deaf?'" (Evelyn HCD)

8.2.2 Having to prove oneself to caregivers: undermining one's sense of agency

For the majority of women (n=17), the biological act of giving birth correlated with an immediate ontological shift to motherhood, experienced 'instantly' (Selina PCD) or within the first week after the birth of their baby.

'When he [son] was born and I looked at him and held him then I felt I'm a mum now.' (Helen PAd)

'I remember when he [son] was born, the nurse turning around and saying 'it's alright you're going over to your mammy now, she's just over there' and I remember thinking wow, that was the first time, I'd heard anybody saying mother and referring to me.' (Natasha PCD)

However, for Louise, Selina, Lorna, Betty and Christine, their ontological shift to motherhood was a gradual one.²²² The delay was due, in part, to the attitudes, actions and behaviours of caregivers

²¹⁹ The emphasis on screening did not concur with the women's concerns. In fact, the majority of women with a physical disability or sensory impairment did not consider having a baby with a disability a concern; rather their focus was on the baby's health and viability, not their ability or disability.

²²⁰ Especially the women who considered their disability to be a defining entity of the self.

²²¹ Evelyn and her husband were hearing impaired. The partners of three of the women (Louise (PCD), Evelyn (HCD) and Sharon (HCD) had a physical disability (n=1) or sensory impairment (n=2)).

²²² All five women had a congenital disability.

encountered in the early postnatal period and partly due to the temporal space needed to come to terms with the change in self.

'There was a lot of questions on 'how are you going to manage, how are you going to look after this baby and are you going to be able to do things'. The paediatrician came one day and she was very good, she was great but she was watching me, she asked me to put the baby's clothes back on and I felt like I was being observed.' (Betty VCD)

'...the nurses were very judging, I got those vibes, and they were going around to all the other mothers in the ward saying 'how is she going to cope with the baby?' Then other mothers would say 'they [women with a hearing impairment] shouldn't be having babies', if I was a hearing person I would have been respected more.' (Christine HCd)

These five women were more consumed with proving that they could competently mother.

'I was an absolute basket case, there was [husband's name], myself, 3 physiotherapists and the ward sister observing me, I was expected to change a child's nappy with 10 pairs of eyes on me. It was very difficult and I actually broke down...I don't even like anyone looking over my shoulder if I'm reading a newspaper and here I was doing probably the most difficult thing in my life and expected to do it competently and being judged while people were observing me, it was absolutely horrible.' (Louise PCD)

Undoubtedly, this overwhelming need to prove one's ability impeded the women's ontological shift to motherhood and extended the delay to well beyond the first week of baby's life.²²³ Furthermore, the women feared if they could not demonstrate competence and confidence in doing mothering they would lose custody of their baby. This fear eroded the women's confidence in their ability to mother and delayed the process of making meaning. This delay in making meaning impeded the women's understanding of the self as a mother, without this understanding the women could not embark on the process of reforming the self or their assumptive world.

'I was referred to the medical social worker because I had a disability...you couldn't do that to any other group in society, you couldn't do that to black people, to travellers, to Muslims, to any other section of society, you couldn't just block them all and say 'all those people have to be sent to a social worker', it's not acceptable, and yet it is acceptable if you have a disability...it did knock my confidence, that feeling I was being scrutinised and knowing that all it took was one person to say that 'I wasn't able to look after her [baby]' and she would be taken away.' (Anne VCD)

²²³ In some cases the ontological shift only occurred when their child showed a preference for them, or when their child began using the title of mother when referring to them. For two women with a physical disability the sense of being a mother became a reality when their son or daughter started crèche and they found themselves relating to and associating with other mothers.

'This woman [midwife] pulled my mother aside and basically said 'your daughter is not fit to look after this baby, this baby is going to end up being taken away by social services', after that I was always afraid that the social worker would ring social services or something.' (Sinead PCD)

The women were anxious to get home where they could begin to make sense of their experiences outside the gaze and surveillance of caregivers. Home was an oasis that provided a spatial and temporal reprieve where the women could engage in and experience the doing of the physical, physiological, cognitive, emotional and social activities of mothering.

'I couldn't wait to get home because then I could be on my own.' (Louise PCD)

'I don't think feeling like a mother really hit me until after I got to bring him [son] home.' (Kerrie HCd)

At home, the need to prove one's ability to caregivers abated. Situated in this environment the women (i) regained a sense of control, (ii) took responsibility for the self and the activities of mothering, and (iii) regained a sense of independence and agency. Thereafter the women experienced a renewed sense of self-worth, self-belief and self-confidence and this renewed self negated the sense of helplessness experienced pre-motherhood and in the early motherhood period.²²⁴ Once their sense of agency and control was regained the women began to create meaning and construct an understanding of the self as a mother with a disability.

8.2.3 Taking on the responsibility associated with motherhood

Motherhood entails taking responsibility and being accountable for the child's development and growth. Indeed, this sense of responsibility is reinforced through government policies on child health so, failure to meet this responsibility may result in the enactment of punitive sanctions like losing custody (Lawler 2000), a real fear experienced by five women who contributed to this study. All twenty-two women discussed how the doing of mothering meant taking responsibility for the growth, development and

²²⁴ For some women their sense of autonomy was accentuated by the relationship established with the public health nurse (PHN), who by legislation were required to visit all women when discharged from the maternity services on at least one occasion. Some women described how they developed an affective, reciprocal relationship with the public health nurse. The women appreciated being treated in a respectful, dignified way and welcomed the nurturing, caring mother like attributes and behaviours exhibited by them. This experience was not representative of all the women's experiences, for some, the public health nurse obliterated the sense of retreat and security their home afforded them. The interactions with them affected the woman's sense of resilience, confidence and competence especially when the only concern was the woman's disability, not motherhood.

socialisation of their child(ren). All agreed that the sense of responsibility accompanying the role of mother was a compelling aspect of motherhood. Louise, Natasha, Kim, Selina, Aine, Helen, Olive, Aoife, Anne, Kerrie and Jackie described how they were overwhelmed by the unrelenting, intense and profound sense of responsibility invoked at birth but nonetheless all were realistic in their expectation that the intensity of their responsibility would diminish over time as their son or daughter got older.²²⁵

‘...the awesome responsibility of this person, it hit me very shortly after she was born, suddenly you realise another little person is so dependent on you, for the rest of my life I am responsible for this person, even when they’re eighteen, nineteen, twenty, they’re still your child, until your dying day.’ (Louise PCD)

‘...just a sense of responsibility that I was responsible for him [baby] and all of his actions and everything he does or not do, will reflect on me and it’s down to me, so it’s down to the way I rear him and I remember thinking ‘oh my god, I’m responsible for him for the rest of my life’.’ (Natasha PCD)

The women described how being responsible meant they needed to create and develop a nurturing and caring environment where their children’s physical, psychological, social, emotional, cognitive and cultural growth would be fostered and enhanced.²²⁶ The women spoke about wanting the best for their child(ren) while Lorna, Evelyn, Helen and Emily wanted their child(ren)’s experiences to be different, more positive, than their own experiences.

‘I want them [children] to have the opportunities that I didn't have, to open up different avenues; I want them to have and live a better life.’ (Lorna VCD)

‘I want to give my children encouragement and confidence and self-belief, I want to make sure that they have more choices than I did, I want to protect them from the negativity I received, I want them to receive positive encouragement and affirmation.’ (Evelyn HCD)

8.2.3.1 Taking responsibility for the social development of child(ren)

The women described how they felt responsible for their son or daughter’s social development. The majority of women (n=19) wanted their child(ren) to be exposed to and integrated into both a disabled and non-disabled world. To facilitate this process the women altered their own patterns of socialising and rethought their relationships with others, they wanted to ensure that the relationships engaged in as a mother were purposive and worthwhile. They became involved in community activities, activities

²²⁵ The women felt responsible for the (i) growth and development of their child(ren), (ii) socialisation of their child(ren), (iii) setting morals and standards and (iv) the safety and protection of their son or daughter.

²²⁶ The women articulated how open channels of communication, encouraging individuality and expression of feelings, particularly as the child got older, were all necessary prerequisites for their child(ren)’s growth and development.

they shunned pre-motherhood. This altered pattern of socialising helped to instil a sense of community and was instrumental in the regaining of a sense of belonging and place, something that pre-motherhood was imperilled through the behaviours of others, particularly caregivers encountered while preparing for motherhood.

'We went to the Summer Fest, which is a family day, I probably wouldn't have gone to that before, but now we have [baby's name] I want her to be included in the deaf and hearing communities, I wanted her to have the best of everything.' (Maggie HCd)

'...the residents association had the children's sports day and before we always said we can't go there, we don't have a child...but this year we went and we had a great time, it was a conscious decision to network, to meet other parents, you want her [baby] to have other opportunities.' (Birte VCD)

The women were conscious of the need to be a good role model, to set morals and standards that would stand their child(ren) in good stead in later years. This desire to be a good role model was, as evident in Sinead, Evelyn, Louise and Natasha's accounts; cited as one reason why, when their statutory maternity leave ended, these women returned to work. This return to work and the intricacies involved in integrating motherhood with other entities of the self, like the occupational self, facilitated in the development of an understanding of how the different entities of the self were compatible and could co-exist.

'I'm always aware of being a role model for my children and communicating that to them and teaching my children the right way.' (Evelyn HCD)

'I want him [son] when he gets old, to recognise that 'my mam always worked and she never got anything for free, she's worked for what she has and I'll have to do the same, there's no such thing as a free lunch, I'll have to do the same and I will do the same'' (Natasha PCD)

Many (n=11) welcomed the feeling of being needed that was implicit in the doing of mothering. This feeling offset the sense of dependence and helplessness that was prominent in phase one. It also caused the women to explore the aspects of the self that encroached on their ability to mother, including their pattern of socialisation and the impact work may have on the maternal self. This exploration caused the women to contemplate relinquishing aspects of the self that they deemed were incompatible with being a mother.

'It's nice to have people looking up to you, it's nice having people depending on you, it makes you feel more important, more responsible, more grown up. As a person with a disability it's the other way round, you have people looking out for you and helping you.' (Christine HCd)

All twenty-two women gained confidence in their ability to mother through the doing of mothering and gaining mastery over skills associated with mothering. Gaining confidence was a gradual process, one that was enhanced as the women became more proficient in meeting the needs of their child(ren) and overcoming the physical and sensory tasks of mothering. The sense of confidence that ensued signified progress in this phase of the theoretical model. It accentuated the woman's sense of independence and instilled a sense of self-belief and self-worth. This sense of independence and confidence motivated the women to challenge those they had regarded as experts and the expert knowledge they espoused. Accordingly, the women turned to others, primarily their own mothers and other mothers, for information on mothering. So, as the women's needs changed so too did the interpersonal relationships they engaged in, this caused the majority of women to examine and reconfigure their relationships with others in their social world.

8.2.3.2 Feeling unprepared for the doing of mothering

Natasha, Aine and Lorna struggled with the notion that the doing of mothering was a natural, instinctive endeavour, they were overwhelmed by the feeling of not knowing what to do and the profound sense of responsibility accompanying the role. Indeed the early motherhood period was, for the majority of women who participated in this study, often characterised by confusion, anxiety and fear. These emotions affected the women's perception of the self and their self-confidence (Ball 1994). Similar to the non-disabled women who contributed to Bailey's (1999a, 1999b) study, eight women felt unprepared for motherhood, the reality of motherhood and the personal experiences of doing mothering did not always resonate with their expectations of being a mother (Bailey 1999a, 1999b). The discrepancy between one's expectations and reality delayed the making meaning process and hindered progress through this phase.

'There were times I thought I'm going to die, just going to sit here and die. The constant work that has to go into raising a child...and I don't think that's any different because I've got a disability, I imagine that's the same for everybody.' (Natasha PCD)

'...it's [mothering] a big responsibility...there is two people that rely on me, you don't realise how much work and care it involves until you're actually here.' (Aine PAd)

8.2.4 Establishing a relationship and connection with their child(ren)

Doing mothering does have specific repercussions for women with a disability, especially when developing a relationship with their child(ren). For the six women with a visual impairment, doing mothering, connecting and relating with their son or daughter was a very sensory and tactile process.

'Mothering, for me it is very visual thing. I remember that very early in the hospital when I closed my eyes I could see her [daughter's] face. I could see her in my head...it's such a part of the bonding process...it's sensory, tactile and all that, if you've been blind for a long time you are more in tune with that kind of thing.' (Aoife VCD)

'I have light reception so I can see their [children's] blonde hair, I can see that it's bright and from feeling their face I know the shape of their face, so there is a lot of touch involved. I think because of my blindness we're probably going to have to be a lot closer, more touchy feely.' (Lorna VCD)

Lorna's account captured how her sensory differences, caused her to miss the visual cues exhibited by their son and/or restricted the activities she did with him. This engendered a feeling of frustration, she felt that her visual impairment impacted on how she connected and bonded with their son. She described how the sense of attachment she expected to feel immediately after the birth was delayed. This delay was attributed to the fact that she could not see her son's facial expressions and although she competently mothered, her sense of attachment was only realised at eight months when her son began to use verbal cues. The sense of detachment that developed in the first eight months delayed the meaning making process and significantly impacted on Lorna's progress through this phase.

'Little things I miss out on, like a smile, I didn't actually get that feeling of bonding until the baby laughed, that little laugh, like people would say 'ah he's smiling up at you', and I'm going, 'oh, alright'. It meant nothing to me because like what the eye doesn't see the heart doesn't dance for. It wasn't until I got a physical reaction from him, then I started to bond with him.' (Lorna VCD)

The inability to do certain physical, visual or auditory things with their child(ren) did cause four other women to question their ability to be a good, competent mother.

'I wanted her [daughter] to do baby swimming, her dad is doing it with her, sometimes I have to stop myself thinking wouldn't I be a better mother if I could drive to baby swimming with her and do that and is she going to lose out because I can't do X,Y, Z with her.' (Birte VCD)

'...he [son] knows that to speak to me, he knows I need to be looking at him, it was something I had to explain from very early on.' (Kerrie HCD)

The women identified how, from a very young age, they expected their child(ren) to be independent and responsible.

‘When you’ve got a disability you have to put more effort into what you’re doing...I don’t have the legs to run after him [son] so in order to keep him safe and in order to ensure that he knows, and understands right from wrong and what I expect from him, he has to think and have more responsibility, he wouldn’t have that responsibility if I didn’t have a disability, so I had to make sure from the very get go that I was very clear in what I was saying to him, that he understood what I was saying to him, that I was consistent, that there was consequences, I trained him with consequences, so that if he didn’t follow through on what I was asking him to do that there would be consequences and that I would follow through on those consequences. If I hadn’t a disability I wouldn’t probably put half that into it, if I hadn’t had a disability I’d think ah sure I can run after him, but I can’t do that.’ (Natasha PCD)

Moreover, many of the women (n=14) described how, from a very early age, their son or daughter developed an intuitive awareness of their mother’s physical and sensory differences and how they altered their actions and behaviours accordingly. They developed an acute awareness of the different things their mother and father could do with them. Fathers represented physicality, while their mother was more sensory and tactile. Their child(ren)’s intuitive awareness helped to ameliorate the sense of guilt some felt at not being able to do certain things with their child(ren). This guilt was a compounding emotion that interrupted or hindered the woman’s progress during the transition to motherhood but once the sense of guilt began to dissipate progress occurred.

‘He [son] knows mammy can’t see, he knows with [partner’s name] there is a difference, he will hold up a toy and say ‘daddy look, does this fly’...but he’ll come over to me and say feel this.’ (Lorna VCD)

‘I’m fun in different ways, daddy does all the rough and tumble, but I play music with her, I read to her, we do jigsaws, and more arty kind of crafts.’ (Selina PCD)

‘He [son] knows intuitively that mammy has to be dealt with gently...the kids say I do what they call mammy’s special hugs and kisses, the gentle stuff, mammy will count the teddies or mammy will sit down and read a story. They won’t expect me to dive on the floor with them.’ (MSK PAD)

8.2.5 Ensuring protection and safety of child(ren)

Twelve of the women²²⁷ described going to great lengths to ensure the protection and safety of their child(ren), especially when in the public domain. The women recalled how ‘motherhood made them

²²⁷ Of these twelve women four has a physical disability, four a visual impairment and four a hearing impairment.

more protective' (Kerrie HCd) of their child(ren).²²⁸ Many articulated how they feared that if someone attempted to abduct their child(ren) they would be unable to protect them. To ameliorate this fear, the women changed their pattern of socialisation, they rarely ventured out alone and when they did they remained vigilant about who was in their immediate environment. Many preferred to be accompanied, so their sense of dependence on others escalated. However, this sense of dependence was different to the dependence experienced in phase one. The sense of dependence engendered then was induced by the environmental challenges encountered while negotiating the built environment but the sense of dependence invoked as a mother was more profound, it was induced by the women's desire to keep their child(ren) safe. The women needed to understand the origins of this dependence, once understood they readily accepted and often requested the support offered by others. Doing so exemplified how these women had created meaning regarding the self as a mother.

'I had one experience where I was afraid [baby's name] could have been abducted, in my head that's what I was thinking. I was putting him into the car, it was lashing rain, this fella came over out of nowhere and took him [son] by the hand and said 'I'll put him in', I said 'no you won't, get your hand off him', I couldn't control the situation and I was thinking if you just take him and go, he was ahead of me and I was saying 'let him go, let him go, I'll do it, you're not doing it, take your hands off him, he's my child get your hands off him'...just the fear of I can't stop him, he's going to take him, I can't stop him, but thankfully he didn't, he let go and I took [baby's name] and put him on my lap and got him into the car straight away.' (Natasha PCD)

8.2.6 Realising one's strengths and abilities

The challenges encountered with doing the physical and sensory aspects of mothering accentuated some women's awareness of their physical and sensory differences. Motherhood intensified the visual and auditory differences of all twelve women with a sensory impairment. Realising this, the women willingly instigated measures to limit the effect of their impairment.²²⁹

'It [baby] was another being, a life suddenly dependent on you, it just made me realise, probably for the first time ever that I do have a disability and the limitations associated with that, it was the first time that I ever thought Jesus, my disability actually is having a very serious impact.' (Louise PCD)

²²⁸ When in the public domain the women expected their child(ren) to remain in close proximity, within voice range, to adhere to and be responsive to verbal instructions. They were unequivocal about the importance of providing clear verbal explanation and instruction, and the necessity to highlight the potential consequences if the child(ren) were non-compliant with such instructions. Many highlighted how their son or daughter understood the importance of complying with maternal requests.

²²⁹ One woman with a visual impairment knew, it would be impossible for her to singlehandedly bring her children to play in the public park, so she always had someone accompany her. While women with a hearing impairment realised the difficulties they had in contacting services, particularly the emergency services, and in hearing their baby's cues.

'I think I became more aware of what I can't hear, basically not hearing what's going on, I couldn't call the emergency number, if there was an emergency I wouldn't be able to ring them.' (Christine HCD)

Five women's heightened awareness of their disability engendered a sense of vulnerability that affected their self-confidence as they considered how their impairment may affect their ability to mother.

'I felt really vulnerable because I wouldn't be able to hear her [daughter].' (Maggie HCD)

'I felt quite vulnerable and I still do to a certain extent, I think I felt quite vulnerable because I had a disability and because it was so visible with the guide dog...I haven't always had reasonably high, self-esteem but it took a bit of a knock when I became a mother.' (Anne VCD)

Ironically, the measures taken to address their disability caused the women to become more aware of their own strengths and abilities. The women, especially the four with an acquired disability, no longer viewed disability as a negative entity of the self, as a mother, they began the process of integrating their disability into their biography and assumptive world.

'As a mother I knew I had to deal with it [disability] so that I could do the things a mother should do with her baby...doing the less physical things with him [son], like reading was good for me, it forced me to take time out, take a rest that was good for my MS.' (Emily PAd)

Unlike in the previous phase, the women were: (i) pragmatic about their need for help and their dependence on others, (ii) reconciled with the resulting sense of dependence that accompanied motherhood and (iii) acutely aware of the need to develop a support matrix comprising of people who would provide the necessary physical, psychological, social and emotional support and assistance. Nonetheless, the women's ability to care for their child(ren), albeit with the help of others, engendered a sense of self-belief and confidence, the women became less self-conscious of their physical and sensory differences²³⁰ and the positivity that ensued facilitated progress through this phase.

'I've always been able to do things pretty much myself when I want to do it in an independent kind of way, but in order that she [daughter] gets everything that she needs sometimes I have to ask for help and that's not so easy that's been kind of a change but I've accepted it, it's a question of asking for the help that you need and that you want rather than having it imposed on you, that's important...I've become much less self-conscious about my disability.' (Anne VCD)

²³⁰ This caused one woman with an acquired disability, who pre-motherhood was obsessed with concealing her disability, to reflect and consider the impact this behaviour may have had on her pre-motherhood sense of being.

8.2.7 Overcoming challenges encountered when doing mothering

The women were determined to 'figure out' (Lorna VCD) a way to overcome the physical and sensory challenges encountered when doing mothering. This determination was consistent with the experience of non-disabled women who, on becoming a mother, developed new skills, gained confidence in their own abilities to mother and became more resilient and assertive (Bailey 1999a, 1999b). The twenty-two women were adamant that the challenges they encountered when doing mothering would not define their mothering ability. They willingly sourced and accepted formal or informal support and assistance. Their determination to develop new skills, to be innovative and creative, and their ability to 'think outside the box' (Louise PCD) were all problem focused coping strategies (Lazarus and Folkman 1984) implemented to manage the challenges encountered.

'When you have a disability you have to think outside the box...there's ways and means around everything, you do have to re-skill, you do have to do things differently, because at the end of the day I wanted to do as much for her [daughter] as I could.' (Louise PCD)

Informal supports like the support of family, especially their own mother, helped the women gain confidence and mastery when doing mothering (Prilleltensky 2003, Prilleltensky 2004a, 2004b). Consequently, the nature of the women's relationships with others in their family, particularly their mothers, changed as they became stronger and more intense.

'...to be around a fellow mother, to speak to somebody who's been there and done that, who utterly understands...to have that support and that person at every level is just invaluable...it just makes the whole thing manageable.' (Emily PAd)

When geographic location prevented some women (n=3) from accessing physical support from their mother or other family members, the women sourced other means of support including; the experience of other mothers, both non-disabled and disabled, in the form of a mother and toddler group and/or sought resources from voluntary agencies. The women appreciated the sense of sameness and equality promoted by the other mothers attending the mother and toddler group, and how they did not judge their mothering ability or define them according to their disability.²³¹ Such affirming actions motivated

²³¹ Two women with a physical disability employed a third person to help them with the physical aspects of mothering. One woman did so of her own volition but the other did so under duress. Louise, on the instance of caregivers, employed a person to reside in her home to aid with the physical aspects of mothering. She expected this action would reassure the caregivers and obliterate their concerns regarding her ability to mother and the safety of her baby, and would rescind the threat of losing
Footnote continued on next page.

the women to evaluate the nature and quality of their existing interpersonal relationships and where necessary, to contemplate reconfiguring such relationships.

'I went to a mother and baby group, that made a huge difference, I'm still friendly with the girls from that group. I think the great thing about them is they take me as I am, they don't judge me, it gave me confidence, it encouraged me to go out more with him [son]...most of the mothers in the mother and baby group would have been in the same situation as me, some of them are foreign, some of them have families living far away, so they didn't have the family support either. So they were keen to get the support of other mothers, we were all in the same boat.' (Christine HCD)

Where formal support was lacking, as in the case of Anne, Natasha, Christine and Birte, the women's sense of vulnerability intensified and their experiences of doing mothering were hindered.²³² Any hindrance to the doing of mothering hampered the meaning making process, fractured one's understanding of the self as a mother and encumbered the process of reforming the self.

'There's no supports in place, there's no training, no support for disabled parents, I did feel quite alone in the sense that you had to go and find your own way of doing it [mothering].' (Anne VCD)

8.2.8 Ability to mother undermined by others

The majority of women described how, when in the public domain, they wanted to portray an image that resonated with existing theories of motherhood, a capable, competent, good, responsible mother (Ruddick 1980, Malacrida 2009), many spoke about altering their appearance and behaviours to correspond with this image. But notwithstanding this, the woman's ability to mother was often questioned and undermined by others, sometimes significant others, using the dictum of the baby's safety and protection as justification for their actions and behaviours.

'I was kind of moving around and holding her [daughter] and for whatever reason my mother in law just kept following me around, like a mother hen watching my every move, going 'oh my god mind her head' and 'don't do this' and 'don't do that' and saying things like 'I think we should take her with us, she's not safe here'.' (Birte VCD)

custody of her daughter. Unfortunately, this arrangement left one woman feeling undermined, it impinged on her self-confidence and she feared that the person would encroach on her role as mother. Within a short period of time, both women terminated this arrangement.

²³² One woman with a physical disability, described how she was unable to access any support, either informal or formal, and although her ability to cope and manage with the physical and sensory aspects of mothering instilled a sense of achievement, the experience was difficult. Pre-motherhood she welcomed the independence promoted by their family however when she became a mother this need and desire to be independent negated and her need for support and assistance intensified but this need went unmet.

These actions caused women with a disability to feel undermined, belittled and demoralised; they obstructed the women's progress through this phase of the theoretical model. But as Natasha's account exemplified, once the women gained confidence in their mothering ability, the resultant self-assurance provided them with the skills to confront and discount others' assumptions and perceptions of them.²³³

'I was in the shopping centre and we were in the shop and [son's name] picked up a ball and was playing around the shop with the ball, I didn't mind, I knew he was going to put it back. He started saying 'mammy can I have the ball', so I said 'no you can't, you've 4 or 5 balls at home, you're not getting another one, you've loads of them, put it back', he didn't want to put it back and he was giving out and in the end I took the ball off him and put it back, then I said 'out you come, let's go.' We were only outside, when this man hands him [son] the ball, and said 'I bought him it' and I looked at the man and I said 'why did you do that' and he turned around and said 'ah I just seen you, he's a grand little fella', I said 'no you didn't, I said 'you did that because I'm in a wheelchair', I said, 'if I was up walking around you wouldn't do that, you only done that because you felt sorry for him because I'm in a wheelchair and what you have done, is you have completely undermined me as a mother' and then I turned around and I took the ball and handed it back to the man and I said 'no, I don't want it' and I said 'how dare you undermine me.' I was so annoyed.' (Natasha PCD)

8.2.9 Sustaining elements of pre-motherhood self while doing mothering

All twenty-two women acknowledged and welcomed the significant impact doing mothering had on the self but Louise, Sinead, Maggie, Evelyn, Aoife and Lorna articulated the importance of trying to retain elements of the pre-motherhood self. This retention was achieved by: (i) returning to work outside the home, (ii) socialising with friends, and/or (iii) taking personal time for the self. However, even when the mothers took time for the self, they found it difficult to relax because as Lorna explained, their son or daughter was always uppermost in their thoughts. Interestingly, all six women were adamant that motherhood was an important entity of the self but it was not their defining characteristic, it was one of the many compatible entities of the self that harmoniously co-existed.

'You do need a break from motherhood, I don't care what anyone says, it's good to just break away from the norm...things like having your shower at leisure, like I've never appreciated a shower as much in all my life, than when the kids come along. It's the only bit of time you actually have to yourself...I can escape motherhood if I want to, yeah I can escape with colleagues if they're going out on a Saturday night I can go out and enjoy myself.' (Lorna VCD)

²³³ Performing mothering in the public domain was also hindered by an assortment of infrastructural barriers that impeded the woman's ability to mother and increased her dependence on others.

Indeed the majority of women (n=16) queried whether or not, with the all consuming, all sacrificing nature of being a mother if retention of any aspect of the pre-motherhood self was achievable.

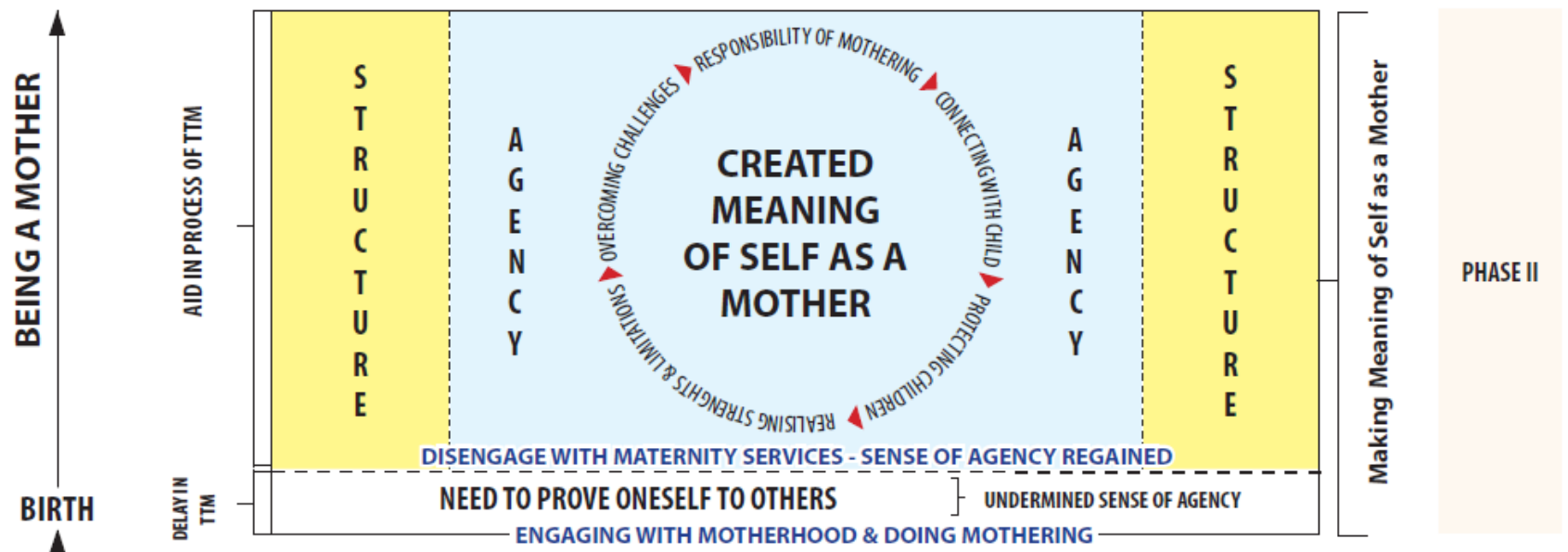
‘When the kids are not with me I wouldn’t know what to do with myself, I think the first thing I’d do is see if there’s anything on telly, I never get to watch it, I record things but I never get to watch them. I’d probably make a cup of tea and sit down but time to myself, it’s not a big deal at the moment.’ (Christine HCd)

8.3 Summary of ‘Making Meaning of the Self as a Mother’

Making meaning represents how through engaging with motherhood and doing mothering women with a disability gained an understanding of the self as a mother. Pre-motherhood, all twenty-two women had anticipated that motherhood would redefine the self but when there was a discrepancy between their personal knowledge, and the information received from others the women experienced a disruption of their assumptions of the self and assumptive world. To manage this disruption the women implemented problem and emotional focused coping strategies to create meaning about the self as a mother, a mother with a disability. For some (n=3, Maggie, Sharon and Sara) the information received from others was consistent with her personal knowledge so the disruption experienced was minimal, their ontological shift to motherhood was immediate and their transition through this phase relatively smooth. But for others the disruption to their assumptions was so great it delayed their ontological shift to motherhood and their transition through this phase was more complicated and convoluted. The women’s ontological shift to motherhood varied but, this shift was vital in the process of adaptation to motherhood for women with a disability. The women created meaning by engaging with motherhood and doing the activities associated with mothering. The process of engagement and doing was a constant, evolving one, it was a process that reaffirmed or caused the women to regain a sense of agency (see Figure 8.2 diagrammatic representation of this phase, phase II Making Meaning of the Self as a Mother). The meaning that evolved from this process was enhanced by the women’s relationship with others in their social world and the availability of formal or informal support. Once gained, the women integrated this meaning into the global self. They then embarked on the process of reforming the self and their assumptive world to incorporate motherhood. The actions employed to achieve this are discussed in the following chapter ‘Reforming the self as a mother’. Engaging with motherhood and doing mothering caused the women to contemplate what was worthwhile in their life, their life took on a different meaning, consequently they became aware of the need to let go of aspects of the pre-

motherhood that they considered incompatible with the maternal self. This is an important signpost; it signifies that progress has occurred in the making meaning phase and that the woman was progressing into the final phase of the theoretical model whereby she recognises the need to: (i) modify her social behaviour, (ii) alter her physical appearance, (iii) reprioritise her life and personal goals, and (iv) reconfigure interpersonal relationships in order to incorporate motherhood into her assumptive world.

Figure 8.2
Diagrammatic Representation of Phase II - Making Meaning of the Self as a Mother



Chapter 9 Reforming the Self as a Mother

9.1 Introduction

This chapter presents the third and final phase of the process of transition to motherhood for women with a disability. Reforming the self as a mother represents the extent to which women, having made meaning of the self as a mother, try to resolve the discrepancies between their experiences and their previously held assumptions regarding the self and how they reform and reconstruct the self and their assumptive world through complex physical, cognitive, behavioural and emotional changes in order to integrate motherhood. From a temporal perspective, progression through this phase is synonymous with women making the conscious decision to change or modify activities of the self²³⁴ and assumptions regarding the self and their assumptive world. The maternal self is a relational self, it will continue to be revised through relationships with others for many years after the birth of one's baby therefore there is no definitive endpoint to this final phase.

All twenty-two women created meaning about the self as a mother and successfully revised their assumptions regarding the self; these assumptions informed the creation of a new, viable assumptive world. All the women described motherhood as an important entity of the self, part of their psyche. Some (n=9) considered it their defining characteristic while others (n=13) considered it an important characteristic of the self but one that would successfully merge and was compatible with other entities of the self, like the spousal and occupational selves. Psychologically, the women's willingness to let go of the pre-motherhood self, even if to differing degrees and their readiness to reform the self was tantamount to their progression into this, the final phase of their transition to motherhood. The women's search for meaning stopped when they willingly accepted that they had to let go of the pre-motherhood self so as to incorporate motherhood, the self and their assumptive world. Six women (Louise, Sinead, Maggie, Evelyn, Aoife and Lorna), all with a congenital disability, were adamant that motherhood was an entity of the self that would blend and merge with other entities of the self and were resolute in their determination that as a mother they would try and retain some aspects of the pre-motherhood self. Despite this assertion, all six women consciously reformed the self and their assumptive world. Five of these six women returned to full time work, outside the home, for them they successfully achieved the desired blending of entities.

²³⁴ For example, like reconfiguring relationship with others and modifying one's lifestyle.

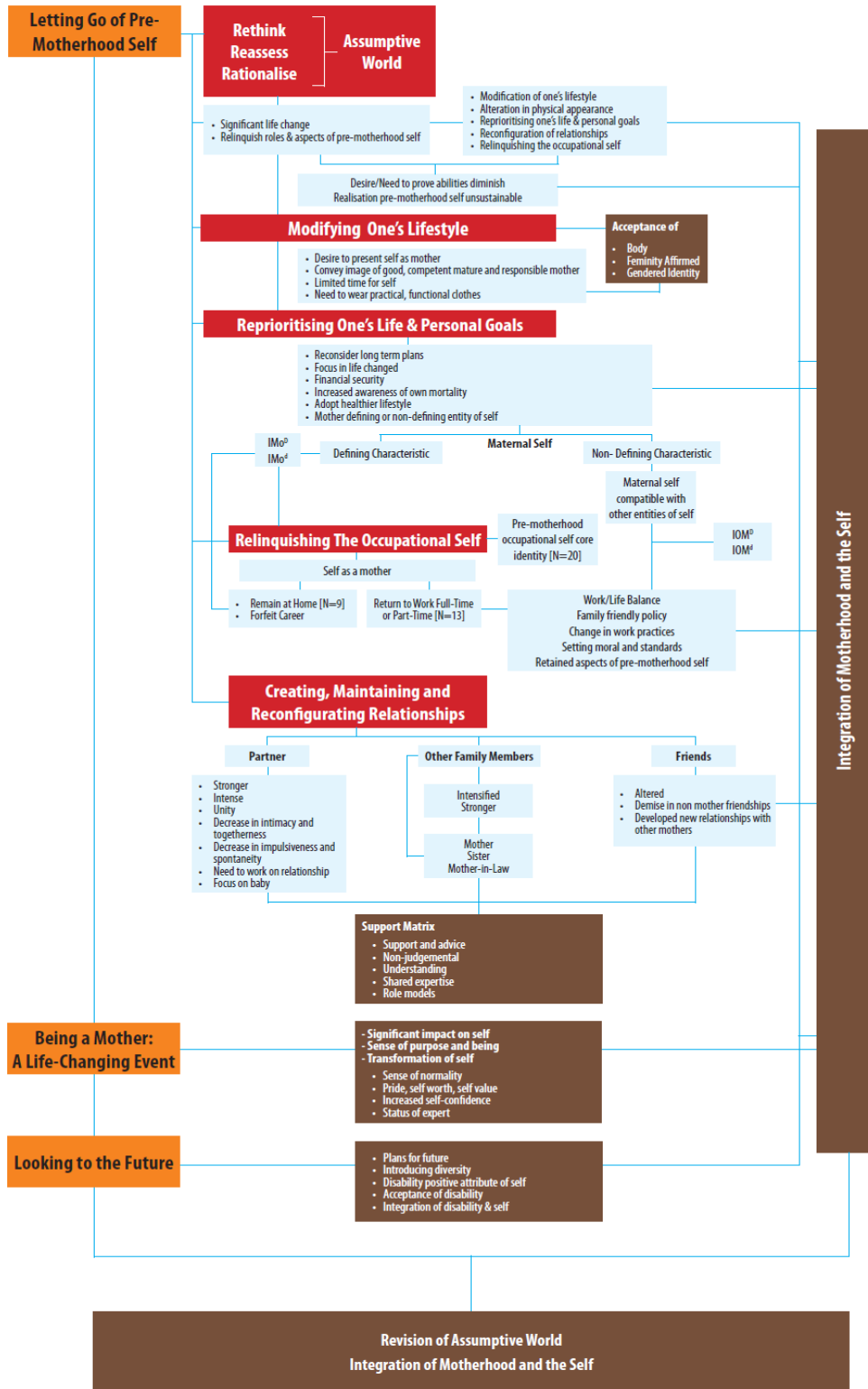
All twenty-two women progressed to the final phase and this led to the reformation of previously held assumptions regarding the self but for Natasha, Christine, Emily, Louise and Helen, this reformation was tentative, their search for meaning was reignited when new information that did not correspond with their own altered assumptions of the self as a mother with a disability was received from others located in their social world. When this occurred the women were catapulted back to phase two to make meaning of their experiences. Regardless of this back and forth movement, all the women described how the process of becoming a mother was a positive one, a process of intense personal growth and self-definition, change and transformation, one that afforded them or reinstated a sense of belonging to and acceptance by a society that heretofore shunned them (see Figure 9.1 diagrammatic representation of this phase, phase III Reforming the Self as a Mother).

9.2 Letting go of one's pre-motherhood self

The ontological shift to motherhood, achieved through the doing of mothering, acted as a catalyst for all twenty-two women to rethink and reassess their assumptions of the self and assumptive world. The transition to motherhood stimulated and motivated the women to make significant life changes, in order to integrate motherhood, the self and their assumptive world. The construction of a maternal self required the women to relinquish roles and aspects of their pre-motherhood self that they considered incompatible with mothering. Through this cognitive process the women autonomously chose to either retain or renounce and let go specific features of the pre-motherhood self. Letting go was an essential practice that contributed to the construction of new assumptions about the self as a mother. Through the act of engaging with and doing mothering women gained a sense of enlightenment as to what was worthwhile in their life, their life took on new meaning, consequently the women engaged in a process of rethinking their life plans and personal goals. The process of letting go was discernible in the woman's behaviour and actions, it included; (i) a modification in the woman's social behaviour, (ii) an alteration in their physical appearance, (iii) a reprioritising of their life and personal goals, and (iv) a reconfiguration of their interpersonal relationships.

Figure 9.1

Reforming the Self as a Mother



The women's reconstructions suggest that for some, the process of letting go began antenatally as the women prepared for motherhood but there was no definitive endpoint. Six of the women (Louise, Sinead, Maggie, Evelyn, Aoife and Lorna) were still, at the time of second interview, actively engaging in actions and behaviours to retain aspects of the pre-motherhood self.²³⁵ Others, like Helen, found that once they embarked on the process of letting go, their adaptation to motherhood became easier, their desire to prove themselves to others evaporated and they realised their pre-motherhood self was a 'hollow vacuous one' (Helen PAd).

'I just found that I let go of trying to make people understand, let go of what I thought other's perceptions of me were and of trying to fight against people's perceptions. When I let go, it got a lot easier; I didn't have to prove myself to people anymore.' (Aoife VCD)

9.2.1 Modifying one's lifestyle

When they became pregnant all twenty-two women modified their lifestyle including their social behaviour and appearance and this continued into motherhood. As the pregnancy advanced, the women's focus shifted from the public to the private domain; subsequently the women became less sociable and their pattern of socialisation altered.

'Before I was a mother I was very sociable, going out and going to different events, but that changed when I became pregnant and became a mother.' (Maggie HCD)

'...my lifestyle has changed, now it's 'let's have a couple of drinks at home in front of the TV', the kids are in bed and we have friends over for a barbecue or something like that and we have fun that way, it's definitely a slower pace of life now, not as fast as it was before, but I'm happy.' (Kerrie HCD)

Pre-motherhood, the women's occupation and appearance were the means by which they presented the self to the external world. When they became a mother, the majority of women (n=19) wanted to portray an image that was in keeping with that of being a good, competent, mature and responsible mother. The women modified their appearance to convey an image that correlated with this representation. The change in image that ensued was attributed to the limited time one had to spend on the self, especially in early motherhood and the need to wear practical, comfortable, functional

²³⁵ These women spoke about their need and desire to ensure elements of the pre-motherhood self were retained including a reluctance to sever ties with friends and others in their social environment that undermined their role as mother or being adamant that their return to work was not only for financial reasons but it was also a mechanism that afforded them the opportunity to retain aspects of their pre-motherhood self.

clothes that facilitated and made the doing of mothering easier.²³⁶ Interestingly, many women commented on how their appearance as a mother was comparable to that of their own mother's.

'I've really become my mother, I feel like, sometimes I look like her twin because of how much I've changed, before I used to wear sexy dresses and now I think well no I couldn't...even my hairdresser said 'oh you're having the same hair cut as your mother'.' (Evelyn HCD)

'Before motherhood, I was just a perfectionist in everything, including appearance, whereas now I really couldn't give a monkeys, now I'm fairly happy with the difference...I think before I would have gone for the high heels and the impractical outfits, I like fashion, I like clothes, that hasn't changed, but now if I spend a day in a t-shirt and jeans and a pair of scruffy old runners I don't feel awful.' (Helen PAd)

'I wear mumsy clothes because it makes sense, it's practical, you don't want to be walking around in skinny jeans the whole time, holding yourself in, there is an element 'oh here I am warts and all', you have little time to think about yourself and that's such a break from how I would have been before I became a mother.' (Emily PAd)

The change in appearance also contributed to the women's acceptance of their bodies, affirmed their femininity and was influential in bestowing a gendered identity.

'Being a mum, certainly made me feel more as a real woman, rather than a disabled woman, when you're a disabled person, you are not seen as a person at all, the idea of parenthood, or relationships, or sexual expression, just isn't considered, being a mother is a very positive, a very strong reinforcement of your femininity as well as your sexuality, for me, it started with getting married, and having my own home but then the final piece of the jigsaw that really said 'yes, I am a real woman, I'm a hundred percent a woman', was becoming a mother.' (Selina PCD)

For three women with a sensory impairment, Aoife, Maggie and Birte, their daughter's appearance took precedence over theirs; they considered her presentation to the outside world to be more important than theirs, it reflected their mothering abilities.

'...the baby almost becomes your presentation to the world, how she is dressed and looks, I would be embarrassed if someone saw my child in a dirty top...I see her as an extension of myself, if my daughter looks okay I don't have to, so I'm not bothered about my appearance.' (Aoife VCD)

9.2.2 Reprioritising one's life and professional goals

Becoming a mother and the corresponding responsibilities associated with mothering caused the women to reconsider and reprioritise aspects of their life, including long-term plans and professional

²³⁶ This includes activities like breastfeeding and playing.

goals. Nine women described how their family, their child(ren) and their role as a mother took precedence over other aspects of their life, including their career. For the remaining thirteen women being a mother was an important entity of the self but it did not take precedence, it fused, blended and was compatible with other entities of the self, including being a wife and their occupational self. When they became a mother, the majority of women adopted a more responsible and mature approach to life, long term planning became the norm. The narratives reaffirmed how as a mother, just like their non-disabled women, the women willing let go of aspects of the self that they perceived incompatible with motherhood.

'The children are my priority, they come before me, I used to think it was me first but no it's my children come first above everything else, they're at the forefront of my mind all the time, I couldn't possibly be without them.' (Evelyn HCD)

'As soon as my son was born things that I had at the top of my list of priorities went straight to the bottom because he went straight to the top, you've got to put the children before anything and anybody else, whatever he needs, he comes first.' (Kerrie HCD)

The women described how their focus in life changed and how they needed to think ahead and plan for the future. This was exemplified in their desire to be financially secure. Motherhood also increased the women's awareness of their own mortality, inspiring many to adopt a healthier lifestyle.²³⁷

'When you've children your priorities change...your priorities are more focused on your child...you have to start planning, you plan for the future, you start putting things in place, you start thinking about things that you mightn't have thought of before like financial things.' (Louise PCD)

9.2.3 Relinquishing the occupational self

Pre-motherhood, twenty women²³⁸ were engaged in full time employment, the remaining two were full time students undertaking doctoral degrees. The twenty women used adjectives such as 'career focused', 'highly-driven', 'determined' and 'motivated' to describe their occupational self. All were

²³⁷ One woman with a visual impairment articulated how becoming a mother caused her to contemplate and discuss her own mortality with their partner. They agreed that in the event of something detrimental happening to her, their daughter's safety and protection would be the first priority. However, if the circumstance was reversed and Aoife was to choose between her partner and her daughter, she would choose her partner; she envisaged the loss of her partner would have a greater affect on her sense of being and self.

²³⁸ Of these 20, 16 women had a congenital disability (six physical disability, six hearing impaired and four visually impaired) and four women had an acquired physical disability.

resolute in their assertion that pre-motherhood, their occupational self was their defining characteristic, a characteristic that meaningfully contributed to their sense of self.

'If I didn't work I'd crumble...it's an important part of who I am.' (Lorna VCD)

'I'm very determined, I have a strong career path, I love my work, it's an important part me.' (Evelyn HCD)

Their occupation provided focus, routine, structure and order, and reaffirmed their sense of belonging in a society where attitudes towards people with disability are changing but the pace of change is protracted (NDA 2002, 2007a, 2007b, 2011). The women's sense of belonging was reinforced by understanding and supportive colleagues who saw beyond their disability and treated them like any other person in a dignified and respectful manner. The occupational self reinforced the woman's sense of independence, self-worth and self-value instilled by significant others in early childhood. It provided a sense of fulfilment, competence and achievement that empowered the woman and endowed a sense of agency.

'They [employers] put me into a section that wasn't fulfilling because I wasn't working on the same level playing field as my other peers so I went in to the head of my department and said 'look, I'm out there and I can't do the same work as everyone else because it's all based on handwritten forms' [woman has a visual impairment] and they said 'how can we make it better' and I said 'well, put me in a job where I can do the same work as everyone else'.' (Lorna VCD)

'I'd be very forward about needing training and the fact that they [employers] have to write everything down for me because I can't hear what they want me to do [woman has a hearing impairment], I love my job, I would have been one of the persons on the team that did most of the work, who did the biggest workload, I wanted that because I knew I could do it.' (Christine HCD)

Those with an acquired physical disability (n=4) used their occupational self to conceal their disability from others. For them, it was a means of proving their abilities to others.

'I'd make sure to do the best in my job, I wanted to push myself and disability wise that came in as well, in a sense that, I would put in the longer hours and do the extra work and make sure nobody saw that I was doing that maybe to make up for my limitations.' (Emily PAd)

The four women took extraordinary measures to prove their ability; they completely immersed themselves in their work, often, to the detriment of other relationships and with devastating effects on the self.

'I would have stayed later than anyone else, six, maybe seven of an odd evening to make sure to get things done.' (Helen PAd)

They used work as a stage to act out a performance that inferred a sense of sameness, inclusiveness and normality but in reality what they were really doing was concealing the true self.

'I was very driven, career wise I was determined, I was always going to work despite my disability and it was my biggest goal to progress up through the ranks...I felt professionally I was quite good...but behind the scenes I had sacrificed everything else to have this show of normality.' (Helen PAd)

'...keeping your best foot forward all the time that's important, you can't afford to have a bad day, so I always try and keep going regardless just until I get home and I can go 'oh refuge, I'm home' but when I am out I do like to keep a positive aura about myself.' (Emily PAd)

When they became a mother, nine women willingly forfeited their career and professional goals. Nine women described how their family, their child(ren) and their role as a mother took precedence over other entities of the self including the occupational self. Nine women²³⁹ chose not to work outside the home; they remained at home where they assumed primary responsibility for childcare. Being a mother became their defining characteristic, other entities of the self were voluntarily surrendered.²⁴⁰

'I had to think about going back to work after maternity leave and I had a lot of discussions about it, so I said I really want to take time out because the kids aren't going to be babies forever, I want to enjoy them for as long as I can...my husband and family said take a career break.' (Kerrie HCd)

'I don't have much of a life now really like I did before but that's okay, I'm happy with that, being a mother is more important.' (Aine PAd)

'I mammy, it's my job...the 'I' has taken a backseat.' (MSK PAd)

For the remaining thirteen women being a mother was an important entity of the self but it did not take precedence, it fused, blended and was compatible with their other entities, including their occupational self. When their statutory maternity leave came to an end, thirteen women,²⁴¹ returned to full-time paid employment, outside the home. For these thirteen women their return to work confirmed that it was possible to have multiple entities of the self that were compatible, complementary and could co-exist harmoniously.

²³⁹ Two of these women, one with an acquired physical disability and one with a congenital hearing impairment chose to take voluntary redundancy when the package was offered by their employers. While Kerrie, a woman with a hearing impairment decided to avail of a five year career break, an institutional policy available to all employees where she worked.

²⁴⁰ Two women who choose to put their career on hold did express an intention to return to, either full time or part-time, employment when their son or daughter started school. One woman even expressed a wish to change her career to one that was childcare focused.

²⁴¹ Two of these women Birte and Aoife, both with a congenital visual impairment, were students who intended to return to work once their studies were complete.

'It was just nice to get back to work, I felt great, everyone was giving me big hugs saying they were delighted to have me back and I felt great, it's great to be back as Maggie and to mix with other adults, it felt brilliant.' (Maggie HCD)

'Working Evelyn goes home, and working Evelyn is gone and I'm mother Evelyn at home and then the children go to bed and then I become wife to [husband's name] and the two of us talk, we're just husband and wife and then the next day I can go and become working Evelyn again so I've a few different Evelyns in there, I've a lot of different kind of aspects to myself that I pull out at different times of the day but they all work together.' (Evelyn HCD)

Three women commented on how their return to work was a means of setting morals and standards for their child(ren).

'I have a responsible job, it's a big part of me, a huge part of who I am...If I didn't work I'd be living on benefits...what would I be teaching my son at the end of the day.' (Natasha PCD)

Although the women's experiences of returning to work and combining a career with mothering were varied, all were resolute in their desire to find a work/life balance, so that their family life and the doing of mothering were not encroached upon. However, this was not always achieved.²⁴²

'To find the balance is important but there's always going to be trade off, I felt when I was at work I was missing out on so much, I wanted to be at home, be there every second and not leave them [children] so I choose to be at home with the kids.' (Aine PAd)

'When I got home, I was tired, I didn't have the energy to play with him [son], he was only two and his mammy was tired and not interested in playing with him, I had to find a balance.' (Kerrie HCD)

The presence of a family friendly policy in the work place helped the women to combine their occupational and maternal selves.

'As well as being a mum I also work full-time, I'm lucky that I work for an extremely good organisation, their family friendly policies, and their whole attitude towards families and working parents, is fantastic, in that respect I'm very, very lucky, they're very well orientated towards family...the flexi-time is fantastic, and certainly very useful as a working parent.' (Selina PCD)

²⁴² Aine, a women with a physical disability, found returning to work difficult, not because of her physical disability, but because she felt that she was missing out on the day to day interactions with her son and more critically she felt relegated to the role of passive bystander as others, primarily her mother who was providing childcare assistance, got to witness key developmental milestones. Kerrie also found that her work, significantly impacted on her relationship and interactions with her first baby. Both mothers decided to put their professional life on hold.

But unfortunately, as Natasha's account exemplifies, not all women worked in an environment that had such a policy.

'I think there's a huge lack of understanding and a huge lack of flexibility at work...you're expected to do the job but there's no consideration for working mothers...if you were to put me against a colleague that doesn't have any children, I have to work 10 times harder in the morning just to even get here, now on top of that I've got a disability. So I'm actually fitting in 10 times the effort...I give everything to the job but it annoys me that there's no flexibility and no consideration of my situation.' (Natasha PCD)

On returning to work, the woman's work practices changed. While their productivity was the same, sometimes it was even greater than pre-motherhood, the women described how they were less flexible and this was not always appreciated by their employers.

'My attitude towards work changed, prior to becoming a mother I would have maybe stayed in a little later, six, maybe seven of an odd evening, I don't do that anymore because I feel I've done my nine to five, these are the hours I'm paid for, I have to commute home and I want to spend some time with my daughter and my husband but if there's some big deadline that has to be met, yes I will stay back but that's a very, very rare occasion and I don't feel, I don't feel guilty about doing it...my family are more important.' (Louise PCD)

9.2.4 Creating, maintaining and reconfiguring relationships

The extant literature (Rubin 1967a, Bailey 1999a, 1999b), contends that transition to motherhood increases the importance of relationships for non-disabled women. This assumption was supported by all twenty-two women who contributed to this study. Following the birth of their baby, changes occurred in many components of the women's lives, central amongst them was the redefinition and reconfiguration of interpersonal relationships with others in their social world. In early motherhood, the women attributed the necessity to attend to, accommodate and address the needs of their baby as a fundamental need that impacted on the amount of time available to interact and socialise with others. All of the women described how their relationships with others, especially their partner and own mother altered, these were often strengthened, while other relationships, such as those with friends who were not mothers declined and eventually dissipated.

9.2.4.1 Relationship with partner

The women's relationship with their respective partners underwent significant restructuring when they became a mother. Pre-motherhood, the women were focused on meeting her and her partner's needs. However, the birth of a new generation caused a discernible shift in the woman's primary focus (Smith 1994, Sethi 1995, Smith 1999, Bailey 1999a, 1999b, Yeates 2004) and this caused a significant alteration in the configuration of her relationship with her partner. Subsequently, the couple's relationship was transformed in three ways: (i) it changed from a woman-partner to a family unit configuration, where roles were reassigned and the couple's identity was modified; (ii) the baby and meeting his/her needs became the woman's priority and (iii) the focus of interaction changed, it tended, in the majority of cases, to revolve around the baby.

'Your relationship with your husband does change completely.' (Aine PAd)

Five of the women described how their relationship with their respective partner intensified and became stronger. Motherhood solidified their relationship and united them as a couple, making them 'complete' (Maggie HCD).

'My husband and myself are closer than before, of course we often argue over the children and so on, the same as other parents do, but we're much closer than we were before we had children...once we had children that solidified everything.' (Evelyn HCD)

Many of the women found that from a physical, psychological, emotional and social perspective the doing of mothering was all consuming. Consequently, this impacted on woman's ability to be close and intimate with their partner.

'Your relationship changes so much when you're parents, my relationship with my husband is so much deeper...I suppose most of our conversations revolve around the children, it's very difficult just to become lovers again, to have a sexual relationship...that is a challenge.' (Emily PAd)

Motherhood obliterated the impulsiveness and spontaneity present in their pre-motherhood relationship. Many described experiencing a decrease in their sense of togetherness. While others spoke about the importance of making time for each other and the need to work on their relationship as a couple.

'Being a mother it does put a lot of pressure on your own personal relationship because you don't have time really for that other person anymore...we've grown so far apart now, I know the connection is still there but we have to work on it...I think both of us are just putting our energies into working and providing a better life for our children.' (Lorna VCD)

9.2.4.2 Relationship with other family members

Relationships with other family members also changed. For several women, the relationship with female relatives, their own mother, sister and mother in law, became stronger and deeper. As illustrated in phase one, pre-motherhood the majority of women had a good relationship with their mothers, a relationship that was based on mutual trust, respect and admiration. In fact, many described how their mother was instrumental in the development of a positive sense of self. When describing their mother several women used nouns such as advocate, advisor, confidante, counsellor and role model. In this instance, the existing closeness and intimacy and sense of admiration intensified when the women became mothers.

'I've such close relationships with my family anyway...mum and I have always been close anyway, and that's never changed, she's my counsellor and my advisor...when anything goes wrong she is the first person I look for.' (Selina PCD)

Alternatively, Anne described her pre-motherhood relationship with their mother as fraught, dysfunctional and practically non-existent, there was no closeness or intimacy and their interactions were often marred by tension and stress. However, motherhood changed the dynamic of their relationship, it brought them closer, their relationship became deeper and stronger, and there was an enhanced understanding of each other.

'I'd had quite a fraught relationship with my own mum...there were certain expectations that my mum would have of me...and if I didn't live up to them then she wasn't proud of me...that knocked my confidence but since the baby has arrived the relationship between us has gotten to a good stage.' (Anne VCD)

A similar strengthening of relationships occurred with sisters and mother in laws. The women welcomed the new found closeness and intensity of these relationships. They attributed the basis of this closeness to the sharing of a common experience, that of being a mother.

'...with my mother and my sister, I'm not sure changed would be the right word but there's certainly an added dimension to it...I think my relationship with my mother in law has also deepened, discussing children seems to do that...we have a deeper relationship now, there were a couple of bumps in the road and we kind of manoeuvre them together.' (Birte VCD)

9.2.4.3 Relationship with friends

In addition to relationships with female relatives becoming deeper and more intense, relationships with friends also experienced significant reconfiguration. Reiterating the findings of other studies who explored the experiences of non-disabled women (Rubin 1967a, 1984, Sethi 1995, Bailey 1999a, 1999b, Lawler 2000, Nelson 2003) almost all of the women (n=19) who contributed to this study described how their pre-motherhood friendships completely altered after the birth of their baby. If their friends were not mothers, the friendships dwindled and eventually dissipated. In essence, motherhood set women who were mothers aside from those that were not mothers (Oakley 1980, Sethi 1995, Smith 1999, Bailey 1999a, 1999b, Flakowicz 2007, Malacrida 2009).

'When I became a mother, a lot of friendships did kind of dissipate, my friends who didn't have any children fell more away and my friends who did have children became closer.' (Evelyn HCD)

The demise of their friendship with friends that were not mothers were attributed to tiredness, and a lack of time and inflexibility, particularly in early motherhood, a period where the women's energy was focused on meeting the multiple needs of her newborn baby, and the establishment of a routine and structure. When meeting friends, the women talked about the need to and importance of planning ahead, many were reluctant to alter the baby's routine, a routine that may have taken some time to establish. So, it was difficult to meet friends impulsively. Occasionally, it was necessary to cancel arrangements that had been made, sometimes with very little notice. Friends who did not have children found it difficult to understand these constraints.

'You can't be as spontaneous as you used to be before the baby arrived because with a baby you really have to plan ahead. I have this routine and I'm very strict with my routine and I stick to it and some people just don't understand that.' (Maggie HCD)

'I don't have as much in common with friends that don't have children, some of them are very understanding, they would have had nieces and nephews...they'd have seen how difficult mothering is so they understand how hard it is for me and that it's not as easy for me to get out as much as I used to but non mothers have backed off.' (Kerrie HCD)

Consequently, the women developed new relationships with other mothers. A sense of commonality and the ability to share experiences with people who understood the complexities of mothering were the foundations that reinforced their friendship with other mothers. Other mothers looked beyond the woman's disability, they were not judgemental; they accepted the woman's differences and provided the much sought after affirmation that the women were good, competent and responsible mothers. They became a valuable source of support, advice and information and were an essential component in the woman's support network.²⁴³

'I had a much stronger connection, relationship with my friends who had children...I think support was a big part of it, if I was concerned about my child, I would contact them and ask them and they'd say 'oh the same thing happened to me' and we'd share experiences, we'd share our anxieties and so on and they understand, it was a great relief to have that support.' (Evelyn HCD)

'There's a group of mothers who meet, they're nothing but accepting of me and who I am.' (Anne VCD)

Evelyn described how becoming a mother made her more self-aware and conscious of the need to locate the self in a supportive environment, where quality friendships rather than quantity took precedence. Evelyn felt comfortable and confident with the self that evolved (and continues to evolve) with motherhood; the maternal self was a self with an inner strength, a strength that relegated the need to pretend so as to feel part of society.

'I might only have a few friends but they're the right ones, if they're not the right person I feel more confident about letting them go, I know more clearly, more strongly what I want now. Before becoming a mother, I remember playing all sorts of mind games, I'd pretend that I like the person...whereas now I know much more clearly, more decisively who I am and what it is that I want from friends and friendships.' (Evelyn HCD)

Evelyn's account also exemplifies how, for the majority of women who contributed to this study, motherhood was a transformative event, instead of trying to fit into a society that tended to exclude people with a disability, the women became more aware of and confident in their abilities and

²⁴³ One woman with a congenital hearing impairment explained how her relationships with her friends were reconfigured, not on the basis of them being a mother or non-mother but rather, on the basis of hearing or non-hearing. Maggie described how all her hearing friends were mothers and how, with them, their relationship was primarily based on her being a mother. When engaging and interacting with these hearing friends she tended to be more mature and responsible. Conversely, her deaf friends were not mothers. She welcomed how these friends did not define her according to her mothering role or ability, when compared to her hearing friends they were more understanding and were less inclined to judge her. The closeness and sense of attachment established pre-motherhood with her deaf friends continued when she became a mother, but this was not the case with her hearing friends.

strengths, consequently they re-evaluated their sense of self in an upward direction whereby their perception of the self became more positive.

9.3 Being a mother: a life changing event

Consistent with the experiences of non-disabled women, becoming a mother was a life changing event, a defining event that had a significant impact on the self and the assumptive world of women with a disability, for most the change was a transformative one (McMahon 1995, Sethi 1995, Bailey 1999a, 1999b). The most significant change was evident in the narratives of the four women with an acquired disability. Pre-motherhood these women had difficulty accepting their disability and were determined to conceal it from others. For them, the self as a woman with a disability was a subdued one, one where the focus was on their differences rather than their strengths, but motherhood changed all that, becoming a mother was a process that facilitated 'healing and acceptance' (Helen PAd).

'I realise how important I am in the wheel of the family now [post-motherhood]...being a mother kind of reminds me or it makes me go, 'yeah, you know what you really are important' and that is kind of nice in a way. I'm enjoying who I am, I like who I am now, I now know exactly who I am, I'm very settled and very happy in my myself, I like talking about the motherhood hat that I wear and I think my next step is to be open about my disability.' (Emily PAd)

'I feel enormous satisfaction, I'm less apologetic. I'm more relaxed, my son has made me realise that I probably am a good person, I'm really happy now, my heart has kind of thawed a bit, there is something amazingly healing about having someone who you're just their favourite person in the world looking up to you.' (Helen PAd)

In order to implement strategies that would assist them in the doing of mothering Aine, Helen, MSK and Emily had to accept their physical disability and recognise how it impacted on the self. The women began the process of integrating their physical disability, the self and their assumptive world and were, at the conclusion of the study, learning to live with a progressive physical disability.

'I finally had to admit my limitations, now I could wear a t-shirt that says I really like myself, it's almost like being a mum gave me permission to sort of say I'm getting off the hamster wheel and that's been immensely beneficial to everybody, it just changed me for the positive.' (Helen PAd)

Motherhood provided all twenty-two women with a disability with a sense of purpose and being. It afforded them a sense of normality and sameness, now it was their ability to mother and not their

physical or sensory differences that was their defining attribute, a change in status long-awaited and embraced by some (n=9). Being a mother engendered a sense of pride, purpose, self-worth and value, and reinstated the sense of belonging and place imbued in childhood by significant others but lost during the women's preparation for motherhood especially when interacting with caregivers engaged in the provision of maternity care.

'I think I feel more normal, more like everybody else.' (Christine HCd)

'...being a mum has taken the focus off me and my disability, it's made me feel more normal.' (Helen PAd)

'I have this sense of worth, I know in my heart and soul that this job of being a mother is a job that I can do and my blindness just doesn't come into it...nobody else will be able to step in and do it for me. I admire myself for it, I'm just so proud of myself; I feel it gives me status.' (Lorna VCD)

'It [motherhood] gives me purpose because if I just had the MS I'd be working two or three days a week and then I'd be lying down four days a week. I'd be resting and taking it easy or, whatever I needed to do, where now I have a purpose. I have little people who need me; it gives me something to do constantly.' (MSK PAd)

Motherhood provided the women with a focus, a 'new lease of life' (Kerrie HCd), they were more 'patient, tolerant and open' (Louise PCD), it provided a sense of 'completeness, contentment, satisfaction, happiness and fulfilment' (Maggie HCD). It affirmed the women's sense of femininity and instilled a state of maturity that some described as lacking pre-motherhood (Rubin 1967a, 1967b).

'I just think it's [being a mother] an amazing special thing to do in your life and I feel my life wouldn't have been complete without it.' (Aoife VCD)

'It's a transformation, it's not like a change overnight, it's a process, it happens over time, I became a much calmer person, I learned more about communication after I became a mother. I was more vulnerable before [pre-motherhood], I'm so much stronger now, I have more faith in myself. I'm much more confident now. I don't feel like I have to please society.' (Evelyn HCD)

'I think it's [motherhood] made me a better person because I'm more grounded, more grown up, it makes you cop on.' (MSK PAd)

Being a mother enhanced the women's self-confidence; as a mother they are more 'assertive, more confident' (Christine HCd) and less willing to accept the non-affirming actions of others in their social world, especially caregivers they may encounter in subsequent pregnancies.

'This time around [second pregnancy] I'm a lot more able for them [caregivers] I'm not taking any shit, I don't care what they threaten me with, I'm not putting up with any shit from anybody this time around.' (Louise PCD)

9.4 Looking to the future

All twenty-two women were optimistic about the future. Selina discussed how she hoped to expose her daughter to a multicultural world and in order to achieve this, despite her physical disability she intended to travel the world with her daughter and partner.

'I've done so much travelling over the years [pre-motherhood], there are so many amazing things I've seen, and I can't wait to go back, and bring her [daughter], and let her see them and see what her reaction is. There's places I want to show her, I can't wait for the day that I bring her to Toys R Us in Times Square and sit her into the Ferris wheel, inside Toys R Us and bring her to Hollywood and let her run up and down the giant piano that you saw in that movie "Big" and bring her to Paris, up the Eiffel Tower, bring her into the Victoria and Albert Museum in London, to the Clothing Exhibition, the Science Museum, and the stuff that I did, that I loved, but it would be so much better second time around with young eyes, and sharing it with her, so that's definitely an adventure.' (Selina PCD)

The women expressed how being a mother gave them a more positive perception of the self.

'My son has made me realise that I am a good person'. (Helen PAd)

'I know my own strengths and motherhood has really brought that home to me, I'm just so proud of myself that it's a job I can do really, really well, there are no challenges when I'm at home nurturing the children'. (Lorna VCD)

'The kids are fun, they make me smile everyday they would say and do funny things, I would be in stitches laughing and that's what sums it all up for me'. (Kerrie HCd)

9.4.1. Introducing diversity into son or daughter's life

The eighteen women with a congenital disability considered their disability to be a positive variable in their son or daughter's life. They identified how their physical or sensory differences introduced and deepened their child's awareness of the existence of a diverse society and imbued the notion that people with a disability are not abnormal people to be feared or pitied but rather, independent, autonomous agents, living full and active lives.

'She [daughter] is growing up with her mum being in a wheelchair, I think that is really positive and it means nothing really to her, it's normal for her, it will help her to be a more balanced person, because she won't grow up seeing disabled people as being something different or separate, it will just be a normal part of her life, she will be very comfortable and relaxed around disabled people.' (Selina PCD)

The women welcomed how their child(ren), unlike others they had encountered during their transition to motherhood, accepted their disability unrelentingly and how, although they were curious about the women's disability, they were not uncomfortable or embarrassed by it.

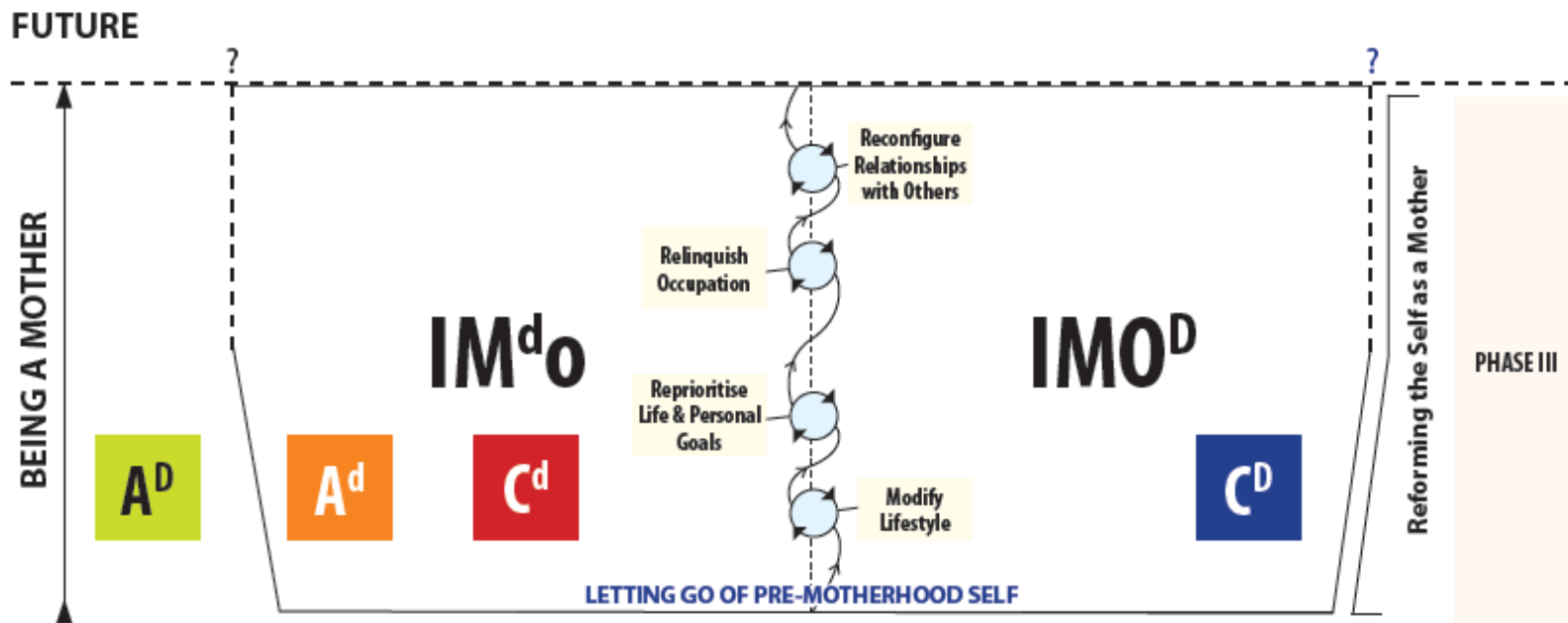
'He [son] sat on the sofa beside me a couple of months ago and he said 'mammy can you see that television', it was on and I said 'no' and he said why, I said 'because mammy's eyes don't work' I turned and he turned his head and he came up to my face and said 'but mammy, they do work, your eyes do work, look..'how do you explain to a child that you just can't see?, so I said 'look close your eyes' and I said 'you can't see when you close your eyes, well that's kind of what it's like for mammy'.' (Lorna VCD)

The women were adamant that they did not want others to perceive them as a burden, to be cared for in the future, by their son or daughter. Indeed, they wanted to shield and protect their child(ren) from the negative attitudes they experienced. This intention to shield their child(ren) from society's attitudes towards people with a disability evolved from their own experiences of having to contest and negate the stereotypical images of dependency and helplessness imbued by a society influenced primarily by the medical model of disability. Selina's experiences of interacting with caregivers from a very young age were influential in shaping how she interacted with her daughter.

'Being a disabled person and having contact with the medical professional throughout my life has made me much more respectful of her [daughter] and of her as an individual. I was very conscious of not just going over and starting doing things to her, I'd talk to her, I'd talk her through what I was doing. One reason for this was, as a disabled person, having been in hospital many times, and having experience of the medical profession and knowing how they love to park disabled people over at a wall, or they would come in and just start doing things to you without asking permission, I was very conscious that she shouldn't have that sort of a negative experience. So right from the start I've always told her what I was doing, while doing it.' (Selina PCD)

The women's desire to protect their child(ren) from the negativity experienced by them, their hope and desire to ensure that their child(ren) have a normal, happy family life illustrates how the focus of attention moved from wanting to prove their abilities to others to embracing their disability and recognising how it was a positive attribute of the self influencing their and their child(ren)'s assumptive world (see Figure 9.2 diagrammatic representation of this phase, phase III Reforming the Self as a Mother).

Figure 9.2
 Diagrammatic Representation of Phase III - Reforming the Self as a Mother



9.5 Summary of 'Reforming the Self as a Mother'

Being a mother caused the women to reappraise all aspects of their life including the various roles they occupy as a mother (Stern 2006).²⁴⁴ Reforming the self as a mother represents how, having made meaning of the self as a mother, women with a disability engaged in the practice of letting go, a practice that resulted in them revising and reforming the self and their assumptive world to incorporate motherhood. The twenty-two women who contributed to this study were all biological mothers and just like non-disabled women, being a mother was for them a normal psychological development, a turning point in their life, a change that augmented significant changes in their self-concept and relationships with others (Oakley 1980, Sethi 1995, Smith 1999, Bailey 1999a, 1999b, Stern 2006, Flakowicz 2007, Malacrida 2009). While the process involved in the transition and progress of movement through the three phases of '(Re)constructing Myself' varied from woman to woman, the transition was relatively smooth for three of the women, Maggie, Sara and Sharon (see Table 9.1, characteristics of a smooth progression through the different phases of (Re)constructing Myself). The critical variable here was the caring, understanding and compassionate caregivers engaged in the provision of maternity care. These encounters were instrumental in sustaining the sense of belonging, inclusion, equity and individualism the women had established through early childhood interactions with significant others. They reaffirmed the women's self-belief and confidence that they would be good, competent, responsible mothers. Consequently, the disruption to the women's assumptions of the self and assumptive world was minimal. Additionally, after the birth of their baby the women experienced an immediate ontological shift to motherhood. This combined with minimal disruption to the woman's assumptions and the support, and affirmation of significant others facilitated in the development of a positive understanding of the self as a mother. Once gained the women then set about reforming the self and their assumptive world to incorporate motherhood. Maggie and Sara returned to work full-time, outside the home, their maternal self co-exists harmoniously with their other entities of the self, while for Sharon being a mother became her defining characteristic.

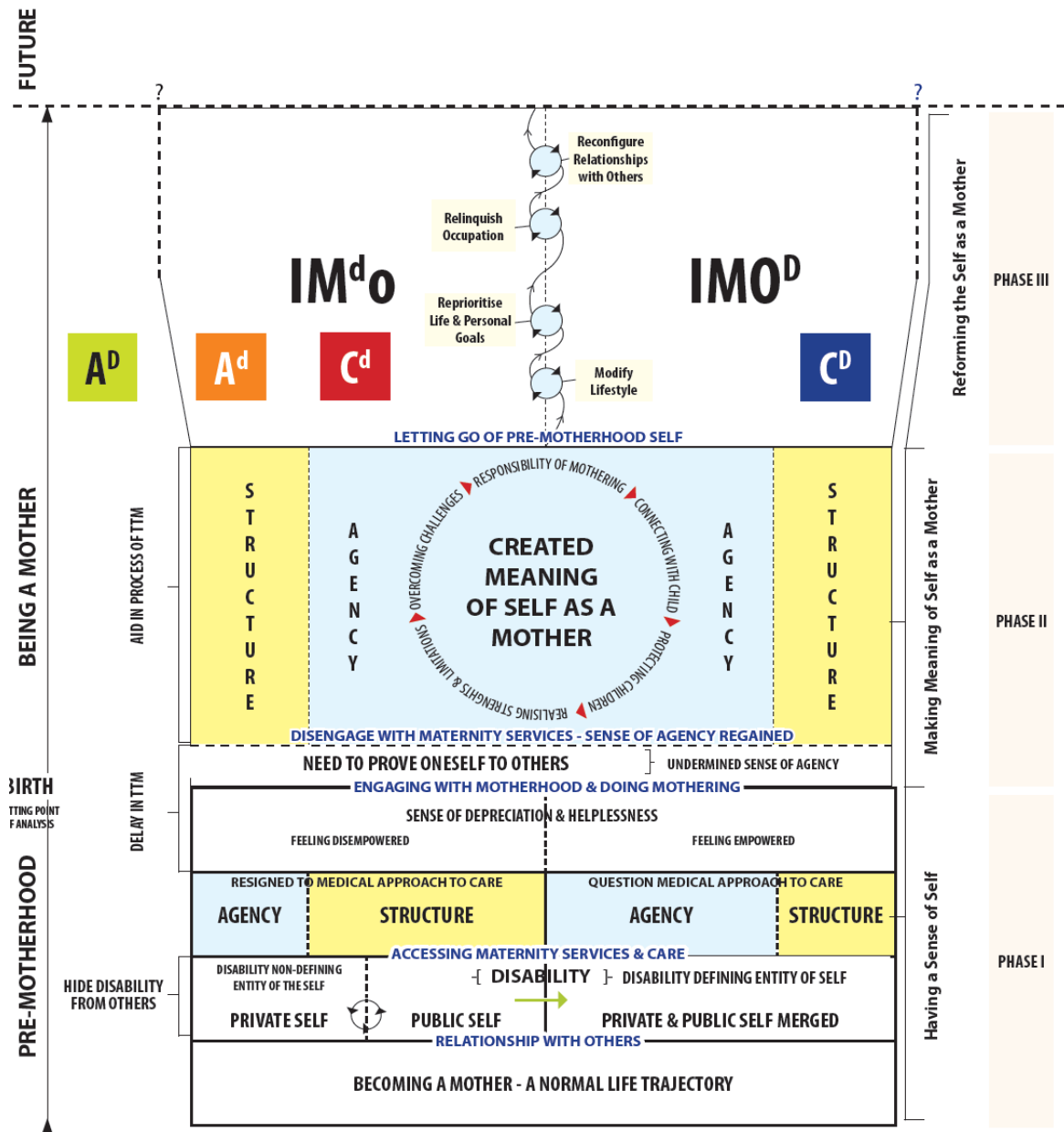
For the remaining nineteen women, the process of transition to motherhood was more convoluted and intricate (see Table 9.2, characteristics of a difficult progression through the different phases of (Re)constructing Myself). Their interactions with others, particularly caregivers they met when

²⁴⁴ These roles include the roles of woman, mother, wife, partner, daughter, friend, daughter in law, career, her role in the family, in society, legal status and herself as a person with responsibility for another.

accessing maternity care, significantly disrupted their assumptions regarding the self as a woman with a disability and the self as a mother. This disruption was accentuated when, in the case of five women with a congenital disability (Louise, Selina, Lorna, Betty and Christine), their ontological shift to motherhood was delayed. This delay was partly due to the non-affirming attitudes, actions and behaviours of the caregivers encountered and partly due to the temporal space needed to come to terms with the change in the self. It was further stifled by the women's desire to prove to others that they were good, competent, responsible mothers. The women had to invoke a variety of coping strategies to manage the disruption, to make meaning of and gain an understanding of the self as a mother. Meaning was only really created when the women were discharged from the maternity services and when the need to prove one's ability to others, primarily caregivers, abated. However, for Natasha, Christine, Emily, Louise and Helen their understanding of the self as a mother was a tentative one. Their search for meaning was reignited when new information received from others in their social world did not correspond with their own altered assumptions of the self. Consequently, the women moved back and forth between the second and third phases of the theoretical model but although the women successfully reformed the self and their assumptive world to incorporate motherhood, when compared to the other seventeen women who contributed to the study, this reformation was a tenuous one.

Interestingly, the women in this study did not experience the sense of loss of self that permeated other studies relating to the transition to motherhood (Oakley 1980, Sethi 1995, Barclay et al. 1997, Nelson 2003, Flakowicz 2007, Urwin 2007, Darvill et al. 2010). Moreover, being a mother bestowed a sense of completeness, fulfilment and liberated women with a disability from the pervasive societal contention that they were asexual, dependent, helpless individuals incapable of caring for another person. Indeed, through the process of planning for and engaging with motherhood, and the doing of mothering, women with a disability reformed and reconstructed the self and their assumptive world. Becoming a mother was, for all twenty-two women, a redefining event, one that positively impacted on the self and contributed to the formation of a positive sense of self (See Figure 9.3 diagrammatic representation of the three phases (phases I, II, III) of the theory of (Re)constructing Myself).

Figure 9.3 Diagrammatic Representation of “(Re)constructing Myself: The Process of Transition to Motherhood for Women with a Disability”



A^D = Women with an acquired disability where disability is part of core self
A^d = Women with an acquired disability where disability is **not** part of core self
C^D = Women with a congenital disability where disability is part of core self
C^d = Women with a congenital disability where disability is **not** part of core self
IM^d = Maternal identity core identity, disability is **not** part of core self
IM^D = Maternal identity core identity, disability is part of core self
IM^d o = Maternal identity core, occupation relinquished, disability is **not** part of core self
IMO^D = Maternal identity & occupational identity **are** compatible, disability is part of core self
TTM = Transition to motherhood

Table 9.1 Characteristics of a smooth progression through the different phases of '(Re)constructing Myself'

PHASE I: HAVING A SENSE OF SELF	PHASE II: MAKING MEANING OF SELF AS A MOTHER	PHASE III: REFORMING SELF AS A MOTHER
<p>Sense of:</p> <ul style="list-style-type: none"> - security, protection, acceptance and belonging - sameness and inclusiveness <p>Family:</p> <ul style="list-style-type: none"> - traditional role to parenting, - positive relationship with own mother - acceptance of daughter's disability - acknowledgement of sexuality <p>Disability:</p> <ul style="list-style-type: none"> - defining entity of the self - embraced disability <p>Motherhood:</p> <ul style="list-style-type: none"> - normal life plan - no difficulty confirming pregnancy <p>Personal knowledge and expectations of motherhood:</p> <ul style="list-style-type: none"> - motherhood would be achievable and doable - excited and looked forward to becoming a mother - beginning of a major adjustment of the self - willing to ask for help - expected to be treated like any other woman taking on the role of mother - role modelling – cared for siblings - role training - engaged in role play as child - antenatal classes effective <p>Accessing maternity services and care:</p> <ul style="list-style-type: none"> - no difficulty in accessing built environment - encountered affirmative attitudes of caregivers - not classified as high risk - emphasis on screening not considered inappropriate - discrepancy between women's assumptions of self and others perceptions of her minimal - valorising of expert knowledge re motherhood - no sense of vulnerability, insecurity, isolation or marginalisation <p>Feelings:</p> <ul style="list-style-type: none"> - sense of self-worth, self-esteem, agency & autonomy - self-doubt about ability to mother minimal - minimal disruption of assumptive world 	<p>Interactions with caregivers:</p> <ul style="list-style-type: none"> - appropriate assistance and support from caregivers - no sense of surveillance - no sense of need to prove oneself to caregivers <p>Immediate ontological shift to motherhood (at birth) Did not feel overwhelmed by sense of responsibility associated with mothering</p> <p>Immediate engagement in doing of mothering</p> <ul style="list-style-type: none"> - altered pattern of socialising - regained sense of belonging and place - reviewed own social behaviours - being a good role model, to set morals and standards - mother important entity but not defining entity of self - different entities of the self are compatible and co-exist - gained confidence in own ability to mother through the doing of mothering and gained mastery over skills associated with mothering - sourced information from own mother and other mothers - examined and evaluated relationships with others 	<p>Minimal disruption to assumptions of self and assumptive world:</p> <ul style="list-style-type: none"> - re-thought and reassessed assumptions of the self and assumptive world - relinquished roles and aspects of their pre-motherhood self that was considered incompatible with mothering - retained or renounced specific features of the pre-motherhood self - gained a sense of enlightenment as to what was worthwhile in life, life took on new meaning - rethink of life plans and personal goals <p>Modified social behaviour:</p> <ul style="list-style-type: none"> - emphasises shifted from the public to the private domain - less sociable, pattern of socialisation altered <p>Alteration in their physical appearance:</p> <ul style="list-style-type: none"> - modified appearance - motherhood affirmed sense of femininity <p>Reprioritising of life and personal goals</p> <ul style="list-style-type: none"> - motherhood compatible with their other entities of self - responsible, mature approach to life and long term planning - adopt a healthier lifestyle - returned to work full-time (family-friendly policy) <p>Reconfiguration of interpersonal relationships</p> <ul style="list-style-type: none"> - relationships with others, especially their partner and own mother altered, stronger deeper & intense - new relationships with mothers, relationships with non-mother friends dwindled

NOTE: Content in blue colour donates characteristics specific to a smooth progression through the different phases of (Re)constructing Myself.

Table 9.2 Characteristics of a difficult progression through the different phases of '(Re)constructing Myself'

PHASE I: HAVING A SENSE OF SELF	PHASE II: MAKING MEANING OF THE SELF AS A MOTHER	PHASE III: REFORMING THE SELF AS A MOTHER
<p>Sense of:</p> <ul style="list-style-type: none"> - security, protection, acceptance and belonging - sameness and inclusiveness <p>Family:</p> <ul style="list-style-type: none"> - traditional role to parenting - no relationship with mother - acceptance/non-acceptance of disability <p>Disability:</p> <ul style="list-style-type: none"> - defining not an entity of the self - inability to embrace disability - visibility of disability - no acknowledgment of sexuality <p>Motherhood:</p> <ul style="list-style-type: none"> - normal life plan - difficulty confirming pregnancy <p>Personal knowledge and expectations of motherhood:</p> <ul style="list-style-type: none"> - uncertain of expectations - excited and looked forward to becoming a mother - expected physical elements of mothering to be difficult - willing to ask for help - expected to be treated like any other woman taking on the role of mother - role modelling cared for siblings but misfit between knowledge and experience - role training - engaged in role play as child - antenatal classes ineffective <p>Accessing maternity services and care:</p> <ul style="list-style-type: none"> - difficulty in accessing built environment - increased dependence on others - encountered negative, patriarchal attitudes of caregivers: was labelled, stereotyped, perceived as being dependent, in need of sympathy and pity - experienced stigma - disability pathologised, classified as high risk - emphasis on screening not in keeping with woman's assumptions of self - eugenic ideology and medical model of disability 	<p>Interactions with caregivers:</p> <ul style="list-style-type: none"> - minimal assistance and support from caregivers - sense of surveillance - focus was on child protection - disability took precedence over role of mother - emphasis on screening in motherhood - misfit between woman's perception of disability and caregivers perceptions - need to prove oneself to caregivers - delay in ontological shift (occurred after first week of motherhood) <p>Overwhelmed by the unrelenting, intense and profound sense of responsibility associated with motherhood</p> <p>Immediate engagement in doing of mothering</p> <ul style="list-style-type: none"> - altered pattern of socialising - regained sense of belonging and place - reviewed own social behaviours - being a good role model, to set morals and standards is important element of motherhood - mother important entity of self is either defining or non-defining entity of the self - welcomed feeling of being needed by others - woman gained confidence in own ability to mother through the doing of mothering and gained mastery over skills associated with mothering - woman regained sense of independence and confidence - woman motivated to challenge those they had regarded as experts and the expert knowledge - woman sourced information from other mothers - woman examined and evaluated relationships with others <p>Felt unprepared for motherhood:</p> <ul style="list-style-type: none"> - woman was overwhelmed by the feeling of not knowing what to do - being a mother not natural instinctive process - woman experienced a misfit between expectations and 	<p>Major disruption to assumptions of self and assumptive world:</p> <ul style="list-style-type: none"> - re-thought and reassessed assumptions of the self and assumptive world - relinquished roles and aspects of their pre-motherhood self that was considered incompatible with mothering - retained or renounced specific features of the pre-motherhood self - gained a sense of enlightenment as to what was worthwhile in life, life took on new meaning - rethink of life plans and personal goals <p>Modified social behaviour:</p> <ul style="list-style-type: none"> - emphasises shifted from the public to the private domain - less sociable, pattern of socialisation altered <p>Alteration in their physical appearance:</p> <ul style="list-style-type: none"> - modified appearance - motherhood affirmed sense of femininity <p>Reprioritising of life and personal goals</p> <ul style="list-style-type: none"> - motherhood defining characteristic OR compatible with their other entities of self - responsible, mature approach to life and long term planning - adopt a healthier lifestyle - returned to work full-time (no family-friendly policy) <p>Reconfiguration of interpersonal relationships</p> <ul style="list-style-type: none"> - relationships with others, especially their partner and own mother altered, stronger deeper & intense - new relationships with mothers, relationships with non-mother friends dwindled

Table 9.2 Characteristics of a difficult progression through the different phases of '(Re)constructing Myself' cont'd

PHASE I: HAVING A SENSE OF SELF	PHASE II: MAKING MEANING OF THE SELF AS A MOTHER	PHASE III: REFORMING THE SELF AS A MOTHER
<ul style="list-style-type: none"> - in consistent with women's subscription to social model - valorising of expert knowledge re motherhood - sense of vulnerability, insecurity, isolation and marginalisation <p>Feelings:</p> <ul style="list-style-type: none"> - diminution of self-worth, self-esteem, agency & autonomy - self-doubt about ability to mother - feeling disempowered - sense of helplessness - sense of depreciation - intentionally assumed a state of helplessness - major disruption of assumptive world 	<p>personal experiences of being a mother</p> <p>Questioned own ability to mother:</p> <ul style="list-style-type: none"> - experienced an inability to do certain physical things associated with motherhood - woman had high expectations of son/daughter - child had intuitive awareness of mother's abilities - woman fearful at not being able to protect son/daughter - doing mothering accentuated woman's physical or sensory differences: woman aware of her differences and strengths, instigated measures to limit the effect of disability - woman pragmatic about need for help and dependence on others - woman reconciled with the resulting sense of dependence that accompanied motherhood - woman acutely aware of the need to develop a support matrix - sense of self-belief and confidence regained through doing mothering so woman was less self-conscious of physical or sensory differences - inherit determination to develop new skills, to be innovative and creative - support of family important - sourced extra-familial support - woman's ability to mother was often questioned and undermined by others, woman felt undermined, belittled and demoralised <p>Desire to retain elements of the pre-motherhood self</p>	

NOTE: Content in red colour denotes characteristics specific to a difficult progression through the different phases of (Re)constructing Myself.

Chapter 10 Discussion

10.1 Introduction

In contemporary society, women are exposed to a range of maternal constructions, including; celebrity mothers, working mothers, teenage mothers or older mothers but missing from this catalogue of choice are mothers with a disability. This is not surprising considering that for centuries, women with a disability were marginalised and their reproductive rights shunned. Recent evidence suggests that despite introducing legislation²⁴⁵ asserting the rights of people with disability, in Ireland, the pace of change in attitudes towards people with a disability is protracted (NDA 2002, 2007b, 2011). Becoming a mother is an important event in the life of most women but knowledge of the process involved in the transition to motherhood from the perspective and experiences of women with a disability and the relationship of the process to the self is limited. The twenty-two women who participated in this study have, by contributing to our understanding of the process of the transition to motherhood, helped to alter this. The temporal process of transition these women engaged in when becoming a mother and the relationship of the process to the self and one's assumptive world were described in the three preceding chapters (chapters 7-9). The theoretical model presented in this thesis demonstrates how the process of transition commenced pre-motherhood. It also clarified how becoming a mother was, for all twenty-two women, a normal life trajectory but, because the self is an entity constructed continually through the woman's everyday interactions with others, the endpoint of the process is indefinite. The self will continue to alter and change as the women continue to interact with others.

The purpose of this study was to contribute to the knowledge base underpinning the transition to motherhood and to explore the relationship of that process to the self. '(Re)constructing Myself' fulfils that purpose, as it represents the process of transition to motherhood from the perspective and experiences of women with a disability. The theoretical model represents: (i) the psychological and emotional disturbance experienced when the women's assumptions of the self as a woman with a disability and the self as a mother were inconsistent with information received from others located in their social world, (ii) the subsequent disruption experienced to their assumptive world and (iii) the process of adaptation the women engaged in as they became mothers. Through the adaptive process

²⁴⁵ This includes the National Disability Strategy (2004), Disability Act (2005) and the Equality Act (2000; 2004).

the women reformed the self and their assumptive world in order to incorporate motherhood. To date, as previously discussed in chapter 4, the existing literature regarding the transition to motherhood is mainly from the perspective and experiences of non-disabled women. While some of this literature is relevant to women with a disability (see Table 7.2, chapter 7), the idea that the process of transition to motherhood can disrupt the woman's assumptions regarding the self and assumptive world has not, with the exception of work by Ann Oakley (1980)²⁴⁶ (who alludes to the notion but does not explore it), been explored in any depth.

The theoretical model presented and discussed in this thesis does not set out to prove or disprove earlier theories relating to the transition to motherhood. Rather, the purpose is to demonstrate how the model contributes to and expands existing theories. The model provides a different perspective on the phenomenon, a perspective that heretofore was under-explored. The intention is not to corroborate, refute or unsettle existing conceptualisations but to expand previous models while increasing caregivers' understanding of the process involved in the transition to motherhood from the perspective and experiences of women with a disability. The conceptual framework to emerge from this study will inform midwifery practice and will contribute to the academic and theoretical debate on the subject. In this, the penultimate chapter, the salient concepts and issues that underpin the model are discussed and explored. The chapter is structured in three sections, these sections will: (i) situate the theoretical model within the context of extant literature on disability, self and transition to motherhood, (ii) discuss the relationship between the process involved in the transition to motherhood, the self and the woman's assumptive world and (iii) discuss the important role symbolic interactions with others located in the woman's social world play in the transition to motherhood for women with a disability.

10.2 Situating the substantive theory within the framework of extant theories on the transition to motherhood

Understanding the process of transition to motherhood and the relationship of that process to the self involved exploring the women's conceptualisation of the self as they became mothers within a

²⁴⁶ Ann Oakley (Oakley 1980) alludes to the notion of motherhood causing a disruption to the woman's assumptive world but does not explore the concept in any great depth or detail.

contemporary social context. In the context of this study, the self was not considered as a bound or fixed entity but a reflective one that altered as the women reflexively interpreted the information received from others located in their social world. The first phase of the model *'having a sense of self'* represents the pre-motherhood self. It corroborates symbolic interactionists' contention that the self is an interactive self, constructed relationally, through symbolic relationships with and appraisals of others, particularly significant others located in the woman's social world and confirmed how others had the capacity to empower or disempower, accept or disavow the woman, a woman with a disability (Sedikides and Brewer 2001, Gelech and Desjardins 2011). Significant others, specifically the woman's own mothers, were, in all but five cases, integral to the formation of the pre-motherhood self and the construction of one's assumptive world. They inundated the women with symbolic signs that informed the construction, perception and understanding of the self and assumptive world but in five cases (Helen, Kim, Anne, Aine and Louise); it was their father who was the influential person. The support and affirming actions of these significant others galvanised the woman's resolve to pursue her life objectives, including that of becoming a mother. It was this pre-motherhood self that formed the basis for the reconstruction of the self as a mother.

The women's relationship with significant others, established from early childhood, facilitated in the development of a sense of agency and individuality, a sense of belonging and inclusiveness and was instrumental in the establishment of abstract, global assumptions that provided meaning and a sense of ontology and purpose to the women's life. These assumptions were fundamental in the creation of the women's assumptive world. Membership in a caring, accepting family offered the women the opportunity to be independent and different while simultaneously being interdependent and to experience a sense of sameness. Their everyday interactions with significant others were, for the majority of women, generally founded on stability and longevity; they were affirmative and positive. This positivity was instrumental in the women's acceptance of their disability and its assimilation within the self albeit at a defining or non-defining level. The sense of connectedness and relatedness that ensued from these positive affirming relationships intensified the woman's sense of belonging and significantly impacted on the women's psychological and emotional wellbeing. Belonging is a psychological construct, a multidimensional phenomenon considered from a number of different perspectives - psychology, sociology and physical. While belonging is an element of connectedness, connectedness is conceptualised as a dimension of relationships, a dimension that creates a sense of

togetherness and cohesiveness (Hill 2006).²⁴⁷ Experiencing a sense of belonging was, for the women who contributed to this study, instrumental in the creation of a positive understanding of the self. It enabled the women to integrate disability and the self and to function at a physical, psychological, emotional, cognitive and spiritual level. As Natasha, Kerri, Maggie, Evelyn, Kim, Christine, Lorna, Sharon, Jackie and Louise's narratives attest, when women experienced this sense of belonging, the sense of attachment that followed positively influenced their self-understanding, self-esteem and self-worth. But when, as in the case of Helen, Sara²⁴⁸ and Emily,²⁴⁹ this sense of connectedness and belonging was derailed by their relationship with others (in this instance their father), a sense of frailty and powerlessness ensued.

Over five decades ago Maslow (1957) conceptualised the need to belong²⁵⁰ as a human necessity, a fundamental right, one that came into existence when the physical needs of food, hunger, safety and others were satisfied (Maslow 1954). This study reaffirmed how a sense of belonging was a significant variable in the psychological, emotional and cognitive development and wellbeing of women with a disability (Thompson and McRae 2001). Expanding Maslow's conceptualisation of belonging, Baumeister and Leary (1995) described the need to belong as a powerful and pervasive human motivation present in all individuals, guiding the individual's emotional, cognitive and behavioural actions and motivating them to develop social bonds. The need is further described as so vital that it underlies one's ability to survive, reproduce, defend or protect oneself from external threats (Baumeister and Leary 1995). Clearly, for the women who contributed to this study, a sense of belonging motivated them to form affirming social bonds with others in their social world; it connected the women to others, places and things and provided them with a sense of security (Hagerty et al. 1992, Andersen and Chen 2002) and status (Beart et al. 2004), and it augmented their social integration and positively contributed to their physical, psychological, emotional and cognitive wellbeing (Lindgren 1990, Hagerty and Patusky 1995, Ghavami et al. 2011). When the women's perception of the self corresponded with

²⁴⁷ Hagerty and Patusky (1995) devised The Sense of Belonging Instrument (SOBI), a 27 item self-report instrument designed to measure an individual's sense of belonging. The instrument was devised to measure the antecedents and psychological effects associated with a sense of belonging but as the this study was analytical and not statistical in nature the instrument was not used however further research using the instrument will provide statistical data on the sense of belonging women with a disability may experience in contemporary Irish society.

²⁴⁸ Sara was a woman with a congenital visual impairment.

²⁴⁹ Emily was a woman with an acquired physical disability, pre-diagnosis her relationship with her father was described as estranged but tolerable however post-diagnosis their relationship diminished to the extent that at time of interview she had very little contact with her father, a fact Emily attributed to him having difficulty in accepting that she had a disability.

²⁵⁰ Interestingly Maslow did not offer a definition of belonging instead he referred to Carl Roger's definition of being loved in doing so he linked the concept of belonging with a feeling of being loved.

others' perceptions of them, when they felt important to, valued, needed and accepted by others, their sense of belonging intensified (Hagerty et al. 1992, Hagerty and Patusky 1995). However, when a sense of belonging was absent, as was the case when interacting with some caregivers, the resulting sense of non-belonging threatened social bonds and generated negative perceptions of the self.

For the majority of women, their interactions with significant others, were in complete contrast to those with caregivers engaged in the provision of maternity care. The attitudes of caregivers and the structural challenges encountered while accessing maternity services significantly disrupted the women's assumptions of the self and sense of belonging, and subsequently disrupted the women's assumptive world. The stigmatising, prejudicial, non-affirming, patriarchal attitudes and actions of caregivers created a sense of otherness and the resulting sense of non-belonging, exclusion and marginalisation affected the women's sense of self. The sense of non-belonging that evolved was injurious to the self, it caused a disruption at a biological, psychological, emotional, cognitive and sociological level (Sargent et al. 2002:p121), that (i) impaired the women's psychological and social functioning (Hagerty and Patusky 1995), (ii) engendered a sense of helplessness, (iii) generated feelings of inadequacy regarding their ability to be a good, competent, responsible mother and (iv) caused the women to feel stressed, anxious, fearful and depreciated.

Moreover, the first phase of the model, *'having a sense of self'*, elucidates how others located in the women's social world influenced how they accepted and assimilated their disability into the self. The women perceived their disability to be either a defining or non-defining entity of the self. For the eighteen women with a congenital disability, their disability informed their understanding of the self, thirteen of these women described it as a defining entity of the self. These women were more likely to be immersed in the disability community and were the ones who questioned the concept of normality. The remaining nine women considered their disability as a non-defining entity of the self. Those with an acquired disability were determined to conceal their disability from others because they feared being labelled as different. In this regard the occupational self took precedence as the women completely immersed themselves in and overcompensated at work. But as Helen's (PAd) narrative illustrates this had far-reaching physical and psychological consequences for the self and others in her social world, *'just tense and pressured...stressed and just really, really worn out trying to keep work as my focus...I'd invested so much energy in keeping going that I thought I can't let any bit of it go, I was just stressed to*

the max.’ Actually, pre-motherhood, work was central to all twenty-two women’s biography,²⁵¹ it was the means whereby they produced a self that was socially credible and valued.

Researchers who have explored the transition to motherhood from the perspective of non-disabled women theorised that becoming a mother equates with a loss of self or self-identity²⁵² but this sense of loss did not resonate with the experiences of the twenty-two women who contributed to this study. Rather, as chapters 7-9 illustrate, women with a disability used the biological act²⁵³ of becoming a mother to reconstruct the self and their assumptive world. While pre-motherhood Helen, Louise and Emily perceived motherhood as an all encompassing, consuming endeavour, their subsequent personal experiences of motherhood and the emotional rewards accompanying it changed this perception. Helen’s (PAd) narrative clearly demonstrates this point, pre-motherhood she considered mothers to be *‘pathetic creatures’* but as a mother Helen described how she was enormously satisfied and how there was *‘something amazingly healing about having someone [her son] who you’re just their favourite person in the world looking up to you.’* Generally, motherhood represented, as Oakley (1980) suggested, a gain, whereby it promoted a sense of achievement, it enhanced the women’s self-esteem and engendered a positive sense of self. With motherhood, the women engaged in a process of affirming the attributes of the self that they valued while recognising other elements that needed changing or modifying.²⁵⁴ They (i) identified their strengths and limitations, (ii) established more supportive and fulfilling relationships, (iii) reprioritised their life and (iv) relinquished entities of the self they considered incompatible with the maternal self. More importantly, unlike the pre-motherhood self, this reformed self was not eclipsed by their disability.

²⁵¹ At the time the study was conducted two women with a congenital visual impairment, Aoife and Birte, were doctoral students completing doctorate degrees.

²⁵² In chapter 4 I explained how previous studies concerning the transition to motherhood, whilst not explicitly concerned with exploring the self, have explored the impact motherhood has on a woman’s self-image and how it relates to the woman’s pre-motherhood self, specifically occupational self. These studies, reflecting the philosophies of the era in which they were conducted, suggest that becoming a mother, especially for the first time, precipitates a loss of personal identity, as the woman renounces work, outside the home, to take on the domestic roles of wife and mother. This assumption was founded on the premise that employment outside the home is self-enhancing, instills a sense of independence, provides an opportunity for self-expression and promotes intellectual and emotional development whereas motherhood has a counter-effect instilling a sense of dependence, isolation, a loss of identity and status (Baker 1989). Accordingly, when compared to working women, being a mother constitutes a lower social status (Oakley 1980, Pistrang 1984).

²⁵³ All 22 women were biological mothers therefore the applicability of the theoretical model to non-biological mothers is needs to be tested.

²⁵⁴ Examples of this can be found in chapter 8, section 8.4 doing mothering, specifically realising one’s strengths and limitations, and overcoming the challenges of doing mothering.

10.3 The relationship of the process of transition to motherhood to the self

During the analytical phase of the study as the process moved from description to conceptualisation I found that the concepts informing the coding paradigm, although useful as an analytical guide, did not account for the main concern being resolved by women with a disability during their transition to motherhood. One theory that did capture their experiences was the theory of loss of assumptive world, a theory advanced by Colin Parkes (Parkes 1971, Parkes 1975) and Ronnie Janoff-Bulman (Janoff-Bulman 1992). These authors theorised that a psychosocial event, such as a loss, could disrupt one's assumptive world. Although none of the twenty-two women who contributed to this study described their experiences within the confines of loss, becoming a mother did equate to a life changing psychosocial event. Furthermore, the idea that motherhood could disrupt a woman's assumptive world was not, as chapter 4 (see appendix 4)²⁵⁵ illustrated, considered in any depth or in any of the conceptualisations on the transition to motherhood. This study does, it conceptualised the experiences of women with a disability within the frame of meaning reconstruction, by doing so it provides an alternative perspective on the phenomenon and contributes to the existing knowledge relating to transition to motherhood.

Motherhood represented a meaningful gain for all twenty-two women who contributed to this study but even when planned and eagerly anticipated it still took the form of a disruptive event causing disruption to the women's assumption of the self and assumptive world, a world populated with abstract, global assumptions that grounded, secured and directed the course of their life, providing meaning and purpose. These assumptions tended to be hinged on the concept of benevolence, meaningfulness and self-worthiness²⁵⁶ (Janoff-Bulman 1992). In this study, each woman had a fundamental set of assumptions that were created through early childhood interactions with significant others. These assumptions resided at the core of their psyche, they informed the self, the woman's life and actions therein, and served as a guide and filter for life experiences. One critical assumption populating the assumptive world of all twenty-two women was the self-belief that they would be good,

²⁵⁵ Three decades ago, Ann Oakley suggested that motherhood may have a disruptive affect on the woman's assumptive world, she conceptualised the disruption as a loss but the idea was never really explored in any great depth (Oakley 1980).

²⁵⁶ In her theory of loss of assumptive world Janoff-Bulman (1992) suggested that there are three value beliefs: the world is benevolent (relates to people and events, to one's world and future events), the world is meaningful (refers to the relationship between the person and what happens to them, this relationship is characterised by justice and control. Justice - good, decent, moral person deserve good things to happen, positive outcome. Control - implies a person can control or influence what happens to them) and a belief in self-worth (self-worth is centered on the belief that one is essentially good, decent and moral in character and effective in one's actions).

competent, confident and responsible mothers. However, as the first and second phases of the model identified, during the process of transition to motherhood the women's assumptions regarding the self were disturbed²⁵⁷ by both the life changing event (of becoming a mother) and the information received from others in their social world that did not correspond with the woman's own assumptions of the self.

The construct of an assumptive world was first introduced by Colin Parkes (1971) in the thanatology literature through his exploratory work on psychosocial transitions. The concept is founded on the perception that readily accessible assumptions, which are mainly cognitive and constructed in childhood, constitute one's assumptive world (Parkes 1971, Parkes 1975). Conversely, Janoff-Bulman (1992) theorised that individuals construct their assumptive world through the psychological act of believing. Therefore an individual's assumptive world is a believed world, formed and informed by value beliefs of benevolence, meaningfulness and self-worthiness. Neimeyer (2010) disagreed with this assertion, suggesting instead that assumptions are best thought of as 'deeply embedded and obscured in habitual life' (Neimeyer 2010:p41), operational in all aspects of the individual not just cognition and beliefs. Although Parkes (1971, 1975), Janoff-Bulman (1992) and Neimeyer (2010) disagree on the origins of assumptions, they agree that, regardless of their origins, assumptions orientate the individual and their lifeworld, giving them a sense of meaning, reality, control and purpose but once disrupted the level of disruption experienced will depend on the nature and extent of the challenge. Minor events may not threaten the individual's assumptive world so the resulting disruption can be relatively easy to manage. However some events, such as motherhood or loss, can have a profound affect on the individual's assumptions and may challenge, derange or even shatter their assumptive world (Janoff-Bulman 1992). In this instance the individual will be required to make meaning of their experiences and once achieved they then set about formulating new assumptions that will form a new, viable assumptive world but this endeavour is a challenging process, both cognitively and emotionally.

'Having a sense of self' demonstrated how the women's parents, especially their mothers, were instrumental in assisting their daughter to establish assumptions about the self and their world. These interactions provided a base from where the women's sense of self-worth and self-belief evolved. The women developed assumptions that were further built upon and revised through life experiences but their earliest representations remained the most powerful and influential (Janoff-Bulman 1992). These

²⁵⁷ Examples of this can be found in *'confirming the pregnancy'* (see section 7.6, chapter 7) and *'preparing for motherhood'* (see section 7.8, chapter 7).

early assumptions, rooted as they were in early childhood interactions, provided the women with a belief that they were invulnerable consequently, the women especially those with a congenital disability, viewed their world in an optimistic way, they did not perceive themselves to be weak or fragile.²⁵⁸ Accordingly, the women confidently set life goals, one being to become a mother, and understandably they expected these goals to be realised. Quintessentially, for each woman in this study, their assumptive world was an organised schema about everything they considered to be true; pre-motherhood this world was the only world the women knew or thought they knew; a world that included their interpretations of the past and expectations for the future.

The theoretical model presented in the preceding chapters represents how the life changing event of becoming a mother caused a substantial disintegration of, threatened and disrupted, the assumptive world of the majority of women with a disability (n=19) (Janoff-Bulman 1992). This life changing event caused an invalidation of the women's expectations regarding the workings of the self and their lifeworld (Stroebe and Schut 2010), it induced a psychological and emotional crisis, ranging in intensity, that challenged the women's assumptions about the self and their assumptive world. The disruption was augmented by the discrepancy that arose when the women's personal knowledge regarding the self and the information received from others, especially caregivers, encountered during the process of becoming a mother were inconsistent. Lacking an internal guide to help them navigate this disruption, the women, while interpreting their experiences, needed to adopt creative responses to cope with and manage the disruption. They were required to: (i) reorient the self, (ii) recognise what was happening, (iii) restructure their way of viewing the world and (iv) establish new assumptions and a plan of action to deal with the disruption. These actions facilitated the reconstruction of a new, viable assumptive world that took account of the women's experiences. The women substituted her pre-motherhood set of assumptions with the new, modified assumptions of the self as a mother with a disability and their assumptive world changed accordingly.

²⁵⁸ This sense of fragility was experienced post-diagnosis by the four women with an acquired physical disability, informing their sense of fragility was their preconceived idea, pre-disability, of people with a disability; these ideas were informed by the medical model of disability.

10.3.1 Coping with the disruption to one's assumptive world

When the women experienced a discrepancy between their assumptions and understanding of the self and other's perceptions of them, the resulting disruption invoked a crisis of meaning at a deep cognitive and emotional level whereby existing meaning disintegrated. The women had to manage the disruption and to do this they initiated a variety of coping strategies that resulted in the creation of new meaning whereby they gained an understanding of what it meant to be a mother. Coping refers to the women's 'constantly changing cognitive and behavioural efforts [enacted by women] to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman 1984:p141). Conceptualising the coping process Lazarus and Folkman (1984) suggested that individuals appraise a specific situation to determine whether it is a stressor or not and once the situation is determined to be stressful they then enact problem or emotional focused coping strategies to manage that situation. Women with a disability, in managing the disruption that occurred to their assumptive world, enacted both types of strategies. Once invoked, these coping strategies²⁵⁹ facilitated the reconstruction of a viable, non-threatening assumptive world, a world rebuilt on the newly created assumptions of the self, based on their understanding of what it meant to be a mother and developed from their experiences of becoming a mother, being a mother and doing mothering.

Before employing these strategies, the women needed to appraise their experiences to determine the extent of disturbance to their assumptive world to do this they needed to appraise the level of disturbance. Chapters 7-9 illustrated how, through their engagement with maternity services and by accessing antenatal education classes and sourcing information from others, the women tried to determine the effect motherhood would have on the self and their assumptive world.²⁶⁰ For some (n=3), this was a successful endeavour, and once determined they considered the options and resources available to help them to manage and cope with the physical, social, psychological and emotional disruption experienced as a consequence of motherhood.²⁶¹ Problem focused coping strategies were invoked when the woman took direct action to deal with the disruption wherein the woman attempted to define the disruption, create solutions and pursue a plan of action to address the problem. Evidence of this can be seen in the '*making meaning of the self as a mother*' phase as the women, in realising

²⁵⁹ As evident in the phases *making meaning of the self as a mother* and *reforming the self as a mother*.

²⁶⁰ This act of deciding whether or not motherhood would have an adverse effect on the self was the woman's primary appraisal of the situation.

²⁶¹ This consideration of the options and resources available to manage the transition to motherhood was the woman's secondary appraisal of the situation.

their strengths and abilities, took active measures to overcome the obstacles encountered while doing mothering. Alternatively, when the women tried to avoid the caregivers who exhibited negative, patriarchal attitudes, they were invoking emotional focused coping strategies to manage their emotions before becoming overwhelmed by process involved in the transition to motherhood.²⁶²

Whilst Lazarus and Folkman's (1984) framework provided some insight into the theoretical underpinnings of the coping strategies invoked by the women as they managed the disruption that occurred to the self and assumptive world during the process of transition to motherhood it failed to explain adequately why the women may use one strategy rather than the other or how these women interpreted the information associated with the process and the resulting disruption to their assumptive world. Two concepts, advanced by Jean Piaget, provided clarity in this regard, these were assimilation and accommodation (Piaget 1952 cited in Janoff-Bulman 1992). The women employed both concepts in the '*making meaning of the self as a mother*' and the '*reforming the self as a mother*' phases of the theoretical model, as they attempted to: (i) make changes to new, incoming information from others in their social world so as to achieve a fit with their existing assumptions regarding the self or, (ii) they embodied the changes that accompanied motherhood within their pre-existing assumptions in order to achieve a fit with the new incoming information. Essentially the women had a choice to make, either retain the pre-existing, pre-motherhood assumptions pertaining to the self that were no longer viable or applicable or accept the changes accompanying motherhood and reform the self and one's assumptive world accordingly. Consequently, three different outcomes resulted: (i) the women maintained existing assumptions pertaining to motherhood, these were unchanged despite the information received (n=0) or, (ii) the women abandoned their existing assumptions regarding motherhood, and developed and adopted new assumptions shaped by their experience of becoming a mother, being a mother and doing mothering (n=19) or, (iii) the women developed an integrative middle ground while continually negotiating the challenges motherhood caused to their assumptive world (n=3). To manage and cope with the disruption, induced by the transition to motherhood, the women needed to embrace their reformed assumptions of the self and use these to re-establish a new, viable assumptive world. Evidently, in this study, all twenty-two women did achieve this but for Natasha, Christine, Emily, Louise and Helen, this reformation was a tenuous one, and their search for meaning was reignited when the

²⁶² Examples of problem and emotional focused coping strategies can be found in sections 7.7, chapter 7; 8.2, chapter 8 and 9.2, chapter 9.

information received from others in their social world did not correspond with their reformed assumptions of the self as a mother.

10.3.2 Constructing meaning about the self as a mother

Individuals are meaning makers and meaning is an essential requirement to everyday living (Landman 2002, Neimeyer et al. 2002). During the process of transition to motherhood each woman who contributed to this study constructed new meaning, emotionally and cognitively, to understand what it meant to be a mother. Thompson and Janigan (1988) define meaning as: (i) the ability to identify new goals and purpose when an individual experiences a disruptive event or (ii) the ability to reconstruct a self to incorporate the experience of a disruptive event (Thompson and Janigan 1988, Janoff-Bulman 1992, Davis 2010). The actions taken during the second phase of this theoretical model helped the women make meaning and gain an understanding of the self as a mother, once created they established new assumptions that shaped how they reformed the self and their assumptive world to incorporate motherhood. In their attempts to make meaning the women engaged in a process of resolving cognitive dissonance whereby they let go of the old, pre-motherhood self and through their actions of: (i) modifying their lifestyle, (ii) reprioritising their personal and life goals, (iii) relinquishing their occupational self and (iv) reconfiguring relationships with others the women set the foundations for the establishment of a coherent set of assumptions that incorporated motherhood and resulted in the creation of less naïve perceptions of the self and their world (Rando 2002).

Each woman that participated in this study experienced an unexpected discontinuity in the self and their assumptive world albeit to differing degrees. Consequently, one of three alternative outcomes²⁶³ resulted: (i) constructive bankruptcy whereby no dimension of meaning was achieved and the women's experience was positioned in either a positive or negative domain (n=0),²⁶⁴ (ii) dissociated construction, a process where the women created constructs that were subsequently used to interpret and deal with the processes of becoming a mother, being a mother²⁶⁵ and doing mothering (n=19), and

²⁶³ In their original format the three alternatives - constructive bankruptcy, dissociated construction and elaborate growth – were described by Kelly (1955) as processes individuals enacted when coping with anxiety associated with a post-traumatic event.

²⁶⁴ None of the 22 women who contributed to the study fitted within this configuration.

²⁶⁵ Nineteen women engaged in this process of dissociated construction whereby they constructed new meaning and this resulted in them engaging in activities that were instrumental in the formation of a reformed self.

(iii) elaborative growth²⁶⁶ (n=3) whereby the women made minor adjustments to the self and their assumptive world to incorporate motherhood (Kelly 1991). Regardless of the level of disruption experienced, all twenty-two women needed to and did reconstruct new meaning that created a renewed perception of the self as a mother with a disability. The process of making meaning increased the women's mindfulness and reflexive awareness that their life was transformed and enhanced as a result of being a mother and how, in the case of nine women, other things like occupational success, which was extremely important to the women pre-motherhood, were no longer considered as important. This was reflected by the fact that these nine women chose not to work outside the home, they considered being a mother to be their defining characteristic. The remaining thirteen women considered their maternal self to be important, but it was not their defining characteristic, rather it was an entity that was compatible with other entities of the self like their occupational self, they returned to work but on return to work all noted how their working practices and priorities had changed.

Once meaning was achieved the woman had to become accustomed to their new understanding of the self and had to learn to incorporate their altered assumptions and use them to rebuild a new, viable assumptive world. This relearning process involved learning new ways of acting and being in the world, a world that pre-motherhood was lived through the occupational self. This process of relearning one's world involved the interchange of meaning making and meaning finding. By '*engaging in and doing the activities of mothering*' the women created meaning about the self as a mother whereby they: (i) assigned meaning to their experiences and actions, (ii) generated unparalleled patterns of understanding, (iii) moved forward with new, meaningful assumptions and (iv) reconstructed and reinterpreted aspects of their lives. Alternatively, meaning finding refers to the times when the women were less self-conscious and were more passive, when they resorted to assumptions already established, returning to experiences and actions that had a familiar meaning²⁶⁷ (Attig 2002). With the new meaning that was created the women reformed the self and reshaped and redirected their lives; motherhood was a new chapter in their life, one that incorporated their new assumptions of the self, established from their lived experience of becoming a mother, being a mother and doing mothering, a life with new direction and purpose (Attig 2010, Neimeyer 2010).

²⁶⁶ Three women engaged in the process of elaborative growth whereby they made minor adjustments to their assumptive world to accommodate motherhood consequently, the level of disruption experienced was minimal.

²⁶⁷ Example of this can be found in the '*having a sense of self phase*', while interacting with caregivers the women assumed a state of helplessness whereby they tried to gain an element of control over their experiences.

10.3.3 Reforming the self as a mother

'(Re)constructing Myself' represents how, when the assumptive world of a woman with a disability was disrupted by the biological act of becoming a mother and the information received from others regarding her ability to meet the requirements implicit in that role, the process of rebuilding one's assumptive world was a complex undertaking. Nevertheless the process was achieved by the activation of two systems 'the cognitive and emotional, the rational and the experiential' (Janoff-Bulman 1992:p 94), which required the woman: (i) to manage and process the information gained from her personal experience of becoming a mother, being a mother and doing mothering, (ii) to reinterpret this information so as to ascertain its fit with her assumptive world, and (iii) to determine the actions needed to facilitate the integration of motherhood and the self. The sociological discourse on the transition to motherhood suggests that during the transition, women experience a loss of self and self-identity. However, as previously discussed, this did not resonate with the experiences of the women who contributed to this study, moreover the conceptualisation to emerge here, that the self is reconstructed not lost, is a more optimistic representation of the relationship between the process of transition and the self.

10.3.4 The importance of letting go

The cognitive practice of letting go was an important practice in the process of transition to motherhood for women with a disability. It was an essential cognitive practice that contributed to the reconstruction of new assumptions about the self. When women embarked on this practice they relinquished specific entities of the pre-motherhood self that they perceived to be incompatible with the new maternal self. Moving from being a non-mother to a mother had an immense impact on all aspects of the women's lives. The biological act of becoming a mother and being a mother altered and transformed the women cognitively, emotionally, psychologically, physically and socially. New information achieved from becoming a mother, being a mother and doing mothering provided a sense of enlightenment regarding what was worthwhile in their life, their life took on new meaning, they reprioritised life plans²⁶⁸ and they gained a new appreciation of the self.

²⁶⁸ Examples can be found in '*creating, maintaining and reconfiguring relationships*' (see section 9.2.4, chapter 9) and '*reprioritising one's life and professional goals*' (see section 9.2.2, chapter 9).

The process of transition to motherhood also signified a shift in the women's priorities, in the majority of cases their own needs became surplus to the needs of their child(ren), in the case of Louise, Natasha and Sinead this created a conflict between the 'individual and the inter-subjectivity' (Holloway 2010:p26). *'Realising one's strengths and abilities'* captured how during the process of doing mothering some women paused to take stock of their lives, to identify their strengths and abilities and to devise 'a personal inventory of their capabilities' (Czuchta and Johnson 1998:p33). This practice of taking stock resulted in the women implementing measures, such as the seeking of assistance and support from others, to help manage the physical and sensory tasks associated with mothering and, in doing so, increased the women's self-esteem and self-confidence. Being a mother and doing mothering also provided the women with new possibilities that resulted in life-style changes. Pre-motherhood the women's career and occupation were significant contexts in which they constructed and preformed the self (van Schalkwyk 2005) but once they became a mother, a significant number of women chose to downscale their occupational ambitions, and prioritised motherhood over work. Kerrie took extended maternity leave; Aine, Christine, Helen, Emily and Jackie decided that the financial cost of childcare and the associated emotional cost of having someone else care for their child(ren) were much greater than the loss of one salary; Sharon and MSK, decided to take the voluntary redundancy package on offer from their respective employers. Consequently, the women experienced a shift in the pace of their life, moving from a regimental working life pre-motherhood to a more fluid pace of life as a mother (Brunton et al. 2011). Many of these women also had to re-conceptualise the self, from one that, pre-motherhood, was financially independent to one that was financially dependent on their respective partners but nevertheless the women's decision not to work outside the home did not, as some suggest, cause them to feel less valued (White 2010).

While nine women considered the occupational and maternal selves to be competing entities, thirteen considered their occupational and maternal selves to be complimentary but these women reiterated the importance of achieving a work/life balance. The practical and moral complexities involved in being a working mother were captured in *'relinquishing the occupational self'*. The women described how, while pre-motherhood their occupational self took precedence, once they became a mother their work practices altered and although their productivity was the same or greater than pre-motherhood, they were less flexible with their time. Echoing the experiences of non-disabled women, the existence of a family friendly policy impacted on the woman's productivity and her ability to combine her occupational and maternal selves harmoniously (White 2010). Selina worked in an environment that had such a policy but for Louise and Natasha the lack of a family friendly policy and

flexibility within their workplace was the source of much debate and anxiety.

10.4 The importance of symbolic interactions with others located in one's social world

'Having a sense of self' illustrates how others located in the women's social world, especially their mother, were instrumental in the construction of an assumptive world that, once disrupted, needed to be rebuilt. The process of rebuilding a valid, supportive assumptive world was embedded in the context of symbolic interactions with, and the appraisals of, others located in their social world. During the second phase of the model, the women accessed four different types of support: (i) esteem support - where others in their social world provided information that inferred how they were accepted, valued and respected; this support, as evident in *'having to prove oneself to caregivers'*, affected the woman's ontological shift to motherhood; (ii) instrumental support - referring to the ability of others to provide financial support, resources and services that would assist the women in their maternal role, this support was mainly provided by the woman's partner; (iii) informational support - a support network that provided information that assisted the women to cope with and manage motherhood, this support was received from the women's own mother and other mothers; and (iv) social companionship - this support was gained when the women reconfigured their relationship with others, especially when they developed new friendships with other mothers (Cohen and Willis 1985). Many of the women established a support network that validated their self-worth and provided the safety and protection necessary for them to cope with and manage motherhood.

While the role of others can be affirmative it can also be unconstructive. This and other studies (Kallianes and Rubinfeld 1997, Thomas 1997, Thomas and Curtis 1997, Thomas 1998, Faber 2000, Grue and Tafjord-Laérum 2002, McKeever et al. 2003, Prilleltensky 2003, McFarlene 2004, Prilleltensky 2004a, 2004b, Lee and Oh 2005, McKay-Moffat and Cunningham 2006, Smeltzer 2007, Malacrida 2009, Begley et al. 2010, Walsh-Gallagher et al. 2012) identified how women with a disability were vulnerable to the assumptions and judgements of others in their social world, some of whom assume that these women do not conform with dominant social norms. Such responses were expressions of stigma, imbued and motivated by fear, confusion and a lack of understanding of people with a disability (Kralik and Telford 2005a). This study revealed how when the women encountered interactions infused with negativity and experienced a diminution of support they suffered a secondary disruption to their assumptive world. In an endeavour to manage this secondary disruption many women purposefully distanced themselves

from others (for example, friends who were not mothers). This was a means of protecting and preserving the self, a means of maintaining a sense of control over their relationships with others.

10.4.1 Experiencing stigma

Putting '(Re)constructing Myself' into context, women with a disability expressed a desire to reside in a world that recognised them as independent, autonomous agents, a characteristic that eluded them pre-motherhood because of the negative and marginalising actions of a society that considered disability within the confines of the medical model of disability, a functional deficit to be cured or ameliorated. The theoretical model presented in this thesis represents how the self is informed by wider social and structural variables (Goffman 1963, Edwards and Imrie 2003). The women's descriptions of interacting with others, particularly pre-motherhood when '*preparing for motherhood*' and as a mother when '*engaging in and doing the activities of mothering*' corresponded with the descriptions of stigma and its consequences proposed by Goffman and Jones (Goffman 1963, Jones et al. 1984). Undoubtedly, this study echoed the findings of other studies that indicate how stigma and discrimination remain the greatest challenges women with a disability encounter in modern society (NDA 2002, 2007a, 2007b, Russell et al. 2008, Begley et al. 2009b, 2010, Briant et al. 2011, NDA 2011). Many of the women experienced differing degrees of acceptance by others who had a tendency to perceive them as helpless, dependent individuals. Stigma affected the woman's sense of self and belonging (Sargent et al. 2002), it inferred a state of otherness, whereby the woman was defined not by her abilities but by her physical or sensory inabilities (Edwards and Imrie 2003). Goffman defined stigma as a disparity occurring when an individual's social identity does not correspond with the anticipated social identity and is realised when the attitudes of others 'reduce the bearer from a whole and usual person to a tainted, discounted one' (Goffman 1963:p3). Conversely, when an individual conforms to the anticipated expectations of a specific identity they are considered to fall within the sphere of normality. '(Re)constructing Myself' reaffirms how the experience of stigma is a relational one, constructed through the women's interactions with others, specifically caregivers and others located in the woman's social world. Evidently, stigma developed when others concluded that the woman's disability was an attribute that represented her differences (Jones et al. 1984). Consequently, the women were exposed to a range of tactless behaviours, ranging from patronising comments to clear contempt and hostility²⁶⁹

²⁶⁹ The women were subjected to stereotypical, negative, prejudicial attitudes; they encountered structural, information and communication discrimination, felt isolated, belittled, demeaned and marginalised (see sections 7.6 and 7.8, chapter 7).

(Begley et al. 2009b, Barnes and Mercer 2010, Begley et al. 2010), which left the women feeling belittled, demeaned, devalued and humiliated.

The women engaged in a number of strategies namely, passing, covering and withdrawal to manage the information, regarding their disability, imparted to others. Goffman's conceptualisation of stigma is confined to within the individual but recent conceptualisations move it outwards to the socio-cultural processes of contemporary society. Here, stigma is perceived as a process that labels, stereotypes, isolates, discredits and discriminates individuals who are perceived as different (Crocker et al. 1998, Link and Phelan 2001, Scambler 2009). It has a significant effect on all aspects of the individual's life; a fact exemplified by the experiences of women in this study, their experiences of stigma, external and internal, caused them to feel demoralised and engendered a sense of unworthiness.

10.4.2 Assuming a state of helplessness when interacting with others

While interactions with caregivers were a momentary interlude in the women's lives, these interactions were influential, they enhanced or marred the women's experiences of pregnancy, childbirth and early motherhood (Benoit 1987, McCrea 1993, Berg et al. 1996, Halldorsdottir and Karlsdottir 1996, Harcombe 1999, Siddiqui 1999, Walsh 1999, Coyle et al. 2001, Hunter 2001, Hunter 2002, Pratt 2002, Freeman 2006, Hunter 2006, Lundgren and Berg 2007, Hunter et al. 2008). Caregivers were instrumental in shaping the women's expectation and experiences of motherhood during pregnancy and in the early motherhood period²⁷⁰ but in late motherhood²⁷¹ it was the interactions with other mothers, particularly their own mothers; that were instrumental in shaping the women's experiences. In early motherhood the women, particularly first time mothers (n=10) lacked experiential knowledge so they referred to caregivers, the perceived experts, to guide them in their decisions and practices. There was a valorisation of professional knowledge, a knowledge influenced by biomedicine, technology and the concept of risk. This was evident in the women's willingness to engage in the medicalised practices implicit in the preparation for motherhood. Although some women rejected the

²⁷⁰ Early motherhood refers to the first six week after the birth of the baby, a time when the woman is still under the care of caregivers so they continue to be influenced by the actions, behaviours and knowledge of these caregivers.

²⁷¹ Late motherhood refers to the period after the first six weeks post the birth of the baby, a time when the woman disengages with caregivers and is discharged from maternity services. During this period the women accesses support and information on motherhood and mothering beyond caregivers, they engage with other mothers and other women they regard as role models, like their own mother.

over emphasis on screening for abnormalities in the unborn or newborn and many encountered numerous structural, attitudinal and information obstacles while negotiating maternity services, none, with the exception of one woman (Betty), questioned the medicalised nature of the services or care being provided. The women did question: (i) the attitudes encountered when interacting with caregivers and (ii) the practice of pathologising and problematising of their disability. Although the caregivers' attitudes and practices disrupted the women's assumptions of the self, none of the women questioned or rejected the normative practice of the medicalisation of childbirth, the majority of women willingly submitted the self to the authority of the medical discourse (Oakley 1979, 1980, Rothman 1989, Sargent and Bascope 1997, Fox and Worts 1999, Miller 2000a, 2000b, Kennedy 2002, Miller 2003, Miller 2005, O'Connor 2006, Devane et al. 2007).

This valorisation of professional knowledge is consistent with the findings of Miller's (2005) study but inconsistent with the findings of other studies (Oakley 1979, 1980, Rothman 1989). This practice of prioritising professional knowledge was embedded in childhood. *'Having a sense of self'* highlighted how professionals indoctrinated in the medical model of disability; biomedicine and technology were successful in persuading some parents to use interventions in their attempts to ameliorate their daughter's disability. This practice affected how women with a disability assimilated disability and the self. During pregnancy and in the early motherhood period, the women, especially those pregnant with their first baby, perceived caregivers to be experts and the knowledge they espoused was accredited as valuable while the woman's experiential knowledge was relegated to a lower status but as the women disengaged with caregivers and gained experience, confidence and competence in mothering there was a shift in this categorisation. Louise's (PCD) narrative demonstrated how the women began to question the knowledge and practices espoused by caregivers *'this time around [second pregnancy] I'm a lot more able for them [caregivers] I'm not taking any shit, I don't care what they threaten me with, I'm not putting up with any shit from anybody this time around.'* Clearly, the valuing of professional knowledge was fluid and transient, the women moved from a position of valuing professional knowledge and the expert status espoused by caregivers to a position where they recognised the self as the expert, in possession of expert knowledge.

When the women's interactions with caregivers were marred by stigma the women were motivated to act from within and outside the self. One such action was to assume a state of

helplessness, a state induced by the many structural constraints²⁷² that affected the women's sense of agency. In trying to understand why the women would conform to such a state, I discovered the theory of learned helplessness²⁷³ (Peterson et al. 1995). This theory provided the theoretical underpinnings that helped me understand why women, particularly those with a congenital disability, who consider disability to be a defining entity of the self (n=13), would intentionally assume a helpless state. Paradoxically, for these women assuming a state of helplessness was a coping mechanism, a way of maintaining control over a situation that they had assessed as uncontrollable. The women knew from their previous experiences of interacting with medical professionals, both in childhood and adulthood that they could not control the attitudes and behaviours of the caregivers they encountered during their transition to motherhood. What appeared to be helplessness was in fact the woman's attempt to gain control over a specific situation.²⁷⁴ Conversely pre-disability, the four women with an acquired disability perceived people with a disability to be helpless; they considered helplessness to be an associated attribute of disability, one they readily assumed when interacting with caregivers during their transition to motherhood.

The theory of learned helplessness was first described in 1960,²⁷⁵ since then it has been used to describe individuals' behaviour in a variety of circumstances, most notably with depression. As previously discussed, helplessness was a specific cognitive, coping strategy invoked when the women, especially those with a congenital disability, assessed the situation they found themselves located in as uncontrollable. Interacting with caregivers was the stimulus that was associated with negative connotations, like stigma and discrimination and so, as the women continually interacted with the caregivers they became non-responsive and assumed a passive state. This passivity was a psychological act enacted to help them meet the demand of the situation as they prepared for and became mothers. The premise of learned helplessness is based on three essential elements: (i) contingency, (ii) cognition and (iii) behaviour. Contingency refers to the objective relationship between the women's actions and

²⁷² Structural constraints refer to the structural, informational and communicational challenges women with a disability encountered while accessing the publicly-funded maternity services in Ireland.

²⁷³ Just like the notion of an assumptive world, the idea that women, during the process of becoming a mother, adopt a state of learned helplessness was alluded to by Ann Oakley (1980) but was not expanded on.

²⁷⁴ Control took the form of primary or secondary control. Primary control describes the women's ability to align their environment with their wishes; it encapsulates the women's first and preferred response to the uncontrollable situation, one such response being the adaptation of a state of helplessness. Secondary control and its three configurations: i) predictive control referring to instances where the woman downgrades her abilities, skills and accomplishments, ii) illusory control referring to the control gained when a woman aligns circumstances with chance or fate and iii) vicarious control referring to the action of aligning oneself with powerful individuals or groups where such associations infer a sense of control, represented the women's ability to align the self with their environment.

²⁷⁵ In experimentations with laboratory animals.

the outcomes experienced. In this study the women felt that they had no control over the interactions with caregivers, this feeling contributed to the women's sense of uncontrollability. Cognition alludes to the way the women explained contingency.²⁷⁶ When the women interacted with caregivers, they temporarily assumed a passive, helpless state but once they were discharged from the maternity services and the interactions with caregivers concluded the helplessness dissipated and they regained a sense of agency. Passivity was the means by which they coped with the inferred stigma and discrimination of others. In addition to experiencing a sense of helplessness the women also experienced impaired cognition, low self-esteem and a feeling of depreciation. The resulting motivational and cognitive disturbance did disrupt some women's ability to mother effectively especially while in the maternity units and affected their ontological shift to motherhood.

10.4.3 Reconfiguration of relationships with others

With the arrival of a new generation, the woman's relationships with others changed accordingly to accommodate their new role as mother. Overall, the women's relationships with others became more solid and contained. Their relationship with their partner 'changed completely' (Aine PAd), this change was augmented by the new demands of parenting. In becoming parents, the couple needed to work together to mesh their changing individual biographies. For Maggie, Evelyn, Sharon, Aine, Helen, Selina, Olive, Louise and Emily, their relationship with their respective partners became deeper and stronger but for Christine, Kerrie, Aoife, Lorna and Helen their relationship with their respective partners was often offset or replaced by the mother-child relationship. The consuming nature of doing mothering made it very difficult for the women and their respective partners to be intimate and close, the spontaneity and impulsiveness present in their pre-motherhood relationship dissipated and sexual intimacy diminished. For one woman (Natasha), the birth of her son coincided with the end of her relationship with her partner. The end of this relationship was not necessarily associated with being a mother or doing mothering but motherhood did cause her to reconsider and reevaluate the basis and quality of the relationship. While parenting was generally described as a joint endeavour, the extent to which the division of labour was egalitarian varied. Christine, Kerrie, Lorna, Aine, Jackie, MSK, Birte and Sharon assumed a more traditional role to parenting whereby they were primarily responsible for

²⁷⁶ Cognition was achieved by the enactment of several steps: (i) the woman needed to understand the contingency; (ii) she then explained what it was she perceived it to be and (iii) used this explanation to anticipate future action. When located in a similar situation to the one where helplessness was experienced previously she could expect to feel helpless again.

childcare.

Many women indicated how their own mother played an important role in the reformation of the self as a mother. For some, particularly Helen, Emily and Anne, becoming a mother enhanced their relationship with their own mother, a relationship that pre-motherhood was fragile and in some cases fraught with conflict, but motherhood helped these women develop an understanding of their mother and the role she adopted in the family unit that heretofore eluded them and was a source of animosity between them. The women re-evaluated their relationships with their mothers; they experienced a sense of intense connection not present pre-motherhood. This identification and renewed connectedness with their mother caused some to revisit their own childhood. Moreover, the importance of generation and kinship on the development of a female biography was demonstrated by the women's desire to mother in a similar manner to the way they were mothered (Lawler 2000). Many considered their own mother to be a role model; they, unlike the participants in previous studies (Thomson and Kehily 2008, Thomson et al. 2011), wanted to replicate the parenting styles and practices employed by their mother. Relationships with siblings and friends, especially those with children, also became stronger or were re-energised, the women appreciated the sense of commonality and support inherent in such relationships (Mauther 2002, Thomson et al. 2011).

10.5 Does the nature of one's disability inform the construction of a sense of self?

Twenty-two women participated in this grounded theory study. While twenty-two is a relatively small number, this is the norm for qualitative studies aiming to explore an individual's subjective experience. The narratives of the twenty-two women who participated in the study revealed that the nature of the woman's disability did influence and inform the woman's assumptions of the self and assumptive world before and after they became mothers. The data illustrated how pre-motherhood women with a congenital disability (n=18), with the affirming support and sense of belonging instilled by their parents, especially their mother and siblings, successfully assimilated their disability and the self. Accordingly they described their disability as a defining or non-defining entity of the self. Thirteen of the eighteen women claimed a disability identity (Watson 2002, Shakespeare 2006) whereby they described their disability as a defining entity, a positive attribute of the self. These thirteen women rejected the negative implications of dependence and helplessness more commonly associated with the medical model of disability. Rather, they considered their disability to be caused by the exclusionary and unjust

social obstacles frequently encountered (Shakespeare 1996). Those with a congenital disability questioned the notion of normality and the concept of a normal body, they rejected physicality as an essential constituent of the self, their disability and related physical or sensory limitations were perceived to be part of the self and their self-identity. The women's notion of self was formulated on what they felt the self to be, not how others perceived them to be. This perception of the self was significantly altered when accessing and availing of maternity care during pregnancy, childbirth and early motherhood. The misfit and inconsistencies that evolved between health professionals' perceptions of the woman and the women's perceptions of the self caused a significant disruption to the women's assumptions of the self. Consequently the women were compelled to instigate a variety of coping strategies that facilitated in the creation of new assumptions about the self and this in turn helped the women to make meaning of their experiences. This meaning contributed in the reconstruction of the self, a self as a mother, a mother with a disability.

Conversely, pre-motherhood the four women with an acquired disability considered disability to be an anomalous entity of the self. They did not take on a disability identity rather the acquisition of a disability significantly impacted on the women's assumptions of the self, their self-esteem and self-image. Disability disrupted their assumption of the self and their assumptive world in a negative way. The women formed a negative sense of self, they experienced difficulty adjusting to and living with a disability. They had to reconstruct a self capable of residing in a society whereby the majority of its population are perceived as functional, independent, capable individuals with the capacity to engage in social reciprocity (Lindgren 2004, Barnes and Mercer 2007, NDA 2007a). The women perceived the post disability self to be separate from the old self (Murphy 1990, Wendell 1996, Lindgren 2004). This new, revised self was deemed to be less of a person, a burden on others and on society. The women's difficulties in coping with and living with a disability were accentuated by the stigmatising and discriminating perceptions of non-disabled individuals located in their social environment, this included health professionals encountered during the continuum of pregnancy, childbirth and early motherhood. Stigma and discrimination, generated from negative, patriarchal attitudes, created obstacles and challenges that impeded the women's adjustment and adaption to living with a disability. This difficulty was reinforced by the challenges encountered by the women when doing the physical activities of mothering, and when others, primarily individuals with no disability, questioned the woman's ability to mother and protect her baby. Becoming a mother and doing mothering did cause the women to consider the impact their physical disability would have on their ability to mother. Accordingly, the women developed an awareness of their physical limitations but more importantly they became aware

of their strengths. This awareness of one's strengths caused a shift in the perceptions of the self to a more positive domain, this shift towards positivity assisted women to accept, to cope and live with their disability. Saliently, the process of transition to motherhood was transformative for women with an acquired disability, through the continuum of pregnancy, childbirth and motherhood their sense of self transformed from a negative to a positive one.

10.6 Unique contribution of thesis to existing knowledge on transition to motherhood

This study set out to explore the process of transition to motherhood and the relationship of the process to the self from the perspective and experiences of women with a disability. Previous studies exploring the transition to motherhood did not include women with a disability in their sample. So the experiences of these were undocumented and the appropriateness of current extant theories on transition to motherhood unexplored. Furthermore, most of the existing theories on the transition to motherhood use attainment, adjustment and adaptation to describe how women manage the transitional process involved in becoming a mother. Moreover few have explored how the process of change affects the self. The theory developed from this study and presented in this thesis supplements existing theories on transition to motherhood, self and identity. It substantiates some and refutes other theories regarding the transition to motherhood. Saliently, within the frame of meaning reconstruction the theory of (Re)constructing Myself offers new knowledge about the conceptualisation of motherhood, the transitional process involved and the relationship of this process to the self from the perspective and experiences of women with a disability. It is intended that the conceptual framework presented in this thesis will be used as a tool to assist health professionals as they support and facilitate women with a disability in their transition to motherhood.

10.7 Reflections on the use of grounded theory as a methodology

Methodologically, the decision as to how this study would be conducted was determined by the purpose of the study. The study was concerned with exploring the process involved in the transition to motherhood from the perspective of women with a disability. Chapter 4 catalogues the anthology of

theories that currently exist in relation to the transition to motherhood. These theories are primarily from the perspective and experiences of non-disabled women, the experiences of women with a disability were under documented so further research on this phenomena from the perspective and experiences of these women was required. Grounded theory, specifically Strauss and Corbin's logical-deductive approach to grounded theory, with its focus on process and meaning was deemed to be the most appropriate methodology to address the purpose of the study. The substantive theory to emerge, grounded in women's experience, will expand the current knowledge base on the conceptualisation of motherhood, the transitional process involved and the relationship of this process to the self from the perspective and experiences of women with a disability.

When choosing a methodology I was conscious of the importance of aligning the chosen methodology with the purpose of the study and with my own epistemological and ontological positions. Commonly aligned with interpretativism and post-positivism grounded theory fitted with my epistemological position of constructionism and ontological position of critical realist wherein I believe that there is one reality however imperfectly apprehendable. Since its inception in 1967 grounded theory has gained momentum and credibility. Several texts elaborating, expanding and debating the methodology have been published. I like others using grounded theory for the first time, read and consulted the myriad of texts. Once consulted, I realised there were major philosophical differences between the different approaches to grounded theory. These philosophical differences compounded the well published rift that occurred between the co-origins Glaser and Strauss. This rift resulted in the emergence of two different approaches to grounded theory, the Glaserian approach and the Strauss and Corbin approach. I used a Strauss and Corbin approach, firmly rooted in symbolic interactionism and pragmatism, this approach offered procedural guidance on the different forms of sampling and data analysis but what was missing was practical guidance on the how to issues of the approach so I, at the outset of the study, grappled with the many issues catalogued below.

The first issue that created a lot of anxiety was the requirement to have or not have a research question at the outset of the study. While most researchers embarking on a research study set out with a research question, this was not the case for me. My starting point was not a question but a general interest in the process involved in the transition to motherhood for women with a disability. Research questions did evolve much later in the study; they were a product of analysis. While reading the seminal texts on grounded theory I realised that in grounded theory not having a research question at the outset of the study was reasonable. However, this knowledge did little to dispel the anxiety felt when colleagues and others would ask what is your research question?

The second issue I grappled with was the requirement to have a tabula rasa. The Glaserian approach advocates a tabula rasa but I was uneasy with this requirement, principally because of my professional background, my knowledge of theories on the transition to motherhood and my involvement in a previous study exploring the experiences of women with a disability while accessing the publicly funded maternity services. While acknowledging that the setting aside of perceived theoretical ideas would ensure an inductive approach to data collection and analysis, I think it is impossible to conduct a study and to enter the field during data collection with a tabula rasa, especially when the topic being explored is aligned with the researcher's professional area and when a large volume of literature exists on the topic. Strauss and Corbin's approach to grounded theory recognise the irrationality of a tabula rasa; they advocate a more logico-deductive-inductive approach to the development of a substantive theory.

A third challenge I encountered when using grounded theory was the practical know how of how to code the data. The process of coding the data and the procedures involved are well documented in the various texts but nonetheless I still wrestled with the practical issues of: (a) open coding, (b) categorising the data, (c) recognising whether the data was a category or indeed a property or dimension of a certain category, and deciding on/choosing a core category. I was concerned that the core category may not be the correct one, the one that would capture and explain the experiences of women with a disability. In the end I settled on the core category of (Re)constructing Myself because I genuinely felt it captured the transitional process involved in becoming a mother and the relationship of the process to the self. The process of coding occurred simultaneously with data collection; once the first interview was conducted I began open coding. This was a laborious process; it involved looking at each line, allocating codes to words or a collection of words. In their latest text, Strauss and Corbin (Corbin and Strauss 2008) provide examples of how to code the data but despite these examples I still encountered a heightened level of anxiety in regard to: (a) the codes I applied to the data, specifically that they may not be plausible and may not be interpreted in the same way by others and (b) at times it was difficult when applying concepts not to use concepts from the existing literature. As the process of coding proceeded I moved from open coding to axial coding, it was at this point that open codes were grouped into categories and subcategories, and the relationship between categories determined. A stumbling block I encountered at this point was deciding which of the categories, was in fact, a property of another. Consequently some categories were elevated, some downgraded, the decisions as to which categories were ungraded or downgraded lay in the constant comparison of the data, where I looked for patterns in the data. I was very aware of the importance of finding the relationships between categories

and the how this was critical in the generation of theory. Strauss and Corbin's approach involved the use of a coding paradigm where in order to establish the relationships between categories; I examined the data for context, conditions, actions/interactional strategies, intervening conditions and consequences. Initially, when applying the coding paradigm, I did experience some anxiety and the relationship between codes and categories difficult to decipher. I used the coding paradigm to make distinctions in the data, these distinctions helped in the formation of categories. Throughout axial coding I harboured a concern that lay at the heart of the dispute between Glaser and Strauss, the co-originators of grounded theory, I was concerned that by using a coding paradigm I was in fact forcing the data into a conceptual description rather than allowing the concerns of women with a disability to emerge freely. This fear dissipated as my confidence grew over the duration of the study and I found the procedure of memoing, which intensified as the process of analysis deepened, invaluable. The use of theoretical memos and integrative diagrams enhanced the process of coding; they were vital to the development of my ideas about the data and were instrumental in the creation of links/relationships between categories. The memos and diagrams were invaluable when explaining the emergent theory, to myself and others. Diagrams allowed me to visualise the relationships between categories. They were very useful when explaining the emerging theory to others, more importantly they were a tool which provided a different view of the developing theory, as a visual person this was extremely helpful during coding especially when conceptualisation seemed to plateau.

So to conclude, on reflection, despite encountering the many issues outlined above, particularly those around coding, and the related heightened level of anxiety that accompanies a study at doctoral level, grounded theory was indeed the most appropriate approach to use in this study. The anxiety I felt in the earlier part of the study dissipated as my confidence and my competence in coding grew over the duration of the study. The substantive theory that emerged from the study provides a new conceptualisation on motherhood, the transitional process involved and the relationship of that process to the self from the perspective of women with a disability.

10.8 Conclusion

Mothering is an embodied experience; an experience located within a frame of responsibility, whereby there is a cultural and moral imperative to take responsibility for the baby, an experience that

has a profound affect on the self and the woman's assumptive world. '(Re)constructing Myself' captured the moral growth and process of transcendence involved in the construction of the self as a mother with a disability. Motherhood was transformative for women with a disability it inferred a new positioning in society and a new sense of personhood. The personal experience of becoming and being a mother affected the self and the women's worldview. It initiated the creation or restoration of positive constructions of the self and was instrumental in the reconstruction of a self that was confident in both the public and private domains (van Schalkwyk 2005). Motherhood instilled hope, which was manifested in the 'anticipation of a future which is good and is based upon: mutuality (relationships with others), sense of personal competence, coping ability, psychological wellbeing, purpose and meaning in life, as well as a sense of the possible' (Miller 1992:p414). If caregivers are to provide effective, supportive women-centred care²⁷⁷ for women with a disability, then they need to develop an awareness of the extant theories regarding meaning reconstruction following a life changing psychosocial event, like motherhood. The conceptual framework generated during this study and presented in this thesis is intended to be used as a tool to assist caregivers in this regard as they support and facilitate women with a disability in their transition to motherhood. The concluding chapter offers clear, simple and mostly cost-neutral recommendations, based on the women's experiences that will support caregivers in the provision of care for women with a disability and facilitate their transition to motherhood. If women with a disability are to receive truly women-centred care and if their transition to motherhood is to be facilitated, consideration must be given to the development of a coherent, comprehensive national infrastructure to support mothers with a disability. This would include the introduction of a national midwifery disability advisor, an invaluable supportive intervention that would ensure continuous access to support and advice during pregnancy, childbirth and the transition to motherhood for women with a disability.

²⁷⁷ The concept of woman-centred care originated in the second wave of feminism in the 1960-1970's, it forms the bases of midwifery practice philosophy whereby: (i) there is a focus on the woman's individual needs, aspirations and expectations, (ii) a recognition that women need choice, control and continuity from known caregiver(s), (iii) it encompasses the needs of baby, woman and family, and others determined to be important by the woman, (iv) follows the woman interfacing with acute and community settings, (v) addresses woman's specific needs and expectations and (vi) recognise woman's right to participate in the decision-making process (Leap 2009).

Chapter 11 Recommendations

The substantive theory of '(Re)constructing Myself' represents the psychological and emotional disturbance women with a disability experienced when, during their transition to motherhood, their respective assumptive worlds were disrupted and the subsequent process of adaptation the women engaged in during the transition. The disruption occurred when their assumptions of the self as a woman with a disability and the self as a mother did not correspond with the information received from others located in their social world. The theory presented in this thesis highlights the observable actions the women implemented to make meaning of their experiences and to gain an understanding of the self as a mother. Once gained, they integrated this meaning into the global self and created new assumptions of the self, these new assumptions informed the creation of an new assumptive world, a world where motherhood and the self were incorporated. This final chapter sets out the recommendations arising from this study.

11.1 Institutional and Professional recommendations from this research

The data from this study highlighted how specific data relating to women with a disability was not available or easily accessible. While databases do exist²⁷⁸ they do not capture essential data on the number of women with a disability accessing maternity services, an essential statistic if funding is to be sourced and ring fenced to enhance and ensure maternity services are truly equitable, accessible and appropriate for this population.²⁷⁹ Therefore, it is recommended that:

(i) Specific data relating to women with a disability during pregnancy, childbirth and motherhood be collected as part of existing ESRI/perinatal and disability databases.

²⁷⁸ For example, the Health Research Board physical and sensory databases. Findings from the National Disability Survey (CSO 2008) suggest that approximately 38,500 women of childbearing age, between the age range 18-44yrs have a disability but how many of these access maternity services is unclear.

²⁷⁹ These principles are the guiding principles that inform the Quality and Fairness: A Health System for You (DOHC 2001a).

This study highlighted how the majority of women encountered great difficulty negotiating the built environment while accessing maternity care and how measures need to be taken to address this; therefore, it is recommended that:

- (ii) A review of maternity services be undertaken urgently to assess their appropriateness for women with a disability and to consider the development of an integrated care pathway ensuring that these women have equitable and fair access to appropriate services that meet their specific needs,²⁸⁰
- (iii) Departmental service plans should incorporate plans that include the development of national clinical protocols and guidelines governing the provision of care for women with a disability when accessing generic primary, secondary and tertiary care centres.

The data illustrated how women with a disability were required to access maternity services and care that are specific to and primarily configured for non-disabled women. To ensure services and care are more accessible for women with a disability, it is recommended that:

- (iv) A coherent and comprehensive supportive infrastructure for mothers with a disability be developed to include the introduction of a national midwifery disability advisor. This person would have a strategic role in the formation of policy, professional guidelines, clinical standards, service planning and delivery, education and research. Development of such a specialist position will ensure that women with a disability and caregivers have access to a midwife well informed and experienced in the field of disability.²⁸¹

One of the major challenges encountered by women with a disability during the early motherhood period was the negative patriarchal attitudes of caregivers engaged in the provision of maternity care. These caregivers had a tendency to pathologise the woman's disability and tended to focus more on the woman's inabilities rather than abilities. To overcome this challenge, and to ensure caregivers competently and professionally address the specific issues related to women with a disability within the confines of a partnership approach and women-centred care, it is recommended that:

²⁸⁰ The current equality, anti-discrimination and disability legislation can be used as a guide when conducting the review of maternity services.

²⁸¹ It is envisaged that this person would be located in the Department of Health and Children and be at the level of Assistant Director of Midwifery or above.

- (v) A post-registration programme (continuous development programme) be developed for all staff involved in the provision of care for women with a disability,
- (vi) Issues relating to equality, diversity, and disability are included in all curricular guidelines and standards in professional undergraduate and postgraduate programmes in midwifery, nursing, medical and allied health professional education,
- (vii) Specialist posts at Clinical Midwife Specialist (CMS) or Advanced Midwife Practitioner (AMP) level be created and developed in each maternity unit to support women with a disability.

11.2 Recommendations for practice

'(Re)constructing Myself' is a model of adaptation representing how the assumptive worlds of women with a disability were disrupted and subsequently revised during their transition to motherhood. It provides caregivers with a framework to understand how women respond to the disruption and how, through the introduction of simple but effective measures, they can facilitate women in their transition to motherhood. The model is presented diagrammatically in Chapters 7-9 (see Figures 7.1, 7.2 and 7.3, chapter 7; Figure 8.1 and 8.2, chapter 8 and Figure 9.1, 9.2 and 9.3, chapter 9); Figure 7.1 also presents the women-centred measures that if implemented would facilitate progress in each phase of the process. During pregnancy and motherhood service providers have a responsibility to provide quality of care to all women including women with a disability and to adhere to disability and equality legislation when so doing. It is recommended that:

- (i) All relevant staff be provided with disability and diversity training and awareness,
- (ii) All women's needs are assessed at first point of contact with the maternity services and an individualised plan of care is devised, implemented and evaluated in conjunction with each woman.

11.3 Recommendations for midwifery education

The findings of this study can contribute to midwifery education and preparation for practice in many key areas; it is recommended that:

- (i) Equality, diversity and disability issues be included in pre and post registration midwifery education programmes, to provide midwifery students with an awareness and understanding of the rights of women with a disability and issues that arise for women with a disability while accessing maternity care,
- (ii) A meaning reconstruction framework be used to explain the process of transition to motherhood, and the relationship of the process to the self, to midwifery students, in order to provide them with an alternative perspective on the transition to motherhood, a perspective that explains how when the woman's assumptive world is disrupted during the process of becoming a mother, this will assist them in the provision of responsive, women-centred care.

11.4 Recommendations for future research

This thesis has presented the process of adaptation women with a disability engage in during their transition to motherhood. The model represents the observable actions women engaged in while reconstructing meaning when their assumptive worlds were disrupted, a disruption that evolved when their assumptions of the self as a women with a disability and the self as a mother did not correspond with others' perceptions of them in that role. This thesis introduces the concept of meaning reconstruction, a consideration that has not been considered in regard to the transition to motherhood before now. It is important that:

- (i) The theory that emerged from study and the strategies associated with the process involved should be tested and assessed,
- (ii) The appropriateness of the theory to other women, for example, women with an intellectual disability or enduring mental health issues, and non-disabled women, should be investigated,
- (iii) The strategies that women implement to overcome stagnation, or slow progress through the three phases of the theory requires further exploration,

- (iv) The appropriateness, applicability and acceptability of a national midwifery disability advisor should also be evaluated. The impact of this role also warrants evaluation.

11.6 Limitations of the study

- (i) The majority of women recruited to this study were recruited from voluntary agencies or through a snowballing technique (n=17), so it is possible that women not using the services of the voluntary agencies might engage additional or alternative actions to resolve their concerns. Theoretical sampling of these women may have resulted in the development of additional categories that could have been integrated into the theory and may have extended it further. This needs to be considered in future modifications of the theory,
- (ii) In this study data collection continued until the categories were theoretically saturated however I am mindful that theoretical saturation is a subjective interpretation and so there is potential that further data collection could provide alternative accounts; this exemplifies the modifiable nature of this grounded theory study,
- (iii) In this study data were collected from women with an acquired and congenital disability; while those with a congenital disability considered their disability as a defining (n=13) or non-defining entity of the self (n=5), those women with an acquired disability described it as an anomalous entity of the self (n=4). Women with an acquired disability who considered their disability as a defining entity of the self were not sampled, doing so could potentially produce different accounts and additional categories, again this needs to be considered in future modifications of the theory,
- (iv) (Re)constructing Myself was constructed within a particular temporal and cultural context; women's experiences of the transition to motherhood, their concerns and related social processes may change over time so, readers of this thesis must take account of this.

11.7 Dissemination

The process of disseminating the findings of this study has begun. To date, elements of the data have been presented in five international and eleven national nursing and midwifery conferences (see Appendix 16). Three papers are in the process of being peer reviewed for an international peer reviewed journal, several others are being prepared for presentation and submission to international peer reviewed journals. I was invited, by the editor of *Practising Midwife*, to submit a paper relating to the midwife's role and responsibilities regarding the provision of maternity care for women with a disability (see Appendix 17). In addition the three reports that emerged from the qualitative descriptive study that provided data for the first phase of the theoretical model was published in electronic format and are available from the National Disability Authority (Begley et al. 2009a, Begley et al. 2009b, 2010).²⁸² I have also disseminated information on the women's experiences of accessing maternity services in Ireland to the voluntary agencies that assisted in the recruitment process.

All twenty-two contributing women were contacted and informed that the study was complete and were advised that the findings were available. Three women requested information on the findings and all have received them. Additionally, I hope, with international involvement, to develop a proposal seeking funding to explore the appropriateness, applicability and acceptability of the role of a national midwifery disability advisor.

11.8 Conclusion

The existing theories on the transition to motherhood that have explored the phenomenon from the perspective and experiences of non-disabled women have a tendency to conceptualise it from

²⁸² These are available from: *Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood: Literature Review*. Available: [http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/\\$File/literaturereview.pdf](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/$File/literaturereview.pdf)
Women with Disabilities: Policies Governing Procedure and Practice in Service Provision in Ireland During Pregnancy, Childbirth and Early Motherhood. Available: [http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/\\$File/policyreport.pdf](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/$File/policyreport.pdf)
The Strengths and Weaknesses of Publicly-funded Irish Health Services Provided to Women with Disabilities in Relation to Pregnancy, Childbirth and Early Motherhood. Available: [http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/\\$File/NDA%20report%20final%20draft%20_full_%2018th%20May%202010.pdf](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/0/419BBFC356BC438A80257705003FA51D/$File/NDA%20report%20final%20draft%20_full_%2018th%20May%202010.pdf)

an adaptation and role attainment perspective. None, to date have conceptualised it from the perspective and experiences of women with a disability or within a framework of meaning reconstruction. Using a grounded theory approach, this study explored the experiences of women with a disability and the substantive theory that emerged contributes to what is already known on the phenomenon. It does not negate existing theories rather it provides an alternative perspective that dovetails with existing knowledge. (Re)constructing Myself presents a new understanding of the process involved in the transition to motherhood and the relationship of that process to the self. It does so by conceptualising the experiences of women with a disability within the frame of meaning reconstruction as the women, having experienced a disruption to the assumptive world, reconstruct the self and assumptive world to incorporate motherhood. Finally, for the twenty-two women who contributed to this study, (Re)constructing Myself exemplifies how becoming a mother, being a mother and doing mothering was, for them, a (re)defining event, one that caused them (and others) to realise their abilities rather than disabilities. Being a mother bestowed a status and a sense of value and purpose that pre-motherhood eluded these women.

'Of all the rights of women, the greatest is to be a mother.'

Lin Yutang

References

- ABA (2007) Guidance To Nurses And Midwives Regarding Ethical Conduct Of Nursing And Midwifery Research. An Bord Altranais, Dublin, Ireland.
- Allen, B. & Allen, S. (1995) The process of social construction of mental retardation: towards value based interaction. The Journal of the Association for Persons with Severe Handicaps, **20**(2), 158-160.
- Althusser, L. (1971) Lenin and Philosophy And Other Essays. London: New Left Books.
- Amundson, R. & Tresky, S. (2007) On a bioethical challenge to disability rights. Journal of Medicine and Philosophy, **32**(6), 541-561.
- Andersen, S.M. & Chen, S. (2002) The relational self: an interpersonal social-cognitive theory. Psychological Review, **109**(4), 619-645.
- Anderson, P. & Kitchin, R. (2000) Disability, space and sexuality: access to family planning services. Social Science & Medicine, **51**(8), 1163-1173.
- Anells, M. (1997a) Grounded theory method, part I: within the five moments of qualitative research. Nursing Inquiry, **4**(2), 120-129.
- Anells, M. (1997b) Grounded theory method, part II: options for users of the method. Nursing Inquiry, **4**(3), 176-180.
- Antonak, R.F. & Livneh, H. (2000) Measurement of attitudes towards persons with disabilities. Disability and Rehabilitation, **22**(5), 211-224.
- Appleton, J. & King, L. (1997) Constructivism: a naturalistic methodology for nursing inquiry. Advances in Nursing Science, **20**(2), 13-22.
- Aron, A. & McLaughlin-Volpe, T. (2001) Including others in the self: extensions to own and partner's group membership. In Sedikides, C. and Brewer, M. B. (Eds.), Individual Self, Relational Self, Collective Self (pp. 89-108). Philadelphia: Psychology Press: a member of the Taylor and Francis Group.
- Arthur, A., Unwin, S. & Mitchell, T. (2007) Teenage mothers' experience of maternity services: a qualitative study. British Journal of Midwifery, **15**(11), 672-677.
- Asch, A. (1998) Distracted by disability. Cambridge Quarterly of Healthcare Ethics, **7**(1), 77-87.
- Ashmore, R.D. & Jussim, L. (1997) Self And Identity: Fundamental Issues. Oxford, UK: Oxford University Press.
- Attig, T. (2002) Questionable assumptions above assumptive worlds. In Kauffman, J. (Ed.), Loss Of The Assumptive World: A Theory Of Traumatic Loss (pp. 55-68). New York: Routledge: Taylor and Francis Group.
- Attig, T. (2010) Relearning the world: making and finding meanings. In Neimeyer, R. A. (Ed.), Meaning Reconstruction And The Experience of Loss (4th ed., pp. 33-53). Washington, DC, 20002: American Psychological Association.
- Bailey, L. (1999a) Birth rites: power, the body and the self in the transition to motherhood. Department of Sociology, PhD, University of Bristol, Bristol, UK.
- Bailey, L. (1999b) Refracted selves? a study of changes in self identity in the transition to motherhood. Sociology, **33**(2), 335-352.
- Baker, D. (1989) Social identity and the transition to motherhood. In Skevington, S. and Baker, D. (Eds.), The Social Identity Of Women (pp. 84-105). London: Sage Publications.

- Ball, J.A. (1994) Reactions to Motherhood: The Role of Postnatal Care. London: Books for Midwives.
- Barclay, L., Everitt, L., Rogan, F., Schmied, V. & Wyllie, A. (1997) 'Becoming a mother' - an analysis of women's experience of early motherhood. Journal of Advanced Nursing, **25**(4), 719-728.
- Barlow, C. & Cairns, K. (1997) Mothering as a psychological experiences: a grounded theory exploration. Canadian Journal of Counselling, **31**(3), 232-237.
- Barnes, C. & Mercer, G. (2007) Disability. Cambridge: Polity Press.
- Barnes, C. & Mercer, G. (2010) Exploring Disability. Cambridge: Polity Press.
- Baumeister, R.F. & Leary, M.R. (1995) The need to belong: desire for interpersonal attachments as a fundamental motivation. Psychological Bulletin, **117**(3), 497-529.
- Beart, S., Hardy, G. & Buchan, L. (2004) Changing selves: a grounded theory account of belonging to a self-advocacy group for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, **17**(2), 91-100.
- Begley, C., Lalor, J., Lawler, D., Higgins, A., Alexander, J., Nicholl, H., Keenan, P., Touhy, T. & Kavanagh, R. (2009a) Women With Disabilities: Policies Governing Procedure and Practice In Service Provision In Ireland During Pregnancy, Childbirth And Early Motherhood. National Disability Authority, Dublin, Ireland.
- Begley, C., Lalor, J., Lawler, D., Higgins, A., Sheerin, F., Alexander, J., Nicholl, H., Keenan, P., Touhy, T. & Kavanagh, R. (2009b) Women With Disabilities: Barriers And Facilitators To Accessing Services During Pregnancy, Childbirth And Early Motherhood. National Disability Authority, Dublin, Ireland.
- Begley, C., Lalor, J., Lawler, D., Higgins, A., Sheerin, F., Alexander, J., Nicholl, H., Keenan, P., Touhy, T. & Kavanagh, R. (2010) The Strengths And Weakness Of The Publicly-Funded Irish Health Services Provided To Women With Disabilities in Relation To Pregnancy, Childbirth And Early Motherhood. National Disability Authority, Dublin, Ireland.
- Belenky, M., Clinchy, B., Goldberger, N. & Tarule, J. (1997) Women's Ways Of Knowing: The Development of Self, Voice And Mind. New York: Basic Books.
- Benoit, C. (1987) Uneasy partners: midwives and their clients. The Canadian Journal of Sociology, **12**(3), 275-284.
- Benotiel, J. (1996) Grounded theory and nursing knowledge. Qualitative Health Research, **6**(3), 406-428.
- Benzies, K.M. & Allen, M.N. (2001) Symbolic interactionism as a theoretical perspective for multiple method research. Journal of Advanced Nursing, **33**(4), 541-547.
- Beresford, P. (2012) Lets Build On Paralympic Success. The Guardian, London, UK, Sunday 9th September 2012.
- Berg, B. (1998) Qualitative Research Methods For The Social Sciences (3rd ed.). Boston: Allyn & Bacon.
- Berg, M., Lundgren, I., Hermansson, E. & Wahlberg, V. (1996) Women's experience of the encounter with the midwife during childbirth. Midwifery, **12**(1), 11-15.
- Berger, P. & Luckmann, T. (1966) The Social Construction Of Reality: A Treatise In The Sociology Of Knowledge. London, UK: Penguin Press.
- Berger, P. & Luckmann, T. (1991) The Social Construction Of Reality: A Treatise In The Sociology Of Knowledge (2nd ed.). London, UK: Penguin Press.
- Bergum, V. (1989) Woman To Mother. Massachusetts: Bergin and Garvey.

- Bickenbach, J.E., Chatterji, S., Badley, E.M. & Ustun, T.B. (1999) Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science and Medicine*, **48**(9), 1173-1187.
- Birks, M. & Mills, J. (2011) *Ground Theory: A Practical Guide*. London, UK: Sage Publication Ltd.
- Blackford, K.A., Richardson, H. & Grieve, S. (2000) Prenatal education for mothers with disability. *Journal of Advanced Nursing*, **32**(4), 898-904.
- Blumer, H. (1998) *Symbolic Interactionism: Perspective And Method*. Berkeley: University of California Press.
- Bogdan, R. & Taylor, S.J. (1987) Towards a sociology of acceptance: the other side of the study of deviance. *Social Policy*, **Fall**, 34-39.
- Brandt, E.N. & Pope, A.M. (1997) *Enabling America: Assessing The Role Of Rehabilitation Science And Engineering* Washington, D.C: National Academy Press.
- Briant, E., Watson, N. & Philo, G. (2011) *Bad News For Disabled People: How The Newspapers Are Reporting Disability*. Strathclyde Centre for Disability Research and Glasgow Media Unit, University of Glasgow & Inclusion London, Glasgow.
- Brook, B. (1999) *Feminist Perspectives On The Body*. London: Longman.
- Brown, I. (2010) Ambivalence of the motherhood experience. In O'Reilly, A. (Ed.), *21st Century Motherhood: Experience, Identity, Policy Agency*. New York: Columbia University Press
- Brunton, G., Wiggins, M. & Oakley, A. (2011) *Becoming A Mother: A Research Synthesis Of Women's Views On The Experience Of First-Time Motherhood*. EPPI Centre, Social Science Research Unit, Institute of Education, University of London, London.
- Bruyere, S.M., van Looy, S.A.B. & Peterson, D. (2005) The International Classification of Functioning, Disability and Health: contemporary literature overview. *Rehabilitation Psychology*, **50**(2), 113-121.
- Buckley, C. & Waring, M. (2009) The evolving nature of grounded theory: experiential reflections on the potential of the method for analysing children's attitudes towards physical activity. *International Journal of Social Research Methodology*, **12**(4), 317-334.
- Burke, J.P. & Stets, J.E. (2009) *Identity Theory*. Oxford, UK: Oxford University Press.
- Burley, E.S. (2003) *Antenatal Education in the Transition to Motherhood*. Faculty of Social Science and Business, PhD, University of Plymouth, UK.
- Burr, V. (2003) *Social Constructionism* (2nd ed.). Hove, East Sussex: Routledge.
- Bury, M. (1996) Defining and researching disability: challenges responses. In Barnes, C. and Mercer, G. (Eds.), *Exploring the Divide* (pp. 18-38). Leeds: The Disability Press.
- Butler, J. (1996) *Bodies That Matter: On The Discursive Limits Of Sex*. London: Routledge.
- Campion, M.J. (1997) Disabled women and maternity services. *Modern Midwife*, **7**(3), 23-25.
- Carolan, M. (2005) 'Doing it properly': the experience of first mothering over 35 years. *Health Care for Women International*, **26**(9), 764-787.
- Charmaz, K. (2000) Constructivist and objectivist grounded theory. In Denzin, N. K. and Lincoln, Y. S. (Eds.), *Handbook Of Qualitative Research* (2nd ed., pp. 509-535). Thousand Oaks CA: Sage.
- Chatterji, S., Ustun, T.B. & Bickenbach, J.E. (1999) What is disability after all? *Disability and Rehabilitation*, **21**(8), 396-398.
- Chesney, M. (2001) Dilemmas of self in the method. *Qualitative Health Research*, **11**(1), 127-135.

- Chodorow, N. (1978) *The Reproduction of Motherhood: Psychoanalysis And The Sociology Of Gender*. London: University of California.
- Choi, P., Henshaw, C., Baker, S. & Tree, J. (2005) Supermum, superwife, supereverthing: performing femininity in the transition to motherhood. *Journal of Reproductive and Infant Psychology*, **23**(2), 167-180.
- Clark, L. (2002) *Accessible Health Information: Liverpool Central Primary Care Trust Project Report*. Liverpool Central Primary Care Trust, Liverpool.
- Clarke, A. (2003) Situational analyses: grounded theory mapping after the postmodern turn *Symbolic Interaction*, **26**(4), 553-575.
- Clarke, A. (2006) Qualitative interviewing: encountering ethical issues and challenges. *Nurse Researcher* **13**(4), 19-29.
- Cohen, S. & Willis, T.A. (1985) Stress, social support and the buffering hypothesis. *Psychological Bulletin*, **98**(2), 310-357.
- Colbourne, L. & Sque, M. (2004) Spilt personalities: role conflict between the nurse and nurse researcher. *Nurse Researcher*, **9**(4), 297-304.
- Conine, T.A., Carty, E.M. & Wood-Johnson, F. (1986) Provision of preventive maternal health care and childbirth education for disabled women. *Canadian Journal of Public Health*, **77**((March/April)), 123-127.
- Cooley, C.H. (1964) *Human Nature And The Social Order*. New York: Schocken Books, Inc.
- Corbin, J. (2009) Taking an analytic journey. In Morse, J. M., Noerager Stern, P., Corbin, J., Bowers, B., Charmaz, K. and Clarke, A. (Eds.), *Developing Grounded Theory: The Second Generation* (pp. 35-53). Walnut Creek, California: Left Coast Press Inc.
- Corbin, J. & Morse, J.M. (2003) The unstructured interactive interview: issues in reciprocity and risks when dealing with sensitive research topics. *Qualitative Inquiry*, **9**(9), 335-354.
- Corbin, J. & Strauss, A. (2008) *Basics Of Qualitative Research 3e* (3rd ed.). London, UK: Sage Publications, Inc.
- Corker, M. & French, S. (1999) *Disability Discourse*. Buckingham: Open University Press.
- Cowan, C.P. & Cowan, P.A. (1995) Interventions to ease the transition to parenthood: why they are needed and what they can do *Family Relations*, **44**(4), 412-423.
- Coyle, K., Hauck, Y., Percival, P. & Kristjanson, L. (2001) Ongoing relationship with a personal focus: mothers' perceptions of birth centre versus hospital care. *Midwifery*, **17**(3), 171-181.
- Creswell, J., Hanson, W., Clark Plano, V. & Morales, A. (2007) Qualitative research designs: selection and implementation. *The Counselling Psychologist*, **35**(2), 236-264.
- Crocker, J., Major, B. & Steele, C. (1998) *Social Stigma*. Boston: McGraw Hill.
- Crotty, M. (1998) *The Foundations Of Social Research*. London, UK: Sage Publications, Ltd
- Crow, L. (1996) Including all of our lives: renewing the social model of disability. In Barnes, C. and Mercer, G. (Eds.), *Exploring The Divide*. Leeds: The Disability Press.
- CSO (2008) *National Disability Survey 2006: first results*. National Statistics Office, Dublin. http://www.cso.ie/releasespublications/documents/other_releases/nationaldisability/National%20Disability%20Survey%202006%20First%20Results%20full%20report.pdf (Accessed 4th March 2009).
- Cusk, R. (2001) *A Life's Work: On Becoming A Mother*. New York: Picador USA.
- Cutcliffe, J. (2005) Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, **51**(4), 421-428.

- Czuchta, M. & Johnson, B.A. (1998) Reconstructing a sense of self in patients with chronic mental illness. *Perspectives in Psychiatric Care*, **34**(3), 30-36.
- Dartington, T., Miller, E.J. & Gwynne, G. (1981) *A Life Together*. London: Tavistock.
- Darvill, R., Skirton, H. & Farrand, P. (2010) Psychological factors that impact on women's experiences of first time motherhood: a qualitative study of the transition *Midwifery*, **26**(3), 357-366.
- Davies, D. & Dodd, J. (2002) Qualitative research and the question of rigor. *Qualitative Health Research*, **12**(2), 279-289.
- Davis, C.G. (2010) The tormented and the transformed: understanding responses to loss and trauma. In Neimeyer, R. A. (Ed.), *Meaning Reconstructed And The Experience Of Loss* (4th ed., pp. 137-155). Washington, DC, 20002: American Psychological Association.
- Dearnley, C. (2005) A reflection on the use of semi-structured interviews *Nurse Researcher*, **13**(1), 19-28.
- Deaux, K. & Perkins, T.S. (2001) The kaleidoscopic self. In Sedikides, C. and Brewer, M. B. (Eds.), *Individual Self, Relational Self, Collective Self* (pp. 299-313). Philadelphia: Psychology Press: a member of the Taylor and Francis Group.
- DeJong, G., Palsbo, S., Beatty, P., Jones, G., Kroll, T. & Neri, T. (2002) The organisation and financing of health services for persons with disabilities. *The Millbank Quarterly*, **80**(2), 261-301.
- Denzin, N.K. & Lincoln, Y.S. (2005) *The Sage Handbook Of Qualitative Research* (3rd ed.). Thousand Oaks, CA: Sage Publication Inc.
- Devane, D., Murphy-Lawless, J. & Begley, C.M. (2007) Childbirth policies and practices in Ireland and the journey towards midwifery-led care. *Midwifery*, **23**(1), 92-101.
- Dewsbury, G., Clarke, K., Randall, D., Rouncefield, M. & Sommerville, I. (2004) The anti-social model of disability. *Disability and Society*, **19**(2), 146-157.
- Di Matteo, M.R., Khan, K.L. & Berry, S.H. (1993) Narratives of birth and the postpartum: analysis of the focus group responses of new mothers. *Birth*, **20**(4), 204-211.
- Dickson-Swift, V., James, E.L., Kippen, S. & Liamputtong, P. (2006) Blurring boundaries in qualitative health research on sensitive topics *Qualitative Health Research*, **16**(6), 853-857.
- DiLapi, E.M. (1989) Lesbian mothers and motherhood hierarchy. *Journal of Homosexuality*, **18**(1-2), 101-121.
- Dingwall, R. (2001) Notes towards an intellectual history of symbolic interactionism. *Symbolic Interaction*, **24**(2), 237-242.
- DOH. (1994) *Shaping A Healthier Future: A Strategy For Effective Healthcare In The 1990s*. Dublin The Stationery Office.
- DOH. (1997) *A Plan for Women's Health (1997-1999)*. Dublin: The Stationery Office.
- DOHC. (2001a) *Quality And Fairness: A Health System For You*. Dublin: The Stationery Office.
- DOHC. (2001b) *Primary Healthcare: A New Direction*. Dublin: The Stationery Office.
- Donalek, J.G. (2005) The interview in qualitative research *Urologic Nursing* **25** (2), 124-125.
- Doniger, W. (2005) *The Woman Who Pretended To Be Who She Was: Myths Of Self-Imitation*. Oxford: Oxford University Press.
- Dowling, M. (2006) Approaches to reflexivity in qualitative research. *Nurse Researcher*, **13**(3), 7-21.

- Draucker, C.B., Martsolf, D.S., Ross, R. & Rusk, T.B. (2007) Theoretical sampling and category development in grounded theory. *Qualitative Health Research*, **17**(8), 1137-1148.
- Duncombe, J. & Jessop, J. (2002) Doing rapport and the ethics of faking friendship In Manthner, M., Birch, M., Jessop, J. and Miller, T. (Eds.), *Ethics In Qualitative Research* (pp. 107-122). London, UK: Sage Publication Ltd.
- Dyer, E.D. (1963) Parenthood as crisis: a restudy. *Marriage and Family Living*, **25**(2), 196-201.
- Earle, S. (2000) Pregnancy and the maintenance of self-identity: implications for antenatal care in the community. *Health and Social Care in the Community*, **8**(4), 235-241.
- Edwards, C. & Imrie, R. (2003) Disability and bodies as bearers of value. *Sociology*, **37**(2), 239-256.
- Elias, N. (1994) *The Civilizing Process*. Oxford: Blackwell Publication.
- Elliott, A. (2010) *Concepts Of The Self*. (2nd ed.). Cambridge: Polity Press.
- ESRI (2011) *Perinatal Statistics Report 2009: Health Research And Information Division*. The Economic and Social Research Institute, Dublin.
- ESRI (2012) *Perinatal Statistics Report 2010: Health Research And Information Division*. The Economic Social and Research Institution, Dublin.
- EU (2006) *European Disability Action Plan (2006-2015)*.
http://www.coe.int/t/e/social_cohesion/socsp/Rec_2006_5%20Disability%20Action%20Plan.pdf. (Accessed 24th August 2008).
- Eurostat (2012) *Crude birth rate*. Eurostat,
<http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&plugin=0&language=en&pcode=tps00112>. (Accessed 19th May 2012).
- Evans, M. (2003) *Gender and Social Theory*. Buckingham: Open University Press.
- Faber, R. (2000) Mothers with disabilities: in their own voices *The American Journal of Occupational Therapy*, **54**(3), 260-278.
- Fine, G.A. (1993) The sad demise, mysterious disappearance and glorious triumph of symbolic interactionism. *Annual Review of Sociology*, **19**(1), 61-87.
- Finkelstein, V. (1993) Disability: a social challenge or an administrative responsibility? In Swain, J., Finkelstein, V., French, S. and Oliver, M. (Eds.), *Disabling Barriers – Enabling Environment* (pp. 34-43). London: Sage Publications.
- Finlay, L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, **2**(2), 209-230.
- Fisher, J., Astbury, J. & Smith, A. (1997) Adverse psychological impact of obstetric interventions: a prospective longitudinal study. *Australian and New Zealand Journal of Psychiatry*, **31**(5), 728-738.
- Flakowicz, M. (2007) Daughter, mother, wife: transitions from ideals to the real family. *Infant Observation*, **10**(3), 295-306.
- Fontenot, H.B. (2007) Transition and adaptation to adoptive motherhood. *JOGNN: Journal of Obstetric, Gynecology and Neonatal Nursing*, **36**(2), 175-182.
- Fox, B. & Worts, D. (1999) Revisiting the critique of medicalised childbirth. *Gender and Society*, **13**(3), 326-346.
- Freeman, L.M. (2006) Continuity of care and partnership: a review of the literature. *Women and Birth*, **19**(2), 39-44.

- Gagnon, A.J. & Sandall, J. (2009) Individual Or Group Antenatal Education For Childbirth Or Parenthood, Or Both (Review). *The Cochrane Collaboration in The Cochrane Library 2009, Issue 2*.
- Gelech, J.M. & Desjardins, M. (2011) I am many: the reconstruction of self following acquired brain injury. *Qualitative Health Research*, **21**(1), 62-74.
- Ghavami, N., Fingerhut, A., Peplau, L., Grant, S.K. & Wittig, M.A. (2011) Testing a model of minority identity achievement, identity affirmation and psychological wellbeing among ethnic minority and sexual minority individuals. *Cultural Diversity and Ethnic Minority Psychology*, **17**(1), 79-88.
- Gibbs, G. (1988) Learning By Doing: A Guide To Teaching and Learning Methods. London, UK: Oxford Centre for Staff and Learning Development, Oxford Polytechnic.
- Giddens, A. (2009) Modernity And Self-Identity: Self And Society In The Late Modern Age. Cambridge, UK Polity Press.
- Gillett, G. (2004) Clinical medicine and the quest for certainty. *Social Science & Medicine*, **58**(4), 727-738.
- Gilroy, P. (1997) Diaspora and the detours of identity. In Woodward, K. (Ed.), Identity And Difference. London: Sage in association with The Open University.
- Gittins, D. (1993) The Family Question. Basingstoke: Macmillan.
- Glaser, B. (1992) Basics Of Grounded Theory Analysis. Mill Valley, CA, USA: Sociology Press.
- Glaser, B. (1998) Doing Grounded Theory: Issues And Discussions. Mill Valley, CA, USA: Sociology Press.
- Glaser, B.G. & Strauss, A.L. (2010) Status Passage. New Jersey: Transaction Publishers.
- Glenn, E.N., Chang, G. & Forcey, L.R. (1994) Mothering: Ideology, Experience, and Agency. New York: Routledge.
- Goffman, E. (1963) Stigma: Notes On Management Of Spoiled Identity. New Jersey: Prentice Hall.
- Goffman, E. (1990) The Presentation Of Self In Everyday Life. London: Penguin Books.
- Goodman, M. (1994) Mother's Pride And Others Prejudice: A Survey Of Disabled Mothers' Experiences Of Maternity. London: Maternity Alliance.
- Grabois, E., Nosek, M.A. & Rossi, D. (1999) Accessibility of primary care physician's office for people with disabilities: an analysis of compliance with the Americans with Disabilities Act. *Archive Family Medicine*, **8**(Jan/Feb), 44-51.
- Green, J., Coupland, V. & Kitzinger, J. (1990) Expectations, experiences and psychological outcomes of childbirth: a prospective study of 825 women. *Birth*, **17**(1), 15-24.
- Grue, L. & Tafjord-Laérum, K. (2002) Doing motherhood: some experiences of mothers with physical disabilities. *Disability and Society*, **17**(6), 671-683.
- Guba, E.G. & Lincoln, Y.S. (1994) Competing Paradigms in Qualitative Research. In Denzin, N. K. and Lincoln, Y. S. (Eds.), Handbook Of Qualitative Research (1st ed., pp. 105-117). Thousand Oaks CA: Sage.
- Gubrium, E. & Koro-Ljungberg, M. (2005) Contending with border making in the social constructionist interview. *Qualitative Inquiry*, **11**(5), 689-715.
- Hagerty, B., Lynch-Sauer, J., Patusky, K., Bouwsema, M. & Collier, P. (1992) Sense of belonging: a vital mental concept. *Archives of Psychiatric Nursing*, **6**(3), 172-177.
- Hagerty, B. & Patusky, K. (1995) Developing a measure of sense of belonging. *Nursing Research*, **44**(1), 9-13.

- Hahn, H. (1985) Disability policy and the problem of discrimination. *American Behavioral Scientist*, **28**(3), 293-318.
- Hahn, H. (1988) The politics of physical differences: disability and discrimination. In Nagler, M. (Ed.), *Perspectives On Disability* (2nd ed., pp. 37-42). Palo Alto, CA Health Markets Research.
- Hall, S. (2000) Who needs 'identity'? In Du Gay, P., Evans, J. and Redman, P. (Eds.), *Identity: A Reader* London: Sage Publications Ltd.
- Hall, W. & Callery, P. (2001) Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research*, **11**(2), 257-272.
- Haldorsdottir, S. & Karlsdottir, S. (1996) Empowerment or discouragement: women's experience of caring and uncaring encounters during childbirth. *Health Care for Women International*, **17**(4), 361-379.
- Hammersley, M. (1992) *What's Wrong With Epistemology? Methodological Explorations*. London, UK: Routledge.
- Harcombe, J. (1999) Power and political power positions in maternity care. *British Journal of Midwifery*, **7**(2), 78-82.
- Harris, J. & Bamford, C. (2001) The uphill struggle: services for deaf and hard of hearing people - issues in equality, participation and access. *Disability and Society*, **16**(7), 969-979.
- Hartrick, G.A. (1997) Women who are mothers: the experience of defining self. *Health Care for Women International*, **18**(3), 263-277.
- Heath, H. & Cowley, S. (2004) Developing a grounded theory approach: a comparison of Glaser and Strauss. *International Journal of Nursing Studies*, **41**(2), 141-150.
- Heshusius, L. (1994) Freeing ourselves from objectivity: managing subjectivity or turning toward a participatory mode of consciousness? *Educational Researcher*, **23**(3), 15-22.
- Hewitt, J.P. (2007) *Self And Society: A Symbolic Interactionist Social Psychology* (10th ed.). Boston: Pearson Education Inc. Allyn and Bacon.
- Hilfinger-Messias, D.K. & DeJoseph, J.F. (2007) The personal work of a first pregnancy: transforming identities, relationships and women's work. *Women and Health*, **45**(4), 41-64.
- Hill, D.L. (2006) Sense of belonging as connectedness, American Indian worldview and mental health. *Archives of Psychiatric Nursing*, **20**(5), 210-216.
- Hobbs, D.F. (1965) Parenthood as crisis: a third study. *Journal of Marriage and the Family*, **27**(3), 367-372.
- Hobbs, D.F. (1968) Transition to parenthood: a replication and an extension. *Journal of Marriage and the Family*, **30**(3), 413-417.
- Hobbs, D.F. & Cole, S.P. (1976) Transition to parenthood: a decade replication *Journal of Marriage and the Family*, **38**(4), 723-731.
- Hobbs, D.F. & Wimbish, J.M. (1977) Transition to parenthood by black couples. *Journal of Marriage and the Family*, **39**(4), 677-689.
- Holloway, W. (2010) Relationality: the intersubjective foundations of identity. In Wetherell, M. and Talpade Mohanty, C. (Eds.), *The Sage Handbook Of Identities*. Los Angeles: Sage.
- Holstein, J.A. & Gubrium, J.F. (2000) *The Self We Live By: Narrative Identity In A Postmodern World*. Oxford, UK: Oxford University Press.
- Holstein, J.A. & Gubrium, J.F. (2003) *Inside Interviewing New Lenses, New Concerns*. Thousand Oaks, CA: Sage Publications Inc.

- Houston, S. (2001) Beyond social constructionism: critical realism and social work. *British Journal of Social Work*, **31**(6), 845-861.
- HSE (2008) *The National Intercultural Strategy (2007-2012)*. Health Service Executive, Naas, Kildare, Ireland.
- Hubbard, G., Backett-Milburn, K. & Kemmer, D. (2001) Working with emotions: issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology*, **42**(2), 119-137.
- Hull, R. (1998) Defining disability – a philosophical approach. *Res Publica*, **iv**(2), 199-210.
- Hunter, B. (2001) Emotion work in midwifery: a review of current knowledge. *Journal of Advanced Nursing*, **34**(4), 436-444.
- Hunter, B. (2006) The importance of reciprocity in relationships between community-based midwives and mothers. *Midwifery*, **22**(4), 308-322.
- Hunter, B., Berg, M., Lundgren, I., Olafsdottir, O.A. & Kirkham, M. (2008) Relationships: the hidden threads of tapestry of maternity care. *Midwifery*, **24**(2), 132-137.
- Hunter, P.L. (2002) Being with woman: a guiding concept for the care of labouring women. *JOGNN: Journal of Obstetric, Gynecology and Neonatal Nursing*, **31**(6), 650-657.
- Jackson, M. (2011) Maternity focus: deafness, antenatal care and access. *British Journal of Healthcare Assistants*, **5**(6), 339-341.
- James, W. (1961) *Psychology: The Briefer Course* New York: Harper and Brothers.
- Janoff-Bulman, R. (1992) *Shattered Assumptions: Towards A New Psychology Of Trauma*. New York: Free Press.
- Jette, A.M. (1994) Physical disablement concepts for physical therapy research and practice. *Physical Therapy*, **74**(5), 380-386.
- Johns, C. (1995) Framing learning through reflection within Carper's fundamental ways of knowing in nursing. *Journal of Advanced Nursing*, **22**(2), 226-234.
- Johnson, B. & Macleod-Clarke, J. (2003) Collecting sensitive data: the impact on researches. *Qualitative Health Research*, **13**(3), 421-434.
- Jones, E.E., Farina, A., Hastorf, A.H., Markus, H., Miller, D.T. & Scott, R.A. (1984) *Social Stigma: The Psychology Of Marked Relationships*. New York: W.H. Freeman and Company.
- Kallianes, V. & Rubenfeld, P. (1997) Disability, women and reproductive rights. *Disability and Society*, **12**(2), 203-222.
- Kaplan, D. (2000) The definition of disability: perspective of the disability community. *Journal of Health Care Law and Policy*, **3**, 352-364.
- Keil, R. (2004) Coping and stress: a conceptual analysis. *Journal of Advanced Nursing*, **45**(6), 659-665.
- Kelly, G.A. (1991) *The Psychology Of Personal Constructs* (2nd ed.). London: Routledge.
- Kendall, J. (1999) Axial coding and the grounded theory controversy. *Western Journal of Nursing Research*, **21**(6), 743-757.
- Kennedy, P. (2002) *Maternity In Ireland: A Woman-Centred Perspective*. Dublin: Liffey Press.
- Kennedy, T. & Lingard, L. (2006) Making sense of grounded theory in medical education. *Medical Education*, **40**(2), 101-108.
- Kitzinger, S. (1992) *Ourselves As Mothers*. London, UK: Doubleday.
- Kolb, A.Y. & Kolb, D.A. (2005) Learning styles and learning space: enhancing experiential learning in higher education. *Academy of Management Learning and Education*, **4**(2), 193-212.

- Koniak-Griffin, D., Logsdon, C.M., Hines-Martin, V. & Turner, C.C. (2006) Contemporary mothering in a diverse society. *JOGNN: Journal of Obstetric, Gynecology and Neonatal Nursing*, **35**(5), 671-678.
- Kralik, D. & Telford, K. (2005a) *Transition In Chronic Illness: Interacting With Others (Booklet 8)*. RDNS: Royal District Nursing Service of SA Inc and RDNS Foundation of SA Inc,
- Kralik, D. & Telford, K. (2005b) *Transition In Chronic Illness: Shifts In Self And Identity*. RDNS: Royal District Nursing Service of SA Inc and RDNS Foundation of SA Inc,
- Kralik, D. & Telford, K. (2010) *Shifts in Self and Identity*. Wayville: University of South Australia.
- Kralik, D., Visentin, K. & Van Loon, A. (2006) Transition: a literature review. *Journal of Advanced Nursing*, **55**(3), 320-329.
- Kritzinger, J. (2011) *Exploring The Barriers And Facilitators To Health Care Services And Health Care Information For Deaf People In Worcester*. Department of Psychology, Master in Arts, Stellenbosch University, Stellenbosch, Matieland, South Africa.
- Kvale, S. & Brinkmann, S. (2009) *Interviews: Learning The Craft Of Qualitative Research Interviewing* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Lalor, J.G. (2007) *Recasting hope: a longitudinal study of women's experiences of carrying a baby with a fetal abnormality up to and beyond the birth*. Department of Health Science, PhD, Trinity College Dublin, Dublin, Ireland.
- Landman, I.S. (2002) Crises of meaning in trauma and loss. In Kauffman, J. (Ed.), *Loss Of The Assumptive World: A Theory Of Traumatic Loss* (pp. 13-30). New York: Routledge: Taylor and Francis Group.
- Lawler, D. & Sinclair, M. (2003) Grieving for my former self: a phenomenological hermeneutical study of women's lived experience of postnatal depression. *Evidence Based Midwifery*, **1**(2), 36-41.
- Lawler, S. (2000) *Mothering The Self: Mothers, Daughters, Subjects*. London, UK: Routledge: Taylor and Francis Group.
- Lawler, S. (2008) *Identity: Sociology Perspectives*. Cambridge, UK Polity Press.
- Lazarus, R. & Folkman, S. (1984) *Stress, Appraisal And Coping*. New York: Springer.
- Leap, N. (2009) Woman-centred or women-centred care: does it matter? *British Journal of Midwifery*, **17**(1), 12-16.
- Lee, K.O. & Oh, H. (2005) A wise wife and good mother: reproductive health and maternity among women with disability in South Korea. *Sexuality and Disability*, **23**(3), 121-144.
- Lee, P. (2007) The social construction of disability and motherhood. In McKay-Moffat, S. (Ed.), *Disability In Pregnancy And Childbirth* (pp. 1-18). Edinburgh: Churchill Livingstone.
- LeMasters, E. (1957) Parenthood as crisis. *Marriage and Family Living*, **19**, 352-355.
- Leonardi, M., Bickenbach, J.E., Ustun, T.B., Kostanjsek, N. & Chatterji, S. (2006) The definition of disability: what is in a name? *Lancet*, **368**, 1219-1221.
- Lerner, M.J. (1980) *The Belief In A Just World A Fundamental Delusion: Perspectives In Social Psychology*. New York: Plenum Press.
- Letherby, G. (1994) Mother or not, mother or what? Problems of definition and identity. *Women's Studies International Forum*, **17**(5), 525-532.
- Lewis, N. & Nicholson, P. (1998) Talking about early motherhood: recognizing loss and reconstructing depression. *Journal of Reproductive and Infant Psychology*, **16**(2-3), 177-197.

- Liamputtong Rice, P. & Ezzy, D. (1999) *Qualitative Research Methods: A Health Focus*. South Melbourne Australia: Oxford University Press.
- Lincoln, Y. & Cannella, G. (2004) Dangerous discourses: methodological conservatism and governmental regimes of truth. *Qualitative Inquiry*, **10**(1), 5-14.
- Lindgren, C.L. (1990) Burnout and social support in family caregivers. *Western Journal of Nursing Research*, **12**(4), 469-487.
- Lindgren, K. (2004) Bodies in trouble: identity, embodiment and disability. In Smith, B. G. and Hutchinson, B. (Eds.), *Gendering Disability*. New Brunswick: Rutgers University Press.
- Link, B. & Phelan, J.C. (2001) Conceptualising stigma. *Annual Review of Sociology*, **27**(1), 214-219.
- Lipson, J.G. & Rogers, F.G. (2000) Cultural aspects of disability. *Journal of Transcultural Nursing*, **11**(3), 212-219.
- Lollar, D. & Crews, J. (2003) Redefining the role of public health in disability. *Annual Review Public Health*, **24**, 195-208.
- Longmore, P.K. (1986) Talking back to the media. *Disability Studies Quarterly*, **6**(Summer), 1-2.
- Lundgren, I. & Berg, M. (2007) Central concepts in the midwife-woman relationship. *Scandinavian Journal of Caring Science*, **21**(2), 220-228.
- Lutz, B.J. & Bowers, B.J. (2003) Understanding how disability is defined and conceptualised in the literature. *Rehabilitation Nursing*, **28**(3), 74-78.
- Maijala, H., Paavilainen, E. & Astedt-Kurki, P. (2004) The use of grounded theory to study interaction. *Nurse Researcher*, **11**(2), 40-57.
- Maines, D.R. (1988) Myth, text and interactions: its complicity in the neglect of Blumer's macrosociology. *Symbolic Interaction*, **11**(1), 43-57.
- Malacrida, C. (2007) Negotiating the dependence/nurturance tightrope: dilemmas of motherhood and disability. *CRSA/RCSA*, **44**(4), 369-493.
- Malacrida, C. (2009) Performing motherhood in a disablist world: dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*, **22**(1), 99-117.
- Malterud, K. (2001) Qualitative research: standards, challenges, and guidelines. *The Lancet*, **358**, 9280-9286.
- Manderson, L., Bennett, E. & Andajani-Sutjahjo, S. (2006) The social dynamics of the interview: age, class and gender. *Qualitative Health Research*, **16**(10), 1317-1334.
- Marshall, J.L., Godfrey, M. & Renfrew, M.J. (2007) Being a 'good mother': managing breastfeeding and merging identities *Social Science & Medicine*, **65**(10), 2147-2159.
- Maslow, A. (1954) *Motivation And Personality*. New York: Harper.
- Massie, B. (2006) *Participation: Have We Got An Attitude Problem?* NDA 5th Annual Conference Civic, Culture and Social Participation: Building An Inclusive Society, Dublin, Ireland, 16th November 2006.
- Mauger, M. (1998) *Songs From The Womb: Healing The Wounded Mother*. Cork: The Collins Press.
- Maushart, S. (1999) *The Mask Of Motherhood: How Becoming A Mother Changes Our Lives And Why We Never Talk About It*. New York: Penguin.
- Mauther, M. (2002) *Sistering: Power And Change In Female Relationships*. Houndsmill: Palgrave.
- McBride, A. & Shore, C. (2001) Women as mothers and grandmothers. *Annual Review of Nursing Research*, **19**, 63-85.

- McCabe, J. & Holmes, D. (2009) Relexivity, critical qualitative research and emancipation: a Foucauldian perspective. *Journal of Advanced Nursing*, **65**(7), 1518-1526.
- McCall, G.J. & Simmons, J.L. (1978) *Identities And Interactions*. New York: Free Press.
- McCann, T. & Clark, E. (2004a) Ground theory in nursing research: part 1 - methodology *Nurse Researcher*, **11**(2), 7-18.
- McCann, T. & Clark, E. (2004b) Grounded theory in nursing research: part 2 critique. *Nurse Researcher*, **11**(2), 19-28.
- McClimens, A. (2005) From vagabonds to Victorian values: a social construction of a disability identity. In Grant, G., Goward, P., Richardson, D. and Ramcharan, P. (Eds.), *A Life Cycle Approach To Valuing People*. United Kingdom: Open University Press.
- McCourt, C. (2007) Becoming a parent. In Page, L. A. and McCandlish, R. (Eds.), *The New Midwifery: Science And Sensitivity In Practice* (2nd ed., pp. 49-71). Philadelphia: Churchill Livingstone.
- McCrea, H. (1993) Valuing the midwife's role in the midwife/client relationship. *Journal of Clinical Nursing*, **2**(1), 47-52.
- McElwain, A.D., Grimes, M.E. & McVicker, M. (2009) The implications of erotic plasticity and social constructionism in the formation of female sexual identity. *Journal of Feminist Family Therapy*, **21**(2), 125-139.
- McFarlene, H. (2004) *Disabled Women And Socio-Spatial Barriers to Motherhood*. PhD, University of Glasgow, Glasgow.
- McGuinness, F. (2006) Effective communication is the core effective practice. *British Journal of Midwifery*, **14**(8), 452.
- McKay-Moffat, S. & Rotheram, J. (2007) Maternity services and women experience's. In McKay-Moffat, S. (Ed.), *Disability In Pregnancy And Childbirth*. Edinburgh: Churchill Livingstone.
- McKay-Moffat, S. & Cunningham, C. (2006) Services for women with disabilities: mothers' and midwives' experiences. *British Journal of Midwifery*, **14**(8), 472-477.
- McKeever, P., Angus, J., Lee-Miller, K. & Reid, D. (2003) It's more of a production: accomplishing mothering using a mobility device. *Disability and Society*, **18**(2), 179-197.
- McMahon, M. (1995) *Identity, Self-Transformation In Women's Lives*. New York: The Guilford Press.
- McMillan Boyles, C., Bailey, P.H. & Mossey, S. (2008) Representation of disability in nursing and healthcare literature: an integrative review. *Journal of Advanced Nursing*, **62**(4), 428-437.
- Mead, G. (1934) *Mind, Self And Society*. Chicago: University of Chicago Press.
- Meltzer, B.N., Petas, J.W. & Reynolds, L.T. (1975) *Symbolic Interactionism: Genesis, Varieties and Criticism*. Boston: Routledge & Kegan Paul.
- Mercer, R.T. (1981) A theoretical framework for studying factors that impact on the maternal role. *Nursing Research*, **30**(2), 73-77.
- Mercer, R.T. (1985) The process of maternal role attainment. *Nursing Research*, **34**(4), 199-204.
- Mercer, R.T. (1986) Predictors of maternal role attainment over the first year. *Nursing Research*, **34**(4), 198-204.
- Mercer, R.T. (2004) Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship*, **36**(3), 226-232.
- Michalailakis, D. (2003) The system theory concept of disability: one is not born a disabled person, one is observed to be one. *Disability and Society*, **18**(2), 209-229.

- Miller, J.F. (1992) *Coping With Chronic Illness: Overcoming Powerlessness* (2nd ed.). Philadelphia: Davis.
- Miller, T. (2005) *Making Sense Of Motherhood: A Narrative Approach*. Cambridge: Cambridge University Press.
- Miller, T.A. (2000a) *An exploration of first time motherhood: narratives of transition*. PhD, University of Warwick, Warwick, UK.
- Miller, T.A. (2000b) Losing the plot: narrative construction and longitudinal childbirth research. *Qualitative Health Research*, **10**(3), 309-323.
- Miller, T.A. (2002) Adapting to motherhood: care in the postnatal period. *Community Practitioner*, **75**(1), 16-18.
- Miller, T.A. (2003) Shifting perceptions of expert knowledge: transition to motherhood. *Human Fertility*, **6**(3), 142-146.
- Mills, J., Chapman, Y., Bonner, A. & Francis, K. (2007) Grounded theory: a methodological spiral from positivism to postmodernism. *Journal of Advanced Nursing*, **58**(1), 72-9.
- Moore, D. (1998) Acceptance of disability and its correlates. *The Journal of Social Psychology*, **138**(1), 13-25.
- Moore, L. (2002) Conducting research with visually impaired older adults. *Qualitative Health Research*, **12**(4), 559-565.
- Morgan, D.L. (2007) Paradigm lost and pragmatism regained: methodological implications of combining qualitative and quantitative research methods. *Journal of Mixed Methods Research*, **1**(1), 48-76.
- Morse, C.A., Buist, A. & Durkin, S. (2000) First time parenthood: influences on pre and postnatal adjustment in fathers and mothers. *Journal of Psychosomatic Obstetrics and Gynaecology*, **21**(2), 109-120.
- Morse, J.M. (2009) Tussles, tensions and resolutions. In Morse, J. M., Noerager Stern, P., Corbin, J., Bowers, B., Charmaz, K. and Clarke, A. E. (Eds.), *Developing Grounded Theory: The Second Generation* (pp. 13-20). Walnut Creek: Left Coast Press Inc.
- Morse, J.M., Barrett, M., Mayan, M., Olson, K. & Spiers, J. (2002) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, **1**(2), 1-19.
- Murphy-Lawless, J. (1998) *Reading Birth And Death: A History Of Obstetric Thinking*. Cork: Cork University Press.
- Murphy, R.F. (1990) *The Body Silent*. New York: W. W. Norton.
- Myers, J.K. (1965) Consequences and prognoses of disability. In Sussman, M. B. (Ed.), *Sociology and Rehabilitation* (pp. 35-53). Washington D.C: American Sociological Association.
- NDA (2002) *Attitudes To Disability In Ireland In 2001*. National Disability Authority, Dublin, Ireland.
- NDA (2007a) *Literature Review On Attitudes Towards Disability*. National Disability Authority, Dublin, Ireland.
- NDA (2007b) *Public Attitudes To Disability In Ireland In 2006*. National Disability Authority, Dublin, Ireland.
- NDA (2011) *A National Survey Of Public Attitudes To Disability In Ireland*. National Disability Authority, Dublin, Ireland.
- Neimeyer, R.A. (2010) *Meaning Reconstruction And The Experience Of Loss* (4th ed.). Washington, DC 20002: American Psychological Association.

- Neimeyer, R.A., Botella, L., Herrero, O., Pacheco, M., Figueras, S. & Werner-Wildner, L.A. (2002) The meaning of your absence. In Kauffman, J. (Ed.), *Loss Of The Assumptive World: A Theory Of Traumatic Loss* (pp. 31-48). New York: Routledge: Taylor and Francis Group.
- Nelson, A.M. (2003) Transition to motherhood. *JOGNN: Journal of Obstetric, Gynecology and Neonatal Nursing*, **32**(4), 465-477.
- Nicholson, P. (1998) *Postnatal Depression: Psychology, Science And The Transition to Motherhood*. London: Routledge.
- Nightingale, D. & Cromby, J. (1999) *Social Constructionist Psychology: A Critical Analysis Of Theory And Practice*. Buckingham: Open University Press.
- Nightingale, D. & Cromby, J. (2002) Social constructionism as ontology: exposition and example. *Theory and Psychology*, **12**(5), 701-713.
- Noerager Stern, P. (2009) In the beginning Glaser and Strauss created grounded theory. In Morse, J. M., Noerager Stern, P., Corbin, J., Bowers, B., Charmaz, K. and Clarke, A. E. (Eds.), *Developing Grounded Theory: The Second Generation* (pp. 24-29). Walnut Creek, California: Left Coast Press Inc.
- Nolan, M.L. (1997) Antenatal education - where next? *Journal of Advanced Nursing*, **25**(6), 198-204.
- Nolan, M.L. & Hicks, C. (1997) Aims, processes and problems of antenatal education as identified by three groups of childbirth teachers. *Midwifery*, **13**(4), 179-188.
- Nomaguchi, K.M. & Milkie, M.A. (2003) Costs and rewards of children: the effects of becoming a parent on adults' lives. *Journal of Marriage and the Family*, **65**(2), 356-374.
- Norton, L. (1999) The philosophical bases of grounded theory and their implications for research practice. *Nurse Researcher*, **7**(1), 31-44.
- Nosek, M.A. (1992) Point of view: primary care issues for women with severe physical disabilities. *Journal of Women's Health*, **1**(4), 245-248.
- Nosek, M.A., Howland, C., Rintala, D.H., Young, M.E. & Chanpong, G.F. (2001) National study for women with physical disabilities: final report. *Sexuality and Disability*, **19**(1), 5-39.
- Nosek, M.A., Young, M.E., Rintala, D.H., Howland, A., Foley, C.C. & Bennett, J.L. (1995) Barriers to reproductive health maintenance among women with physical disabilities. *Journal of Women's Health*, **4**(5), 505-518.
- NWCI (2006) *Women's Health In Ireland Meeting International Standards*. National Women's Council of Ireland, Dublin, Ireland.
- O'Connor, M. (2006) Conjuring choice while subverting autonomy: medical technocracy and home birth in Ireland. In Symon, A. (Ed.), *Risk And Choice In Maternity Care: An International Perspective* (pp. 109-122). London: Churchill Livingstone.
- O'Driscoll, K., Meagher, D. & Robson, M. (1993) *Active Management Of Labour: The Dublin Experience* (5th ed.). London, UK: Mosby.
- O'Reilly, A. (2010) *21st Century Motherhood: Experience, Identity, Policy, Agency*. New York: Columbia University Press.
- Oakley, A. (1974) *The Sociology Of Housework*. Bath: Martin Robertson: The Pitman Press.
- Oakley, A. (1979) *From Here To Maternity: Becoming A Mother*. Harmondsworth: Penguin.
- Oakley, A. (1980) *Women Confined: Towards A Sociology Of Childbirth*. Oxford: Martin Roberston.
- Oakley, A. (1981) Interviewing women: a contradiction in terms. In Roberts, H. (Ed.), *Doing Feminist Research*. London: Routledge and Kegan Paul.

- Oakley, A. (1993) Essays On Women, Medicine And Health. Edinburgh: Edinburgh University Press.
- Oakley, A. (2000) Experiments in Knowing: Gender And Method In The Social Science. Cambridge: Polity Press.
- Oliver, M. (1990) The Politics of Disablement: A Sociological Approach. Basingstoke: Palgrave MacMillan.
- Oliver, M. (1996) Defining impairment and disability: issues at stake. In Barnes, C. and Mercer, G. (Eds.), Exploring The Divide. Leeds: The Disability Press.
- Olkin, R. & Howson, L.J. (1994) Attitudes toward and images of physical disability. Journal of Social Behaviour and Personality, **9**(5), 81-96.
- Onken, S.J. & Slaten, E. (2000) Disability identity formation and affirmation: the experience of persons with severe mental illness. Sociological Practice: A Journal of Clinical and Applied Sociology, **2**(2), 99-111.
- Onorato, R.S. & Turner, J.C. (2001) The 'I' the 'me' and the 'us': the psychological group and self concept maintenance and change. In Sedikides, C. and Brewer, M. B. (Eds.), Individual Self, Relational Self, Collective Self (pp. 147-170). Philadelphia: Psychology Press: a member of the Taylor and Francis Group.
- Parkes, C. (1971) Psycho-social transition: a field for study. Social Science & Medicine, **5**(2), 101-115.
- Parkes, C.M. (1975) What becomes of redundant world models? A contribution to the study of adaptation to change. British Journal of Medical Psychology, **48**(2), 131-137.
- Parnis, D., Mont, J. & Gombay, B. (2005) Co-operation or co-option? accessing the methodological benefits and barriers involved in conducting qualitative research through medical institutions. Qualitative Health Research, **15**(5), 686-697.
- Parratt, J. (2002) The impact of childbirth experiences on women's sense of self: a review of the literature. Australian Journal of Midwifery, **15**(4), 10-16.
- Parsons, T. (1951) The Social System. New York: Free Press.
- Parton, N. (2003) Rethinking professional practice: the contribution of social constructionism and the feminist ethics of care. British Journal of Social Work, **33**(1), 1-16.
- Patston, P. (2007) Constructive functional diversity: a new paradigm beyond disability and impairment. Disability and Rehabilitation, **29**(20-21), 1625-1633.
- Patton, J. (1982) Practical Evaluation. Beverly Hills CA: Sage.
- Peel, E., Parry, O., Douglas, M. & Lawton, J. (2006) It's no skin off my nose: why people take part in qualitative research. Qualitative Health Research, **16**(10), 1335-1349.
- Peterson, C., Maier, S.F. & Seligman, M.E.P. (1995) Learned Helplessness: A Theory For The Age Of Personal Control. USA: Oxford University Press.
- Phoenix, A. (1991) Young Mothers? Cambridge: Polity Press.
- Phoenix, A., Woollett, A. & Lloyd, E. (1991) Motherhood: Meanings, Practices and Ideologies. London, UK: Sage Publications.
- Piaget, J. (1952) The Origins Of Intelligence In Children. New York: International Universities Press.
- Piantanida, M., Tananis, C.A. & Grubs, R.E. (2004) Generating grounded theory of/for educational practice: the journey of three epistemorphs. International Journal of Qualitative Studies in Education, **17**(3), 325-346.

- Pinder, R. (1996) Sick but fit or fit but sick? ambiguity and identity at the workplace. In Barnes, C. and Mercer, G. (Eds.), *Exploring The Divide: Illness And Disability*. Leeds: The Disability Press.
- Piotrowski, K. & Snell, L. (2007) Health needs of women with disabilities across lifespan. *JOGNN: Journal of Obstetric, Gynaecology and Neonatal Nursing*, **36**(1), 79-89.
- Pistrang, N. (1984) Women's work involvement and experience of new motherhood. *Journal of Marriage and Family*, **46**(2), 433-447.
- Prasad, P. (1993) Symbolic processes in the implementation of technological changes: a symbolic interactionist study of work computerization *The Academy of Management Journal* **36**(6), 1400-1429.
- Pratt, D.D. (1998) *Five Perspectives On Teaching In Adult And Higher Education*. Malabar, FL: Krieger Publishing Company.
- Pratt, J. (2002) The impact of childbirth experiences on women's sense of self: a review of the literature. *Australian College of Midwives Incorporated*, **15**(4), 10-16.
- Price, B. (2002) Laddered questions and qualitative data research interviews. *Journal of Advanced Nursing*, **37**(3), 273-281.
- Pridham, K.F. & Chang, A.S. (1992) Transition to being the mother of a new infant in the first 3 months: maternal problem solving and self-appraisal. *Journal of Advanced Nursing*, **17**(2), 204-216.
- Prilleltensky, O. (2003) A ramp to motherhood: the experience of mothers with physical disabilities. *Sexuality and Disability*, **12**(1), 21-47.
- Prilleltensky, O. (2004a) My child is not my carer: mothers with physical disabilities and the well-being of children. *Disability and Society*, **19**(3), 209-223.
- Prilleltensky, O. (2004b) *Motherhood And Disability: Children And Choices*. Hampshire: Palgrave, MacMillan.
- Raman, S. & Levi, S.J. (2002) Concepts of disablement in documents guiding physical therapy. *Disability and Rehabilitation*, **24**(15), 790-797.
- Ramazanoglu, C. & Holland, J. (2002) *Feminist Methodology: Challenges And Choices*. London: Sage Publications.
- Rando, T.A. (1986) *Loss And Anticipatory Grief*. Lexington, MA: Lexington Books.
- Rando, T.A. (2002) The curse of too good a childhood. In Kauffman, J. (Ed.), *Loss Of The Assumptive World: A Theory Of Traumatic Loss* (pp. 171-192). New York: Routledge: Taylor and Francis Group.
- RCN (2007) *Pregnancy And Disability: RCN Guidance For Midwives And Nurses*. Royal College of Nursing, London.
- Redwood, T. (2007) *Becoming a mother: a phenomenological exploration of transition to motherhood, its impact and implications for the professional lives of nurses, midwives and health visitors*. School of Nursing and Midwifery, PhD, University of East Anglia London.
- Reinharz, S. & Chase, S.E. (2003) Interviewing women. In Holstein, J. A. and Gubrium, J. F. (Eds.), *Inside Interviewing: New Lenses, New Concerns*. Thousand Oaks, CA: Sage Publications Inc.
- Rich, A. (1977) *Of Woman Born*. London: Virago.
- Richardson, D. (1993) *Women, Motherhood and Childrearing*. Basingstoke: Macmillan.

- Rogan, F., Schmied, V., Barclay, L., Everitt, L. & Wyllie, A. (1997) 'Becoming a mother' - developing a new theory of early motherhood. *Journal of Advanced Nursing*, **25**(5), 877-885.
- Rolfe, G., Freshwater, D. & Jasper, M. (2001) *Critical Reflection For Nursing And The Helping Professions*. Basingstoke, UK: Palgrave.
- Rossi, A.S. (1968) Transition to parenthood. *Journal of Marriage and the Family*, **30**(6), 26-29.
- Rothman, B.K. (1989) *Recreating Motherhood*. New York: Norton Press.
- Rubin, R. (1967a) Attainment of the maternal role. Part 1: processes. *Nursing Research*, **16**(3), 237-245.
- Rubin, R. (1967b) Attainment of maternal role. Part 2: models and referents. *Nursing Research*, **16**(3), 342-346.
- Rubin, R. (1984) *Maternal Identity And Maternal Experience*. New York: Springer.
- Ruddick, S. (1980) Maternal thinking. *Feminist Studies*, **6**(2), 342-367.
- Ruddick, S. (1989) *Maternal Thinking: Toward A Politics Of Peace*. Boston: Beacon.
- Russell, H., Quinn, E., King O'Riain, R. & McGinnity, F. (2008) *The Experience of Discrimination In Ireland: Analysis Of The QNHS Equality Module*. The Economic and Social Research Institute & The Equality Authority, Dublin.
- Safilios-Rothschild, C. (1990) *The Sociology And Social Psychology Of Disability And Rehabilitation*. New York: Random House.
- Sandelowski, M. (1986) The problem of rigor in qualitative research. *Advances in Nursing Science*, **8**(3), 27-37.
- Sandelowski, M. (1993) Rigor or rigor mortis: the problem of rigor in qualitative research. *Advances in Nursing Science*, **16**(2), 1-8.
- Sandelowski, M. (2002) Re-embodying qualitative inquiry. *Qualitative Health Research*, **12**(1), 102-115.
- Sandelowski, M. (2004) Using qualitative research. *Qualitative Health Research*, **14**(10), 1366-1386.
- Sargent, C.F. & Bascope, G. (1997) Ways of knowing about birth in three cultures. *Medical Anthropology Quarterly*, **10**(2), 213-236.
- Sargent, J., Williams, R., Hagerty, B., Lynch-Sauer, J. & Hoyle, K. (2002) Sense of belonging as a buffer against depressive symptoms. *Journal of American Psychiatric Nurses Association*, **8**(4), 120-129.
- Sawyer, L.M. (1999) Engaged mothering: the transition to motherhood for a group of African American Women. *Journal of Transcultural Nursing*, **10**(1), 14-21.
- Scambler, G. (2009) Health-related stigma. *Sociology of Health and Illness*, **31**(3), 441-445.
- Schon, D. (1983) *The Reflective Practitioner: How Professionals Think In Action*. New York: Basic Books.
- Schopp, L.H., Sanford, T.C., Hagglund, K.J., Gay, J.W. & Coatney, M.A. (2002) Removing service barriers for women with physical disabilities promoting accessibility in the gynaecologic setting. *Journal of Midwifery and Women's Health*, **47**(2), 74-79.
- Schwandt, T. (2001) *Dictionary Of Qualitative Inquiry*. Thousand Oaks, CA: Sage Publications Inc.
- Schwandt, T. (2003) Three epistemological stances for qualitative inquiry: interpretivism, hermeneutics, and social constructionism. In Denzin, N. K. and Lincoln, Y. (Eds.), *The Landscape of Qualitative Research Theories And Issues* (2nd ed.). Thousand Oaks, CA: Sage Publications.

- Scotch, R.K. & Schriener, K. (1997) Disability as human variation: implications for policy. *The Annals of the American Academy of Political and Social Science*, **549**(1), 148-159.
- Sedikides, C. & Brewer, M.B. (2001) Individual self, Relational self, and collective self: partners, opponents or strangers? In Sedikides, C. and Brewer, M. B. (Eds.), *Individual Self, Relational Self, Collective Self* (pp. 1-3). Philadelphia: Psychology Press: a member of the Traylor and Francis Group.
- Seligman, M.E.P. (1975) *Helplessness: On Depression, Development and Death*. San Francisco: W. H. Freeman.
- Sethi, S. (1995) The dialectic in becoming a mother: experiencing a postpartum phenomenon *Scandinavian Journal of Caring Sciences*, **9**(4), 235-244.
- Shakespeare, T. (1996) Disability, identity and difference. In *Exploring The Divide: Illness And Disability*. Leeds: The Disability Press.
- Shakespeare, T. (2002) *The Disability Reader: Social Science Perspectives*. London: Continuum International Publishing Group.
- Shakespeare, T. (2006) *Disability Rights And Wrongs*. London: Routledge: Taylor and Francis Group.
- Shakespeare, T. & Watson, N. (2001) The social model of disability: an outdated ideology? In Shakespeare, T. and Watson, N. (Eds.), *Research In Social Science And Disability. Vol 2: Exploring Theories And Expanding Methodologies* (pp. 9-28). London: Elsevier Science Ltd.
- Shamai, M. & Kochal, R.B. (2008) Motherhood starts in prison: the experience of motherhood among women in prison. *Family Process*, **47**(3), 323-340.
- Shapiro, A.H. (2000) *Everyone Belongs*. London, UK: Routledge.
- Siddiqui, J. (1999) The therapeutic relationship in midwifery. *British Journal of Midwifery*, **7**(2), 111-114.
- Silva, M.C. & Sorrell, J.M. (1995) From Carper's pattern of knowing to ways of being: an ontological philosophical shift in nursing. *ANS: Advances in Nursing Science*, **18**(1), 1-13.
- Sin, C.H. (2003) Interviewing in place: the socio-spatial construction of interview data. *Area*, **35**(3), 305-312.
- Smeltzer, S. (2007) Pregnancy in women with physical disabilities. *JOGNN: Journal of Obstetric, Gynaecology and Neonatal Nursing*, **36**(1), 88-96.
- Smith, E.R., Coats, S. & Murphy, J. (2001) The self and attachment to relationship partners and groups. In Sedikides, C. and Brewer, M. B. (Eds.), *Individual Self, Relational Self, Collective Self* (pp. 109-122). Philadelphia: Psychology Press: a member of the Taylor and Francis Group.
- Smith, J.A. (1994) Reconstructing selves: an analysis of discrepancies between women's contemporaneous and retrospective accounts of the transition to motherhood. *British Journal of Psychology*, **85**(Part 3), 371-392.
- Smith, J.A. (1999) Identity development during the transition to motherhood: an interpretative phenomenology analysis. *Journal of Reproductive and Infant Psychology*, **17**(3), 281-299.
- Smith, M. (1998) *Social Science In Question*. London, UK: Sage Publications Ltd.
- Snow, D.A. (2001) Extending and broadening Blumer's conceptualization of symbolic interactionsim. *Symbolic Interaction*, **24**(3), 367-377.
- Spidsberg, B.D. (2007) Vulnerable and strong - lesbian women encountering maternity care. *Journal of Advanced Nursing*, **60**(5), 478-486.

- Spruill, L.C. (1999) Social, legislative and clinical influences on defining disability: implication for information management. *Topics in Health Information Management*, **19**(3), 10-14.
- Stanley, L. & Wise, S. (1993) *Breaking Out Again: Feminist Consciousness And Feminist Research* (2nd ed.). London, UK: Routledge Kegan Paul.
- Stern, D.N. (2006) *The Motherhood Constellation*. London: Karnac Books.
- Stern, D.N., Bruschiweiler-Stern, N. & Freeland, A. (1998) *The Birth Of A Mother*. New York: Basic Books, a member of the Perseus Group.
- Stern, P.N. (1995) Eroding grounded theory. In Morse, J. M. (Ed.), *Critical Issues In Qualitative Research Methods* (pp. 212-223). Thousand Oaks, CA: Sage.
- Strauss, A. & Corbin, J. (1990) *Basics Of Qualitative Research*. Newbury Park, CA: Sage.
- Stroebe, M.S. & Schut, H. (2010) Meaning making in the dual process model of coping with bereavement. In Neimeyer, R. A. (Ed.), *Meaning Reconstruction And The Experience Of Loss* (4th ed., pp. 55-73). Washington, DC, 20002: American Psychological Association.
- Susman, J. (1994) Disability, stigma and deviance. *Social, Science and Medicine*, **38**(1), 15-22.
- Swain, J. & French, S. (2000) Towards an affirmation model of disability. *Disability and Society*, **15**(4), 569-582.
- Tate, D.G. & Pledger, C. (2003) An integrative conceptual framework of disability *American Psychologist*, **58**(2), 289-295.
- Taylor, S. & Bogdan, R. (1998) *An Introduction To Qualitative Research Methods: A Guidebook And Resources* (3rd ed.). New York: John Wiley.
- Thomas, C. (1997) The baby and the bath water: disabled women and motherhood in social context. *Sociology of Health and Illness*, **19**(5), 622-643.
- Thomas, C. (1998) Becoming a mother: disabled women (can) do it too. *MIDIRS: Midwifery Digest*, **8**(3), 275-278.
- Thomas, C. (2004) How is disability understood? An examination of sociological approaches. *Disability and Society*, **19**(6), 569-583.
- Thomas, C. & Curtis, P. (1997) Having a baby: some disabled women's experiences. *Midwifery*, **13**(4), 202-209.
- Thompson, D.A. & McRae, M.B. (2001) The need to belong: a theory of the therapeutic function of the black church tradition. *Counseling and Values*, **46**(1), 40-53.
- Thompson, S.C. & Janigan, A.S. (1988) Life schemes: a framework for understanding the search for meaning. *Journal of Social and Clinical Psychology*, **7**(2-3), 260-280.
- Thomson, R. & Kehily, M.J. (2008) *The Making Of Modern Motherhood: Memories, Representations, Practices*. Buckingham, UK: The Open University.
- Thomson, R., Kehily, M.J., Hadfield, L. & Sharpe, S. (2011) *Making Modern Mothers*. Bristol, UK: Policy Press.
- Thorne, S. (1997) The art (and science) of critiquing qualitative research. In Morse, J. M. (Ed.), *Completing A Qualitative Project: Details And Dialogue* (pp. 117-132). Thousand Oaks, CA: Sage Publication Inc.
- Thorne, S. & Darbyshire, P. (2005) Land mines in the field: a modest proposal for improving the craft of qualitative health research. *Qualitative Health Research*, **15**(8), 1105-1113.
- Tice, D.M. & Baumeister, R.F. (2001) The primacy of the interpersonal self. In Sedikides, C. and Brewer, M. B. (Eds.), *Individual Self, Relational Self, Collective Self* (pp. 71-88). Philadelphia: Psychology Press: a member of the Taylor and Francis Group.

- Tighe, C. (2001) Working at disability: a qualitative study of the meaning of health and disability for women with physical impairments. *Disability and Society*, **16**(4), 511-529.
- Tilley, C.M. (1998) Health care for women with physical disabilities: literature review and theory. *Sexuality and Disability*, **16**(2), 87-102.
- Trevvy, D. (2000) *Collins English Dictionary* (5th ed.). London: Collins.
- Ueda, S. & Okawa, Y. (2003) The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation*, **25**(11-12), 596-601.
- UN (1948) *Universal Declaration Of Human Rights*. United Nations, <http://www.unhchr.ch.udhr/lang/eng.htm>. (Accessed 14th September 2008).
- UN (1971) *Declaration On The Rights Of Mentally Retarded Persons*. United Nations, http://www.unhchr.ch/html/menu3/b/m_mental.htm. (Accessed 14th September 2008).
- UN (1975) *Declaration On The Rights Of Disabled Persons*. United Nations, <http://www.unhchr.ch/html/menu3/b/72.htm>. (Accessed 14th September 2008).
- UN (1993) *Standard Rules On The Equalization Of Opportunities For People With Disabilities*. United Nations, http://www.who.int/disabilities/policies/standard_rules/en/index.html. (Accessed 24th August 2008).
- UN (2006) *Convention On The Rights Of People With Disabilities*. United Nations, <http://www.un.org/disabilities/convention/conventionfull.html>. (Accessed 24th August 2008).
- UPIAS (1979) *Fundamental Principles of Disability* Union of Physically Impaired Against Segregation, London.
- Urwin, C. (2007) Doing infant observation differently? researching the formation of mothering identities in an inner London borough. *Infant Observation*, **10**(3), 239-251.
- Ustun, T.B., Chatterji, S., Bickenbach, J.E., Kostanjsek, N. & Schneider, M. (2003) The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability and Rehabilitation*, **25**(11-12), 565-571.
- van Gennep, A. (1960) *The Rites Of Passage*. London: Routledge and Kegan Paul.
- van Schalkwyk, G. (2005) Exploration of post-divorce experiences: women's reconstructions of self. *ANZJFT*, **26**(2), 90-97.
- Voh, J. (1993) On belonging: a place to stand, a gift to give In Turnbull, A. P., Patterson, J. A., Behr, S. K., Murphy, D. L., Marquis, M. J. and Blue-Banning, M. J. (Eds.), *Cognitive Coping: Families And Disability* (pp. 151-163). Baltimore: Brookes.
- Walsh-Gallagher, D., Sinclair, M. & McConkey, R. (2012) The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological understanding. *Midwifery*, **28**(2), 156-162.
- Walsh, D. (1999) An ethnographic study of women's experience of partnership caseload midwifery practice: the professional as a friend. *Midwifery*, **15**(165-176).
- Waring, M.J. (1995) *Gatekeeping Processes: Grounded Theory, Young People And Physical Activity*. PhD, Loughborough University of Technology, Loughborough.
- Watson, N. (1998) Enabling identity: disability, self and citizenship. In Shakespeare, T. (Ed.), *The Disability Reader: Social Science Perspectives*. London, UK: Cassell.
- Watson, N. (2002) Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. *Disability and Society*, **17**(5), 509-527.

- Weaver, J. & Usher, J. (1997) How motherhood changes life – a discourse analytic study with mothers of young children. *Journal of Reproductive and Infant Psychology*, **15**(1), 51-69.
- Weeber, J.E. (2004) *Disability Community Leaders' Disability Identity Development: A Journey Of Integration And Expansion*. Department of Educational Research, Leadership and Counselor Education, PhD, North Carolina State University, US.
- Welner, S.L. (1997) Gynecologic care and sexuality issues for women with disabilities. *Sexuality and Disability*, **15**(1), 33-40.
- Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections On Disability*. New York, US: Routledge.
- Wengraf, T. (2001) *Qualitative Research Interviewing*. Thousand Oaks, CA: Sage Publications, Inc.
- Westbrook, M.T. & Chinnery, D. (1995) The effect of physical disability on women's childbearing and early childrearing experiences. *Australian Disability Review*, **9**(3), 3-17.
- White, B. (2004) Discourse analysis and social constructionism. *Nurse Researcher*, **12**(2), 7-16.
- White, V. (2010) *Mother Ireland: Why Ireland Hates Motherhood*. Dublin, Ireland: Londubh Books.
- WHO (1993) *ICIDH: International Classification Of Impairments, Disabilities And Handicap*. World Health Organisation, Geneva, Switzerland.
- WHO (2001) *ICF: International Classification of Functioning, Disability and Health*. World Health Organisation, Geneva, Switzerland.
- Williams, P. (2005) *What is social support: a grounded theory of social interaction in the context of the new family*. Department of Public Health, PhD, University of Adelaide, Adelaide, Australia.
- Williams, S.J. (1999) Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health and Illness*, **21**(6), 797-819.
- Williamson, J. (1986) *Consuming Passions*. London, UK: Marion Boyars.
- Wilton, T. & Kaufmann, T. (2001) Lesbian mothers' experiences of maternity care in the UK. *Midwifery*, **17**(3), 203-211.
- Woodward, K. (1997) *Identity And Difference*. London, UK: Sage in association with The Open University.
- Woodward, K. (2004) *Questioning, Identity: Gender, Class and Ethnicity*. London, UK: Routledge.
- Yeates, N.R.M. (2004) *Identity and Transition to Motherhood in First Time Mothers*. PhD, University of East Anglia, London, UK.

APPENDICES

Appendix 1 Members of the multidisciplinary team

Appendix 2 Explanatory note on individual and collective self

Appendix 3 Diagrammatic representation of conditional matrix

Appendix 4 Table of literature reviewed on the transition to motherhood

Appendix 5 List of voluntary agencies contacted during the conduct of study

Appendix 6 Poster for first phase of the study

Appendix 7 Information leaflet for women expressing an interest in phase one of the study

Appendix 8 Participant information and consent forms for phase one and two of the study

Appendix 9 Ethical approval to conduct study

Appendix 10 Lone worker policy

Appendix 11 Demographic details of twenty two women who contributed to the study

Appendix 12 Interview guide for phase one and two of the study

Appendix 13 Diagrammatic representation of data analysis and collection process

Appendix 14 Diagrammatic representation of the Helix Model

Appendix 15 Exemplar of memo

Appendix 16 National and international presentations

Appendix 17 Publications to date

Appendix 1 Members of the multidisciplinary team

Appendix 2 Explanatory note on individual and collective self

Appendix 3 Diagrammatic representation of conditional matrix

Appendix 4 Table of literature reviewed on the transition to motherhood

Appendix 4A Search terms used in the study

Appendix 4B Table of literature reviewed on the transition to motherhood

Appendix 5 List of voluntary agencies contacted during the conduct of study

Appendix 6 Poster for first phase of the study

Appendix 7 Information leaflet for women expressing an interest in phase one of the study

Appendix 8 Participant information and consent forms for phase one and two of the study

Appendix 8A Letter to women meeting inclusion criteria for the first phase of the study (n=54)

Appendix 8B Consent form to contact the women who express an interest in participating in the first phase of study (n=54)

Appendix 8C Letter to women expressing a willingness to participate in face to face interviews in the first phase of the study (n=54)

Appendix 8D Information booklet for women participating in the first phase of the study (n=54)

Appendix 8E Pre-interview participant consent form for the first phase of the study (n=54)

Appendix 8F Recruitment letter to women participating in the second phase of the study (n=22)

Appendix 8G Consent form to contact the women who express an interest in participating in the second phase of the study (n=22)

Appendix 8H Pre-interview participant consent form for the second phase of the study (n=22)

Appendix 9 Ethical approval to conduct study

Appendix 10 Lone worker policy

Appendix 11 Demographic details of the twenty two women who contributed to the study

Appendix 12 Interview guide for phase one and two of the study

Appendix 12A Interview schedule for individual interviews in the first phase of the study (n=54)

Appendix 12B Interview schedule for individual interviews in the second phase of the study (n=22)

Appendix 13 Diagrammatic representation of data analysis and collection process

Appendix 14 Diagrammatic representation of the Helix Model

Appendix 15 Exemplar of memo

Appendix 16 National and International presentations

Appendix 17 Publications to date