



Libraries and Learning Services

University of Auckland Research Repository, ResearchSpace

Copyright Statement

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

This thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognize the author's right to be identified as the author of this thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from their thesis.

General copyright and disclaimer

In addition to the above conditions, authors give their consent for the digital copy of their work to be used subject to the conditions specified on the [Library Thesis Consent Form](#) and [Deposit Licence](#).

**Not inherently vulnerable:
An examination of paradigms,
attitudes and systems that enable
the abuse of dis/abled women**

Deborah Mary Hager

**A thesis submitted in fulfilment of the requirements for the
degree of Doctor of Philosophy in Health Science,
University of Auckland, 2017**

Abstract

Despite worldwide evidence that between 33% and 90% of disabled women are abused by a partner, family member or person in the wider community, in New Zealand there are virtually no initiatives to prevent or respond to this abuse. Using the theoretical structure of health promotion, critical emancipatory theory and more specifically, feminist disability theory, this thesis investigates the underlying paradigms that inhibit or enable conversations and collaboration within and between the domestic/sexual violence and disability sectors to address the abuse of disabled women. Eighty-seven people working in the violence and disability sectors and related government organisations and ministries in New Zealand were interviewed. The resulting data was transcribed verbatim and examined using thematic analysis, revealing multiple barriers that inhibit service responses, constructive responses from government, and societal impetus to address the lack of attention currently paid to this issue. The most pragmatic barriers are lack of resources and varying staff competency within the sectors, followed by the existence of two distinct world views: medical/individual deficit and socio-political. These paradigms are closely related to practice across the sectors – best, good and poor. In addition, underlying social and governmental attitudes and practice result in invisible, silenced, controlled and uncounted dis/abled women. Finally, vulnerable/vulnerability emerges as a paradigm that disempowers and disables all women, one consequence of which is the assumption that we (women) will be abused. This, when examined using feminist disability theory and understandings of hegemonic masculinity, ultimately provides an explanation for the lack of services, resources and processes to prevent violence against dis/abled women and keep abused dis/abled women safe from further harm. A paradigm shift, in language and perception, is proposed to shift the focus from women to the systems and attitudes that enable harm to occur.

Acknowledgements

Supervisors Dr. Jennifer Hand, Associate Professor Elsie Ho, Dr. Laura Wilkinson-Meyers. Yes, I was very lucky. I had three wonderful women steering me through this project of a PhD. Not only did I finish, I understood each stage of the journey and enjoyed nearly all of it. What an amazing achievement. Thank you so much.

Participants in the research. Thank you very much for sharing your knowledge, expertise and opinions with me. As this thesis is entirely based on our discussions, this truly couldn't have happened without you.

Network coordinators in the domestic/sexual violence and disability sectors, and others, who facilitated the setting up of interviews and focus groups. I'm not naming you because it contravenes anonymity of participants. But you know who you are and I very much appreciate your support.

My family. The people who not only cheered me on and provided role models for perseverance and achieving great work, but facilitated my progress by both practical support (spelling, food, grammar and editing) and by love, understanding and the belief that I could succeed. Thank you Neil Miller, and Mandy, Belinda and Nicky Hager.

My friends. Thank you for putting up with my lack of communication, my forgetfulness and my occasional lapses in social secretary duties.

Cristy Trewartha. PhD buddy. For conversation and support.

Dr. Rachel Simon-Kumar, Dr. Janine Wiles and Professor Peter Adams, Social and Community Health, University of Auckland, for discussions about theory and methodology to underpin my thinking and begin a theoretical analysis of my subject. Debbie Espiner, University of Auckland, College of Education for generously sharing her knowledge of disability literature and helping me on my journey to understand the history and progression of critical disability studies. Associate Professor Missy Morton, University of Canterbury, for support, confirmation, ideas and theory to underpin thinking.

Monique Jonas (SOPH) for ethics approval help and support.

Debbie Waayer – for formatting and other support. Without Debbie there would be no formatting.

Members of DVD and DCAV, many of whom are pioneers in this field, some of whom have been working towards change for 30 years.

Philip Patston, Sherry Connell and Fran Phillips who worked alongside me and guided me as we developed training and education about disability and sexuality for able-bodied people who worked as caregivers and managers and others in the disability sector, in the early 1990s.

Cate Anderson, who told me that I couldn't do sexuality education with disabled people without the participation of disabled people – then introduced me to Fran, Sherry and Philip.

Librarians, Helen O'Carroll, Liz Wilkinson, Simon Esling (Epsom), Darryl Hayman, Danielle Moreau (Tamaki), Sue Foggin (Philson) and Gay Richards, (NZ Family Violence Clearing House), for helping me understand the systems, source information, understand how to find things and (Gay) print them out.

Mark Taylor and others at the University of Auckland Research Office who rescued me and made the systems work.

Clare Murphy for helping me to understand hegemonic masculinity and being a role model for completing a PhD, plus providing many suggestions for how to keep writing.

Stowe Alrutz, fellow SOPH PhD student, for helping me navigate the system and explaining how it all works.

Those who formally assisted me. I was hugely helped by Robin Ingram, Sharon Lacassie and Trisha Meagher-Lundberg, who transcribed interviews for me. Catriona MacLennan did the final edit. Thank you Catriona for wonderfully perceptive and pedantic editing.

Thanks to Lily for accompanying me on many tramps in the bush while I pondered my data and the possible learnings/findings from them. Lily died in October 2015.

Contents

ABSTRACT	I
ACKNOWLEDGEMENTS	II
LIST OF FIGURES	X
LIST OF TABLES	X
CHAPTER 1 OVERVIEW	1
Introduction	1
Violence against women.....	3
Violence against disabled women	3
Aims and research question.....	4
Health promotion paradigm.....	5
Definitions	5
Structure of the thesis	8
CHAPTER 2 VIOLENCE AGAINST DISABLED WOMEN	10
Introduction	10
Sources of literature.....	10
Violence against women.....	12
Domestic and sexual violence.....	12
Health effects of violence against women	15
Gender and power.....	17
Data collection and cohesion.....	19
Violence against disabled women	20
Settings and perpetrators.....	20
Forms of violence	21
Difficulties in quantifying the prevalence of abuse.....	23
Current gaps in service provision and alignment of sectors.....	23
Gaps in service provision and best practice.....	24
Why this lack of service provision needs to be addressed.....	27
Incorporating women’s voices in policy and practice	28
Violence against disabled women in New Zealand.....	28
NZ literature.....	28
Prevalence	29
National legislation and policy	31

National practice policies.....	34
Nationally specified qualifications required for working in the violence or disability sector	34
Accessible services	36
Government responsibility.....	39
Incorporating women’s voices in policy and practice	40
Structure of the domestic and sexual violence, elder care and disability sectors in New Zealand.....	41
Overall findings – an absence of information and integration.....	42
Conclusion.....	43
CHAPTER 3 SITUATING THE RESEARCH AND EXAMINING PARADIGMS AT THE INTERSECTION OF VIOLENCE AGAINST DISABLED WOMEN	44
Using paradigms, models and theory to investigate violence against disabled women	44
Models/discourses of disability	45
Models and discourses of violence	51
Why these models are insufficient at the intersection of violence and abuse	54
Theories to situate and connect the research	55
Health promotion	55
Intersectionality	59
Paradigms that marginalise and devalue disabled women	63
Ableism.....	63
Rape culture	64
Hegemonic masculinity	64
How are these paradigms manifest and perpetuated?.....	65
Issues at the intersection of violence and disability	69
Myths, stigma and blame	69
‘Real’ victims – complicit victims.....	72
Expectations of independence or dependence rather than interdependence	74
Conclusion.....	76
CHAPTER 4 RESEARCH METHODOLOGY AND METHODS.....	78
Introduction	78
Overall research approach	78

Emancipatory research and key elements	79
Unifying the results and interpretations – feminist disability theory	84
Linkages between the theories used in the thesis	86
Who can speak about disability issues or, what right do I have to speak on disability issues?	87
Evolution of the research question	88
Ethical issues	89
Data collection methods	91
Literature review	91
Material provided by research participants	91
Official Information Act (OIA) requests	92
Semi-structured key informant interviews	93
Focus groups	94
Interview questions	94
Recruiting participants	96
Venues and timing of interviews	98
Participant characteristics	98
Anonymity of participant information and identification of participant sector area specialisations	99
Data analysis methods	100
Ensuring rigour	107
Conclusion	109
CHAPTER 5 TOO HARD, NOT MY PROBLEM, NOT A PROBLEM: PRAGMATIC REASONS FOR NON-COLLABORATION	110
Introduction	110
Levels of interaction between sectors	111
Too hard	115
Undervaluing of the caring role in society and the consequent under-resourcing of the sectors	117
Lack of mandated training, qualifications and service specifications	119
Fear of working collaboratively	120
Not my problem – not a problem at all	121
Not believing that disabled women can be/are abused	124
Hiding behind poor legislation or policy	127

Lack of service accessibility.....	128
No shared language and concepts.....	132
Conclusion.....	138
CHAPTER 6 PARADIGMS OF PRACTICE	140
Introduction	140
Models/paradigms people work from.....	141
Individual deficit/medical paradigm.....	141
Socio-political paradigm.....	143
Good and bad practice	148
Good practice.....	148
Best practice.....	152
Poor practice	154
Practice model	159
Conclusion.....	161
CHAPTER 7 EXCLUSION NOT INCLUSION – THE PROCESSES OF EXCLUSION AND INVISIBILITY.....	163
Introduction	163
Hegemonic repression and devaluing of dis/abled women	166
Lack of data collection in mainstream research.....	170
Lack of representation in policy, legislation.....	171
Societal myths, stereotypes, stigma and discrimination – and the harm caused by these.....	174
Not seeing dis/abled women as ‘real’ victims of abuse and violence	180
Not seeing dis/abled women as credible witnesses	183
Objects not subjects.....	184
Lack of trust of the ‘other’	185
Regulation of bodies: organisational, state and interpersonal constraint and control	187
Learnt Compliance.....	191
Conclusion.....	194
CHAPTER 8 VULNERABLE	195
Introduction	195
Meanings of vulnerable from the literature	197
Dis/abled women are socially constructed as vulnerable.....	200

Dis/abled women are not inherently vulnerable	205
It is expected that vulnerable women will be abused	207
Vulnerable women will be preyed upon.....	208
Society doesn't protect those who are perceived as vulnerable	210
Conclusion	212
CHAPTER 9 DISCUSSION CHAPTER	214
Introduction	214
Underlying reasons for inaction - theoretical and empirical findings	214
Services – not valued – too hard, no resources.....	215
Paradigms of practice.....	215
Exclusion of dis/abled women – invisible, silenced, controlled.....	216
Vulnerability	217
An examination of vulnerability.....	218
Expectations of equality.....	219
What purpose does the construction of vulnerability serve?	220
New learning from this research.....	223
The research question	224
Answering the research question	224
Conclusion	228
CHAPTER 10 CONCLUSIONS AND RECOMMENDATIONS	230
Introduction	230
Participant recommendations	230
Recommendations for action at government level	230
Recommendations for action at organisational service provider level.....	233
My recommendations	235
Limitations of the research and directions for future research.....	238
Conclusion	239
REFERENCES	241
APPENDICES	266
Appendix 1. New Zealand Disability Action Plan, 2014 – 2018	266
Appendix 2. Structure and responsibilities of sectors interviewed	267
Appendix 3. Meaning of domestic relationship	271
Appendix 4. Material gathered from interview participants	272

Appendix 5. Employer information/permission sheet.....	274
Appendix 6. Key informant employer interview consent form.....	277
Appendix 7. Key informant interview consent form.....	279
Appendix 8. Key Informant Participant Information Sheet	281
Appendix 9. Network coordinator invitation and information sheet.....	285
Appendix 10. Focus group participant information sheet	288
Appendix 11. Transcription/interpreter confidentiality agreement.....	292
Appendix 12. Interview schedule – key informant and focus groups	293
Appendix 13. Search terms, data bases and sources of literature.....	295
Appendix 14. New Zealand literature about violence against disabled people...	297

List of Figures

Figure 1: Health outcomes contributing to the disease burden of intimate partner violence for women in Victoria, Australia	16
Figure 2: Women’s services as organised by bureaucracy	26
Figure 3: Factors contributing to the occurrence and experience of violence in Indigenous communities	57
Figure 4: Four layers of findings.....	104
Figure 5: Vicious cycle of harm caused by constructing disabled women as vulnerable.....	212
Figure 6: Current national violence response and prevention infrastructure - as of July 2014	270

List of Tables

Table 1: Circles of risk.....	52
Table 2: Themes and sub-themes that have emerged from analysis of service level responses	111
Table 3: Themes and sub-themes – paradigms of practice	141
Table 4: Model of best, good and poor practice.....	160
Table 5: Themes and sub-themes – exclusion not inclusion – the processes of exclusion and invisibility	165
Table 6: Sub-themes associated with the concept of vulnerability	196
Table 7: Model of best, good and poor practice.....	237

Chapter 1

Overview

People say these things didn't happen, but they did. Or they say that if these things did happen then they were unusual. That it was just a few people who did bad things. I've spoken to people all over New Zealand who lived in Kimberley and places like it. In fact, all over the world people have told me their stories and they are all the same: institutions are places of abuse.

Robert Martin in McRae (2014, p34)

Introduction

In July 1987 a group of disabled activist women met with the New Zealand Ministry of Women's Affairs (MWA) to discuss issues associated with disabled women. Among the many issues that were raised in the consultation was violence against disabled women. The report of the meeting states:

...women with disabilities are particularly susceptible to violence and sexual abuse. There is a lot of consciousness raising work to be done to get people to realise that women and children with disabilities do get abused. There should be funding made available to enable refuge and rape crisis personnel to work with women with disabilities as paid consultants to work out appropriate ways of assisting abused women...(Disabled Women's Support Group, 1987, p22).

This has not happened, nor is there evidence of any further consultation with disabled women (Personal correspondence, MWA, 2013). A number of these women, 30 years later, are still actively raising the same concerns and attempting to use the existing structures to initiate a prevention and service response at government level.

In 2014 the New Zealand Government launched the New Zealand Disability Action Plan, 2014 – 2018, a cross-government initiative, in collaboration with disabled people's organisations. The plan has four action areas, one of which is "Ensure personal safety" which focuses on "*promoting systems and practices to protect disabled children and adults in all settings*" (Office of Disability Issues [ODI],

2014, p6). Within this are 7 ‘priority areas’ (see Appendix 1), one of which is educating disabled people about their right not to be abused and what abuse is, and supporting people to speak up for themselves about abuse. What is not included anywhere in the Action Plan is any initiative to respond constructively to identified abuse. There is no provision to upskill providers in either the disability or sexual/domestic violence sectors or to create accessible and responsive justice and violence services to ensure that those who disclose abuse will have safe and appropriate services to respond to their needs. It is therefore left to the sectors themselves to develop services that can respond to the needs that will be identified once this process of education begins. No resources or support have been promised or contributed by government.

The Action Plan was updated in 2015 to include under this same action area:

Explore options to reduce violence, abuse (all types, including bullying) and neglect of disabled people and understand the impact of different cultural contexts. This work will include:

- *building on previous work to educate disabled people about their rights*
- *ensuring the needs of disabled people are built into the [Ministry of Social Development] Family Violence work programme*
- *scoping a new work programme for abuse by non-family members (ODI, 2015, p14).*

There is still no articulated provision to upskill providers and it will be some time before we know what these new provisions are referring to. However, as a consequence of on-going lobbying and activism primarily by disabled women, there is an increasing consciousness of the high rates of violence against disabled women. Despite this, there is still very little interaction between sectors and very few accessible sexual or domestic violence services or services with staff who have expertise to work with disabled women (NZ Family Violence Unit/Hager, 2013).

The Auckland Domestic Violence and Disability working group (DVD), established in 2008, is a voluntary collaboration between people working in the disability and violence sectors to address the abuse of disabled people. DVD provides training about the intersection of violence and disability for people from the three sectors: disability, sexual violence and domestic violence. DVD’s experience is that it is very difficult to attract participants from the violence services. In response to this, in 2013 I began this PhD research project to investigate why the violence and disability sectors, while acknowledging the need to be inclusive to address the abuse of disabled people, are not engaging with DVD or with each other.

Violence against women

The United Nations describes violence against women as:

Any act of gender-based violence that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life (United Nations General Assembly, 1993, Article 1).

Globally, 30% of women aged 15 years and over will experience physical or sexual violence from an intimate partner in their lifetime (Devries et al., 2013, WHO, 2016). In New Zealand one in three (33%) women will experience domestic violence (physical or sexual) from their male partner during their lifetime (Fanslow & Robinson, 2004). Research into same sex violence indicates that violence also occurs in lesbian and gay relationships – so in these circumstances men and women are both victims and perpetrators of violence (Brown & James, 2014).

The World Health Organisation (WHO) identifies violence against women as a public health problem of epidemic proportions (WHO, 2012). In Victoria, Australia, domestic violence accounts for 9% of the overall burden of disease for women between the ages of 15–44 and 3% for all Victorian women (VicHealth, 2004). Kazantzis, Flett, Long, Macdonald and Millar (2000) report that in New Zealand domestic violence may account for as much as 12% of psychological distress and 7% of physical illness among adult women. In addition, Cadilhac et al.'s (2015) research into the health and economic benefits of reducing the prevalence of intimate partner violence (IPV) reports that:

A 5 percentage point absolute reduction in the lifetime prevalence of IPV in the 2008 Australian female population was estimated to produce 6000 fewer incident cases of disease/injury, [and] 74 fewer deaths...(p1).

These findings indicate the existence and extent of violence against women as an epidemic public health problem.

Violence against disabled women

Prevalence rates of sexual and physical abuse of disabled girls and women are even higher than for non-disabled women and girls (Banks, 2003; Frawley, Dyson, Robinson, & Dixon, 2015; Howe, 2000; Thiara, Hague, Bashall, Ellis, & Mullender, 2012), although it is difficult to quantify rates due to the lack of systematic data collection around the world (Hughes et al., 2012). As Thiara et al. say: “*The first*

thing the research literature tells us is that there is not very much of it in any country” (2012, p25). However, when there are prevalence studies we find, for example, women in Britain with severe mental illness are 2–8 times more likely to experience sexual and domestic violence than the general population and more likely to suffer psychological illness as a consequence (Khalifeh et al., 2015). The high level of abuse, associated with the lack of services available to respond to violence against disabled women, indicates that this is an even more immediate and epidemic public health concern.

Violence against women – and particularly against disabled women – is not just a medical issue. It is indicative of the broader social construction of both women and disabled people as devalued, low status and not deserving of full societal involvement and support (Bashall & Ellis, 2012). This is indicated, in New Zealand, by a lack of legislative and policy acknowledgement of violence against disabled women and any policies, funding streams or service provision that provide either protection from violence or a constructive response to it.

This research is a consequence of this gap and my theoretical paradigms of health promotion and feminism. It is inequitable and unethical for services to exclude women on the grounds of a perceived impairment: therefore it is envisaged that this research will help to begin the process of enabling New Zealand violence and related services to meet the needs of all women.

Aims and research question

As violence against disabled women is well documented internationally (for example, prevalence as above, (Barbuto & Napolitano, 2014; DVD, 2010; Frawley et al., 2015; Gilson et al., 2001; Harpur & Douglas, 2014; Healey, Howe, Humphreys, Jennings, & Julian, 2008; Powers & Oschwald, 2004; Radford, Harne, & Trotter, 2006; Walter-Brice, Cox, Priest, & Thompson, 2012;)) this research is not attempting to replicate prevalence studies or investigate women’s experiences of abuse. As previously described, this research is intended to uncover why disabled women are excluded from violence sector service provision and also why the disability sector is doing so little to prevent violence against disabled women and respond constructively when violence occurs. Accordingly the focus of this study, while theoretical in construction and investigation, is on gaining information that will lead to productive conversations across sectors. The intention of conversations and action between sectors is to develop healthy public policy and create supportive environments for constructive prevention and practice initiatives in response to violence against disabled women.

The research question is:

What are the explicit and implicit ideas, models, values and paradigms that practitioners and policy makers in the domestic/sexual violence and disability sectors subscribe to/hold (or employ) when working in their own sector and how do these ideas constrain or enable action to address violence and abuse of disabled women both within and across sectors?

From this, what actions can be identified to begin the process of engagement both within and across sectors?

Health promotion paradigm

This research is sited in a health promotion paradigm. The Ottawa Charter (WHO, 1986) explains health promotion as:

The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize [sic] aspirations, to satisfy needs, and to change or cope with the environment (para. 3).

The Charter then provides health promoters with five strands of action for addressing public health concerns: build healthy public policy, create supportive environments, strengthen community actions, reorient health services and develop personal skills. Healthy public legislation and policy underpin all of these strands, creating environments that enable constructive personal and societal changes to occur. It is this – the development of environments that enable change to occur – that I hope to achieve through the findings of this thesis.

Definitions

This section provides definitions of terms that have multiple definitions, for example, domestic violence, or which may not be familiar to all readers.

The terms *family violence*, *intimate partner violence* and *domestic violence* are used in New Zealand to refer to violence and abuse that happens within a family or domestic relationship. Family violence is a term for abuse directed at different people within a domestic setting. It incorporates elder abuse, child abuse, dating violence, sibling abuse, abuse by in-laws and other relations, and intimate partner abuse.

Intimate partner violence (IPV) is violence between people in an intimate relationship; this can be dating violence, or violence between de facto or married partners.

Domestic violence is, in New Zealand, defined by the Domestic Violence Act 1995 and is abuse between people in a domestic relationship – this can mean (non-cohabiting) dating or people living together, including flatmates. There does not have to be a sexual relationship between these people. While this term does not describe the breadth of abuse of disabled people, it is the term that will be used in this research as it incorporates the many dimensions of violence described by ‘family violence’ and has, through common usage, a more gendered aspect and is inclusive of children’s issues along with those of their mother (Laing, Humphreys, & Cavanagh, 2013).

Sexual violence is also commonly called rape, sexual abuse and sexual assault. The government taskforce that was charged with investigating prevention and response to sexual violence in New Zealand was called the Taskforce for Action on Sexual Violence (Ministry of Justice [MoJ], 2009). Sexual violence is the term that will be used in this thesis as it encompasses the range of behaviours and harm related to sexual offending.

In this thesis *disabled women* include women with physical disability, mental health problems, learning disability, brain injury, chronic illnesses that result in disability and women with age related disability. Disability can be caused by accident, illness, trauma, a genetic condition, ageing or by birth. It can be obvious or hidden, constant or intermittent. As the WHO says; “*Disability is complex, dynamic, multidimensional, and contested*” (WHO, 2011, p3).

There are a number of terms used to describe *disabled people*. These include people with a disability, people with disabilities, people with impairments and people experiencing disability. The United Nations Convention on the Rights of Persons with Disabilities (2006) puts this term into common usage. In this thesis the term disabled people will be used. This is the language adopted in the NZ Disability Strategy after wide consultation with disabled people (MOH, 2001). Sullivan (2000) explains ‘people with disabilities’ is indicative of the medical model of disability, locating the problem/the disability within the individual, whereas ‘disabled people’ reflects the social model of disability, locating the problem in a society that disables impaired individuals (Sullivan, 2000; see also Oliver & Barnes, 2012; Swain & French, 2008).

Recently in New Zealand there has been a switch from the language of intellectual disability, to *learning disability*. Others use the words mental retardation, learning difficulty, developmental difficulty (Bruder & Kroese, 2005) and cognitive disabilities, which includes head/brain injury (Powers & Oschwald, 2004). This thesis will use the term learning disability.

Many in the community of people with hearing impediment use the term *Deaf* (capital D) to describe a community of identity. This convention will be used in this thesis.

Auckland Domestic Violence and Disability Working group (DVD). A voluntary coalition of people working in the violence, disability and related sectors, based in Auckland, that meet monthly to develop and initiate work and advocate to government to address violence against disabled people.

Disability Coalition Against Violence (DCAV). A voluntary, national coalition of disability and violence sector advocates and activists that worked to raise awareness at government level of violence against disabled people. Now disbanded.

The terms *carer/s*, *caregivers* will be used to describe those who provide support and other personal and/or intimate care services to disabled and older women. While there is some debate about the use of this word – some people preferring helper or personal assistant (Herring, 2014) – it is understood and used in literature discussing employment/wage rates for this occupation, excuses for violence (carer stress) and other issues.

Enabling is a term identified in the Ottawa Charter for Health Promotion (WHO, 1986) as a key function of health promotion practice. It is understood to mean working alongside people rather than ‘doing for’ them. Health promoters provide skills, knowledge, resources, networks, and other support to populations and communities, to enable communities to explore and take their own power.

I am using the term *dis/abled women* to be inclusive of both non-disabled and disabled women when appropriate in this thesis. This construct has been used by Shildrick (2009) to indicate that the state of being able bodied is, at best, provisional. My use of the term is to indicate the similarities between non-disabled and disabled women in the situations described.

Kaupapa Maori services. Maori are the indigenous people of Aotearoa/New Zealand. The Treaty of Waitangi protects their status as the first people of Aotearoa.

Kaupapa Maori services are those based in Maori values, world-views, cultural knowledge and traditions, and reo - Maori language. These services are not exclusively for Maori, or compulsory for Maori. Anyone can use the services, which provide an alternative framework to mainstream.

I am using the definition of *patriarchy* written by Edstrom and Shahrokh (2016):

Patriarchy is a term used to describe social orders - or systems of organising societies, generally acknowledged to have been prevalent over several millennia – in which men dominate over women. This includes male dominance in politics, social relations, the economy and culture, typically through hierarchical masculinised power relations.

Importantly, this is replicated at the level of ‘the family’ where males – especially ‘the father’ – have traditionally held power over women, children, property and resources (Johnson, 1997). Male centredness, privilege and supremacy are all ‘flip - sides’ of the marginalisation, discrimination and subordination of women and ‘lesser’ males (younger males, disabled men, men with alternative sexual orientations, trans-men, etc.) (p4).

Ministries – for example, of Health, Social Development and Women’s Affairs. Unless stated otherwise, these are New Zealand Ministries.

The term ‘*other*’ is being used to indicate those who are perceived to be different from the hegemonic norm. MacIntyre (1999) explains:

So we are invited, when we do think of disability, to think of the “disabled” as “them”, as other than “us”, as a separate class, not as ourselves as we have been, sometimes are now and may well be in the future (p2).

Structure of the thesis

Chapters 2 and 3 examine the literature relating to: the use of models and paradigms to investigate underlying reasons for action and inaction; the abuse of dis/abled women; the models and discourse used to understand disability and violence against women; policy, literature and service responses in relation to violence against disabled women in New Zealand; two theoretical paradigms for situating the research – health promotion and intersectionality; gaps in service provision; and paradigms that disable and discriminate against women.

Chapter 4 explains the methodology and methods used in the research. This includes siting the research in a critical emancipatory paradigm and using feminist disability theory as the specific theory to examine the findings.

Chapters 5, 6, 7 and 8 are findings chapters. These investigate the increasingly theoretical levels of findings from the data. Chapter 5 presents the most pragmatic reasons for lack of engagement between sectors – lack of staff and other resources and a lack of policy and legislative incentive to respond. Chapter 6 examines the values and paradigms identified from the data and how these result in good, best and poor practice in both domestic/sexual violence and disability agencies and related services. Chapter 7 presents information about the underlying reasons for this practice; examines the lack of attention paid to the issue, including how dis/abled women are silenced and excluded; and discusses how the NZ system narrows the criteria for domestic violence and related services by prescribing ‘real’/deserving victims of abuse and others who are less deserving of services and support. Chapter 8 investigates the paradigmatic underpinning of all these findings by examining the concept of vulnerable/vulnerability – a word that was used frequently in the data to explain/describe the abuse of disabled women. This chapter suggests that vulnerability is a construction that enables predation – and also a lack of practical and service responses to that predation.

Chapter 9 is the discussion chapter. This chapter summarises the key findings and links the findings to the theoretical underpinnings of the research. There is discussion about why the findings are important, and examination of the consequences of these findings for women’s equality and for women working to address the abuse of disabled women.

Chapter 10 is the conclusion chapter. This discusses participants’ recommendations to address the lack of engagement between the disability and the violence sectors and my own recommendations to address the finding about vulnerability. It also discusses the limitations of the research and possible ways forward.

Chapter 2

Violence against disabled women

Introduction

The literature review is in two chapters. This first chapter outlines the theoretical underpinning of the research and examines violence against dis/abled women. The second chapter examines why the usual theoretical positions used to describe disability and violence are not sufficient for an examination at the intersection of the two issues, and describes theoretical positions that do enable the exploration of the inter-sectorial experience. It then examines some of the attitudinal/paradigmatic barriers to effective practice to prevent and respond to this violence. In addition to the literature reviewed in these two chapters, literature specifically related to the findings has been incorporated into the relevant findings chapters.

This chapter begins with an explanation of the sources of literature used in the thesis. This is followed by an investigation of violence against women, including the health effects of violence, and an examination of the literature about gender and power. The focus then narrows to specifically interrogate what is known about violence against disabled women including: what constitutes violence against disabled women, who the perpetrators are, types of violence and abuse, and the difficulties of measuring prevalence. As one envisaged outcome of this research is providing information to encourage a constructive service response to violence against disabled women, the literature is then examined to understand current responses and gaps in the service response. The final section examines what is known about violence against disabled women in New Zealand. This includes New Zealand literature, prevalence, policies and legislation, qualifications required to work in the violence and disability sectors, accessible services and the funding and organisational structure of the two sectors under investigation – the disability and violence sectors in New Zealand.

Sources of literature

Existing literature “*provides us with a theoretical framework for research as well as a justification for carrying it out*” (Henn, Weinstein & Foard, 2009 p281). In health promotion/public health we call upon a range of disciplines to inform the work that we do (Davies, 2013; Labonté & Schrecker, 2007). This research uses literature from public health and health promotion, disability studies, feminist/women’s studies, human rights, social psychology, domestic and sexual violence research and other disciplines that examine issues of power, marginalisation and exclusion. Ackerly and True (2010) recommend researchers reading widely outside their

disciplines in order to gain new and critical perspectives on their question and subject area. They also suggest looking at scholarly and non-scholarly sources. My literature review includes a variety of ‘grey literature’ (Frawley et al., 2015; Pitts & Smith, 2007) such as reports and other non-peer reviewed material, as this is where much important community-based research (Frawley et al., 2015) and most of the (small amount of) information about abuse and disability in New Zealand is to be found.¹

Literature was gathered through databases provided by the University of Auckland: PsycINFO, Scopus, Google Scholar, International Bibliography of Social Sciences, Academic Search Premier, Proquest, Sociology Abstracts, Sage Journals Online, Gender Studies data base, Gender Watch, Australian Family and Society abstracts data base and Pubmed. In addition to these I searched subject specific sites such as: Australian National Research Organisation for Women’s Safety (ANROWS), New Zealand Family Violence Clearinghouse (NZFVC), Women’s Aid (UK), UK Disability Archive, Donald Beasley Institute (NZ), CCS Disability Library (NZ), People First (NZ), NZ Human Rights Commission, NZ Government Family Violence Unit, NZ Government websites and related New Zealand Ministerial libraries (MOH, MSD, Justice) and Te Puna – National Library of NZ. I also searched specific journals e.g. Violence Against Women and Disability and Society.

I used search terms such as:

<ul style="list-style-type: none"> • Disabil* • Disabled • Disability • Disability/violence • Domestic/family violence • Sexual violence • Abuse • Violence against women 	<ul style="list-style-type: none"> • Models and theories • Paradigms/woman • Disability and domestic violence • Women and disability • Disabled women • Feminist disability theory • Exclusion/stigma/ /myths/ disability
---	--

¹ Please note. Some information from earlier drafts of this literature review has been used in the Report to the Universal Periodic Review of New Zealand 18th session of the Working Group on the UPR, *Abuse of disabled people in New Zealand, January 2014*. This is a joint NGO submission submitted by: Auckland Domestic Violence and Disability Working Group, Auckland Disability Law Incorporated, Peace Movement Aotearoa, and supported by CCS Disability Action Northern Region and People First Northern Region. Some information has also been used in: New Zealand Family Violence Unit & Hager, D. (2013). *Evidence brief: Issues and opportunities for addressing family violence within the disability sector*. Prepared for the Taskforce on Family Violence. Wellington, New Zealand: NZ Family Violence Unit, MSD.

For a full list of search terms, data bases and sources of literature see Appendix 13.

In order to find NZ material, and inform searches, I contacted key informants across the sectors for information and references – for example academics at four NZ universities who have written about disability, various advocates at the intersection of violence and disability, peak bodies such as the peak body for disability service providers (The New Zealand Disability Support Network), and Age Concern. I tracked down specific people who might have information – for example, about women’s pay rates in the various sectors, examples of policy and/or legislation about training and qualifications required in the two sectors, national policy documents and accessibility of services. I conducted three Official Information Act (OIA) requests for information and policy. I also asked all research participants for documentation – some of which added to the literature but not about NZ situations.

As the research and data analysis progressed, related issues arose which were investigated, including known/existing practice, for example, women’s pay rates in the various sectors, existing policies and legislation and best practice at the intersection of the sectors. This was incorporated into the literature review or as background to the findings. To elicit this information I phoned people including staff at the Human Rights Commission, the Ministry of Health, Te Pou, the Office of Disability Issues and Auckland Disability Law. This material has been referenced as “personal communication”.

My particular interest is the intersection of gender, violence and disability. So while I read literature that described each aspect specifically, I was particularly looking for literature that could elucidate the intersection. My strategy for the literature review was to describe each aspect of the intersection separately then integrate the various issues within a feminist disability theory.

Violence against women

Domestic and sexual violence

Article 2 of the United Nations General Assembly Declaration on the Elimination of Violence against Women (1993) says:

Violence against women shall be understood to encompass, but not be limited to, the following:

- a) *Physical, sexual and psychological violence occurring in the family, including battering, sexual abuse of female children in the household,*

dowry-related violence, marital rape, female genital mutilation and other traditional practices harmful to women, non-spousal violence and violence related to exploitation; ...

- c) *Physical, sexual and psychological violence perpetrated or condoned by the State, wherever it occurs* (para. 2).

Domestic violence is emotional, physical or sexual violence perpetrated against a person with whom one has a domestic relationship (United Nations, 1993). Sokoloff and Dupont (2005) define it as including, but not limited to “*physical, emotional, psychological and sexual violence and control against women*” and also “*a purposeful course of action buttressed by familial, institutional, social and cultural practices*” (Jaaber, 2001, cited in Sokoloff & Dupont, 2005, p1).² These two definitions encapsulate important aspects of domestic violence. Domestic violence is not random violence or abuse – it is particular to the people involved and happens over a sustained period of time – the aim being to have power over and control of another person or group of people (Healey, 2013). Societal attitudes, norms and laws enable abuse.

Domestic violence occurs across all ethnicities, cultures, classes and abilities (Ministry of Women’s Affairs, (MWA) 2011). In New Zealand domestic violence legislation, domestic violence is defined as occurring between people who live in a domestic relationship – not necessarily a sexual relationship. This can be parents, partners, children, siblings, flatmates, a person we go out with such as a boy or girl friend but don’t necessarily live with, and others with whom we have a domestic relationship. For disabled women the relationships that this can include are much wider (Gilson, Cramer, & DePoy, 2001), as disabled women are reliant on a range of people to support them and, in some cases, to perform very intimate functions. This can be family, partners, paid or unpaid carers and those who provide medical, transport and other services. This indicates the complexity of the relationships that disabled women manage and the higher risk of sexual and/or domestic violence that a disabled woman is susceptible to (Disability Coalition against Violence, 2010). While some of these relationships are included within the Domestic Violence Act, many are not, as the current Act specifically excludes people who are in employee - employer or landlord – tenant relationships (See Appendix 3). Nor is there protection for disabled women in institutional or residential service settings (Barnett, 2015), despite these being the domestic residences of the women residing there.

Sexual violence is defined as:

² This reference is from a conference presentation, a written copy of which does not appear in any accessible archives, despite detailed searching. The author has died. I have spoken to Ms. Sokoloff and she does not have a copy of the original paper, therefore I am citing her book.

...any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic, or otherwise directed, against a person's sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work. Coercion can cover a whole spectrum of degrees of force. Apart from physical force, it may involve psychological intimidation, blackmail or other threats – for instance, the threat of physical harm, of being dismissed from a job or of not obtaining a job that is sought. It may also occur when the person aggressed is unable to give consent – for instance, while drunk, drugged, asleep or mentally incapable of understanding the situation (Jewkes, Sen, & Garcia-Moreno, 2002, p149).

This includes rape, and “*any act (verbal or physical) which breaks a person's trust and/or safety and is sexual in nature... (for example) rape, incest, child sexual assault, marital rape, sexual harassment, exposure and voyeurism*” (Auckland Sexual Abuse Help [ASAH], n.d.).

Sexual violence occurs primarily between people who know each other; however, there is also a significant amount of stranger rape and abuse (ASAH, n.d.). It is a gendered crime experienced disproportionately by female victims (Barnett, Miller-Perrin, & Perrin, 2011; Jewkes et al., 2002). Victims are aged from birth to very old age. Perpetrators are overwhelmingly male (MWA, 2012). Prevalence research indicates that 20% of New Zealand girls will experience sexual violence and 29% of New Zealand women (MWA, 2012). Sexual violence advocates and police estimate that, in New Zealand, only 10% of sexual violence is reported to the police and of those cases reported, only 13% result in a conviction (McDonald & Tinsley, n.d.).

There is no single view of violence and causation articulated by Maori, however, there are similar themes. Te Puni Kokiri (2010) argues that the undermining of whanau structures and relationships within whanau, including gender relationships, by colonisation, is a causal factor in current whanau violence and that current approaches to violence do not address this issue. Ruwhiu (2009) posits a gendered analysis of violence, recognising the abuse of power inherent in gender inequity. Many Maori who work in the sector say that violence is a consequence of learnt behaviour resulting from colonisation, institutionalised racism and marginalisation and Maori concepts of family and interconnection (Maori Taskforce on Whanau Violence, 2004; Pihama, Jenkins, & Middleton, 2003).

There is general agreement that domestic and sexual violence are crimes that can cause long-term harm to the victims. The definition of these practices as crimes has

occurred through the drafting of laws such as the Domestic Violence Act 1995 and the 1961 Crimes Act (NZ Government, 1961), which criminalises sexual violence, specifically Sections 127 to 144C inclusive.

Health effects of violence against women

The awareness of the health effects of violence has been driven by women working with victims of abuse both in New Zealand and overseas (see, for example, Elvidge, 1997; Kapoor, 2000). In 1994, Heise, Pitanguy and Germain identified the health effects of domestic violence in a report for the World Bank and this work was updated by WHO in 2002 (Heise & Garcia Moreno, 2002) and 2014 (WHO, 2014). These include:

- Death
- Low self esteem, anger, guilt and self blame
- Physical injury including abdominal injuries, thoracic injuries, burns/scalds, fractures and lacerations
- Disability; for example, blindness, hearing impairment and impaired mobility
- Physical illnesses such as hypertension, cardiovascular disease, abdominal pain and other gastrointestinal disorders, chronic pain, arthritis, asthma, cancer, diabetes, kidney problems, liver disease and stroke
- Head and brain injury and neurological disorders causing short and long term disability
- Self harming behaviours – alcohol and substance abuse, eating disorders, sexual promiscuity and lack of self care
- Suicide and suicide attempts
- A range of mental health problems particularly depression, anxiety and post traumatic stress disorder, but also attention deficit, hyperactivity and externalising behaviours
- Sexually Transmitted Infections including HIV
- Unintended pregnancies, including adolescent pregnancies and pregnancy complications
- Miscarriage, stillbirth and abortion
- Gynaecological disorders including complex pain syndromes and chronic pelvic pain
- Lack of medical care
- Nutritional deficiency

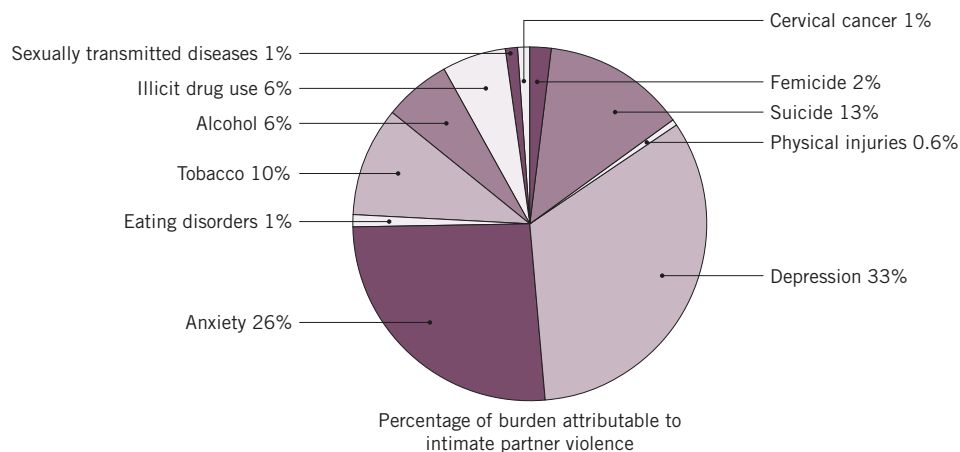
(American Medical Association cited in Fanslow & Robinson, 2004; Barnett et al., 2011; Gulliver and Fanslow, 2013a; Heise et al., 1994; Heise & Garcia Moreno,

2002; Powers & Oschwald, 2004; Radford, et al., 2006; VicHealth, 2004; WHO, 2014).

Sexual violence has been correlated with the risk of almost every indicator of deprivation and poor health, lifelong low socioeconomic status and other ‘social problems’ including increased smoking, drug and alcohol over-use, relationship breakdowns, truancy, teenage pregnancy and lack of ability to parent well (MoJ, 2009). It is also linked to an increased risk of mental health problems, increased suicide ideation and attempts. Sexual violence can result in sexual health complications, unwanted pregnancy, social ostracisation, and physical disability (Jewkes et al., 2002).

Both deliberate and unintentional neglect and abuse can cause chronic illness and loss of mental and physical functioning, resulting in long-term disability (DVD, 2010).

As identified in the list above, violence against women results in a variety of mental health problems. The VicHealth (2004) study of the burden of disease related to male to female domestic violence in Victoria demonstrates that mental health problems, including self-harming behaviours, account for 95% of the total related burden of disease. See Figure 1 below. Note: Femicide is the gender related murder of women and girls.



Source: VicHealth (2004, p11)

Figure 1: Health outcomes contributing to the disease burden of intimate partner violence for women in Victoria, Australia

New Zealand research (Fanslow & Robinson, 2004; Gulliver & Fanslow, 2013a) identifies that across the NZ population, women (18–64 years) who had experienced severe physical violence were three times more likely to have suicidal thoughts and eight times more likely to attempt suicide compared to women who had not

experienced violence, and almost four times more likely to report current symptoms of emotional distress and suicidal thoughts. Women who require treatment in the mental health system may be subject to institutional abuse such as forced treatment and the use of seclusion and restraint, and have inadequate access to justice to challenge these abuses (Barnett, 2015). People with learning disability also experience these institutional abuses, particularly indefinite detention (Barnett, 2015).

Gender and power

Internationally there is an understanding that domestic violence is a gendered crime, primarily perpetrated by men against female partners, inherent in patriarchal culture (Barnett et al., 2011; Brown & James, 2014; Frawley et al., 2015; Heise & Garcia Moreno, 2002; Ministry of Women's Affairs, 2011; NZ Family Violence Clearinghouse [NZFVC], 2007; Our Watch, ANROWS, & VicHealth, 2015; Pihama et al., 2003; Sokoloff & Dupont, 2005; United Nations, 1993; Walsh, Spangaro, & Soldatic, 2015). The United Nations Commission on the Status of Women (UNCSW, 2013) identifies violence against women as being caused by:

...historical and structural gender inequality in power relationships between women and men...characterised by the use and abuse of power and control in public and private spheres and...intrinsically linked to gender stereotypes (p2).

International organisations such as WHO (Krug, Dahlberg, Mercy, Zwi, & Lozano, 2002) and New Zealand groups working to prevent and respond to violence understand domestic violence as the use of a variety of strategies by one person to have power and control over another. These strategies can be physical, sexual, financial or emotionally abusive behaviours (National Collective of Independent Women's Refuges, n.d.). This definition incorporates the idea of patterns of behaviour rather than one-off episodes of argument or anger. The Ministry of Social Development (n.d.) defines domestic violence as "*a broad range of controlling behaviours, commonly of a physical, sexual and/or psychological nature, which typically involve fear, intimidation and emotional deprivation*" (para. 1). Perpetrators of violence against disabled women – both intimate partners and other carers – also use abusive power and control behaviours ((Healey, 2013; Thiara et al., 2012). This includes isolating women and exploiting their dependency, as carers "*may have a huge amount of power over the woman they are caring for in isolated one-to-one situations*" (Thiara et. al., p29). WHO (2012) and organisations working to prevent violence and support victims, such as ASAH, represent sexual violence as primarily an abuse of power (ASAH, n.d.).

The analysis of violence as a gendered abuse of power – a ‘feminist’ analysis – is a contested understanding in New Zealand and internationally. Men’s rights groups and some academics argue that men and women are equally to blame for domestic violence and that women are as violent as men. This is articulated in press releases, on blog and websites and in the academic literature (Dragiewicz, 2008). Dragiewicz (2008) contends that it is primarily men associated with Fathers’ Rights groups who champion gender neutral violence perpetration, while also insisting on the assertion of patriarchal relationships between men and women.

A key strategy that these groups and their supporters use to de-gender domestic violence is the Conflict Tactics Scale (CTS, Straus, 1999), a tool developed by Murray Straus in the 1970s and subsequently revised by Straus and others (NZFVC, 2007). The Conflict Tactics Scale measures “*different acts people use in situations of conflict within intimate relationships including reasoning, verbal aggression and physical violence*”(NZFVC, 2007) but fails to contextualise the violence in terms of relative physical strength, self-defence or how much fear is generated by the activities. It measures only physical violence, excludes sexual and emotional abuse and does not investigate the motivation of each partner, their respective rates of initiating violence, or the consequences of violence for each partner (Barnett et al., 2011; Dragiewicz & DeKeseredy 2012; Kimmel, 2002; Saunders, 2002).

The New Zealand Family Violence Clearinghouse *Family violence and gender fact sheet* (2007) points out that:

The CTS does not gather information concerning the meaning(s) attached to the violence by either the perpetrator or victim, who initiated the violence, or what their motivation was. It also assumes that violence only happens during arguments or conflict, and so fails to capture violence that occurs at other times, especially ‘control-motivated’ instrumental violence and coercion by perpetrators attempting to maintain power over their victim (p1).

Hester’s (2012, 2013) research about police arrests for domestic violence in England concludes that violent and abusive behaviour between heterosexual couples is gender asymmetrical, with men being the primary perpetrators in the greater number of incidents and being considerably more violent and dangerous. Her research (2012) examined police files of domestic violence cases where women were arrested either as sole perpetrators of abuse or where both partners were arrested. She determined that, in many of the cases, women’s use of violence was in self-defence or to prevent further violence. If violence was directed towards men, they often used their positions of gendered power to ensure their safety, as men are not as frightened by violence as women are in similar situations (Hester, 2012). Deborah Mackenzie (2009) investigated similar situations of police arrest in Auckland between April and

September 2008. She identified that over half of the arrested women in heterosexual relationships had experienced sustained and severe violence from their partners in the past. This resulted in only 10% of women arrested being principal offenders. These women were primarily offending against women. Of this 10%, police assessed only one woman as high risk, and none of the women arrested for assaulting men was assessed as even moderate risk.

“The gender debate is one of the enduring controversies in domestic violence research” (Braaf & Barrett Mayering, 2013, p1). Using a variety of Australian data, Braaf and Barrett Mayering (2013) found two differences between those who consider that domestic violence is gendered (feminist researchers) and those who claim that women are as violent as men. One is the way the two groups conceptualise violence in relationships and the other is how they collect data. Feminist researchers use a variety of quantitative and qualitative data to examine not only the incidence of violence, but *“why it occurs, how it manifests and victim outcomes”* (Braaf & Barrett Mayering, 2013, p1). The researchers who believe that women are as violent as men primarily use scales such as the Conflict Tactics Scale and other surveys that record specific acts of violence, without consideration of context, motivation and outcome (Braaf & Barrett Mayering, 2013). They conclude that data available from multiple sources, excluding data collected using the Conflict Tactic Scale and similar surveys, indicates that there is gender asymmetry in domestic violence and that women experience greater levels of harm and coercion from all forms of violence than men.

Data collection and cohesion

One problem related to the collation of data measuring the prevalence of violence against women, and the corresponding consistent generation of statistics and development of coherent policy, prevention and practice, is the lack of clear and consistent definitions across researchers, sectors and ministries. As Radford et al. (2006) state, this *“unsettled debate over definitions of domestic violence”* (p240) complicates examinations of prevalence because narrow definitions provide lower prevalence rates than broader ones. Gulliver and Fanslow (2013b) explain:

Without consistent definitions underpinning our data collection systems, we cannot hope to answer policy questions about trends over time....If effective monitoring of the extent of family violence in the community is to take place, there needs to be a consistent theoretical definition that underpins administrative data collections used for reporting family violence at the population level....community perceptions of the nature, extent and social acceptance or disapproval of family violence changes...influenced by community advocacy and policy changes. These changes in perceptions can affect operational definitions...A common theoretical definition and an

explicit specification of the operational definitions in use is imperative to promote a clear understanding of use of the data by policy makers and the general public. Key concepts to be specified in order to arrive at a meaningful theoretical or operational definition of family violence include the specific behaviours to be included, and the relationship between the perpetrator and the victim (Gulliver & Fanslow, 2012, p8-9).

Bogard (2005) warns that this lack of data is not a minor consideration, as credible statistics are crucial for the distribution of funds and the creation of social policy. The policy and related funding in turn affect women's mental health and safety as they shape the development of mental health, justice, violence and other services.

Violence against disabled women

Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Most extended families have a disabled member, and many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities (WHO, 2011, p3).

There are multiple disabled identities (D'aoust, 1999). For many people it does not seem sensible to talk about disabled people as a homogenous group, as disability is complex and variously defined. However, disabled people, while diverse in impairment, age, gender, sexual orientation, ethnicity, socio-economic status, religion etc., also share experiences that are similar. These are primarily aspects of oppression: medical, verbal, physical and sexual abuse; neglect; educational exclusion; enforced poverty; harassment by bureaucracies; job discrimination; segregation; isolation; and inaccessible public and private spaces and information (Wendell, 1996).

Settings and perpetrators

Disabled women experience violence perpetrated by people in a wider variety of settings and from a wider range of perpetrators than non-disabled women (Healey, 2013). In 2013, Michael Roguski carried out a study of the abuse of disabled people in Gisborne, New Zealand. He spoke to 10 disabled people and a number of family members and staff of disability organisations. His research, which was not gender disaggregated, identified institutional abuse that occurred in: residential services for physically, mentally and intellectually disabled people and people with brain injury; general residential nursing services; and institutional settings such as hospitals and other temporary institutional settings.

Abuse in both residential and organisational settings can be perpetrated by staff, including health and welfare professionals, or other clients; in educational settings by teachers and others such as caretakers and drivers; in home-based environments by landlords, care-givers, health and welfare professionals and the person's partner and wider family and friends; and in community settings by strangers, employers, neighbours, people in faith communities, in cultural groups, in the street, in educational settings, businesses and other civic environments (Roguski, 2013; Thiara et al., 2012).

Forms of violence

Disabled women experience the range of abusive behaviours common to all abusive relationships – physical, sexual, verbal, emotional and financial (Powers & Oswald, 2004) including patterns of power and control (Barbuto & Napolitano, 2014; Walter-Brice, Cox, Priest, & Thompson, 2012). However, there are forms of abuse that are more specific to disabled women, or that have more debilitating effects if women are disabled. These include:

- keeping women short of money, making financial decisions for women or misusing their money
- never letting a disabled woman be alone with a health practitioner or other helping professional
- forcing a disabled woman to have an abortion or be sterilised
- preventing women from having children
- withholding food or medication, or overmedicating - which could constitute attempted murder or make a person endure pain for much longer than necessary
- restraint and control
- withholding communication and mobility aids
- using prejudices about disabled women and patriarchal beliefs to humiliate women and destroy their self-worth
- controlling menstruation
- threats to withdraw care or institutionalise women
- abuse of Power of Attorney
- institutional abuse (Barbuto & Napolitano, 2014; DVD, 2010; Frawley et al., 2015; Gilson et al., 2001; Harpur & Douglas, 2014; Healey, Howe, Humphreys, Jennings, & Julian, 2008; Ortoleva & Lewis, 2012; Radford et al., 2006).

According to Barbuto and Napolitano (2014) specific violence that disabled women may encounter includes: role violation; sexual violence; structural violence – determined by the structures and social contexts disabled women live in; and

violence in health care settings where women's bodies are treated as objects to be worked on and investigated rather than intimately related to privacy and women's wellbeing. Howe (2000) identifies institutional violence, chemical restraint, drug use and medical exploitation. Thiara et al. (2012) call these "*impairment specific abuse*" (p27).

Gilson et al. (2001) believe that the portrayal of disabled women as limited in mind and body is one factor that changes potentially harmless situations into harmful ones, causing disabled women to get caught in cycles of poverty and/or isolation that can increase their likelihood of being harmed and, "*because the paternalistic attitudes of perpetrators diminish disabled women's sense of strength and resilience, the ...abuse is exponentially harmful*" (Gilson et al., 2001, p229).

Abuse can be intentional – doing something to hurt, frighten or upset a dis/abled woman – or it can be caused by either intentional or unintentional neglect, such as forgetting to pick up or provide medication, not providing adequate care, leaving an immobile person alone for long periods of time or not providing meals (DVD, 2010) or failing to provide support that is required (Powers & Oschwald, 2004). Radford et al. (2006) found that neglect has been omitted from mainstream domestic violence understandings, but explored in the disability literature. They equate the difficulties of defining neglect with those of defining psychological violence – both are pervasive, both fit definitions of violence, but both, on their own, are difficult to define (Radford et al., 2006).

Roguski (2013) identified physical, sexual, emotional and financial abuse, and also forms of abuse that he calls silencing, locked in and dehumanising processes and treatment. Silencing refers to disabled people being pressured to refrain from reporting abuse, or having their complaints ignored. Disabled people in the study felt constrained by: previous negative experiences when trying to complain; fear of retribution; a concern that a family member or care-giver would be removed if they made a complaint; disparagement of the complaint or complainant; questioning of the complainant's reliability or the truth of the complaint; and collusion to protect abusers. There were also instances of the abused person believing they were deserving of abuse; abuse becoming normalised and therefore not being reported; people not knowing their rights to be safe; and difficulties communicating. Locked in abuse refers to situations where a person's mobility or ability to communicate are purposely removed. This behaviour isolates people and makes them dependent on the abuser for mobility and/or communication with the outside world. Dehumanising processes and treatment do not cause direct physical harm. Rather, disabled people are objectified, their personal choice and voice are invalidated and they are not accorded the same rights as non-disabled people. Roguski explains that

this dehumanising process and treatment is manifest in the removal of a person's rights, social exclusion and invisibility.

Difficulties in quantifying the prevalence of abuse

Roguski (2013) reports international prevalence rates ranging from 90% of disabled women (Curry, Renker, Robinson-Whelen, Hughes, Swank, Oschwald & Powers, 2011) to 62% (Young, Nosek, Howland, Chanpong & Rintala, 1997), and between 3 times (Brownridge, 2006) and 4 times (Martin, Ray, Sotres-Alvarez, Kupper, Marocco, Scandlin & Kiya, 2006) greater risk of sexual assault than non-disabled women. Sobsey and Doe (1991) identified that disabled women had a 78% greater risk of sexual assault as a result of interactions with the disability service sector. Cramer and Plummer (2010) identify similar prevalence rates in American studies.

Other studies indicate that prevalence rates of sexual and physical abuse of disabled girls and women are higher than for disabled men across all areas of disability (McCarthy & Thompson, 1997; NZ Family Violence Unit & Hager, 2013; Turk & Brown, 1993) and higher than abuse of non-disabled women and girls (Banks, 2003; Howe, 2000). Women with learning disability are at even more risk of abuse than women with physical disability. High rates of sexual abuse have been identified (Turk & Brown, 1993) and also hate crimes (People First in Partnership, 2012) such as bullying, name-calling and physical assaults by members of the public, school pupils and caregivers. An Italian study identified that women with disabilities, particularly those with psychiatric difficulties or who live in institutional settings, are seen as 'easy targets' and are at high risk of violence and abuse (Barbutto & Napolitano, 2014).

The consensus is that violence against women with disabilities is not only more prevalent, but also more diverse in nature, than for women in general (Howe, 2000; Ortoleva & Lewis, 2012). The invisibility caused by the lack of definitive evidence creates the first barrier to recognition of violence against disabled women.

Current gaps in service provision and alignment of sectors

In order to investigate the gap in service provision for disabled women, this section first examines identified best practice, and then investigates (the lack of) existing services. There is not a lot of literature about good practice at the intersection of violence and disability, but what there is provides important guidelines for services and policy.

Gaps in service provision and best practice

Research highlights gaps at the level of policy and service provision for abused disabled women in Australia, England, Europe and North America (for example, Banks, 2003; Barbuto & Napolitano, 2014; Frawley et al., 2015; Healey et al., 2008; Healey, 2013; Healey et al., 2013; McClain, 2011; Thiara et al., 2012; Walter-Brice et al., 2012).

One example is a 2005 study in Teesside, England that investigated understanding of violence against disabled women in disability and domestic violence agencies (Radford et al., 2006). Results included only one service having a formal definition of disability and other services recording information in various ways. None of the disability agencies kept notes about domestic violence and some said they did not ask about it. This lack of knowledge is concerning, as disclosure is unlikely to occur if the circumstances are not appropriate. Most disability services stated that they would refer clients disclosing domestic violence to other agencies. Some would refer to domestic violence services, while others mentioned doctors, occupational therapists, nurses, social workers and the police. Many of these avenues are indirect and could be barriers to effective help-seeking (Radford et al., 2006). Domestic violence services identified a number of barriers to service uptake by disabled women: physical access issues; communication difficulties; women unable to find/access information about available services; and the problems generated by dependency on the perpetrator/carer (Radford et al., 2006).

Lightfoot & Williams (2009) report Deaf participants saying that a domestic violence organisation would be the last place they would go to report abuse unless they had no other options and were faced with a life or death situation. Even then, they may choose not to access any services. This was because the organisations were considered inaccessible or inappropriate and not perceived as culturally competent.

According to Thiara et al. (2012) disabled women face multiple barriers to leaving violent relationships/situations and accessing safety. These include sources of assistance available to non-disabled women not being accessible, plus specific barriers related to leaving an accessible house, having disability support tied to certain places or carers, and being dependent on an abuser who is also a primary carer.

Frawley et al. (2015) say that:

...immediate tertiary prevention requires a rapid, coordinated response which should ideally encompass the range of services needed by victims once violence has occurred. In the immediate term this includes policing, medical

care for physical injuries, safety planning, advocacy, legal services and refuge services. In the medium to longer-term services such as trauma counselling, support groups, employment assistance, transitional housing, children's services and specialist support and advocacy services are also part of the tertiary response (p12)

They identify three principles of good practice: data collection about tertiary responses to service use by disabled women, effective services with adequate staffing levels to meet service user needs, and physically accessible services that address programmatic access and are underpinned by cross-sector collaboration (Frawley et al., 2015, p18-19).

Further best practice principles are suggested by Healey et al. (2008, see also Healey, Humphreys, & Howe, 2013; Healey 2013) and include that: domestic/sexual violence and disability services need to collaborate with each other; disabled women are included in all processes including staff and sector employment and education; appropriate risk assessment processes be developed and implemented; and ensuring that all services and information are accessible and appropriate. Additionally, “*a social model approach that seeks to remove barriers for disabled women; an inclusive approach to all forms of violence against women...nothing about us without us: [and] partnerships with disabled women at all levels*” are the principles of good practice proposed by Thiara et al. (2012, p126).

My own research (Hager, 2011), an investigation of twelve specialised refuge services for women with drug and alcohol and mental health problems in Australia, England and Scotland, identified a number of structural and other changes that would be required in order to provide adequate, consistent and appropriate services to disabled women no matter how old they are and whether or not they have dependent children. The recommendations include that all mainstream and specialised refuges be resourced to:

- house women regardless of age. There should be no upper age limit and no age discrimination. If women require refuge, they should not have to give up their independence and go into institutional care to escape abuse
- house women with and without children – currently most New Zealand funding is linked to children
- have units that are fully accessible and self-contained, with accessible communal spaces
- provide medium and long-term housing for women escaping violence

My research also identified the need for purpose-built, well-funded, specialised refuges for women with mental health and drug and alcohol problems related to domestic violence.

Many more women with disabilities and complex mental health problems could be housed in mainstream refuges if specialised disability, drug and alcohol and mental health worker support was available both to the women and to the refuge staff. This service could be provided by enabling clusters of refuges to employ staff with clinical expertise and a comprehensive analysis of domestic violence to work alongside the staff with complex needs clients (Hager, 2011). As well as this, in order to ensure that inpatient services are effective and safe for vulnerable clients, my research recommends that all drug and alcohol and mental health inpatient services must be gender specific, and outpatient units must have women-only components. This does not mean just having separate sleeping areas for inpatient units, it means having separate services for men and women with gender appropriate staff, i.e. female staff for women's units, male staff for men's units. This also applies to the outpatient services by having, for example, separate days for each gender, or services for men and women staffed by gender-appropriate staff (Hager, 2011). See Figure 2.



Source: Illustration by a member of the Joint Forum Women's Group, Liverpool, in Hager, 2011

Figure 2: Women's services as organised by bureaucracy

This research did not investigate service level responses to sector alignment as there are a number of reports that discuss both the lack of alignment between sectors and service provision, and constructive ways to remedy this (Barron, 2004; Elizabeth, 2004; Frawley et al., 2015; Hager 2011; Herbert, Hill, & Dickson, 2009; McClain, 2011; Thiara et al., 2012; VicHealth, 2011).

Why this lack of service provision needs to be addressed

As identified above, disabled women are significantly more likely to be abused than either disabled men or non-disabled women. This situation poses both an ethical and public health concern. It is not ethical to provide violence response services to only a small proportion of abused women; therefore it is important that refuge and related violence services are available to everyone, including those who experience the highest rates of abuse and those who are most damaged by it. From a public health perspective, this is a large population group with significant unmet needs that result in immediate and long term disabling conditions. From a fiscally responsible point of view accessible and specialised refuges; related sexual and domestic violence services; mental health and alcohol and drug services; and justice/police services could save millions of dollars in long term service provision (welfare payments, health and social services, justice and police) to women suffering trauma-related and other consequences of violence, enabling them to become more self-sufficient, self-managing members of the community rather than long-term users of health and social services. Fully accessible services would mean that all women, regardless of age and ability, would be able to access the same level of safety, support and recovery. As Healey et al. (2013) say: “*The argument ... for inclusive domestic violence sector standards is informed by the principles of social justice and human rights to develop policy and practice for all populations* (p51).

There is an international human rights obligation to provide accessible prevention and violence services. The preamble to the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2006) says:

q: Recognizing [sic] that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation and...

s: Emphasizing [sic] the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities (para. 17 & 19).

Article 5 says:

- 1. States Parties recognize [sic] that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law* (para 38).

Article 16 says that governments have responsibility to prevent all forms of abuse of disabled people, to provide rehabilitative services to disabled people who have been

abused, and to provide effective legislative processes to ensure that violence against disabled people is investigated and prosecuted (UNCRPD, 2006). As New Zealand is a signatory to this convention, there is a contractual obligation to ensure that violence services are accessible for all, and specifically meet the needs of disabled women.

Incorporating women's voices in policy and practice

Barbuto and Napolitano (2014) suggest that the lack of accessible/any services available to respond to violence against disabled women is because of the “*continued presence of the medical model of disability which is concerned with the disabled person only from a biological perspective*” (p163) and disregards disabled women as people with individual emotions, dreams, aspirations and interpersonal relationships. One way of addressing this medical model thinking and changing the paradigm of service organisations was proposed by Marles (1986) who recommended that the most constructive way to change attitudes and improve service provision was to consult with, and employ disabled people in positions of responsibility. This solution has been affirmed by Thiara et al. (2012), who explain that accessible, responsive domestic violence services must be developed by disabled women. Domestic violence support staff, counsellors and others can support this by enabling survivors of abuse to develop the skills, competencies and confidence to engage in advocacy and to participate in these processes (Murray, King, Crowe, & Flasch, 2015). This would enable the development of better policies in all services (justice, police, health, social services, disability services, sexual and domestic violence) to recognise and respond to disabled women/women with complex needs (Hager, 2011).

Violence against disabled women in New Zealand

This section outlines what is known about violence against disabled women in New Zealand. Many of these issues will be further explored in the findings chapters as they relate to key themes that participants identified.

NZ literature

Using the search strategy identified earlier in this chapter, literature was sought about the abuse of disabled women, and a service response to this, in New Zealand. There are two distinct discourses in the New Zealand literature: one is related to the experience of disability and provision of services, and a second body of literature specifically focused on sexual and domestic violence. This includes literature published in peer-reviewed journals and some grey literature, primarily government and NGO reports.

Literature specifically related to the abuse of disabled people is more limited. There is one journal article specific to a small prevalence study (Briggs & Hawkins, 2005, discussed further in the prevalence section), some grey literature that comprises government (Ministry of Health, 2001; New Zealand Family Violence Unit & Hager, 2013; Van Eden, 2013) and NGO reports (Appleton-Dyer & Soupen, 2017; Cranson, 2010; Disabled Women's Support Group, 1987; People First in Partnership, 2012; Wilson & Webber, 2014) including a shadow report to the Special Rapporteur on the Rights of Persons With Disabilities (Barnett, 2015), one thesis (Hickey, 2007) and chapters from two books (McRae, 2014; Morton & Munford, 1998). There is also one booklet written for the government anti-domestic violence campaign, *It's Not OK* (Domestic Violence and Disability Working Group, 2010). The only recent research specifically about the abuse of disabled people is Michael Roguski's study conducted in 2013 that investigated the abuse of disabled people in Gisborne, New Zealand. Roguski interviewed 10 disabled people (men and women), a number of their family members and staff of disability organisations and identified and described institutional abuse occurring in: residential services for physically, mentally and intellectually disabled people and people with brain injury; general residential nursing services; and institutional settings such as hospitals and other temporary institutional settings.

There is also my own work; this comprises an investigation into the relationship between domestic violence and mental illness (*He Drove Me Mad*, Masters research, 2001) and a report developed with Winston Churchill Foundation funding; *Finding Safety: Provision of specialised domestic violence and refuge services for women who currently find it difficult to access mainstream services* (Hager, 2011) that investigated best practice violence sector responses in Australia, England and Scotland for women with mental health problems, substance abuse problems and/or physical disability and how this knowledge could be used to improve services in New Zealand. In addition I have written a number of reports, conference presentations (for example, Hager & Hager, 2013) and papers in conjunction with New Zealand community organisations.

All of this material has been incorporated into the thesis. For a list of this NZ literature see Appendix 14.

Prevalence

The latest New Zealand population figures for disabled women are from the 2013 Disability Survey that reported 24 percent of the New Zealand population as disabled, a total of 1.1 million people. Of these, 516,000 were male and 545,000 female. The numbers of disabled women increase with increasing age (Statistics NZ, 2014).

As identified in the previous chapter, in New Zealand, as in many other countries, it is very difficult to establish prevalence rates for the abuse of disabled women because of the lack of systematic data collection here and around the world (Hughes et al., 2012). National domestic violence prevalence studies have not, to date, included questions about disability, or sought to be inclusive of disabled women. The closest measure is the Disability Survey (2013) that asked about experience of crime. This identified that 14,000 disabled women living in private homes, from a total response population of 456,000, were victims of violent crime and 53,000, from the same population, were victims of any crime (Statistics NZ, 2013). However, this is not deconstructed as the questions ask only if people have been victims of a violent crime in the last 12 months and if they feel safe when at home alone, so there is no indication if this is physical, sexual, emotional or other violence, or of the relationship with the perpetrator.

Two prevalence studies were carried out in New Zealand institutions over 30 years ago; however, because participants were guaranteed anonymity and almost all of the participants disclosed abuse, the studies have never been published or released, as anonymity is not possible in New Zealand with that level of disclosure (Personal Communication, New Zealand Human Rights Commission, 2015). A study among children in special education units in New Zealand schools (Briggs & Hawkins, 2005) established that children with learning disabilities were far more likely than non-disabled children to experience physical violence, bullying and sexual abuse including rape. It also showed that although these children, especially the girls, often tried to report the abuse, they were frequently ignored

In 2017 Dickson surveyed gender diverse disabled people about their experiences of partner violence and abuse. 159 people responded to the survey, 89 of whom identified as female. The ages ranged from 16 – 70+ years. All of these people had experienced abuse from a partner. This included verbal, emotional and psychological abuse, isolation and threatening behaviour. 56% of the participants in the survey had experienced violence including for some, beatings (17%), being choked or suffocated (22%), having knives or guns used against them (9%) and having mobility or communication devices removed (7%). Participants were also asked about sexual violence. Three quarters of the participants “*reported unwanted touching of sexual body parts; nearly half of respondents had experienced this from at least three people*” (Dickson, 2017, p.18). One in five participants had been threatened with sexual assault by three or more people and more than half had been forced to “*perform or receive unwanted oral, anal or vaginal penetration in various circumstances*” (Dickson, 2017, p.19). Partners (62%), family members (20%), friends, work colleagues and strangers perpetrated the abuse.

Other prevalence information comes via less formal channels. For example, Louise Collins, National Advisor Elder Abuse and Neglect Prevention Services for Age Concern (a New Zealand NGO), compiled statistics for January to December 2014 – which were only from Age Concern (i.e. not from any other services that work with older people). Her statistics for elder abuse and neglect reported 1,842 total cases, of which 77% were confirmed, after investigation, as abuse or neglect. The gender breakdown is female 64%, male 36% (Personal Communication, March 11th, 2015).

Apart from these studies and data compilation there are general surveys of disabled people including questions about crime (as above), or surveys of the wider population that disabled people participate in, but these studies did not specifically ask about sexual or domestic violence and the data were not always gender disaggregated. There is a national domestic violence prevalence study underway currently (August, 2017) that is attempting to be inclusive of disabled people and may provide more specific data.

National legislation and policy

This section discusses the Domestic Violence Act, (1995), the Crimes Amendment Act (2011) and policy related to enforcing and prosecuting these Acts.

Domestic Violence Act

The New Zealand Domestic Violence Act (New Zealand Government, 1995) is the legislation that criminalises violence against women and children in a ‘domestic’ environment or relationship. The Act defines a domestic relationship as a person who “*ordinarily shares a household with another person*”, or people who do not necessarily have a sexual relationship, but have a close personal relationship (see Appendix 3). This indicates that people who live in residential and flatting situations with other dis/abled people or, for example, other elderly people, should have their ‘domestic’ circumstances included within the Act. Excluded specifically from the Act are employer/employee relationships, which effectively excludes carers and support people, who may be intimately involved in a disabled person’s life (see Appendix 3).

Despite residential and flatting situations being acknowledged as ‘domestic’ situations within the Act, an example of active exclusion of disabled women in these situations was a change in how police enforce the Domestic Violence Act (1995). In 2012, seemingly without consultation with either Disabled People’s Organisations (DPOs), women’s groups or the violence sector, and without retrospectively telling these groups about the new policy, the police made a significant change to their Family Violence Policy and Procedure. Using the rationale that the changes would enhance the police approach to family violence (New Zealand Police, 2012a), the part of the Act which defines a domestic relationship as ordinarily sharing a

household or having a (non-sexual) close personal relationship, is no longer being enforced by the police – despite it still existing in the Act. The police have not examined the implications of this exclusion for disabled people. When I became aware of this policy change I attempted to obtain further information using Official Information Act requests to the police in 2014 and 2015. Information gained from these requests reveals that at the police executive meeting on March 5th, 2012, the police identified, under the summary of key changes, “*that the Police response to FV will be concentrated on intimate partner violence (IPV), whilst retaining overview of ‘other’ FV response*” (p1). The Policy and Procedures Manual (2012b), which was updated in line with this decision, explains when the provisions of the Domestic Violence Act 1995 do not apply:

*These family violence policies and procedures **do not** [existing emphasis] apply to violence complaints/occurrences when the parties involved are:*

- *flatmates*
- *In a close personal relationship but are not current or former intimate partners, except where it is necessary to issue a Police safety order” [existing emphasis] (New Zealand Police, 2012b, p2).*

There is an indication in the documentation provided by the Police (2014) that Women’s Refuge was consulted about this change, but who their spokeswoman was, and what the outcome of the discussion was, has not been provided to me, despite a second OIA (2015). This suggests the possibility that there was no formal or informal consultation other than informing the National Collective of Independent Refuges that the change had occurred.

I was not provided with any explanation about why the policy change was made despite the intervention of the Ombudsman’s office. I have requested interviews (2014/15) with the relevant police officials in Wellington to discuss the implications of this policy change for disabled people, but these requests have been denied. In 2016 there was a review of police processes in relation to domestic violence but this exclusion has not been addressed.

As identified above, there is also no provision in the current New Zealand Domestic Violence legislation to be inclusive of abuse by paid carers as they are specifically excluded from the Act by being employees. Evaluation of a joint pilot project between WDHB³ Older Adult and Vulnerable Adult Abuse Prevention Coordinator,

³ Waitemata District Health Board. A government funded tertiary health service in Auckland, New Zealand

People First New Zealand⁴, and Auckland Police in 2016 identified that carers, both paid and unpaid, abuse disabled people and that Police did not have the knowledge and skills to follow up and prosecute and/or refer abused people to support services until the interventions provided by the project provided training and resources to police. This initiative has not been continued, despite achieving very good outcomes for the 40 people supported over the 6 months of the pilot (Appleton-Dyer & Soupen, 2017).

The government has updated domestic violence legislation that has just been reported back from Select Committee (August 2017). In response to lobbying and a number of submissions the Select Committee has recommended that disabled people be specifically named in the legislation as people who experience family and whanau abuse (Justice and Electoral Select Committee, 2017) and that the following clause be added to section 3B, describing psychological abuse:

(ea) in relation to a person unable, by reason of age, disability, health condition, or any other cause, to withdraw from the care or charge of another person, hindering or removing (or threatening to hinder or remove) access to any aid or device, medication, or other support, that affects, or is likely to affect, the person's quality of life: (Justice and Electoral Select Committee, 2017, p. 19)

If these draft amendments are passed into law it will be a significant improvement to current legislation – however the new Bill does not acknowledge paid professionals and care givers as potential abusers, as noted in the Green Party of New Zealand Minority View Statement (2017).

Crimes Act

In 2011 there was an amendment to the Crimes Act (Crimes Amendment Act, 2011). The section (*s195 Ill-treatment or neglect of child or vulnerable adult*), identifies a group of people, defined as vulnerable adults, who for various reasons are not able to remove themselves from risk of serious harm. This provides a legislative structure for prosecution if victims of abuse fit the definition of vulnerable people in the Act.

There are barriers to the use of this legislation. The definition of vulnerable people in the Crimes Amendment Act, s195, (2011) refers to a very small group of people. This is because not all disabled people are vulnerable within the definition of the legislation, nor do they want to be defined as vulnerable (Personal communication, various disabled people, 2013-2017). A high level of impairment is required for people to meet the definition of vulnerable in the Act and there is a high threshold

⁴ A self-advocacy NGO for people with learning disabilities

(gross negligence) required for investigation and prosecution to occur (Personal Communication, Director, Auckland Disability Law, 2017). There are also problems related to evidential issues for 'stand-alone' crimes. In 2010 changes were made to the Solicitor General's guidelines for prosecution (Crown Law, 2013), which increased the threshold for evidence required for crimes to be prosecuted. This means that in cases where it is he says/she says (domestic and sexual violence) the prosecutor is less likely to proceed to prosecution as police find it difficult to gather sufficient evidence – especially if the abuse occurred in private and left no physical marks or if rape myths and other myths hinder belief in the victim's veracity. As a consequence of this a disclosure of abuse by a disabled person is unlikely to proceed to prosecution, as disabled people are not perceived to be credible witnesses (Hager, 2001, 2011)

National practice policies

There are no nationally specified policies for violence services about responding to the abuse of disabled people. Nor are there nationally specified policies for disability or elder care organisations. However, under the provision of the Crimes Amendment Act, 2011, section s195, in association with sections *s151 Duty to provide necessities and protect from injury* and *s157 Duty to avoid omissions dangerous to life*, services that work with vulnerable adults (as defined within the Act) are required to have policies in place to identify and respond to abuse of this specific group of people. Disability and elder care services in New Zealand are at various stages of developing and implementing this policy process.

The New Zealand Disability Strategy Action Plan (ODI, 2015), that sets out priorities that promote action to achieve the New Zealand Disability Strategy (2016) does not include initiatives to upskill providers in either the disability or violence sector to recognise and respond to the abuse of disabled people.

Nationally specified qualifications required for working in the violence or disability sector

An option for influencing collaboration across the sectors is by employing well-qualified staff that have a strong orientation to their sector and the recognition of violence and abuse. In both the disability and violence sectors clinical staff must have professional qualifications – for example, nursing, psychology, counselling – but for general staff, including those who work with abused women or work in residential services, there are no nationally mandated qualifications or competency requirements.

Domestic violence sector

According to the Northern Region Domestic Violence Portfolio Manager in the Ministry of Health there are no mandatory baseline qualifications or training

programmes for people who work in the sexual/domestic violence sector (Personal Communication, January 12, 2015). Murphy and Fanslow identified this lack of training in 2012 and said that even if training were to be mandated, professionals may be resistant to it; there is little or no funding for training; high turnover in the sector means it is difficult to retain knowledge and skills; and, currently, good practice relies on specific individuals' skills and passion (Murphy & Fanslow, 2012).

Three government services provide staff training about 'family' violence (the organisational language used). There is mandatory training for staff in hospital settings who are required to screen patients for domestic violence and/or respond to disclosures. Work and Income (WINZ) provides training about domestic violence to its frontline staff and Corrections have started training staff about domestic violence. All of these trainings have been specifically developed for the particular service.

In June 2017 the government released a Workforce Capability Framework (MSD, 2017) that describes good practice across a range of issues related to working in the violence sector. Despite strong submissions and advocacy, the circumstances of disabled people, and constructive responses to them, have not been included in this framework.

Disability sector

Ministry of Health contract specifications for disability services communicate the requirement for organisations to provide training that enables staff to carry out their work safely, and in the service specifications, outline the core competencies that are expected of general staff. These general competencies do not include the identification of violence and abuse. There is, however, a clause (7.6. Prevention of abuse and/or neglect) in residential contracts which specifies keeping service users, staff and visitors safe from abuse, including the necessity to have policies and processes in place to do this. Despite this, when I enquired about baseline qualifications required in the disability sector, I was informed that no baseline qualifications were required (Personal communication, Te Pou, January 14, 2015). To date (November 2017) although there are qualifications required to work in dementia units, there are still no baseline qualifications required to work in most parts of the disability sector and therefore no mandated provision to train staff to identify and respond to abuse or to prevent it from occurring.

In July 2015 the Kaiāwhina Workforce Action Plan was developed for staff in aged care, disability and home support. This is a 5-year action plan for the upskilling of the disability sector. As part of this process a new qualification has been developed: the *New Zealand Certificate in Health and Wellbeing (Level 3, 2017)*, which includes the compulsory module *Recognise and describe responses to vulnerability and abuse in a health and wellbeing setting*. Organisations are being encouraged to

put all of their staff through this training. There is increased incentive for this as the training will be linked to a pay raise, granted as part of a recent agreement with aged care, disability and home support staff nationally (Personal communications with Jackie Blue, Human Rights Commissioner and Ray Lind, Chief Executive Officer Careerforce NZ, June 2017).

The Institute of Medicine (2002) identifies that a major barrier to medical practitioners and related personnel effectively engaging with those living with family and domestic violence is inadequate education, training and support given to practitioners to intervene effectively. This can lead to practitioners:

- reinforcing societal myths about family violence;
- neglecting to understand the complicated lives of victims, with the result that victims are not identified, or are re-victimised or blamed;
- interfering with victims' strategies to escape violence;
- not holding perpetrators accountable for their behaviours;
- discriminating against victims in a manner that impacts on their access to crucial services; and
- having over-confidence in assessing situations when there is a lack of evidence to inform practice (Institute of Medicine, 2002).

The lack of nationally specified (or any) qualifications required for working in the violence and disability sectors would suggest that all of the problems raised by the Institute of Medicine (2002) are occurring when disabled people in New Zealand attempt to disclose abuse.

Accessible services

Currently, in New Zealand, there are no specialised sexual violence services for disabled women, and if mainstream services are physically accessible they very rarely have staff that have knowledge of disability-specific issues (Personal Communication, Auckland Sexual Abuse Help, 2013). There are no known accessible refuges in New Zealand and very few domestic violence services that are accessible to disabled women (Cranson, 2010; Disability Coalition Against Violence, 2010; Hager, 2001, 2011; NZ Family Violence Unit & Hager, 2013).

Building the Evidence (Healey et al., 2008) is a research project undertaken in Victoria, Australia, to understand how disabled women are recognised and responded to in Australian policy and service provision for domestic violence. From my own observations, the findings from this project (in italics) reflect a similar situation in New Zealand.

- *“Family violence sector standards and codes and guidelines say little about how to support women with disabilities (p10).”* In New Zealand there are no

specific policies about responding to violence against disabled women developed for use by women's refuge staff, associated domestic violence agencies and those working in health, social services, justice or police.

- “*Most services do not routinely collect data on disability and family violence (p10).*” In New Zealand no services routinely collect data on disability related to sexual or domestic violence. This makes it very difficult to ascertain the extent of the problem or the effectiveness of the response to victims and perpetrators.
- “*Most family violence workers consulted had minimal or no training in supporting women with disabilities (p10).*” In New Zealand there is no training offered to the family violence sector about disability and domestic violence, other than that offered by DVD in Auckland. To date (2017), the attendance at these training sessions has been good from disability and associated agencies, but very poor from the domestic, family and sexual violence sectors.
- “*Little is known about the help-seeking experiences of women with disabilities experiencing violence.*” (Healey et al., 2008, p10). There is some research into the help-seeking behaviours of women with mental health problems from a New Zealand perspective (Hager, 2001), but no research into the experiences of women in the wider disability sector, apart from the work of Roguski (2013), which was specific to one town and the findings were not gender disaggregated.

In 2010, the New Zealand National Collective of Independent Women's Refuges (NCIWR) released a *Diversity Report* (Cranson, 2010). This reports that New Zealand refuge workers feel that they have significant skills to meet the needs of women with a diverse range of impairments and can, if unable to house women, work with them constructively in the community. However, despite this perception of competence, Cranson reports that there are many impediments to this:

- Very few New Zealand refuge premises are fully accessible (Barnett, 2015; Cranson, 2010) – in fact many of them are not accessible at all for blind women, women in wheelchairs or those requiring other aids for mobility or communication, nor for women with learning disabilities.
- No refuges have overnight staff (Cranson, 2010), which means that women who require support for personal care and women with mental health or substance abuse problems who require 24 hour monitoring and support cannot be housed in existing refuges.
- There is recognition that very few refuge staff have the necessary skills to support a woman with complex physical care needs. When there are skilled staff members in a refuge, there is no formalised way to share these skills

with other staff, very little informal sharing of skills and there is no register of where this knowledge is held (Cranson, 2010).

- The NCIWR has no internal policies about working with disabled women, and no formal agreement with outside agencies. This means that support is inconsistent across sites, as are the agencies that staff members engage with (Cranson, 2010).
- NCIWR does not provide any training about the dynamics of violence and how to constructively respond to it to outside agencies that support disabled women (Cranson, 2010).
- In New Zealand there is very little training offered to either the domestic violence or the disability sectors about disability and domestic violence (Cranson, 2010).

There are no specialised violence services to respond to the abuse of mentally ill or substance dependent women and most mainstream refuges are not available to these women - either because they are not physically accessible or because there are agency policies that exclude women with mental health or substance abuse problems (Hager, 2001).

The increased focus, in New Zealand, on providing services only for deserving women with young children ('real victims') means that it is increasingly difficult for violence services to deliver support to women without dependent children. As many disabled women do not have children, and women with mental health and substance abuse problems are more likely to have had their children removed (Hager, 2011), this further restricts these women's access to services.

Roguski's (2013) New Zealand report identifies a number of structural issues that contribute to the lack of service and other responses to prevent and respond to abuse:

A low level of societal awareness of disability abuse; a variety of silencing processes; a lack of appropriate monitoring; poor management practices of a variety of disability - related residences and services; inadequate reporting options; existing legislation, and powers emerging from legislation, are inadequate. ... [and] the individual does not receive adequate protection during the investigation of abuse (Roguski, 2013, pvii-viii).

Related to this, participants in Roguski's study talked about a lack of appropriately trained staff in residential, institutional and home settings; poor hiring practices, including not vetting for criminal histories; nepotism; and staff with inappropriate attitudes. There were considerable reporting barriers identified, including people being punished by caregivers for complaining of abuse; significant barriers to

engaging with police, including police attitudes; difficulties gathering evidence sufficient to meet evidential thresholds; and demonstrations of prejudice. For women who lived at home and did not receive health or disability services, there was often no oversight or monitoring of their situation, leaving them at risk of abuse. Participants also identified as barriers a lack of awareness of disabled people's rights and a lack of knowledge about services and processes (Roguski, 2013). Although Roguski's study was conducted in one city (Gisborne) in New Zealand, the findings reflect the wider New Zealand situation as shown in the New Zealand booklet about violence against disabled people written by the Disability Coalition Against Violence (2010) and the report by the New Zealand Family Violence Unit and Hager (2013).

Added to these identified barriers, that exclude women from seeking help or entering violence services, is the time it takes to negotiate inaccessible systems. In their study of societal barriers to disabled people's participation in day-to-day life, Wilkinson–Meyers et al. (2014) state that many disabled people require additional time to achieve similar tasks to their non-disabled peers. This is partly because, for some people, certain tasks take longer; however, often the additional time required is because of environmental or societal constraints, or time spent waiting for support people, transport and other services that are not delivered in a timely way. This additional time becomes not just an accessibility problem, but potentially life-threatening when attempting to escape abuse and access violence services.

Government responsibility

There is no government ministry that has responsibility for ensuring that government services and related information - such as housing, transport, welfare and even health services - are accessible. The Office of Disability Issues, who could be expected to carry out this function, explain their role as:

- supporting the Minister for Disability Issues;
- coordinating and reporting on implementation of the United Nations Convention on the Rights of Persons with Disabilities, New Zealand Disability Strategy and the Disability Action Plan;
- providing advice to government agencies on disability issues;
- sharing ideas and growing the understanding of issues that are important to disabled people;
- helping to facilitate an effective working relationship between the disability sector and government agencies; and
- providing secretariat support to the New Zealand Sign Language Board and Fund (ODI, 2017).

This means the ODI is tasked with developing the Disability Strategy, engaging government agencies to lead each part of the strategy work plan, monitor progress and report on progress to the Ministerial Chief Executive disability group. Progress is monitored using a traffic light system – green for moving forward, orange for stalled, red for no progress. From 2018 the ODI monitoring report will go directly to Cabinet, which should result in more progress. What the ODI does not have is any power to compel government agencies and ministries to take action, nor can they initiate action. They can only provide advice and support. (Personal communication, Brian Coffey, Chief Executive ODI, September 2017). What this means is that – as stated above, there is no government agency with responsibility for ensuring that action occurs.

An example of the active exclusion of disabled women’s experiences from the research/policy process is the New Zealand government’s decision to cancel the 2018 Disability Survey. David Matthews, Chief Executive of CCS Disability Action (a key New Zealand disability support organisation) says that this will result in the invisibility of disabled people in local and central government policy and planning (CCS Disability Action, 2015). This is compounded by Statistics New Zealand not offering telephone dictation services for those with limited mobility or vision for the 2018 census (Barnett, 2015).

Incorporating women’s voices in policy and practice

In 2012 the New Zealand Taskforce on Family Violence published a report called *Incorporating the voice of experience: Family violence – service user involvement guide*, recommending that all services that work with survivors of violence incorporate the voices of service users in their planning and processes (Close & Peel, 2012). The report lists the benefits of incorporating service users, including more effective services, improved outcomes and increased safety for service users, improved accountability and efficiency, and improved communication between service users and the organisation/staff. The report recommends incorporating the voices of disabled women to ensure accessibility of services.

This report was partly written in response to a New Zealand collective of survivors of domestic violence, *It’s STILL Not OK*, who produced a report in 2010 outlining how individual government departments were failing women attempting to escape domestic violence, and made recommendations about how each department could respond to abused women to provide support and ensure greater safety for victims and their children. Lisa Close, the spokesperson for the group, wrote in the introduction to the report:

We applaud the Domestic Violence Act 1995 (the Act) which is both forward thinking and representative of the caring kiwi society we live in.

Unfortunately the Act has not been fully implemented into the Government agencies where the true help and difference to victims and their families' lives can be made. The Act has failed to deliver on its intent, meaning the victims remain victims and the power and control still sits in the hands of those deemed to have done wrong – the perpetrators.

Our Government is spending vast amounts telling New Zealanders that Domestic Violence 'Is Not OK'. Women and children are calling for help and leaving abusive relationships in greater numbers than before, only to find that the same government doesn't support them after they leave. What message is this lack of support giving our children and as our future generation how will this impact on the cycle of violence?

Society does not want to know about Domestic Violence. It is very difficult for us as victims to openly explain our experiences. We are often "shut down". Society does not feel it is something that should be discussed. This leaves victims feeling uncomfortable and ashamed (It's STILL Not OK, 2010, p7).

To date, despite the 2012 guide and government rhetoric about the high priority of addressing domestic violence (for example, *Community Investment Strategy priority three: Supporting adult victims/survivors, addressing perpetrators' behaviour, and reducing violent crime*, MSD, 2015), no government department appears to have made changes based on the feedback provided in either report.

Disabled women's voices are often expressly excluded from government policy and legislation development. There was no consultation with disabled women's groups who have knowledge of violence and abuse about the development of the NZQA qualification (described pp35-36), the violence sector Workforce Capacity document (despite advocacy for this) or the new Family and Whanau Violence legislation currently before parliament (August 2017). When disabled women's views are included it is as a result of ongoing lobbying and advocacy from activists working at the intersection of the two issues.

Structure of the domestic and sexual violence, elder care and disability sectors in New Zealand

Within New Zealand, the violence, elder care and disability sectors are not coherent structures with clear linear responsibilities and relationships. Each sector is a mixture of government statutory services such as health, justice, police, Oranga Tamariki: Ministry for Vulnerable Children (OTMVC) and the Ministry of Social Development (MSD); and a variety of NGO, charitable and voluntary services, with some for-profit residential services.

Funding comes from a variety of places. Funding for disability and elder care services comes primarily from the Ministry of Health (MoH), with some philanthropic funding for non-government organisations (NGOs), whereas domestic and sexual violence service funding comes from a mixture of MSD, justice, police, OTMVC, health and philanthropic funding.

Responses to violence provided by statutory agencies include: investigation (Police, OTMVC, Ministry of Justice (MoJ)); criminal justice responses (courts, probation, police); crisis forensic investigation (police, health); and the provision of welfare payments (MSD).

NGO services include crisis support, residential services, trauma and other counselling, perpetrator programmes, programmes for child and adult victims of violence and some restorative justice programmes.

For more information about this structure, see Appendix 2.

Overall findings – an absence of information and integration

An examination of the New Zealand situation clearly identifies that almost nothing is known about the abuse of disabled women in New Zealand. Perhaps as a consequence of this, no legislation or policies are inclusive of disabled women nor are there accessible services to respond to violence against disabled women and keep women safe if they need to escape violence.

As identified above, there is very little New Zealand literature about violence against disabled women and there is no national prevalence data. The domestic violence legislation is not inclusive of disabled women's circumstances and actively excludes care givers and other employees who abuse disabled women, and the policies of police in regards to enforcement of the existing legislation (levels of evidence required and excluding some provisions in the Domestic Violence Act) place further barriers on the reporting, investigating and prosecuting of violence against disabled women. There are no mandatory policies in either the violence or disability sectors to guide staff and managerial practice about the identification of abuse of disabled women and how to respond, and there are no formal qualifications required to work in the violence or disability sectors.

Violence services are not accessible and very few services have staff with any specialised knowledge of the dynamics of violence against disabled women and how to work with disabled people. It is very rare that the voices of disabled women are included in government or civil society consultation processes, and this only occurs as a result of their continued determination to be included.

Very little data is collected about disabled women and their experience of violence; no data about disability is collected by violence services, nor is there consistent data collecting of violence against disabled people by disability services. Because police and other justice sector organisations are not responding to violence against disabled women there is no data collection in these services and as noted on page 40, the government is impeding the collection of general data from national surveys.

Finally, there is very little connection between the sectors, and there is no government strategy to engage the disability and violence sectors to work together to address the abuse of disabled women.

Conclusion

This chapter first examined various understandings of men's violence against women and the consequent health effects. This included an investigation of the literature relating to understandings of gender and power dynamics in violence perpetration and victimisation, the research indicating that men primarily perpetrate violence against women, and that women are significantly less likely to be perpetrators than men. The chapter then discussed violence against disabled women, detailing the range of abusive behaviours disabled women experience and the multitude of possible perpetrators in disabled women's lives. There was discussion about various reasons for the lack of consistent prevalence data. Following this there was an investigation into service provision to respond to violence against disabled women and discussion about including women's voices in service and policy development. Finally there was an investigation into what is known about the abuse of disabled women in New Zealand. This identified that very little information has been collected and no specific services exist to respond to violence against disabled women. In the next chapter I discuss the use of paradigms and models to investigate violence against disabled women and review various discourses of disability and violence. This review highlights the lack of an intersecting theoretical underpinning for the research, so the chapter then examines theories that enable cross-sector investigation.

Chapter 3

Situating the research and examining paradigms at the intersection of violence against disabled women

Introduction

This chapter begins with an examination of the purpose of making models and paradigms the focus of the research, rather than an investigation that focuses purely on practice. There is then a review of disability and violence models and discourse. Having carefully examined the models and paradigms related to violence and disability, I identify the lack of an intersecting theoretical underpinning for the research. This chapter next considers theories that bring the two concepts together in a way that allows similarities, rather than differences, to be examined. As I have worked within a health promotion paradigm since 1986, this research is situated within that understanding and structure. This chapter will describe a health promotion/determinant focus and then move to an introduction to intersectionality. These two overarching theories inform the work. The more specific methodological basis of the research – feminist disability theory and the wider critical-emancipatory underpinning – will be discussed in the method chapter.

As the focus of this research is theories and paradigms that enable or constrain collaboration across sectors, I next examine paradigms that marginalise and devalue dis/abled women and investigate how this occurs via language and other processes. Finally, as the literature review is iterative, I have returned to the literature as findings have emerged from the data (Henn et al., 2009). The last part of this chapter investigates concepts that have been investigated in this process, as these are more suitably explored here than in the findings chapters. These concepts are: myths and stigma associated with, and oppressing of, dis/abled and abused women; concepts of blame; real, deserving victims versus undeserving or not-real victims; and interdependence versus dependence or independence.

Using paradigms, models and theory to investigate violence against disabled women

This literature review (and thesis) examines various theoretical understandings of disability and domestic and sexual violence and where these models, understandings and paradigms may or may not intersect. A paradigm is a worldview – a framework of beliefs and values (Joubish, Khurran, Ahmed, Fatima, & Haider, 2011; Patton, 1999) that shapes how we think and how we formulate our opinions about the world. Within paradigms there are sets of alternative implicit or explicit realities (Morgan, 1980) and, therefore, if we are to understand how and why people are thinking about

subjects/topics in various ways, we must uncover the core assumptions that characterise and define any given world view (Morgan, 1980).

A paradigm is a worldview built on implicit assumptions, accepted definitions, comfortable habits, values defended as truths, and beliefs projected as reality. As such, paradigms are deeply embedded in the socialization [sic] of adherents and practitioners: paradigms tell them what is important, legitimate and reasonable. Paradigms are also normative (Patton, 1999, p1206).

Models are tools that help us solve problems (Brett, 2002); provide an aid to understanding; help conceptualise theory; and can be used as a way of representing the ‘real world’ (Llewellyn & Hogan, 2000). Models are descriptive (Brett, 2000) of how ideas are conceptualised, but should not be mistaken for paradigms (Llewellyn & Hogan, 2000). The models that will be examined in this research will be indicative of people’s values and paradigms in relation to sexual/domestic violence and disability. A theory provides a framework or perspective (Gabel & Peters, 2004) that enables an idea or set of ideas to be understood or organised in order to investigate or communicate the ideas encapsulated by the theory. Hunter (2011) has related these concepts, explaining how theories and models help us to frame our thinking and interpret findings when investigating the nature and prevalence of a problem, its aetiology, or its consequences. Theories and models also help us to “*plan and review the structure of the service system in responding to problems*” (Hunter, 2011, p1). Examining models and theories enables an investigation of the paradigms within which people operate.

Models/discourses of disability

There are a number of models and discourses (Fulcher, 1989) of disability. In New Zealand, while the primary models are the medical and social models, other models such as Maori, human rights, affirmative and managerial are also current. This thesis uses a social and human rights model.

The medical model of disability emphasises individual impairments and consequent individual handicap (Frawley et al., 2015; Oliver, 1990a). Oliver (1990a, 2009) explains the medical model as hegemonic in modern medicine, incorporating a view of the body as a machine that breaks and requires fixing when it is broken (Baum 2008; Waddell & Aylward, 2010). This leads to a model of health and illness that is a “*medical treatment model*” (Waddell & Aylward, 2010). Fulcher (1989) identifies the genus of this model as reflecting the influence and authority of the medical profession and how its ideas inform and penetrate everyday and professional discourse about disability. She posits a number of components of the medical discourse:

- Disability as an observable or intrinsic objective attribute or characteristic of a person (rather than a social construct)
- (Therefore) disability as individual deficit, [and]
- The medical model/discourse depoliticises disability by individualising and professionalising it. It takes the knowledge of the impairment, and subsequent disability, away from an individual and makes it a matter for ‘objective’ professional judgment. (Fulcher, 1989)

As the hegemonic model, the medical model has been used to develop definitions, policy and service provision, such as rehabilitation, vocational training, income maintenance and the provision of aids and equipment (Nikora, Karapu, Hicky, & Te Awekotuku, 2004). As Fulcher (1989) identifies:

Social workers, therapists, physiotherapists, nurses, teachers, borrow the logic and politics of the medical discourse on disability and deploy its authority and influence to legitimise their own professional practices (p25).

WHO used the model as the basis for the development of the International Classification of Impairments, Disabilities and Handicaps (ICIDH, WHO, 1980). This was a deficit model that posited that a person’s lack of functions or abilities (their individual injury, disease or impairment), results in limitations of functioning related to day to day living which in turn individually handicaps them (creates restrictions in social and economic participation including employment) (Waddell & Aylward, 2010). The medical model response to disability is to heal or fix the individual fault, to provide rehabilitation, to help people to be as normal as possible and/or to provide special residential and educational facilities for people who are not able to function ‘normally’ (Crow, 1996). However, for many disabled people, finding a cure or making people ‘normal’ is difficult, as not all disabilities are amenable to treatment (Nikora et al., 2004). Brett (2000) further explains this as disabled people having the responsibility to adapt to the environments that they encounter, through individual effort – and that if they are unable to do this, they (the disabled people) are seen as failures or as not belonging to mainstream society. Oliver (1990b) claims that the medical model socialises people into a disabled role that is further sustained and legitimised by the medical and welfare structures and bureaucracies set up to respond to disability. Also, the medical response may be considered offensive and unwelcome – as people may not perceive their impairment as requiring fixing, or strive to be normal (Personal correspondence, various disabled women and men).

Banks (2003) identifies the gendered nature of medicalisation and the medical model. She states that medical conditions that are associated with men – such as

brain trauma and heart disease – are under-diagnosed, but that women are over-diagnosed with psychiatric disorders and conditions that are seen as age-related rather than treatable. A New Zealand example of this is that head injury sustained by an All Black is recognised and treated; yet similar injuries caused by domestic violence frequently go undiagnosed (and untreated). Banks also identifies a history of stigmatising and minimalising women’s experience of illness with labels such as hysteria (2003).

Disabled people also call the medical model the personal tragedy or individual model (Crow, 1996; Oliver, 1990b). The tragedy model “*encompasses many perceptions of disabled people, which are nearly always negative...include[ing] notions of inferiority, inadequacy, pity, sadness, evil and disgust*” (Swain & French, 2008, p6). Tragedy is ascribed to both being disabled and parenting disabled children (Swain & French, 2008).

Criticisms of the medical model include that it ‘*abnormalises*’ disabled people and imposes a paternalistic regime of problem solving led by experts. This restricts disabled people’s rights, their ability to make choices, control over their lives and ability to develop their own potential (Nikora et al., 2004).

This [the lack of a service response to the abuse of disabled women] occurs because of the continued prevalence of the medical model of disability, which is concerned with the disabled person only from a biological perspective, ignoring his or her potential as a human resource able to form a life plan with thoughts, fantasies, emotions, within a network of interpersonal relations. (Barbuto & Napolitano, 2014, p163).

The structures and services designed to respond to disability from a medical/personal tragedy model have resulted in the critique described as the charity model of disability. This describes the provision of services by not-for-profit organisations generally aligning with medical definitions of a particular condition (Drake, 1996) and has been associated with the provision of oppressive, abusive and occasionally lethal policy and practice (Swain & French, 2008). Oliver (1990a) identifies how the fund-raising practices of charities reinforce dependent tragic depictions of disabled people. Traditionally, the images and language that are used to market disability have portrayed disabled people as objects of pity who are childlike, helpless, passive, needy and grateful (Fulcher 1989; Oliver, 1990a; Swain & French, 2008). The charity model can also stigmatise disabled people via, for example, the vehicles used for the transport of disabled people that have large signs on the side describing what and who the vehicles are for and the organisation that is supplying them. Oliver points out the disincentive for change to occur when so many non-disabled people are dependent on a charity or related organisation for their employment (Oliver,

1990a). These professional helping roles are created and maintained by disability policies and paradigms that shape power structures, models of disability, the function and administration of services and the dispersal and use of funds. This employment/power-related issue impedes change, as do state funding models that make organisations dependent on the state and therefore unable to criticise the policies under which they operate (Oliver, 1990a). Another concern related to this model is the legitimising of the medical model. Many charities classify people by impairment, thereby segregating, and, in some cases institutionalising people, according to medical definitions of disability (Nikora et al., 2004).

In response to pressure from disabled people and others involved in activism and scholarship, the medical understanding of disability, and the response to it, has been revised. Disabled people in New Zealand endorse a model of disability, expressed in the New Zealand Disability Strategy (MoH, 2001), that says:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have (p7).

This describes the social model of disability that asserts that, rather than being disabled by their individual impairment, people are disabled by the way society is organised and built, the social structures that underpin society and the attitudes, values, stigma, discrimination and behaviours that disabled people encounter in their interactions with non-disabled people – in other words, people are disabled by a society that fails to be accessible to the range of needs and abilities present in the population (see for example: Brown, 2006; Frawley et al., 2015; Oliver, 1990b; Swain & French, 2000; Swain & French, 2008). This model recognises that environmental and contextual factors can be either facilitating or disabling and links well with health promotion concepts. For example, Frawley et al. (2015) point out that gender is a “*socio-political factor of disability that was not accounted for by the medical model*” (p8). Extending this concept, Dolmage (2011) identifies that disability is constructed or produced in relation to a hegemonic ideal.

As the social model has been developed, there have been criticisms from a number of people (see for example Crow, 1996; Gabel & Peters, 2004; Morris, 1991). Many of these centre on an argument about whether disability is entirely caused by a disabling society, or if some disability is in fact caused by impairment (French, 1993; Morris, 1991). Some fears have been expressed about criticising the social model in this way. One of the identified risks inherent in critiques of the social model is the concern that identifying the personal effects and constraints of

impairment, including pain, “has been to risk the oppressive seizing of evidence that disability is ‘really’ about physical limitations after all” (Shakespeare, 1992, p40.)

The WHO/World Bank World Report on Disability addresses the tensions inherent in the social model debate by redefining disability as “a dynamic interaction between health conditions and contextual factors, both personal and environmental” (2011, p4). This is a “*compromise*” between the individualised medical model of disability as defined by WHO in 1980, focusing on individual deficit, and the social model (WHO, 2011). It is called the “*bio-psycho-social model*”. This model represents the concept that disabled people can be healthy and feel fully able to participate in life, yet be constrained by contextual restrictions such as discrimination or environmental barriers. However, in accordance with the various critiques of the social model from both within and outside the disabled community, this definition acknowledges that disabled people can experience problems related to their health conditions or impairment – for example pain and the frustrations of lack of function of body and/or mind and also the fear of dying (Morris, 1991).

Historically, Maori appear to have viewed disability as either an infringement of tapu or as makutu (a curse) (Nikora et al., 2004). Contemporary Maori critique the medical model with its focus on individual impairments and independence, emphasising instead holistic Maori concepts of health focusing on interdependence, whanau and determinants of health (Ratima & Ratima, 2007). Maori concepts of health and wellbeing incorporate the elements of the Te Whare Tapa Wha model, reviewed by Durie (1994), which encompasses te taha wairua – spiritual wellbeing; te taha hinengaro – mental wellbeing; te taha tinana – physical wellbeing; and te taha whanau – family wellbeing (Christensen, 1997). This model has been augmented by adding maintaining a secure cultural identity and access to cultural resources including whenua – land; te reo – language; and tikanga – custom and teachings (Durie, 1999). This concept of health accords with the social model of disability that focuses on the interaction between the individual with impairment and the environment (Ratima & Ratima, 2007). From this comes a model for Maori concepts of disability and disability support that:

...emphasise the creation of environments conducive to attainment of balance, spiritual and emotional wellbeing, maximum functioning, strengthening positive interdependence (whanau will be central), and maintaining and reinforcing a secure cultural identity (Ratima & Ratima, 2007, p190).

There are other models that have been developed. Arising out of consideration of the tension between the medical and social models is the affirmative model. This model, developed by Swain and French (2000), is described as a non-tragedy model,

based not on a problem (society or the individual), but “*disability as a positive personal and collective identity and disabled people living fulfilled and satisfying lives*” (Swain & French, 2000, p571). The affirmative model asserts that quality of life for disabled people, as for non-disabled, is dependent on access to appropriate resources both at a societal and personal level, in order to “*achieve a lifestyle of choice*” (Swain & French, 2000, p576). Currently this model is primarily expressed through a variety of arts mediums (McCormack & Collins, 2012). This concept aligns with a health promotion and Maori understanding that wellbeing is associated with a strong sense of identity, social cohesion and participation (Durie, 1999).

The response to disabling barriers in the New Zealand Disability Strategy is a human rights approach, aligning the discrimination that disabled people experience to, for example, racism and sexism. This approach describes the rights model which takes a human rights approach to disability, equating disabled people’s rights with those of other marginalised and/or stigmatised populations such as gay, ethnic minorities and women (Frohman, Dowse, & Didi, 2015; Oliver & Barnes, 1998). The rights model has developed out of disabled people’s dissatisfaction with services and policies that were perceived to be more responsive to the needs of service providers than to the people with disabilities they were set up to serve (Bickenbach, 2001). Fulcher (1989) describes the key components of the rights model as self-reliance, independence and consumer wants rather than needs, and explains that these oppose the themes of dependence, oppression, discrimination, exclusion and help in the medical, lay and charity models. She says that the rights model is “*overtly political in contrast to the submerged politics of a professional discourse on disability*” (p36).

There are a number of other models; these include social role valorisation (Hartnett, 1997; Wolfensberger, 2011), an approach designed to improve the circumstances of disabled people’s lives and enable them to live respected ‘normal’ lives. This model was developed, adopted and taught throughout South America and the western world, including New Zealand, in the 1970s–1990s (Hartnett, 1997). Another is lay discourse, which is informed by non-disabled people’s focus on someone’s external appearance and the amount of control they have over their body. Lay perceptions of disability are informed by “*fears, lack of understanding, misplaced patronage, apathy and even pity ... most commonly it is ignorance and prejudice that underly [sic] the discrimination....*” (Marles, 1986, pA7). Managerial/corporate discourse (Fulcher, 1989) is a neo-liberal response to disability. A key theme of this approach is managing people, based on the idea that people are objects or problems to be managed (customers or consumers). This involves risk management, which moves people who require support from living an ordinary life to a risk managed life. This model results in people who have no knowledge or experience of disability making decisions about funding, resourcing and other aspects of the lives of disabled people. The managerial discourse treats disabled people as children who are not permitted to

take risks. This is a response to privatisation and compartmentalisation and categorises people by the medical model (Fulcher, 1989).

Models and discourses of violence

In New Zealand, domestic and sexual violence are understood from a number of perspectives.

There are a number of versions of feminist theory relating to domestic violence. Elements common to them all include an understanding of societal attitudes that position men as the dominant class with greater access to material and symbolic resources in relation to women; women being perceived as subservient or inferior to men; domestic violence as a common dimension of family life; and a feminist perspective that prioritises women and advocates for women's rights (Loue, 2001). Related to this is patriarchy theory – the concept that some men believe that patriarchal dominance and control of women is their right and that this dominance can be enforced by violence. It also assumes that patriarchy, and the use of violence to maintain women's subordination, is acceptable to society (Loue, 2001; Walsh et al., 2015).

There are a number of models of domestic violence that operate from the individual/couple perspective. These investigate individual pathology; substance use; stress; levels of testosterone; cost benefit analysis of relationships and using violence; social learning theory – which is used to explain intergenerational abuse; theories of power and powerlessness within relationships; and the concept of traumatic bonding – used to describe why women do not leave abusive relationships (Loue, 2001). Alongside these, some researchers look for the cause of violence against women within families. They examine family relationships and structure, including who holds power within families; societal attitudes towards violence against women and violence in general; individual traits which are encouraging of violence or causal (such as mental illness); cultural sanctions for and against violence; and theories of evolution that normalise violence against women as an evolutionary survival factor (Barnett et al., 2011; Loue, 2001).

Others have tried to incorporate an understanding of different kinds of domestic violence – partly to balance the findings of the conflict tactics scale and more feminist understandings. This distinguishes between various forms of violent abuse – “*Intimate terrorism and violent resistance*” and “*situational*” abuse (Johnson, 2006, p1003) – which occur between couples. Some women in the sector find these distinctions useful; others are concerned that the police and judiciary are using these definitions to trivialise violence against women.

A model that is compatible with a health promotion perspective on domestic violence is the ecological model, which links violence in families with wider societal and determinant factors such as gender inequity, education levels, income, levels of societal violence and societal attitudes to violence and violence against women. There are many variations of this model, which can be used to investigate individual risk (Loue, 2001); as a treatment model; or as a model for prevention and health promotion initiatives (Garcia-Moreno, Guedes & Knerr, 2012; Hann & Trewartha, 2015), including at the level of social and political change (Jack, 2000). This model is taught to social workers to counter an individualised model of social work or to encourage them to look for causation outside an individual's (perceived) pathology or specific personal characteristics (Healy, 2005). Practitioners use this model to address contextual issues such as poverty, power, social location and diversity (Healy, 2005). An assumption of the ecological model is that practitioners will identify and address policy, organisational practice and legislation/regulation at all levels in the cause of social justice (Healy, 2005).

The model is also used for risk analysis (Barnett et al., 2011). For example, Jaaber and Dasgupta (2002) explain the levels of risk that women must negotiate to disclose domestic and sexual violence:

We can conceive of social risks as bricks of concentric walls that encircle the battered woman, keeping her confined in the status quo. The closest wall of social risks may consist of immediate pressures that a woman has to deal with. The second wall is the institutional policies and practices, and the third comprises of cultural issues and social attitudes that are more amorphous than the previous two (p18).

As seen in Table 1, these layers of risk relate to layers of determinants of health – organisational and legislative policy and processes and wider community and societal norms – at the individual, community and socio-political levels.

Table 1: Circles of risk

Circle I: Immediate Personal Risks	Circle II: Institutional Risks	Circle III: Cultural Risks
Homelessness	Child protection service	Religion
Financial responsibility for family	Criminal justice system	Nationality
Drug addiction	Immigration status	Class
	Civil justice system	Responsibility for family

Charge of domestic abuse	Law enforcement (e.g.,	honor [sic] and integrity
Other criminal charges	Immigration and	Cultural norms and
Poverty	Naturalisation Service,	standards
Lack of skills and	border patrol, local police,	Childhood socialization
education	prosecution)	[sic]
Sexual identity	Transnational laws	Race
Age	Federal laws impacting	
Abilities	tribal laws	
Language	Social service (welfare)	

Source: Jaaber & Dasgupta, 2002, p18.

An ecological model has also been used to explain the abuse of disabled people. This model includes personal factors such as limited physical and/or cognitive skills, increased isolation, and interactions and relationships that encourage physical and emotional dependence. It also addresses wider issues such as the tendency of caregivers to use power and control behaviours and for those who prey on people they perceive as powerless to seek employment in organisations caring for disabled people (Cramer & Plummer, 2010).

A model commonly used in New Zealand and internationally by domestic violence services to help victims conceptualise abuse, is the Power and Control Wheel. This model, in the shape of a wheel, explains domestic violence as physical and sexual violence combined with a variety of controlling tactics. Around the rim of the wheel are sexual and physical violence. The spokes of the wheel are financial abuse; isolating women; using coercion, threats and intimidation; using children; emotional and verbal abuse; mind games; minimising, denying and blaming; and the use of male privilege. At the centre of the wheel are power and control, the 'purpose' of the abusive tactics (Domestic Abuse Intervention Programme, 1984). Price (2012) explains that this model has been taken out of context, as it is a model that is intended to be used alongside another wheel that examines institutional, cultural and structural collaboration with the abuser and to tie the individual experience of violence to the wider structural supports for violence against women (ibid).

Lenore Walker (Walker, 1979, in Walker, 2000) developed the concept of a cycle of violence. This illustrates the cyclical pattern of behaviours associated with abusive relationships. The cycle has three parts: tension building, the acute battering [sic] incident and loving contrition. This cycle can take years, months or days. The cycle does change, however; usually the violent incidents become more prolonged and dangerous, the time between violent episodes shortens and the loving contrition

period gets shorter until it disappears. This is a sign that the risk of a lethal incident is very high (Walker, 2000).

Hand et al. (2002) have reconceptualised the cycle as a spiral. Working from the top of the spiral to the bottom is a useful way of understanding the increasing emotional, mental and practical restraints to attaining safety that women face over time as men's violence increases and intensifies. Concurrent with this intensification is the undermining of women's ability to function, caused by living with increasing stress and violence. However, the spiral can also explain how women who are caught in violent relationships can become stronger and, as they take action, eventually leave the relationship. Working from the bottom of the spiral to the top demonstrates how, each time a woman leaves a violent relationship, she learns either about the futility of leaving, the resources that are available to her or about the disappointment of returning. The spiral is an image of increasing stress, back and forth, with the possibility of increasing strength based on experience and better knowledge of possibilities. This helps to explain why women often leave several times before making the final break (Hand, 2002).

Why these models are insufficient at the intersection of violence and abuse

The various models of violence and disability examined above are useful to understand current thinking about the sectors and why there is so little congruence between people who subscribe to the various discourses and models. The medical model of disability and individual/couple perspective of violence both take a behaviourist focus and emphasise individual deficit and/or pathology. Within these models, responsibility for action is either sited within the person with impairment being abused, or from outside intervention in order to fix or remediate the identified individual deficit. From my methodological and health promotion perspective these are not useful models as they fail to consider structural, political, attitudinal and social barriers and enablers to community and individual action. I believe the use of these models can result in practices that, for example, build dependence and increase powerlessness, and place individuals and communities in unwinnable situations where the choices they have continue to be constrained by unaddressed societal barriers. In contrast, the social/rights model of disability sits well with a health promotion understanding of, for example, the social and structural barriers to integration and acceptance of disabled women. The power and control model of violence, informed by the spiral of forming and escaping a violent relationship, is useful to me as a way of understanding the dynamics of violence experienced by dis/abled women. The ecological model is a useful public health tool to shift practitioner's thinking from individual deficit and behaviour change to wider social and economic constraints on women's lives and choices. However, these models, while having similarities across sectors, are just that – models. They do not offer me

an integrating theory that can be used to examine the lack of policy, service and sector collaboration to address violence against disabled women. Therefore, in the following section, I discuss two overarching theories that bridge the divide between sectors and enable a broad view of the constraints on cross-sector practice.

Theories to situate and connect the research

Health promotion

The Ottawa Charter (WHO, 1986) definition of health promotion has been further defined in the Bangkok Charter by adding the word determinants to the original definition; “*Health promotion is the process of enabling people to increase control over their health and its determinants, and thereby improve their health*” (WHO, 2005, para.7).

There are a number of critical concepts in this definition. Health promotion does not use a construction of health that is binary (sickness/health) (Michailakis, 2003) as the medical perspective does, but constructs health as “*a state of complete mental and physical wellbeing*” (WHO, 1986, para.3). This is a state that everyone, regardless of her medically defined state of wellness, can aspire to. The definition stresses people having control over the determinants of health. From a health promotion perspective, the social determinants of health are the structural determinants and conditions of daily life (Committee on the Social Determinants of Health [CSDH], 2008) such as the gradient between rich and poor within and between countries; the “*unequal distribution of power, income, goods, and services, globally and nationally*” (CSDH, 2008, p14); and equitable or inequitable access to education, housing, income and employment, cultural identity and acceptance, and social cohesion (National Advisory Committee on Health and Disability, 1998). Increasingly, gender, racism, discrimination and experience of violence (CSDH, 2008) are being recognised as ‘meta’ determinants of health that enable or restrict access to the social and economic determinants such as housing and income, yet are amenable to change through health promotion action.

Overall, in the definition of health proposed by the Charters, people must be able to “*identify and to realise aspirations, to satisfy needs, and to change or cope with the environment*” (WHO, 1986, p1). The issues being investigated in this thesis - violence against women, and the stigma and discrimination associated with both the female gender role and disability – constrain women’s choices and ability to fully participate in life. Examining the barriers to constructive responses and prevention strategies can lead to an understanding of some of the determinant level issues that either enable or prevent constructive responses to abuse of disabled women, which in turn may help to improve their wellbeing and improve their ability to take control of their lives more fully and fulfil their potential.

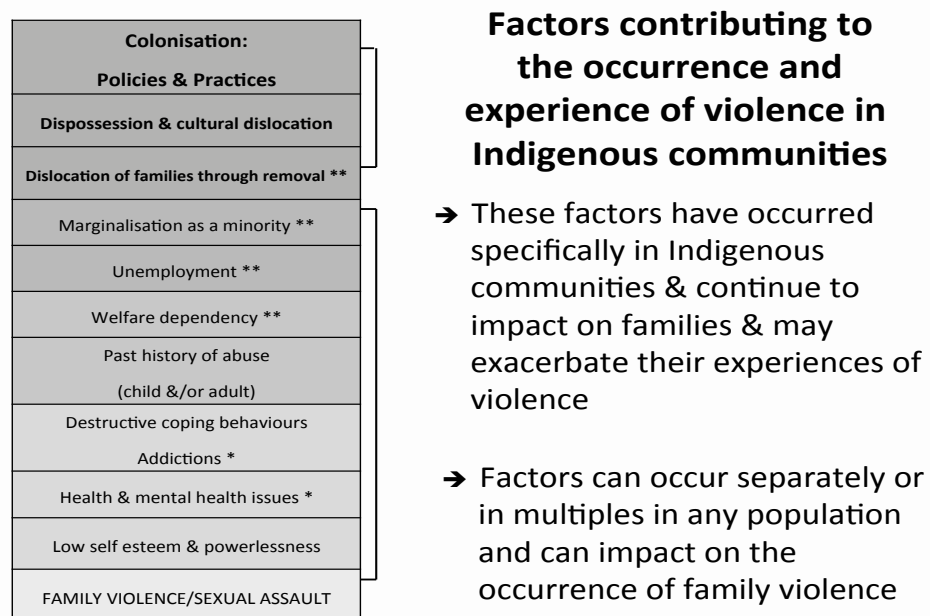
From a medical perspective, both domestic/sexual violence and disability can be seen as a personal/individual problem – located in the person (Oliver, 1990a) (abused woman, person with an impairment). This individualisation can be perceived either as behavioural or as an inherent quality of the individual. From a health promotion perspective, this individualising is neither constructive nor correct. It blames the victim (Baum, 2008) and does not take into account the contextual, paradigm and determinant issues that construct, constrain and influence choice and opportunity (Baum, 2008). This is consistent with the medicalising of other risk related behaviours such as smoking, substance abuse and unsafe sex, without examination of the determinant level issues that impact on the individual and her consequent behaviour.

Individualising and victim blaming can also be understood as the product of neo-liberal discourse (Anderson & Doherty, 2008). Within this discourse good citizens are “*self reflexive*” (Anderson & Doherty, 2008, p129), and knowledgeable in relation to risk and therefore responsible for their own safety and happiness (Anderson & Doherty, 2008). This self-responsibility aligns with patriarchal hegemonic understandings of gender and heterosexuality (Anderson & Doherty, 2008; McClain, 2011). For example, in this relationship, women are frequently blamed for being raped and/or abused, as they should have taken responsibility to prevent the rape occurring – so raped women are perceived to have contravened good feminine normative behaviour (Anderson & Doherty, 2008). This aligns with the individualising of problems inherent in the medicalisation of issues.

Much disability is socially caused and constructed. Impairments, the “*physical, sensory and intellectual features of human beings which count ‘as abnormalities of the body and mind’ in our society*” (Thomas, 2001, p47) can be caused by war, poverty, sexual and physical violence, medical misadventure or lack of medical care, work related accidents, stress and injury, pollution of the environment (causing, for example, birth defects), stress related illness and lack of the basic essentials of life – clean water, food and shelter (Wendell, 1996). Four of the greatest contributors to the world prevalence of impairment are age, poverty, living in a less developed country and female gender (WHO, 2011). Disability is caused by societies failing to provide the supports and environments that impaired people require in order to function and participate on an equal footing with non-disabled people.

WHO identifies violence against women as a public health problem of epidemic proportions (WHO, 2012). From this public health/health promotion perspective violence is not an individualised behavioural problem but related to wider issues of gender norms, power and privilege (WHO, 2012) – the paradigms mentioned above.

Figure 3 identifies the power, privilege and related determinant issues of colonisation and the consequent effects and contributing factors of violence in indigenous communities in Australia (Cripps & Adams, 2014). These factors would be very similar for Maori and other colonised communities, but are also very similar to the experiences of disabled people – frequently removed from their families and placed in institutional ‘care’, marginalised from mainstream (non-disabled) society, high rates of unemployment, under-achievement in education, high rates of abuse, welfare dependency, low self-esteem and the resulting mental health problems and powerlessness.



Source: Cripps & Adams, 2014, p405.

Figure 3: Factors contributing to the occurrence and experience of violence in Indigenous communities

This diagram can be explained by an investigation of the consequences of determinant issues. Solar and Irwin (2010) explain it in this way.

Social contexts, which include the structure of society or the social relations in society, create social stratification and assign individuals to different social positions. Social stratification in turn engenders differential exposure to health-damaging conditions and differential vulnerability, in terms of health conditions and material resource availability. Social stratification likewise determines differential consequences of ill health for more and less advantaged groups (including economic and social consequences, as well as differential health outcomes per se) (p5).

An example of this is provided by Williams and Collins's (2002) research, which suggests that the disability related to the diagnosis of schizophrenia is caused not only by the symptoms and processes of the illness, but by social interactions with mental health professionals, family, friends and the wider community. These interactions produced feelings and experiences of dependency, inadequacy, disconnection, alienation, devaluation and being dysfunctional. The messages that people received relegated them to a stereotypical state of being poor, unemployable, dishevelled, unproductive and unkempt (Williams & Collins, 2002). They postulate that it is partially this construction of disability and the subsequent social isolation and lack of support and resources that creates the long-term problems associated with the illness.

A health promotion/determinants perspective identifies similarities between the perpetration of domestic and sexual violence and the 'disabling' of people with impairments. Four of these similarities, that I have identified, are the marginalisation and disempowerment of the respective affected communities; negative social attitudes towards the communities, including blaming, shunning and exclusion; gender inequity and harm caused by the inequity; and the levels of stigma and discrimination the communities experience. Violence against dis/abled women is, from this perspective, indicative of the broader social construction of both women and disabled people as devalued, low status and not deserving of full societal involvement and support.

Knight identifies that "*political, social and economic institutions are designed to respond to some people's vulnerabilities better than others, so risk and exposure is manifested in uneven ways*" (2014, p18). It is these "*political arrangements*" that make certain populations more likely to be harmed through the creation of structural inequalities that inequitably distribute access to determinants between populations. As she says, "*...it comes as no surprise that disability tracks with social status*" (2014, p18).

The 2008 report *Closing the gap in a generation: health equity through action on the social determinants of health* (CSDH, 2008) identifies flourishing living environments; safe and healthy working environments; protection across the life course; equity including gender equity; and political inclusion and participation as prerequisites for healthy living. All of these determinants reflect the multitude of contexts that can increase violence and exclusion of non-disabled and disabled women or provide protective factors.

Underlying these aspects of health promotion are specific values that are the basis for all health promotion work. These are equity, social justice, empowerment, interdependence and, in New Zealand, an honouring of Te Tiriti O Waitangi and improving wellbeing for Maori (Health Promotion Forum (HPF), 2012). These values underpin my own work.

Intersectionality

“... violence against women with disabilities is understood to be the result of complex, interlocking systems of gender-based discrimination, disability-based discrimination and other forms of exclusion and domination” (Healey, 2013).

Intersectionality is another way of describing the contextual and diverse components of women’s lives, including the overlapping power relationships that enable or constrain individuals and groups of women. Intersectionality has been described as a tool for analysis (Dhamoon, 2011), advocacy and policy development that *“addresses multiple discriminations and helps us understand how different sets of identities impact on access to rights and opportunities” (AWID, 2007, p1)*. More recently it has been described as a theory (Carbin & Edenheim, 2013; McKibbin, Duncan, Hamilton, Humphreys, Kellett, 2015) which McKibbin et al., (2015, p101) have named as *‘intersectional feminism’*. This theory can be used as *“a methodology, a tool for data analysis, a nodal point in feminist theory, a feminist project or platform, and a framework for social policy development” (McKibbin et al., 2015, p100)*.

Intersectionality places gender at the centre of any analysis but recognises that women’s lives are diverse and that racism, sexuality, socio-economic status and class, caste, skin colour, religion, dis/ability, residential status, legal status, discrimination, prejudice and health status (AWID, 2007) combine to affect women’s socio-economic position and the way that the world and particular societies and situations are experienced.

Intersectionality recognises the multi-layered identities of women, identifying the discrimination and advantages that various combinations create. The intersecting of gender and other identities is not cumulative or additive, but creates *“substantively distinct experiences” (AWID, 2007, p2)*, even within the same geographical space. An example from New Zealand compares these differences with reference to the experience a disabled Maori woman has of sexual violence in contrast to that of a non-disabled white woman, because of the ethnic histories of violence, abuse, colonisation, social responses, stigma, power relationships and access to services (Hickey, 2007).

Collins (2012) describes this as:

Within intersectionality, the emphasis on the social location, multiplicity, and relationality of social locations and worldviews...has enabled the field to develop a deeper understanding of power. In essence, systems of power (such as race, gender, class, sexuality, ability, age, country of origin, citizenship status, etc.) cannot be understood in isolation from one another; instead, systems of power intersect and co-produce one another to result in unequal material realities, the distinctive social experiences that characterize [sic] them, and intersecting belief systems that construct and legitimate these social arrangements. Stated differently, racism, sexism, class exploitation, and similar oppressions mutually construct one another, drawing upon similar practices, forms of organization [sic], and ideologies (p455).

Intersectionality critiques essentialism via the investigation of the interlinking of issues associated with the oppression, discrimination and marginalisation of women. Dahmoon (2011) identifies that the central tenet of “*an intersectional-type research paradigm is a critique of the work of power—how it operates, its effects, and the possibilities of transformation (p240)*”. It is this analysis of power – as a site for “*struggle and transformation*” (p241) that Dahmoon (2011) says gives intersectional analysis its critical edge. Cockburn (2007) utilises the concept of positionality to describe intersectionality and its relationship with the investigation of power. She indicates that positionality relates to power relationships in terms of class, race and gender and describes intersectionality as the way “*dimensions of positionality cross cut each other*” (p.8) so that each person or group experience several dimensions of positionality simultaneously.

Intersectionality developed from the work of African American women in the 1950s to 1970s (in particular, Kimberlé Crenshaw) and their developing understanding of multiple oppressions, which was explicitly linked to social justice agendas (Collins, 2012). The 1980s saw the movement of these concepts into academia. According to Collins (2012) the term intersectionality emerged in the space between social justice movements and academic study.

While most researchers, practitioners and others acknowledge gender asymmetry in the perpetration of domestic and sexual violence, there is less agreement that gender inequality is the only cause of violence against women (Sokoloff & Dupont, 2005). An important tenet of early work on domestic violence is that it was a “*monolithic phenomenon that affected all women the same*” (Sokoloff & Dupont, 2005, p2). This was important as it moved the focus from being about violence towards ‘other’

women to violence being about all women, at all levels of society. However, more recently, lesbians, women of colour and women from poor/marginalised communities believe that the universalising of the experience of domestic violence hides the wider realities of many women's lives and results in a model based on white middle class experience that both describes a 'real victim' and determines responses to abused women that penalise those who do not fit this (white, middle class, heterosexual) model (Richie, 2005; Sokoloff & Dupont, 2005). Lockhart and Mitchell (2010) suggest that traditional approaches that compare one group to another presume and reinforce the notion that one group can be used as the criteria against which another is measured – therefore reinforcing and legitimising the marginalisation and oppression of the 'other'.

An intersectional approach recognises that abused women's "...*oppression is often multiplied by their location at the intersections of particular race, ethnic, class, gender; and sexual orientation systems of oppression and discrimination*" (Sokoloff & Dupont, 2005, p2). For example, Frawley et al., (2015) observe that from an Australian perspective, those seeking to understand violence against disabled women must have knowledge of gender, disability and other factors of diversity such as being indigenous and living in a remote area. Intersecting oppressions, multiple cultural identities, double communication barriers, lack of trust in the system and lack of culturally appropriate accessible services are intersectional issues identified by people of colour with disabilities in a study by Lightfoot, & Williams (2009). 'Double' oppression was described as double stigma and discrimination associated with "*racism...poor financial resources, poor education, impoverished living conditions, and high unemployment*" (p142) and a compounding of the problems faced by disabled people such as access to housing, jobs and services. Participants identified becoming exhausted trying to define the discrimination they were experiencing as "*racism, sexism, ablism, or some combination of the three*" (Lightfoot, & Williams, 2009, p142)

Violence against women is different for women who live in communities where disadvantage is concentrated... structural arrangements seriously complicate individual options for women who are marginalized [sic] and ... no one monolithic response will work to eradicate individual or systemic abuse (Richie, 2005, p xvi-xvii).

Dahmoon (2011) identifies four possible areas of intersectional analysis. These are identity (of individuals or social groups marked as other), categories of difference such as race or gender, the processes of differentiation, for example, the process of gendering, and the systems of domination such as sexism and ableism. She concludes that the "*study of process and systems is most effective for analysing the complex dynamics of power*" (p233). From this perspective investigating the

intersections of oppression and discrimination enables a contextual, structural analysis of domestic violence rather than an individual pathology or victim blaming perspective.

This intersectional analysis strongly accords with health promotion practice and analysis. Recognising the structural barriers women encounter, as health promotion asks us to do, permits a more nuanced analysis of power, oppression and discrimination, identifying, for example, that in some communities the police may be a source of oppression and abuse, rather than safety and security (Richie, 2005); and allows us to recognise agents of choice and constraint in women's lives (Sokoloff & Dupont, 2005).

Salthouse (2007) attributes the marginalisation of disabled women to "*the twin discriminators of gender and disability*" (p2), which make disabled women at particular risk of more frequent and prolonged incidents of domestic violence. Many writers also describe the intersection of stigma and discrimination faced by particular groups of disabled women, such as sexuality, race/colour and gender (for example: Banks, 2003; Garland-Thompson, 2004; Hickey, 2007; Morris, 1998). Healey (1993) discusses the differences and similarities between old women and disabled women. She points to similarities including oppression, ageism, ableism, poverty, lack of supportive appropriate health care provision, inaccessible environments and the insensitivity and impatience of society. She also points out that both groups are marginalised, stigmatised, hated, feared, have very low status in society and are individually blamed for their circumstances.

I am looking for a theory that addresses the broad context of women's lives. Intersectionality and a determinants/health promotion paradigm both look at the economic, social, political and cultural situation of women globally and the barriers and enablers inherent in particular situations. This broad context enables researchers to investigate more universal, underlying motivations for actions and processes that occur at a national, organisational and individual level, via analysis and understanding of the paradigms and values people, organisations and governments hold. This permits the investigation of the circumstances of the most marginalised and oppressed sub-groups in society, because unless researchers address these specific, contextual circumstances, we will not be working to achieve social justice and human rights for all women (AWID, 2004), but only for those who fit dominant paradigms or who are sufficiently empowered to have a voice. Intersectionality also enables a closer, more nuanced investigation of power dynamics and discrimination at the intersection of circumstances, both within the group affected and between the group and the various legislation, policies and institutions with which they interact (AWID, 2004).

This all fits with good health promotion practice, post Bangkok, which insists that researchers understand and address the political and social environments of women's lives, rather than the individual and group behaviours that are a manifestation of living in a particular context.

Paradigms that marginalise and devalue disabled women

This section investigates paradigms that marginalise and devalue dis/abled women. This is investigated in order to understand the attitudinal and paradigmatic barriers to effective policy and practice to prevent and respond to violence against disabled women.

Morris (2008) has identified two paradigms that oppress and exclude disabled women. One is the universality of the male perspective and the other is the rightness of the able-bodied experience. Both being male and being able-bodied are treated as universally positive positions from which all other experiences are perceived as other, limiting, and negative – and against which all other experiences are compared. This research examines the values, theories and models that people use to explain their work and their understandings of their sector, in order to uncover the paradigms they work from and how this in turn influences their motivation to respond to the abuse of dis/abled women. Existing paradigms that are relevant to this investigation are ableism, the concept of rape culture and hegemonic masculinity.

Ableism

Disability activists have coined the term ableism to describe:

...discrimination against people with disabilities, including the expression of hate for people with disabilities, denial of accessibility, rejection of disabled applicants for housing and jobs, (and) institutionalised discrimination in the form of benefit systems designed to keep people with disabilities in poverty” (Feminists With Disabilities, n.d).

Kelly (1999) discusses disabling attitudes including the prejudice evidenced by “*subtle acts of misguided, uninformed kindness*” (p70). She posits this as being as prejudicial and demeaning as acts of hatred. McLean (2005) says:

The effect of a system of classification based on ableist beliefs is to assist dominant, non-disabled groups to render the existence and concerns of disabled people either invisible, or subject to the exercise of patronage and benevolence. At the same time the benefits of being not disabled remain invisible and seldom acknowledged... (p65)

Rape culture

Feminists, sexual violence organisations and women's groups talk about a rape culture (for example, Anderson & Doherty, 2008; Buchwald, Fletcher, & Roth, 1993) that describes societal attitudes, beliefs and behaviours that “*encourage male aggression and support violence against women*” (Buchwald et al., 1993, Preamble) and allow rape to occur and frequently to go unpunished. They explain that in a rape culture women experience a continuum of sexual assault from sexual remarks and touching, to rape, and that because of the values and attitudes that condone this, many men and women believe that this behaviour is inevitable (Buchwald et al., 1993). Anderson and Doherty (2008) talk about a “*rape-supportive culture*” (p10) that describes values and expectations surrounding gender, sexuality and sexual violence that construct the hostile social environment that rape, and the subsequent vilifying and blaming of rape victims, occurs in. This (rape) culture includes hegemonic beliefs about masculinity, gender stereotyping and heterosexuality (Anderson & Doherty, 2008).

Hegemonic masculinity

Murphy (2009) defines hegemonic masculinities as:

Configurations of practice that reflect the contemporary most honoured ways of being a man, but that are deployed variously in different contexts to stabilise hierarchies of masculinities and to ensure men's collective dominance over women continues. Honoured practices can include physical violence, coercive control, psychological abuse, aggression, courage, strength, acts of freedom and independence, acting as a father, protector, provider and sustaining a heterosexual sexual relationship. The maintenance of hegemonic masculinities is supported through ideology, cultural policing, persuasion and institutions that honour these particular practices and denigrate effeminate practices (p ix)

These practices are supported by complicit masculinities – those men who “*condone the hegemonic project*” (Murphy, 2009, p viii) and do not challenge the hegemony or the subordination of women, and therefore benefit from it. These men may not use power and/or domination over other men and women, but may engage in similar behaviours to those of hegemonic masculinities. Subordinated masculinities are those men who do not engage with the hegemonic project, or who are perceived, by hegemonic men, to display characteristics and behaviours associated with stereotypical gay men.

Literature identifies hegemonic attributes as: independence; physical prowess, including the ability to beat up other men; bravado; hyper-masculinity; dominance;

virility; assertiveness; aggressiveness; athleticism (able to engage in hyper-masculine sports); being the financial supporter and protector of family (women and children); having personal and economic power and privilege; and heterosexuality (Scott, 2014; Shakespeare, 1999; Shuttleworth, Wedgwood, & Wilson, 2012).

It is one intention of this research that the ideas uncovered and examined will be indicative of the various paradigms/understandings of the participants in relation to the two 'universal' standpoints (hegemonic masculinity and ableism) and related paradigms, leading therefore to a greater understanding of the barriers and potential areas of congruence within and between sectors.

How are these paradigms manifest and perpetuated?

In 1985 Dale Spender investigated the sexism inherent in the English language and the sexualisation and trivialising of language pertaining to women – the “*patriarchal universe of discourse that accords priority to masculine experiences, values and interests*” (Wood, 2004, p262). Spender (1985) identified that, in English, there were more words, and more positive words, for men than women and that many of the words for women had negative sexual overtones. Some specific instances of this sexualisation and denigration of women are: bachelor and spinster – spinster has negative connotations; calling a woman an old man is not an insult, calling a man an old woman is; courtier retains its high status, while courtesan has become degraded and sexualised; governor also retains status while a governess is associated with the care of babies; sir is in common usage as a respectful title/form of address while madam is associated with the running of a brothel; and there is a huge discrepancy between the terms master – powerful and dominating – and mistress – a woman kept for sex (Spender, 1985). Spender attributes these differences to the existence of a semantic rule that determines that any symbol associated with being female is ascribed a negative and/or sexualised meaning, for example, the word tramp when applied to girls or women. Julia Stanley (1977) investigated words men use for women who are sexually available to men. She found 220, all of which were demeaning, oppressive or shameful and included offensive terms for women who were not sexually available on demand such as frigid and cold. She found 22 words for sexually promiscuous men (Stanley, 1977).

Just as language is used to debase and render relatively powerless those who are not members of the dominant gender, it is also used to stereotype and negate disabled people and their experience. Swain and French (2008) point out the use of words and phrases such as short-sighted – colloquially meaning lack of insight – to indicate the commonly held negative perceptions of disabled people. They call attention to the underlying devaluing inherent in the language of disability – dis-abled (not abled), in-valid (not valid), sufferers and victims (also used to describe abused women).

The language of impairment is frequently used to stereotype and minimise people by reducing them to identification only with what is perceived to be wrong with them (their impairment) – for example ‘an amputee’ or ‘a blind person’ (Swain & French, 2008). Wendell (1996) refers to this as asserting value by taking control of language. Finkelstein (2004) points out how language is used to label those who are ‘other’ to identify them as less or different from the dominant culture. For example, the identifier ‘man’ is synonymous with people - “huMANity” - while “woMEN” is a subcategory of men (Finkelstein, 2004). The hegemonic paradigm of being ‘able’ is exemplified by how we describe and understand public spaces – for example public spaces are for non-disabled – and they can be wheelchair accessible. A public toilet is for non-disabled – a disabled toilet is identified (Finkelstein, 2004). To be able-bodied is the accepted paradigm against which others are measured, even though very few people measure up to the ideal of a perfect non-disabled body (Finkelstein, 2004).

As Stanley (1977) points out:

...any given stereotype embodies the assumptions of the culture that perpetuates the stereotype...at the same time making it unnecessary for those who accept the stereotype to examine or question those assumptions (p2).

She further explains that this process embeds these stereotypes as facts that maintain cultural assumptions about the person/group/issue being stereotyped. The truth or falsity of the stereotype/assumptions is irrelevant, as this categorising of people, as we think they are, embodies our judgments and defines our future perceptions (Stanley, 1977).

Related to this stereotyping, many words associated with disabled people are used as insults. Words such as “*cripple, gimp, spastic, retard...psycho*” (Wendell, 1996, p76). Garland-Thomson (2004) clusters “*sick, deformed, crazy, ugly, old, maimed, afflicted, mad, abnormal or debilitated*” (p77) as pejorative words that disadvantage disabled people by devaluing and marginalising bodies (and minds) that do not conform to normative standards. She further identifies how being a woman has been, and still is, perceived as disabled in relation to being a man.

A New Zealand example of the use of language associated with disability to discredit and highlight ‘otherness’ (and to reinforce women’s ‘natural’ role as wife and mother) is this quote from the Labour MP Gerald Wall (1979) when discussing the feminist pro-abortion lobby – note the use of lesbian rather than feminist; this conflation is also reinforcing stereotypes designed to scare ‘real’ women.

...I'm not being unjust to them when I say they are psychological cripples. If you consider the person who can walk upright and straight and the normality of the human gait and then the attitude and approach of the person who is severely crippled you'll find that that comparison bears closely on the situation that exists between a woman who has an ordinary attitude of approval towards men and approval towards children, and the psychological attitude of so many of the lesbians who are not only anti-men but distressingly, increasingly anti-children (Wall, 1979, pp64-65).

This comment identifies how the language of deficiency and abnormality is used to devalue women who depart from hegemonic feminine roles and norms (Garland-Thomson, 2004).

Language is also used to render invisible the (male) perpetrators of violence against women and devalue and invalidate the women and children who are recipients of male violence. Women 'suffer' domestic violence and rape and are 'victims' of these experiences. This language invalidates the agency of women and the processes that they have used to leave dangerous situations and keep themselves and their children safe.

Julia Penelope (1990) discusses linguistic processes that protect paradigmatic male dominance of discourse and minimise or make invisible the violence that men do to women. One way of doing this is the removal of an active agent (man/men) from a sentence. This is demonstrated in the following way: (note the word *object* is used here to indicate a grammatical characteristic, despite the irony of the woman being treated as an object).

<i>Agent</i>	<i>Verb</i>	<i>Object</i>
<i>Five men</i>	<i>raped</i>	<i>the housewife</i>
<i>Object</i>	<i>Verb</i>	<i>Agent</i>
<i>The housewife</i>	<i>was raped</i>	<i>by five men</i>
<i>Object</i>	<i>Verb</i>	
<i>The housewife</i>	<i>was raped</i>	(Penelope, 1990, p146)

In this process of changing the sentence structure from active to passive, the agent – the person or persons (human agents) who carried out the action (verb) – are deleted, leaving us only with the action and the object of the action. This renders invisible the perpetrators of the act. Penelope identifies other examples of how this grammatical form is used to deny or hide responsibility for action. “*Hanoi was*

bombed, Grenada was invaded, the price of fuel has been raised” (p146). This structure removes the focus from the agent to the victim/recipient of the action and enables men to hide or deny responsibility for their actions (Penelope, 1990).

Another grammatical construction that removes responsibility and agency is ‘false deixis’ (Penelope, 1990), the use of, for example, ‘it’, ‘that’ and ‘this’ to substitute for the significant noun or word that points to the key issue in a sentence. These words are commonly used and, in much conversation, the deixis (identifying word) meaning is easily assumed from the preceding words or sentences – for example “I walked to the chair and sat in it”. In false deixis these words are used to obscure meaning. Penelope (1990) provides the following example of a man talking about his child, who he raped: “*Nicole was fine. She said that didn’t happen, it wasn’t true*” (p137). ‘It’ and ‘that’ are used in the sentence to avoid using the language that describes the actions being discussed, the rape and sexual abuse of his daughter. Not only does the use of ‘that’ and ‘it’ obscure the perpetrator’s actions, it enables him to minimise his actions via this obscuring process. People use false deixis to avoid naming specific types of behaviour, particularly those they want to pretend did not happen (Penelope, 1990).

Over the past thirty plus years, disabled women across the world have been critical of non-disabled feminists and the women’s movement for failing to embrace disability as one of the differences that non-disabled feminists investigate and incorporate into their practice and research (Fawcett, 2000; Garland-Thomson, 2004; Morris, 1991; Shildrick, 2009). They note that the most common feminist response to disability has been to investigate the position of caregivers – and the lack of status, remuneration, training and opportunities that are provided for those who do formal and informal care and support (Morris, 1991). Those who are cared for have been virtually invisible in this process unless they write or speak on their own behalf. This inter-sectorial lack of engagement with disabled women has been mirrored in New Zealand feminist processes and research and in the development of services to address violence against women. This lack of engagement further entrenches these negative and constricting paradigms.

Feminists are not wrong to research and raise awareness of the working and conditions of caregivers and their status in society (see for example, Human Rights Commission, 2012). Wendell (1996) reminds us of the sexism inherent in caregiving and attitudes to people who are perceived to be dependent. Assigning disability and the related caring roles to women and/or the personal domain of the home renders them unimportant (women’s work) and hides the responsibility of the state and the public realm to respond constructively (Wendell, 1996). Similarly, the idea that home is the ‘natural’ realm of women, children, elderly and disabled people makes disability a private and family ‘problem’ rather than a state responsibility

(Wendell, 1996). This also signals a disregard for those who are perceived to be powerless/without political voice. So while the inequity of care-giving is a constructive area of study for feminist and other women, it is equally important to recognise and affirm the agency of those who require some level of support to live their lives, and to examine our perceptions and attitudes about reciprocity, independence and dependence to check that they are not reflecting male paradigms.

Issues at the intersection of violence and disability

Myths, stigma and blame

Ken Lay, in his role as Chief Commissioner of Police in Victoria, Australia, has said this about the blame placed on victims of violence:

...we are constantly misapprehending the nature of violence. We do this because we want to feel safer—so we apportion complicity to those who die violently. In our heads, we make them somehow responsible for the wickedness that befell them.

When we do this, we feel better. We feel safer.

And it's also much, much easier to do this when the crimes are domestic—when they're behind closed doors.

When it happens we might think 'Well, why did she marry him?' just as we might think of a rape victim, 'Well, why was she wearing a short skirt?'

When we imagine this sort of complicity for the victim—when we essentially blame them—we are congratulating ourselves for our superior judgement, a judgement that will ensure it never happens to us...

When we do this, we come up with the wrong answers about why violence happens.

And when we do this, we make it less likely anybody will care enough to do anything.

In blaming victims, we create a lot of myths about family violence.

Here's some of them:

- *that the victim must have incited the abuse;*
- *that the victim is guilty of awful judgement;*
- *that if the woman's life was endangered, she would simply leave.*

No, no, no. (Lay, 2013)

As identified by Ken Lay, one of the complicating issues when addressing disability and violence is the effects of underlying societal attitudes based not on reality, but on the myths and stigma associated with disabled people and abused women.

One identified source of stigma against disabled people is the equating, in some societies, of disability and mental illness with punishment for personal or parental wrongdoing and sin, the influence of evil spirits or actions committed in previous reincarnations (Covey, 2005; Livneh, 2012; Makasiale & Williams, 1997; Nikora et al., 2004). There is also socialised mistrust of disabled people as a consequence of the way that disabled people have been portrayed in literature and other arts (films, drama etc.). In these mediums, disabled people – for example ‘hunchbacks’, the ‘mentally retarded’ or people with a limb missing – are associated with evil (Margolis & Shapiro, 1987) or with total helplessness, dependence and the consequent (to others) burden of needing care (Margolis & Shapiro, 1987). Peters (1996) identifies additional characteristics of disabled people in books and films as undesirable and pitiable, with incomplete bodies and minds; and that disabled women are portrayed as bitter, submissive and full of self-loathing. The media also perpetuates myths and stereotypes about disabled people. For example, Barnett (2015) identifies negative media portrayals and the invisibility of disabled people’s voices – especially Maori and Pasifika.

The discrimination and stigma arising from these stereotypical portrayals frequently results in disabled people experiencing verbal and physical abuse, denial of rights, segregation and lack of accommodation (WHO, 2011) and denial of appropriate health care (Barnett, 2015). The consequences of this discrimination are fear, withdrawal, isolation, and/or reduced social and economic participation; low self-esteem; and sometimes having to move to a new (geographical) area (WHO, 2011).

Being a victim of domestic or sexual violence is also stigmatised and there are many societal myths that hinder women’s ability to escape from abuse and reintegrate into non-violent society, including blaming women for the abuse they have experienced. The Glenn Inquiry People’s Blueprint report (Wilson & Webber, 2014) draws on interviews with approximately 500 people in New Zealand, including frontline family and sexual violence staff, victims of violence and some perpetrators. From this evidence the Inquiry concluded:

...traumatised people are reluctant to seek help for fear of provoking further distress and trauma. Asking for help is fraught and often accompanied by stigma, humiliation, fear of further abuse, re-traumatisation and rejection. Attempting to disclose abuse and violence means risking ridicule and not being believed. Encounters with service providers who are disrespectful, have judgmental, unsympathetic, impatient or intolerant attitudes and behaviour, are major impediments for people affected by violence (Wilson & Webber, 2014, p31).

For disabled women, this is compounded by the myths and stereotypes associated with disability.

Barnett et al. (2011) identify 10 common societal myths about violence against women. These are:

- *Family violence is uncommon*
- *Only poor people are violent*
- *Abused children always become abusive partners or parents*
- *Battered women ask for it*
- *Family violence sometimes “just happens”*
- *Minor acts of family violence are always trivial and inconsequential*
- *Alcohol and drugs are the real cause of family violence*
- *Women who claim date rape are “lying”, “deserve what they get” or were “asking for it”*
- *Some people cannot be raped and anyway, coercive sexual contact is not damaging*
- *If he ever laid a hand on me I’d leave. (pp33-34)*

These myths encapsulate some of the problems related to lack of societal acceptance of the seriousness and prevalence of domestic and sexual violence against non-disabled women. For disabled women, these problems are compounded. As disabled women are seen as having less value than non-disabled women (and all men) they become increasingly marginalised and discounted because they are fighting a number of different stigmatisations, not just the expected ones. Shakespeare (1999) comments that, as a consequence of the myths about disabled women - such as innocent, vulnerable, dependent and objectified – gender and disability combine to reinforce the second class status of dis/abled women. This leads to myths such as the idea that disabled women – and in particular women with learning disabilities - are not affected by sexual and other abuse as they are used to it and/or don’t understand it (Calderbank, 2000; McCarthy & Thompson, 1997). Another myth is the perception that disabled women suffer less from the dependency imposed by disability than men, because women are inherently more dependent and therefore don’t suffer the same debilitating effects of being reliant on others and being less able to participate in an inaccessible world (Morris, 1991). Because of the stigma and discrimination associated with mental illness, women who are already perceived to be mentally ill/crazy/mad will frequently find that their testimonies about abuse are given less credence than those of other women, or that they are not believed at all – while the abuser is believed/seen as ‘sane’ (Hager, 2001; Khalifeh et al., 2015).

Crenshaw (1992) has identified the way racist myths prevent professionals from receiving dis/abled women's stories as credible reports of their situations and abuse. "...even when the facts of our stories are believed, myths and stereotypes about black women influence whether the insult and injury we have experienced is relevant or important" (Crenshaw, 1992, p1470). The lack of relevance and importance placed on the testimony of black American women is echoed in the difficulty disabled women experience when attempting to disclose abuse – as identified in Chapter 2.

Alongside the persistent negative myths is the discourse of the "good cripple" (Brownworth, 1999, p xvii), a person who is happy with the role of "cripple" and who, because of this, provides insight and wisdom to the non-disabled. Brownworth compares this to the "Uncle Tom" slave mythology of the slave satisfied with enslavement and loath to change the status quo. This myth is of a brave person struggling against the restrictions imposed on her life by the non-disabled community, but always happy and uncomplaining. Brownworth identifies this stereotype as an invention of the non-disabled – a prototype of what a good disabled person should be. This stereotyping enables non-disabled people to "*laud the disabled for their "bravery", while alternatively denying them full citizenship*" (p xviii).

'Real' victims – complicit victims

Associated with the myths and stigma surrounding both domestic violence and disability is the social and professional perception of who constitutes a real victim and how this guides practice and response. This is closely aligned to how blame is assigned to victims, as complicit in their own abuse.

Bogard (2005) examines constructions of real victims and how the intersection of race, class, sexual orientation and gendered notions of violence influences who is seen as a real or appropriate victim, and how this validation of real victims "*implicitly denies the victimisation of others*" (p30). She identifies courts, police and others as having less empathy for prostitutes, HIV positive women, drug users and those who fight back, for example, and says that for these groups, who are not deemed legitimate victims, protection and services may be scarce or non-existent.

Meyer (2016) argues that no victim of intimate partner violence fits the criteria of an "*ideal, innocent*" (p75) victim. She posits that those seen as "*weak, shy and vulnerable and those who suffer victimization [sic] at the hands of a stranger are more likely to be seen as the ideal victim, worthy of empathy and support*" (Meyer, 2016, p76). This is because those who experience violence from a partner or other

intimate, especially those women who return to an abusive situation, are seen as complicit in their abuse – and therefore less deserving of help and support. This, she suggests, is because of the social understanding that abused women are somehow complicit, have some personality defect that attracts violence or are “*weak willed*” (Meyer, 2016, p80). This is an interesting contention when discussing abused disabled women. Women who are identifiably disabled may be considered more ‘innocent’, yet complicit in abuse as they are difficult to care for and create caregiver stress. Women who have, for example, mental illness or substance abuse problems may not be seen as innocent as they are perceived as creating their own problems (Hager, 2001).

For women who experience mental illness or substance abuse problems either concurrently with, or as a result of, domestic, family or sexual violence and abuse, the stereotyping and discrimination can result in not only being perceived as not credible when attempting to get help, but being:

- identified as the problem
- seen as a bad, potentially dangerous mother (resulting in a strong risk of children being removed – and potentially the abusive partner being given custody)
- blamed for the abuse
- pathologised – requiring medication and other treatment – for example, being placed in mental health in-patient care (Hager, 2001).

These women find it particularly difficult to be taken seriously by family, friends and professionals and consequently to obtain adequate help to escape abusive relationships. This is compounded by the lack of options for them to remove themselves to places of safety (Hager, 2001).

Matthews (2014) discusses the blame ascribed by society to those who are abused, particularly by sexual and domestic violence, as conferring a judgement of “*imprudence*” (p792) on people for allegedly putting themselves at risk. He says that there is a “*moral danger*” (p792) in public declarations of blame because this removes perpetrator responsibility and harms those who are abused. This harm occurs via the internalisation of blame and, more perniciously, as a consequence of victims being held responsible for their own safety; vulnerable citizens (those who can be abused by individuals or the system) must constrain their activities and liberty to accommodate the “*vicious activities of others*” (Matthews, 2014). He further explains victim blaming as having the effect over time of “*delegitimising and making less visible members of groups apt to be targeted*” (p797). This marginalisation of certain groups then creates a situation where just existing and engaging in normal activities becomes justification for violence to occur. Victim

blaming in this context also results in exclusion from societal protections such as legal representation (Matthews, 2014).

Expectations of independence or dependence rather than interdependence

One of the seven health promotion guiding values (HPF, 2012) is interdependence, which is described as “*recognition of the interdependence of individuals, families, communities and the broader environment*” (p9). However, in mainstream culture, it is independence that is perceived to be an essential trait of Western masculinity and a commonly verbalised goal for all citizens to achieve. Independence evokes related concepts of powerfulness, leadership, personal agency and ability. Dependency, on the other hand, evokes concepts of childishness, powerlessness and lack (Hager & Hager, 2013; Wood, 2004). Interdependency is a concept that is very rarely used or described.

Through the development of feminism, women have been encouraged to acquire/own/assert many qualities that are associated with Western concepts of independence. While this has enabled a strengthening of women’s self-esteem and expression, and provided the impetus for women to increase their participation and roles in the world outside the home (Hager & Hager, 2013; Wood, 2004), these same ideas have inadvertently excluded and marginalised many of the interconnected ways women function and have particularly excluded women who, because of age and disability, are reliant on others for support in some aspects of their lives (Morris, 1991). However, the dichotomy between non-disabled independent people and disabled dependent people does not stand up to analysis. Non-disabled people are given (and expect) lots of help in their lives - education, training, recreational opportunities, organised sports and all the other services that people use (Wendell, 1996). For example, Healey (1993) identifies elevators, escalators and maids/cleaners as examples of services that are designed to help non-disabled people. Using equipment or hiring others to provide these services is not considered help – it is entitlement, offered to citizens who fit the social able-bodied paradigm, who “*by definition are not considered dependent on social support*” (Wendell, 1996, p41). It is only when people require support that falls outside this paradigm that they are considered dependent (Wendell, 1996).

When someone is wealthy, this interdependence/privilege of wealth is called power (Healey, 1993). When women are poor, disabled, struggling to juggle childcare and employment, or when they are ill, elderly and/or unemployed, the need for interdependence – for some level of support and help – is called dependency, and the connotations are negative and stigmatising. So, if women are able to choose to buy help they are powerful – and those from whom they purchase services are perceived as legitimate members of society (Hager & Hager, 2013). When women are reliant on some level of support – financial or personal – they are perceived as dependent

and those who provide caregiving and support services are also frequently devalued and stigmatised. This is clearly demonstrated in New Zealand by the very low wages paid to the (mainly) women who work in elder care (Human Rights Commission, 2012), disability (Van Eden, 2013) and the women's anti-violence sector (FVDRC, 2014). Wendell (1996) describes this as self-deception. Non-disabled people perpetuate the hegemonic myth that independent adults do not need each other's help, that we are not all profoundly dependent on one another. Yet it is often socially constructed barriers and/or gender roles that have created the need for help (Wendell, 1996). In relation to this Julia Wood (2004) says:

Within a patriarchal universe of discourse, women's interdependence and concern for relationships are viewed as a lack of independence, not as a choice for relatedness; women's willingness to nurture children and others who need help is admired less than earning a high income; women's cooperativeness and their efforts to achieve equality are recast as fears of success and lack of competitive instinct...If we operated within a matriarchal universe of discourse, we'd be more likely to disparage men who focused on jobs to the neglect of family life and we'd criticise men for lacking a cooperative instinct and for being too insecure to enter into interdependence with others (p264).

Hicky (2007) equates the concept of interdependence with Maori wellbeing and custom, reminding us that this concept is as valid a part of the multi-cultural inheritance of New Zealand as the masculine/colonial concept of independence/man alone.

Maori see interdependency with whanau as the key to well-being for Maori. This is in opposition to the concept of independence being pushed by Western models for well-being and rights-based models for disabilities which is centred on individual human rights rather than collective human rights. There are often clashes with the cultural concept of interdependence, a concept which would suit Maori with disabilities well as independence often means isolation and exclusion. Interdependence on the other hand, encourages involvement and inclusion with whanau. Western models encourage independence through capitalism and individualism as the key to well-being, yet [disability] funding is individual and does not take into account broader needs such as whanau needs to support the individual with the impairment. For Maori with disabilities, independence is less desirable than interdependence, which is about relationships within whanau units benefitting the whanau as a whole unit, not just the individual (p176).

When working to change how society thinks of people with disabilities and those around them, I suggest starting from recognition of the value of mutual support and inclusion rather than acquiescing with:

...current values about individualism, damaging negative cultural assumptions about those who need assistance, and unjust neo-liberal social policies that reduce [access to] various forms of social assistance in the guise of ending 'dependence' (Lippman, 2013, p1).

Lippman goes on to say:

The marketplace is not the way to manage personal relationships, needs, and problems by assigning 'tasks' to strangers who are on appallingly low wages and who are often not respected for their crucial work (p3).

Interdependence recognises and values the interconnections and relationships that bind us all together – the reliance that we all have on the skills, support, and company of others. It is only when society understands interdependence to be a relationship between equals – a relationship that brings greater power and benefits to both parties – that we will start to change the patriarchal paradigm of independence and the stigmatisation of collaboration and interdependence (Hager & Hager, 2013). As Jones (1999) says, interdependence is not about charity, but about unity. It requires a change of values and attitudes that admit the interconnections between us all and the need to ask for and offer help and support.

Conclusion

This and the previous chapter have investigated various aspects of the abuse of disabled women from the perspective of prevalence, women's experiences of violence, and models, theories and paradigms. The investigation of paradigms has uncovered thinking that devalues women and increases the difficulties abused women experience accessing services to help prevent violence and/or support women when violence has occurred. Overall, the chapters show that, while there is a high prevalence of violence against disabled women, there is a lack, world-wide, of communication and collaboration between the violence and disability sectors (McClain, 2011). This chapter has also investigated a number of concepts that arose during data analysis: myths, stigma and blame; real victims verses complicit victims; and interdependence. The next chapter describes the method (who the participants are, how the data was gathered and analysed) and methodology used in this research, including the specific theories that are being used to explore the research question.

Chapter 4

Research methodology and methods

Women are disabled by the patriarchy in the same way that impaired people are disabled by the system (MN5).

Introduction

This chapter explains the methodology and methods of this research. It first describes the overall approach to the research – qualitative methods within an interpretivist research paradigm; and then describes the underpinning theory – critical emancipatory and feminist disability theory. The evolution of the research question is discussed and ethical issues relating to the research are investigated. The chapter then details the methods of data collection, the rationale for, and recruiting of, participants and the process of data analysis.

Overall research approach

...the purpose of academic discourse is not only to describe and explain the world, but also to change it (Baker, Lynch, Cantillon, & Walsh, 2004, p169).

This research project uses qualitative methods within an interpretivist research paradigm. The overarching interpretivist position is critical-emancipatory (Henn et al., 2009). The thesis is uncovering underlying societal values and paradigms about dis/abled women by interpreting the collected data through the lens of feminist disability theory.

Contrary to an interpretivist methodology, the positivist approach to research is based on scientific methods that measure the natural world to elicit truth and immutable laws about how the natural and social worlds function. It uses mostly quantitative methods to test an existing theory or hypothesis. This is known as a ‘theory then research’ (Henn et al., 2009) or a ‘theory testing’ (Ackerly & True, 2010) approach to research.

I have chosen an interpretivist approach because I am theory seeking rather than theory testing. This means that theories have been generated from the collected data, rather than using the data to prove an existing theory or hypothesis (Ackerly & True, 2010). Theory seeking is a function of an interpretivist approach to research. An interpretivist position rejects the positivist concept of one social reality or truth that will be uncovered by value-free research and instead incorporates the possibilities of

multiple realities that are constructed by the context, ideologies and paradigms of both the research subjects and the researcher (Hesse-Biber & Leavy, 2007; Truman, Mertens, & Humphries, 2000). For example, in their work about rape attribution and societal attitudes, Anderson and Doherty (2008) assert that positivist research, through the construction of the research methods and viewpoints, replicates, and fails to enable the challenging of societal rape myths. In comparison, however, an interpretivist methodology enables these societal rape myths to be examined and critiqued as the potentially underlying messages guiding various perceptions and interpretations of information about rape and sexual violence. It is this underlying construction that this research is attempting to elucidate.

Critical social research has an emancipatory agenda. This paradigm determines that, in order to understand the social world, researchers must take notice of, and critique, the “*historical, cultural, social and political contexts, which constrain human thought and human action*” (Henn et al., 2009, p17). This type of research is intended to address issues of minority, marginalised, stigmatised and silenced populations and to:

- *expose inequalities, malpractices, injustices and exploitation;*
 - *give a voice to these excluded and marginalised groups; and*
 - *help explain generalised oppression in order to precipitate social change.*
- (Henn et al., p17).

Qualitative research methods are appropriate for an interpretivist approach to research as they focus on the social rather than the natural world, via the stories and language used by research participants (Liamputtong, 2013). This enables the voices of people who are otherwise marginalised, ‘othered’ or silenced by the dominant social order (Henn et al., 2009) to be heard through the research process. This suits my research as it is intended to elicit information about how the theories and language used by people in the violence and disability sectors silence or enable conversations and collaboration between the sectors, using people’s own understandings of their work and the paradigms that they work within. Baum (2008) suggests that qualitative data can be used to identify and explain the “*economic, political, social and cultural factors that influence health and disease in more depth*” (p 181) than surveys and other measures. This enables an exploration of contextual and determinant level obstacles to the response to violence against disabled women. Within my research, this involves the exploration of dominant paradigms in the violence and disability sectors and investigation of how these paradigms have hindered an effective response to the abuse of disabled people.

Emancipatory research and key elements

Emancipatory research methodology shares the key values of health promotion – and of the researcher – which are empowerment, equity and social justice (Truman et al.,

2000; WHO, 1986), as well as working at a determinants of health (CSDH, 2008) level to make changes to the upstream structural and ideological circumstances that enable or inhibit personal choice and opportunity. It is a research process that aims not only to prioritise the experiences of people who have been marginalised or rendered invisible by traditional research (Humphries & Truman, 1994) but to produce information that “*direct[s] attention to the possibilities for social transformation*” (Baker et al., 2004, p178). Emancipatory research does not cause change, but it can reinforce and stimulate the desire for change (Barnes, 2004).

The way research questions are framed is key to this methodology. Traditional studies of non-hegemonic subjects generally approach the subjects as problematised and deviant (Humphries & Truman, 1994). Rethinking the structure of questions to address the paradigms and political and institutional ideologies and behaviours that perpetuate marginalisation and harm is an important first step in anti-discriminatory, emancipatory research. Hona (2007) and Smith (2002), in the context of using New Zealand indigenous research models and processes for indigenous research, identify the counter-hegemonic, transformative power of this reframing process. Part of this disruption of hegemony is reframing questions. For example, in domestic violence research this means asking, “why do men abuse their partners?” or “what societal values and attitudes encourage the perpetration of domestic violence?” rather than “why do women stay in abusive relationships?”

An emancipatory counter-hegemonic agenda involves, in this research, interrogating the dominant paradigms that oppress women through disabling and sexist practices. This research is not intended to identify a particular group or population as the locus of the problem (Baker et al., 2004; Humphries & Truman, 1994). Rather, it seeks to elucidate the contextual and structural disabling (Oliver, 2006) and patriarchal paradigms and models that constrain or enable progress in the development of a policy and service response to the abuse of disabled women. The research seeks to identify what Oliver (2006) calls the “*disablism ingrained in the individualistic consciousness and institutional practices of what is, ultimately, a disablist society*” (p279).

According to Penny Germon (1998) the emancipatory approach must establish relationships with disabled people; listen to their voices; encourage researchers to consider how the research can provide solutions and practical strategies; provide a forum for sharing skills, knowledge and experience; and be informed by the work of disability organisations and disabled people, not just treat them as participants. This research aims to encompass all of these objectives through an ongoing relationship with DVD and also through the subsequent dissemination of the research findings via conferences, seminars and training opportunities around New Zealand and internationally.

Some of the participants in this research are disabled people. This means that they speak from a position of both insider and expert sector knowledge. It also means that they chose to participate as prospective beneficiaries of the final outcomes of this research. This benefit will not necessarily be personal – but beneficial in their roles as sector representatives of the wider community of disabled people. What makes this research different – and potentially emancipatory – is that, rather than asking about deficit, the experience of particular impairments, discrimination, abuse or prejudice, as much disability/abuse related research appears to do, this research is based on questions about ideas, paradigms and solutions, initiated by discussions within DVD. The research methodology treats all participants as providers of expert knowledge and does not discriminate (or even ask about) disability status.

Truman et al. (2000) describe the elements of emancipatory research as:

1. *Locating the 'self' in the research process in terms of personal, social and institutional influences on research and analysis*
2. *Exploring the political/power dimensions of empowerment*
3. *Being explicit about the tensions that arise in research, and relating as much about how the tensions remain as about how they are resolved*
4. *Linking research to wider questions of inequity/social justice (p13).*

1. Locating the self

As with most researchers, early experiences have influenced why I am undertaking a PhD at this time of life and my choice of research subject. I am dyslexic. This meant that I struggled in a school system that did not recognise dyslexia and caused me to believe that I was not academically capable, and as a consequence I experienced marginalisation and stigma. However, I was raised in a very supportive family who strongly believed in social justice and equity, which has guided my choice of career, community contribution and research interests.

I teach health promotion at the School of Population Health, University of Auckland. I am a feminist who has worked for many years in a variety of NGO and voluntary agencies and groups to advance the wellbeing of marginalised women. I have researched women's homelessness, the effects of domestic and sexual violence on women's mental health and wellbeing, policy and service responses to this and the effects of government policy changes on women and their ability to live free from violence. I am explicitly grounded in the ongoing political struggles for women's human rights and in particular the provision of specialised services to ensure that no women remain in danger and all women have access to gender-based therapeutic services.

My previous work includes Masters research into the relationship between domestic violence and mental illness (Hager, 2001) and a report developed with Winston Churchill funding entitled *Finding Safety: Provision of specialised domestic violence and refuge services for women who currently find it difficult to access mainstream services* (Hager, 2011). This investigated best practice violence sector responses in Australia, England and Scotland for women with mental health problems, substance abuse problems and/or physical disability and the implication of these findings for best practice to respond to the needs of this population of women in New Zealand.

I have worked with a number of mental health organisations – both NGO and consumer run, and sexual and domestic violence organisations - as a staff member, consultant or trustee. I am one of the founding members of DVD, a voluntary coalition of people from the disability and domestic and sexual violence services who are working to raise awareness of the abuse of disabled people and the lack of service and policy response to this. The current research arises out of discussions within this group about the barriers to communication between the disability and sexual and domestic violence sectors and the lack of progress on policy and service responses for abused disabled people.

2. Exploring the political/power dimensions of empowerment

Empowerment can happen at a variety of levels. The continuum of empowerment (Laverack, 2010) is a theoretical model to guide health promotion involvement with the community. It moves through personal action, small group development, community organisation, and partnership development to social and political action. As Oliver (2006) reminds us, people cannot be empowered – but once people have decided to empower themselves, we can ask how our research can facilitate this process and at what level of action we can usefully participate.

This research is not intended specifically to empower individuals who have been, or are at risk of, abuse. Its purpose is to empower the groups already working to improve responses to disabled people by providing information that can be used to increase communication between sectors and with policy makers, to provide new directions for strategic thinking and planning, and to improve evidence for social and political action. From a health promotion perspective, this is creating supportive environments. From a disability perspective, this is working within the social model of disability to challenge the invisible, but inherently disempowering, cultural norms and social practices that occur as a consequence of disabling paradigms, and to change society to make it more accessible and responsive to disabled women. Both these approaches work from an environmental, contextual framework, rather than a victim blaming/behaviour change perspective.

3. *Being explicit about the tensions that arise in research, and relating as much about how the tensions remain as about how they are resolved*

I have used DVD as a reference group to pre-test interview questions and garner feedback on themes and conclusions reached in the research. This could, potentially, lead to some controversy over who owns the information and processes of the research. To date, this has not occurred. However, this tension will need to be mediated if it arises, to ensure that the needs of both the researcher and the members of DVD are met and that positive possibilities arise from the process and outcomes of the research. This will occur as a consequence of ongoing meetings, updates, discussions and my contributions to the work of the group.

Oliver (2009) believes that, in order to be emancipatory, all research must be wholly owned by disabled people. Others (See Baker et al., 2004; Barton, 1996; Truman et al., 2000) prioritise the aims, process and outcomes of the research as being of primary importance – the identification of structural oppression and the transformational/political/participatory processes that emerge from the research process, alongside a values system that is shared by the researcher and research participants (Heron, 1981). Morris (2008) identifies non-disabled researchers as allies. Being an ally involves doing research that empowers disabled people; includes a questioning of the researcher's attitudes to disability; puts the spotlight on the oppressors; and makes the personal experience of disability political (Morris, 2008). As Balderston (2013) says:

...whilst the nature of individual doctoral study sets some restrictions on the co-construction of meaning in the analysis, feminist frames could still be employed. The reciprocity of skills and resources...helped equalise the outcomes from the study, even if one's doctoral thesis could not be truly collective and emancipatory... (p34).

Working with DVD and related groups means that the analysis and conclusions will potentially have several distinct audiences. There will be the theoretical conclusions that have an academic audience, the policy implications and recommendations for policy and decision makers and both the policy and practical recommendations for the sexual and domestic violence services, the disability services and advocacy groups to use. Gorman (1998) asserts that all information and research outputs of emancipatory research must be accessible and available to activists. From my perspective, all levels of analysis and dissemination are for advocacy and social change purposes.

4. *Linking research to wider questions of inequity/social justice*

As I have identified, my personal and professional values align with the values of emancipatory research and feminist disability theory. These values underpin and

direct the research process. This has impacted on the questions asked, the process of analysis, the conclusions reached and the choices about what information to disseminate, the audiences for dissemination and how this will be done.

Unifying the results and interpretations – feminist disability theory

As a way of unifying the information gathered from these various sectors, I am using feminist disability theory as the lens to interpret the information (data) gathered and also to critique the data and enable a deeper and more nuanced examination of the underlying causes of the lack of communication about this issue. Feminist disability theory is a relatively new theoretical construct based on a fusion of feminist and disability theoretical perspectives and analysis.

The genesis of feminist disability theory, while not named as such, occurs in the seminal work edited by Michelle Fine and Adrienne Asch (1988). In their book Fine and Asch use emerging work by disabled women, disability scholarship and second wave feminist analysis and critique to explore disabled women's lives. They point out that (in 1988) while much work had been done to incorporate women of different ethnicities, sexual orientation and other diverse realities into feminist thinking, disabled women had been markedly ignored in feminist processes.

Wendell (1996, p244) wrote: “*disabled women struggle with both the oppressions of being women in male dominated societies and the oppressions of being disabled in societies dominated by the able bodied*”. One of her suggestions to address this was the development of a feminist disability theory as, while both disability and feminist/women's studies were well-established disciplines, neither recognised the other, and both would benefit from an understanding of each other's issues and concerns (Wendell, 1996).

Garland-Thomson (2002, 2004) has further progressed the concept of a feminist disability theory – integrating disability into the categories of analysis in feminist postmodern investigation (Garland-Thomson, 2004). The overarching premise of the theory is described below.

The informing premise of feminist disability theory is that disability, like femaleness, is not a natural state of corporeal inferiority, inadequacy, excess or a stroke of misfortune. Rather disability is a culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender (Garland-Thomson, 2004, p77).

She states that the two central tenets of this theory are integration and transformation. Integration is about full inclusion for those who have been excluded and subordinated and transformation is about re-imagining established ideas, knowledge and “*the order of things*” (Garland-Thomson, 2002, p2). She posits that feminist disability theory goes beyond the investigation of existing disability topics such as illness, health, beauty, genetics, eugenics, ageing, reproductive technologies and access, to include broader feminist issues such as the construction of the category of woman, the privilege of normalcy and social constructions of identity. A combination of disciplines, she believes, enables a deeper understanding of issues shared between the two disciplines – dependence/independence, individualism, the integrity and medicalisation of the body, bodily differences, oppression, minority group definitions, community, and ideas of progress and perfection.

A feminist disability theory “*denaturalizes [sic] disability by unseating the dominant assumption that disability is something that is wrong with someone*” (Garland-Thomson, 2002, p77). This interrogation of disability uses a similar process to the feminist critique of gender, class, race, ethnicity and sexuality as exclusive and oppressive systems, rather than the natural and appropriate order of things (Garland-Thomson, 2002). To do this, feminist disability studies use fundamental premises of critical theory, including that:

- *representation structures reality*
- *the margins define the centre*
- *gender (or disability) is a way of signifying relationships of power*
- *human identity is multiple and unstable*
- *all analysis and evaluation has political implications* (Garland-Thomson, 2002, p77).

As Garland-Thompson (2002) points out, including disabled women in research and analysis does not narrow the focus of inquiry only to disabled women. Nor is it a discrete focus on a particular set of issues or concerns. Many of the issues that are raised by including disabled women are issues pertinent to all women – not only as we age or otherwise acquire disabilities. As we interrogate the socialised construction of woman we find there are many overlapping and complementary issues. This is reflected by my use of dis/abled women in various parts of the text.

In this thesis feminist disability theory is being used to examine the data for multiple layers of power, exclusionary and inclusionary processes and to look beyond the obvious to the underlying determinant of the findings from this research. It is no use writing a thesis to record once again that there is little, if any, connection between the sectors. The purpose must be to drill down through the obvious, more hidden and almost invisible layers, to understand what is creating this situation at the

intersection of the construction of, and social norms about, being a woman and being disabled.

Linkages between the theories used in the thesis

Intersectionality, health promotion, emancipatory theory and feminist disability theory share features that link them as concepts for exploring and interpreting the association between disability and violence and the (lack of) relationship between the violence and disability sectors.

Emancipatory research methodology grew out of social movements for equity and social justice, including feminism and the disability movement, and disability studies also started with this social movement. These movements and methodologies share the key values of health promotion, which are empowerment, equity and social justice (Truman et al., 2000; WHO, 1986), as well as working at a determinants of health level (CSDH, 2008) to make changes to the upstream structural and ideological circumstances that enable or inhibit personal choice and opportunity. Emancipatory research is a process that aims not only to prioritise the experiences of people who have been marginalised or rendered invisible by traditional research (Barton, 2005; Humphries & Truman, 1994) but to produce information that “*direct[s] attention to the possibilities for social transformation*” (Baker et al., 2004, p178), as does emancipatory disability research (Barton, 2005) and feminist disability theory. Emancipatory research does not cause change, but it can reinforce and stimulate the desire for change (Barnes, 2004). Good health promotion practice (WHO, 1986) and intersectional research and analysis (Cockburn, 2007; Collins, 2012; Dahmoon, 2011; Sokoloff & Dupont, 2005) are also based on the premise of transformative change.

Amy Allan (2007) discusses the three tasks of a feminist critical theory. She identifies these as the analysis of subordination not just of women but other intersections – for example, class and sexuality (and, I would add, disability), the critique of such subordination, and the understanding of how transformation could occur. This accords with Garland Thompson’s (2002) description of the key purposes of feminist disability theory.

These examples demonstrate the many links between the theories. Feminist disability theory, emancipatory theories, intersectionality and health promotion are all concerned with the underlying determinants of health and wellbeing, and an expectation of the examination of marginalisation, oppression and oppressive institutional and state systems. They critique essentialism (universalising issues); they all also insist on the examination of underlying causation. This means not taking paradigms, hegemonic understandings and existing power structures for

granted and not looking for the surface and behavioural/individual causes of problems, but examining the overarching political, attitudinal and structural contexts that create risk situations – or enhance wellbeing.

The theories expect researchers to look beyond the surface reasons/effects of particular behaviours and processes to the underlying reasons and complexities and there is an expectation that the results of emancipatory research will be accessible and available to the study population for advocacy and social change purposes (Germon, 1998).

Who can speak about disability issues or, what right do I have to speak on disability issues?

Sokoloff and Dupont (2005) discuss the “*controversy*” (p 8) about who should speak for marginalised, abused, women. They claim that for many women from minority or oppressed groups, even well-meaning mainstream (white, middle class, heterosexual) women can oppress by speaking on behalf of a particular group, as this process risks silencing and further marginalising those they purport to speak for.

Feminist disability theorists (for example, Fawcett, 2000; Shildrick, 2009) discuss who should speak about disability. It is essential that as social justice/emancipatory movements such as feminism and disability movements begin, primacy must be given to the voices of these minority and/or oppressed women striving to place themselves in the world. This privileging of personal experience is expressed in standpoint theory (or, as recontextualised by Rosemarie Garland-Thomson (2002), sitpoint theory), an important component of consciousness raising and the development of an oppressed group’s ability to develop critical questioning/thinking skills – the ability to ‘ask why’ (Laverack, 2009) and/or as Fawcett (2000) says, to theorise personal experience. However, as social movements mature, questions are raised about the ongoing efficacy of this individualising of experience and the appropriateness of deciding between diverse experiential positions. Questions such as whose voice can be perceived to be the most representative; who is the most oppressed; or whose account is the most accurate (Fawcett, 2000) become complicating and, as experience is collected and theorised, communities need to move on from this position.

As these issues have been debated, activists have recognised that privileging the experience of oppression risks masking the responsibility of the perpetrators of oppression. In response to this possibility, Shildrick (2009) discusses how both post-conventional theory and critical disability studies place the responsibility for enquiry and analysis of disability (and other oppressions) not only on those who are negatively affected by oppression and marginalisation, as in the past, but on “*all*

those who participate in the relevant structures” (p15). This perspective invites people who have hegemonic power in a particular situation – (white, male, heterosexual, non-disabled) to recognise their responsibility in the oppression, and develop strategies to redress this (Shildrick, 2009). Also, as Kelly, Burton and Regan (1994) recognised, people do not have to experience a particular oppression in order to develop an understanding that enables a committed response.

Mirfin-Veitch and Ballard (2005) discuss the role of able-bodied people in disability research. They believe that researchers must examine their own practices to establish whether they are part of the disabling process, or part of the solution. Being ‘complicit’ in the disabling process can involve being non-reflective – accepting the existing paradigms without questioning their inherently disabling effects. For that reason the process of this research is both self and academically reflective, to ensure that both the processes and results of the research will contribute to anti-discriminatory and emancipatory outcomes.

In light of this discussion, I reiterate that this research is not about disabled women’s experiences of abuse, but about the (lack of) relationship between the disability and violence sectors and why this lack of relationship is occurring.

Evolution of the research question

The research question has undergone a number of transformations. The PhD journey started, for me, with a simple question – “*what are the barriers to the violence and disability sectors engaging with each other to address the abuse of disabled women?*” As I thought about this question I realised that what I was interested in was the way people thought about their work and violence against dis/abled women, not just the pragmatic and political barriers that can be described when examining service level responses to an issue. It was also important, I felt, to identify potential enablers if the research was to produce results that could be used to make progress in developing inter-sectorial relationships. As a result of this thinking the initial research questions to be answered were proposed as:

1. What the paradigms/models (domestic/sexual violence and disability) are, what congruence there is between them, where and how they differ and how they can be used to encourage communication and collaboration between the sectors
2. How new and emerging concepts such as human rights or a determinants approach could be developed to engage the sectors in collaborative relationships
3. Possible shared constructions of causation and prevention of violence against

disabled people

4. What processes would be necessary for the sectors to make a paradigm shift if another identified approach would be more constructive and more conducive to good communication, practice and policy?

As can be seen, the initial objectives of the research were concrete, focusing on strategies and theoretical models that would enable cross-sector conversations and practice. As the research has developed, the ideas being examined have become less practice focused and instead have concentrated more on underlying and often invisible paradigms that are inhibiting any response to this issue – as identified in my first question above. This has occurred in response to the data and as a consequence of the emancipatory and feminist analysis applied to the material gathered from participants. The data gathered generated interesting latent concepts associated with (lack of) service provision and engagement across sectors, which can be used to reorientate services (WHO, 1986) to be more inclusive (Garland-Thomson, 2002) of disabled women in violence services and to enhance recognition and response to abuse in disability services. However, this level of analysis does not elicit information about underlying semantic causation – why this work is not already happening. As emancipatory and feminist disability theories seek transformational change (Garland-Thomson, 2002) – a change to the underlying values and attitudes marginalising and excluding disabled women – this research had to look further to discover these underlying concepts and barriers.

Consequently, the research question has contracted to become:

What are the explicit and implicit ideas, models, values and paradigms that practitioners and policy makers in the domestic /sexual violence and disability sectors subscribe to/hold (or employ) when working in their own sector and how do these ideas constrain or enable action to address violence and abuse of disabled women both within and across sectors?

From this, what actions can be identified to begin the process of engagement both within and across sectors?

Ethical issues

Research, especially positivist, that investigates marginalised, poor or ‘other’ (non-white, non-heterosexual, non-male, disabled) people often begins by locating the problem to be investigated, and the causative factors leading to inequality, within the attributes of the research subject/s (Baker et al., 2004). This is often seen in health research that blames victims of various circumstances for their own oppression,

situation and consequent poor health – a “*stereotyping of the very groups the data purport to support*” (Humphries & Truman, 1994, p4). In order to avoid this, a number of processes were attended to in the research methodology and design.

- a) The research is not investigating lived experience of abuse. It is instead looking at theories and paradigms that enable or constrain the abuse of disabled women and the development of responses to this abuse.

- b) As Truman and Humphries (1994) argue, anti-discriminatory research does not have to be about sensitive topics that are threatening to those being studied. It can be about the wider issues of how knowledge and paradigms are constructed and disseminated. From the point of view of this research project, unless participants are concerned about how their organisations may construe the answers that they provided, or the possible critiquing of their responses by the researcher, there was very little information being requested that should cause participants to feel stressed or disturbed. Very little service-related information is being used in the thesis or other written or orally presented material. All personal data is anonymised within the thesis and when the information is used for feedback to participants, reporting, conferences etc. If quotes are being used it is more difficult to promise total confidentiality, as the domestic and sexual violence sectors are relatively small and the champions and many of the professionals and activists are well known in both the violence and disability communities. Therefore, care has been taken to disguise (via the use of obfuscating letters and numbers) the people who might most easily be identified by the tone or content of their words and certain information has been omitted from quotes in an effort to disguise place or organisation (Letherby, 2003).

- c) On a practical level, while this research was asking participants about ideas, theories and models, there will be people in all of the identified groups who have personal, family or professional experience of sexual and/or domestic and/or institutional violence. In order to ensure the safety of these people during and after the interviews or focus groups, information about local specialist violence counselling services was available to all participants so that support could be accessed if required. No participants accepted this information when it was offered.

Ethics approval was sought through the University of Auckland Human Participants Ethics Committee and approved on 26 July, 2013.

Data collection methods

The aim of research is to increase knowledge. All processes in research are value driven – the choice of topic, the way information is collected and the processes of analysis are all driven not only by the dictates of a particular discipline but also by the political purposes and goals of the researcher and the environment within which they are operating (Baker et al., 2004). Therefore, as part of the production of knowledge, it is critical that researchers can name and defend the frame that they use to seek and analyse information (Caelli, Ray, & Mill, 2003).

Feminist, anti-discrimination, egalitarian and emancipatory research methodologies do not prescribe any particular methods, but invite the researcher to use the tools that will elicit the most useful information and conclusions. It is the process of using these methods that is important – to be guided by the underlying philosophy of the methodology, to be reflective and critical throughout the process (Ackerly & True, 2010), the partnership that is established with the community being investigated and who the results of the research benefit – the researcher or the researched (Baker et al., 2004).

Methods used in this research process are: literature review; collation of materials from participants; semi-structured interviews; focus groups; and Official Information Act (OIA) requests.

Literature review

The initial literature review provided a foundation for my research by outlining the research that had already been done in the field. It also broadened my perspective on the research topic and suggested directions for questioning during data collection. Once the data from focus groups and interviews had been gathered and analysed, I went back to the literature to re-examine the conceptual models, previously identified, and to interrogate and define, more clearly, the information generated by the data. This required a rewriting and rethinking of the literature review – to ensure that it underpinned the material I was examining and the theories and methodology I am using in my work. It also entailed including literature within the findings chapters, to underpin and reinforce the participant's words and ideas and my own interpretation of that data.

Material provided by research participants

Representations of models and other literature were elicited from interview participants to be evaluated as part of the analysis of the models and paradigms arising from the interviews. Material collected was:

- Literature, mostly about the abuse of older women

- Organisational values and aspirations
- Service-related brochures
- Evaluation of services
- Brochures about abuse
- Information about human rights.

This has been incorporated in the following ways. The literature has been used when it illuminates, develops or explains either the literature review or findings. The information about organisational values and aspirations has been incorporated into the analysis of values and paradigms. The service-related brochures and brochures about forms of abuse have been used to inform the findings or the literature review. The information about human rights has been read, but has not been incorporated, as this area of research has not been pursued in the findings and discussion. (See Appendix 4 for a full list of material gathered from participants).

Official Information Act (OIA) requests

Material was requested via three OIA requests when it was pertinent to the research. The information requested was:

- February 28th, 2014. To the Police: Information was requested pertaining to the change of police policy regarding how assaults or abuse between flatmates and/or those in a wider (non-familial) domestic relationship are dealt with as a crime and no longer as domestic violence as described in the Domestic Violence Act 1995. The purpose of this was to discover why the circumstances of many disabled people were being excluded from police enforcement of the Domestic Violence Act, although it is included in the definitions in the Act. No satisfactory response was provided, despite the intervention of the Office of the Ombudsman.
- October 28th, 2014. To the Minister for Disability Issues and Housing New Zealand: I requested information about why Housing New Zealand was not upholding its obligations to provide accessible buildings for violence services, as HNZ is the landlord for many refuges, sexual violence and other violence services in the country. Initially my request went unanswered. I then wrote a follow-up OIA to the Minister for Housing (asking why my original request had not been answered), which resulted in a response to my original enquiry.
- January 31st, 2015. To the Ministry of Social Development: I requested papers provided to Cabinet about the costs of family violence in New Zealand, 2000 – 2015. The purpose of this was to get some idea of the costs to government of responding to domestic violence. This information was not released to me; however costs have since been released in the Government's

report on progress on the work plan for family and sexual violence
(Ministerial Group on Family Violence and Sexual Violence, August, 2015).

This material has been used in the findings, as appropriate.

Semi-structured key informant interviews

In-depth semi-structured interviews with people from the disability and domestic/sexual violence sectors, related government services and related Ministries, enabled participants to explore issues in their own words and from their own frames of reference (Henn et al., 2009). One-on-one interviews were used to gain an understanding of the participants' world-views (Liamputtong, 2013), in relation to domestic and sexual violence and disability, in a context that enabled discussion of feelings, doubts (Liamputtong, 2013) and ambiguities as well as the ideas and concepts that participants feel confident with, and expert in.

Semi-structured interview questions are primarily open ended (Creswell, 2014), enabling discussion and conversation. A pragmatic benefit of semi-structured interviews, in comparison with more quantitative methods such as questionnaires or surveys, is that they enable points to be developed or clarified during the interview process, and, if it occurs, straying from the intended questions to explore issues in more depth or to investigate ideas that arise as a consequence of the discussion - whereas with quantitative methods the questions are structured and rigid and do not allow for expansion of concepts. Furthermore, with questionnaires, case studies, vignettes etc., the parameters are set by the paradigm of the researcher, which means that research participants must uncritically, and often unknowingly, participate from the perspective of the researcher without the opportunity to contest or challenge the paradigm. This means that the bias of the researcher becomes an uncontested part of the research results, potentially replicating previously-held beliefs rather than challenging them (Anderson & Doherty, 2008). With semi-structured, open-ended questions the inherent explicit or implicit bias and assumptions of the researcher can be challenged and disputed by the participants, which can add extra depth to the results.

The interviews were undertaken to discover how each sector defines itself and the other sector, the conceptual models or theoretical underpinnings of their work, and to elicit information about where the barriers and potential congruence are between these sectors/ideas.

All interviews were recorded on a digital recording device and transferred to computer, prior to transcription (see transcriber's confidentiality agreement, Appendix 11).

Focus groups

Initially I intended to run up to 10 focus groups, as focus groups have a slightly different purpose to one-on-one interviews. A focus group is a gathering of people, who have some level of shared cultural or social experiences, to discuss a specific issue (Liamputtong, 2013). The benefit of a focus group is the interaction between participants, which enables issues to be debated and contested and may reveal hidden information that would not have emerged in a one-on-one interview situation (Liamputtong, 2013). Focus groups offer an opportunity for participants to express a diversity of opinions and can often illuminate cultural or environmental contexts.

However, focus groups did not work. It was too difficult for people to organise themselves to attend at times and places that I had arranged, rather than me attending times (and places) that suited my participants. I organised focus groups in three venues before deciding that this was not a constructive use of my time or that of the network coordinators involved.

Three people attended a South Island group, two people attended a North Island group and another meeting was cancelled as no one indicated that they could attend. Subsequently I attended one domestic violence network meeting with 10 participants, which functioned as a focus group. Otherwise I interviewed people individually, unless they chose to be interviewed together. This occurred a number of times. There were two situations where three people chose to speak to me together and six situations where I spoke to two people at the same time.

Interview questions

Interview and focus group participants were asked to examine these key ideas:

- How each person understands the issues they work with:
 - what philosophies, models and/or theories their work is based on – institutionally and personally
 - what their own political/theoretical context is – what is it that motivates their work in this field?
- How they understand the related issue (i.e. domestic and sexual violence for those in the disability field) and what philosophies, models and/or theories they think the other sector's work is based on.
- What they think the issues are at the intersection of disability and domestic and sexual violence.
- What they think the barriers are to collaborative work, policy and service development to address the abuse of disabled people – what attitudinal and other barriers they recognise in their sector and in the other sector.

- What they think would be a useful way forward to bridge the current communication gap between sectors to enable the issue of violence to be constructively addressed.
- What they think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused.
- What opportunities they have engaged with to learn more about the other sector and what has enabled or hindered this; if they have ever been asked to do any work to investigate possible service provision or other work in this area, or if any work has been carried out by their agency? (Full list of questions Appendix 12).

DVD was involved in the development of the research questions and methods via discussions about various issues that arose in my thinking and reading about the methodological process. The questions were also trialled with two potential participants. The initial questions appeared to obtain the breadth of information I was hoping for, so I started the interviews with the original questions. The questions stayed much the same during the interview process; however there were unexpected problems obtaining answers to some questions – and as the interview questions were intended to engage participants in conversations about the key issues I did add some concepts for discussion and slightly adapt certain questions to encourage more engaged participation. For example, I began by asking people how they would describe/explain disability/domestic/sexual violence (the work they were involved in). People told me what they would say without saying it – “I’d tell you it’s...”. So I tried telling a story about how they had just met someone at a party who asked what their job was, then asked for an explanation of what the terms mean – i.e. domestic/sexual violence, disability – and how they would tell them. People told me they did not talk about their work at parties. Then I tried asking people to explain it to me as if I knew nothing about the subject. People told me I was lying, that I did know. So then I asked people to explain it to me as a layperson. This means this question had variable responses. So some questions were reframed and other ideas were added as participants discussed things. I didn’t initially ask about myths about disabled women and feminists, however I included this question as myths had arisen in a number of participant interviews and I wanted to explore what was meant by it. Also, as I thought about the responses that I was getting, I recognised that some participants were answering from a position of understandings of either disability or violence that was based on myths and/or stereotypical beliefs. Therefore the question “Do you think that societal myths and misunderstandings about disability/feminism prevent people engaging with the issue? What sort of myths/misunderstandings would this be?” was added to the list of questions.

Initially I asked all participants questions about their services in relation to policies and training. However, as the interview process progressed, I focused less on these

questions and more on eliciting information about values and paradigms, as so few participants had ever engaged with the issue before. The question about possible new concepts to link the sectors has not been explored in the findings, as very little support or understanding for these concepts, particularly human rights, emerged in the data. Most people indicated that they enjoyed discussing the issues and being asked the questions because it gave them time to think about the issues and articulate their ideas. Many of the interviews were conversations, as I was able to share information as I gathered it, and to ask about it and discuss it.

Recruiting participants

There were two rounds of recruitment. Initially I approached the coordinators of formal sector networks in the towns that I wanted to work in, discussed the scope of my research and asked if they would facilitate the recruitment of participants. These contacts were followed up by email and phone, to enable discussion and allow me to answer questions about the research, the interview process, who I was hoping to interview, and for us to agree when I would come to the particular town (outside Auckland). This discussion also included whether the coordinator wanted me to run workshops about disability and domestic violence when I was in the town. If she supported the research, the coordinator of the sector network invited all network members to participate, via letters and announcements at meetings. The letter that was distributed included the participant information sheet (see Appendices 5–10 for participant information sheets, invitation and related letters). Those who were interested in participating contacted me by email or phone. I responded by email and at least one phone call to answer questions about the purpose of the study, how I intended to use the data, when I was visiting the town, when and where the interview would occur, and to obtain verbal consent. Prior to commencing all interviews, any further questions about the study and its purpose and use were answered and written consent was obtained.

This initial process had varying degrees of success, depending on the network coordinator and the interest they had in the research project, and resulted in approximately 40 participants around the country. However, it did not recruit nearly as many, and as diverse a range, of participants as I wanted to interview. The second round of recruitment involved snowballing (Liamputtong, 2013), drawing on the networks and connections of those already recruited, and also using my own connections to investigate other formal networks that I had not had access to. For example, talking to people in the violence sector that I had already contacted in a town to find out if there was a disability sector network and who I should contact to begin the process of recruitment in their sector. This was much more successful than the first round of recruitment as the people referring me to the next round of networks knew who I was, were already interested in the research and workshops

that I had offered to facilitate, and I could use their names, with their permission, to introduce myself to the next round of coordinators.

It was my intention to engage with Pacific and Maori services but some did not respond, despite numerous follow-ups and others, who did indicate a willingness to participate, just were not available when I went to do the organised interviews, as they were busy somewhere else.

Participants in the key informant and focus group interviews were:

- managers and/or staff of domestic and sexual violence services
- managers and/or staff of disability services
- managers and/or staff of disabled people's organisations
- staff from relevant government agencies and ministries
- past and present members of voluntary groups working at the interface of disability and domestic/sexual violence. These groups are the (now defunct) Disability Coalition Against Violence (DCAV) and the Auckland Disability and Domestic Violence Working Group (DVD).

This group of participants is deliberate (Creswell, 2014), as it is not lived experience of either disability or abuse that is being investigated, but the way that those who work in the sector or related Ministries conceptualise the area that they work in and, as a consequence, how they make decisions and prioritise the inclusion or exclusion of the abuse of disabled people in their thinking and planning. An important process in the research was the development of a relationship with participants that valued and recognised them as experts in their field who could help to illuminate the issues being investigated, rather than being either the victims or cause of violence against disabled women. No one who offered to participate in the research was excluded, as everyone related to the sectors being investigated was presumed to have knowledge relevant to the enquiry.

Temblay (1957, p692) identified five characteristics of an 'ideal' key informant. These are:

- Role in the community: the participant's role in the community must expose them to the information being sought by the practitioner
- Knowledge: in addition to having access to information, the participant must have absorbed it in a meaningful way
- Willingness: the participant must be willing to communicate their knowledge and cooperate with the researcher
- Communicability: the participant must be able to communicate her information in a manner that is coherent to the researcher

- Impartiality: the participant must present unbiased information – or must make their bias known so the researcher can take this into account when analysing data.

Of these, the first four are pertinent for this research. It is the participant's role in the community or sector and the knowledge that they have gained from this that is being investigated. Communication problems are not the responsibility of the participant – it was the researcher's responsibility to ensure that if adaptive communication processes were required, that these were enabled – for example, New Zealand Sign Language interpreters. Temblay wrote this list in 1957, when all research was assumed to be scientific and neutral. We now know that all research reflects bias and paradigms. In fact, if the participants were not biased, the interview process would not have produced conflicting and interesting data.

Venues and timing of interviews

Interviews were held between October 2014 and March 2015. The interviews took between one and one and a half hours each.

Interview venues were decided in two ways. I booked spaces for focus groups and participants attended at the prescribed time and place. However, as explained above, few of these occurred as it was difficult for people to fit around my timing. If the interviewees were in my home town I discussed a venue, date and time to suit the participant. Participants in other towns chose the time and venue to suit their situations (Letherby, 2003), within the parameters of when I was visiting their town. I organised the interviews to be held sequentially over a few days in each town. Nearly everyone was interviewed at their work place, however, seven people were interviewed in their homes and one person chose to come to my house.

Participant characteristics

Eighty-seven people participated in the research, in five towns and cities in the North and South Islands of New Zealand. They included:

- 23 people from the domestic violence sector
- 21 from the disability sector
- 6 from the sexual violence sector
- 14 from government agencies – Work and Income NZ (WINZ), District Health Boards (DHBs), Child Youth and Family (CYF), Human Rights Commission, UNICEF and the police
- 4 from services specifically for the elderly
- 5 from government ministries related to domestic and sexual violence or

disability

- 14 people who are activists at the intersection of violence and disability.

Social research is often exploring differences in experience of people by personal characteristic – Maori or Pakeha, able bodied or disabled, men or women. This was not the intention of this research, so very few personal identifiers were asked for. There was only sufficient information sought to enable me to differentiate between sectors (disability, violence, government, etc.), organisations and organisational position and a name of each participant in order to collect further information if required, to invite people to subsequent feedback and fact checking sessions and to provide them with a summary of the research when completed. I did note gender, as I was curious about how many men would be included in the research. Twenty-two of the eight-seven participants were male. I did not ‘count’ ethnicity, however a number of participants self-identified as Maori and there were participants who identified as being part of a minority ethnic group in New Zealand. Further increasing the diversity, a number of women in both sectors identified themselves as non-heterosexual.

Anonymity of participant information and identification of participant sector area specialisations

To ensure anonymity of participants, each participant is identified only by one or two upper case letters, and a number – for example, P1 or NP4. This disguises participants but enables me to individually identify people and correctly attribute their quotes. If there is a risk that a participant, or what they have said, might be particularly identifiable, I have attempted to obscure their identity further, using my code. To increase the depth of the data for readers, participants are also identified by the particular sector they come from. Therefore, as well as the identifying number and letters, participants were given one of the following lower case letters, directly related to their sector affiliation.

The decision about which of these to use is mine, based on people’s occupation and/or my knowledge of them. However, I did check with some participants as to which category they primarily identified with. This means that the identifying codes seen in relation to participant quotes in the thesis will, for example, be SE2v or D6m, with the lower case letter identifying sector affiliation.

- managers/staff of domestic and sexual violence services (v)
- managers/staff of disability services (d)
- staff from related government departments (g)
- staff from related government ministries (m)
- managers/staff of elder care organisations (e)

- activists at the intersection of disability and violence (a).

Data analysis methods

Having examined the theoretical underpinning of qualitative data collection and analysis, and reading the literature about emancipatory theory and research, critical social research, feminist research and interpretivist methodology, I investigated many qualitative data analysis methods. It was necessary that the method chosen for the research analysis invited a critical interpretation of data so that it would be coherent with the expectations of the foundational and interpretive theories.

Foundational theories - health promotion, emancipatory theory and intersectionality - *“shape the process by which enquiry is conducted* (Adams & Buetow, 2014. p. 100), and the interpretive theory, feminist disability theory, is the lens used to interpret, critique and examine the data.

The method for analysis of the data collected in this research project is a general inductive approach (Thomas, 2006), also called thematic analysis (Braun & Clarke, 2006). Braun & Clarke, (2006) and others (Guest, MacQueen, Namey, 2012; Liamputong, 2013; Thomas, 2006) say that thematic analysis is frequently used in social service and health research because of the insightful interpretations that it produces, but is often not specifically named, or it is called by more seemingly sophisticated names such as discourse analysis or narrative analysis while still using the analytic processes of thematic/inductive analysis.

Thomas (2006) describes inductive/thematic analysis as approaches that use *“detailed readings of raw data to derive concepts, themes or a model through interpretations made from the raw data”* (p238). It can be done from a realist perspective – giving voice to/reporting experiences, or it can be constructionist - looking at the broader context and underlying ideas within the data (Braun & Clarke, 2006). The method enables *“identifying and describing both implicit and explicit ideas within the data”* (Guest, MacQueen, Namey, 2012, p9) and *“interpreting the resulting thematic structures by seeking commonalities, relationships, overarching patterns, theoretical constructs, or explanatory principles”* (Lapadat, 2010, p926). As Thomas (2006) says, inductive analysis is not a linear analysis process but an interpretive one.

Thematic analysis has a number of benefits for this study. It enables analysis of large data sets (Braun and Clarke, 2006; Guest, MacQueen, Namey, 2012), which was necessary when examining 87 interview transcripts. It has a broad scope and is a very pragmatic method (Guest, MacQueen, Namey, 2012). Thematic analysis involves the researcher searching the data for important themes that are derived from close examination of the material in relation to the perspective of the researcher and

the context and paradigm from which the data is examined (Braun and Clarke, 2006). This is consistent with the theory-seeking approach described earlier in the chapter. It means that themes are generated from the collected data, rather than using the data to prove an existing theory or hypothesis (Ackerly & True, 2010). These themes are then used in the analysis (Liamputtong, 2013).

Finally, thematic inductive analysis encourages interpretation of data. According to Braun and Clarke (2006), as the development of the themes involves interpretative work, the analysis that is produced is not only descriptive, but already theorised. It is this final stage that allows leaps of understanding, supported by the data (Thomas, 2006). Without these interpretive leaps, the resulting analysis would be a documentation of opinion, rather than a critical exploration resulting in new insights and processes.

The method of thematic inductive analysis I am using is based on the work of Thomas (2006) and Braun and Clarke (2006) who have provided a clear methodical process that requires a number of decisions to be made as the analysis progresses.

The first question that must be addressed is whether there will be a rich description (Tuckett, 2017) of the entire data set or a detailed account of one particular aspect of it (Braun & Clarke, 2006). In this analysis I have chosen to describe the breadth of findings (relating to the entire data set) as they help to elucidate the key findings and theoretical positioning of the discussion. There is also a decision to be made between using semantic (explicit) or latent (interpretive) themes. I have chosen to describe both levels of findings as the semantic findings are interesting from a public health service and policy perspective, as discussed in Chapters 5 and 6; however, as discussed in further findings chapters, they obscure the underlying reasons, exposed in the latent analysis, for the lack of engagement with this issue.

I am describing the data analysis process as linear steps; however, it is never a straightforward process. It is “*recursive*” (Braun & Clarke, 2006, p86) moving backwards and forwards as the theory and data are examined and various stages are re-examined. My process involved six steps. The first four were data analysis processes; the final two were reporting processes.

Step one in the data analysis was transcription of the recorded data from the interviews and focus groups. Three paid transcribers were used and all sound files were transcribed verbatim. I did not make the transcripts available to participants to amend.

Step two involved my close reading of the literature provided to me by participants and the transcripts, and carefully listening to the recorded interviews and focus groups. Transcripts were read to make sense of the data, identify examples and descriptions of the models and the theoretical underpinnings of people's work and begin to generate ideas about themes that were appearing in the data. Using both the written and aural data, all the interviews were coded for meaning. Morse (1995) indicates it is important that at the beginning of the analysis process no data is discarded or ignored and that all data must be given equal consideration in the coding process. Coding was done with post-it notes, noting potential categories and confluence of ideas, both latent and semantic in relation to the research questions. These initial categories were constantly checked for relevancy, overlap and redundancy (Thomas, 2006). Once this coding was completed the relevant data sets were manually collated into named categories. As a cross check, quotes and ideas from all interviews were also manually collated under labels directly from the questions: (1) *motivation*, (2) *definitions of domestic violence/disability*, (3) *barriers*, (4) *outcomes*, (5) *values*, (6) *power*. Once this was completed the coding process was repeated. It was easier to see discrete ideas once they were separated from the structure of a transcript. This coding was integrated with the previous work.

Data saturation: Morse (1995) defines data saturation as data adequacy. This is achieved by collecting data until no new information is obtained. Fusch and Ness (2015) explain that this occurs when no additional codes can be identified (see also Guest, Bunce, Johnson, 2006). Tuckett (2017) clarifies this further by explaining that in qualitative studies it is not the amount of data that is important but the richness of the data that is collected – “*not the total counts but the detailed descriptions*” (p56).

This is the first study of its kind in New Zealand and therefore sets the foundation for further research in this area. This is one reason for interviewing so many people, as I was trying to capture a wide range of information in this initial survey of participants. Consequently, in this study, due to the wide range of knowledge, experience and the varied perspectives of the participants, saturation was not attained until I had analysed and coded 87 interviews, at which time no new categories (codes) were being identified. Once data saturation was reached, my plans to interview people from a further two towns were cancelled.

My intention was to analyse data from the three different sectors (sexual and domestic violence, disability and ministries/government departments). However, as I read and listened to the various transcripts I realised that the most interesting ideas were not between sectors, but across and within them; so the results have been

analysed and reported using this configuration, rather than as three separate analyses. (See Chapter 9, pp. 225-228 for a fuller discussion of this decision.)

Step three involved looking across the coded data sets for similarities and differences or “*repeated patterns of meaning*” (Braun & Clarke, 2006, p86), and developing initial and then more substantial themes. The themes were also checked for redundancy, overlap and relevancy and grouped into main and sub-themes (Braun & Clarke, 2006). It was important to ensure that the themes arose from the data, and not from pre-conceived categories or theories (Hesse-Biber & Leavy, 2007) or from the literature. The initial themes were, for example, (1) *socially sanctioned*, (2) *everyone thinks someone else has to do something about it*, (3) *silenced* and (4) *language*. I kept reading through the lists, looking at my original post-it note ideas and going back to the interviews to look further at the context of the quotes to see if I was missing critical ideas and how the information related. There was a vast amount of information, so I reread Braun and Clarke (2006) who suggested mind mapping the ideas to examine the connections between them. I also reread the wider methodology looking particularly at the information about semantic and latent themes, breaking down the surface of materials to examine deeper understandings and how to use ideas from feminist disability theory to investigate the transformational potential of the material. This resulted in more robust themes that were checked and revised in consultation with DVD.

Step four involved further analysis and interpretation of the themes to develop the underlying theory of this thesis – the “*development of a theory about the underlying structure of experiences or processes that are evident in the text data*” (Thomas, 2006, p238). This was the inductive part of the process – allowing the themes and ideas to synthesise, form patterns and intersect in previously unseen ways. My method of deeper analysis of themes to elicit the underlying causation and issues of power, identity, equality and oppression was somewhat idiosyncratic. Over a period of several months I would read and reread the emerging and identified themes, draw diagrams of the relationships between them and go back to the original transcripts to check context, then put a pen and notebook in my pocket and take Lily (the dog) tramping in the Waitakeres. I think best when I am moving. The tramping provided me with long periods of reflective time to think about the data and themes and to allow my mind to make new connections and uncover potential themes that I had not previously thought of or seen. These ideas were captured in my notebook and the investigative process would proceed with more reading of themes and drawing of diagrams. Drawing diagrams helped collate the material into coherent themes – showing where each part of the information fitted and helped the organisation of the findings into dominant themes and subthemes. The process resulted in the final themes and subthemes, in particular the various layers (semantic and latent) that were identified from the process. This is the process of inductive analysis identified by Thomas (2006) being used to “*unpick or unravel the surface of reality*” (Braun &

Clarke, 2006, p81) which resulted in the theoretical analysis described in Chapters 8 and 9.

This process, and the findings identified by it, are illustrated in Figure 4. There are four levels of findings. These move from surface level, material, pragmatic reasons; identified values and paradigms for work and practice; underlying more semantic reasons creating invisibility; and then on to the most hidden and conceptual underlying reasons for the ignoring of violence against disabled women and the consequent lack of response to the problem from all sectors.

4 layers of findings	
Pragmatic reasons for non-collaboration	Semantic analysis
	Resource and competency issues
Paradigms and practice	Semantic and latent analysis
	Individual deficit and socio-political paradigms
Exclusion	Semantic and latent analysis
	The process of exclusion and invisibility
Vulnerable	Latent analysis
	Paradigm that underpins the practice, paradigms and exclusionary practices above

Figure 4: Four layers of findings

An example of the various layers of interpretation possible from participant data is explained by a breakdown of how the four findings themes were developed. Each theme has been developed in a different way.

The first level of findings includes themes related to the pragmatic reasons for non-collaboration, and is developed from issues identified directly from the data. I provide, as an example, an explanation of the first subtheme – *Too hard*. In response to questions about their work, their understandings of the other sector and the relationship and/or barriers between sectors, participants discussed the lack of contact between sectors “*the disability sector is really insular*” including a perceived and/or articulated lack of knowledge of each other’s sectors “[working together] *would be a big learning curve*”. The lack of engagement was compounded by people in both sectors feeling overwhelmed by the high levels of work required in their own sector, exacerbated by low wages and insufficient staff and resources “*we don’t have time, we don’t have the money and we don’t have the resources*”. This

results in people feeling they have no capacity to learn about and engage with another area of complexity and “*it's just too hard*”, which I ultimately used to name the theme.

The second layer identifies participant paradigms and the practices that develop as an outcome of these. This theme is not identified directly from participant data. It is deduced from participant's expressed values “*some values in feminism*”, ideas inherent in the models “*medical model*” and theories “*Marxist thinking theory... social learning theory*” used in people's work and, for example, ideas that perpetuate stereotypes or the “*dominant metanarratives*”. There is also analysis of the language participant's use to describe their own practice, or use to describe the work of others in their sector. This includes comments such as “*one of them*” and ascribed motivations “*both fields attract rescuers*”. These various concepts coalesce into two overarching paradigms that are described - individual deficit and socio-political. Further analysis then identifies the practices related to each paradigm.

The exclusion theme is not developed by a process of counting the number of times a particular idea is mentioned (Tuckett, 2017), but from diverse comments coalesced into one coherent theme. For example:

- One person talked about the *controls on disabled people* and how they can spend their money.
- Another said that disabled people *are on a different racetrack*.
- One person said that *disabled people are objects not subjects*
- One person said disabled people should experience *inclusion not declusion*
- One person talked about the *lack of judicial and police responses to the murder of disabled people*, and this related to previous findings about the lack of organisational response to abuse of disabled people.

These comments were identified during the coding process when labels such as (1) *control*, (2) *lack of value*, (3) *social exclusion* and (4) *objectifying* were placed against specific quotes and ideas. As described earlier in the chapter, analysis progressed from this direct labelling to investigating how this diversity of ideas related to each other. During the process of inductive analysis the ideas inherent in quotes such as these united into a coherent theme.

The theme about vulnerability was identified in a different way from the preceding three themes. Vulnerability, or the use of the word *vulnerable*, was a very consistent concept in participant data, which lead me to investigate how the word was used and the contexts it was used in. This stage of the analysis identified various understandings of the word and different ideas connected to the use of the word or

the concept of vulnerability. From these, various subthemes were identified. These are:

- Dis/abled women are socially constructed as vulnerable
- Vulnerability is not inherent
- It is inevitable that vulnerable women will be abused
- Predators seek out women perceived as vulnerable
- Society doesn't protect those who are constructed as vulnerable.

This is a different way of coming to a theme. It is not diverse ideas coalescing into one theme, but one word that diversified into several subthemes in order to understand its use across the data set.

In summary, 4 major levels of themes were identified through the analysis:

- Theme one is surface issues identified directly from the data
- Theme two is paradigms identified via, for example, language, verbalised motivations and the models, values and theories expressed and described by participants.
- Theme three developed from diverse comments and ideas that coalesced into one coherent theme of exclusion.
- Theme four developed from one idea of vulnerability that was frequently encountered across the data set. Examination of this word identified diverse meanings and concepts within the idea that were extrapolated into subthemes.

It is these various levels of thinking and analysis that inform the presentation of the findings in the following chapters.

Step five. Once this thematic analysis had occurred, I reported the draft findings and my ideas about how I wanted to pursue the concepts from the data, to DVD. I incorporated their feedback, which confirmed the direction I wanted to take in investigating the data, then went back to the locations where I had collected data and gave six seminars about the findings, including facilitating discussion among participants. There were two presentations in Wellington, one at the offices of People First, a Disabled People's Organisation (DPO) and one at MSD. A total of 17 people attended these two seminars. There was one seminar in the regional North Island town where I had conducted interviews – 19 people attended. There have been three seminars in Auckland, two at the Auckland Women's Centre (one at the Auckland Central domestic violence networking meeting) and one on the North Shore at the North Shore domestic violence network meeting. 30 people attended between these three meetings. At each of the seminars, people who I had interviewed attended – but so did others who were not participants but who were

interested to listen to the information and participate in the discussion.

Key outcomes from these discussions were a confirmation of the investigation of vulnerability; discussion about the learnt behaviour of compliance – and disabled people’s fear that they will lose what they have got if they talk about abuse or other things; internalised stigma; the dignity of risk versus protecting people; questions about how my ideas relate to international literature and cultural competencies; a suggestion that I examine the language of altruism such as helping and rescuing that philanthropic societies use; and the lack of any mandatory training and standards related to abuse and/or disability in the violence and related social services.

Participants felt that social work and counselling degrees were still orientated around the evidence-based medical model and were increasingly depoliticised. These discussions have been incorporated into the findings.

I have also presented the information at six workshops for students training in violence studies. I have not presented the information back to participants in the South Island, as the network coordinators, when contacted, have not expressed interest in this occurring.

Step six. The final step is the writing of the thesis in a way that “*tells the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis*” (Braun & Clarke, 2006, p93). During the process of writing up the results of the research, the conclusions formed were considered alongside the theoretical underpinnings of the study as identified in the literature. This “*helps to contextualise our results as well as confirming or challenging existing theory. Without this discussion, our results become isolated and have no relevance to the body of knowledge to which we are seeking to add*” (Henn et al., 2009, p282). It also helps to make sense of our data, by relating it to previous work (Henn et al., 2009). However, it is important to emphasise that the themes and subthemes that I am writing about have arisen from the data in the manner described above, not from the literature and being retrospectively identified.

Ensuring rigour

Liamputtong (2013) describes a number of strategies to ensure rigour in research projects. These include:

- Rich (thick) description
- Interpretation and evidence
- Reflexivity
- Triangulation
- Member checking

1. *Thick rich description.* This, if achieved, occurs during the writing process – ensuring that the information provided about the process of carrying out the research clearly describes the choices made, methods used and the rationale for the methods, problems experienced and overcome, the relationship of the researcher with the reference groups and participants, any issues that emerged and the experiences and relationship that I bring, as the researcher, to the data and the analytical process (Curtin & Fossey, 2007). I have attempted to fully explore these issues in this chapter and the findings chapters – making the process of analysis and the data and themes uncovered through this process explicit.

2. *Interpretation and evidence.* My own biases in interpretation of the material have been examined by DVD and in this chapter. In the findings chapter, verbatim quotes from participants are used to exemplify and support my findings.

3. *Reflexivity.* Within an emancipatory methodology, reflexivity has two meanings. One is the role of the researcher to illuminate the contextual ideologies, processes and political environments that oppress and constrain the populations that are being researched, and the imbalances of power that are inherent in their relationships with institutions and wider society (Henn et al., 2009). The other is ensuring that she make her own paradigms, beliefs, personal history and relationship with the research population explicit, in order to determine personal and intellectual bias. The processes of illuminating the context of the research and findings have been incorporated into the literature review, method chapter, findings and discussion as they are inherent in what is being investigated and how this is conceptualised, how the data has been understood and the themes and constructions that have emerged from the data. My own positioning is most explicit in this chapter, as I discuss my perspective in regards to emancipatory processes and my right to research and speak about this subject and in the literature chapter that outlines the overarching theoretical background of the research.

4. *Triangulation.* In order to ensure rigour in the collection, interpretation and analysis of qualitative data, data should be gathered from more than one source, use more than one method of data collection, and/or involve more than one method of analysis (Curtin & Fossey, 2007). This data uses triangulation of sources (Patton, 1999), person and space (Curtin and Fossey, 2007). Source triangulation is the examination of information from different sources (Patton, 1999). In this study data was gathered from people working in a variety of situations across the relevant sectors, all of whom bring different points of view and differing perspectives to the subject being examined (Patton, (1999). Within this is also person triangulation – the gathering of data from people working at different levels of the organisations or sectors being investigated (Curtin & Fossey, 2007). People interviewed in this research were managers and staff at various levels of service provision and

government. All of this data was then analysed in relation to the material provided by participants, information from the OIAs and the relevant literature. So four sources were triangulated. It also uses space triangulation (Curtin & Fossey, 2007), the gathering of data about the same phenomena from two or more settings. This data was gathered from numerous sites in each of five geographical areas.

5. Member checking. This research began from discussions within DVD about the apparent lack of connection between the disability and violence sectors. They were involved during the development of the interview questions and formally and informally during the analysis process. When analysis had been completed, and my initial themes, theories and conclusions formed, the thematic material was presented to DVD, other activists and research participants for feedback and to enable debate about my conclusions. The information gathered from these meetings was incorporated as data. This enabled a richer final set of conclusions through direct questioning and challenging of my interpretations and the opportunity again for different perspectives and points of view to be included and examined.

Conclusion

This chapter first discussed the theoretical underpinnings of the research project, which is emancipatory, using feminist disability theory as the specific theory against which the data is considered, and then detailed the methods used in data collection and analysis.

The theoretical framework used to analyse data enables the information provided by participants to be understood from both a semantic and latent perspective. It is this lens that has informed the four findings chapters. Each chapter describes a deeper layer of analysis of the data, beginning with the most pragmatic, material level of responses and progressing through the levels I identified in the diagram on page 89. Chapter 5 examines the pragmatic resource and competency responses; chapter 6 identifies values and paradigms and the implications for practice; chapter 7 examines underlying, more semantic ideas that create invisibility of dis/abled women; and chapter 8 is the most conceptual, investigating vulnerability, which is at the heart of my thesis.

Chapter 5

Too hard, not my problem, not a problem: Pragmatic reasons for non-collaboration

Introduction

This is the first of four results chapters. Findings from this research indicate multiple layers of reasons why the disability and domestic/sexual violence sectors are not communicating about, or working together to address, the abuse of disabled women. This chapter examines the semantic findings – pragmatic resource and attitudinal reasons for the non-communication between sectors. Chapter 6 examines the values, theoretical underpinnings and paradigms that people hold in relation to their practice and how these manifest in good and poor practice. Chapter 7 looks specifically at exclusionary practices identified in the data, and the impact this has on the sectors and on disabled women’s ability to be safe from violence and supported to seek help. Chapter 8 examines the underlying reason for the lack of resourcing in the sectors and the exclusionary practices and attitudes that disabled women encounter. I interrogate the construction of the concept of vulnerability and how this enables those who are perceived as vulnerable to be ignored and unprotected by legislation, practice and policy. It also produces, as a consequence of this lack of structural protection, powerless dis/abled women, who are available to those who predate on powerlessness.

In this chapter I first discuss the various levels of interaction between the violence and disability sectors – the level of dis/engagement and knowledge of each other’s sectors, values and practice and how this affects possible interactions. I then examine the other identified themes which have arisen in relation to the question participants were asked about barriers to the domestic and sexual violence and disability sectors working together to address the high rates of abuse of disabled people. A common response was “it’s too hard” and/or “it’s not my problem”. Three key themes and six sub-themes describe these responses (Table 2). This level of analysis uncovers the lack of value given to dis/abled women and the role of caring and enabling within the community; the resulting poorly funded, under-resourced services; the lack of mandated qualification requirements for people working in the violence and disability sectors; the lack of service specifications directly related to the prevention or identification of the abuse of disabled women; the lack of information and understanding about the abuse of disabled women; and the inaccessibility of the various services. The themes are addressed individually, but are highly interrelated.

Table 2: Themes and sub-themes that have emerged from analysis of service level responses

1. Levels of interaction between sectors
2. Too hard <ul style="list-style-type: none"> • undervaluing of the caring role in society and the consequent under-resourcing of the sectors • lack of mandated training, qualifications and service specifications • fear of working collaboratively
3. Not my problem – not a problem at all <ul style="list-style-type: none"> • not believing that disabled women can be/are abused • hiding behind poor legislation or policy
4. Lack of service accessibility including physical environments, information, communication and support <ul style="list-style-type: none"> • no shared language and concepts • how language is used to minimise and hide abuse.

Levels of interaction between sectors

A number of researchers (see for example, Frawley et al., 2015; Healey et al., 2013; Murphy & Fanslow, 2012) identify that cross-sector collaboration between the violence and other sectors is considered to be an important element of effective outcomes for abused women. Collaboration involves sharing knowledge, resources and activities between two or more organisations, with the intention of mutual benefit (VicHealth, 2011). For both the disability and violence sectors this requires recognition of the abuse of disabled women and girls as significant, and part of their core business. However, this cross-sector collaboration very rarely occurs in practice (Frawley et al., 2015).

Boon, Verhoef, O'Hara and Findlay (2004), addressing relationships between medical and related health professionals, offer a seven-point continuum of relationships from parallel to integrative. This model defines parallel process as individual practitioners working in a shared setting with their own practice – the non-coordination model (Boerma, 2006). The relationships become more entwined along the continuum to integrative, where practitioners, both medical and non-medical, work in a non-hierarchical environment based on specific shared values, consensus building and mutual respect (Boon et al., 2004). My research identifies that currently the violence and disability sectors are working in parallel. A number

of participants identified various levels of ideal or potential participation between sectors, but very few of them were actually doing anything to initiate these processes. There are collaborations occurring in some areas, but these are person-specific and may not continue when the individuals concerned leave their positions.

The process of relationship development, with an aim of mutual capacity development and developing inter-sectorial relationships (VicHealth, 2011) was the level of engagement described by some participants; note, however, that this is describing what should happen – not what is.

The first thing is that we have to come together and somehow have a conversation but sometimes meetings just turn into meetings that aren't always productive. So it's somehow inviting the sectors to be a part of each other's world in some way. And whether that's sharing of knowledge and information, whether that's being committed to working together and advocating together, in the political arenas or communities, being present in that kind of way, I think that's a good...that's purposeful, and not just having a meeting to think okay now what are we going to do next...So there's things that I think each sector can identify... (A1v).

The overall finding from this research is not just that cross-sector collaboration is not occurring, but that the sectors are not talking to each other at all, unless specific individuals initiate conversations. Within this, specialist sexual violence and (some) aged care services that I spoke to were doing slightly more to be inclusive of disabled women than their colleagues in the domestic violence sector. Those working in both sectors in smaller towns had much better relationships between and across sectors than people who worked in the three larger cities. This quote is from a participant in a small town.

Yes, we would work with the Women's Centre maybe, or we have a male room here if it's a male who's being abused; and that can start it off with somebody just gently, somebody who is trained and knowledgeable gently talking through what's happening to help the person to actually just straighten it up in their own mind; sometimes that's needed before you start the official channels. I mean it very much depends what it is...Police if that's necessary, CYF if that's necessary, Stopping Violence services; we've got a route through to behavioural management services; basically whatever the need is we will source what the official line is when the person is at the stage of wanting to do that (B1d).

However, for many participants, the sectors are seen as mutually exclusive which results in both sectors having a lack of awareness and knowledge of each other's services (identified in the interviews) and an almost total lack of interest in each other, indicated by the lack of any formal or informal interactions or networking between sectors in most places.

The following quote identifies a number of recurring concepts that underpin the lack of connection between the services. This includes each sector seeing the other as unimportant and the insular nature of the sectors. It also identifies a number of reasons, explored in the next chapters, as to why this is occurring, including the lack of acknowledgment of violence against disabled women, belief in the asexuality of disabled people, and the lack of knowledge about disability and abuse in the violence sector.

I know the disability sector is really insular. So...you could work in the disability sector for your entire life, and work in five agencies that do, you know, remarkably the same thing....I mean, obviously there's the barriers of access. But those are people experiencing abuse. But in terms of talking... I think the two professions haven't connected. I don't think that either profession thinks the other is important. I think that because the disability sector doesn't believe ...that there's violence, you know, it's a bit like thinking that disabled people are asexual, so therefore if we're all asexual we don't have sex so therefore we can't get abused. And, yeah, I think the domestic violence sector is the same as other parts of the community that don't know about disability. It's like, oh, so do they, do they get abused? (GR2a).

As identified in the previous quote, the sectors are operating very much autonomously. This participant identifies that while the motivation for working in the sectors may be similar, each sector becomes very focused and specialised and does not take the time to connect with the other sector in either practice or knowledge.

I think that there's similarities in some ways around people wanting to be involved working with people and what that actually means and the things around that, so I think those are the similarities. I think the ideas around the specialty, so we can get quite narrowed and focus on certain things which then can prevent us at times to look at broader issues or how the intersectionalities actually do occur and exist. And I don't think we, either sector, always does a good job at that. And I think at times...it's also what we put forward. So our priority is sexual violence and we can say [unclear – it crosses all over?] and we can mention that, but I don't know we always do a good job at bringing up the others. Where, I think in the disability sector

it's very much the disability is the forefront but not always the sexual violence or other types of violence that are there (A1v).

Overall the feeling from the disability sector was:

...there's just one more issue to have to think about and it's hard and I don't think that the violence sector comes and meets us half way and we get tired of meeting them half way, you know. And they are reinventing the wheel, so I think there does need to be a structured approach. Structured, systemic approach (R3a).

As well as comments within the interviews, such as those above, where a lack of interaction was identified, I asked participants specific questions to elicit their own or their agency's involvement at the intersection of the two sectors. The questions asked were whether the organisation had done any work to investigate possible cross-sector service provision or related work; what, if any, policies the agency had to respond to allegations of abuse from disabled people; and what opportunities individuals and services had been offered to find out more about this intersection. Most participants answered negatively to all these questions.

DH: So have you even been offered training at that intersection of domestic violence and disability? Or run it yourselves?

MD4g: No.

M2s: Don't remember anything.

ME3v: No, I don't think so.

DH: No? And...have any of your agencies initiated work on it?

MD4g: Not specifically, no.

M2s: No.

If people had done any work on the issue, it was mainly attending a presentation or workshop that either DVD or I had run in the past.

DH: Have you ever been offered any opportunities to learn more about the issue of disability and domestic violence?

R5v: Not in this role, though I wouldn't be...oh yeah, sorry, when you presented, in the xxx, I went to that...So it was like, this is, came through the network and everyone went, gotta go to that...But it has to be, it comes from outside the organisation, generally, I think. There's not a lot.

Another question that indicated a lack of contact between sectors was enquiring what people knew about the values, ideas and models of practice of the other sector. Many of the participants said they had no knowledge at all. If they did have knowledge, it was often as a result of having worked in the other sector in some capacity – suggesting a similar motivation and set of values between the sectors, also identified by participants above.

Some organisations (domestic and sexual violence services mainly, as expected) had policies about disclosure but almost none, except (some) specialist disability services, had disclosure policies specifically about the abuse of disabled people.

Too hard

A common response across sectors was participants expressing that, as both domestic and sexual violence and disability are such huge problems – and they are already struggling to cope with one huge problem – that it is ‘too hard’ to learn about, and take on, another hugely complex area of work.

I mean if you're serious about working in the disability community, that is a huge amount of knowledge there, and every day you find something that you didn't know and you have to go and find it out. And so, and then you look at this other sector and go, that looks really hard and you're kind of scared to dabble in it because you go if I start dabbling in it then that's going to be enormous as well and I can't do two enormous things I can only do one enormous thing (NP2a).

The quote below identifies this main theme and also sub-themes that have emerged from the data, including lack of resourcing of the sectors and violence against disabled people not being seen as a big or important enough issue to require a response.

DH: So what do you think the barriers are to us addressing this [violence against disabled people]?
E2a: It's just too hard. [Laughs] You know, what it is about is...government philosophy and funding streams, you know...the problem isn't seen as being big enough.

Too hard is related to a perceived lack of capacity in both the violence and disability sectors.

But I think because of lack of resources and lack of capacity and all the other reasons why we don't...have those kinds of conversations to allow us to speak similar messages and keep messages consistent and be able to support each other in ways that we can (A1v).

This, and the following quote, explain the feeling that participants expressed of being overwhelmed by the amount and complexity of work they were doing in their own sectors with very little funding and human resources – and explains why they felt unable to contemplate learning about another huge issue. The participant below also identifies another common issue described elsewhere, that services will not work with disabled clients if they are not directly asked to do it – by either service providers or by government directive.

I think from our perspective, we see people with disability but we don't see people with extreme disability, where communication with them would be a real challenge. We have had hearing impaired people and we've had people with mental health challenges and intellectual disability, who have accessed our services, not a lot, but I can recall some clients who have had those disabilities. But I think one of the biggest things, while we are aware that that sector of society are more vulnerable and we don't actively pursue, how can we help, sort of thing, really is down to money. That we already hugely over deliver what we are contracted to do and just keeping our heads above water, if you like, and providing those services that it would be a big learning curve and the skills development that would be needed for us to engage with people who have difficulty communicating. And so it comes down to money and resource and training. I don't even know where you would get the training to – I mean in order to be approved for government contracts you have to be able to prove your ability to work with European people, Maori people and Pacific Island people and they are all a bit different, so you need to have tweaked your service delivery to cater for certain populations and this would just be another group that you would really have to be experienced and trained and familiar with how to engage and we just really, when I really thought about it honestly, we don't have time, we don't have the money and we don't have the resources. And we've never been asked, so we haven't gone looking (B4v).

You can hear the stress and exhaustion in the voice of this participant. Many service providers in both sectors are exhausted trying to run caring and effective social services for people who are not valued by society. It is understandable why taking on more complexity feels too hard.

The lack of resources identified in the last two quotes and the consequent lack of engagement are indicative of the lack of value accorded to the sectors – as women’s work and caring work.

Undervaluing of the caring role in society and the consequent under-resourcing of the sectors

[It’s] indicative of the stereotypes that come with women’s work – that if you’re in a caring profession that somehow you’re not professional, because the emphasis goes on the caring not the providing for...and I find it extraordinary, because as professionals we can care for our people (C1v).

This quote is indicative of two societal expectations related to gender roles: one is that caring in all its manifestations is women’s work, the other is that such work has no value, including refuting the possibility that those who provide caring and support work can be considered to be professional. As a result of these attitudes and the consequential low levels of funding available to the women’s violence sector, the NGO aged care sector and the NGO disability sector, services for dis/abled women rely on staff who either have some level of passion or ideological orientation to the work they do, or those who have very few other employment alternatives. Participants identified both these situations within the sectors.

Those who are driven by a passion for the work were described as “*Women, mostly...very committed, very focused, overworked, underpaid. Usually very passionate about what they do...*” (P1a). This reliance on commitment and passion, as opposed to well-paid, well-respected jobs, indicates a systemic lack of respect and valuing of the enabling/support role by successive New Zealand governments.

...I would say that nearly all of the staff are here for the clients...Certainly my social workers they’re definitely here for the clients, ‘cause I know what I pay them. I know my...coordinators are here, or one of my nurses is definitely here for the people...My day service people, who do day respite, they definitely do it ‘cause they like it, ‘cause they know they’re not going to get a fortune (C7e).

More concerning for clients are the staff for whom there are few other employment options and who have no choice but to work for the minimum wage. The participant below identifies that many people who work in the disability sector are very committed and passionate about their work – but that, due to the lack of options and low wages, there are others who are only interested in a job – who have no empathy

or commitment to the role. This participant identifies that services would be able to employ more qualified and engaged staff if they were able to pay more.

...I think if you're able to pay people better they'd be more likely to be interested in doing it for the sake of why the job is interesting rather than just to get the money...I think there are a lot of people that just do it for the money, do it because...it pays slightly better than a cleaning job...And actually that's what they see themselves as – somebody who's a cleaner with a slightly easier life... I get to sit around or go to the park occasionally rather than just cleaning...[discussion of low pay]...it's understandable that people aren't highly motivated necessarily, under those conditions...And I know from our personal experience as a family...at least half of the caregivers that support my sister are wonderful people, you know, really amazing, committed beautiful people who'd look after her very well. And there are some people who just are adequate, at best, and are not very interested – and they tend to drift away after a while, or get shifted around from place to place. But I think sometimes appointments are made on the basis of the best of a bad bunch, rather than not appointing at all. And I think that's unfortunate (L1g).

As identified by this participant, many rest home and other residential and home care service staff are not well educated, not trained and not well supervised. They are frequently alone with clients with no one to check on their behaviour. An example of this lack of capacity was participants who said that services are so stretched that they only work with people who present to their service; they don't go out and look for people or follow up those who fail to engage.

Well is it ignorance or lack of knowledge around the issues that the disability could be facing around abuse [or] is that we have enough work on our hands and we don't need to go digging for more (B2g).

The following participant investigates this concept via her ministerial overview of the domestic violence sector responses to people who fall outside of the easily accessed client group.

So...they wouldn't be seeing the people who don't access, who can't access their services. They wouldn't be seeing how they're not providing support in particular ways 'cause they're not out looking for it. They're only just coping with the ones who come into them and manage to get into their services. So they wouldn't be aware of, and they're not actively seeking to find out, who aren't we reaching, who aren't we supporting? Who are marginalised by not

only the violence and the system but by our services? ...I think that domestic violence services are feeling so overwhelmed and swamped and underfunded...they're just working with what's in front of them, really, and not even thinking about what else could we do and how could we improve? Say for example, if they've gotta follow-up on twenty different families from FVIARS⁵, and they find one family that's hard to engage, they just don't. 'Cause they just [unclear] have the time, so they don't bother putting the, well they can't, or they don't, put the extra effort in to engaging that family, for whatever reason is keeping them from taking out the offer of support...So they'd never find out why they weren't a good service, or why they weren't accessible, or why they weren't approachable, or why they didn't meet the needs of that family. 'Cause they'd just focus on the ones...they were able to engage with. Yeah, so it's a kind of a matter of not hearing, or not even seeing...what they're not covering (S1m).

The participant below identifies that their service is waiting for women to present, as the numbers of women who need their services already overwhelm them and they are struggling to keep their service afloat.

...the barriers around that as well for me is just the, just keep doing the work, you know, just like head down, tryna have the funding and the contracts, all that stuff sorted. But I realise we are missing a lot of people. And it came, someone asked me at the People First meeting, so do you all go into residential facilities, how do you create conversation with people who are there, because if they're not people who are willing to call or maybe not have access to a phone or whatever it might be – then do you go? And it's like no we don't. So we're very much an agency that sits here, and we need to think about our mobility but then again it comes back to resources (A1v).

As a consequence of lack of resourcing and feeling overwhelmed by the service outputs they are expected to achieve, many agencies are working only with those women who present to their services. However, this lack of engagement could also be a result of the lack of expertise in the sector, identified below.

Lack of mandated training, qualifications and service specifications

There is a feeling that the expertise of those able to be employed in both sectors may be dropping, partly as a result of the wages being so low and partly as services change because of changing government contracting requirements.

⁵ FVIARS – (NZ) Family Violence Interagency Response System

...the workforce in the sector is...very low-paid, there's a high turnover, it's undervalued...so all those things mean that not everybody at the front-line is going to be as well-trained as we would like them to be (C2d).

This results in people entering both sectors, and continuing to work in the sectors, without the underlying values and knowledge essential to provide empowering, safe and constructive services to their own clients, let alone having the skills and competency to work across sectors.

I think professional capacity is a biggie. It can be really challenging for professionals in professional settings to put their hand up and say, actually I don't know about that stuff or I don't have good awareness or I need to know more about that stuff. I think there is a certain amount of head nodding that goes on and certainly if you have worked in the sector for a long time, there is almost an assumption that you have a skill set and so often at meetings or hui, people will assume there is a certain level of knowledge. But often many people in the room will not have achieved or aspired to the level of knowledge that has been assumed (C1v).

The lack of qualifications was identified as indicative of the low value placed on the sector.

...but I wonder if that's seen as even a less than kind of role and then we don't even have a disability studies, tertiary qualification in NZ, so that just says something, we don't even know what that is, we don't even look at that, so disability is so, kind of, low down (S6a).

This lack of adequate, specific, education for many of the people who engage with abused women and perpetrators is one of the reasons for the poor practice identified in this study (see next chapter).

Fear of working collaboratively

The lack of funding and increasing competition for funding and resources creates a fear of working collaboratively. There is a perception that if services do not fiercely protect themselves they will lose funding and be unable to function.

GB6v: I think the way that [government services are] set up, it doesn't really encourage cross-sector collaboration.

GQ5v: Yeah...It encourages competition. Encourages...organisations to be quite inward in how they're specialised and what they can provide that's different, because we're in a position of putting tenders out for the funding. Whereas if our funding structure was set up to recognise...the complexities and need for multiple different niche services to be involved, I think...that we would be benefited by coming together more than we currently are.

This results in organisations isolating themselves from others working with the same clients, which significantly reduces the opportunities for developing cross-sector responses to violence and abuse.

We tend to work a lot in isolation...because we're in the competitive funding environment, you do tend to work in isolation unfortunately. Funding that people get isn't conducive to making collaborative relationships. It's dog eat dog; 'cause if you get the funding it means I might have to let somebody off, so therefore I want it; and I don't care if I shaft you. We're not as bad as it used to be. We've got some very good relationships now...We try not to compete for funding that other people are competing for...If we say we can do it, and start to, all we will do is nick staff off them; who's going to suffer? Their clients. It's pointless. And there's a few of us are happy to do that. But generally it's still an exception in a competitive environment (C7e).

Not my problem – not a problem at all

A number of participants told me that there was no need for their service to be accessible, as there were no, or very few, clients who would require such a service. Under-resourcing and under-capacity, lack of recognition that violence against disabled women is domestic or sexual violence, and services working only with easily engaged clients, results in people working in violence services and police never or rarely encountering abused, disabled women, as these women rarely ever make it to their services. If they do, they are referred on to alternative services, for example, Age Concern for older women or health and disability services for disabled women, without considering their own responsibility to these women.

Compounding this abdication of responsibility was the frequent comment (again from both sectors) that if the other sector wants to engage with us about violence against disabled women, they need to approach us – it is not our job to reach out to them.

One of the family violence managers said, when I started this project... 'well if disabled people want to have more access to the services, they need to campaign for that' (C3v).

The same comment has been made from government.

I think it would be really helpful if, the best way to do this would be through D.P.Os⁶ themselves making a fuss about it. Like People First, like D.P.A⁷., like Blind Foundation. Like all of those agencies that represent people with disabilities, if their voice was out there saying this is a problem for us, it's quite a quiet voice, it doesn't hit the newspapers very often. I really think that the United Nations convention gives them a platform that they can stand on, now, because we've signed up to it and they can say, look, here's this article whatever it is that says that people have got to be safe. They've got a tool that they can use. I think they need to speak more (B1m).

From a health promotion, social justice perspective government should be taking a lead on this, not expecting disabled people (those who have the least voice and resources) to lobby for rights that other sectors of society take for granted – especially given the government's responsibility under the UN Convention on the Rights of Persons with Disability (United Nations General Assembly, 2006).

One participant from the government sector identified that the abuse of disabled women was not a priority for managers of disability services, as they were more concerned with meeting contractual outputs and managing budgets, than the safety of their clients.

I think at the end of the day, managers are managing to a budget. That's what drives them. They're managing to the bottom line. They have to make it work. And it's really a difficult sector to make things work in. It's hard at the best of times and if you're a manager you're going to attend to the things that are up at the top of mind, and if abuse isn't top of mind it's just not gonna be there. There's so many other things to think about: compliance of standards; meeting your contractual requirements; actually dealing with complaints; and dealing with the day-to-day staffing issues and rostering and all of, you know, there's a whole heap of stuff that managers do. So unless it's forced to be top of mind, then it's not going to happen. And I don't think it's a blame thing. I think it's just the way it is... There's not enough emphasis being put on it by anybody (B3m).

⁶ Disabled People's Organisations

⁷ Disabled People's Assembly

This is compounded by the ongoing problem of managers not wanting to engage with the issue of violence because it is perceived as being complex and difficult – and once identified, has to be responded to. This is a barrier that people who work in the domestic violence sector often encounter in their interactions with non-domestic violence services.

C7e: In some ways I would be absolutely terrified of training our support workers in that [recognition of abuse], because we would suddenly end up with so much reporting. 'Oh Mrs Smith, I've seen her this morning and she's looking absolutely miserable, what shall I do about it', and it's like 'Oh my God, here we go, don't know, send out the coordinator and we'll have a, make sure she's OK'. We'd do it that way. Unfortunately often a little bit of knowledge is too dangerous.

DH: You mean people might pick things up that weren't there?

C7e: Yes.

This participant said that in their care-giving service for over 1000 elderly and/or disabled clients they would “*be lucky*” to see one case of suspected elder abuse a year. But, as identified above, they are actively not looking for it. The statistics from Age Concern previously described, (January to December 2014, 1,842 reported cases of neglect or abuse), suggests that the participant above would discover numerous cases within his client base if staff were trained to look for signs and screen for abuse.

If leadership and concern to identify and address abuse is not coming from management – and before that, from government - it is very difficult for staff to incorporate it into their day-to-day work – they may in fact get penalised for it, if it is not their job.

And if the organisation says, we want you to tell us, that's so powerful in terms of the staff knowing that actually this is not okay, even though it might seem okay within a little cohort of staff...It's at the management level that the difference is made. So unless the top manager is onto it, then nothing's going to happen. Unless the C.E.O. is leading it, it's not going to happen. (B3m).

Further, some participants expressed an organisational concern to prioritise staff safety over client's/resident's wellbeing. This concern for keeping staff safe means that potentially abusive situations will not be addressed, as staff do not want to confront people who they believe are “nasty” or dangerous. A manager of a service, talking about weighing up whether or not to intervene in a case of domestic violence

against a disabled person, decides that the safety of her staff is more important than the risks of intervention.

...I think too, dealing with the person, and I'm talking about Person B, who is known to be a very controlling, domineering abus-...vocal, nasty person, there's a very fine line between keeping yourself safe and keeping staff safe and being confrontational. And...well, we had to make some decisions in that area, focused on keeping staff safe, so that's all the staff safe, from someone who can be extremely nasty (J7d).

This is compounded by management and others, in this case the union, who are concerned primarily with the safety of their members. Interestingly, this participant identifies the lack of training in the workforce, which causes situations to escalate to abuse that may harm the staff member, but is equally (more likely) to result in harm to the disabled person.

I don't engage with people from the violence sector, as such. And there's a stigma, I think, associated maybe with the sort of, the violence thing in that, um, I actually, this afternoon I'm going to a disability safer industry forum. And the unions are quite focused on violence in the workplace. Now this is violence towards the workers. And it's not, it's not, I don't know how to say this very PC (DH. Don't say it in a PC way, just...) I won't say it in a PC way. It's not the image we want to project of our sector, that the workforce are exposed to violence. And in many ways, a really well-trained workforce by and large will manage those situations so it doesn't come to actually being violent (C4d).

Not believing that disabled women can be/are abused

A number of people interviewed identified an issue that disabled people feel is a common problem. Many people – those who do not work in social services or think about the issues of violence and abuse day-to-day – do not believe that disabled people are abused. One interview participant clearly articulated this as their own point of view.

I was trying to think that, you know how it could, when you asked about disability what that's got to do with violence and I couldn't quite see the connection. Because to me a disability is, you know, well, actually the word itself means you're lacking in ability, doesn't it? So I don't know, to be honest I really don't understand how the two, I mean almost an oxymoron I would have thought, disability and violence. I don't see any connection (GM10v).

This lack of belief in a connection between disabled people and violence is a result of entrenched attitudes, values and beliefs about disabled people, including a subtheme that is explored in the exclusion chapter that dis/abled women are not seen as credible witnesses to their own abuse or believed when they disclose.

...often times the people with disabilities they're seen as asexual and so wanting to express a sexuality...what that might mean for them. I think a vulnerability can be if they come forward and say this is something that happened to me and I didn't like it or I didn't want it to. They're often not believed because of people's own misconceptions and stereotypes...[Unclear – Saying?] that couldn't have happened or if they're not able to articulate in a way that we often do and understand. If they aren't able to, yeah, if they're able to articulate in a way or tell someone right away then often times they just get kind of ignored or dismissed because...they're not often believed in those situations (A1v).

This participant expresses similar ideas, highlighting society's unwillingness to acknowledge that disabled women are abused.

It's a bit like when I was talking before about, you know, the disabilities, knowledge of the violence sector, and it's kinda like society doesn't want there to be violence...they cannot understand this violence. And...the only thing that's kind of probably more distressing than mainstream domestic violence is violence against impaired people. You know, so...society don't wanna own the fact people do that sort of shit. So then the effect of that is that the victims don't exist because people didn't do that...so that's kind of, that's a really big stumbling block (E2a).

Myths and stereotypes are strongly implicated in this lack of belief about the abuse of disabled women.

[I] think barriers in the disability sector, one is that we find it really hard to believe that people could be mean to disabled people so we just have this fantasied, idealised patronised, vision of disabled people that's often, you know, made into children and sort of – as if people are holier than something else, you know, there is kind of fantasy that disabled people are being wrapped in cotton wool and just protected and looked after and isn't that wonderful and what they need and how fabulous (S6a).

This participant identifies that the circumstances of disabled women's lives are not even thought about by non-disabled people.

...I'm honestly not sure that people give it that much thought. It's hard to imagine that if you spent 5 minutes explaining a situation to a person that knows nothing about disability and you said to them, look there is a young disabled woman with cerebral palsy uses a wheelchair, needs care to clean herself, shower, feed herself, gets support from an agency who provides 3 or 4 different staff members a week, who are earning about \$12 or \$13 an hour, most of them don't have any training, there's some vetting of their background but they're generally underpaid and under supported. Do you think that's a risk, puts that person in danger at all? I find it hard to believe that most people would say, 'no, no that's fine'. If they just spent five minutes thinking about it, surely alarm bells would go off. People get abused in the most public of institutions and it's hidden, you don't find out about it. This is home care or people relying on other people in power because they don't have their own power. So I don't think it's necessary...if there is a myth, it's a myth that's fuelled by ignorance and apathy, it's not an active dismissal, people just don't seem to think about it very hard. Which is remarkable but it's probably the case (D5d).

Strongly related to this, a number of people from both sectors identified that the disability sector does not necessarily recognise the abuse of disabled people as either sexual or domestic violence – so they do not seek information and support from these specialised services. The next two participants are talking about their own experiences; one was trying to find specialist support for an abused woman identified by her service, the other was talking about her experience of the lack of engagement by staff in the disability sector.

We knew of Elder Abuse, so that's a service set up for elderly people. To me there's nothing set up for younger disabled people...we asked social workers, working in the health er, the hospital environment...colleagues who may have dealt with similar situations...We felt a lack of knowledge in the sector. But now that I'm talking to you we actually didn't talk to an organisation...such as Stopping Violence or It's Not Okay⁸. We actually did not. That's one gap that we probably didn't go through to ourselves...Whether that's a lack of knowledge or a lack of willingness to, or

⁸ Family violence: It's Not OK. A New Zealand social marketing campaign to change attitudes and values related to the identification of family violence and encourage asking for help if perpetrating violence. <http://www.areyouok.org.nz>

ability to do any more, I don't know...Maybe we didn't really identify it as violence, and the word domestic violence (J7d).

The participant above did not identify the abuse of disabled women as domestic violence. The participant below talks about her experience of services not responding to sexual violence or referring to the specialist services.

I know that there are some really good workers out there, who work really hard to make a difference. However I know that there are still areas where abuse is happening, whether it's within the system or by an individual. So I know that there are things that can be done, and you know one thing that I know is generally workers in that area [disability], or even organisations, aren't willing to...get specialist help in when it's needed for individuals. And I'm sure there's many reasons for that; whether it's they don't know we're here, or whether something's happened and they're ashamed of it, or because there are inadequate services around sexual abuse for the disability sector. So although I'm sure there are many, many good workers out there, I think, and speaking from experience of a couple of cases that we've had come through, that there are still huge gaps where the mentality is that these human beings are less than others. Which I find quite offensive. But we have come across it... (S8v).

Hiding behind poor legislation or policy

Another aspect of participants believing it is 'not my problem' is people hiding behind, or constrained by, inadequate or non-existent legislation or policy directives. It is not my job because no one says I have to do it. As one participant discussed:

DH: So you don't screen [for elder abuse]?

C7e: No, that's not our job. Our job, we're contracted to the DHB⁹ to provide a service, clients are screened by the DHB for suitability for us to go and help them.

DH: Do they screen?

C7e: I have no idea. No, they don't. They never asked my mother in law when she got help whether she was in an abusive relationship. But then she was a solo person. They didn't ask her, again to the best of my knowledge, was the family abusing her in any way.

DH: So do you do any training about signs to watch for when people go into people's houses?

⁹ District Health Board

C7e: At the moment a lot of our work, our training is built around what legislatively we have to do. We have enough trouble keeping up with legislations; and there's a bunch of stuff we have to train to every year. So we have to do Treaty workshops, we have to do dementia. We don't have to do one on 'is a client having the crap beaten out of them?', or 'are they being pushed around by their relatives?' ...we don't train specifically.

Lack of service accessibility

As identified by a number of participants, there are differences between working with women with disabilities and working only with non-disabled women. Women may require physical assistance, interpreters may need to be booked, staff may need to develop skills in communicating with people with learning and other disabilities who communicate in non-traditional ways. *"Some people do not communicate at all and it's just a blink of an eye that will tell you all. Some people cannot hear and do not even have any understanding of sign language"* (AZ4v). While organisations may be willing to work with disabled people, often there is no one with the skills required. *"...they're just as entitled to help or support as anyone else...but it has to be done in a different way and that's where the sector struggles"* (S8v).

There are a number of access problems related to the use of interpreters. Interpreters are in high demand and not always available when required (Wilkinson-Meyers, Brown, Reeve, McNeill, Patston, et al., 2014). Usually they must be booked in advance (Wilkinson-Meyers et al., 2014) and this is neither possible nor feasible when a woman is trying to escape violence. Additionally, services may have to pay for interpreting services, as there is no specific funding for interpreting for domestic or sexual violence.

Interpreters often know the people, or the families of the people, they are interpreting for, so there are concerns about confidentiality, and also that they may be traumatised by the disclosures and discussion that they interpret.

...a lot of the interpreters know the families that they're working with, and so that creates quite an ethical dilemma around sexual abuse and sexual assault; and the other aspect of it is; for that interpreter do they have training around sexual abuse and sexual assault? Because potentially they're going to be hearing things that aren't very pleasant, and what training do they or what supports do they to be able to, kind of, hold that information and not be kind of traumatised? We don't want to traumatise someone else, the potential that they've had their own history (S8v).

Other access barriers to the use of interpreters are in the section about language, below.

A frequently identified barrier is the lack of physical accessibility to violence services. Most violence sector providers acknowledge that they do not have accessible services and that they do not know of any referral processes to provide services to disabled women.

I'm just thinking about our safe houses, for instance. We can't accommodate women with physical disabilities that go beyond having a walking stick or a crutch; we don't go much beyond that (J4v).

Again it comes down to, it would be great to see an accessible - I don't know if there is one - an accessible Refuge (GQ5v).

In her response to an Official Information Act request, the Disability Issues Minister, Hon. Nicky Wagner asserts that:

...as part of its provider approval process, the Ministry of Social Development seeks assurances from providers that services are provided from premises which are accessible to disabled people...(or) in situations where premises are not accessible, then providers are expected to have proper referral processes in place to ensure that a disabled person can receive a similar level of service in another location or from another provider....I understand it is Housing New Zealand Corporation's[HNZC] policy to consider each request for modification individually. HNZC will agree to modifications where these can be accommodated. However, some properties, for example because of the location, may not be able to become fully accessible. In situations where a property is not able to be made accessible then it is the responsibility for HNZC to identify another property for the provider. (Personal Communication, January 16, 2015).

The government states that they ensure that their premises are accessible or they will either make the necessary physical adjustments to premises, or ensure that alternative premises can be found. However, the experience of refuge managers is that this does not happen.

Can I give you a simple example? All xxx refuges are set up by Housing NZ, right, Housing NZ houses. There should be a standard policy within the Housing NZ, any buildings, because the Government is the landlord, should

have a disability access. Many of our houses don't have a disability access, even our drop in centre in xxx doesn't have a disability access. We challenge Housing NZ, 'why is there not a disability access?' They say it is not a requirement...That means that there is no standard process. For example if there is a 5 bedroom house refuge, what happens if we get a disabled person, that means we can't service, there is no ramp, toilet doors are not wide enough, showers doesn't have disability...I think environment plays quite a bit of role, like if you have a disabled client who can't get out through the door, can't move around in the house, how can we take her in? (AF5v).

This lack of accessibility is about more than just physical accessibility – it extends to a lack of understanding of how (and where) to work with certain women.

Like refuge is not safe for some women, blind women, it's not safe for them, generally speaking because the refuge system doesn't understand how to deal with blind women and why should they have to leave their environment that they know and trust because some bastard is being violent (R3a).

Despite what the Minister said about Housing New Zealand being responsible for the provision of accessible premises (Chapter 2), even well-respected national organisations lobbying for change have managed to achieve very little movement towards making refuges accessible to disabled women.

But even when Refuge lobbied places like Housing New Zealand, 'cause a lot of the refuges are Housing New Zealand owned, you know, they didn't come to the party, they didn't. I think a couple of houses got...adjustments made to them, so they could deal with wheelchair access, for example, or something like that. But you know...including children with disabilities...and older boys with disabilities, it was all of that kind of stuff that there were access issues around (T1v).

Even if physically accessible services are provided, there are levels of knowledge and competency that are required to work constructively with disabled women, including those with mental health and substance abuse problems. This knowledge is not required in either sector and so is fragmented and randomly available through the services.

T2v: There are some...[accessible refuges]. But most of them don't have the ability to be accessible...Refuge did an environmental scan around the country... I think there might have been three or four people across the country that could sign, for example...so the help was very limited in terms of

access, and I'm talking about access to actually physically the refuge but actually just access to some really good advocacy and services as well...So a lot of the access was, it really was practical, it was things around doorways and access for wheelchairs and...we also worked with women that had head injuries from violence, you know...so they were sort of put in the disability sort of thing as well. And...I don't believe that we really had the skill or the capacity to be working with that either. Because there's a whole lot of stuff that can come alongside that. And definitely disability, drugs and alcohol, mental health, oh my God, where do you go with that? And I have seen that...and really, really, really difficult, almost no, well, no access almost anywhere...

DH: The xxx Women's Refuges always say they take women with drug and alcohol problems.

T2v: Yes. I would challenge that, Debbie...They don't always take women with drug and alcohol problems. Women are often turned away because of drug and alcohol problems and mental health from Refuge across the country... So, yeah, in my view I don't think women get good access to Refuge across the country. .

This was reiterated by other participants:

My worry is that all the stuff gets done, there's a little bit here and little bit there and a police woman in Auckland who's learnt sign language, and it's great but it actually doesn't do anything for anyone else, anywhere else (R3a).

Without any identifiable, accessible pathways to safety, disabled women become invisible and excluded from statistics, service provision and the discourse.

...if you're deaf, there's no one that will interpret for you and if there's an emergency it's very hard to get help. If you are physically disabled and you have your carers, you can't go into any of their homes, in Auckland they put you into the Ronald McDonald House because there's no safe house for a wheelchair person and you can't bring your dog. So you can't leave your relationship where the violence is occurring because there's nowhere to go plus they're not accessible or if they are they're only accessible in 'window dressing' only. There's absolutely no culture in the domestic violence world that deals with disability, so there's the huge barrier. The carers and the mechanical side are completely ignored by the domestic violence side (H1a).

No shared language and concepts

Another identified barrier to the sectors constructively communicating with each other is the lack of a shared language and shared understanding of sector-related concepts. Participants expressed concerns about lack of clarity of language, and the concepts and practices related to interpretation and understanding of language both within and between the sectors. When they raised language as a concern, participants frequently discussed the need for a shared definition of key terms.

...I also think that the anti-violence people, they have a language and an argot, as I say, in the same way that the disability community does and the two are different and they probably don't understand each other very well yet (R3a).

When asked to define the sector they worked in – either domestic violence, sexual violence or disability – some people realised they had not thought about how to clearly articulate what they did in their work, or how the language they used was defined, as they assumed that their colleagues and others would know what they meant by the language they used.

What it is highlighting for me is we make, because we're so used to working within the sector, we make a lot of assumptions that everyone's on the same page as we are, and what I've found working with disability, 'cause we've just been moving into working with disabilities as far as the xx network, is that you actually have to go right back to beginnings, when you're forming relationships outside the sector, because...you can't go on those assumptions (S2v).

When participants did articulate definitions it was in various different ways, and while there is no necessity for everyone to use language identically, it can create confusion between and within sectors. For example, one participant identified that there are three definitions/understandings of family violence used by different government agencies.

Well...first thing is we acknowledge, is that formally there's lots of formal definitions of family violence in New Zealand...So, for example, there's the Act itself. Even within the Act there's some variations, but let's say the Act...is it the Care of Children Act? There's two definitions, statutory ones that I'm aware of. In fact there's three. Cause there's a definition of family violence in the Family Violence Death Review arena as well (JS11g).

Cripps and Adams (2014) have identified that the naming and defining of violence occurring within families has been highly contested over the past forty years. This is partly due to changing social values, but also to differing interpretations between individuals, services, research disciplines and also between cultures. They observe that people use terminology differently in the various literature, which creates confusion around the meanings of terms such as family violence and domestic violence (Cripps & Adams, 2014) and how this can mask the reality of violence and minimise the harm that is caused (Wilson, Smith, Tolmie, & de Haan, 2015).

A further barrier is created by the difference between women's descriptions of their experiences and what professionals hear. Professionals and others interpret women's descriptions of abuse and relate them to their own understandings of violence and the language they use in their professional capacity (Cripps & Adams, 2014; Wilson et al., 2015). This reinterpretation of information, and the lack of an agreed language that adequately describes dis/abled women's experiences of violence, the harm that is caused by violence, and women's resistance to violence, can result in professionals minimising violence and the related potential harm, creating increased powerlessness and further trapping dis/abled women in abusive, dangerous situations (Wilson et al., 2015).

...I think that's the same with mental health and disability, what you [the professional] write, what your G.P. writes in your notes or when you're referred from one place to the other, those negative, unintelligent comments follow you and actually people are pre-judging you before you've even arrived or where your next destination is. Extremely detrimental (GB6v).

One participant discussed the It's Not OK campaign and how getting people to talk about domestic violence will make it easier for people to get help.

...I remember when I first started working at Women's Refuge, and so many women would come in and say that they had no one to help them. Like no one would listen, their friends wouldn't listen to them, their parents or their mum told them you've made your bed, you go and lie in it. They had no help, they had no support...The more that we can make it okay for people to have a conversation, to feel comfortable to talk about it, then it's gonna be easier for people to get help (S1m).

He Drove Me Mad (2001) is my Masters research into the relationship between domestic violence and mental illness. Ten women with personal experience of domestic violence from their partners, who felt the experience had driven them mad, and twenty service providers who worked in either violence or mental health

agencies were interviewed. One of the key themes identified was that a number of the participants – women who felt that they had been driven mad by the abuse they had experienced – felt that during the period they lived in the abusive relationship, they had no specific language to describe the abuse which was occurring (Hager, 2001). While the *It's Not OK* campaign enables conversations to occur about violence, it does not provide specific language to describe the dynamics of abuse – the behaviours that women are experiencing. Wilson et al. (2015) have identified that one critical change that must occur to improve service delivery and safety for abused women in New Zealand is the development of clear and concise language to describe women's experiences, which can be used by women to describe their own experiences, but also by practitioners, to ensure that professionals' use of language fully describes the behaviours and harms of abuse. They recommend uptake of the language of coercive control rather than power and control. This language, defined in the Family Violence Death Review Committee's [FVDRC] fourth report, defines abusive behaviours:

Coercion involves the use of force or threats to intimidate or hurt victims and instil fear. Control tactics are designed to isolate and foster dependence on the abusive partner and their lifestyle. Together these abusive tactics undermine a victim's ability for independent decision-making and inhibit resistance and escape (FVDRC, 2014).

Fully integrating this clarity of language into professional practice and common parlance would enable a discussion of violence that more truly reflects the danger and harm.

Participants from both violence and disability sectors acknowledged that when the 'wrong' language was used it could cause defensive responses that silenced communication.

Once you meet somebody from that other kind of sector and you don't have a shared language and then these people say something that offends those people...the initial tendency is just that everybody closes down, instead of being able to have that dialogue that people kinda go, oh, you know...you go to the first meeting and somebody talks about deaf and dumb people and so you go 'we don't use the word deaf and dumb', and they go 'oh shit we'd better not say anything', and you go 'there's no point in listening to them because they use the wrong words' (P1a).

This silencing can be very powerful, as identified by this participant:

...some trepidation among domestic violence people about how to talk of disability and not wanting to say the wrong words...[talking about a disability presentation they attended] someone jumped on him about something he'd said...Yeah she was sitting at my table, and I thought crap, I'm just going to be quiet...it's a bit of a mine-field (D2v).

Language cognition can be constrained by societal perceptions of the issues being discussed. This includes the complex social attitudes, myths and stigma that surround both violence against women and disability.

DH: So how do you explain what sexual violence is to somebody who doesn't understand it? Not somebody who's experienced it – but like to Rotary?

S8v: And that's an interesting one, because of all the rape myths that are out there, because of the rape culture that we live in. It becomes quite hard to explain to someone to a point where they understand it...we see that all the time, you know, in jury trials and that, offenders getting found not guilty because of what she was wearing or the fact that she'd been drinking and that sort of thing.

This will be discussed further in chapter 7.

Certain cultures do not have language to explicitly describe violence against women. This occurs in the Deaf community and also a number of non-English languages.

If I explain to you Debbie, I would be explaining very different than I explain to a woman from my community...I understand the translation gets mixed up, I would explain more, you know what they said, that he doesn't give you any money or things like that, that is the way I would go – storytelling process – and explaining and then slowly dropping the words, and a lot of these words don't have translation in my language. In English I can tell you the whole process. Financial abuse I can't translate in my language. I would say differently, he thinks money belongs to him. When we say it in English I would say it physical abuse and then go on, but when I go in xxxx, I would say everything else apart from physical abuse, as I have no translation of that (AF5v).

Interpreters are not specifically trained to understand sexual and/or domestic violence as they interpret for victims in either the Deaf community or ethnic

minority communities, and there is a concern that therefore they will not have appropriate language skills for the work required.

So I think with domestic violence there's still the development of language - to talk about domestic violence it's still quite formative, still quite in its early years. So...one of the problems, is that when it comes to sign language, the sign for violence, the sign for abuse is this, which is a fist, basically punching a finger, which represents a person, so that's violence, but that's physical violence but it's not necessary psychological violence, so doing this sign for psychological and then violence doesn't really make sense in sign language. So...there's not really enough language yet, in the Deaf community, to talk about domestic violence, that's one of the problems (D5d).

One example that emerged from the data is the use of the word empowerment. A number of participants identified misuse of this word, and subsequent poor practice, in their discussion of the concept and practice of empowerment in violence services and raised concerns about abused dis/abled women being unsupported as they negotiated the welfare, justice and other systems.

R3a: I don't like the term empowerment, I think it's a 'woosie' word because - and I know that if you take the true meaning it isn't - but I think it's often bandied around and used as a weasel word. People talk about empowerment but in some ways they don't...they use it as a cop out word, you know.

DH: Can you tell me more about that because a couple of people have started talking about this?

R3a: Well I think a lot of bureaucracies talk about empowerment, they really don't know what they are talking about. There is such a thing as empowerment and I think that People First are a great example of empowerment, where people are joined together and are saying 'no, we won't put up with this any longer' and I think that's really good, but they are still struggling, they still struggle to be seen as an equal on things like the welfare working groups, things like that, that kind of stuff...The Deaf community, I reckon too. The Deaf community have empowered themselves, generally speaking, because it wasn't given to them, they had to fight every inch of the way. As of most groups I suppose, that's true of all groups that are disempowered in the proper sense of the word. But I do think it's used as a weasel word and people don't really understand what it means. Some people think it's about government. Revenue stuff, like decent benefit and I'm not knocking that, I think people do need a, if they can't work, then they need something to live on but that's not about empowerment in a sense.

Empowerment is about being in charge of your own destiny. So it might include having a living, enough to live on but it might also include your

fighting for your rights, in particular circumstances or not necessarily being compliant.

The concept of empowerment was used by participants in a number of different ways – as something unconstructive; “...*not empower, so much, because that sounds like they're handing power over...*” (B1m); expecting individual women to feel empowered as a consequence of their own actions; and as a constructive concept: walking alongside women to achieve the things they want to do; and creating material, policy and political circumstances that enable women to make constructive changes in their lives.

...one of the best things you can do is believing the woman and listening and understanding so that sort of empowers them to think ‘actually it’s not in my mind and it’s not OK’ and all that kind of stuff; so it’s about trying to build up their belief in themselves and a belief that actually what’s happening is not OK. Just keeping those parameters clear though...I guess for me empowerment is about building up her sense of wellbeing and self-worth so that she manages to manage her situation and take the appropriate routes wherever she need to be at that particular time (G3v).

What is identified from this is the necessity to have shared understandings not only of the language used within and between sectors, but of the practices that are associated with the language. As there is not yet any coherence of language and best practice within the New Zealand violence sector (Herbert & Mackenzie, 2014; Wilson et al., 2015) it will be difficult to gain coherence across sectors.

The FVDRC (2014) has also identified this and says that providing women with information and leaving them to negotiate the processes alone is government and NGO sector misuse of the concept of empowerment, which can potentially lead to increased violence towards – and possible death of – abused women.

The empowerment framework, utilized [sic] by many family violence services, aims to respect women’s agency. It is a powerful discourse that influences service providers’ and statutory agencies’ understanding of how to work alongside women experiencing abuse. The regional reviews highlight the difficulties and risks when expecting an IPV [intimate partner violence] victim facing lethal violence to quickly or safely move from a situation of entrapment to one of empowerment.

It is important to put the concept of empowerment within victims’ complex and sometimes chaotic lives, as structural inequities constrain and shape the

lives of victims, albeit in different ways. The concept of 'empowerment' is problematic when working with victims facing lethal violence, who also frequently face severe structural disadvantages. This is because it makes it appear as though an individual's inability to keep themselves or their children safe is a result of their decisions and choices. It renders invisible the systemic barriers that impede those choices (such as lack of stable housing and access to money, poverty, racism, sexism and the legacy left behind by colonisation).

In the regional reviews, it was evident that frequently the well-intentioned focus of the FVIARS meetings was on empowering the victim to make their own choices, which in effect resulted in a list of actions the victim would take to make herself and her children safe (such as go into refuge, separate from her abusive partner or get a protection order) (FVDRC, 2014, p83).

The defining of women's independent agency to instigate change as a service imperative, or conversely, decreeing that women are unable and incompetent to make autonomous decisions, is explained by Bogard (2005):

...approaches to personal choice in oppressive social contexts have tended to rest on the premise either that all individuals can create safe lives or that the disenfranchised are helpless victims in an unresponsive and unchanging hostile world... (p24).

In health promotion terms this is the difference between expecting women to develop constructive personal skills in the absence of any socio/political contextual support and the development of healthy public policy that creates supportive circumstances for women's help-seeking and safety (WHO, 1986).

Conclusion

This chapter detailed the findings related to pragmatic barriers to the sectors communicating. Primarily, the sectors have not sought to engage with each other. This is due to a lack of knowledge and awareness of each other's related concerns and a strong feeling in both sectors that they are overwhelmed with the work they already do – and that adding disability or recognition of violence to this mix would be just too hard. Underlying this lack of knowledge and resources is a lack of will to engage with this issue. The lack of government policy and funding, lack of training, lack of guidelines for violence and disability services and the political, institutional and societal lack of respect both for those who provide care, and those who require it, are evidence of this.

There are two potential enabling factors identified in this chapter. First, some small towns have more advanced relationships between sectors than the larger towns and cities. However this is not occurring in all smaller centres, so would appear to be dependant on individuals who have worked to develop cross sector understanding and cooperation. Secondly, people in both sectors want to help the people they work with – but this does not seem to be sufficient for them to understand, and respond to, each other's issues and concerns.

Feminist disability theory complicates feminist investigations of caregiving by insisting on an examination of the power dynamics between those who provide care and those who receive it (Garland-Thomson, 2004). It questions the established understanding of who benefits from this relationship and who requires care and support, and it requires that the voices and considerations of those who are being cared for be of equal value to those providing the service. These issues have been identified in this chapter; the next looks slightly deeper, to understand the paradigms that each sector works from and how this manifests in practice. It examines these issues from the perspective of a feminist disability ethic of care – pushing the boundaries of examination of women's role as carers, to incorporate a consideration of reciprocity and the voice and agency of those for whom care is being provided.

Chapter 6

Paradigms of practice

Feminists haven't always treated disabled women well (S6a.)

Introduction

The reasons provided by participants, in the previous chapter, for not addressing the abuse of disabled women in a collaborative and constructive way are utilitarian, based on the practical realities of lack of government leadership and direction, the consequent insufficient funding and resources, and lack of government and sector knowledge and skills.

This chapter moves from consideration of the pragmatic reasons for lack of connection between the sectors, to a deeper semantic analysis of the paradigms and related practice that inhibit collaboration or conversation across sectors. The participants interviewed are all very skilled and have many years of experience in their particular sector. What differentiates people, in their grasp of the issues and in their day-to-day practice, is the underlying paradigm that they base their practice on. In order to determine participants' fundamental paradigms in relation to the sectors they worked in, they were asked a number of questions about their values, the underlying models and theories they used in their work, why they worked in their particular sector and how they understood the other sector. The analysis of the answers to these questions resulted in two distinct outlooks on how and why participants work in both the violence and disability sectors. The similarities in responses were distributed both within each sector and between them. As identified in Chapter 5 and further in this chapter, a common theme between sectors is the participants' desire to improve the lives of their clients. This could be a potentially enabling factor to start conversations across sectors. This chapter examines the findings in relation to the various understandings of what helping and supporting clients means and, as will be demonstrated, how these underlying paradigms indicate poor, good or best practice. However, the poor practice identified in this chapter does not reflect on the research participants – it is extrapolated from their knowledge of their sectors and their familiarity with organisational and staff practice.

There are two main themes explored in this chapter. These are models and paradigms and good and bad practice (Table 3).

Table 3: Themes and sub-themes – paradigms of practice

1. Models/paradigms people work from <ul style="list-style-type: none">• Individual deficit/medical paradigm• Socio-political paradigm
2. Good and bad practice

Models/paradigms people work from

Two significant levels of sectorial understanding or paradigms were identified. I have identified these as individual deficit and socio-political. These two paradigms relate to the medical and social models explained in disability literature, but are also easily identifiable within the domestic/sexual violence sector. The various constituents of each paradigm were distributed within and between sectors.

An important component of these paradigms is how the relationship between practitioner/carer/support person and those being provided with support and care is understood and negotiated. Acknowledging that both parties in this relationship, in both sectors, are undervalued and without symbolic power in our society, one paradigm engages in discussion about the benefits and risks of western masculine concepts of autonomy, independence and interdependence, and the other operates from unquestioning adherence to them.

Individual deficit/medical paradigm

The lives of many dis/abled women are constrained and directed by the discourse and processes of the professionals they interact with. Therefore if these professionals view disability through a medical model lens, and understand disability as individual deficit rather than the result of disabling societal conditions, they will configure their services and responses accordingly (Morton & Munford, 1998). The medical or individual model is based on the assumption that the problem - for example violence and abuse/disability – resides within an individual. In the disability sector, this results in providing services to fix or remediate people and/or keeping people in dependent relationships, rather than looking at the systemic and cultural barriers to participation and citizenship. In the sexual/domestic violence sector, it manifests in blaming women for their circumstances and expecting them to take personal action to stop the perpetrator's abuse.

So disability is, it's a whole range of things, it can be everything and anything. You know, um, we have diagnoses, we have a whole medical model which we use to describe people in particular ways and define them by

labels, autistic, schizophrenic, victim even, perpetrator; so these are all labels that, that's one way of thinking about disability (B5g).

and:

...people perceive disabilities as, that's their issue, it's the disability and not those other issues that make them vulnerable to abuse. So when I just think about here at the hospital, we have a team, physios, OTs, work with that person with disability because they have a disability, that is the focus...they focus on the disability, the activities around, what does this disability person need, so they'll have this kind of OT assessment as to what kind of wheelchair, what kind of cushion, do they need any handrails in their bathroom. Physio talks about what kind of exercises do they need. The social worker will look at packages of care...who is going to come in and socialise with the person, those kinds of things. That's what I meant by the focus on the actual disability, what it is and what they need to support the person with that type of disability (B2g).

People working from this model individualised the issues that they worked with – domestic/sexual violence or disability. Women – either abused and/or disabled – were identified as victims of their circumstances who were to be pitied (tragedy model) (Crow, 1996; Oliver, 1990b); poor, deserving women who needed help and rescuing (charity model) (Drake, 1996; Swain & French, 2002); or super-heroes overcoming overwhelming odds to get on with their lives.

There's a guy, a disabilities rights thinker from a university in Tasmania called Christopher Newell, he died about 4-5 years ago, but he used to talk about the thinking that dominated disability...and many other areas, was metanarratives. Triumph over tragedy is one or the other one is the burden on society or deficit and that gets replicated through the media, through families, within schools, professionals, health professionals. Each profession might have its different narrative around, not disabled people, but others and it aligns with other socially dominant metanarratives about growing up with violence, sexual abuse, a stereotypical rape victim; asking questions, did she ask for it, what was she wearing, those are some dominant metanarratives (P1g).

From a public health perspective, individualising the issues of disability and abuse means that, for example, there is no collation of statistics about the abuse of disabled women, no analysis of the underlying systemic/determinant level reasons for the abuse of dis/abled women and no societal or political responses.

A number of participants in the disability sector did not understand the question about which model they worked from – medical or social. This indicates that they had not been introduced to the concepts. The participant below exemplifies this. She identifies with, and works from, a medical model – understanding the social model to mean that people’s social needs will be addressed by interaction with an appropriate service or programme. While this may be a service that people want to avail themselves of, it does not indicate a social model approach as it focuses on specific responses to individuals and their health and other problems or requirements for services. A social model response would be orientated more towards creation of mainstream environments that were accessible without special support.

I guess we work here partly social, partly medical, by employing health professionals to do specific tasks or provide specific programmes. So we have four registered health professionals who provide specific services and work in with the medical specialists or teams so that's the medical model. But a lot of the work they do too is providing the social needs so it's working in to making sure that the needs are met via Work and Income, benefits and entitlements and what have you, plus also access to other services, whether it would be things like counselling or some type of support group or something that that person has identified (J7d).

Within an individual deficit model, power is used paternally and choices available to dis/abled women are controlled and constrained. This is not just abused, dis/abled women, but any woman who requires support for various reasons. This will be discussed further in the next chapter.

Services or individuals who work from a deficit paradigm tend to be entirely focused within their own sector. Because they perceive the ‘problem’ of abuse to be individualised in the person, they do not make the connection with other sectors to access appropriate support and information. Nor do they identify wider theoretical underpinnings of their work. There was, in some participant interviews, no discussion of feminism, human rights or social justice – the wider context of working to improve the wellbeing of marginalised people.

Socio-political paradigm

In contrast to the individual deficit model are those who work from a socio-political analysis of the world and the sector they work in. From a health promotion perspective, a socio-political analysis means understanding the interaction and relationship between politics, access to the wider determinants of health and how the contexts of people’s lives, political and lay ideologies and economic and

environmental concerns all impact on how society is shaped and how this, in turn, influences the choices that people can make in their lives. As with the social model, the underlying values inherent in this are respect for all people as equal, a strong orientation to the realisation of human rights for all, the enabling of voice, and an analysis of power and oppression – with the aim of creating equitable accessible environments for all. This entails recognising the inherent right of all women to be equally represented across all aspects of the socio-political spectrum, and respecting the voices and expertise of all women.

...attitudes...how they respect disabled people, respect attitudes, their attitude towards, they look at the person, they ask the person first, not the support people...But give the respect to the disabled person first. Just be supportive...just be willing to open your mind, that disabled people are people, yeah, just respect them for them as, I can't say normal people, but they get respect, so why not respect disabled people the same way, for being themselves (R7d).

This model necessitates people having a critical analysis of power and how it operates interpersonally and across communities and government. It entails people understanding and critiquing the structural and systemic enablers and constraints on dis/abled women's lives, including a gendered analysis of such systems, and understanding oppression, inequity and the mechanisms that silence and create invisibility for both women and disabled people.

This model is identified in participant discourse by various markers. One is a feminist analysis as this incorporates understandings of oppression, power and disempowerment and signals complexity thinking.

...the power dynamics that occur, the bits around why it's more against women and what that actually means...so some values in feminism...where one person, usually a male who in some way takes power over someone else. So whether it's in a coercive kind of way, whether it's out of fear...embedded in our culture (A1v).

and:

...I guess the theories I go by are the ones like the feminist theories, feminist discourse, even tho I don't call myself a feminist. Maori call ourselves 'Wahine Toa'. But feminist, feminist discourse...(H1a)

Others talked about these ideas from a perspective of social justice, incorporating an analysis of power into this. This participant also raises the concept of complexity thinking by observing that binary thinking is not helpful when trying to address violence.

[The] value base of justice, you know social justice is very important to me, and I would hope that people working in this area would have an appreciation of what social justice is, in the broader sense; so when I think about issues around power, um, I'm not just talking about the power and control wheel here, I'm talking about structural power that organisations, institutions hold, I'm talking about discourse, talking about all of that sort of stuff that these people who are working in that area are working with. The idea that social justice takes account of these various aspects of power and how it's, um, engaged with; and that's a big ask and I understand that. But I'm a bit tired of working in a sector which often I come up against, you know, a very binary approach to, you know, family violence; good, bad, perpetrator, victim, right, wrong; you know, my experience in working just with bad is we tend to just keep doing what we're doing and it just seems to be bottomless and endless, and I'm looking forward to the day when we can move beyond the simple paradigms of that (B5g).

Social justice also incorporates, for some people, a human rights approach. This participant talks about this and also about the mythology that constrains practise and empathy.

Being very focused around human rights. Around social justice. Not having stereotypical attitudes and behaviours themselves. So being very mindful of behaviours that may in some way perpetuate mythical behaviours around the whole culture of sexual violence. And being very aware of the myths...around sexual violence, what perpetuates sexual violence, victim blaming, being very aware of that. So that you can actually bring around a conscious awareness raising amongst people who start talking about behaviours that would be victim-blaming...It's around people being treated...the way they deserve to be treated, and that is like human beings, all human beings being awarded the same rights. There's a whole document around constitutional rights...and a lot of countries have actually agreed to sit in human rights conditions that they have brought into their own country. So all those rights being conformed to. And at a lower level that whole idea of respecting each other, valuing differences, acknowledging similarities, sort of de-, looking at the inequality in the community and trying to bring around equality (AZ4v).

Human rights are not just an abstract concept. They can be particularly powerful as this participant identifies:

...like I found with this malnutrition stuff that when you started talking about well... actually you're in breach of peoples' human rights...if their disability's preventing them being fed or having a drink the same as everybody else and they're not because they're blind and they didn't see that the tray came and nobody told them, you're in breach of their human rights. So you need to step it up, you know. And that's powerful for people when they haven't really thought about, they've just put the tray down and gone. So it's not just that that was a bit rude, you're actually in breach of someone's human rights, it's powerful language to use (S5d).

These various ideas are summed up in the following quote, which also identifies the need to incorporate an understanding of colonisation as part of complexity thinking:

So we'd definitely look at, um, forms of oppression from a structural level, so some of the feminist thinking around that, some of the Marxist thinking theory. And also it would be good to have some knowledge of social learning theory, colonisation. They are all big thinking theories, so we wouldn't expect someone to come in with a vast knowledge, 'cause they're all quite complex in their own right just a general understanding as to how the systems work to oppress or hold power over groups in society (T3v).

From a positive perspective this model encourages system level responses to the needs of dis/abled women, rather than expecting women to conform to the needs of the systems to keep themselves safe. It also requires people to have a system level analysis of domestic violence and to understand how power is used within society – not just at an interpersonal level.

Obviously have good, sound analytical skills but need to have a good socio-political awareness of what family violence [is] and how it's perpetuated at different levels of society would be really essential; to have that in order to work effectively in the field and to understand the wider impact of violence on people, not on just the physically but the emotional and all the different levels that it can impact on people and families and communities...you can go at the political level and look at political systems that exacerbate and create opportunities for family violence to happen by the varying nature of the policies that are made – people in power... (B2v).

The participant below identifies that the concept of disability is contingent on time and place – that it is not a fixed concept. This was reiterated by a number of people.

[Disability is] culturally and societally and contextually defined so that at a particular time in society, in a particular thing, then it is a disability. In another time and another society that person could be considered to be blessed with magical powers. So where's the disability? What's the disability? (B5g).

This understanding aligns with a social model of disability. Social model thinking was frequently the default position for people providing an explanation of disability – often without being aware of the (social model) language around their definition. For others, however, the use of the social model of disability was very explicit.

I think the Ministry...the way I see it, it's very social model. Consumers are very clear with us that they're not medical problems. They're people with lives. And so the social model has been well and truly adopted as the way of seeing people with disabilities (B1m).

This participant explains the social model, highlighting that it is not a woman's impairment that disables her, but an inaccessible society.

Disability is what a community and a society does to a person who has some sort of impairment. So for instance you could have an impairment which could be, say you're blind, that could be your impairment. Now whether that becomes a disability or not depends whether that impairment is a barrier for you to access and do all the activities and involvement in society, community, that you want to do. So for some people it really doesn't become a barrier and I would say they're not disabled because they are able to travel, they're able to work, they're able to have functional relationships, just the whole plethora of life. They are able to function the same as anyone else...So there's no barrier or impedance for them to give a full life, like as if they were sighted. But for another person who might be also blind, that might be a disability because that might mean that they don't feel comfortable going out in public, that they are hesitant to use public transport, that employment has become very difficult to attain, that those other parts of being in a community and living a full life become very hard for them to access. And if that's the case then the lack of sight is a disability. So it's a subjective thing, disability, and even in the census it's self-selected. So one person may feel they have a disability. Another person may feel that they don't. But they may have impairments (C4d).

It is these different paradigms that inform the good and poor practice identified across sectors.

Good and bad practice

As identified in the literature review, research has highlighted gaps at the level of policy and service provision for abused disabled women in Australia, England, Europe, North America and in New Zealand. A consequence of this lack of policy and service provision is that there is very little literature that I can find on good practice for responding to the abuse of disabled women, other than that discussed in Chapter 2 (Frawley et al., 2015; Healey et al., 2013; Healey et al., 2008; Thiara et al., 2012). There are examples of mainstream good practice responses to violence against women in specific circumstances (for example, Snell & Small, 2009), but there is no mention of the abuse of disabled women in the World Report on Violence and Health (Krug et al., 2002) or the Global Status Report on Violence Prevention (WHO, 2014) and no specific mention of prevention of violence against disabled women in the World Report on Disability (WHO, 2011). Macy, Giattina, Montijo and Ermentrout (2010) state that a problem in the evaluation of programmes that respond to violence against women is that there is so little literature about best practice. Therefore, the information that is presented here about good, best and poor practice is my own, elicited and interpreted from the data I have collected.

Good and bad practice is generic across the violence and disability sectors. It is about how people work, how they understand the women they work with and how staff see themselves in relation to the women they work with. It is also about whether or not staff have respect for people, whether they inherently value people or whether they do not, whether they see themselves in a position of power over – controlling people’s choices and actions (Laverack, 2009) – or in an enabling and supportive role, using their professional power to enable dis/abled women to make their own choices in a supportive environment (Laverack, 2009).

There are two levels to the constructive practice identified – good and best practice.

Good practice

Good practice is about working from a socio-political values base and having an inherent respect for all people. *“As long as the attitude is right I can build on the knowledge. So I’m looking for someone who is going to keep the individual at the centre of everything we do”* (B3d). This means, in practice, support people, carers and others listening to dis/abled women; doing what dis/abled women want, not what the support people/others think is best for them; and offering real choices – not

choices constrained by poor systems. It means enabling dis/abled women to take control of their lives, not protecting or rescuing them.

It's gotta be client-centred and it's gotta be what they need and what they want, not us pushing what we think on them; again that's their own power. They've already had their power taken away, we're not gonna go and do that again. It's their journey and only they can walk that journey. We're just there alongside them to give them the support they need to do it (S8v).

Alongside this is enabling the voice of dis/abled women to be heard, respected and responded to. “*The human rights perspective is a really important one, that right to be safe, that right to have a voice, to be heard*” (GBv6). This needs to happen not just in service provision to abused women, but in service and policy development and in the development of legislation that impacts on dis/abled women’s ability to live healthy and safe lives.

A key part of this process is the identification and elimination of local and national systemic barriers to both service provision and ongoing safety. This entails not only using available systems, but also actively seeking solutions to problems, identifying gaps in service provision or legislation, and working to eliminate these.

Inherent in the change of thinking that is required to do these things is the understanding and enactment of the concept of interdependence – understanding the interconnectedness of all people and the responsibility society has to provide the level of support that each person requires to participate fully in the world.

So the social model is about removing the barriers, eh...And the citizenship model is knowing that it's absolutely peoples' right to do and be. So the social model isn't as progressive as the citizenship model. 'Cause you assume that if you remove barriers that other people have to do that for you. But the citizenship model says that you can and are expected to do stuff if you're given the right support (GR2a).

This is because everyone – at different times of their lives - requires varying levels of support, and for some people, support will be required throughout their lives.

Well, I think people with a disability have got another layer, in that they're very dependent, often, and each person's different, but in each, has a different kind of depend – we're all dependent on each other – but they've got sort of a little added layer in the sense that they may not be able to walk or they might

not be able to talk or they might not be able to express, they might not be able to remember, or they look weird, or, you know, they've got all these, so they need people in their lives to help them, to assist them (P3d).

Good practice requires that services understand and embrace the concept and practice of interdependence, which means walking alongside traumatised/abused dis/abled women, rather than creating dependence or expecting independence.

...very often our person is right there, literally right there alongside the individual, making sure they understand, making sure they're processing things, making sure they understand what's being asked and that they're clear on what answers they're giving...if you don't walk alongside them whilst you get other people involved, it's not going to happen and that's the rest of their life in an abusive situation (B3d).

Walking alongside abused dis/abled women is not just about good practice – it recognises the harm that violence and trauma inflict on dis/abled women and their ability to function coherently in the world.

Giving them choices, walking alongside them, absolutely. For people that have been abused...for all the reasons, they're just often exhausted...it's not that they are lazy, they just need someone to help, to walk alongside them and yeah; but not to push into any decisions, that's important too; give the options but, um, it needs to be what they want to do, otherwise if you're pushing them into something before they're ready for it, you're just re-abusing them, really (GC4v).

It is a requirement of good practice that professionals/staff of organisations understand what their roles are, and the boundaries of their roles. This means, in both sectors, that professionals work from a position of enabling and supporting autonomy, which means not taking charge or making themselves feel good because they are helping (rescuing) someone. One participant described this as people who do not need you to say thank you.

I think there are some very useful things that people have to know, you know, the obvious things around communication, listening, time taking, organisational things, all of those help to work in the disability sector, because in the sector there a high level of frustration, a high level of people having to fight for what they need and...if you find someone who's generous with, whatever it is, their time, their energy, their willingness, that's such a bonus for disabled people, when someone is prepared to go that little extra

mile where you don't have to ask for everything, when they understand if you don't say thanks, it's not because you're not grateful, it's because if you said thanks for everything they've done, you'd be saying thanks a million times a day...people with enough self-esteem, so that they don't have to put themselves in the centre all the time, but people that don't have such a big ego that they have to be in charge (S6d).

Most importantly, good practice is about not victimising or blaming women for their circumstances. Primarily this means acknowledging that abuse is the responsibility of the perpetrator, not the victim and that it is the perpetrator who must change. “give responsibility to the perpetrator for the violence to change, what they need to change” (B4e).

Matthews (2014) states, in regard to this: “If we focus on the act of the perpetrator, then we see clearly how profoundly unreasonable it is to stop at the victim” (p804). This also requires understanding that the purpose of support services for abused dis/abled women is to enable women to move away from danger and recover from the trauma they have experienced.

A process that was discussed as being important to good practice was advocacy. This is a politically contested concept as government does not permit most organisations that receive health funding to advocate politically for legislation or policy change – and did until recently deregister charitable organisations which were perceived to be primarily political advocates for a particular cause – for example Greenpeace and the National Council of Women. Advocacy was understood by participants to have a variety of meanings and practices attached to it. Some of these are supported by the current political ideology, for example self-advocacy and individual advocacy for clients; however, other forms of advocacy, such as lobbying and working for legislation change, are not.

The funny thing is, though, advocacy has become like feminism, and that is a dirty word (GQ5).

Different types of advocacy are identified by the participant below:

I mean most of us go to work every single day as advocates. You're an advocate every day with the big submissions you write into government and the stuff that you bring out to us. That's advocacy. As I see it. So individual, regional, national, you know, yeah, yeah. And I think that the sort of a choice thing, or the pro-choice, whatever, women's choice, women's process, is a model of practice that we work with all the time. We're always working

with women's processes, where she's at...[also] agency. You know, like advocating for someone or someone advocating or being an agent for themselves. Agent of change (T2v).

Below, a group of people working in the violence sector recognise that they are all advocates in their work.

T2v: What do they think it is we're doing all day long? Like, you know, all of us. We're all advocating in our different sectors, you know.

GP7v: If advocacy is defined as identifying an issue and then either taking action or speaking out to change it, doesn't it actually underpin everything you do?

GQ5v: Yes, everything.

GB6v: That's what we're doing. Every day.

Related to this is the necessity to do this work with integrity and to learn from the people who are the experts in the situation – the abused dis/abled women that services are engaged with.

...because to be a good advocate you have to be able to learn from the people that you're working with (S1m).

Participants from the government sector identified organisational advocates as critical to good government policy making.

...we are at a national level working with some of these groups, through their advocacy groups, or people who are advocating for them in the community...(JS11g).

Best practice

Best practice involves more than the concepts above. The key component is an ability to deal with complexity – to engage in critical thinking about the world and the circumstances of women generally and those who are abused in particular. Working with abuse is not linear or simple.

...domestic violence is...what literature defines as a wicked problem and the guts of something that's a wicked problem, it's not easy to define, it's not easy to put a box around it, it's not easy to say it's this and we'll do this. If you're in the health system you can say that diabetes is diabetes and the

scientific evidence says to do ABCD and not DEF, here's the drug you should take. Something like DV, if you try and put that simplistic definition on the problem, you automatically try and put a simplistic approach as to what you might do about it. And that, I think, is at the very core of where we are going wrong in NZ (A2v).

For domestic and sexual violence there are no solutions that fit every situation – people who work in the sector must be “...comfortable with uncertainty” (J1v). Therefore, best practice entails having an analysis and understanding of oppression, power structures and political processes in order to identify and constructively address the systemic determinants of violence and inequity. Associated with this is the ability to understand interpersonal and institutional discrimination and stigma and how this creates and reinforces the oppression, silencing and invisibility of certain groups of people, leading to the creation of populations who are perceived as being of less value and therefore not as deserving of care and support.

Understanding the complexity of the issues, (violence against women and disability) and how these are constructed by hegemonic privilege and socialisation requires people to be informed about the history of both movements. This means understanding how and why core concepts of social justice, inclusion, enablement, human rights and control are inherent parts of the growth and aims of both movements. These core concepts and values are a critical component of best practice.

...the value of fairness, justice, a sense of justice really, and values, just being honest, and ethical. Compassion. All those things, those kind of things, people things. An understanding of people's human rights, without necessarily having studied it (P3d).

Identified organisational values that provide an underlying philosophy of practice to support best practice include valuing diversity, understanding that all people are of equal value – “understanding the intrinsic value of each person” (L1d) – inclusiveness, a belief in the possibility of change, feminism, a human rights approach, non-discrimination and social justice.

Everybody has equal rights...not that whole idea about the level playing field but recognising that some people are discriminated against or don't have the same opportunities and we need to do things to help those people live better lives and share the resources in the bigger sense, you know, fairly in our society (S1m).

Interestingly, only two participants expressed non-violence as a value.

Poor practice

It is a lack of these two levels of good and best practice that describes poor practice across the sectors. This includes not working from a values base, not inherently valuing the people you work with, not working in an empowering way, having no knowledge of the history of the movements that have created the service you work in and not having the ability to comprehend and work with the complexity of the issues that are involved in both the violence and disability sectors. This research reinforces the findings of Woolson-Neville and Gremillion (2015), who found that in New Zealand, domestic violence advocates increasingly focus on individual change and lack a clear political and feminist analysis of violence.

Poor practice was identified from the interviews primarily in two ways. A number of participants, from all sectors including the government sector, talked about their observations of practice of other people working in the field. These people came from a social/complexity values and practice model but were frustrated by what they saw as poor practice/medical model/oppression model practice (disability sector) or individualist model practice (domestic/sexual violence sector). The practitioners of this poor practice were described as people who do not have a broad systemic understanding of the dynamics of violence and what is going on in any particular situation - and therefore look at individual issues case by case, are much more judgemental, and place responsibility on the victim for her circumstances (also identified by the FVDRC, 2014).

[At the] moment there's quite a lot of people who are working in the domestic violence area that don't have any training...they don't have any domestic violence training let alone any other training. So I think that they are approaching domestic violence as that individual relationship one to one kind of dynamic, and not really understanding at all the other wider, structural issues around domestic violence. So that they might, they'll be thinking, now I'm just projecting onto this, but they might be thinking they know about relationships and violence and it doesn't matter who that person is, whatever their ability, whatever their ethnicity, whatever their age I can work with them, 'cause it's about the violence, and it's the same for everybody. Where, yeah, so they haven't got that kind of structural analysis, maybe, around violence (S1m).

The participant below identifies, as a barrier to collaborative practice, a lack of understanding of the dynamics of violence especially in disability and related services.

A lack of awareness around family violence. That they don't buy into, they don't understand it, you know, they don't have the right analysis. I don't know whether you've ever heard that phrase? I hear it a lot that you have to have the right analysis with family violence (B5g).

Part of this is an inattention to the dynamics of power in relationships between professionals and clients. As this participant asserts, those who hold very little power in their lives may use the opportunity of working with those who they perceive as less powerful to be oppressive and controlling.

I think ironically that probably the domestic violence sector would know a lot more about the power and control stuff and own that stuff more than people in the disability sector do. So you know that the scariest thing is...when our sector doesn't know that they are, um, consciously or sub-consciously taking control. 'Cause they're so used to it...if they're oppressed then they will also oppress (GR2a).

Poor practice is about rescuing and 'helping' people:

...a token gesture of just wanting to help...that's still kind of very much existing in a power relationship of the helper knowing, having all the knowledge and helping this poor vulnerable person, which I think a lot of people in the sector are like. That's why a lot of people come in, 'cause they just wanna help those poor women or they just wanna help those poor children (S3d).

Participants expressed a feeling that this attitude was widespread in both sectors. "...there's a huge number of rescuers, the whole 'doing for' and it attracts rescuers, both fields attract rescuers" (S6a). This also relates to the comments of a number of participants that support/caregiving in the disability sector is often just about very pragmatic things – what kind of wheelchair, what kind of adjustments in the bathroom (J8a) and:

in [the] disability sector, support is often 'hands on' – how do you catch the bus, how do you boil an egg, how to make a coffee, you know, let me help you with a shower, you do need to go to the toilet, that very practical, down to earth kind of way, and it's often 'I'll do that for you' (S6a).

This focus on practical support, while necessary, appears to eclipse thinking about

wider constraints – social attitudes, lack of accessible services, transport, information and unhelpful legislation. While this was primarily identified in the disability sector, there was discussion about this kind of short-term, task-focused thinking beginning to emerge in the violence sector for the reasons identified above. The following participant identifies that this focus on short-term practical support becomes even more problematic when it occurs at the intersection of violence and disability:

[The] sort of meaning of support from that domestic side is, I'll support you in a crisis, and then you'll be able to do it yourself, which is a little bit like the medical model, in terms of the conflict with impairment is, I'll just give you this treatment, then you'll be fine but actually this doesn't work for disabled people this way, you still have this impairment, so, you can give me all the support in the world, and I'll still need support to do the things I can't do for myself (S6a).

Poor practice is about practitioners thinking that they know what is best for a woman rather than listening to what she wants and needs. Working without a critical analysis is disempowering for the women being worked with. It takes away dis/abled women's choice and agency and does not change anything in women's lives. For example, working in an enabling way, in a professional capacity, assumes equal power between professionals and dis/abled women. Expecting a person to say thank you is the assumption of conditional support – of an unequal power relationship. It is about the feelings of the support person and their sense of self-satisfaction, rather than the needs and wants of the dis/abled woman they are working with.

I think...he or she needs to be very pro-supporting victims in understanding what's happening to them and making productive, healthy changes within their own life, but not actually babying them. Like enabling people to actually make their own decisions to move on. I think that's really important. I think we can swamp people with too much, you know, you do this and you do that, rather than getting them, to help them, make their own decisions (J8a).

Alongside this, is a lack of understanding of the concept of interdependence and what this means in professional practice. Poor practice either creates dependence – by rescuing and doing things for women rather than with them, or, as was frequently identified as a developing problem in New Zealand violence services, expecting women to be independent – for example, providing the information to women leaving abusive relationships that they must apply for a welfare benefit and then requiring them to negotiate the system alone, despite their lack of knowledge of the

system, the increasingly complex and hostile environment of the service and their traumatised state (FVDRC, 2014).

...when I was at Refuge you would go with the woman to Work and Income...lots of them aren't doing it. So that women are turning up at court by themselves. They're turning up at the hospitals by themselves. They're getting sent to Work and Income and lawyers alone, because they're just told to go rather than supported to go (S1m).

Poor practice blames and victimises abused women. It places the blame and responsibility for abuse within abused women and something they have done – rather than placing responsibility with the abuser (Institute of Medicine, 2002). According to Barnett et al. (2011), abused women are frequently blamed for the abuse they are experiencing – by perpetrators, families, members of the public, faith community leaders and entire cultures. Those whose job is to help women escape abuse - agency personnel and professionals such as law enforcement, criminal justice personnel, welfare workers, child protection workers and medical personnel - also blame them. This includes women who are trained to help victims of violence such as refuge workers. Refuge workers can be hostile and fail to help women they perceive as blameworthy (Barnett et al., 2011).

Yeah, and she's often, you know, as we know, often blamed, or seen as being complicit in her abuse in some way. Yeah. If only she, if only she. And she's usually done a whole lot of stuff [to get out]. Instead of it being more about why he's doing it, and why doesn't he stop (D3v).

As identified by the FVDRC:

This individualist approach to safety planning had the unintended and dangerous consequence of placing the responsibility to stem the abusive partner's violence and initiate safety plans solely on the victim – someone who was extremely vulnerable, with limited resources and social supports, and in a state of considerable trauma. In the regional reviews, it sometimes appeared as though the abusive (ex-) partners disappeared from the frame and there was little system accountability put in place to curtail their ability to use violence or to enable opportunities for potential long-term behaviour challenge and change (FVDRC, 2014. p 83).

Women are blamed for their circumstances for a number of reasons. This includes the belief that abused women have done something wrong, which has led to the abuse that they experience. This can be not doing what their male partners tell them

to do, resisting abuse physically or verbally or being too passive. Women are blamed because they are perceived to be involved in a consensual relationship, because they have not left the offender or because they do not fit stereotypical perceptions of a good mother and wife (Barnett et al., 2011). Dis/abled women who require help and support are blamed for abuse when their caregiver gets tired and harassed and 'carer fatigue' sets in, leading to abuse. This is often excused as the 'poor under-supported carer' with the difficult burden of a disabled and/or elderly person to care for, becoming frustrated, resulting in 'inadvertent' abuse from family members and others.

We have the odd case of perhaps the older daughter has stayed home to look after Mum, may have given up her career and just gets tired and frustrated, 'I won't take Mum out of bed today, I'll leave her there', she may need to go to the toilet and she just goes 'nah, I'm not going to do it', or doesn't give her her meds. It's those things that you can understand, but it still amounts to abuse. So for older people it's a whole range of things...it's about neglect... older people are often neglected by family. Financial things, we have a lot of it in xxxx, were there's a breach of power of attorney. For example, 'yes I've got enduring power of attorney, therefore, suddenly I have all of this control', when it doesn't really work like that. Taking the eftpos card, going and spending the money. People getting into relationships and getting taken advantage of (T1e).

This risk of carer abuse was also described in the context of carers being alone with the people they are providing services to and how this can create the circumstances for carer abuse to occur, as a consequence of the behaviour of the disabled woman.

So if they have somebody coming in, an hour in the morning to get them up and dressed and showered and then going back an hour at night, go to bed, there's only one to one, there's a lot of space there for abuse, especially if the person with the disability is annoying, for whatever reason. They might be annoying because they can't do some things. Or they might be having a bad day or whatever (B2m).

Women who drink or take drugs, who fight back when being abused or are angry and abusive to police are often seen as problematic and causing abuse rather than resisting it. Hager (2001) identified a number of ways that women who have developed mental health problems as a consequence of domestic violence are blamed for their circumstances. This includes 'stropy' women who argue with their partners or don't fulfil traditional female roles and women who present to professionals as angry, mentally ill, or drunk. Alongside this is the pathologising of these women as mad, drunk, difficult, hysterical or otherwise aberrant (Harris &

Wideman, 1988). Consistent with a medical model approach to deficit, once these women's experience is pathologised and/or perceived as aberrant, it must therefore be responded to with behaviour change, treatment and rehabilitation (Hager, 2001) – i.e. it is the abused woman who becomes the focus of change, rather than the abuser. Participants in this study independently reinforced these findings.

We've had an interesting situation just at xx this week where some of my colleagues from Probation were justifying a perpetrator's violence because of the victim's mental health issues and how difficult it must be to live with this woman because of their involvement that she's a loose cannon and therefore, you know, the fact that he does what he does, it's really minimal compared to how frustrating she must be to live with (D2v).

At the same time that a woman's behaviour is being used to justify blaming her for the abuse she is experiencing, men's mental health problems and drinking are used to excuse their violence.

...when we're talking in domestic violence terms...a mental health disability, the fact that this guy was...so mentally unwell, that his drugs weren't working, is an excuse for his violence. But...when it's the woman that's mentally unwell, it's the reason it happens [and] the reason why she can't care for her children...That explains why he murdered his children, because his medication wasn't working...but with women, no wonder he's abusing her, she's nuts (A2v).

Poor practice can begin with poor organisational values and processes. If organisations do not have a clear, well-articulated values base that all staff are expected to adhere to, there is no guidance for good practice. Many of the organisational values that were articulated by managers and staff of various organisations were personal attributes expected of staff – such as integrity, compassion, honesty and being non-judgemental. They did not provide an underlying philosophy for practice.

Exacerbating this, very few organisations had policies about how to receive, and respond to, disclosures of abuse from disabled women.

Practice model

From this information a model of practice can be developed (Table 4). As identified previously, there appear to be no documents that describe best practice at the intersection of violence and disability in either sector in New Zealand. There are

service specifications for disability services, which require the employment of suitably qualified staff to provide services, but no indication of what this means or what it might require in the way of knowledge and attitudes.

Table 4: Model of best, good and poor practice

<p>Best practice</p> <ul style="list-style-type: none"> • Understands interpersonal and institutional discrimination, stigma and oppression • Works from a socio-political contextual orientation and analysis • Understands hegemonic structures/privilege and questions this • Comfortable with complexity • Has a good analysis of power (political, social, economic, privilege) including empowering processes • Informed. Understands the history of both movements (disability and violence) – social justice, inclusion, enablement, inherent human rights, control and current political context • Decisions, policy, legislation etc. developed with core group (e.g. dis/abled women).
<p>Good practice</p> <ul style="list-style-type: none"> • Everyone is a person – inherent respect for all people • Listening, doing what women want, not what you think is best, offering real choices and options • Honesty, integrity • Enabling not protecting • Eliminating barriers, enabling voice • Non-blaming – not victimising • Interdependence rather than independence or dependence • Empowering = walking alongside, building power – not expecting people to act alone • Responsibility placed on the perpetrator of violence, not the victim.
<p>Poor practice</p> <ul style="list-style-type: none"> • Rescuing, helping, protecting • Working from a medical/individual deficit paradigm • Without critical analysis • Wanting people to say thank you • Individualisation as a consequence of lack of training • No, or little, knowledge of history, of social movements, complexity or determinants • Expecting independence or dependence – no informed concept of interdependence

- No values base
- Blaming/victimising
- Responsibility placed on victim of violence, not perpetrator
- Decisions, policy, legislation etc. made without reference to core group – voices not trusted
- Hegemonic values adhered to and believed
- Uninformed, untrained, not resourced
- No shared understanding within and between sectors.

The model explains the various levels of practice from an individualising, victim blaming, rescuing position (poor practice) along a continuum to an understanding of power, oppression, discrimination, complexity and the socio-political environment that the service is operating within, and the socio-political environment of dis/abled women (best practice). Broadly, the model describes those who collude and those who have the ability to question and reframe.

As a number of participants identified, when recruiting staff, it is important to prioritise people who hold the values that are important and inherent to the employing organisation, as the specific content can be taught. *“Values are much more important than knowledge – you can impart knowledge quite easily but it’s difficult and exhausting perhaps, trying to impart values”* (D5d).

This model suggests that in order to ensure good/best practice we need an educated workforce that brings the values and understandings identified in the model to the sector. This requires people not necessarily educated to understand the sector-specific content, but well-enough educated to understand the world, with skills in critical thinking and the ability to understand the complexity and theoretical implications of the contexts they are working in. There are many good people working in both sectors, however, as identified earlier, there are also many people who work in the sectors, especially the disability sector, who are relatively uneducated and have very few employment options. As Healey et al. (2013) explain:

Although not a change strategy in, and of themselves, standards, codes and guidelines can provide a platform from which dedicated managers and workers can lead, train and shift practice in and across organizations [sic].
(p50)

Conclusion

The paradigms and related practice identified here are, like the previous chapter, based on varying levels of knowledge, training and analysis of the issues relating to

the sectors worked in, and about how participants value and respect dis/abled women. It is clear from my research and from the work of the FVDRC, that there are still many people working from an individualised understanding of violence and related support. This results in harm to dis/abled women, re-abuse by the people provided to support them, and lack of options for many women who require safety.

There is one potentially enabling factor identified in this chapter. This is the shared desire, identified in Chapter 5, to help people. Two understandings of helping are identified in this chapter. One is rescuing and ‘fixing’ women by telling them what to do and creating either relationships of dependence, or expecting total independence, including women being expected to negotiate complex government welfare and justice systems alone. This understanding of helping can victimise and blame women who are unable to negotiate safety or full independence. The other understanding of helping is interdependence; enabling women to find their own solutions, while supporting them as required.

This chapter has looked at individual and organisational issues related to the lack of constructive response to the abuse of disabled women. The next chapter examines societal and governmental attitudes and resulting practice, and more fully describes how these exclude dis/abled women from society and impede their ability to escape violence.

Chapter 7

Exclusion not inclusion – the processes of exclusion and invisibility

Because a woman is a woman, is a woman, whether she's black, brown, pink, white and certainly all the other complexities that are around her, shape her. But I don't necessarily know if that woman's needs and having a disability is any – her needs inside are no different from a woman that is able bodied (J4v).

Introduction

The previous two chapters identified a number of pragmatic reasons and underlying paradigms that prevent constructive collaboration between the violence and disability sectors. But pragmatic concerns and poor practice are the effects of inattention to the issue of abuse of disabled women – they are not the reasons that this issue has remained unexamined and unresponded to for so long. Underlying these day-to-day restraints on practice are far more embedded and insidious attitudes that prevent most people in society ever knowing that there is an issue to be addressed. Many of these attitudes pertain to both women and disabled people.

As discussed in the literature review, Morris (2008) identified two paradigms that oppress and exclude disabled women. The first is the universality of the male perspective and the second is the rightness of the able-bodied experience. Both being male and being able-bodied are treated as universally positive positions (the hegemonic position) from which all other experiences are perceived as other, limiting, and negative (Morris, 2008).

It's this whole myth that exists about us, myths exist about everything, it's like the masculinity myth, this myth of the masculine. It only exists through showmanship, there is no such thing as true masculine identity or true feminine identity, they are socially constructed identities. They're constructs, we can get rid of them at any time (H1a).

The negative conceptualising of dis/abled women as 'other' (Frawley et al., 2015) enables the discounting of dis/abled women's words and experiences, which in turn makes dis/abled women's experiences invisible, unimportant or aberrant. This chapter first examines ideas that have been uncovered in this research that are indicative of the various paradigms/understandings of the participants in relation to these two 'universal' standpoints. This leads to a greater understanding of the barriers within and between sectors.

Closely related to this negative conceptualisation of dis/abled women are the exclusionary processes that create invisibility of people and issues. The (New Zealand) National Health Committee (1998) identified social inclusion/exclusion as one of the determinants of health that have either a positive or negative impact on health and wellbeing and indicate that disabled people are one group particularly susceptible to social exclusion. WHO (2011) reports that disabled people are excluded from equal access to education, employment and health care – including disability-related services – and are excluded from “*everyday life activities*” (p xxi).

Social exclusion can be understood as:

...dynamic, multi-dimensional processes driven by unequal power relationships interacting across four main dimensions – economic, political, social and cultural – and at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights, which leads to health inequalities (Popay, Escorel, Hernández, Johnston, Mathieson, & Rispel, 2008, p2).

What is identified in this research is the “*multi-dimensional disadvantage that social exclusion causes*” (Appleton-Dyer & Field, 2014, p15).

DH: So how do you see yourself in relationship to the domestic violence and sexual violence services...Is there overlap?

R7d: I'm not being mean, but they don't see us disabled people getting, 'cause it's about equality, they don't see disabled people as getting abused. So we have to do it our self...They haven't put us as equal, as we get abused too...I don't see them mingling in with disabled people, so it doesn't sound like they're treating disabled...people as people, that have been abused, like the whatever people. It's just they're not mingling, weaving together, or, they're on one side, we're on, disabled people are on another side. There's nothing. It's declusion and it's not inclusion.

In their review of factors that contribute to the exclusion of disabled people, Appleton-Dyer and Field (2014) found that exclusion occurs via determinant of health level issues such as social policy, the labour market, societal attitudes and perceptions about who fits societal ideals and who is ‘other’, and perceptions of valued and devalued roles. This, they say, is not about individual responsibilities and choices – it involves agency on the part of those (individuals, institutions and structures) who are excluding either actively or passively.

The exclusion of disabled people begins in institutions and homes that do not value disabled children and adults. One participant talked about staff and family carers becoming habituated to bad practices in group flats or homes, which are run as “*mini institutions*” (P1g). In this situation disabled people are “*raised without love*” (P1g) and consequently suffer all the harms associated with lack of attachment and lack of loving care. As one person said, “*the more quality relationships people have, the safer they are*” (GR2a).

The participant below identifies the loneliness and feelings of exclusion that can be experienced by disabled people who are living in the community, but not part of a community:

The analogy is that you can still be alone in a crowd. So, we can put you into the community and we can set you up well, but unless you're part of that community there's no real outcome for you except that you live here...But you're still alone, you've still got nobody you know, the only people you know are the people who are paid to be there. And they have varying degrees about how they treat you, what they think of you (G1a).

Many women who experience domestic and sexual violence feel stigmatised by the professionals and services that they go to for help. This includes police, justice, physical and mental health professionals, parenting support programmes and domestic violence agencies (Crowe & Murray, 2015). The kinds of stigma experienced have been described as: “*blame, discrimination, loss of status, isolation, shame, dismissed/denied, and blatant unprofessionalism*” (Crowe & Murray, 2015, p162).

The research identifies a number of ways that dis/abled women are stigmatised, marginalised and excluded generally in our society and specifically from consideration when sexual, domestic and wider family violence services are being legislated for, developed and funded. The second and third themes in this chapter examine this marginalisation and exclusion and the harms it causes. Table 5 presents the three themes and seven sub-themes examined in this chapter.

Table 5: Themes and sub-themes – exclusion not inclusion – the processes of exclusion and invisibility

1. Hegemonic repression and devaluing of dis/abled women

- Lack of data collection in mainstream research
- Lack of representation in policy and legislation

2. Societal myths, stereotypes, stigma and discrimination – and the harm caused by these

- Not seeing dis/abled women as ‘real’ victims of abuse and violence
- Not seeing dis/abled women as credible witnesses

3. Objects not subjects

- Lack of trust of the ‘other’
- Regulation of bodies: organisational/state control and surveillance
- Learnt compliance

Hegemonic repression and devaluing of dis/abled women

The hegemonic ideal within Western and other societies – male, heterosexual, white, non-disabled (Morris, 2008), with economic power and personal characteristics that determine high status on a hierarchy of hegemonic masculinity (Hatfield, 2010; Murphy, 2009) – was identified by a number of participants. “*The standard that we have for equality is male*” (D1m). Hegemonic positioning was identified as problematic by participants; they recognised it as a marker of inequality between men and women and non-disabled and disabled people. It positions dis/abled women as ‘other’ in relation to the dominant hegemony and results in abused dis/abled women being perceived as deficient and of very little value in the world.

...we predominantly live in a patriarchal society where men's needs are put first and women are busy supporting how things run and supporting the status quo... just in terms of how children are treated differently, girls and boys depending on their gender, in terms of how we deal with violence or behaviours...the basic stuff like how we support certain things for boys and other things for girls. In fact more support for boys in certain areas...and men's jobs, women's jobs, and just the subtle ways girls and boys are influenced and how they behave. And...I tell you what's particularly prevalent in domestic violence...there is a real sense of hierarchy, depending on gender, so we very often see that the father leaves and suddenly the boy feels he has to be head of the household ...just tryna think back to when I did the men's groups, it was really obvious with some of the men as to what their roles were in the house. Though there were other men who did all the equal stuff, you know, did the cooking and all that, but they still had that control thing. And when it came down to it their attitude was that they were more right than the woman...Somehow there's always these biological reasons of why women are in one position and men are in the other (R5v).

Murphy (2009), using Connell’s (Connell, 2005; Connell & Messerschmidt, 2005) theory of masculinities, positions women below both marginalised and subordinated

masculinity (men) and identifies that many abusive men “are motivated by social messages that represent hegemonic masculinities as superior” (p329).

So there's things around power, there's things around how men are perceived in our society and how they're allowed to be perceived. So what it means to be a male, what it means to be above women, 'cause often times it's portrayed that these are the qualities of men and anything less than that are what's always attributed to women. And so with the imbalance of that...(A1v).

These social messages become internalised by many men who consequently devalue women’s opinions and beliefs and choose only to listen to men’s words and ideas, particularly those men who are considered higher on the dominant masculinity scale (Murphy, 2009). This renders dis/abled women invisible in private and public discourse – because even if women are speaking about private or public issues, they are not heard or may be actively ridiculed and threatened to prevent them speaking out (for example, see recent discussions of cyber hate).

Understanding the factors that come in around patriarchal types of oppression and those inequalities which many women were campaigning for in the second wave in the early 1960s, which is still as relevant and prevalent today. Understanding all the mechanisms that can render women silent (C1v).

This also enables the discounting of women’s experiences of abuse, as women are not perceived to be credible witnesses to their own, and other women’s, experience. Women also internalise and transmit these messages of male superiority, further reinforcing the collective paradigm.

A developing understanding from the academic investigation of structural hierarchies and privilege, is that it is not only men who silence certain women. For many years women of colour, lesbian and disabled women have been investigating the Eurocentric, hetero-normative thinking of the women’s movement (for example: Crenshaw, 1992; Morris, 2008; Shildrick, 2009; Sokoloff & Dupont, 2005). Shildrick (2009) discusses non-disabled feminists’ lack of engagement with disabled women and the issue of disability and disableism and how this creates non-disabled women as the hegemonic unexamined paradigm with the “*problematic of difference*” (p34) being sited within disabled women’s bodies.

...I think even within the feminist movement, even the fact that you know, we're looked at as very much a white middle class movement that come out with some of these ideas and I think, yeh, there is a hierarchy. That even as a

feminist woman myself, I'm part of that hierarchy in a place privileged probably more than a lot of people with disabilities. So I think it's really important to take on the critiques or certainly the idea that we need to look at the able-bodyism, ethnicity, social, economic, and look at our own place of privilege; and I suppose being able to reflect on that. So absolutely there's a hierarchy and disability, I would say, would feature not very high at all (T3v).

Alongside this is the hierarchy of who is valued and prioritised in policy, funding and support provision. The participant below identifies that currently many government policies are focused on vulnerable children:

We have a devil's own job if we need to transfer a woman...we cannot get women without children into any refuge in Auckland and that is their funding, I understand that, that that is their funding. So a couple of the refuges do have a bed that they will hold for single women and they are all absolutely constrained by this and...it's an ethical dilemma for them because they have the same passion that we do. It's not only the acknowledged refuges and we researched a lot of other places in Auckland where women could go and be safe but they just won't accept them, because there is no funding (J4v).

Feminists are concerned that the focus on children not only eliminates mothers from policy and funding consideration, including increasingly, government only funding domestic violence and similar services for women who have young children in their care (Confidential personal communications 2014–2015, with various domestic violence sector service providers)¹⁰, but totally excludes women who do not have children or children in their immediate care. As many disabled women are actively discouraged from having children, including, for some, forced sterilisation, these women are triply excluded from service provision – abuse not recognised, no accessible services, no children.

Another participant felt that disabled people are not valued as highly, in government policy and responses to abuse, as non-disabled children:

Working with [disabled] people seems to be very undervalued and we've got to bring changes and that will also help with better supporting people and

¹⁰ These providers must remain confidential as government 'gagging clauses' prevent organisations from discussing or in any way publicising this clause in their contracts.

hopefully you won't see abuse happening so much. It has been happening. We heard about that place in Auckland and there are a few other places that have been reported with things that are happening to people with disabilities and, in this day and time, it shouldn't be happening. Why are these things happening to people with disabilities? They jump up and down when it happens to children but when it's people with disabilities, we don't even blink an eyelid. So why is that? Why are people with disabilities the lowest end of our society still? (R4a).

Other participants talked about how older women were almost totally ignored in service provision, research, policy and legislation – except being seen as burdens/a cost to the community:

No one calls the police for the elderly – they call family or health professionals. Both these groups are limited in what they can do – and neither tends to call the police. Even when there is long-term domestic violence, no one will work with old women (MC6e).

and:

...in particular past roles that I've had, elder abuse just falls off the radar (DS4a).

This participant reflects on the intersectional disadvantage of being Maori and disabled:

...I'm going to say from my point of view, women with disabilities, I'm not talking about men. So women with disabilities are [not] even acknowledged, they are so far down the pecking order. If you're a Maori woman in a wheelchair, what hope have you got really? It's just so far down that pecking order for people with disabilities (H1a).

All of these things indicate a hierarchy of value that is perceived by those who sit outside the dominant paradigm, but frequently remains unexamined and unquestioned by those who benefit from it.

It is that right, the dominant culture, the dominant paradigm doesn't need to take account of the minority as long as they act accordingly. So be a disabled person and whatever and don't challenge outside that, then there's no problem, the dominant hegemony, yeh...and that's what makes it so

difficult to address, that it's so, um, present that it becomes invisible and that's its power. That's...where power gets exercised...in that thing of, in that moment the person just thinks 'I'll just go to the toilet'. Somebody else with a disability thinks 'Oh God is there a toilet I can get into and get out of' (B5g).

Faith (1994) identifies one reason for the lack of progress on changing/challenging this paradigm. She contends that one unintended consequence of feminism and of breaking the silence about violence against women was the increased public perception of women as powerless. I note, for example, that many of my students immediately use the words 'learned powerlessness' when they talk about abused women and other groups perceived as marginalised or powerless. Faith explains this as women, while no longer objectified as male property, becoming objectified as the victim – which conflicts with demands for equality. How, she asks, can those who need protection in the real world (real world = male world), be equal? She claims that the hegemonic enshrining of male values into everything – law, economics, science, religion, medicine and social policy – facilitates and creates rationales for victimising women.

Lack of data collection in mainstream research

If society is assuming heterogeneity based on hegemonic norms, the lives and specific situations of many individuals and groups of people become invisible in policy and planning and in mainstream interactions, conversations and consideration. Bogard (2005) describes this as socially structured invisibility. This invisibility can be created by assumptions about race, class, sexuality, gender and the social value placed on certain groups. For example, if information is not obtained or available in New Zealand Sign Language, then Deaf people will not be able to access it and information about their circumstances will not be collected. As national surveys about domestic and family violence do not include people who live in residential situations (group homes, rest homes, etc.), employ New Zealand Sign Language interpreters, or specifically ask people about impairment, there is no way of knowing the real prevalence of violence against disabled women.

...it's suggested that 1 in 5 women experience DV, (DH: 1 in 3), so if that's the case and we have a high rate of disabled with violence in any way, with abuse of some form, then it would suggest to me that it would be much higher for disabled women and even much higher for indigenous disabled woman, because it's suggested that 1 in 2 Maori have faced domestic violence of some sort, so if that's the case then how much is it for Maori disabled? To me, I believe that it's much higher but we have no proof of that, because nobody looks into it because it's not regarded as important enough or we're invisible or you become a hidden stream of the main stream (H1a).

Sometimes, including disabled people in research can be excluding of their real needs, including by not asking the right questions or investigating a non-representative group of people (Shuttleworth et al., 2012). Wilkinson-Meyers et al. (2015) have found, for example, that in New Zealand the identifying and prioritising of resources for disabled people often relies on surveys of current use by disabled people. This approach can minimise need as disabled people may not be aware of possible services or may be unable to afford the available service – hence underestimating actual need.

Lack of representation in policy, legislation

The exclusion of dis/abled women from the research and policy/legislative process can further re-victimise and marginalise these women. Professionals do this by excluding dis/abled women from decision-making, ignoring what dis/abled women say and not adequately supporting women to participate in consultation processes (Hager, 2011). Dis/abled women can be excluded from consultative processes by impacts of poverty and/or social class; an inability to attend – having more pressing day-to-day concerns; feelings of shame or lack of entitlement; cultural imperatives or differences; concerns about safety and confidentiality; and the ongoing effects of abuse-related trauma (Hague, Mullender, & Aris, 2003). The harm caused by this exclusion is the invisibility of dis/abled women’s lives and experiences in statistics and research and therefore in policy, legislation and other solutions. This lack of representation can occur in two ways; one is by passive exclusion – disabled women’s circumstances and voices not being considered when policy and legislation are being written; the other is active exclusion. *“There is a lack of knowledge, like ...do you know that the MOH keeps a tally of domestic violence deaths? But they don’t include disability”* (R3a).

Both active and passive exclusion from research and data collection create invisibility of the issue and the population group.

...there is a lack of evidence...out there, there’s a lack of other research to have other knowledge and information in there and it’s also hard to talk about disability because it tends to be largely invisible. Because we don’t have this data and we don’t have the voices articulating and talking to government and other players and there’s other priorities on-board...But it’s not like things have been explicitly ignored, it’s just that they haven’t been actively identified and addressed as a discrete population group (P2m).

This lack of policy and legislative response is attitudinal, a disregarding of the rights of dis/abled women, which means that there are very few avenues for services to use when abuse is recognised.

[for children] what we can do straight away is go to CYF and do a report of concern. So there's a statutory, and an agency and a mechanism that allows for an intervention. But people with disabilities and the elderly it's really difficult. There...are very few mechanisms; so unless the person themselves says 'I'm being abused', in which case that's fine we can go to the police or whatever or Age Concern, GPs, or Support Works to get assessments done and alternative care provided for them. But if the person themselves is in a situation where they're being abused and isn't prepared to describe it that way, or disclose it, we know it's going on, it's really difficult...So we did get Age Concern involved. But again...they don't have statutory authority over anything, so they can't, technically they can only go in when they're invited in (B5g).

The participant above identified a number of potential avenues for responding to the abuse of disabled women. Only one of them, however, has any statutory power – the police; the others are primarily a health service response – assessment and respite, which neither hold the perpetrator responsible nor prevent harm. As discussed in Chapter 2, in New Zealand there is no domestic violence or related criminal legislation that acknowledges the reality of disabled people's lives and the people who they interact with in an intimate and domestic context.

Some of that's around gaps in legislation...one of the gaps you've got is family violence legislation...doesn't cover everybody that's experiencing abuse, it falls outside if it's around carers or it doesn't fall under the definition, under a close personal relationship. So as a nation we need to look at legislation so it supports people wanting to tell their stories, but to put the interventions in place to make sure it doesn't happen again (GB6v).

The following participant identifies that there are also considerable barriers to using the courts and related polices for protection.

Now the crimes against us, I believe, are hate crimes, but because we are not seen in the domestic violence field we have no protection. The only thing that we can do is put out a trespass order but beyond that to get a harassment order or protection order requires a lot of work. Protection order you can't get, you can go harassment order but harassment orders are notoriously difficult to get. And that means a lawyer. How many disabled people are

lawyers? So there is nowhere for disabled people to go to be protected (H1a).

Integral to the ignoring of certain groups of people is creating policy, legislation and services about and for people, rather than with them. We have a long tradition in New Zealand (and the rest of the world) of making policy about and for women and disabled people without listening to their voices or considering the consequences of government and other's actions for their safety and wellbeing. This lack of engagement is evidence of hegemonic thinking (what works for white able-bodied, wealthy men will be suitable for everyone) and also of stigma, discrimination and the desire to avoid/not have to make contact with, not give credibility to, dis/abled women (Allport, 1954). A number of people have written about the need to consult and address the articulated needs of specific communities in order to produce good policy and create services and responses that really work for specific groups or communities (for example Hague et al., 2002; McClain, 2011).

This research uncovered a number of examples of consultation, policy and legislation made without reference to disabled women (or men). One example was an Auckland Council meeting designed to bring the wider domestic violence sector together to discuss issues and develop an Auckland-wide plan.

The example of that was when we were at the Marae that time and the disability group wanted to present but were told they couldn't – and there were five Maori presentations, there were only meant to be three, and I don't know why they couldn't all present together. I am Maori, but sometimes it's just a bit overboard (H1a).

A participant who works as a Violence Intervention Programme coordinator for a District Health Board, responsible for all training of staff and overseeing the hospital screening for domestic violence, identified that nowhere in either her contractual obligations or the MOH guidelines that guide practice responses for screening and responding was there any mention of disabled people.

B2g: I'd have to go back and have a look at my service specification.. I'm almost certain I've never seen anything written around disabilities in here, not even child disability. Talks about Maori, Pacifica, Whanau Ora, so that's it...Have you seen the MOH guidelines, is it in there?

DH: No, I don't think so.

B2g: They do talk about gay/lesbians/transgender. One of our exercises in our training, to look at how difficult it is to seek when you have other potentially stigmatising types of, you know what I mean. But I don't think a

person with a disability is mentioned. It's gay/lesbian/migrant women, what are the barriers for them to help seek if they are in a violent relationship. But I don't believe that one of those people is a person with a disability...It's shocking; we're doing it within our own sector, in a way – marginalising – and by doing that, increasing the risk to this group of people in our population (B2g).

The response of participants from government ministries, in relation to addressing the abuse of disabled women, was interesting. While they acknowledged the need to address the issue from a policy perspective, most participants abdicated responsibility to initiate action by saying that it was, of course, an issue they would participate in discussions about, but that these discussions would be led by other parts of government. This was also articulated as various ministries working in silos – and that this would need to be overcome in order for the two distinct areas of violence and disability to be addressed.

...government has a clear role in that, disability advocates as well as refuge advocates, and probably we are siloed in government really, it doesn't do anything to undo the silos. The silos, I'm not saying there's a cause and effect, because I don't really know. To some extent it's probably a mutual interplay going on there (LK4m).

Societal myths, stereotypes, stigma and discrimination – and the harm caused by these

As identified in the literature chapter, there are many myths and stereotypes about both disabled people and victims of sexual and domestic violence. These include a number of myths at the intersection of these two issues that are particularly devaluing of the experiences of disabled people and devastating in their effects. The relationship between societal myths and stigma is described by the participant quote below, where myths and the associated stigma about domestic violence, disabled people and feminism are all identified:

B2g: There are still myths out there, strong myths around family violence as you know.

DH: So what sort of myths are you talking about?

B2g: Well, that it's not that big a problem that people think it is or it's too big, there's nothing you can do about it, it's an anger management issue and all of those kind of things, it's the woman's fault. This morning I was in maternity with a woman, who is a professional woman, who actually did the training that I did, that I provide and was saying a lot of the text book

answers about he says he loves, he didn't really mean to do it, all those things that women say because it gets distorted in their brains, even though one on one she knows the other messages as well, so if our community and our cities and our country are all saying the same thing, eventually it has to have some impact, I believe.

DH: What's the overlap between violence and disability?

B2g: Vulnerability and no voice. I think people with disability are even worse, struggle more because they are stigmatised because of their disability and I think women in violent relationships are stigmatised as well, labelled, looked upon as inferior and things like that...and...that's a stigma too, feminist, because it engenders a whole lot of...discussion around just the use of those words when we talk about [it] ...people don't want to be associated with it because of the stigma that is attached to it and there is an example of how it perpetuates in our society...unfortunately that word, for a variety of reasons...feminist, is not perceived in a positive way but if people read and understand what it actually means, you can't but agree with it, because it is about social justice, really, at the bottom line.

The stigma of being feminist was mentioned in a number of interviews.

...it's that old saying 'feminism is simply the radical notion that women are people' and it's as simple as that, it doesn't have to be loaded and weighted with radicalist notions or bra burning or those other kind of weird stereotypes (C1v).

The following quote identifies that women are stereotyped and not listened to if they are seen as “*too passionate*” or feminist. These are both attributes that enable women to be ignored.

Being a staunch feminist they're all seen...you're just a woman ranting on...When you're passionate about it...People don't listen when they think you're a feminist or very passionate...(DS4a).

Participants identified a number of myths and stereotypes about disabled women, such as that disabled women aren't abused (see this chapter); disabled women are asexual; and “*You might catch it! I think the fear is that we don't have brains and we're uneducated. But I think more than anything is that we are people to be taken care of*” (R1d) and “*Their probably life-long attitude towards disabled people that they're kids or whatever, they don't have minds and whatever*” (R7d).

One participant observed that some families are fearful for a number of reasons related to mythology and stigma about dis/abled women's sexuality and sexual activity. They are afraid that disability will be inherited, that disabled women are promiscuous, and also, they are frightened not for the safety of their daughters, but how their sexual activity might impact on their own standing in society:

...my daughter, I don't want her to have children because I don't want it passed onto my grandchildren. And so that's a form of abuse where the person doesn't have the ability – yes, no, argue, or whatever, they are put onto the pill, whereupon they don't exactly know what that's about, they just have the normal sexual tendencies, in the community they are seen as something's wrong with them, they are sex mad, they are bound to have something happen to them along the way... Young girls labelled as promiscuous and they didn't know what to do about it or where to go for help. So they go for help and they are told 'oh well, we'll put you on the pill shall we because you're just going to bonk whoever you want anyway' ...but the help isn't there for them because they're put into that context of 'you're always going to do it anyway so what's the point' ... it happens because parents will hide things like that as well, they hide things, like my daughter's out at night sleeping around, they don't want that brought into the notice of a group, especially in a small town, because they don't want it known that their daughter is promiscuous and they haven't got control (D6d).

This perception leads to the next identified myth – “...that these aren't people anyway, so it doesn't actually matter, we can treat them [however we want] and nobody cares about them” (NP2). This total lack of valuing is expressed in the abuse and neglect identified in the poor practice discussed previously.

As identified in the literature review, there is a public/societal fear of disabled people who are perceived as “scary monsters” (C1v).

You can stigmatise disabled people as being violent...it's just like in the mental health sector, if you go back, perhaps 15 years, you'd be stigmatised (C4d).

The fear of, and prejudice against, people with mental health problems, has not abated. “People...equate, even today, mental illness with a perpetrator of violence” (P1g) and “One of the big issues is really the ongoing problem of people misunderstanding the relationship between violence and mental illness, which is really that people are more often the victims than the perpetrators” (L1d). This is particularly concerning in relation to the prevalence statistics of violence against

dis/abled women with mental health problems (For example, Goodman, Rosenberg, Mueser, Drake, 1997; Khalifeh et al., 2015).

The following quote identifies that disability is associated with various easily identifiable ways of being that stereotype disabled people:

I've heard, some of my colleagues, 'but we don't have disabled people come into our work', which I find extraordinary. My question is then 'what does a disabled person look like'? (C1v).

Participants identified that, because of the stigma and discrimination associated with mental illness, women who are already perceived to be mentally ill/crazy/mad/substance dependent will frequently find that their testimonies about abuse are given less credence than those of other women, or that they are not believed at all – while the abuser is believed/seen as 'sane'. This is consistent with my previous findings (Hager, 2001). However, all disabled women experience this lack of credibility, especially women with learning disabilities.

Alongside the myths about disabled women are the commonly held rape myths that focus public, police and judicial attention on abused women's behaviour and culpability, rather than on the behaviour of the rapist (Anderson & Doherty, 2008; Buchwald et al., 1993; Gavey, 2005).

Just thinking back to rape myths. How widely held they are. They're so widely held that people don't know that they're myths. I'm sure that around disability is the same thing. I would be incredibly surprised if it wasn't. And you know, there are those attitudes and beliefs, that need addressing, fundamentally, and I'm not saying that's easy, but for things to change...as we're sort of, you know, aware now with violence with the primary prevention, [if] you really want to stop it then...you need fundamental social change in beliefs and attitudes and norms, and finally behaviours (D7m).

As a consequence of conversations such as those above, I started asking people if they felt that myths about disabled people and feminists could hinder connections occurring between the two sectors. Many participants felt that they would.

Some participants talked about how, in the disability sector, gender isn't as much of an issue as it is in mainstream violence politics and practice, as disabled men are significantly more likely to be abused than non-disabled men.

...because gender, even though women are the main victims, there are men with disabilities, boys with disabilities that are beaten and abused. The ones that were left starving in that rest home, for instance, eating grass, this is in New Zealand, we can't do them under, we can do them under the crimes act, but even that was weak, because they were in domestic relationships, because they were living with them and so, there's this fine line there, we need to cross it sometimes, we need that crossover, but we have to look at gender as it's not always gender based, it's women carers beating up women clients, male carers beating up male clients. The risk we have is that it's not always a gender base; it's based on the power imbalance that exists (H1a).

However, the intersection of gender, violence and disability is problematic from a hegemonic perspective. Referring back to ideas of hegemonic masculinity, it has been recognised that on this scale, disabled men are seen as subordinate and not of value, due to being perceived as dependent, childlike and helpless (Asch & Fine, 1988; Shuttleworth et al., 2012). As a consequence of this stereotyping, disabled men are at the bottom of the hegemonic masculinity scale; however, women are below the scale (Murphy, 2009). Also, despite the increased risk of abuse of disabled men, the prevalence for disabled women, as identified in previous chapters, is higher.

Many more myths and societal misunderstandings hinder the ability of dis/abled women to report abuse and receive constructive responses, and consequently frequently result in discriminatory practices. This quote first identifies how staff ignore allegations of abuse and how the manifestations of frustration and anger that abused disabled people are expressing are re-conceptualised as manifestations of their disability, rather than a communication of reasonable distress.

The other thing I found when I was working in the sector as a caregiver ...mainly with cerebral palsy and some intellectual disability was that two of the clients that I'd worked with had had horrific backgrounds of sexual abuse and they had been in institutions...[one] was non-mobile and non-verbal and a very, very bright young man...And he talked about it and it eventually came out. But when that happened and when he started talking about it, it was probably '92, '93, it was all swept under the carpet....And he would sort of have violent outbursts, just really frustrated, he couldn't get out of his chair, couldn't actually do any damage...and a lot of the psychological stuff as well as sexual abuse that he had suffered. You know, like he was just enraged. And everyone treated him like... he was stupid (Tv2).

The participant then identifies the way that adults are infantilised - treated as children or 'pets' by the staff.

...if you see someone with Downs and everyone starts going ohhhh. You know. That kind of thing. And so, yeah, and like I think some of the other caregivers almost saw them as little pets. You know, I mean that sounds awful, but...yeah, you know, would work with them like they were, um, like little pets or something like that Tv2).

Finally this participant highlights the lack of choices that disabled/older people have in some residential situations including not being perceived as able to legitimately participate in adult sexual relationships.

Even though the...ethos of the service I was working with was about it being driven by these four young people that had sort of come out of institutions and gone flatting together, four young adults, all in their early to mid-twenties, I still don't think that the caregivers or the manager at the time were taking seriously what those four young people wanted in terms of their lifestyle and basic stuff. What they were having for dinner, who they chose to spend time with. One of them was in a sexual relationship and everyone was really, really, really up in arms about it. She was having a fucking good time... You know what I mean...so, yeah, lots of discrimination (T2v).

One outcome of not recognising dis/abled women as credible subjects and responding to stereotypical (mythological) portrayals of dis/abled women, is that non-stereotypical women are frequently not offered the policy and hands-on help that they require to be safe because they are not presenting to services as real or legitimate victims. As Crenshaw (1992) noted, it is “*impossible to deny that society views the victimisation of some women as less important than others*” (p1471). This participant identifies that the abuse of disabled people doesn't make it into the papers, which renders this abuse invisible to mainstream society.

I know personally two or three people that have had sexual abuse by carers, and there's some violent abuse by a carer at the moment I'm sorting, helping sort out. Yeah so it does happen, you just don't see it in the paper sort of thing (R7d).

The following participant identifies that disabled women are not believed when they disclose violence and explains how this lack of credibility and belief results in violence becoming invisible.

Also a really huge challenge is that, and especially with the paternal kind of type violence is that the victims aren't believed. You know, um, often working with people with different perceptions to what mainstream people have, and

so they have a different slant on how it all works. They have different abilities of communicating their experiences and so, you know, violence has always been under-reported, you know...probably even more so when you're talking about the disability sector, and so it doesn't exist because it's not reported, you know (E2a).

Not seeing dis/abled women as 'real' victims of abuse and violence

Associated with the invisibility of the abuse of disabled people is the blaming of dis/abled women for the violent and abusive situations they find themselves in. If women don't fit the public hegemonic concept of a 'real victim' they are perceived as less deserving of help and safety.

Particularly for us, I suppose our key area is working with those impacted with mental [ill] health. And there is a culture within the police, is that there are victims and then there are deserving victims, if that makes sense. And if you've got a mental health issue and you've had three or four violent partners, then you're slightly less deserving than this person here whose had one violent relationship and been married for 20 years and decides that they want to get out of that violent relationship. And...that person's gonna be treated better than the one that's had four or five violent relationships...a lot to do with the disability that they have around their mental illness and how that's been managed (J1g).

The participant above is talking about the stigma and discrimination faced by non-traditional victims. However, the lack of recognition of being a victim can originate with the abused woman not identifying her circumstances as sexual, physical or emotional violence. This can be women not perceiving themselves as victims as they do not fit their own predetermined stereotypes;

I remember how many dozens of middle class Pakeha women spoke to us...and said 'the huge barrier for me to access the service, or tell anyone, is I didn't see myself as a victim of domestic violence', 'I worried that people wouldn't believe me' and 'people didn't believe me when I told them, they didn't believe me, they said, it can't be that bad' or all the things that people say to women to minimise their experience (A2v).

This lack of recognition can also be caused by disabled women who are so used to abusive and/or impersonal treatment from 'carers' that they are unable to articulate their experiences as abuse (discussed below), or women who are so consumed by the effort of day-to-day survival that they do not have the emotional energy to recognise, name and articulate their situation (Hager, 2001). Alternatively, it can be

professionals and laypeople who are dismissive of women's disclosures of abuse, as they only recognise certain stereotypical attributes of a 'real victim'. This refers back to the discussion about how professionals minimise women's experiences of abuse through their use of language and their misunderstanding of the language women use to describe the abuse they experience (Chapter 5). The barriers to professional and lay recognition frequently align with the blame for abuse being placed on the victim and/or the lack of acknowledgment that disabled women are abused.

One particular stereotype of a victim has inadvertently been developed as a consequence of the advertising that the national refuge collective and others have done to publicise fundraising appeals. These appeals have often portrayed a young woman, physically damaged, submissive and frightened, usually with one or more small children in her care.

...when you see the ads on TV it's usually about a [non-disabled] woman; it's not usually a person in a wheelchair that's got a bruise on their face. It's a stereotype. Disabled people who are victims of violence aren't part of the stereotype and neither are older people and I don't know how we change that (T1e).

This relates to the previous 'real victim' identity of the woman who "*had one violent relationship and been married for 20 years and decides that they want to get out of that violent relationship*". These are victims who are seen as deserving of state care and protection, via the law and related services, as they fit stereotypical constructions of good women requiring protection by hegemonic paternalistic systems. It is my own experience, training and consulting with the police and judiciary, validated by the experiences of many of the participants and my peers that the concept of a 'real victim' is prevalent in the police, among judges and also among others who work in the criminal justice system. A real victim, in these circumstances, is someone who fits the media portrayal of a victim, above, and is not disabled or one of the 'stropky', drunk or crazy women previously discussed.

Not presenting to services in the ways, or as the person, services expect can have long-term implications for women who are trying to get help and escape violence. Perhaps because of the lack of ability of some workers in both sectors to work with complexity (identified in the previous chapter), and the lack of training about the immediate and long-term effects of violence and abuse, some staff have problems with women who don't fit their stereotype of a real victim.

I think people who have been victims, both children and women, through family violence, often don't get accepted or don't present in a way in which enables them to get the access and support that they need. To give a bit of an example, you get situations coming across the FIVIERS table at the police station where a woman has been, there's a history of, you know, 21 notifications or 70 notifications, and what that actually does to be living in that kind of environment for a long length of time. And you get police officers writing things like, 'gosh, she's quite mental', or... 'I can understand sometimes why perhaps he does what he does' ... I think often that's a system that is set up for not being easy to go through when you're a person who's been lacking in self-esteem and confidence and not in a position to speak up for what you know to be your rights (GQ5v).

All of these things described above can result in services refusing to work with women, and certainly many women in these situations are denied entry to women's refuge. The participant below recognises that women who have mental health problems as a consequence of violence find it very difficult to access services such as refuge that could help them leave the violent relationship and recover their mental health.

Sometimes for me when women have been refused entry...to the refuge, I wondered what was going on there, maybe that was also because I had worked very closely with these women, so I knew... that they were quite expressive, quite loud, and were not afraid to express an opinion and that could also offend many people but it wasn't an indication, I think, of a mental illness. I think it was insensitive perhaps but it was often born out of frustration. It was indelicate, hard to hear sometimes to be on the receiving end of it but I felt their needs, they were dire, overrode that and ... I don't believe they would have been offensive to other people in the house – I don't believe they would, in any way, would have been violent or unkind or trashed the place, I just think, you know, sometimes their manner is a bit unfortunate...it was unrecognised abuse and...a number of women who have been refused entry into refuge when it was viewed that their mental health issues were so to the forefront of their experience that it would not be safe for them to enter refuge because of the welfare of the other clients they are currently supporting...it's enormously difficult...I have clients that have nowhere else to go...some have gone to the street, some have couch surfed with friends, not always conducive to their wellbeing because it's meant that they [are] couch surfing for a very long period of time when maybe one stable place would be more conducive to their wellbeing...[they] ended up back on the ward (L6d).

The denial of services accentuates women's mental health problems and results in many women becoming increasingly mentally unwell (Hager, 2001; 2011).

Not seeing dis/abled women as credible witnesses

Aligned with the lack of recognition of non-stereotypical victims, is the related problem of not being perceived as a credible witness to their own abuse, when women communicate in non-traditional ways or have a disability or personality that is not understood by police.

Even down to being police. How do we...get police to believe it, you know, people could be credible witnesses in court and things don't make it to court because people are going, well, that's never gonna make it...it's not gonna get past that test of being harassed by the other lawyer. Is there a different court system we need? ...Understanding that whole role about how to support someone to have their say and understand what's happening to them is quite a specialised area and they're not doing enough of it. I think we're just beginning to understand sign language interpreters. And that's quite clear. But this is even a bit more murky (C5g).

The quote below further exemplifies the problems that disabled people have being perceived as credible in the justice system, the problems they have communicating, the silencing processes that occur and, a subject that will be investigated further in this chapter, the fear of speaking up in case the little support that is available is withdrawn.

...If you're trying to plead abuse in court and you have a history of mental illness, no-one will take you seriously. Or if you are Deaf you may or may not get an interpreter or if you're blind you can't describe the person or you're just silenced like that very good report said, it talked about the silencing of disabled people. They're silenced by all kinds of different things, you're supposed to be grateful if you are disabled, not complain – and also if whatever service you are receiving is the only game in town and you complain about it, where might you be? (R3a).

As discussed in Chapter 2, in 2010 changes were made to the Solicitor General's Guidelines For Prosecution (Crown Law, 2013), which increased the threshold for evidence required in order for crimes to be prosecuted. This decreases the likelihood that a disclosure of abuse by a disabled person will proceed to prosecution, as it is a strongly-held opinion of many police and judges that disabled people do not make credible witnesses in court.

I know from personal experience – my sister who lives with xxx had been assaulted by staff within the place where she was living and the prosecution of that person wasn't taken forward by the police because they believed that the only witnesses were other people living in the facility and although those people are quite articulate and able to speak for themselves, and probably the main reason for their being there is actually their physical disability, they do have a, kind of a disability component, but quite able to describe in detail. She was lying on the couch and didn't wanna go to bed, the staff member came in and dragged her across the floor kicking her as she went. If you can say that, to me that's adequate testimony. But the police believed that that wasn't gonna be sufficient. Or a credible witness because of the fact of their living in an institution and having an intellectual disability. So nothing was done about that, other than the person losing their job (L1g).

This lack of credibility extends to people who communicate in alternative ways and feeds into police and other's fears and lack of understanding about disabled people, perceptions of disabled people being childlike and other myths and stereotypes about disabled people.

Also identified by participants, as discussed in the previous chapter, and corroborated by my previous research (Hager, 2001), are the stigma and blame placed on women who do not have traditional feminine role responses to abusers – who are 'stropky', who argue or fight back or who are mentally unwell or have substance abuse problems. All of these things contribute to the public perception that abuse (from a male partner or other domestic relationship) is justifiable.

Objects not subjects

One participant identified the lack of engagement with dis/abled women who are daily affected by policy, legislation and service delivery that is developed without sufficient consideration and consultation, as professionals and politicians perceiving such women as objects, not subjects, of the development and regulation of the material they produce.

Objective 11 [New Zealand Disability Strategy] for Maori is not about Maori doing it for Maori disabled, it's about providers supporting Maori disabled into work. If you read the wording, it's quite badly worded and it does nothing to bring Maori disabled to their autonomy – it's actually about providers doing it for Maori disabled. So we are actually, under that New Zealand Disability Strategy based on the social model, further disempowered. It makes us objects within the policy rather the subjects. Object of the policy rather than subject within the policy (H1a).

This was further described in a discussion about how disregarding people's human rights to make choices reduces people to the role of subject – making them less able to prevent or resist violence.

...Some of the key problems that we have are around peoples' human rights being abused through the disempowerment of having their right to choose taken away. And it's that kind of disempowerment that underlies peoples' vulnerability to violence as well. Because if you're told that you don't know your own mind, and your right to choose about really important things is taken away, often people are left with the sense that they don't have any worth. And so why would they put up a fight or resist being abused by someone when they see themselves as subject. So and that takes it up a couple of levels from violence to a wider issue (L1d).

Lack of trust of the 'other'

A number of writers have talked about the 'othering' of women with disabilities (see for example: Fawcett, 2000; Morton & Munford, 1998; Shildrick, 2009; Wendell, 1996). Fawcett (2000) posits being 'other' as "*all those aspects of the social construction of disability that result from the failure of non-disabled people to identify with people with disabilities...*" (p64), in other words, being 'other' is just not being normal. Wendell (1996) identifies two processes involved in making people 'other'. The first is making people objects of our experience rather than subjects we might identify with. The second is to project symbolic meaning on to the other. This projected meaning, she says, is generally something we are afraid of and want to avoid.

The participant below identifies the objectification of disabled people and relates it to current and historical processes of discrimination and extermination. Note the language of othering in this quote – "*one of them*".

They brought some children to the UN and I asked the lady, 'well did you bring a person with an intellectual disability?' 'Oh no, we didn't bring one of them'. And yet children with intellectual disability are part and parcel of our world and we're seeing a real shift to take them out of our existence around people with downs syndrome, what's happening in Belgium at the moment, it's things like that, worrying things like that. What's a perfect world? Why do we need a perfect world? We need people with disabilities to actually teach us a whole thing of 'well this is us'. We're going to need support throughout our lives, therefore, we're all human beings...we know what happened in the WW2 with the Jews but we don't think about what happened

to people with disabilities. And I've been to Germany and there wasn't one person over the age of 50 with a disability, because they'd all been wiped out. Are we doing this again to people? It's a whole thing of perfection. ...when we brought up the issue [at the United Nations] around 'right to life', right to be born, nobody wanted to touch it with a 40-foot barge pole... Why are some countries allowing, like Belgium, around children to be born or not, or can we get rid of them? There's a very fine line between euthanasia and getting rid of people with disabilities. There's a very fine line and we're getting to that fine line. We've seen it, when we want to get rid of people with downs syndrome, spina bifida, and there's another one too in that kind of area but it's more a physical disability and we're trying to get rid of...[cerebral palsy] (R4a).

Wendell (1996), Morris (1991) and others have written about the ethical issues inherent in arguments about genetic and other prenatal selection of foetuses, and abortion of disabled foetuses. For many disabled women, the abortion of a foetus that is likely to be disabled is disrespectful of all disabled people and devaluing of their lives – assuming that the lives of disabled people are of little or no value, even to those who live these lives. There is also a fear that pre-natal genetic testing, alongside increasingly liberal euthanasia laws, and the increasing commercialism of the perfect body, may be used to attempt to eliminate disabled people from the world.

Aligned with this concern about state-sanctioned death of disabled people is a perceived lack of societal and judicial concern when disabled people are murdered. In New Zealand and around the world, this results in those who choose to abuse or murder disabled people frequently not being punished for their crimes, as the victim's disability is seen as a mitigating circumstance. This can be, as previously identified, described as carer stress, or can be about the lack of cultural value attributed to disabled people's lives.

Like that family in England a while ago, what they did to that man, who they were actually supporting, it was on TV and the abuse and stuff, they didn't get a hell of a lot [of punishment]. It seems like if you do it to a person with a disability, then it's kind of ok and you don't get the prison sentence or the stuff that other people get because they still think that people with disability are down here somewhere and it's not important. But to me it's very important, because people with disability are part of our world and part of our society and also they are citizens of our country. It's about citizenship (R4a).

This participant identifies a similar lack of concern about the murder of disabled people, to the point of colluding with the murderer. The situations described are all from New Zealand.

...cases of people being killed by our medical profession legally by being denied services, cases of parents murdering their children, really upset me, the teenage daughter who was murdered by her mother, Baby C, who was murdered by her father the minute she was diagnosed...and that's quite a danger that we have, because we're all so devalued in the courts, whenever there's any abuse against us, the police don't want to take any cases and the problem you have with that, we don't get to see it until it's too late or the murder of one of our people means that, like the case of the tetraplegic guy and his friend who was an alcoholic – wasn't coping, he was bullying his friend...he killed him...So he was a bully. That was domestic violence as far as I'm concerned. They weren't in a sexual relationship, they weren't family but he lived with him, he was a flatmate and he cared for him but when it came to the courts he tried to get off on mitigating factors. He didn't, which was rare. But the mother of the autistic daughter, got let off quite lightly and the father of Baby C was completely and utterly mitigated, with a suspended 2 year sentence because it was deemed that his alcohol and his drinking and his grief over poured, poor man, he found his daughter to be severely disabled and murdering her when he was drunk, he intentionally did, in order to murder the baby, it wasn't regarded as important, and that's us, as a people (H1a).

Similarly, the government indicates a strong disregard of the full human rights and integrity of all people by refusing to grant citizenship to disabled people. This was pointed out to me in a subsequent conversation with a participant (E2a). This occurred twice in one month (February, 2016). A woman who uses a wheelchair was denied residency because she was seen as a potential burden on the health system – despite being employed - and the son of an academic who had been appointed to a New Zealand university was denied residency because of his autism (naturally the family left the country and the position was not filled).

Regulation of bodies: organisational, state and interpersonal constraint and control

Related to all of the above-mentioned issues is the lack of trust accorded low status members of society. This is clearly indicated by the high rates of surveillance of dis/abled women and the highly controlling environment created for dis/abled women to access help and support. Participants talked about the difficulties of accessing the help provided by government and the complex surveillance accorded

to people who do access services, which was described as “*creating fear as a way of controlling the populace*” (E2a).

This participant went on to explain:

The only way a disabled person can gain access to government funding for personal care and household management disability support services is through a Needs Assessment process which uses a deficit-based tool. The focus is on getting someone to identify what and how much they can't do, rather than focusing on what it would take to achieve the things they could do. People are asked to divulge their whole life history and personal info, usually in a single visit with someone they may have only just met. Subsequent reviews are done over the telephone, and yes, this is some people's preference. Given the initial experience you can imagine why. Based on these conversations, decisions on resource allocations are made, which have a big influence on the standard of lifestyle, study or work opportunities which can be taken up. Once the funding is granted you are allocated to a provider whose MoH contract requires them to help you prepare and review personal goals on an annual basis through a written plan. More sharing of personal information with strangers, paid to be in your home/life, until they flit off to their next client or stepping stone in their career. It's always clear where the power lies - with the state, with the system and all its bureaucratic needs. The degree of structured support and organisation in the daily living of a disabled person is unparalleled, except perhaps for CEOs with personal assistants, drivers, housekeepers, personal chefs etc. Guess who has the better pay packet? (E2a).

A particularly concerning level of surveillance came to a participant's attention in this segment of an article from the chief executive of Manawanui Individualised Funding Support in the *Manawanui inCharge* August 2014 newsletter. This was identified by a participant and sent to me subsequent to the interview process.

Because of all the new developments in the sector, IF [Individualised Funding and in particular, MIC [Manawanui inCharge] are under the microscope...we want to stress to you all that this means the spending is being watched as well.

All the funders have statutory rights to look at your bank accounts and spending patterns without your consent, or ours, or even your knowledge. If they see anything remotely suspicious – they can do an audit on you – and again you may not even be aware (p1).

After further investigation of this the participant identified that the statutory powers utilised by the Audit and Compliance department of the Ministry of Health are:

- The Privacy Act 1993, Principle 11
- The Search and Surveillance Act (2012) which enables the Audit and Compliance department to obtain search warrants to get information, which could be acquired from a bank or other relevant agency without the person's consent or knowledge
- The Ministry of Social Development can serve Section 11 notices under the Code of Conduct to obtain information under the Social Security Act 1964 (NZ Government, 1964). This can be, for example, an investigation into benefit fraud. If agencies do not comply they can be fined \$2,000.

This is indicative of an intense level of scrutiny of people who are receiving legitimate support to enable them to participate in the world.

Overall, welfare is increasingly tightly controlled and women are expected to conform to norms such as regulating their fertility, when they return to work after having children, and how they parent in relation to ex-partner's access to children (Social Security Act, 1964). St John, MacLennan, Anderson and Fountain (2014) report in interactions with Work and Income "a degree of surveillance may be involved that is far from open and transparent" (p2) and that the laws that regulate the allocation of benefits "fail to acknowledge that women have a right to be considered as individuals, independent of either their male acquaintances or relationships" (p2). There are more constraints for abused women who must fit certain criteria to obtain protection orders, access welfare, find safe housing, provide safety for their children, negotiate family court processes and shared custody, and access various services (Elizabeth, Gavey, & Tolmie. 2012). Disabled women are almost entirely excluded from making even the narrow choices available to non-disabled women in these circumstances as so few services are accessible.

And then there is, you know, just the nature of so many of the things, the services that disabled people have to access are so tightly controlled. So if you're trying to access benefits then you have to go to your doctor, you have to have a diagnosis, you have to present this information repeatedly, you know, so every year you have to prove you have downs syndrome again...So you're constantly having to do that. You have to justify, so if you have a special diet and you need to use your disability allowance for that, they go through it and go, why did you buy Freya's bread? You could have bought the basics, home, wholemeal...Pam's. You could have bought Pam's, right, so you're not getting that extra dollar that one cost you. Why did you buy fresh salmon, you could have had tinned, it's just as good. And that kind of level of surveillance people are under. If people are in Housing New Zealand homes,

then, things like if the case manager sees them in the street holding hands with somebody then they'll start being investigated for if they're in a relationship and threatened with losing their tenancy. So there's all of that stuff going on (N1a).

This institutional distrust of dis/abled women is demonstrated in how services respond to abused women, without any consideration for the debilitating trauma and harm to their self-esteem and ability to function that is a result of the abuse they have experienced. The woman described below was being harassed for non-compliance with WINZ rules pertaining to which benefit she should be on, with no understanding exhibited by the staff member of the trauma responses she will be experiencing as a consequence of sexual violence. She has had her baby forcibly removed by police and she is in a situation where she is totally powerless – a reproduction of the situation that caused her PTSD¹¹ to occur.

We also see a lot of discrimination for women who've been sexually abused around the WINZ system, and the lack of understanding in that system, and the lack of room to move, to have understanding of the effects. An example of that would be that I took a client to WINZ a couple of weeks ago and she had her own history [of sexual abuse] and her six week old baby had been taken off her and we went in and the woman said to her 'well why didn't you tell us that you didn't have the baby in your care anymore?' 'Cause she had to go from the sole parent's benefit to the work benefit. And I'm like sitting there going, seriously, she's just had her baby taken off her by six policeman in xxx, so it's completely separate. Of course the first thing she's going to think is, 'of course I must ring WINZ and tell them I don't have baby'. And trying to explain...symptoms of PTSD, and trying to get them to understand that her functioning isn't like my functioning at the moment; she can't process these kind of things because she's traumatised.

So that's another aspect of it – where the system and the people in the system don't have that understanding of the dynamics around the effects of sexual abuse. They are like 'oh that's really sad that person's been sexually abused', but that's as far as a lot of people go, and it affects people's ability to go into WINZ and ask for help, or, people's ability to get financial support that they need, you know it's huge...and that's like no connection! ...You know the mum's had baby taken off her and goes to WINZ, and she would have cracked if I hadn't been there...she would have been locked up or they would have called the mental health unit and that's not helpful for her (S8v).

¹¹ Post Traumatic Stress Disorder

There are many harms associated with this level of surveillance and lack of control. Women can become either dependent and/or fearful of creating fuss and trouble – so unable to behave autonomously – or may be defensive and angry, which will cause further trouble and lead to sanctions; reductions of already scarce resources.

Learnt Compliance

Closely related to the surveillance and controlling of dis/abled women's lives are two other important ideas that were identified in both the initial interviews and the feedback sessions. One is the concept of “*a learnt behaviour of compliance*” (R1d), and the other is disabled women's fear of speaking up about violence and abuse.

You know, we hear stories about what people put up with, you know, it's just terrible. Things that you and I would never put up with. And yet these people with disabilities are putting up with them because they don't feel that they've got any choice (B1m).

Research participants observed that disabled women are trained and rewarded for compliance, silence and not expecting the same opportunities as others, which results in a lack of agency and voice for these women. This has also been identified in the literature (for example, Frohmader et al., 2015; Morton & Munford, 1998).

One participant said “*there is a problem with acculturated violence – disabled people grow up with teasing, emotional violence and they're sort of irrelevant to other people...so they're acculturated to being controlled*” (EK2d). This was further explained as:

...particularly when you look at caregivers, support people, and, like, who has the power in those relationships, because basically if you are relying on somebody to get you to the toilet that gives them huge power over you. And yeah, but it's not only people, it's also systems (J8a).

Participants talked about how disabled children and adults experience a lot of often intimate handling from personal support staff, which makes it difficult to identify where necessary but rough or incompetent treatment becomes abusive and invasive. This was identified by Saxton, Curry, Powers, Maley, Eckels and Gross (2001), as being a result of socialisation processes in childhood and adults that emphasise women's vulnerability and encourage compliance. In Saxton et al.'s 2001 research, participants talked of the difficulty of, for example, judging when vaginal washing moved from “*wash[ing] good [to] too much or too hard*” (p401).

GR2a: But I think when disabled kids are talked to about the good and bad touching, the bad, the touching is so random often, especially if you've got a really high form of physical disability, that touching always happens and so your body isn't your own, you know? And so from that point onwards for lots of young people and kids that, you know, that it starts off, it's a game, not being in control, but that's, this is the real practical stuff...and they can become desensitised to what it means...

G1a: Desensitised, yeah, yeah.

GR2a: I mean I did some work with some people with quite high needs...and each person brought a support person 'cause that needed to happen. But the support people were draped all over these disabled people. You know like it was, it was like a scarf, I've never seen it before. And maybe that's because I haven't been in that high needs environment where everyone has a support worker but they, they were leaning all over their chair and their arms all round the person and they thought that was love and care. But I was thinking, shit, these are really, these are not okay boundaries.

Closely related to this, for women who have very few choices over where they live, who they live with and who provides intimate support, is the fear of speaking up about abuse because of the risk of retribution and losing the small amount of stability and support that they have. The client referred to in the quote below was being emotionally bullied by staff, having food withheld, not being enabled to make choices about her life and, despite being traumatised by an historical rape, had a man moved into her women-only accommodation and was expected to share a bathroom with him.

...and one client that's come through a family member who was visiting from overseas, lives in a group home and the sister tried to bring out some issues just around the care of her sister and got quite a bad reception...So like we're here around her rape that happened 25 years ago but actually part of the role of the worker that will eventually work with her will be generally just keeping an eye on her within the home. But unfortunately it had to be done that way because the sister didn't feel like she could go to who was running the, she tried to go...and didn't get a very positive response. So she didn't want to, 'cause she was only here for a limited time, didn't want to make things worse for her sister than they already were by stirring up trouble. 'Cause they're vulnerable you know and especially living in that group home situation, if there's not someone within that home who's caring for her with her best interest at heart then it's not going to be beneficial to her to be poking the beehive until there's a surety of kind of protection for her within that framework (S8v).

This fear of speaking up about abuse has been identified in a recent New Zealand investigation into institutional/residential abuse, carried out because of a number of cases that came to public attention. “*Many disabled people have learnt to be silent about abuse through fear of retribution, losing services they depend on, or perceiving they deserve to be abused. As a result, many have become invisible*” (Van Eden, 2013). This silencing was also identified in the Roguski (2013) study, discussed in the literature review. These processes of disempowerment, abuse and fear of the consequences of disclosing are discussed by the following participant:

...taking control away from the person with the disability. So they become ...officially or unofficially like a welfare guardian or a property manager or whatever, so they take control of the person and they can take control of the care package and they can then can take control of the financial and the living arrangements. And that has huge implications. I see it too in the carers who come into a disabled person's life, or home, or environment, to provide services. So it's by not turning up or it's by turning up and then deciding that they may go to the pub or they may go and pay, you know, do what they want to do and come back, and that person is left in a, in maybe a compromised position, so they, they don't have their shower or they don't have their meal or they don't have their medication or something until that person comes back to do it. And I see that disabled people, if I can just bluntly say, put up with it, because...the consequences of putting their hand up and saying this is not acceptable, means that their care can be compromised and then the bottom line is if the care package can't be delivered to the person's home the other choice is to go into a care environment, rest home, hospital, some type of that sheltered accommodation and that is not what a person with a disability wants, they want to be living in the community for as long as possible. So I see that as a form of control and domestic violence (J7d).

All of these issues – socialisation of being intimately handled, control, neglect and fear of retribution – further complicate the difficulties of identifying and addressing abuse; because neither disabled women nor their support people may be perceiving behaviours as abusive. If women do feel abused and want it to stop, it is unlikely that others will hear what they are saying and understand their circumstances as abusive. This cumulates in the circumstances related previously, of dis/abled women not being recognised as real victims or credible witnesses to their own and other women’s abuse.

A final comment from Shildrick (2009):

It is hardly surprising...that where disabled people have so often been treated as passive objects of concern, rather than as subjects in their own right, the question of self-directed agency should become a political issue (p7).

Conclusion

The picture that has been drawn in this chapter is of a population of dis/abled women who are marginalised and silenced by society generally and specifically by those whose job it is to offer help and support for both day-to-day living and to escape violence. These women and their circumstances are not visible to mainstream society. No enablers were identified from this data. What the participants described in this chapter is how disabled women are excluded – through the hierarchy of hegemonic ideals, via myths, stereotypes and stigma and via objectification - all of which allow non-disabled people to ignore the circumstances and lives of disabled women. What still is not explained, is why this exclusion, ignoring and abuse of dis/abled women and children continues to occur and why so little is done to prevent it. The next chapter will examine this and discuss a new theoretical framework to understand the continuation of abuse of dis/abled women and the consequent lack of response.

Chapter 8

Vulnerable

Introduction

The previous findings chapters have outlined the consequences of dis/abled women being perceived as other to all men, as well as to hegemonic constructions of real and deserving women. I have identified this process as beginning with the lack of value attached to dis/abled women and the services that work to support them; the consequent reliance on women's passion, or the lack of other employment options, which leads women to work in these under-resourced sectors; the lack of training that results in variable skills among the workforce; the subsequent poor practice that exists across sectors; and the lack of any systems to ensure and regulate good practice. This is exacerbated by the exclusionary and discriminatory practices that prevent many dis/abled women from receiving adequate protection and recognition from the systems developed to provide these services to abused women – or indeed to consider disabled women in data collection, policy and legislation.

From my data, the most prevalent and consistent message about why dis/abled women are abused is that they are vulnerable. This final results chapter examines what this word means, the various ways participants use it, and what an examination of these concepts reveals to us about not only why the violence and disability sectors are not communicating, but why almost nothing is happening to effectively address this issue.

As Fawcett (2009, p473) observes, the “...*identification and management of vulnerability is increasingly being incorporated into legislation and embedded within policy and practice frameworks in Western nations*” (see for example, in New Zealand, the Vulnerable Children's Act, 2014 and the Vulnerable Children's Ministry, 2017). As part of this process, vulnerability is frequently treated as an objective and uncontroversial position with a fixed meaning that is applicable across a range of situations (Fawcett, 2009). Most commonly, this fixed state or position category describes a person who is vulnerable because of some reason inherent to themselves, for example, age, disability or minority status.

It is very rare that any analysis is done about why this category of vulnerable has been applied to this person or subgroup and how this can be changed – i.e. what systems, attitudes and processes have created vulnerability and what purpose this label serves in the wider society. Therefore, if the concept of vulnerability is examined at the determinants level we can follow the causative pathway and undo it

– break down the processes that construct certain people as vulnerable and envisage new pathways that are strength-based and constructive for wellbeing.

The literature review and previous findings chapters identify how, within a medical/individual model, violence and abuse can be understood as being located in a particular person as a result of some inherent quality that somehow invites or is complicit with abuse. Balderston (2013) points out the ethical risk of research that positions crimes against disabled women as a consequence of the women’s impairment, incapacity or inherent vulnerability, rather than “*their experience of barriers to autonomy, justice and safety*” (p34). If the analysis of results had stopped at the previous chapter, I would have left the problem sited within dis/abled women and the (lack of) responses to them from services, and described the cause of the lack of response as the invisibility and silencing of dis/abled women. This would have ignored why that silencing and invisibility occurs. Investigating the concept of vulnerability uncovers another layer of convergence within the findings. My contention, from the findings in my research, is that, despite what I have been told by a number of participants, dis/abled women are not inherently more likely to be attacked or abused – they are abused because our society, globally, via attitudes, actions, discourse, bureaucratic processes, (lack of) service provision, justice processes, funding etc., constructs dis/abled women as vulnerable. As a direct consequence of this construction, dis/abled women are then sought out and preyed upon by those who seek weakness and lack of power, or those who think that they will be unlikely to suffer consequences because of this constructed, systemic vulnerability. Concurrently, society fails to provide adequate resources to enable dis/abled women to protect themselves and remove themselves from harm.

There is only one theme in this chapter – vulnerability. However, within this I am describing the meaning of vulnerable that is being used in this thesis. I then explore the five related ideas that have arisen from the data (Table 6) that begin to describe the underlying causation of violence against disabled women and therefore offer a way forward.

Table 6: Sub-themes associated with the concept of vulnerability

<p>1. Vulnerable</p> <ul style="list-style-type: none">• Meanings of vulnerable from the literature• Dis/abled women are socially constructed as vulnerable• Vulnerability is not inherent• It is inevitable that vulnerable women will be abused• Predators seek out women perceived as vulnerable• Society does not protect those who are constructed as vulnerable.
--

Meanings of vulnerable from the literature

When searching the word vulnerable in the University of Auckland library database, the consistent finding is that the word applies to those who are perceived to sit outside the hegemonic masculine western paradigm. For example, it is about migrant workers, children, older people, poor people, disabled people, sexual minorities, particular marginalised populations (for example: prisoners, Roma) and women. An example at random is Becker, Rankin and Rickel (1998) *High-risk sexual behaviour interventions with vulnerable populations*. The book summary provided in the library database describes specific interventions to meet the needs of “*particularly vulnerable populations: women, ethnic minorities, and the gay community*”. This construction of women (half of the world’s population) as a particularly vulnerable group is an interesting and concerning contention, certainly not limited to the findings of this research. Equally, it is not uncommon to read a statement that says *women and other minorities* without a trace of irony from the author.

This conceptualisation is articulated by a research participant, working in a statutory agency with a mandate to respond to abuse: “...*often in these vulnerable communities...like women at risk, people with intellectual disabilities, people of kind of, some kind of psychiatric or mental health issue...*” (SJ11g).

According to the Oxford Dictionary, the word vulnerable has two main meanings. However, in much of the literature that discusses vulnerability, the meaning of the word is not explained, so it is not always clear which meaning of the word is being used. One definition is that vulnerable means someone or something is open to attack or harm because of forces outside themselves; “*exposed to the possibility of being attacked or harmed, either physically or emotionally*” (Oxford Dictionary, undated). The other definition is that a person or people can be harmed because of some inherent weakness within themselves; “*(of a person) in need of special care, support, or protection because of age, disability, or risk of abuse or neglect*” (Oxford Dictionary, undated).

The New Zealand Crimes Act (1961) defines a vulnerable adult as “*a person unable, by reason of detention, age, sickness, mental impairment, or any other cause, to withdraw himself or herself from the care or charge of another person*”. This equates to the definitions of vulnerable, above, both as an inherent weakness and also as being without adequate systemic protection, i.e., while the weakness is sited in the person, it is a circumstance outside of a person that exposes them to the possibility of harm – for example: power and control, lack of service provision or lack of protection. Matthews (2014, p793) has described it thus:

I take 'vulnerable' in this context to apply to those members of society for whom a relationship of dependency holds. It applies in degrees and arises either from the complement of our natural attributes, or from features that arise because of decisions which structure the relationships of power... Victims may be physically vulnerable or rendered vulnerable by the culture, or both.

Vulnerability is a contested concept in both feminist and disability studies. Burghardt (2013) contrasts two opposing interpretations of vulnerability. One posits that vulnerability is a characteristic shared by everyone because we are embodied, and all bodies can be harmed or otherwise cease to function in some way. The other is that vulnerability is a socially constructed situation which both causes and enables marginalisation and the relegation of marginalised people to dependant and passive states.

Knight (2014) has investigated the concept of vulnerability as a universal state, using the work of MacIntyre (1999; 2000) and Butler (2004; 2009). Based on these and many other author's works (see for example Shakespeare & Watson, 2001), she posits that, as all people can become disabled, disability and hence vulnerability, are universal conditions. Within this, some people require more resources at different life stages (childhood, old age, illness) and other people require more resources as a consequence of life's circumstances. In other words, vulnerability is a shared condition, but not equally shared. The argument that all humans are disabled and vulnerable appears to be used by those who wish to bring to the attention of the non-disabled that they share humanity and precarious embodiment with disabled people, and therefore, to exclude or view disabled people as 'other' is to deny common humanity and opportunity. Hughes (2009) contends that, while this representation of vulnerability and frailty attempts egalitarianism, it has two unhelpful consequences. One is that it emphasises lack – a deficit framing of humanity - rather than an acknowledgement of the capabilities and strengths we all bring to the world. The second is that this representation denies the specific oppression, exclusion and discrimination experienced by dis/abled people, who then must accept their "*poor but equal treatment*" (Hughes, 2009, p402).

The inequitable sharing out of vulnerability identified above is posited as a result of two things: political arrangements that create structural inequalities and the subsequent inequitable distribution of vulnerability across the community; and the (societal) marginalisation and dehumanising of certain populations that causes them to be disproportionately exposed to violence, injury and death (Knight, 2014). From a health promotion perspective, these structural and societal processes underpin the concept of vulnerability as a construct. This does not deny that we are all, at some

times in our lives requiring of help and support, but I am opposed to the idea that *vulnerability* is inevitable for humans.

Further to the concept of vulnerability as a societal construction, Hughes (2009) identifies the labelling of those who are counter hegemonic as vulnerable and reiterates the hegemonic ideals identified in previous chapters – of being a heterosexual male and non-disabled.

The vulnerable, like many negative or paternalistic appellations for disabled people, acquires its metaphorical power from the tribunal of anatomical perfection against which it is measured. The strong, well-formed, non-disabled, masculine body is the benchmark and against this benchmark a woman is found wanting and a disabled person – man or woman – is weak and vulnerable (p400).

Importantly, this quote identifies that the construction of dis/abled women as vulnerable is designed to make this group of people illegitimate. This is as pernicious as racism, for example, because the concept of vulnerable must be applied in negative relationship to some other concept – and that relational concept is a hegemonic norm. In other words, no person can be vulnerable without others having power over them.

Burghardt (2013) identifies vulnerability as a “*socially constructed entity that shores up oppressive and limiting barriers in the lives of people with disabilities*” (p557), historically linked with concepts of passivity, fragility and the need for protection. Vulnerability is defined as being in relation to normative social structures (the hegemonic ideal noted by Hughes (2009) above – see also previous chapters) and resulting in marginalisation, harm and a lack of structural protection and responsiveness from formal systems (Burghardt, 2013). An example of this is the enabling of child rape in South Africa “*because of a series of ideas that make children vulnerable through creating opportunities for abuse*” (Jewkes, Penn-Kekana, & Rose-Junius, 2005, p1810).

Following on from this, Knox (2014) suggests that one of the most effective ways to control people who are constructed as vulnerable or powerless in society is to make them ashamed of their powerlessness and to self-identify this powerlessness as a consequence of their own character or actions. Matthews (2014) identifies this, in the context of blame ascribed to victims of abuse, as blaming the imprudence of the vulnerable. While many victims of domestic violence appear to be blamed for their character traits or behaviour in relation to the perpetrator (Matthews, 2014; Meyer,

2016), disabled women are apparently blamed for their inability to remove themselves from harm (see previous chapters).

Fine and Asch, in 1988, pointed out that feminism and disability rights scholars and activists have identified that both the experience of being female and of being disabled are social constructions – that the biology cannot be understood outside the contexts and relationships that shape and give meaning to femaleness and disability. They say, in their book *Women with disabilities* “...it is ironic to note that the very category that integrates this text, ‘disabled girls and women’ exists wholly as a social construct...What they share is similar treatment by a sexist and disability-phobic society” (p6). It is sobering that this construction was recognised and recorded nearly 30 years ago but is still the keystone of my thesis as we – as a society and as feminist women – have failed to grasp this and engage to prevent this inequity continuing.

From a population perspective, Butler (2004) sees this process (the creation of a population which will inevitably be harmed) as a corollary of the lack of value accorded to certain populations and their consequent vulnerability to harm and death. She explains the process as the dehumanising of certain populations, which enables those populations to be cast as “*unthinkable*” and “*ungrievable*”, and therefore able to be ignored and forgotten by mainstream society (p xiv, xv). This process occurs through the stratification of populations into those who are privileged and protected and those who, by racism, sexism, ableism, imperialism (colonisation) and classism (Knight, 2014), are exposed to harm.

It is this concept of vulnerable – that it is a societal construction – which I am basing this work on, as it offers the opportunity to challenge the inevitability of the labelling, and also highlights the privileging of the hegemonic experience, which disables and disregards all women. There will be further discussion of these various understandings of vulnerable throughout this chapter. In the next section I investigate what the participants said about the concept of vulnerable, how it was used and what this means in the context of the research.

Dis/abled women are socially constructed as vulnerable

While some participants used the concept of vulnerable without critique, others identified a range of inherent qualities that could make disabled women vulnerable to harm – which aligns with the second meaning of vulnerable as inherent to a person. The concept of vulnerable as being exposed to harm from outside processes was articulated by others who discussed vulnerability as being systemic, sited within society and how it is structured. A number of people used vulnerable just to describe the condition of disabled people in relation to the risk of being abused. “*I think*

people with disabilities are more vulnerable, definitely. They are more vulnerable, there's more vulnerability” (T2v). Similarly, “I think it's about protecting the most vulnerable and not just treating everyone equally. You've got to recognise that some people are more vulnerable than others” (E1v). These comments resonate with Fawcett (2009) explaining how vulnerable is increasingly used as a fixed uncontested concept.

The association of vulnerability with disabled people has been recognised in the UN Convention on the Rights of Persons with Disabilities (2006). This was mentioned by a number of participants.

This is why the disability convention was created in the first place, not to create anything new, just to identify this is a vulnerable, marginalised population that has been invisible and forgotten about, you need to pay attention to it (P2m).

A number of participants provided various understandings of why vulnerability might exist.

Depending on the disability and on the person, it's not quite so easy for them to walk away, or to seek help, because their own disability might get in the way of that. If someone's living in a modified house, their partner's being abusive or family member's being abusive, they can't easily be the one to leave; the rest of us can pack a bag and off we go; they can't because they need that living environment. It's harder for them to just walk away and find somewhere else that they can safely live. Somebody with an intellectual disability, it's so, so, easy to brainwash them, to control them, without them actually knowing how to deal with it, how to get out of it; and sometimes recognising that's what's going on (B3d).

The first part of the quote (above) is about physical accessibility and modified housing, yet sites the inability to protect themselves or escape violence within the abused person – their inability to walk or, in the second part of the quote, to constructively think their way out of a situation. This next quote also discusses inherent reasons for vulnerability – recognising that this perceived vulnerability can increase as people's ability to communicate becomes more tenuous and also as people have decreasing levels of control over their lives. It further addresses the potential of carer abuse – and the inexcusable nature of this abuse.

...well, disabled people, if their impairment means that they are particularly vulnerable, so what I'm talking about there is that communication is an issue,

I mean, largely I think this is one of the biggest problems, around communication. And then there's physical impairment when people are, physically can't get away or are confined to a situation or environment that's not what they want but they can't get out of it because their decision-making rights have been subsumed by somebody else or something else. And disabled people, you know, there's disabled people and then there's a subset with say learning impairment, and then there's a smaller subset of people with learning impairment who have challenging behaviours. And I think that is an area where there is quite a, a fraught area. Because a person with challenging behaviours is obviously very challenging to live alongside, and if they are not accessing appropriate strategies for modifying behaviour then I think you're breeding a situation where violence can occur. And I'm not saying that violence is all one-way. Violence can be two ways. But one person is not in a position to sort of be [Unclear] intentional about it, whereas the other person can be intentional. So a person with a learning disability may not be intentionally being violent, but if somebody retaliates, or, back, that is abuse then because that's intentional and cognisant (C4d).

Closely related to the subsuming of a woman's decision-making powers, power and powerlessness are identified below as the defining determinate of who is perceived as vulnerable.

The dynamics of power [is] ...that lots of members of our society are more vulnerable and less powerful and there are some gender elements to that but not only gender elements...and younger people, children and youth have less power again. And elderly vulnerable people have less power, and disabled people have less power. And people who have power really often don't even notice that and use it in lots of ways to further their own ends and some of those people are abusive (M2v).

This quote also highlights the hierarchy of power and how this hierarchy can become harmful when it is abused.

The participant below identifies how an increased risk of abuse can be attributed to the behaviour and needs of the dis/abled women. This participant is not being deliberately victim blaming; they are discussing the consequences of exclusion and marginalisation, understanding that these things enable women to be preyed upon by men who seek out powerlessness.

I think in, you know, in several ways, um, with the power dynamic, you know, like often people with disability have a learned powerlessness, or a

perception of powerlessness. I think one of the more serious things that I see in mental health is that sort of wanting to be loved at any price sort of thing, so you know, lack of intimacy leads to sort of really inappropriate behaviour or events happening. So that sort of hunger for intimacy, love, affection, you know, closeness, but also lack of experience of it and lack of understanding. You know, also that sort of, their ability, sometimes, to be taken advantage of, you know, to being trusting, gullible, you know, not knowing and not very worldly so they're very, quite vulnerable. Also many people that use disability services have had a lifetime of being told what to do and how to do it. You know, they often have not a great sense of self-belief or self-knowledge, and so they defer to other peoples', sort of, suggestions, which again [unclear] that vulnerability and open to abuse (EK2d).

The narrative intrinsic in the expressions of vulnerable presented so far in this chapter is that they are inevitable because they are inherent to a person and/or the situation that the person is in as a consequence of their disability. This aligns with the definition of vulnerable as unable to remove oneself from harm.

The alternative narrative is that vulnerability is constructed by societal, systemic or structural contexts external to the dis/abled woman. A number of participants identified this.

It's the devaluing of the person that can't contribute and can't participate because of the barriers that are put up by society, so they are not valued by the community and by society (L2e).

The participant below identifies disabled women as being vulnerable to a variety of abusive behaviours and needing people who will “*stick up for them*”:

I don't know that much about it, but when you actually stop and think about the vulnerabilities of these people, we certainly know about institutions and have a little bit of knowledge around institutional abuse of people that are abused in that way and if you think about them engaging with, not only institutions where they live, but their engagement with government agencies or other forms of support or with community in general, then there probably would be quite a lot of difficulties and maybe lower level types of abuse that they probably wouldn't even call that but would be assault under human rights...They're absolutely vulnerable and nobody to keep an eye on them, to stick up for them (B2g).

The lack of people to “*stick up*” for someone can be understood as an example of institutional practices and settings that create circumstances where people are more likely to be abused.

The next participant identifies societally constructed powerlessness as underpinning abuse. They explain powerlessness as being a consequence of the lack of adequate societal structures and supports for disabled children and their parents. This explanation of vulnerability, powerlessness and the relationship with abuse aligns with the definition of vulnerable as being exposed to harm because of inadequate protections, and social systems that exclude and marginalise people. This long quote expresses many of the issues that were articulated about the circumstances of disabled people’s lives in relation to the issues being discussed.

So, absolutely people can experience abuse who are disabled and absolutely there's this really, there's this huge, huge grey area that sits in the middle for older people, for disabled people, for young children, whose parents are so stressed about their disability that they're not, their kids aren't picked up, so they get, well it sounds odd but they get a flat head at the back of their head because they're not being nurtured...so...we're talking about disabled people being more vulnerable to violence and abuse and I think that that can be because of all the other things that cause violence and abuse, but it can also be because of the fact that we start from having no power or little power. So if a kid goes to a segregated day-care, a segregated school, they don't take part in their community 'cause a taxi takes them from home over to the other side of town to somewhere else...So all of those things create really lowered expectations for people and lower expectations of ourselves. So I think that that's, the overlap's in all sorts of areas, the disability and violence. But I think that the grey stuff is around us never having that power and control to start with (GR2a).

Further to this is the internalised lack of value caused by the low expectations of the people who support disabled people and the lack of support and opportunities to fully communicate and develop personal potential.

Lots of us...the expectations have always been low, academic expectations have always been low, people say to disabled people living in institutions oh, you should be grateful 'cause you get three meals a day. You know? So because of those expectations being so low then it's okay to experience violence, it's okay to also beat up your peers, 'cause we, 'cause disabled people are, are not taught to expect too much of themselves, as well as from others. So when a person...who doesn't use words to communicate can't communicate, they'll beat the person up that's next door and they will become

the perpetrator. But at the same time they're not supported to communicate any differently. There's no tools, you know. I know these young people who are still using what we call bliss books, which are symbol books. And there's amazing technology out there. And they're still using these rundown crappy forms of communication. So for me that's abuse. You know that's really clearly...not letting people reach their potential or not even seeing it. We often talk about the race track theory. People on different parts of the race track, and have a different weight of pack to carry around the race track. But for us, I think some of us can't see the race, can't find the race track, aren't even told where the race track is. So you can't even start to compete, because you're not on the same field (GR2a).

The quote above describes dis/abled women as being exposed to harm by the lack of opportunities to develop their potential and participate in an equitable way in the world. Being excluded from citizenship by over-protecting and placing people in institutions was identified as another way that people can be made to be vulnerable – i.e. it is the value that society ascribes to disabled people, and the institutional response to that ascribed value that exposes women to harm.

...[the research] came across to me as, need to protect all these people and I thought maybe that's just an understanding that was missing from it because we don't want to protect all these disabled people – because the easy solution is to put them somewhere with a big fence around them so they are all quite safe. That's been tried before and it didn't quite work, so what's the difference from that? It's about how do you just activate this being part of the community on an equal basis with others? And having protections out there but not protecting these people so they are locked in and waiting for the violence to come to them...the nature of institutions it can make you more vulnerable, that there are not other people in your life (P2m).

However vulnerable was expressed and explained, the common underlying premise was that this vulnerability was a causative factor in the abuse of dis/abled women. The logical conclusion from this would be to investigate how to create processes that mitigate this vulnerability and how to protect dis/abled women from the men (and women) who seek to harm them. This is the default position when investigating the meaning and concept of vulnerability.

Dis/abled women are not inherently vulnerable

As identified above, it is not qualities inherent to dis/abled women that make them vulnerable to harm, but the institutional, attitudinal and other practices which silence and disempower women. This connection was not made until two participants drew

my attention to the fact that dis/abled women are not inherently vulnerable to violence. This was, to me, a revelatory insight, critical to shaping the theory that has been developed from this research.

This participant rejects the concept of inherent vulnerability and redefines causation as exterior to a dis/abled woman. “...*vulnerable, it's not about people, there's nothing inherently vulnerable about us, it's particular situations we're made vulnerable*” (NP2a). This externalisation of vulnerability is critical for understanding the pathway that enables violence to occur and the lack of systemic responses. However, I needed to understand one further step to make the connection between the construction of disabled women as vulnerable and recognising that all women are constructed in this way in relation to hegemonic male attributes.

So we often talk about disability as a risk factor or a vulnerability factor for violence, and that would be a really kind of easy way I guess to explain it. Way back they kind of brought my attention to the fact that it's not disability that's the risk factor. It's our attitudes towards disability that create the risk, that create the vulnerability, rather than anything, than disability per se. So I guess that's what I would see, is that in both cases, in both violence against women and in disability there's still a, there's a power and control over, based on a perceived hierarchy. In this case it's not about gender, it's about ability. When you get the double whammy, where gender and ability and possibly other factors intersect, then yeah, you're sort of getting compounding vulnerabilities. Not necessarily to do with the person, it's to do with what's out there – our attitudes (D7m).

Central to my findings, as identified in the quote above, is the concept that non-disabled and disabled women share many attributes, assigned by society, that enable men to abuse them. Participants identified this to me in comments such as:

Vulnerability and no voice; I think people with disability are even worse, struggle more because they are stigmatised because of their disability and I think women...in violent relationships are stigmatised as well, labelled, looked upon as inferior and things like that. And they may not, similarly in the way to family violence, although this is changing, but have a voice, have their needs recognised as legitimate (B2v).

These ideas, of the similarity between the situation of all women and disabled women, led me to think about why so many people use the word vulnerable when referring to disabled women – and what this means in the context of how vulnerable

is used in the wider literature to describe people who do not conform to hegemonic norms.

What I discovered is a construction of dis/abled women as vulnerable; because women are abused by men, and are not enabled by societal attitudes and systems to protect themselves from men, they are lesser, powerless, and therefore vulnerable. Nowhere in this analysis is there consideration of societal responsibility to prevent this vulnerability and the place of hegemonic construction of who is perceived as powerful and important. As a result of this, linked to the construction of women as victims/powerless/vulnerable, is the expectation that they will be abused.

It is expected that vulnerable women will be abused

Strongly related to the construction of dis/abled women as vulnerable is the acceptance that, as a consequence of being perceived as vulnerable, dis/abled women will be abused:

Well, because they're so, really a more vulnerable group in the population and abuse is a great chooser of vulnerability (M2v).

The participant above makes a causal link between those who are perceived as vulnerable and those who choose to abuse. The quote below highlights some people's attitude that this link is inevitable:

I heard an MOH official, and this was in relation to violence in facilities...and she used the words 'it's inevitable', which I corrected to unacceptability. Now unacceptability and zero tolerance, now that doesn't naively mean it'll never happen but it completely changes the way we think about it and the way we act and do about it (P1a).

This attitude, of inevitability, is particularly concerning as it comes from the Ministry of Health – the agency that is charged with developing policy and protocols to ensure that violence and abuse of disabled women does not occur. What this suggests is that the processes that are being developed by the MOH will not be robust and address underlying causation, as 'it's just going to happen anyway'.

The participant below also appears to identify the inevitability of those who are perceived as vulnerable being abused.

...violence occurs across the board, there are people who are always going to pick on the vulnerable. I guess I get frustrated that they target particular groups...well you know violence is across the board, it's the perpetrators picking on the weak and the vulnerable...it's not about being an older person or disabled person or a child (T1e).

This is an interesting quote that further elucidates the construction rather than the inevitability of the labelling of certain groups as vulnerable. It also points to how this construction is causative in the abuse “*perpetrators picking on the weak and vulnerable*”. Further to this, is the idea that dis/abled woman are deliberately sought out by men to be victims of their abuse. The following quote identifies this deliberate targeting and also, despite the understanding that dis/abled women will be abused, that there is insufficient systemic support for protective and preventative responses.

My understanding of where the two intersect is realising the fact of some abled bodied males, generally, taking advantage of the fact that you cannot, for whatever, whether it be physical or not being able to express yourself, being able to get the assistance and support that you need and so the perpetrator takes advantage of usually a woman in that position because he's there and he can and thinks he can get away with it, because she's an easy target, is more vulnerable. I suppose that's my understanding (JS5v).

This leads to the third sub-theme of this chapter; the concept not just that dis/abled women will be abused, but that they are deliberately preyed upon by certain kinds of people, primarily, but not only, men.

Vulnerable women will be preyed upon

A number of participants made links between dis/abled women's perceived powerlessness, the lack of structural safeguards and enforcement processes, and a deliberate determination to abuse. This deliberate determination is balanced with the perception that dis/abled women and other people constructed as vulnerable have few avenues to disclose abuse, and very little chance of being believed.

I also think the crossover is even around making someone, um, we think about it in terms of the vulnerabilities so again it's that, what I was saying earlier around someone taking advantage of someone that has a certain vulnerability to them, whatever that could mean, and that's the bits in which we see crossover quite often...I think the dynamics of, there's a lot of vulnerabilities for children, so that's another kind of situation as well. I think that when people can – feel like they can, so they can get away with

something because they know in some way in what our society holds they can. So targeting people who might have different vulnerabilities or people who are more at risk, because they're already marginalised anyway so who's gonna believe them in our system (A1v).

In reference to the deliberate targeting of women perceived as vulnerable the word predator was used. “...*the vulnerabilities, you do see, I've seen young women with disabilities that are easy target for predators and you've got the stats, it's high, it's huge*” (B2g).

This risk of predatory behaviour is reinforced by the systemic invisibility of disabled people, identified in the previous chapter, aligned with the lack of structural and procedural safeguards.

I think that some of that invisibility that comes from people within the disability sector means that, for perpetrators, there is a sense that they are easier targets and we certainly know, that in relation to sexual violations, that there is a disproportionate number of people from what we would say is the disability sector that are affected and I think there is a heavy reliance from predators, particularly if somebody doesn't have an ability to communicate very well, whether that be verbally or otherwise with their body, that they can get away with it (C1v).

Many of these predators are not strangers. These people are sometimes deliberately working in disability services. “*I think one of the big risk areas is, for service providers, is people who are not in the business for the right reasons. That they're actually coming in with a predatory intent*” (L1d).

Strangers do also, however, pose a risk to disabled people. For example, this young man was deliberately targeted on the street.

Our young men who have Aspergers, who basically look like they don't have a disability, but they don't have a filter. So they're easy for predators. You know, we had a young man who said to me, 'I'm going to be in film tomorrow'...Very handsome. Aspergers. Sixteen. And my ears went, 'what?', 'sorry'. 'Yes, I'm going to be in a film. I was in [town] and this man, he came up to me and he said you look very handsome, would you like to be in a film?' Yeah. And so the no filter, is, is important. So I think, yeah, around prostitution and that whole seedy scene (S3d).

The research participants, who understand the harm of abuse because of their experience of working in the mainstream domestic violence sector, identify the harm caused to disabled women, especially when the abuse occurs in a relationship of care and support. Related to this, they ask the question of whether some people deliberately target disabled women.

G3g: I guess the perception may be that people with disabilities may be less likely to be able to stand up for themselves and they may seem to be more vulnerable in some cases so may be seen to be easier targets. People might think well that they can't, they're kind of, you know they won't have the ability to either verbalise what's happening to them or the ability to get away from the situation, so they could be like an easy target to just aim for...guess in terms of what it does for their self-worth and self-esteem...but it must be like a double blow in terms of you know here's a person who's maybe reliant on other people's care of them and that kind of trust, I mean that's the case for all abuse, but for them they actually are dependent on other people to help them. So if someone comes in and breaks that trust, then it's kind of like a double whammy isn't it?; that a) you don't have the ability to get yourself out of it, then b) the societal system sets up someone to come in and help you out and they're actually being more abusive to you as well. I could see that could be an issue.

GC4g: And for...some people that abuse people with disabilities it might be, you know, abuse is about power and control, but maybe...there's some hook there where they wouldn't abuse, well every abuser chooses who they're going to abuse, don't they? So maybe for these people this is a target; they can't target anyone else but this is a target they can abuse.

G3g: Just thinking about that, you know how you have your paedophiles who just target children, is there a group of people who do that just with people with disabilities?

Having established that disabled women are deliberately targeted, and that this abuse is expected as a consequence of being constructed as vulnerable, responses to this situation were examined.

Society doesn't protect those who are perceived as vulnerable

An examination of the historical and current social responses to violence against dis/abled women suggests that although it engenders discussion and research, very little is actually done to create an adequate response and free women from abuse. As identified in previous chapters, the violence services that exist in New Zealand are undervalued, underfunded and prioritise stereotypical 'real' victims. As discussed, in New Zealand this means predominantly young women with small children who

conform to a particular demeanour and behaviour that mainstream society believes to be deserving of protection. Those who deviate from this stereotype are frequently denied support and protection from services as a consequence of the constraint of government priorities, and/or services with limited resources (Matthews, 2014). It can also be directly related to discriminatory policies and practices, such as not working with older women, disabled women or women with mental health and substance abuse problems. This quote, from the police, identifies one aspect of this problem.

A lot of people, our so-called street identities, every town has them, where you've got this person out there, kind of perhaps drinking the, they're perhaps labelled as an alcoholic or, like, we used to have places like Cherry Farm and these big institutions. And I mean I agree that it was right to get rid of those places and the format that they were in, but we've now got a lot of these people in the community and they've become really vulnerable people in the community. And they're just a target. They get a benefit. They're often not, you know, it's like, they know to go to police or go to, often they'll come to police and police'll just see them as, not kinda take them seriously sort of thing (J10g).

Aligned with this is the lack, previously identified, of any policy support for violence and other services, including health, to work with abused disabled women or to prevent the ongoing abuse of dis/abled women. Indicative of this is state-sanctioned sterilisation of learning-disabled women and girls. In a number of jurisdictions, for example USA, New Zealand, and including until recently Australia, girls and women can be sterilised without their consent to prevent pregnancy in the situation of risk of/or likelihood of sexual abuse or rape (Brady, Briton, & Grover, 2001; Gates, 2000; Ministry of Health, 2002). These guidelines provide an unambiguous validation of my finding that it is assumed that women labelled as vulnerable will be abused and that this abuse will not be prevented – nor will the perpetrator necessarily be held accountable for his actions. As Barbuto and Napolitano (2014) conclude, sterilisation does not prevent violence against disabled women or improve their physical and emotional wellbeing – it merely eliminates the effects of violence and absolves others of the responsibility to intervene.

Balderston (2013) identifies this lack of protection and response as “*disablist violence [being] perpetuated and sustained by the macro organisation of criminal justice and disability institutions, welfare inequality and research for or about (rather than of or by) disabled and Deaf victims and Survivors*” (p 20). This quote indicates, for me, the lack of systemic protection for dis/abled women.

This is summarised in the following diagram, demonstrating the vicious cycle of harm caused by constructing dis/abled women as vulnerable.

Vicious cycle of harm caused by constructing disabled women as vulnerable

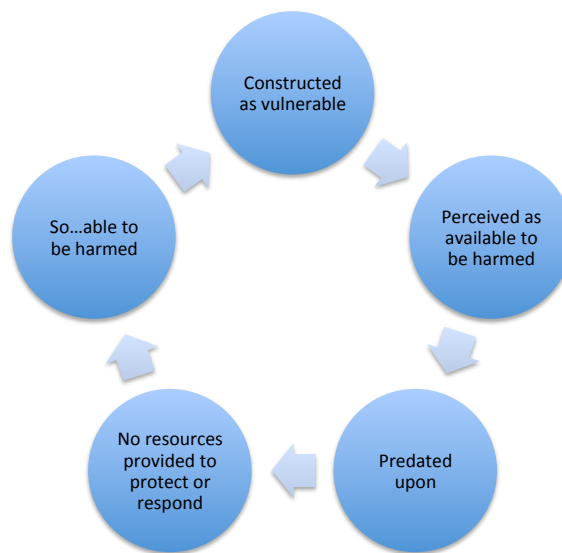


Figure 5: Vicious cycle of harm caused by constructing disabled women as vulnerable

Conclusion

This chapter has illustrated the central findings of this thesis, that dis/abled women are not inherently, but socially constructed, as vulnerable. In this construction dis/abled women are negatively compared with both hegemonic masculinity and able-bodiedness and found lacking in both dimensions. This construction both sites vulnerability within a person, which positions women as being inevitably vulnerable, and creates vulnerability by failing to provide systems and structures that enable prevention and protection (such as ministry and agency policy, legislation, adequate resourcing and education about the dynamics of abuse for those who work across the health, social services, justice, police and NGO sectors). Furthermore, the construction of vulnerable brings with it an expectation that abuse will occur and that those who are vulnerable will be preyed upon by (primarily) men who seek out weakness and those who they believe will not complain or be believed. As a society we know that vulnerable people will be abused, we create the conditions that enable the abuse to occur and yet it appears we choose to do nothing – or nothing constructive – to prevent abuse and respond when it occurs.

Therefore, I contend that it is this social construction of vulnerable that enables the abuse of dis/abled women and the consequent ignoring of this abuse by government, violence and disability services and civil society.

Chapter 9

Discussion chapter

Introduction

When I started this PhD journey I believed that the result of my research would be a list of concrete and constructive actions, linked by shared paradigms, which both violence and disability services could use to begin the process of engagement with each other to address the abuse of disabled women at primary, secondary and tertiary prevention levels. Certainly there are things that the services and government can (and should) do immediately and these are discussed in Chapter 10, however, as I analysed the findings I uncovered limited enablers and multiple barriers to action. These result from strongly ingrained societal attitudes, such as those identified in the quote below, which unconsciously influence the decisions governments and service providers make.

Society and policy makers still see most violence against disabled women and men not as domestic violence, or hate crime, but as a result of some innate 'vulnerability' caused by their impairment. In other words, society takes a medical model approach to violence against disabled people, a separate 'special needs' approach. It uses a 'safeguarding vulnerable adults' approach...and [gives] it a different status and recognition, not to mention different processes for tackling it, most of which do not work (Bashall & Ellis, 2012, p116).

This chapter begins with a summary of the underlying reasons for inaction at the intersection of violence and disability – both the theoretical and empirical findings. This is followed by a discussion about vulnerability including why examination of this issue is important to the achieving of equity for dis/abled women and what societal purpose might be served by constructing dis/abled women as vulnerable. There is then a discussion of the new learning from this investigation. Finally I revisit and specifically answer the components of the research question.

Underlying reasons for inaction - theoretical and empirical findings

The literature identifies the high prevalence of violence against disabled women, the harm caused by the violence, the various forms of violence against dis/abled women, the many perpetrators and the lack of systemic responses from services, to either prevent, or respond appropriately to, the abuse. Therefore, this research did not attempt to reiterate the prevalence of harm and paucity of response, but rather,

sought to understand the underlying reasons for inaction. The reasons uncovered by my research are: (1) services not valued, too hard, no resources – latent findings about the undervaluing, underfunding and under-resourcing of both sectors that result in, among other things, overwhelmed staff who feel unable to work with more complexity than they are already managing; (2) paradigms of practice – which examines the paradigms people work from and how this influences good, best and poor practice; (3) exclusion of dis/abled women: invisible, silenced, controlled – which discusses how dis/abled women are silenced, regulated and made invisible in data, policy, practice and day to day life; and (4) vulnerability, the central, semantic finding that underpins the lack of respect for women’s services and lack of engagement between sectors. The findings in each of these areas are summarised below.

Services – not valued – too hard, no resources

The first layer of findings identified very pragmatic reasons for the lack of interaction between sectors. These included the undervaluing of the sexual/domestic violence and disability sectors and consequent lack of monetary, human and other resources (policy, training, accessible facilities and information, shared language) that practitioners and policy makers felt constrained engagement across sectors. This resulted in many services feeling overwhelmed by the level of service they were required to supply and subsequently feeling unable to address another area of complexity. Some services (in both sectors) felt that the abuse of disabled women was not their problem, but the responsibility of the other sector. At government level, these attitudes are exacerbated by the siloing of oversight and funding into multiple ministries with unconnected areas of responsibility, and a lack of legislative or policy support for baseline qualifications and national service specifications for violence and disability agencies about violence against dis/abled women.

Paradigms of practice

Investigating the models, theories and paradigms people within violence and disability sectors work from resulted in a number of paradigms being identified, which I have clustered into the individual deficit and socio-political paradigms. The individual deficit paradigm privileges medicalisation and individualisation of both disability and abuse, situating the problem, and blame for the problem, within the individual. This thinking results in a behavioural analysis of issues (for example, who did what to whom; victim blaming; personal attributes) and a lack of complexity and system level analysis (for example, how do the systems and socio-political processes enable violence to occur?/fail to prevent violence?). In contrast, the socio-political paradigm privileges system level thinking and the ability to embrace complexity and situates responsibility for abuse with the perpetrator and, more widely, with ineffective systems and societal attitudes that enable violence to occur. Neither of these paradigms is inevitable. The paradigms and related practice are based on varying levels of knowledge, training and analysis of the issues relating

to the sectors worked in and how individual participants value and respect dis/abled women. As noted above, there are no nationally prescribed standards for the violence sector, and those for the disability sector detail only marginal levels of education and skills necessary to work with disabled people.

From these paradigms and further findings I have developed a model, explained in chapter 6 that can be used by policy makers, funders and practitioners/managers to promote and describe poor, good and best practice. The model explains the various levels of practice from an individualising, victim-blaming, rescuing position (poor practice) along a continuum to an understanding of power, oppression, discrimination, complexity and the socio-political environment that the service is operating within; and the socio-political environment of dis/abled women (best practice).

Exclusion of dis/abled women – invisible, silenced, controlled

At the level of service and practice the underlying causation for lack of engagement with the abuse of disabled women was identified as a lack of valuing of dis/abled women, particularly women associated with traditional female caregiving roles and women requiring support and care. The lack of valuing of the caregiving/support role in private and public contexts, identified in this research, was strongly aligned to literature discussing how women are positioned as ‘other’ to the hegemonic position of (able-bodied, heterosexual) men (Garland-Thomson, 2004). The processes that reinforce this positioning are inherent in structures and language (Penelope, 1990; Wendell, 1996); gender roles; ableism; and institutional processes; reinforced by, for example, rape myths (Anderson & Doherty, 2008; Buchwald et al., 1993). Disabled women are doubly stigmatised and described as other. Participants identified dis/abled women as being excluded from participation via myths, stereotypes and stigma; paternalistic control of women’s lives; and objectification; all of which allow non-disabled people to ignore the circumstances and lives of disabled women. One manifestation of this is the societal and institutional controls that are imposed on dis/abled women’s lives – in part monitored by women themselves to avoid being blamed for harm, and in part monitored by society and institutions, because women are seen as unable to be trusted with the regulation of their own lives.

Alongside this is the medicalising/individualising of violence – the concept that it is some character flaw or inability/vulnerability within a dis/abled woman that causes her to be harmed. This individualising of responsibility and imposing of blame (on women) for abuse perpetuates ideals of hegemonic masculinity, reinforces the obscuring of the perpetrator of abuse and holds dis/abled women complicit or causative (by being female, by dressing as women, by being vulnerable, by being out alone, for transgressing gender roles and norms, etc.) for the abuse they experience. Compounding this marginalisation and harm are the processes of de-legitimation –

legitimate verses non-legitimate victims, those who are ‘deserving of’ state protection and services and those who are not, those who are credible witnesses to their own abuse, and those who are considered not to be credible.

All of these things – exclusion, marginalisation, de-legitimisation and institutional and societal controls – function to disempower dis/abled women (Bashall & Ellis, 2012) and create fear of both personal harm – physical, sexual and emotional – and harm caused by negative societal and institutional consequences of transgressing norms and expectations. Moreover, they create a fear of disclosing abuse when it occurs, as the penalties accrue to the complainant, rather than the perpetrator. These penalties include, for example, being denied services or independence (placed in residential care) as a consequence of reporting abuse or being sterilised to prevent sexual abuse causing pregnancy.

Vulnerability

Feminist disability theory has enabled me to examine how dis/abled women are ‘known’ in the world. As part of this I have learnt that underpinning all the research findings is the mostly unchallenged belief that dis/abled women are abused because of their perceived/commonly understood/inherent vulnerability. Feminist disability theory enables critique of the concept, construction and consequences of vulnerability, identifying the “*culturally fabricated narrative*” (Garland-Thomson, 2004, p77) of vulnerability as a fundamental paradigm that prevents society constructively addressing violence against dis/abled women.

This research has identified that vulnerability is not an inherent position; it is a social construct. Constructing dis/abled women as vulnerable supports the processes of marginalisation identified above, making, in the collective mind, violence and abuse inevitable. The inevitability of violence occurring relieves both perpetrators and others of the need to be concerned or to take responsibility and/or action for the abuse of dis/abled women. Therefore, while it is known that dis/abled women will be preyed upon, society does nothing effective to prevent or respond to this harm. Responses tend to focus on women taking responsibility to protect themselves by modifying their behaviours, rather than on changing societal attitudes and norms including challenging hegemonic masculinity and gender inequity, and strongly condemning and penalising violence against women.

The frightening reality of the construction of women as available to be harmed, is that, as a consequence of the expectation of the inevitability of harm and subsequent lack of protection, dis/abled women are available to be, and are, harmed – sexually, physically and emotionally, by men and women who prey on perceived societal powerlessness and lack of value. Further, these abusers know that there will be very little likelihood of societal sanctions or punishments for their offending.

This understanding links me back to the first, pragmatic level of findings. As disabled women are constructed as not valuable and inevitably available to be harmed, then it is no surprise that the services developed to respond to violence are also not valued, are under-resourced and have no nationally consistent plan, training or baseline qualifications attached to them to ensure good practice at a national level.

An examination of vulnerability

What we – as feminist and other women – appear to mean when we label a group of women as vulnerable is that because of a particular set of circumstances this group of women is exposed to more harm (usually from men) than women are generally exposed to, and that action should be taken to remedy the situation. My findings, in contrast, are that what those who subscribe to the hegemonic masculine/able-bodied paradigm hear, when the word vulnerable is used, is that women are available to be exploited and abused. Because dis/abled women are only vulnerable in relation to someone perceived as, or projecting themselves as, non-vulnerable (those who aspire to or collude with hegemonic masculinity and able-bodiedness), this attribution of vulnerability is not a reality, but a construction.

Vulnerable – being exposed to harm in a situation over which one has no control – is a concept that is useful in situations of natural disaster – for example earthquakes, cyclones and tsunamis. In these circumstances people are exposed to risks that are outside human control. It is perhaps also useful in war zones; a situation that is caused by human agency but is overwhelming to those caught up in it and outside the control of many of those who are harmed. However, in most other situations, I contend that this is not a useful concept; in fact it is a harmful, disempowering and disabling concept that prevents dis/abled women gaining meaningful equality of access, equality of participation in society and achievement of their full human rights.

Most situations, other than those just described, where the concept of vulnerable is used, are situations that are caused by human action or inaction motivated by attitudes (such as those about privilege, value and dependency) and ideology (such as political ideology about the distribution of resources and lay ideology about who is deserving of support). In these situations vulnerability is ascribed to a counter-hegemonic population as a result of their exposure to harmful human activities and choices, not as a consequence of their own attributes or circumstances. From this perspective, as participants in the research said, there is nothing inevitable or intrinsic about the abuse of disabled women. This is an entirely modifiable situation.

Feminist disability theory (Fawcett, 2000; Garland-Thomson, 2004; Shildrick, 2009) and health promotion practice insist that we examine underlying causation. This means not taking paradigms and hegemonic understandings for granted and not looking for the surface and behavioural/individual causes of problems, but examining the overarching political, attitudinal and structural contexts that affect access to the social and economic determinants of health such as housing, income, education – and safety. Both gender and racism (and the intersection between them) have recently been identified (CSDH, 2008; Harris, Tobias, Jeffreys, Waldergrave, Karlsen, & Nazroo, 2006; Paradies et al., 2015) as overarching causes of inequity that construct certain groups of people from a deficit position that enforces exclusionary and discriminative institutional and interpersonal practices. By examining the concept of vulnerable (dis/abled women) in this way, I have attempted to uncover the overarching – and therefore invisible – pathway that leads to the disregarding of the abuse of dis/abled women, and which proposes this constructing of vulnerability as a determinant of women’s health and wellbeing. Uncovering this will enable the development of processes that, rather than addressing the consequences of the lack of value, poor practice and exclusion, will reveal the underlying causation of these processes and propose ways we can begin to constructively reverse this. Until this level of causation is addressed, all we will be doing (to use a medical metaphor) is attempting to ameliorate symptoms, rather than addressing the cause of the illness – and as we know, this does not rid someone of their problem. Seemingly inevitable pathways can be interrupted if we understand them, which is what this research is attempting to do.

Expectations of equality

To explain why this situation should be rectified I look to the values underpinning health promotion practice: social justice and equity (WHO, 1986). Health promotion, based on these values, insists that all people are enabled to take control over the determinants of their lives (WHO, 2005). I am characterising the construction of dis/abled women as vulnerable as an experience and as a determinant, aligned with gender discrimination and ableism that prevents many women from fully realising their potential and feeling in complete control of their lives (CSDH, 2008).

As identified previously, a participant noted that:

...the expectations have always been low, academic expectations have always been low, people say to disabled people living in institutions oh, you should be grateful 'cause you get three meals a day (GR2a).

This quote reflects the lack of equality that disabled women experience in their relationships with non-disabled people, and women with men. If the values of social

justice and equity are to be honoured, the abuse of dis/abled women following from the construction of dis/abled women as vulnerable must be addressed as a priority for health, justice, social service and other government spending, and for action from NGO and civil society organisations. However, one barrier to action at this level is the various understandings of what equality actually means and how equality should be distributed.

As the participant quote above suggests, one understanding of equality is that all people should have access to the most basic of human rights “*you get three meals a day*”. This is called liberal egalitarianism (Baker, Lynch, Cantillon, & Walsh, 2009), a key assumption of which “*is that there will always be major inequalities between people in their status, resources, work and power*” (Baker et al., 2009, p25). From this understanding disabled people, whose basic human needs (such as housing, food and right to life) are met by family or the state, have a sufficient level of equality that equates to their capacities and abilities. Liberal egalitarianism is accepting of huge inequalities in the distribution of wealth and other advantages. In this paradigm, equality of opportunity means that all people are perceived to have an equal chance to compete for resources and the acquisition of greater social advantage. This does not take into account people’s particular circumstances, societal inequality and the structures of society (Baker et al., 2009). This means that the exclusion, stigma and discrimination experienced by disabled women are not recognised as barriers to opportunity, and yet their inability to access the same resources as others is accepted as inevitable.

To counter the notion that inequality is inevitable, Baker et al. (2009) propose the concept of equality of condition, which they describe as aiming to eliminate major inequities altogether. This, I contend, is the meaning of equity in the Ottawa Charter: the redistribution of resources to eliminate major inequalities within and between countries. From this position, “*having three meals a day*” is insufficient realisation of an individual or group’s human rights and does not align with principles of equality.

This brief investigation of equality is important if a case is to be made for addressing both the underlying causation of the abuse of dis/abled women, and the political and service-related costs of responding. It is an argument for the redistribution of resources from those who have the most (wealth, advantage, political voice) to those who have the least.

What purpose does the construction of vulnerability serve?

Constructing a woman as vulnerable serves many of the same functions as, for example, rape myths and religious strictures. It creates fear of harm within the person so labelled or strictured; and it defines a certain demeanour and social

persona - a required compliant and grateful response to help and guidance, and restrictions on behaviour (to avoid harm and further stricture). It also creates real, or feelings of, powerlessness, as others assume control and competence over one's life, either directly or indirectly via social norms and roles. Within other non-vulnerable persons (those against whom vulnerability is compared) it engenders feelings of authority, protectiveness, entitlement, competence, and control. It also enables societal and state regulation, surveillance and control, as identified in the exclusion chapter, of those who are assumed to be unable/unfit to make decisions for themselves. This surveillance and control in turn increases fear and creates self-stricture.

White (2004), examining the work of Foucault (1973; 1979; 1980), discusses the concept of 'modern power', which he describes as "*an effective system of social control through what can be referred to as 'normalising judgement'*" (p168) whereby people are actively invited to participate in the judgement of their own and others' lives according to socially constructed norms (hegemonic paradigms). This regulation of our own and other's lives both describes and constructs the socially acceptable parameters of normal and abnormal and polices this via self and others – so people self-mediate their behaviour, looks, etc. and that of others, to be within the normal frame. This also creates a controlled and available group of people who are blamed/blaming themselves for not fitting these hegemonic norms – and consequently blame themselves and are blamed by others for any harm and powerlessness that occurs from not fitting expected parameters of behaviour and constructed norms (Matthews, 2014).

White (2004) contrasts this with traditional systems of power – those which are "*appropriated by certain individuals and groups*" (p153) according to their particular interests. This is monolithic power, usually with a defined centre (often called 'the system') and is top down.

[Traditional power] is power that is characterised as principally negative in its function; that is, it is a power that operates to oppress, repress, limit, prohibit, impose and coerce. This is a power that people are mostly subject to, not one that people generally participate in the exercise of (White, 2004, pp153-154).

Both of these models of power oppress dis/abled women. Modern power, surveillance by self and others, oppresses, shames and excludes women if they don't comply with hegemonic depictions of body shape and function, looks, intelligence (either too intelligent or insufficiently intelligent), interests, personal grooming and sexuality, for example, and also fail to fulfil expected social roles. Traditional power excludes and oppresses for many similar reasons, especially women who transgress

traditional role functions such as those held most fondly by church and state, for example, subservience, motherhood and being sexually available to men. It is interesting to note that those who exemplify the hegemonic ideal – certain men such as rugby players or other sports stars, very rich business men, adventurers – rarely, if ever, get blamed for the physical, emotional, business or other harm they experience – it is always someone else’s fault. But those who are counter-hegemonic seem always to get blamed – it is always their fault – an outcome of something they did that contravened the strictures within which they are supposed to reside/ behave/ live.

Reflecting on not only the results of this research that highlight the lack of value placed on women and women’s work, but the long-term lack of engagement with disabled women by feminist women in their practice and scholarship, I wonder if there is some fear from women’s organisations that if they are associated with disabled women they will be even less valued and have less power? Fine and Asch (1988) say that:

...perceiving disabled women as childlike, helpless and victimized [sic], non-disabled women have severed them from the sisterhood in an effort to advance more powerful, competent and appealing female icons.

They quote a feminist academic who said: “*Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive and needy*” (p4), and go on to say “*...perhaps the conviction that disabled people are inevitably burdensome and that women will be so burdened accounts for feminist resistance to involvement in the disability rights movement*” (p4).

This reason for lack of engagement was not articulated in the data; I doubt it would even be conscious. However, it may well be one reason for the reluctance to engage with this sector. After all, I was talking to women and men who were concerned about either violence against non-disabled and/or disabled women or the wellbeing of disabled women. Many of the participants had a socio-political analysis of the sector they worked in and worked from a values base of social justice and equity – but many had not engaged with the intersecting issue of violence against disabled women.

This may be another area where poor practice and the construction of vulnerability overlap. Many people working in both sectors want to help, save, convert, support, fix etc. an individual and her particular circumstances – but this remains impossible while the systems, structures, discourses and gender-based expectations are inadequate, stigmatising, enabling of abuse, stereotyping of ‘victims’ and supportive of hegemonic constructions of women. Also, from a position of collusion with

hegemonic norms, helping is safe. While women help women there is no focus on the perpetrator – on his harm, on how as a society we enable violence and abuse, and how we label some as less than the normative hegemonic position of able-bodied men. This enables women to collude with abusers while superficially appearing to help and resist. It certainly encourages an ethos of individualisation and encourages poor practice.

Finally, I have discovered that the construction of dis/abled women as vulnerable obscures the perpetrator; as the focus is on deficit – some women's perceived deficits in relation to 'normal', i.e. gender role normal, normal women, and all women's deficits in relation to men. Obscuring the perpetrator allows violence against women to be normalised and relatively unchallenged. Much of what I have discovered has been suggested by the literature. That women in general – and disabled women in particular – are considered second-class citizens and not accorded an equal share of resources and opportunities is not new. Also, as identified, vulnerability has been examined and described as a construction. Related to this – and a well-known human reaction – is that people tend to align themselves with the powerful – not with those who are considered vulnerable or weak; hence many women being unwilling to engage with issues of disability and/or abuse.

New learning from this research

So what is new? The medical and behavioural responses to the abuse of dis/abled women are to remediate or fix the situation on a concrete level and to educate people about the issue – both those who are abused (New Zealand Disability Action Plan) and those who are potential abusers and carers (MOH guidelines about abuse and neglect). The socio – environmental (health promotion approach) asks us to address the determinants – the underlying gender and disabling oppression that allows this issue to occur and be ignored.

Recognising that this is about the construction of women (and those who are 'other') as vulnerable and the resulting lack of any, or marginal responses to this, enables the fundamental construct to be challenged and addressed. In other words, it requires a challenging and changing of the paradigm. This need for a paradigm shift is very familiar to feminists who have been asking for a change to the patriarchal paradigm for many years. It is not even new to disabled people, who have a shorter history of activism, but a similar one. So this research has not uncovered radically new material – but it adds to feminist disability theory by more specifically addressing this particular issue – the construction of dis/abled women as vulnerable and the resulting expectations and enabling of abuse.

Why is this ‘discovery’ of the construction of dis/abled women as vulnerable important to the prevention of, and response to, violence against disabled women? The simple answer is that until we refute this concept of vulnerability, with its concurrent assumption of the inevitability of violence and predation, there is very little societal incentive to respond. In its present iteration our society backs those who are powerful (hegemonic masculinities) – we put very few social and political resources into those who are seen as powerless and/or dependent – despite rhetoric about concern for the elderly, children, victims, etc.

Another benefit of articulating this finding is to raise women’s awareness of how the use of this language and conceptualising of women as vulnerable makes all women more likely to be abused and harmed, and makes it less likely that sufficient processes will be put in place to prevent and remedy abuse. Finally, the important thing about this realisation is that it deconstructs the gap between disabled and non-disabled women. My use of the notion dis/abled women gains legitimacy as this strong connection between all women emerges. As Garland-Thomson (2004) says: in the eyes of men, all women are physically disabled. We women, by not being men, whether impaired or not, are constructed as vulnerable, as likely to be harmed, and therefore, as culpable for the harm that is done to us.

The research question

What are the explicit and implicit ideas, models, values and paradigms that practitioners and policy makers in the domestic/sexual violence and disability sectors subscribe to/hold (or employ) when working in their own sector and how do these ideas constrain or enable action to address violence and abuse of disabled women both within and across sectors?

From this, what actions can be identified to begin the process of engagement both within and across sectors?

Answering the research question

Finally, to specifically answer the research question:

What are the explicit and implicit ideas, models, values and paradigms that practitioners and policy makers in the domestic/sexual violence and disability sectors subscribe to/hold (or employ) when working in their own sector?

As stated in Chapter 4, as I read and listened to the various transcripts, I realised that the most interesting ideas were not necessarily to be found between sectors, but across them. The findings reflect this configuration; for example, it was one person

working in a government ministry and one of the activists who talked about vulnerability not being inherent (Vulnerable, Chapter 8). Findings in Chapter 5, *Too hard, not my problem, not a problem: Pragmatic reasons for non-collaboration*, came from across the spectrum of participants in the violence and disability sectors and from NGOs, government services and ministries.

A number of questions were asked to elicit the implicit and explicit ideas, models, values and paradigms that exist within and between the sectors. These questions related to:

- the knowledge and values that a person needs to have to work in either the violence or disability sector.
- what outcomes people are looking for in their work and what would be the best outcome that could occur?
- what motivates people to work in their particular sector – what really excites them about their job?
- particular models of practice or theories that people use in their work or that help them understand their work.
- any ideas, models, values etc that the sectors have in common that could be used to start conversations between the sectors.

Models, values and paradigms that practitioners and policy makers in the domestic /sexual violence and disability sectors subscribe to were distributed among the participants not by sector, but by understanding and ideology. For example, in the disability sector some people could describe the social and medical models of disability and explain why they subscribed to, for example, the social model. Others could not articulate a model of practice, but through descriptions of their work and values described the medical or social models. People working in the violence sector described a variety of models: the ecological public health model, the power and control model, strength-based processes, feminism and a number of others; however, there were no overarching models that were used across the sector or mentioned by all participants.

In Chapter 6 I discuss the two paradigms I identified from participant's language and their articulated and implicit attitudes and values, which I named the individual deficit and socio-political paradigms. These paradigms were identified from across the violence and disability sectors and from Ministries, NGOs and government agencies (e.g. police, DHBs, WINZ). For example, some people working in the violence sector held views and practised in a way that suggests they understand the world from an individual deficit perspective, wanting to rescue, help and fix the individuals they work with, without consideration of the wider contextual and

systemic constraints on individual's lives, circumstances and choices. Others in the same sector viewed the world from a socio-political perspective, understanding that the choices people make, and the circumstances of their lives, are constrained by power, political ideologies and by systems and processes that can privilege or discriminate against people. The elements of these two paradigms were also identified among people working in the disability sector. People are not being taught these paradigms, they enter their employment with these understandings and/or they are an inherent part of the culture of the organisation that they work for.

An example of this is the outcomes people sought in their work. Across the sectors interviewed the outcomes sought can be grouped into two main domains – people were either looking for change at an individual level “*to ensure that when people leave here they are in better shape than when they walked in*” (C1v), or at a systemic level “*key challenge for government is to identify those systemic or policy barriers that are in the way to prevent that from happening*” (P1g). This, as discussed in Chapter 6, indicates a gap in knowledge, paradigms and understanding between and within sectors as some people are working from a paradigm of individual rescuing and fixing and others are attempting to change the structural inequities that are causing harm and failing to adequately respond.

To summarise, the findings identified two paradigms, individual deficit and socio-political, distributed among the participants not by sector, but by each individual's understanding and ideology. The understanding of vulnerable as a paradigm was examined and found to be causative in the abuse of dis/abled women (Chapter 8). The explicit findings at the practical level include a lack of valuing of both sectors (women's work, low wages, low government funding, no mandatory standards of practice or qualifications), the lack of resources in the sectors (Chapter 5), the invisibility of disabled people in data collection and legislation (Chapter 7), state and organisational control of disabled people's lives (Chapter 7) and the good and poor practice that was identified (Chapter 6).

How do these ideas constrain or enable action to address violence and abuse of disabled women both within and across sectors?

Questions were asked to elicit similarities between people working in the various sectors and to discover potential enablers to initiate cooperation and conversation between the sectors. These questions relate to:

- the knowledge and values that a person needs to have to work in either the violence or disability sector.
- what participants thought would be useful ways to bridge the barriers between sectors.

- whether participants thought a human rights approach would work to start conversations between the sectors.

The questions about motivation, outcomes and ideas, and the models and values that the sectors have in common were also analysed to find answers to this question.

The primary finding that could enable conversations across sectors was a common desire to help or empower people or to improve people's lives and/or the systems that they live within. An example of this is an examination of the motivations people offered for doing their work. Motivations converged into four main themes distributed between and across sectors:

- (1) A personal belief in improving the wellbeing of others, including for some a motivation of social justice
- (2) Personal experience of either disability or violence and hence wanting change
- (3) Enjoying the job and the people worked with, i.e. the job was better than other previous jobs
- (4) Wanting to help and/or empower people.

This shared desire to improve people's lives has not, to date, resulted in any cross sector action to address the abuse of disabled women and while suggesting that people may be open to starting a conversation, does not provide sufficient structure for a shared dialogue as there is a big gap between wanting to help and/or rescue people and understanding systemic abuse and the political processes required to remedy this (as discussed in Chapter 6).

Participants were asked questions about human rights as a potential paradigm for shared action, but there was very little understanding of this evidenced in the responses apart from a general interest in human rights, such as: "*certainly the lifelong disability would be very aware of the human rights convention and charter*" (S7d) or "*so a lot of that is human rights based, that you have the right to say no, that you have the right not to be put into this position*" (S8v). I do not think that this generalised understanding of human rights constitutes a strong enough paradigm for shared action until significant education has occurred.

Participants were also asked if they or their organisations worked at the intersection of violence and abuse. Of the 87 people interviewed, all but the 14 activists and three other individuals said no. This lack of existing work is a further reinforcement of the finding that the sectors do not recognise the legitimacy of each other in relation to their client groups, nor do they see any reason to interact, as they do not see the issues they are employed to deal with as interrelated. This is a major barrier to collaboration or cooperation.

To summarise, the findings identify only constraints to action to prevent and respond to violence against dis/abled women. I believe this occurs because we, as a society, do not value those who are labelled as powerless, and consequently, insufficient resources are put into both the violence and disability sectors. The only enablers identified are the employment of people with a socio-political analysis of violence and disability (Chapter 6) and the elimination of the barriers and constraints identified in the thesis (Chapters 5-8).

From this, what actions can be identified to begin the process of engagement both within and across sectors?

Chapter 10 outlines the very practical political and service level recommendations developed in response to the findings. I have identified the need to reframe the concept of vulnerability: to not talk about women as intrinsically vulnerable, as this creates an environment where harm is inevitable. Instead, I propose refocusing on the extrinsic structural, attitudinal and other processes that enable women to be harmed. I recommend reframing the concepts of dependence and independence to interdependence, as this recognises the interconnectedness of people and the responsibility we all have to provide the level of support that each person requires to participate in the world and more specifically, to disclose domestic and sexual violence and recover from it. I also recommend that the practice model I have developed be used in training and staff selection.

Conclusion

This chapter begins by summarising the four levels of findings from this research. There is then an examination of the consequences of constructing women as vulnerable. It has identified the barriers that this causes to women being perceived as equal to men, by examining two understandings of what equality means. One meaning equates to all people having the right to minimal standards of living and human rights. Put another way, as disabled people and minority/marginalised people in general are treated as not fully human, and so ineligible for full human rights, they learn that they should not expect equality with the privileged hegemonic population. The other meaning of equality is full equality – of opportunity, identity and access to resources for all – not just those who are privileged by able-bodiedness, heterosexuality, wealth, by being male or being white. I then looked at the relationship of this construction with power, identifying how being named as vulnerable disempowers all women, personally and societally. One outcome of this is feminist and other women's fear of association with disabled women, as if disabled women's lack of power will somehow be catching. Furthermore, I asked if working with disabled women, and other women perceived as powerless (for example, victims of violence) enables non-disabled women to safely engage in feminist/female roles without fear of censure from men – as the helping/remediating role is a traditional role for women and enables collusion with, and/or ignoring of,

men's power and violence. I then identify that the new learning from my research is the specific identification of vulnerable as a paradigm that disempowers and disables all women, one consequence of which is the assumption that we will be abused, which provides one explanation for the lack of services and processes to prevent violence against women and keep abused women safe from further harm. Finally, the research question is restated and specifically answered, including a discussion of the differences and similarities within and between sectors.

The final chapter will describe suggestions for action to address violence against disabled women, as suggested by participants, and I will suggest responses to the construction of women as vulnerable.

Chapter 10

Conclusions and recommendations

Introduction

Emancipatory theory, as described in chapter 4, seeks transformational change (Baker et al., 2004; Garland-Thomson, 2002) to the circumstances of the marginalised population being studied, by investigating the “*structures of disablement*” (Henn et al., 2009, p42) inhibiting constructive progress and wellbeing. There is also an expectation that the results of emancipatory research will be accessible and available to the particular population for advocacy and social change purposes (Germon, 1998). In order to ensure that this research can be used for advocacy and social change, this chapter examines both the participant suggestions for action at government and service provider level and my own recommendations for change in response to my findings. I then discuss the limitations of my study and my recommendations for further research that could more fully examine the question I have investigated.

Participant recommendations

Participants were asked what they thought would be useful strategies to prevent violence against disabled women and to provide constructive services to those who are abused. From their replies I have identified the following recommendations. Some of these are extrapolated from the discussions with participants; others are direct suggestions in answer to the question posed.

Recommendations for action at government level

- Develop nationally agreed definitions of language and related practice. This suggestion arose from participant identification of the varying understandings of the terminology used in both sectors. Examples discussed in chapter 5 include various understandings of, for example, domestic violence, disability, empowerment and advocacy. Having nationally agreed definitions of language and the related practice (for example, what does empowerment mean in practice and how is this manifest at government and provider level?) would aid best practice and enable more constructive communication within and between sectors.
- Develop high quality national service specifications for violence services, including responses to disabled women; and service specifications and policies for disability services in regards to violence against disabled women.

- Develop high quality, nationally consistent training for everyone in all related sectors (violence, disability and social work services, health, counselling and therapy, police and justice), including all management staff, about the dynamics of violence and the mental and physical harms caused by violence, specifically including violence against disabled women.
- Develop clear, nationally consistent referral pathways – not into medical services but into well-resourced violence services. Pathways should be accessible from any entry point – health, social services, violence or disability sectors, educational routes (via teachers and counsellors), police etc. Herbert and Mackenzie (2014) describe this as:

When IPV or CAN [child abuse and neglect] is disclosed (to any agency), in effect, it is reported to the one system and mechanisms are in place to ensure seamless and effective service provision regardless of the entry point. There are clear referral pathways between all agencies in 'the system'; entering through any door leads into a broad system of community-wide support. This means anyone entering the system can access services via what might seem unlikely routes. It also means that when someone is being treated in the mental health system, the youth justice system (or the many other connected systems) and it is found that they are suffering from cumulative trauma of IPV or CAN, they can efficiently be 'linked up' with specialist IPV or CAN provider(s) (p4).

- Collect data. Establish a national baseline prevalence study of violence against disabled women, which is periodically updated, as with other prevalence studies. Currently no violence services that I have heard of are collecting statistics about disability and very few disability services have robust processes for collecting information about abuse. Therefore resources must be made available to ensure that nationally consistent systems are established in all services that women use, to ensure disability and violence data is routinely collected.
- Mandate all (relevant) services to prioritise abuse and response and collect information.
- Respect and pay staff more in both sectors. On March 31st, 2016 the New Zealand government announced that it was accepting all the recommendations of a Select Committee report into the funding of sexual

violence services (New Zealand Government, 2016). However, according to Jan Logie, Green Party MP and initiator of the select committee investigation:

The Government qualified their support for three important recommendations: accessible services, remuneration for staff, and strengthening existing kaupapa Maori services (Logie, 2016).

It will be interesting to see how the government does address the need for accessible services and improved remuneration for staff, as the government has accepted recommendation 8 that says “*that the Government allocate funding that takes into account ... additional funding for high needs areas or groups...*” (New Zealand Government, 2016, p6). The government is also currently considering how domestic violence services will be configured and funded, and it is to be hoped that accessibility, kaupapa Maori services and increased remuneration for staff will be considered in this process.

- Provide more resources (particularly staff) for organisations. Because the funding of violence and disability services has been low for so long, many organisations are working with minimal staffing levels. This means staff are highly stressed, often unable to give sufficient time to individual clients and unable to take on more clients. This can lead to unsafe situations – such as only one person going into women’s homes to offer support, potentially enabling abuse to occur, reliance on already stressed and traumatised women to ensure their own and their children’s safety, or overly stressed staff who are unable to fully concentrate on the wellbeing of clients. A number of participants discussed the need for increased staffing to ensure the safety of clients and staff wellbeing.
- Resource ongoing training and qualifications for staff in both sectors. Education improves not just specific practice, but can help develop a wider understanding of the world. Currently many staff in disability services have very little education, therefore national guidelines for basic qualifications and ongoing staff development and education would benefit the health and wellbeing of both staff and clients (National Advisory Committee on Health and Disability, 1998).
- Redefine the domestic violence legislation and how it is enforced to reflect disabled people’s reality. The domestic violence legislation is currently under review in New Zealand, and submissions were made to change the legislation to be inclusive of disabled women’s circumstances. The

government has not yet released its recommendations on these proposed changes (June, 2017).

- Identify and eliminate other policy barriers.
- Make affordable, accessible medium and long-term housing available for women who need safety. It is difficult for any woman to leave an abusive situation if she is moving into insecure, unaffordable, inaccessible accommodation. Most women will be poorer when they leave their relationship, so affordable, accessible, stable housing is a necessity to enable women to recover and move on with their lives.
- Provide women-only accommodation and services for abused women and appropriate services for men. Women-only services enable women who are traumatised by abuse to access services that are safe and supportive of their needs for safety and security.
- Develop cross-government collaboration – stop the silo mentality. Herbert and Mackenzie (2014) find that within government there is a lack of cohesion within and between sectors, with sexual violence and various aspects of domestic violence associated with different ministries; work streams with different priorities and oversight; and Ministers taking lead responsibility for different parts of the sectors. Disability sits outside all of the violence processes, situated in the Ministry of Health. Also, as Herbert and Mackenzie remind us, New Zealand has no current national plan or strategy for violence prevention and response.

Recommendations for action at organisational service provider level

When discussing strategies to ensure that services in both sectors would be responsive to the needs of disabled women, participants made three key recommendations. These recommendations are primarily aimed at service providers, but require government input to ensure that minimum standards and policies are generic across the country.

1. In order to ensure that legislation, policies, policy implementation and service provision meet the needs of disabled women, participants recommended that government and all services work with appropriately skilled disabled women. This is affirmed by the literature as noted in Chapter 2 (Close & Peel, 2012; Thiara et al., 2012). In order to achieve this, participants suggested:

- Working alongside Disabled People’s Organisations (DPOs), investing in building the capacity of disabled women to participate in employment (staff selection and supervision), planning and decision-making at agency and government level.
 - Ensuring that appropriate, skilled, non-token disabled women are on all boards and in decision-making positions of both sectors.
 - That specialist knowledge, skills, lived experience and qualifications are respected and used across sectors – including within justice and police – in planning, employment and service provision.
2. Developing shared competencies and understandings across the sectors. In order to do this, participants suggested:
- Sectors working together with government to create shared language and understanding.
 - Building on existing services (not necessarily starting new services) but ensuring that specialist knowledge exists in and across all services.
 - Collaboration within and between sectors, not patch protection. As identified in chapter 5, the current competitive funding regime means that there is very little cooperation between services, as organisations are afraid of losing funding or of being closed if they collaborate with other organisations.
 - Developing agency policies about screening, disclosure and response. Minimum standards and generic policy about screening and response must be developed at government level. The purpose of this is to enable all services that may encounter abused dis/abled women to respond in a constructive and non-abusive way to ensure women are safe and perpetrators are held accountable for their abusing.
3. Staff recruitment and training. This recommendation aligns with the findings about poor, good and best practice in the sectors.
- Ensuring that all staff have a socio-political analysis of the work they do.

- Clarifying what best practice is and documenting and training for best practice – including role modelling best practice from management.
- Ensuring all staff have a critical analysis of power and powerlessness and the ability to work with complexity.

My recommendations

1) The key paradigm I have discovered in relation to my question is a negative one – the conceptualising of dis/abled women as vulnerable. This means I must consider why this insight I have gained from my research is valuable, and how we (society) should address it. A key tenet of feminist disability theory is transformation (Garland-Thomson, 2002), the reimagining of established ideas, knowledge and particular social, economic, religious and political systems. Therefore feminist disability theory demands that the paradigm I have discovered be deconstructed and reframed to emphasise societal responsibility for the harming of women. So, rather than addressing the deficits of women I suggest we identify the structural, contextual, linguistic and attitudinal positions that require reframing and reorientating to enable change to occur. Borell, Gregory, McCreanor, Jensen and Moewaka Barnes (2009) explain this:

Disparity can be conceptualized [sic] in two distinct ways – in a disadvantage or a privilege framework. In a disadvantage or deficit framework, the scrutiny is on those experiencing the lack. The solution therefore is predominately seen to rest with those who are experiencing the disadvantage, and the duty lies with them to develop the qualities that those not experiencing disadvantage apparently have. Conversely, when seen from a privilege framework, at least part of the onus of responsibility lies with those who are not experiencing disadvantage. Historically, the framework predominately used to view disparity sidelines those with advantage whilst turning the gaze on the disadvantaged. Reframing disparity debates and foci from disadvantage to privilege frameworks may be an effective way of changing public health and social relations by facilitating self-awareness in those with conferred advantage (Borell, et al., 2009, p35).

Further explaining this, the Commission on Social Determinants of Health says:

This unequal distribution of health-damaging experiences is not in any sense a 'natural' phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics (CSDH, 2008, p1).

In line with this reasoning – of placing the responsibility for harm and for change on those who are privileged, and on *bad politics* rather than on the harmed individuals and communities – my recommendation to address this construction of dis/abled women as vulnerable is to change the paradigm. I suggest a reframing of language (and thinking) from dis/abled women as the problem to situating the problem within inadequate systems and social attitudes – such as hegemonic male/able-bodied privilege and norms about gender roles – that enable violence. This would mean talking and writing about social and institutional structures and systems that enable violence against women, and women who are endangered by inadequate systems, structures and social attitudes, rather than vulnerable women. It is a few more words, but this clearly describes where responsibility for the violence lies and would result in a change of language and focus in research, literature and, subsequently, the discourse about both violence against women and disability.

Reframing the paradigm in this way does a number of things. It places responsibility for the violence and abuse that dis/abled women experience, first, on the perpetrators and, secondly, on the social/attitudinal and political systems that either enable violence or fail to prevent it. It acknowledges that no one is inherently more available to be harmed than any other person, but that it is our expectations of violence that enable abuse to occur. Finally, it provides further language and rationale to challenge male privilege and inequitable gender roles and norms, particularly around dis/abled women’s perceived frailty, powerlessness and need for protection. Edstrom and Shahrokh (2016), in their discussion of engaging men in gender equity processes, warn that “*engaging men should not reinforce a sense of male supremacy by simply appealing to men as ‘protectors’ of, or decision makers on behalf of, the interests of women and girls*” (p18). A change of paradigm such as I am suggesting would acknowledge the inherent equality and agency of all people and seek to engage both men and women in a search for more empowering and equitable relationships.

2) Aligned with this is a reframing of the current hegemonic male/neo-liberal construct of independence as the desirable state to achieve and being dependent as a negative, powerless position. I have, in chapter 6, discussed why I believe that independence and dependence are fallacies and shown how we are all interconnected and in need of support from each other. This aligns with the concept of all embodied creatures being vulnerable, able to be hurt (Butler, 2004, 2009; Knight, 2014; MacIntyre, 2000; Shakespeare & Watson, 2001). Therefore, I recommend that women and men reject the hyper-masculine construction of independent, autonomous (male) individual and promote interdependence. My interpretation of this means interdependence between people and also between people and our environment, the air, water, land and other creatures that inhabit our planet. The

affirmation of interdependence and the reciprocal maintenance (WHO, 1986) that this entails speaks to a reframing of relationships away from independence and individualism towards a more equitable, interconnected paradigm.

3) Lastly, in my recommendations, I suggest that violence and disability services adopt the model of poor, good and best practice that I have identified from the data (Table 4, p160). This model does not prescribe specific behaviours or skills in relation to particular tasks or sectors, but identifies ways of thinking that either enhance or inhibit good practice in sectors where staff are required to develop constructive, empowering and supportive relationships with their clients. The model could be used to develop national practice competencies that would inform staff selection and provide the basis for training development and qualifications in both sectors. I am repeating the model below.

Table 7: Model of best, good and poor practice

<p>Best practice</p> <ul style="list-style-type: none"> • Understands interpersonal and institutional discrimination, stigma and oppression • Works from a socio-political contextual orientation and analysis • Understands hegemonic structures/privilege and questions this • Comfortable with complexity • Has a good analysis of power (political, social, economic, privilege) including empowering processes • Informed. Understands the history of both movements (disability and violence) – social justice, inclusion, enablement, inherent human rights, control and current political context • Decisions, policy, legislation etc. developed with core group (e.g. dis/abled women).
<p>Good practice</p> <ul style="list-style-type: none"> • Everyone is a person – inherent respect for all people • Listening, doing what people want, not what you think is best, offering real choices and options • Honesty, integrity • Enabling not protecting • Eliminating barriers, enabling voice • Non-blaming – not victimising • Interdependence rather than independence or dependence • Empowering = walking alongside, building power – not expecting people to act alone • Responsibility placed on the perpetrator of violence, not the victim.

Poor practice

- Rescuing, helping, protecting
- Working from a medical/individual deficit paradigm
- Without critical analysis
- Wanting people to say thank you
- Individualisation as a consequence of lack of training
- No, or little, knowledge of history, of social movements, complexity or determinants
- Expecting independence or dependence – no informed concept of interdependence
- No values base
- Blaming/victimising
- Responsibility placed on victim of violence, not perpetrator
- Decisions, policy, legislation etc. made without reference to core group – voices not trusted
- Hegemonic values adhered to and believed
- Uninformed, untrained, not resourced
- No shared understanding within and between sectors.

Limitations of the research and directions for future research

Once the interviews and focus groups had been recorded and transcribed and I was reflecting on the data obtained and possible data not obtained, I realised that there were a number of questions that were not asked. These are very pragmatic questions that might have illuminated some of the other answers.

- a. Do you talk to the other sector?
- b. What is the reason for this?
- c. How do you make decisions about how to respond to allegations/disclosures?
- d. Who do you refer to?
- e. How did you decide to do this?
- f. What is the thinking behind this? The thought process?

Also, there are questions that would have been useful to explore if there had been a possibility of a second round of interviews, to explore the more latent issues in more depth. These are:

- a. How do participants understand the wider political and social context that their work, and that of the other sector, operates in?
- b. What social and political contexts increase perceived vulnerability?
- c. What do participants understand vulnerability to mean?
- d. What social and political contexts are preventative?

- e. What do participants understand about issues of power inherent in both issues and at the intersection?

It was only after reading all of the transcripts and reflecting on the data obtained that I identified the lack of this level of questioning.

There are also questions that have arisen from the findings that require further investigation. These are connected to the unasked questions about power, above, and would involve more deeply examining non-disabled women's lack of engagement with disability. Is it, as suggested by the literature and some participants, about power? Is it women not wanting to be associated with others who are even lower on the societal value scale? Is it workers in the domestic and sexual violence sector not wanting to work with another level of powerlessness? Do women, who are already undervalued, feel that they would be more undervalued if they worked with disabled women? All of these and the additional questions above would be useful and interesting areas for further research.

Finally, it would be interesting to research responses to my suggestions for reframing the paradigm of vulnerability. Paradigm change is a confrontational, challenging concept – even having hegemonic assumptions challenged can be very threatening for people, so having these ideas challenged and alternatives offered could be very uncomfortable. Yet, if change is to occur, this is a necessary next step.

Conclusion

Using feminist disability theory and findings from interviews with participants from the domestic, sexual violence and disability sectors (and related government services) I have examined the paradigms, models and theories that inhibit or enable conversations and collaboration within and between the violence and disability sectors to address the abuse of disabled women. Doing this has enabled me to understand the multiple barriers that inhibit service responses; constructive responses from government; and societal impetus to address the lack of attention currently paid to this issue. I have identified that underpinning this lack of attention is the constructing of dis/abled women as vulnerable – a construction that presumes the inevitability of harm being perpetrated on women who are categorised in this way. These findings extend feminist disability theory, particularly challenging understandings of how dis/abled women are/should be represented and seeking to transform and re-imagine (Garland-Thomson, 2002) this paradigm (vulnerability) that devalues and disempowers dis/abled women by constructing women as less than men and as inherently damaged and able to be harmed. The transformation requires a paradigm change that shifts the responsibility for, and site of, the problem to the

societal attitudes, structures and systems that not only fail to protect dis/abled women, but enable violence and abuse to occur.

References

- Ackerly, B., & True, J. (2010). *Doing feminist research in political and social science*. Basingstoke, England: Palgrave Macmillan.
- Adams, P., & Buetow, S. (2014). The place of theory in assembling the central argument for a thesis or dissertation. *Theory & Psychology*, 24(1) 93–110. DOI: 10.1177/0959354313517523
- Allen, A. (2008). *The politics of our selves: Power, autonomy, and gender in contemporary critical theory*. New York: Columbia University Press.
- Allport, G. W. (1954). *The nature of prejudice*. Cambridge, MA: Addison-Wesley.
- Anderson, I., & Doherty, K. (2008). *Accounting for rape: Psychology, feminism and discourse analysis in the study of sexual violence*. London, England: Routledge.
- Appleton-Dyer, S., & Field, A. (2014). *Understanding the factors that contribute to social exclusion of disabled people: Rapid review for Think Differently*. Auckland, New Zealand: Synergia.
- Appleton-Dyer, S., & Soupen, A. (2017). *Rapid review of the Waitemata safeguarding adults from abuse (SAFA) pilot report for the Waitemata Police*. Auckland, New Zealand: Synergia.
- Asch, A., & Fine, M. (1988). Introduction. Beyond pedestals. In M. Fine, & A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture, and politics*. (pp. 1–38). Philadelphia, PA: Temple University Press.
- Auckland Sexual Abuse Help. (n.d.). *Sexual violence and prevention*. Retrieved from www.sexualabusehelp.org.nz, May 10, 2012.
- Auckland Sexual Abuse Help. (2011). *Briefing paper to Auckland Council: The community sexual violence sector, Auckland region, 2011*. Auckland, New Zealand: Auckland Sexual Abuse Help.
- AWID. (2004). *Intersectionality: A tool for gender and economic justice*. Women's Rights and Economic Changes: No. 9, August 2004. Toronto, Canada: Association for Women's Rights in Development. Retrieved from www.awid.org
- Baker, J., Lynch, K., Cantillon, S., & Walsh, J. (2004). *Equality: From theory to action*. Basingstoke, England: Palgrave Macmillan. Retrieved from doi: 10.1057/9780230508088
- Baker, J., Lynch, K., Cantillon, S., & Walsh, J. (2009). *Equality: From theory to action*. (2nd ed.). Basingstoke, England: Palgrave Macmillan.
- Balderston, S. (2013). Victimized again? Intersectionality and injustice in disabled women's lives after hate crime and rape. In V. P. Demos, & M. T. Segal (Eds.), *Gendered perspectives on conflict and violence: Part A*. (pp. 17–51). Leicester, England: Emerald Press. <http://dx.doi.org/10.1108/S1529-2126>

- Banks, M.E. (2003). Preface. In M.E. Banks, & E. Kaschak (Eds.), *Women with visible and invisible disabilities: Multiple intersections, multiple issues, multiple therapies*. (pp. xxi – xxxvii). New York, NY: Haworth Press.
- Barbuto, R., & Napolitano, E. (2014). Women with disabilities: From discrimination and violence towards an ethic of reciprocity. *Modern Italy*, 19(2), 161–168.
- Barnes, C. (2004). Disability, disability studies and the academy. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers – enabling environments* (2nd ed., pp. 28–33). London, England: Sage.
- Barnett, H. (2015). *Report to the Special Rapporteur on the rights of persons with disabilities*. United Nations Geneva. Wellington, New Zealand: Disabled People’s Assembly New Zealand.
- Barnett, O. W., Miller-Perrin, C. L., & Perrin, R. D. (2011). *Family violence across the lifespan: An introduction*. (3rd ed.). Thousand Oaks, CA: Sage.
- Barron, J. (2004). *Struggle to survive: Challenges for delivering services on mental health, substance misuse and domestic violence*. Bristol, England: Women’s Aid.
- Barton, L. (1996). *Disability and society: Emerging issues and insights*. New York, NY: Longman.
- Barton, L. (2005). Emancipatory research and disabled people: some observations and questions. *Educational Review*, 57:3, 317-327.
DOI:10.1080/00131910500149325
- Bashall, R., & Ellis, B. (2012). Nothing about us without us. In R. K. Thiara, G. Hague, R. Bashall, B. Ellis, & A. Mullender, *Disabled women and domestic violence: Responding to the experiences of survivors* (pp. 106–136). London, England: Jessica Kingsley.
- Baum, F. (2008). *The new public health*. (3rd ed.). Victoria, Australia: Oxford University Press.
- Baum, F. (2015). *The new public health*. (4th ed.). Victoria, Australia: Oxford University Press.
- Becker, E., Rankin, E., & Rickel, A. U. (1998). *High-risk sexual behaviour interventions with vulnerable populations*. Boston, MA: Springer.
- Bickenbach, J. E. (2001). Disability, human rights, law and policy. In G. L. Albrecht., K. Steelman, & M. Bury (Eds.), *Handbook of disability studies*. (pp. 565–585). Thousand Oaks, CA: Sage.
- Boerma, W. G. W. (2006). Coordination and integration in European primary care. In R. B. Saltman, W. G. Ana Rico, & W. G. W. Boerma (Eds.), *Primary care in the drivers seat? Organisational reform in European primary care*. (pp. 3–21). Maidenhead, England: Open University Press.
- Bogard, M. (2005). Strengthening domestic violence theories: Intersections of race, class, sexual orientation and gender. In N. J. Sokoloff, & C. Pratt (Eds.),

- Domestic violence at the margins: Readings on race, class, gender and culture.* (pp. 25-38). Piscataway, NJ: Rutgers University Press.
- Boon, H., Verhoef, M., O'Hara, D., & Findlay, B. (2004). From parallel practice to integrative health care: A conceptual framework. *BMC Health Services Research, 4*(1), 15. <http://dx.doi.org/10.1186/1472-6963-4-15>
- Borell, B. A. E., Gregory, A. S., McCreanor, T. N., Jensen V. G. L., & Moewaka Barnes, H. E. (2009). It's hard at the top but it's a whole lot easier than being at the bottom: The role of privilege in understanding disparities in Aotearoa-New Zealand. *Race and Ethnicity, 3*(1), 29–50.
- Braaf, R., & Barrett Mayering, I. (2013). *The gender debate in domestic violence: The role of data* (Issues Paper 25). Sydney, Australia: Australian Domestic and Family Violence Clearing House, University of New South Wales.
- Brady, S., Briton, J., & Grover, S. (2001). *The sterilisation of girls and young women in Australia: Issues and progress*. Sydney, Australia: Australian Human Rights Commission.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.
- Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: Is it time for an alternative model of disability? *Disability and Society, 7*(19), 825–843.
- Briggs, F., & Hawkins, R. (2005). Personal safety issues in the lives of children with learning disabilities. *Children Australia, 30*(2), 19–27.
- Brown, J., & James, K. (2014). Therapeutic responses to domestic violence in Australia: A history of controversies. *Australian and New Zealand Journal of Family Therapy, 35*(2), 169–184.
- Brown, P. (2006). The politics of disability. *RCN News, Autumn*.
- Brownridge, D. A. (2006). Partner violence against women with disabilities: Prevalence, risk, and explanations. *Violence Against Women, 12*(9), 805–822.
- Brownworth, V. A. (1999). Introduction. In V.A. Brownworth, & S. Raffo (Eds.), *Restricted access: Lesbians on disability* (pp. xi-xxii). Seattle, WA: Seal Press.
- Bruder, C., & Kroese, B. S. (2005). The efficacy of interventions designed to protect people with intellectual disabilities from sexual abuse: A review of the literature. *The Journal of Adult Protection, 7*(2) 13–27.
- Buchwald, E., Fletcher, P. R., & Roth, M. (1993). *Transforming a rape culture*. Minneapolis, MN. Milkweed Editions.
- Burghardt, M. (2013). Common frailty, constructed oppression: tensions and debates on the subject of vulnerability. *Disability & Society, 28*(4), 556–568. <http://dx.doi.org/10.1080/09687599.2012.711244>

- Butler, J. (2004). *Precarious life: The powers of morning and violence*. London, England: Verso.
- Butler, J. (2009). *Frames of war: When is life grievable?* London, England: Verso.
- Cadilhac, D. A., Sheppard, L., Cumming, T. B., Thayabranathan, T., Pearce, D. C., Carter, R., & Manhnus, A. (2015). The health and economic benefits of reducing intimate partner violence: An Australian example. *BMC Public Health, 15*(625). <http://dx.doi.org/10.1186/s12889-015-1931-y>
- Caelli, K., Ray, L., & Mill, J. (2003). Clear as mud: Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2*(2), 1–13.
- Calderbank, R. (2000). Abuse and disabled people: Vulnerability or social indifference? *Disability & Society, 15*(3), 521-534. <http://dx.doi.org/10.1080/713661966>
- Carbin, M. & Edenheim, S. (2013). The intersectional turn in feminist theory: A dream of a common language? *European Journal of Women's Studies, 20*(3), 233-248.
- Careerforce. (2016). National Certificate in Social Service Work with Abuse, Neglect, and Violence (Level 4). Retrieved from <http://www.careerforce.org.nz/social-services/social-service-work-abuse-neglect-violence-level-4/>
- CCS Disability Action. (2015). *Government plan on data could make disabled people invisible*. Press release. Author. Retrieved from <http://www.ccsdisabilityaction.org.nz/news/914-government-plan-on-data-could-make-disabled-people-invisible>
- Christensen, L. (1997). Te Pumautanga: A Maori perspective on the development of human services. In P. O'Brien, & R. Murray. (Eds.), *Human services: towards partnership and support*. (pp. 151–164). Palmerston North, New Zealand: Dunmore Press.
- Close, L., & Peel, K. (2012). *Incorporating the voice of experience: Family violence-service user involvement guide*. Wellington, New Zealand: Ministry of Social Development on behalf of Taskforce for Action on Violence Within Families.
- Cockburn, C. (2007). *From where we stand: War, women's activism and feminist analysis*. London: Zed Books.
- Collins, P. H. (2012). Social inequality, power, and politics: Intersectionality and American pragmatism in dialogue. *The Journal of Speculative Philosophy, 26*(2), 442-457. Retrieved from http://muse.jhu.edu/journals/journal_of_speculative_philosophy/v026/26.2.collins.html
- Connell, R. (2005). *Masculinities* (2nd ed.). Crow's Nest, Australia: Allen & Unwin.

- Connell, R., & Messerschmidt, J. W. (2005). Hegemonic masculinity: Rethinking the concept. *Gender and Society, 19*(6), 829–859.
- Covey, H. C. (2005). Western Christianity's two historical treatments of people with disabilities or mental illness. *The Social Science Journal, 42*(1), 107–114.
- Cramer, E. P. & Plummer, S-B, (2010). Social work practice with abused women with disabilities. In L. L. Lockhart & F. S. Danis (Eds.), *Domestic violence: intersectionality and culturally competent practice* (pp. 128-154). New York: NY: Columbia. University Press.
- Cranson, H. (2010). *Diversity report 2009 – 2010*. Wellington, New Zealand: National Collective of Independent Women's Refuges.
- Crenshaw, K. (1992). Race, gender and sexual harassment. *Southern California Law Review, 65*(3), 1467–1476.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches*. (4th ed.). Los Angeles, CA: Sage.
- Cripps, K., & Adams, M. (2014). Family violence: Pathways forward. In *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing. Principles and practice* (2nd ed. pp. 399-416). Retrieved from: [http://aboriginal.telethonkids.org.au/kulunga-research-network/working-together-2nd-edition-\(1\)/](http://aboriginal.telethonkids.org.au/kulunga-research-network/working-together-2nd-edition-(1)/)
- Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability* (pp. 206–226). London, England: The Women's Press.
- Crowe, A., & Murray, C. E. (2015). Stigma from professional helpers toward survivors of intimate partner violence. *Partner Abuse, 8*(2), 157–179.
- Crown Law. (2013). *Solicitor-General's prosecution guidelines*. Wellington, New Zealand: Crown Law, New Zealand Government.
- CSDH. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health*. Geneva, Switzerland: World Health Organisation.
- Curry, M. A., Renker, P., Robinson-Whelen, S., Hughes, R. B., Swank, P., Oswald, M., & Powers, L. E. (2011). Facilitators and barriers to disclosing abuse among women with disabilities. *Violence and Victims, 26*(4), 430–444.
- Curtin, M. & Fossey, E. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Occupational Therapy Journal, 54*(2), 88-94
- D'aoust, V. (1999). Complications: The Deaf community, disability and being a lesbian mom – a conversation with myself. In V. A. Brownworth, & S. Raffo (Eds.), *Restricted access: Lesbians on disability* (pp. 115–123). Seattle, WA: Seal Press.

- Davies, J. K. (2013). *Health promotion: A unique discipline?* Health Promotion Forum of New Zealand Occasional Paper Series. Auckland, New Zealand: Health Promotion Forum of New Zealand.
- Devries, K. M., Mak, J. Y. T., Garcia-Moreno, C., Petzold, M., Child, J. C., Falder, G., Lim, S., Bacchus, L. J., Engell, R. E., Rosenfeld, L., Pallitto, C., Vos, T., Abrahams, N., & Watts, C. H. (2013). The global prevalence of intimate partner violence against women. *Science*, *340*(6140), 1527–1528.
- Dhamoon, R. K. (2011). Considerations on mainstreaming intersectionality. *Political Research Quarterly*, *64*(1), 230–243.
- Dickson, S. (2017). *Responses from Disabled Sex, Sexuality and Gender Diverse People: Building Rainbow communities free of partner and sexual violence*. Wellington, New Zealand. Hohou Te Rongo Kahukura – Outing Violence.
- Disability Coalition Against Violence. (2010). *Discussion document to the Taskforce for Action on Violence Within Families, Taskforce meeting 11 August, 2010*. Christchurch, New Zealand: Author.
- Disabled Women's Support Group. (1987). *Women with Disabilities. Report of a consultation meeting of women with disabilities, convened by the Ministry of Women's Affairs*. South, Central Auckland and Wellington, New Zealand: Disabled Women's Support Group and DPA.
- Dolmage, J. (2011). Disabled upon arrival. The rhetorical construction of disability and race at Ellis Island. *Cultural Critique*, *77*, 24–69.
- Domestic Abuse Intervention Programme. (1984). *Power and control wheel*. Duluth, MN: Domestic Abuse Intervention Programme. Retrieved from <http://www.theduluthmodel.org/>
- Domestic Violence and Disability Working Group. (2010). *Domestic violence and disabled people*. Wellington, New Zealand: It's Not OK Campaign, Ministry of Social Development.
- Dragiewicz, M. (2008). Patriarchy reasserted: Fathers' rights and anti VAWA activism. *Feminist Criminology*, *3*(2), 121–144. <http://dx.doi.org/10.1177/1557085108316731>
- Dragiewicz, M., & DeKeseredy, W. S. (2012). Claims about women's use of non-fatal force in intimate relationships: A contextual review of Canadian research. *Violence Against Women*, *18*(9), 1008–1025. <http://dx.doi.org/10.1177?1077801212460754>
- Drake, R. F. (1996). A critique of the role of the traditional charities. In Barton, L. (Ed.), *Disability and society: Emerging issues and insights* (pp. 147–166). Harlow, Essex, England: Addison Wesley Longman.
- Durie, M. (1994). *Maori health development*. Auckland, New Zealand: Oxford University Press.

- Durie, M. (1999). Te Pae Mahutonga: A model for Maori health promotion. *Health Promotion Forum of New Zealand Newsletter*, 49, 2-5.
- Dwyer, M. (2010). *New Zealand women's employment outcomes: The relationship between working shorter hours and low paid, female-dominated occupations*. Wellington, New Zealand: National Advisory Council on the Employment of Women, NZ Government.
- Edstrom, J., & Shahrokh, T. (2016). *Reframing men and boys in policy for gender equity: Conceptual guidance and agenda for change*. EMERGE Framing Paper, Promundo-US, Sonke. Gender Justice and the Institute of Development Studies, Brighton, England: IDS.
- Elizabeth, V. (2004). *Shared lessons: Reflections on differences within a primary violence prevention collaborative partnership*. (Research Paper Number 16) Strengthening Communities through Local Partnerships Programme: Local Partnerships and Governance Research Group. Auckland, New Zealand: University of Auckland.
- Elizabeth, V., Gavey, N., & Tolmie, J. (2012) “. . . He’s just swapped his fists for the system” The governance of gender through custody law. *Gender and Society*, 26(2), 239-260. <http://dx.doi.org/10.1177/0891243211434765>
- Elvidge, J. (1997). *Opening Pandora's Box: The health sector response to male partner violence. A discussion paper of the Family Violence Advisory Committee*. Auckland, New Zealand: Health Promotion Unit, Auckland Healthcare.
- Faith, K. (1994). Resistance: Lessons from Foucault and feminism. In L. H. Radtke, & J. H. Stam (Eds.), *Power/gender: Social relations in theory and practice* (pp. 36-66). London, England: SAGE.
- Family Violence Death Review Committee. (2014). *Fourth Annual Report: January 2013 to December 2013*. Wellington, New Zealand: Health, Quality and Safety Commission.
- Fanslow, J., & Robinson, E. (2004). Violence against women in New Zealand: Prevalence and health consequences. *New Zealand Medical Journal*, 117(1206), 1-12.
- Fawcett, B. (2000). *Feminist perspectives on disability*. New York, NY: Pearson Education.
- Fawcett, B. (2009). Vulnerability: Questioning the certainties in social work and health. *International Social Work*, 52(4), 473-484. <http://dx.doi.org/0.1177/0020872809104251>
- Feminists with disabilities for a way forward. (n.d.) Retrieved from <http://disabledfeminists.com>
- Fine, M., & Asch, A. (1988). *Women with disabilities: Essays in psychology, culture and politics*. Philadelphia, PA: Temple University Press.

- Finkelstein, V. (2004). Representing disability. In J. Swain, S. French, C. Barnes, & C. Thomas. (Eds.), *Disabling barriers – enabling environments* (2nd ed. pp. 13-20). London, England: SAGE Publications.
- Frawley, P., Dyson, S., Robinson S., & Dixon, J. (2015). *What does it take? Developing informed and effective tertiary responses to violence and abuse of women and girls with disabilities in Australia*. Sydney, Australia: Australia's National Research Organisation for Women's Safety Limited. ANROWS.
- French, S. (1993). Disability, impairment or something in between? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling Barriers—enabling environments* (pp. 17-35). London, England: SAGE.
- Frohman, C., Dowse, L., & Didi, A. (2015). *Preventing violence against women and girls with disabilities: Integrating a human rights perspective*. Lenah Valley, Australia: Women with Disabilities Australia.
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416.
- Fulcher, G. (1989). *Disabling politics? A comparative approach to education policy and disability*. Barcombe, Philadelphia, PA: Falmer Press.
- Gabel, S., & Peters, S. (2004). Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability and Society*, 19(6), 585-600.
- Garcia-Moreno, C., Guedes, A., & Knerr, W. (2012). *Understanding and addressing violence against women: Information sheet*. Geneva, Switzerland. World Health Organisation and Pan American Health Organisation.
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *National Women's Studies Association Journal*, 14(3), 1-21.
- Garland-Thomson, R. (2004). Integrating disability: Transforming feminist theory. In B. G. Smith, & B. Hutchison (Eds.), *Gendering disability* (pp. 73–106). Piscataway, NJ: Rutgers University Press.
- Gates, S. (2000). *A human wrong: Sterilisation of young girls and women with intellectual disabilities in New Zealand*. Unpublished position paper. Dunedin, New Zealand: Donald Beasley Institute.
- Gavey, N. (2005). *Just sex: The cultural scaffolding of rape*. London, England: Routledge.
- Gilson, S. F., Cramer, E. P., & DePoy, E. (2001). Redefining abuse of women with disabilities: A paradox of limitation and expansion. *Affilia*, 16(2), 220-235.
- Green Party of New Zealand. (2017). *Minority view statement*. Family and whanau violence legislation Bill: As reported from the Justice and Electoral Select committee. Wellington, New Zealand: New Zealand Government.

- Germon, P. (1998). Activists and academics. In T. Shakespeare (Ed.), *The Disability reader* (pp. 249-255). London, England: Cassell.
- Goodman, L. A., Rosenberg, S. D., Mueser, K. T., Drake, R. E. (1997). Physical and exual Assault History in Women With Serious Mental Illness: Prevalence, Correlates, Treatment, and Future Research Directions. *Schizophrenia Bulletin*, 23(4), pp.685-696
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82. doi:10.1177/1525822X05279903
- Guest, G., MacQueen, K. M., & Namey, E.E. (2012). *Applied thematic analysis*. Los Angeles, Sage Publications.
- Gulliver, P., & Fanslow, J. (2012). *Measurement of family violence at a population level: What might be needed to develop reliable and valid family violence indicators?* Auckland, New Zealand: New Zealand Family Violence Clearinghouse, The University of Auckland.
- Gulliver, P., & Fanslow, J. (2013a). Exploring risk factors for suicidal ideation in a population-based sample of New Zealand women who have experienced intimate partner violence. *Australian and New Zealand Journal of Public Health*, <http://dx.doi.org/10.1111/1753-6405.12110>
- Gulliver, P., & Fanslow, J. (2013b). *Family violence indicators: Can administrative data sets be used to measure trends in family violence in New Zealand?* Research report 3/13. Wellington, New Zealand: SuPERU, a division of the Families Commission.
- Hager, D. (2001). *He drove me mad: The relationship between domestic violence and mental illness*. (Unpublished master's thesis). Auckland, New Zealand: University of Auckland.
- Hager, D. (2011). *Finding safety: Provision of specialised domestic violence and refuge services for women who currently find it difficult to access mainstream services*. Homeworks Trust. Retrieved from www.homeworkstrust.org.nz
- Hager, M., & Hager, D. (2013). *Independence/dependence. Integrating concepts for a future disability inclusive feminism*. Wellington, New Zealand: Unpublished conference paper. Women's Study Association Conference.
- Hague, G. M., & Mullender, A. (2006). 'Who listens? The voices of domestic violence survivors in service provision in the United Kingdom'. *Violence Against Women*, 12(6), 568-587.
- Hague, G., Mullender, A., & Aris, R. (2002). *Professionals by experience: A guide to service user participation and consultation for domestic violence services*. Bristol, England: Women's Aid Federation of England.
- Hague, G. M., Mullender, A., & Aris, R. (2003). *Is anyone listening? Accountability and women survivors of domestic violence*. London, England: Routledge.

- Hand, J., Martin, B., Elizabeth, V., Rauwhero, H., Burton, M., Selby, S., & Falanitule, L. (2002). *Free from abuse: What women say and what can be done*. Auckland, New Zealand: Public Health Promotion Service, Auckland District Health Board
- Hann, S., & Trewartha, C. (2015). *Creating change. Mobilising New Zealand communities to prevent family violence*. Auckland, New Zealand: New Zealand Family Violence Clearinghouse.
- Harpur, P., & Douglas, H. (2014). Disability and domestic violence: Protecting survivors' human rights. *Griffith Law Review*, 23(3), 405-433.
- Harris, A., & Wideman, D. (1988). The construction of gender and disability in early attachment. In M. Fine, & A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture, and politics* (pp. 115-138). Philadelphia, PA: Temple University Press.
- Harris, R., Tobias, M., Jeffreys, M., Waldergrave, K., Karlsen, S., & Nazroo, J. (2006). Racism and health: The relationship between experience of racial discrimination and health in New Zealand. *Social Science and Medicine*, 63(6), 1428–1441.
- Hartnett, M. F. (1997). The challenges of living the practices of social role valorisation. In P. O'Brien, & R. Murray (Eds.), *Human services: Towards partnership and support* (pp. 99–111). Palmerston North, New Zealand: Dunmore Press.
- Hatfield, E. F. (2010). What it means to be a man: Examining hegemonic masculinity in Two and a Half Men. *Communication, Culture and Critique*, 3(1), 526–548.
- Healey, L., Howe, K., Humphreys, C., Jennings, C., & Julian, F. (2008). *Building the evidence*. Melbourne, Australia: Victorian Women with Disabilities Network Advocacy Information Service.
- Healey, L., Humphreys, C., & Howe, K. (2013). Inclusive domestic violence standards: Strategies to improve interventions for women with disabilities? *Violence and Victims*, 28(1), 50-68.
- Healey, L. (2013). *Voices Against Violence: Paper 2: Current Issues in Understanding and Responding to Violence Against Women with Disabilities*. Women with Disabilities Victoria, Office of the Public Advocate and Domestic Violence Resource Centre Victoria.
- Healey, S. (1993). The common agenda between old women, women with disabilities and all women. In M. Willmuth, & L. Holcomb (Eds.), *Women with disabilities: Found voices* (pp. 65-78). New York, NY: Harrington Park Press.
- Health Promotion Forum. (2012). *Nga kaiakatanga hauora mo Aotearoa: Health promotion competencies for Aotearoa, New Zealand*. Auckland, New Zealand: Author.

- Healy, K. (2005). *Social work theories in context: Creating frameworks for practice*. Basingstoke, England: Palgrave Macmillan.
- Heise, L., & Garcia-Moreno, C. (2002). Violence by intimate partners. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi, & R. Lozano, (Eds.), *World report on violence and health* (pp. 87-121). Geneva, Switzerland: World Health Organisation.
- Heise, L. L., Pitanguy, J., & Germain, A. (1994). *Violence against women, the hidden health burden*. (Discussion Paper No. 255). Washington DC, WA: The World Bank.
- Henn, M., Weinstein, M., & Foard, N. (2009). *A critical introduction to social research* (2nd ed.). Los Angeles, CA: SAGE.
- Herbert, R., & Mackenzie, D. (2014). *The way forward: An integrated system for intimate partner violence and child abuse and neglect in New Zealand*. Wellington, New Zealand: The Impact Collective.
- Herbert, R., Hill, A., & Dickson, S. (2009). *Violence against women in Aotearoa New Zealand: An integrated plan of action*. Wellington, New Zealand: Roundtable on Violence Against Women.
- Heron, J. (1981). Philosophical basis for a new paradigm. In P. Reason, & J. Rowan (Eds.), *Human enquiry: A sourcebook for new paradigm research* (pp. 19-36). Chichester, England: John Wiley and Sons.
- Herring, J. (2014). The disability critique of care. *Elder Law Review*, 8, 1-8.
- Hesse-Biber, S. N., & Leavy, L. P. (2007). *Feminist research practice: A primer*. Thousand Oaks, CA: SAGE.
- Hester, M. (2012). Portrayal of women as intimate partner domestic violence perpetrators. *Violence against women*, 8(9), 1067-1082.
- Hester, M. (2013). Who does what to whom? Gender and domestic violence perpetrators in English police records. *European Journal of Criminology*, 10(5), 623-637.
- Hickey, H. (2007). *Claiming spaces: Maori (indigenous persons) with disabilities, making the invalid valid*. Hamilton, New Zealand: University of Waikato MPRU Maori Pacific Psychology Symposium, November 2007.
- Hicky, S. J. (2007). *The unmet legal, social and cultural needs of Maori with disabilities*. (Unpublished doctoral thesis). Hamilton, New Zealand: University of Waikato.
- Hona, D. (2007). *Tikanga rangahau: Research methodology*. Auckland, New Zealand: Manukau Institute of Technology.
- Howe, K. (2000). *Violence against women with disabilities: An overview of the literature*. Australia: Women with Disabilities. Retrieved from www.wwda.org.au/keran.htm

- Hughes, B. (2009). Wounded/monstrous/abject: A critique of the disabled body in the sociological imaginary, *Disability and Society*, 24(4), 399-410. doi:10.1080/09687590902876144
- Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 379(9826), 1621-1629.
- Human Rights Commission. (2012). *Caring counts. Report of the inquiry into the aged care workforce*. Wellington, New Zealand: Author.
- Humphries, B., & Truman, C. (1994). *Re-thinking social research: Anti-discriminatory approaches in research methodology*. Brookfield, VT: Avebury.
- Hunter, C. (2011). *Defining the public health model for the child welfare services context*. [Brochure], National Child Protection Clearinghouse Resource Sheet. Melbourne: Australian institute of Family Studies. Retrieved from www.aifs.gov.au/nch/pubs/sheets/rs11/
- Institute of Medicine. (2002). *Confronting chronic neglect: the education and training of health professionals on family violence*, Washington, DC, WA: The National Academies Press.
- It's STILL Not OK. (2010). *Protecting victims, rebuilding lives, sending the right message: A discussion paper written by survivors of domestic violence*. Wellington, New Zealand: Author.
- Jaaber, R. A., & Das Dasgupta, S. (2002). Assessing social risks of battered women. *Praxis International*. Retrieved from <http://files.praxisinternational.org/AssessingSocialRisk.pdf>
- Jack, G. (2000). Ecological influences on parenting and child development. *British Journal of Social Work*, 30(6), 703-720.
- Jewkes, K., Penn-Kekana, L., & Rose-Junius, H. (2005). "If they rape me I can't blame them": Reflections on gender in the social context of child rape in South Africa and Namibia. *Social Science and Medicine*, 6(8), 1809-1802. <http://dx.doi.org/10.1016/j.socscimed.2005.03.022>
- Jewkes, J., Sen, P., & Garcia-Moreno, C. (2002). Sexual violence. In E. G. Krug, L. L. Dahlberg, J. A. Mercy, A. B. Zwi, & R. Lozano, (Eds.), *World report on violence and health* (pp. 147-174). Geneva, Switzerland: World Health Organisation.
- Johnson, M. P. (2006). Conflict and control: Gender symmetry and asymmetry in domestic violence. *Violence against women*, 12(11) 1003-1018.
- Jones, L. (1999). From each...to each. In V. A. Brownworth, & S. Raffo, (Eds.), *Restricted access: Lesbians on disability* (pp. 48-56). Seattle, WA: Seal Press.

- Joubish, M. F., Khurran, M. A., Ahmed, A., Fatima, S. T., & Haider, K. (2011). Paradigms and characteristics of good qualitative research. *World Applied Sciences Journal*, 12(11), 2082-2087.
- Justice and Electoral Select Committee. (2017). *Family and whanau violence legislation Bill: As reported from the Justice and Electoral Select committee*. Wellington, New Zealand: New Zealand Government
- Kapoor, S. (2000). *Domestic violence against women and girls*. (Innocenti Digest No. 6). Florence, Italy: UNICEF Research Centre.
- Kazantzis, N., Flett, R. A., Long, N. R., Macdonald, C., & Millar, M. (2000). Domestic violence, psychological distress and physical illness among New Zealand women: Results from a community based study. *New Zealand Journal of Psychology*, 29(2), 67-73.
- Kelly, L., Burton, S., & Regan, L. (1994). Researching women's lives or studying women's oppression? Reflections on what constitutes feminist research. In M. Maynard, & J. Purvis (Eds.), *Researching women's lives from a feminist perspective* (pp. 49-71). London, England: Taylor and Francis.
- Kelly, M. (1999). A dialogue on disability: To the person who "helps" me. In V.A. Brownworth, & S. Raffo (Eds.), *Restricted access: Lesbians on disability* (pp. 68-73). Seattle, WA: Seal Press.
- Khalifeh, H., Moran, P., Borschmann, R., Dean, K., Hart, C., Hogg, J., Osborn, D., Johnson, S., & Howard, L. M. (2015). Domestic and sexual violence against patients with severe mental illness. *Psychological Medicine*, 45(4), 875-886.
- Kimmel, M. S. (2002). Gender symmetry in domestic violence: A substantive and methodological research review. *Violence Against Women*, 8(11), 1332-1363.
- Knight, A. (2014). Disability as vulnerability: Redistributing precariousness in democratic ways. *The Journal of Politics*, 76(1), 15-26.
doi:0.1017/S0022381613001266
- Knox, J. (2014). The 'blame and shame society'. *Psychoanalytic Psychotherapy*, 2(3), 244-248. <http://dx.doi.org/10.1080/02668734.2014.933033>
- Krug, E. G., Dahlberg, L. L., Mercy, J. A., Zwi, A. B., & Lozano, R. (2002). *World report on violence and health*. Geneva, Switzerland: World Health Organisation.
- Labonté, R. & Schrecker, T. (2007). Globalization and social determinants of health: Introduction and methodological background. *Globalization and Health*, 3(5). <http://dx.doi.org/10.1186/1744-8603-3-5>
- Laing, L., Humphreys, C., & Cavanagh, K. (2013). *Social work and domestic violence: developing critical and reflective practice*. London, England: SAGE Publications, Inc.

- Lapadat J.C. (2010). Thematic Analysis. In A. J. Mills, G. Durepos & E. Wiebe (Eds), *Encyclopedia of Case Study Research* (926-927). Thousand Oaks, SAGE Publications, Inc. DOI. 10.4135/9781412957397.n342
- Laverack, G. (2009). *Health promotion practice power and empowerment*. Los Angeles, CA: SAGE.
- Laverack, G. (2010). Influencing public health policy: To what extent can public action define the policy concerns of government? *Journal of Public Health*, 18(1), 21-28.
- Lay, K. (2013). *Ken Lay on family violence*. Blog post: Cops and Bloggers. Retrieved from <http://www.vicpolicenews.com.au/blogs/93-oursay/1302-ccp-ken-lay-on-family-violence.html>
- Letherby, G. (2003). *Feminist research in theory and practice*. Philadelphia, PA: Open University Press.
- Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). South Melbourne, Australia: Oxford University Press.
- Lightfoot, E. & Williams, O. (2009). The intersection of disability, diversity, and domestic violence: Results of national focus groups. *Journal of Aggression, Maltreatment Trauma*, 18. 133–152. DOI: 10.1080/10926770802675551
- Lippman, A. (2013). INTERdependence. Retrieved from <http://www.cwhn.ca/en/networkmagazine/interdependence>
- Livneh, H. (2012). Psychological and social impact of physical disability. In I. Marini, & M. A. Stebnicki (Eds), *The psychological and social impact of illness and disability* (6th ed., pp. 13–25). New York, NY: Springer.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability, *Disability and Society*, 15(1), 157-165.
- Lockhart, L. L., & Mitchell, J. (2010). Cultural competence and intersectionality: Emerging frameworks and practical approaches. In L.L. Lockhart & F.S. Danis. (Eds.), *Domestic violence: Intersectionality and culturally competent practice* (pp. 1-28). New York, NY: Columbia University Press.
- Logie, J. (2016). Cited in Kirk, S. (2016, March 31). *Government agrees to overhaul sexual violence support services at budget*. Stuff. Retrieved from <http://www.stuff.co.nz/national/politics/78420964/government-agrees-to-overhaul-sexual-violence-support-services-at-budget>.
- Loue, S. (2001). *Intimate partner violence: Societal, medical, legal and individual responses*. New York, NY: Kluwer.
- McCarthy, M., & Thompson, D. (1997). A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities*, 10(2), 105-124.
- McClain, L. (2011). *Women, disability and violence: Strategies to increase physical and programmatic access to victims' services for women with disabilities*.

- Barbara Faye Waxman Fiduccia papers on women and girls with disabilities. Washington DC, WA: Centre for Women Policy Studies.
- McCormack, C., & Collins, B. (2012). The affirmative model of disability: a means to include disability orientation in occupational therapy? *British Journal of Occupational Therapy*, 75(3), 156-158.
- McDonald, E., & Tinsley, Y. (n.d.). *From real rape to real justice: Prosecuting rape in New Zealand*. Retrieved from http://www.awc.org.nz/userfiles/16_1331772862.pdf
- Mackenzie, D. (2009). *Arrested female offenders in Auckland City, April – September 2008*. Auckland, New Zealand: Safer Homes in New Zealand Everyday. Retrieved from <http://www.2shine.org.nz/library/Documents/arrestedfemaleoffendersinacklcity2009.pdf>
- McKibbin, G., Duncan, R., Hamilton, B., Humphreys C., Kellett C. (2015). The intersectional turn in feminist theory: A response to Carbin and Edenheim (2013). *European Journal of Women's Studies*, 22(1) 99–103.
- MacIntyre, A. (1999). *Dependent rational animals: Why human beings need the virtues*. Chicago, IL: Open Court.
- MacIntyre, A. (2000). The need for a standard of care. In L. P. Francis, & A. Silvers (Eds.), *Americans with disabilities: Exploring implications of the law for individuals and institutions* (pp. 81-86). New York, NY: Routledge.
- McLean, M. (2005). Emancipatory understandings for allies: Recognising ableism. In P. O'Brien, & M. Sullivan (Eds), *Allies in emancipation: Shifting from providing service to being of support* (pp. 65-78). South Melbourne, Australia: Thomson Dunmore Press.
- McRae, J. (2014). *Becoming a person: The biography of Robert Martin. How an intellectually disabled man helped change the world*. Nelson, New Zealand: Craig Potton Publishing.
- Macy, M. J., Giattina, M. C., Montijo, N. J., & Ermentrout, D. M. (2010). Domestic violence and sexual assault agency directors' perspectives on services that help survivors. *Violence Against Women*, 16(10), 1138-1161.
- Makasiale, C., & Williams, P. (1997). A Pacific Islands reflection. In P. O'Brien, & R. Murray. (Eds.), *Human services: Towards partnership and support* (pp. 58-60). Palmerston North, New Zealand: Dunmore Press.
- Maori Taskforce on Whanau Violence. (2004). *Transforming whanau violence: A conceptual framework. An updated version of the report from the former Second Maori Taskforce on whanau violence* (2nd ed.). Wellington, New Zealand: Te Puni Kokiri. Retrieved from <http://library.nzfvc.org.nz>
- Margolis, H., & Shapiro, A. (1987). Countering negative images of disability in classical literature. *The English Journal*, 76(3) 18-22.

- Marles, F. (1986). *Methods of policy development and information dissemination designed to improve understanding between organisations of people with disabilities, government authorities and the public*. A paper presented by the Commissioner for Equal Opportunities, to the international expert meeting on Legislation on Equalisation of Opportunities for People with Disabilities, Vienna. Rehabilitation International. In Report of the Equal Opportunity Board and Commissioner for Equal Opportunity June 1986. Melbourne: Victorian Legislative Assembly.
- Martin, S., Ray, N., Sotres-Alvarez, D., Kupper, L. L., Moracco, P. A., Scandlin, D., & Kiya, G. (2006). Physical and sexual assault of women with disabilities. *Violence Against Women, 12*(9), 823–836.
- Matthews, S. (2014). The imprudence of the vulnerable. *Ethical Theory and Moral Practice, 17*(4), 791–805. <http://dx.doi.org/10.1007/s10677-013-9482-8>
- Meyer, S. (2016). Still blaming the victim of intimate partner violence? Women's narratives of victim desistance and redemption when seeking support. *Theoretical Criminology, 20*(1), 75–90. <http://dx.doi.org/10.1177/1362480615585399>
- Michailakis, D. (2003). The systems theory concept of disability: One is not born a disabled person, one is observed to be one. *Disability and Society, 18*(12), 209-229.
- Ministerial Group on Family Violence and Sexual Violence, (2015). *Progress on the work programme of the Ministerial Group on Family Violence and Sexual Violence*. Wellington, New Zealand: Offices of the Minister of Justice and Minister for Social Welfare.
- Ministry of Health. (2001). *The New Zealand Disability Strategy: Making a world of difference*. Whakanui Oranga. Wellington, New Zealand: Author.
- Ministry of Health. (2002). *Hysterectomies in young women with intellectual disabilities: A briefing paper*. Wellington, New Zealand: Author.
- Ministry of Justice. (2009). *Te toiora mata tauherenga. Report of the Taskforce for Action on Sexual Violence*. Wellington, New Zealand: Author.
- Ministry of Social Development (n.d.) *Defining family violence*. Retrieved from <http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/initiatives/action-family-violence/family-violence-indicators.html>
- Ministry of Social Development. (n.d.). *Are you OK campaign*. Wellington, New Zealand: Retrieved from http://www.areyouok.org.nz/family_violence.php
- Ministry of Social Development. (2015). *Community investment strategy*. Wellington, New Zealand: Author.
- Ministry of Social Development. (2017). *Family Violence, Sexual Violence and Violence within Whanau: Workforce capability framework June 2017*. Wellington, New Zealand: Author.

- Ministry of Women's Affairs. (2011). *Considering a gender-based approach*. Paper written for the Taskforce for Action on Violence with Families taskforce meeting June 1st, 2011. Wellington, New Zealand: Author.
- Ministry of Women's Affairs. (2012). *Lightning does strike twice: Preventing sexual revictimisation*. Wellington, New Zealand: Author.
- Mirfin-Vitch, B., & Ballard, K. (2005). Says who? Supporting participation in disability research. In P. O'Brien, & M. Sullivan, (Eds), *Allies in emancipation; Shifting from providing service to being of support* (pp. 189-198). South Melbourne, Australia: Thomson Dunmore Press.
- Morgan, G. (1980). Paradigms, metaphors and puzzle solving in organisation theory. *Administrative Science Quarterly*, 25(4), 605-622.
- Morris, J. (1991). *Pride against prejudice: Transforming attitudes to disability*. London, England: The Women's Press.
- Morris, J. (1998). *Feminism, gender and disability*. Text of a paper presented at a seminar in Sydney, Australia. Unpublished.
- Morris, J. (2006). Personal and political: A feminist perspective on researching physical disability. In L. Barton (Ed.), *Overcoming disabling barriers: 18 years of Disability and Society* (pp. 283-293). Oxon, England: Routledge.
- Morse, J. M. (1995) Editorial. The significance of saturation. *Qualitative Health Research*, 5(2), 147-149.
- Morton, M., & Munford, R. (1998). Re/presenting difference: Women and intellectual handicap. In R. Du Plessis, & L. Alice (Eds.), *Feminist thought in Aotearoa/New Zealand* (pp. 164-171). Auckland, New Zealand: Oxford University Press.
- Murphy, C. (2009). *Men's intimate partner abuse and control: Reconciling paradoxical masculinities and social contradictions*. (Unpublished doctoral thesis). Brisbane, Australia: Queensland University of Technology. Retrieved from <https://library.nzfvc.org.nz/>
- Murphy, C., & Fanslow, J. (2012). *Building collaborations to eliminate family violence: facilitators, barriers and good practice*. Issues paper 1. Auckland, New Zealand: New Zealand Family Violence Clearinghouse.
- Murray, C. E., King, K., Crowe, A., & Flasch, P. (2015). Survivors of intimate partner violence as advocates for social change. *Journal for Social Action in Counselling and Psychology*, 7(1) 84.
- National Advisory Committee on Health and Disability. (1998). *The social, cultural and economic determinants of health in New Zealand: Action to improve health*. Wellington, New Zealand: Author.
- National Collective of Independent Women's Refuges. (n.d.). *Power and control and the forms abuse can take*. Retrieved from <http://www.womensrefuge.org.nz>

- New Zealand Family Violence Clearinghouse. (2007). *Family violence and gender fact sheet*. Christchurch, New Zealand: University of Canterbury.
- New Zealand Family Violence Unit & Hager, D. (2013). *Evidence brief: Issues and opportunities for addressing family violence within the disability sector*. Prepared for the Taskforce on Family Violence. Wellington, New Zealand: NZ Family Violence Unit, Ministry of Social Development.
- New Zealand Government. (1961). *Crimes Act. ss2(1)*. Retrieved from: <http://www.legislation.govt.nz/act/public/1961/0043/latest/DLM327394.html>
- New Zealand Government. (1964). *Social Security Act*. Wellington, New Zealand: Author.
- New Zealand Government. (2011). *Crimes Amendment Act*. Wellington, New Zealand: Author.
- New Zealand Government. (1995). *Domestic Violence Act*. Wellington, New Zealand: Author.
- New Zealand Government. (2014). *Vulnerable Children Act*. Wellington, New Zealand: Author.
- New Zealand Government. (2016). *Government response to the report of the Social Services Select Committee on its Inquiry into the Funding of Sexual Violence Social Services*. Wellington, New Zealand: Author.
- New Zealand Police. (2012a). *Police Executive Committee cover sheet. PEM /12/07*. Wellington, New Zealand: New Zealand Police Executive.
- New Zealand Police. (2012b). *Family violence policy and procedures manual*. Wellington, New Zealand: Author.
- Nikora, L. W., Karapu, R., Hicky, H., & Te Awekotuku, N. (2004). *Disabled Maori and disability support options; A report prepared for the Ministry of Health, Hamilton Office*. Maori and Psychology Research Unit, Department of Psychology, University of Waikato. Hamilton, New Zealand: University of Waikato and Ministry of Health.
- Office of Disability Issues, (2014). *The Disability Action Plan 2014-2018*. Wellington, New Zealand: Author.
- Office for Disability Issues, (2015). *The Disability Action Plan 2014-2018: Update 2015*. Wellington, New Zealand: Author.
- Office for Disability Issues. (2017). Our role and responsibilities. Wellington, New Zealand: Retrieved from <https://www.odi.govt.nz/about-us/home>
- Oliver, M. (1990a). *The politics of disablement*. London, England: Macmillan.
- Oliver, M. (1990b). *The individual and social models of disability*. A paper presented at the joint workshop of the Living Options Group and the Research Unit of the Royal College of Physicians. England, city not specified.

- Oliver, M. (2006). Changing the social relations of research production. In L. Barton (Ed.), *Overcoming disabling barriers: 18 years of Disability and Society* (pp. 267-282). Oxon, England: Routledge.
- Oliver, M. (2009). *Understanding disability: From theory to practice*. (2nd ed.). New York, NY: Palgrave Macmillan.
- Oliver, M., & Barnes, C. (1998). *Disabled people and social policy: From exclusion to inclusion*. Harlow, England: Addison Wesley Longman.
- Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. Houndmills, Basingstoke, England: Palgrave Macmillan.
- Ortoleva, S. & Lewis, H. (2012). *Forgotten Sisters - A Report on Violence Against Women with Disabilities: An Overview of its Nature, Scope, Causes and Consequences*. Northeastern University School of Law Research Paper No. 104-2012. Available at SSRN: <https://ssrn.com/abstract=2133332>
- Our Watch, Australia's National Research Organisation for Women's Safety (ANROWS), and VicHealth. (2015). *Change the story: A shared framework for the primary prevention of violence against women and their children in Australia*. Melbourne, Australia: Our Watch.
- Oxford Dictionary. (Undated). Oxford University Press. Retrieved from <https://www.bing.com/search?q=What+Does+Vulnerability+Mean&FORM=QSRE1>
- Paradies, Y., Ben, J., Denson, N., Elias, A., Priest, N., Pieterse, A., Gupta, A., Kelaher, M., & Gee, G. (2015). Racism as a determinant of health: A systematic review and meta-analysis. *PLoS ONE*, 10(9). <http://dx.doi.org/10.1371/journal.pone.0138511>
- Patton, M. Q. (1999). Enhancing the quality and credibility of quantitative research. *Health Services Research*, 34(5 Pt 2), 1189-1208.
- Penelope, J. (1990). *Speaking Freely: Unlearning the lies of the fathers' tongues*. New York, NY: Pergamon Press.
- Peters, S. (1996). The politics of disability identity. In L. Barton, (Ed.), *Disability and society: Emerging issues and insights* (pp. 215-236). New York, NY: Longman.
- People First in Partnership. (2012). *'Keeping safe feeling safe' project: Disability related hate crime – People First focus group (2012) findings*. Auckland, New Zealand: Author.
- Pihama, L., Jenkins, K., & Middleton, A. (2003). *Te Rito' action area 13 literature review: Family violence prevention for Maori research report*. Auckland, New Zealand: The International Research Institute for Maori and Indigenous Education (IRI), University of Auckland.

- Pitts, M., & Smith, A. (2007). *Researching the margins: Strategies for ethical and rigorous research with marginalised communities*. Basingstoke, England: Palgrave Macmillan.
- Popay, J., Escorel, S., Hernández, M., Johnston, H., Mathieson, J., & Rispel, L. (2008). *Understanding and tackling social exclusion: Final report to the WHO Commission on Social Determinants of Health*. Geneva, Switzerland: WHO Social Exclusion Knowledge Network.
- Powers, L. E., & Oschwald, M. (2004). *Violence and abuse against people with disabilities: Experiences, barriers and prevention strategies*. Centre on Self-Determination, Oregon Institute on Disability and Development, Oregon Health & Science University. Retrieved from <https://phinational.org/sites/phinational.org/files/clearinghouse/AbuseandViolenceBrief%203-7-04.pdf>
- Radford, J., Harne, L., & Trotter, J. (2006). Disabled women and domestic violence as violent crime. *Practice: Social Work in Action*, 18(4), 233-246.
- Ratima, K., & Ratima M. (2007). Maori experience of disability and disability support services. In B. Robson, & R. Harris (Eds), *Hauora: Maori standards of health IV. A study of the years 2000–2005* (pp. 189-194). Wellington, New Zealand: Te Ropu Rangahau Hauora a Eru Pomare.
- Richie, B. E. (2005). Forward. In N. J. Sokoloff, & C. Pratt (Eds.), *Domestic violence at the margins: Readings on race, class, gender and culture* (pp. xv-xviii). New Brunswick, NJ: Rutgers University Press.
- Roguski, M. (2013). *The hidden abuse of disabled people residing in the community: An exploratory study*. Gisborne, New Zealand: Tairawhiti Community Voice.
- Ruwhiu, L. A. (2009). *Mana Tane echo of hope: dispelling the illusion of whanau violence – Taitokerau Tane Maori speak out*. Whangarei, New Zealand: Amokura Family Violence Prevention Consortium.
- Salthouse, S. (2007). *Completely knocked out: Australian perspectives of disability, disempowerment and domestic violence*. Paper presented to the Domestic Violence, Disability and Cultural Safety National Forum 2007. Diverse and inclusive practice: Redrawing the boundaries. November 8-9, Brighton-Le-Sands, NSW, Australia.
- Saunders, D.G. (2002). Are physical assaults by wives and girlfriends a major social problem? A review of the literature. *Violence Against Women*, 8(12), 1424-1448.
- Saxton, M., Curry, M. A., Powers, L., Maley, S., Eckels, K., & Gross, J. (2001). Bring my scooter so I can leave you: A study of disabled women handling abuse by personal assistance providers. *Violence Against Women*, 7(4), 393-417.
- Scott, J-A. (2014). Illuminating the vulnerability of hegemonic masculinity through a performance analysis of physically disabled men's personal narratives.

- Disability Studies Quarterly*, 34(1), 10-10.
<http://dx.doi.org/10.18061/dsq.v34i1>
- Shakespeare, T. (1992). A reply to Liz Crow. *Coalition*, September, 40-42.
- Shakespeare, T. (1999). The sexual politics of disabled masculinity. *Sexuality and Disability*, 17(1), 53-64.
- Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? In T. Shakespeare, N. S. Watson, N. S. Barnartt, & B. M. Altman-Bingley (Eds.), *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 9-28). New York, NY: JAI.
- Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity and sexuality*. Basingstoke, New York, NY: Palgrave Macmillan.
- Shuttleworth, R., Wedgwood, N., & Wilson, N. J. (2012). The dilemma of disabled masculinity. *Men and Masculinities*, 15(2), 174-194.
- Smith, G. (2002, January). *Kaupapa Maori theory: Transformative praxis and new formations*. A paper presented at the Second International Conference on Cultural Policy Research – Cultural Sites, Cultural Theory, Cultural Policy, Wellington, New Zealand.
- Snell, R., & Small, C. (2009). Best practice family violence services for Aboriginal women: Nunga Mi: Minar Incorporated. *Parity*, 22(10), 46-47.
- Sobsey, D., & Doe, T. (1991). 'Patterns of sexual abuse and assault.' *Sexuality and Disability*, 9(3), 243-259. Cited in M. Roguski. (2013). *The hidden abuse of disabled people residing in the community: An exploratory study*. Gisborne, New Zealand: Tairawhiti Community Voice.
- Sokoloff, N. J., & Dupont, I. (2005). Domestic violence: Examining the intersections of race, class and gender – an introduction. In N. J. Sokoloff, & C. Pratt (Eds.), *Domestic violence at the margins: Readings on race, class, gender and culture*. (pp. 15-24). New Brunswick, NJ: Rutgers University Press.
- Solar, O., & Irwin, A. (2010). *A conceptual framework for action on the social determinants of health*. Social Determinants of Health Discussion Paper 2 (Policy and Practice). Geneva, Switzerland: World Health Organisation.
- Spender, D. (1985). *Man made language* (2nd ed.). London, England: Routledge and Kegan Paul.
- St John, S., MacLennan, C., Anderson H., & Fountain, R. (2014). *The complexities of 'relationship' in the welfare system and the consequences for children*. Auckland, New Zealand: Child Poverty Action Group background paper.
- Stanley, J. P. (1977). *The prostitute: Paradigmatic woman*. Pittsburgh, PA: Know, Inc. Retrieved from <http://library.duke.edu/rubenstein/scriptorium/wlm/prostitute/>
- Statistics NZ. (2013). *Disability survey, social and economic outcomes. Table 8. Experience of crime in the last 12 months for adults (aged 15+) living in*

private households by disability status, age group and sex. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-survey-2013-additional-tables.aspx

- Statistics NZ. (2014). *Disability survey. Table 1.02 Number of disabled people, by year, age group, and sex*. Wellington. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013/Tables.aspx
- Straus, M. (1999). The controversy over domestic violence by women: A methodological, theoretical and sociology of science analysis. In X. Arriga, & S. Oskamp (Eds.), *Violence in intimate relationships* (pp. 17-44). Thousand Oaks, CA: SAGE.
- Sullivan, M. J. (2000). Does it say what we mean, do we mean what it says, do we know what we are doing? Problematising the way disability is conceptualised, written and spoken about. *NZ Journal of Disability Studies*, 8(45), 36–46.
- Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability and Society*, 15(4), 569-582.
- Swain, J., & French, S. (2008). There but for fortune. In J. Swain, & S. French (Eds.), *Disability on equal terms* (pp. 7-20). London, England: SAGE.
- Temblay, M. A. (1957). The key informant technique: A nonethnographic application. *American Anthropologist*, 59(4), 688–701.
- Te Puni Kokiri. (2010). *Arotaki tukino whanau. Literature review on family violence*. Wellington, New Zealand: Author.
- Thiara, R. K., Hague, G., Bashall, R., Ellis, B., & Mullender, A. (2012). *Disabled women and domestic violence: Responding to the experiences of survivors*. London, England: Jessica Kingsley.
- Thomas, C. (2001). The body and society: Some reflections on the concepts of ‘disability’ and ‘impairment’. In N. Watson, & S. Cunningham-Burley (Eds.), *Reframing the body* (pp. 47-62). Basingstoke, England: Palgrave.
- Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*. 27(2), 273–246.
- Truman, C., Mertens, D. M., & Humphries, B. (2000). *Research and inequality*. London, England: UCL Press.
- Tuckett, A. (2017). Qualitative research sampling: The very real complexities. *Nurseresearcher* 12(1), 47-61.
- Turk, V., & Brown, H. (1993). The sexual abuse of adults with learning disabilities: Results of a two year incidence survey. *Mental Handicap Research*, 6(3), 193–216.

- United Nations Commission on the Status of Women CSW57. (2013). *Report on the fifty-seventh session (4-15 March 2013)*. Economic and Social Council Official Records, (Supplement No. 7). New York, NY: United Nations.
- United Nations General Assembly. (1993). *United Nations declaration on the elimination of violence against women* (85th plenary meeting, December 1993). Geneva, Switzerland: Author. Retrieved from <http://www.un-documents.net/a48r104.htm>
- United Nations General Assembly. (2006). *United Nations covenant on the rights of persons with disability*. New York, NY: Author. Retrieved from <http://treaties.un.org>
- Van Eden, K. (2013). *Putting people first: A review of Disability Support Services performance and quality management processes for purchased provider services*. Wellington, New Zealand: Ministry of Health.
- VicHealth. (2004). *The health costs of violence: Measuring the burden of disease caused by intimate partner violence: A summary of findings*. Melbourne, Australia: Victorian Health Promotion Foundation.
- VicHealth. (2011). *The partnerships analysis tool*. Melbourne, Australia: Victorian Health Promotion Foundation.
- Waddell, G., & Aylward, M. (2010). *Models of sickness and disability applied to common health problems*. London, England: Royal Society of Medicine Press.
- Walker, L. E. A. (2000). *The battered woman syndrome* (2nd ed.). New York, NY: Springer Publishing.
- Wall, G. (1979). The political reality of achieving the pro-life ideal. In M. Pryor (Ed.), *Beyond price: Collected thoughts on respect for the value of human life* (pp. 64-65). Wellington, New Zealand: Society for the Protection of the Unborn Child.
- Walsh, J., Spangaro, J., & Soldatic, K. (2015). Global understandings of domestic violence. *Nursing and Health Sciences*, 17(1), 1-4. doi: 10.1111/nhs.12197
- Walter-Brice, A., Cox, R., Priest, H., & Thompson, F. (2012). What do women with learning disabilities say about their experiences of domestic abuse within the context of their intimate partner relationships? *Disability and Society*, 27(4), 503–517.
- Wendell, S. (1992). Towards a feminist theory of disability. In B. H. Holmes, & L. M. Purdy (Eds.), *Feminist perspectives in medical ethics* (pp. 63-82). Bloomington, IL: Indiana University Press.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.
- White, M. K. (2004). *Narrative practice and exotic lives: Resurrecting diversity in everyday life*. Adelaide, Australia: Dulwich Centre Publications.

- Wilkinson-Meyers, L., Brown, P., Reeve, J., McNeill, R., Patston, P., Dylan, S., Baker, R., Ryan, B., & McEldowney, J. (2014). Reducing disablement with adequate and appropriate resources: A New Zealand perspective. *Disability and Society*, 29(10), 1540-1553.
<http://dx.doi.org/10.1080/09687599.2014.966803>
- Williams, C. C., & Collins, A. (2002). The social construction of disability in schizophrenia. *Qualitative Health Research*, 12(3), 297-309.
<http://dx.doi.org/10.1177/104973202129119900>
- Wilson, D., & Webber, M. (2014). *The people's report: The people's inquiry into addressing child abuse and domestic violence. Section one: Honouring their stories, their lives*. Auckland, New Zealand: Glenn Inquiry.
- Wilson, D., Smith, R., Tolmie, J., & de Haan, I. (2015). Becoming better helpers: Rethinking language to move beyond simplistic responses to women experiencing intimate partner violence. *Policy Quarterly*, 1(1), 25–31.
- Wolfensberger, W. (2011). Social role valorization: A proposed new term for the principle of normalization. *Intellectual and Developmental Disabilities*, 49(6), 435–440.
- Wood, J. T. (2004). *Communication theories in action: An introduction* (3rd ed.). London, England: Wadsworth/Thomson Learning.
- Wood, P. (1980). *International classification of impairments, disabilities and handicaps*. Geneva, Switzerland: World Health Organisation.
- Woolson-Neville, D., & Gremillion, H. (2015). *Experiencing women's advocacy: connections with and departures from a feminist socio-political movement to end violence against women*. Research Report Series 2. Auckland, New Zealand: Unitec.
- World Health Organisation, (1980). *International classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease*. Geneva, Switzerland: Author.
- World Health Organisation, Health and Welfare Canada, and Canadian Public Health Association. (1986). *Ottawa Charter for health promotion: An international conference on health promotion—The move towards a new public health, Nov. 17–21, Ottawa*. Geneva, Switzerland: World Health Organisation.
- World Health Organisation. (2005). *The Bangkok Charter for health promotion in a globalised world*. Geneva, Switzerland. Author
- World Health Organisation. (2011). *World report on disability*. Geneva, Switzerland: Author.
- World Health Organisation, Pan American Health Organisation (2012) *Understanding and addressing violence against women*. Geneva, Switzerland: Department of Reproductive Health, World Health Organisation.

- World Health Organisation. (2016). *Violence against women: Intimate partner and sexual violence against women*. Fact sheet No. 239 (Updated January 2016). Geneva, Switzerland: World Health Organisation. Retrieved from <http://www.who.int/mediacentre/factsheets/fs239/en/>
- Young, M-E., Nosek, M. A., Howland C., Campling, G., & Rintala, D. H. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 78(12), S34-S38. [http://dx.doi.org/10.1016/S0003-9993\(97\)90219-7](http://dx.doi.org/10.1016/S0003-9993(97)90219-7)

Appendices

Appendix 1. New Zealand Disability Action Plan, 2014 – 2018

(Office of Disability Issues, 2014).

Ensure personal safety

- Reduce barriers to disabled people making decisions to determine their own lives; Ensure disabled people can exercise their legal capacity, including through recognition of supported decision making;
- Reduce the number of disabled children and adults who are victims of violence, abuse or neglect; Educate disabled people about their rights not to be abused and what abuse is; Investigate funding of DPO partnered programmes that support disabled people to speak up for themselves and ensure this is linked with victims of crime work; Increase safeguards for disabled people who are socially isolated and develop initiatives to remove what is socially isolating them; Review the current care and support processes for disabled children who are (or are likely to be) subject to care under the Children, Young Persons and Their Families Act 1989 to establish whether they are being treated equitably and fairly, and in their best interests, and if not, to provide advice on changes needed to legislation, operational policy, operational delivery and/or monitoring and enforcement.
- Increase the responsiveness to disabled people of civil defence and emergency management around New Zealand.

Appendix 2. Structure and responsibilities of sectors interviewed

Domestic and sexual violence services

Domestic violence network organisations – coordinate networking between domestic violence response agencies, NGO support agencies and related government services in their area, and support practice by providing information, training etc. May engage in advocacy for the sector and for relevant policies and legislation.

Domestic violence response agencies – provide crisis support in the community and provide refuge services to abused women and children. May provide counselling and support groups and may provide groups such as ‘Breaking the Cycle’.

Sexual violence services – provide crisis support and longer term therapy to women who have been sexually abused. May engage in advocacy and education for the sector and for relevant policies and legislation. Some services also accompany women through the justice system and support women in restorative justice initiatives. They also provide prevention education in schools and pre-schools.

Related government services

- **Police** – enforce the Domestic Violence Act and sexual violence legislation under the Crimes Act. Issue Police Safety Orders, enforce Protection Orders, prosecute offenders. Chair FVIARS and similar meetings –the interagency meetings convened to address domestic violence in each region.
- **Judges/Courts** – approve or deny protection orders, make decisions in Family Court (including care and access to children), preside over criminal cases such as male assaults female, child abuse, sexual abuse and rape.
- **Child Youth and Family (CYF)** – investigate allegations of child abuse and recommend responses to keep children safe.
- **Work and Income NZ (WINZ)** – provide benefits to women fleeing violence - record beneficiaries experiencing domestic violence.
- **District Health Boards (DHBs)** – provide primary health care through Primary Health Organisations (PHOs) via mainly GP services and provide tertiary hospital services. All hospitals screen for violence and have a dedicated staff member working on the Violence Intervention Programme (VIP), whose job it is to train staff in screening and response processes and to ensure screening and referral are occurring.
- **The Ministry of Social Development (MSD)** is the primary funder of domestic violence services, although some may be funded from Justice or

Health. Sexual violence services are funded from a number of ministries including Health, Justice and MSD. MSD are the providers of benefits for those unable to work in paid employment and provide access to state housing.

Elder care organisations

A range of **NGO and for-profit services** is mandated to work with older people. Organisations may provide home care, support for people to stay in their own homes, residential support, social work, health related services, companionship, recreation and other services. **Age Concern** has the only contract to provide elder abuse services around the country, however, they have no resources to provide safe houses or legal aid.

There is also a range of services for older people within statutory health services, such as mental health services.

Most elder care organisations are funded from the health budget via DHBs.

Disability services

Disabled people's organisations (DPOs) - these are peer-led organisations that provide advocacy and other services to their members. These are generally disability specific, although DPA is a pan-disability organisation. DPOs have no particular mandate to work on issues of violence and abuse and are at different places in this process. The New Zealand Disability Action Plan (2014) was developed in consultation with DPOs and has one violence related target, 'To ensure personal safety'.

NGO services - there is a range of NGO services that provide services for people with disabilities. These are not peer organisations. They provide specific services such as residential services, home care, supply equipment, offer medical support for certain conditions, provide information for disabled people and their families and some encourage self-advocacy. They may also provide employment opportunities or support people to gain employment. There are also recreational services such as arts and other programmes. None of these services specifically works to address violence and abuse, although they may have the prevention of abuse as part of their contractual arrangement with government.

There is also a range of **for-profit services** providing residential and other services, including employment.

Related services

Government funded services for disabled people include WINZ for benefits, medical services, organisations that assess and provide equipment and enable NGOs to deliver home support services, respite, residential services etc. There is also a Peak Body for providers of disability services. The Ministry of Health (MoH) is the primary funder of disability services.

Voluntary organisations

There is a range of voluntary groups that offer services across these sectors. These are often peer support groups, such as those for victims/survivors of violence, wider family support or disability specific peer groups. There are also voluntary groups doing advocacy and training, such as DVD.

The complexity of the sectors: an example

According to Herbert and Mackenzie (2014) there are many services to address child abuse and neglect (CAN) and intimate partner violence (IPV). These include specialist services, kaupapa Maori services, mainstream drug and alcohol, mental health and other health services, legal and statutory services. They say:

These services are provided by a large number of IPV and CAN specific and mainstream organisations, either directly by government departments or via contracted arrangements with NGOs. There is no publicly-available master list of all family violence services provided or purchased by government. According to MSD's Family and Community Services website¹² they contract with 774 different providers for family violence services. In addition, family violence services are contracted via CYF (e.g. differential response services), Ministry of Justice (e.g. stopping violence programmes), and other government agencies. There are no consistent national service accreditation specifications or practice standards but rather isolated examples of guidelines pertaining to individual groups of services that are purchased.¹³

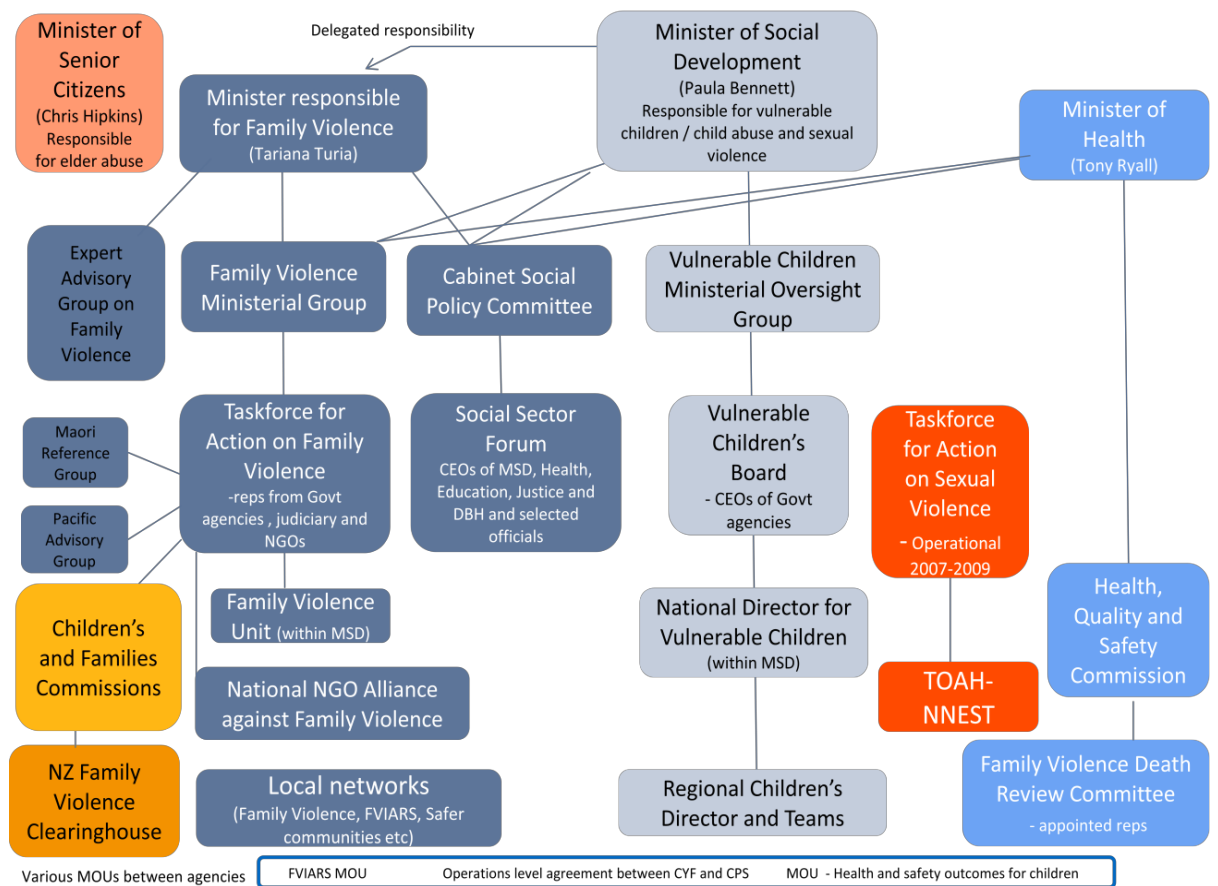
Across the country, community level responses are inconsistent and fragmented, with gaps and duplications. Victims/survivors, abusers and families often find it difficult to navigate their way through a complex maze of disconnected services and systems

¹²<http://www.familyservices.govt.nz/directory/searchresultspublic.htm?cat1=966&searchTerms=&search=Search&azServices=false>

¹³ For example Family Violence Response Co-ordination Funding Agreement Practice Guidelines. Available at <http://www.familyservices.govt.nz/working-with-us/funding-and-contracting/practice-guidelines/family-violence-response-co-ordination-pg-2012.html>

each with different policies and processes. Agencies operate as silos and invariably do not know what other agencies can offer and hence are unable to make appropriate referrals. Therefore some victims/survivors struggle to access the current system at all. Others find themselves in a never ending cycle, lost within the maze...or stuck within specific parts of the system. They cannot get out and move on with their lives (e.g. because of endless hearings in the family court) (p70).

An example of the complexity and lack of cohesion between services is identified in the diagram below. This details government responsibilities for child abuse, sexual violence, domestic violence and elder abuse. Even at government level there is no integrating oversight of the various responsibilities (Herbert & Mackenzie, 2014).



Source: (Herbert & Mackenzie, 2014, p63).

Figure 6: Current national violence response and prevention infrastructure - as of July 2014

Appendix 3. Meaning of domestic relationship

- 1) For the purposes of this Act, a person is in a **domestic relationship** with another person if the person—
 - a) is a spouse or partner of the other person; or
 - b) is a family member of the other person; or
 - c) ordinarily shares a household with the other person; or
 - d) has a close personal relationship with the other person.
- 2) For the purposes of subsection (1)(c), a person is not regarded as sharing a household with another person by reason only of the fact that—
 - a) the person has—
 - i) a landlord-tenant relationship; or
 - ii) an employer-employee relationship; or
 - iii) an employee-employee relationship—
with that other person; and
 - b) they occupy a common dwellinghouse (whether or not other people also occupy that dwellinghouse).
- 3) For the purposes of subsection (1)(d), a person is not regarded as having a close personal relationship with another person by reason only of the fact that the person has—
 - a) an employer-employee relationship; or
 - b) an employee-employee relationship—
with that other person.
- 4) Without limiting the matters to which a court may have regard in determining, for the purposes of subsection (1)(d), whether a person has a close personal relationship with another person, the court must have regard to—
 - a) the nature and intensity of the relationship, and in particular—
 - i) the amount of time the persons spend together;
 - ii) the place or places where that time is ordinarily spent;
 - iii) the manner in which that time is ordinarily spent;—
but it is not necessary for there to be a sexual relationship between the persons:
 - b) the duration of the relationship.

Appendix 4. Material gathered from interview participants

- Referrals to organisational websites for values statements
- Hard copies of vision and value statements
- Mitchell, D., & Chapman, P. (2014). *Men at work: Men's views on a stopping violence service*. Nelson. SVS, Nelson Marlborough District Health Board & Nelson Institute of Technology.
- Families Commission (2008). *Elder Abuse and Neglect. Research report no. 1/08*. Wellington. Families Commission.
- Age Concern pamphlets about elder abuse and neglect and prevention of abuse.
- Deaf Aotearoa booklets about New Zealand Sign Language/ New Zealand Sign Language week
- National Advisory Committee on Health and Disability, (2003). *To have an ordinary life: Kia whai orange 'noa'. Community membership for adults with an intellectual disability*. A report to the Minister of Health and the Minister of Disability Issues. Wellington. Author.
- Glasgow, K., & Fanslow, J. L. (2006). *Family violence Intervention guidelines: Elder abuse and neglect*. Wellington. Ministry of Health.
- Age Concern NZ, (2013). *Briefing to ministers and members of parliament*. Wellington. Author.
- Ministry of Women's Affairs, (2013). *Current thinking on primary prevention of violence against women*. Wellington. Author.
- Disabled People's Association, (2013). *DPA Forum agenda for change: The United Nations Convention on the Rights of Persons with Disabilities*. Wellington. Author.
- Van Eden, K. (2013). *Putting people first: A review of disability support services performance and quality management processes for purchased provider services*. Prepared for the Minister of Health.
- Human Rights Commission (2013). *A new era in the right to sign: Report of the New Zealand Sign Language Inquiry*. Wellington. Author.
- Human Rights Commission (Undated). *Your human rights and making complaints: A guide for disabled people and their families*. Wellington. Author.
- NZ Care Group Limited. (2012). *Policy document. Dealing with allegations of abuse and neglect*.
- Hunt, R. (2013). *Intersections, disability, power and sexual violence*. Unpublished conference presentation.
- Deluth power and control wheel
- Chappel, S. (2013). *Estimating the cost of family violence in New Zealand in 2008*. Draft confidential report to New Zealand government.

- Hann, S. (2007). Power and control in family violence. *Social Work Now* 37 17-25
- Bonomi, A. E., Anderson, M. L., Reid, R. J., Carrel, D., Fishman, P. A., Rivara, F. P. & Thompson, R. S. (2007). Intimate partner violence in older women. *The Gerontologist* 47. 1. 34-41
- McFerran, L. (2009). *The disappearing age: A discussion paper on a strategy to address violence against older women*. Topic paper 18. Australian Family Violence Clearing House.
- NGO Committee on the Status of Women. (2009). *Recommendation on the adoption of a general recommendation on the rights of older women*. New York. United Nations CEDAW Committee.

Appendix 5. Employer information/permission sheet

for the disability, sexual/domestic violence and human rights sectors

Date:

Dear XX

My name is Debbie Hager. I am a Doctor of Philosophy (PhD) student at the University of Auckland, in the department of Social and Community Health, School of Population Health. I am writing to ask your permission for staff of your agency/service to participate in my research. I am doing research to understand how the disability sector and the domestic and sexual violence sectors understand the ideas, theories, models and beliefs that underpin their own work and also that of the other sector. I have attached an outline of the questions below.

The research is not investigating lived experience of abuse and/or disability or related service provision. It is looking at the underlying ideas, theories and/or models that support work in the sexual/domestic violence sectors and in the disability sector. I would also like to gather any written material that supports or further clarifies the issues that we will be talking about – any models, principles, literature or policies that could be shared with me.

I would like your permission for staff of your agency to participate in this research. If you are happy that staff participate, please will you distribute copies of the invitation letter and participant information sheet and request that anyone who is interested contact me. I will follow this letter up with a phone call to answer any questions and discuss your agencies participation. I would like to conduct focus groups or interviews between October 2013 and March 2014.

Interviews and focus groups will take about one to one and a half hours. I will audio record the interviews and focus groups. All personal and identifying information will remain confidential in any verbal or written information prepared from and about the results of the interviews and focus groups. Your agency will not be named as having participated in the research.

The themes and key concepts from the research will be used for my PhD thesis, shared at conferences and in papers and will also be shared with the Domestic Violence and Disability Working Group (DVD), the Disability Coalition Against Violence (DCAV) and representatives of the various sectors for feedback and to check credibility. Participating staff will be invited to participate in this process.

We ask that you give your assurance that the decision of your employees to participate or not will have no effect on their employment. Thank you very much for your time and help in making this study possible. If you have any questions or wish to know more please phone me at work or email me. Debbie Hager Tel. 373-7599 extn. 89208 Email: d.hager@auckland.ac.nz Social and Community Health, School of Population Health, The University of Auckland, Private Bag 92019, Auckland. My supervisors are:

<p>Dr Jennifer Hand, Social and Community Health, School of Population Health, The University of Auckland, Private Bag 92019, Auckland. Tel. 373-7599 extn. 87645 Email: j.hand@auckland.ac.nz</p>	<p>Associate Professor Elsie Ho, Head of Department, Social and Community Health, The University of Auckland, School of Population Health, Private Bag 92019, Auckland. Tel. 3737-599 extn 86097 Email: e.ho@auckland.ac.nz</p>
---	--

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 3737599 extn. 83711.

The questions I will be asking relate to the following areas.

1. How people understand the sector they work in – how they would explain their area of work (i.e. sexual/domestic violence or disability) to someone with no prior knowledge.
2. How they understand the related issue (i.e. domestic and sexual violence for those in the disability field).
3. What they think the issues are at the intersection of disability and domestic and sexual violence.
4. From these answers we will identify the ideas, principles, theories, models or beliefs that their work is based on, how they understand these and how they use them in their work.

We will examine any principles, theories, models or beliefs that they identify or discuss for the other sector and their understanding of these.

Then we will talk about:

5. What they think the barriers are to collaborative work, policy and service development to address the abuse of disabled people
6. What they think would be a useful way forward to bridge the current communication gap between sectors to enable the issue of violence to be constructively addressed
7. What they think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused
8. What opportunities they have engaged with to learn more about the other sector and what has enabled or hindered this
9. If they have ever been asked to do any work to investigate possible service provision or other work in this area, or if any work has been carried out by your agency?

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 6. Key informant employer interview consent form

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Domestic and sexual violence and disability. Understanding paradigms and creating congruence to prevent violence against disabled women

Researcher: Debbie Hager.

I have read and understood the information sheet dated dd/mm/2013 for employers allowing their staff to participate in this research project. I have had an opportunity to ask questions and have them answered and I am satisfied with the answers and that I understand the research. I understand that:

- taking part in this research is voluntary and that employees can stop participating at any time during the interview **Yes/No**
- all personal information provided in an interview is confidential and names and identifying details will not be used when the results of the interviews are written up or in any material that results from the study **Yes/No**
- all findings will be reported in a deidentified way, but I understand that there is always a small risk that individuals may be identified by professionals in the sector I work in **Yes/No**
- participants can withdraw the information that they have provided in the key informant interview up to one month after the interview **Yes/No**
- The interview data will be kept separately from the consent form and all recorded and other material will be destroyed after 6 years **Yes/No**
- information about counselling services is available if participants require support after the interview **Yes/No**
- the interview will be recorded and the recorded material will be transcribed by a third party who has signed a confidentiality agreement **Yes/No**
- I give an assurance that staff employment or participation in any sector networks will not be affected by participation in this research **Yes/No**
- I have had time to consider whether staff can take part in the research **Yes/No**
- I have had time to consider whether staff can take part in the feedback session **Yes/No**
- I agree that my staff can take part in this research **Yes/No**
- I agree that my staff can take part in the feedback session **Yes/No**

Name:

Signature:

Date:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 7. Key informant interview consent form

for the Disability, Sexual/Domestic Violence and Human Rights Sec

The University of Auckland
Private Bag 92010
Auckland
New Zealand

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

Domestic and sexual violence and disability. Understanding paradigms and creating congruence to prevent violence against disabled women

Researcher: Debbie Hager

I have read and understood the information sheet dated dd/mm/2013 for volunteers taking part in this research project. I have had an opportunity to ask questions and have them answered and I am satisfied with the answers and that I understand the research. I understand that:

- taking part in this research is voluntary (my choice) and that I can stop participating at any time during the interview **Yes/No**
- all personal information I provide in an interview is confidential and my name and identifying details will not be used when the results of the interviews are written up or in any material that results from the study **Yes/No**
- all findings will be reported in a deidentified way, but I understand that there is always a small risk that individuals may be identified by professionals in the sector I work in **Yes/No**
- I can withdraw the information that I have provided in the key informant interview up to one month after the interview **Yes/No**
- The interview data will be kept separately from the consent form and all recorded and other material will be destroyed after 6 years **Yes/No**
- information about counselling services is available if I require support after the interview **Yes/No**
- I will be recorded and the recorded material will be transcribed by a third party who has signed a confidentiality agreement **Yes/No**
- I can ask for the recorder to be turned off at any time **Yes/No**
- neither the information that I provide or a recording of the interview will be shared with my employer **Yes/No**
- the employer/network coordinator has given an assurance that participating will not affect my employment or my participation in any sector networks **Yes/No**

- I have had time to consider whether to take part **Yes/No**
- I agree to take part in this research **Yes/No**
- I can be contacted for follow-up questions after the interview **Yes/No**

- **My contact phone number for this is:** _____
- I would like a copy of the research summary **Yes/No**
- I would like to be invited to the feedback session **Yes/No**

My email address for the summary and invitation is: _____

Name:

Signature:

Date:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 8. Key Informant Participant Information Sheet

for the Disability, Sexual/Domestic Violence and Human Rights Sectors

The University of Auckland
Private Bag 92010
Auckland
New Zealand

Domestic and sexual violence and disability. Understanding paradigms and creating congruence to prevent violence against disabled women

Kia Ora.

My name is Debbie Hager. I am a Doctor of Philosophy (PhD) student at the University of Auckland, in the department of Social and Community Health, School of Population Health. I would like you to participate in my research.

I am doing research to help me to develop a theoretical structure to guide future policy and service development to meet the needs of disabled women, both to prevent abuse and respond constructively when it occurs. **The research is not investigating lived experience of abuse and/or disability or related service provision.** It is looking at the underlying ideas, theories and/or models that support work in the sexual/domestic violence sectors and in the disability sector. I would also like to gather any written material that supports or further clarifies the issues that we will be talking about – any models, principles, literature or policies that you could share with me. (The questions are attached at the end of this information.)

You are being invited to participate in this research because of your knowledge and experience in relation to the research topic. I will provide interpreters if this will facilitate your involvement.

If you want to participate please let me know by phoning me on 09 3737599 x 89208. If I am not available please leave me a message with your name and phone number so I can get back to you or email me at d.hager@auckland.ac.nz.

Once you have made contact I will phone or email you to discuss the research and make a date and time for the interview. I would like to conduct the interviews between October 2013 and March 2014. Interviews will take about one to one and a half hours. We can discuss where you would like the interviews to take place. The interviews will be audio-recorded and transcribed. After the initial interview I may want to contact you again just to clarify or follow up information you have given me. I am not making either the transcripts or the recordings available to participants or employers.

The audio material will be owned by me and will be stored securely on University of Auckland machines for 6 years then all forms of data (digital voice recorder, electronic data and copies of the transcripts) will be confidentially destroyed & permanently erased from electronic storage.

During the interview you do not have to answer all the questions and you can stop participating at any time. You can ask for the recorder to be turned off at any time. Any personal information that you provide in an interview is confidential and your name and identifying details will not be used when the results of the interviews are written up. Choosing to participate or not will have no consequence for your employment or for your future participation in sector networks.

The material that I gain from this research will be used in my PhD and will be shared in reports, papers and conference presentations. No personal details will be available or linked to any of the reported material. A meeting will be held in each participating town at which the themes and key concepts from the research transcripts will be verbally shared with the Domestic Violence and Disability Working Group (DVD), the Disability Coalition Against Violence (DCAV) and representatives of the various sectors for feedback and to check credibility. Interview and focus group participants will be invited to participate in this process. At this stage, a summary of the findings will be available for participants. This will enable discussion about my findings and the opportunity for different perspectives and points of view to be included in the final conclusions. Once the research is completed, findings will be made available to DVD and DCAV and other interested groups and individuals for advocacy purposes. No personal details will be available or linked to any of the reported material at any stage of this process. The rights to publication and ownership of the material will remain with me.

While this research is asking about ideas, theories and models, you may have personal or family experience of sexual or domestic violence. If, after the interview, you feel that you would like support and/or counselling about the issues that have been raised I have organised for local, appropriate professional services to be available for you and I will be able to provide you with contact information about this service. This service may require the payment of appropriate fees.

Please note that:

- taking part in this study is voluntary (your choice) and that you can stop participating at any time during the interview
- all information you provide in the interview is confidential and your name and identifying details will not be used when the results of the interviews are written up or reported in any context

- I will provide interpreters if required
- the interview will be recorded
- the recordings will be transcribed by a person who has signed a confidentiality agreement
- you can withdraw the information that you have provided in the key informant interview up to one month after the interview
- all recorded and other material will be destroyed after 6 years
- The employer/network facilitator has given an assurance that there will be no consequence for your employment/ongoing participation in the network
- information about counselling services is available if you require support after the interview
- The questions that I will be asking are outlined at the end of this sheet

Thank you very much for your time and help in making this study possible. If you have any questions or wish to know more please phone or email me.

Debbie Hager Social and Community Health School of Population Health The University of Auckland	Tel. 09 373-7599 extn. 89208 Email: d.hager@auckland.ac.nz Private Bag 92019 Auckland
--	--

My supervisors are:

Dr Jennifer Hand Tel. 09 373-7599 extn. 87645 Email: j.hand@auckland.ac.nz Senior lecturer Social and Community Health School of Population Health The University of Auckland Private Bag 92019Auckland	Associate Professor Elsie Ho Tel. 09 3737-599 extn 86097 Email: e.ho@auckland.ac.nz Head of Department Social and Community Health The University of Auckland School of Population Health Private Bag 92019Auckland
--	--

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 3737599 extn. 83711.

The questions I will be asking relate to the following areas.

1. How you understand the sector you work in – how you would explain your area of work (i.e. sexual/domestic violence or disability) to someone with no prior knowledge
2. How you understand the related issue (i.e. domestic and sexual violence for those in the disability field)
3. What you think the issues are at the intersection of disability and domestic and sexual violence
4. From these answers we will identify the ideas, principles, theories, models or beliefs that your work is based on, how you understand these and how you use them in your work
5. We will examine any principles, theories, models or beliefs that you identify or discuss for the other sector and your understanding of these

Then we will talk about:

1. What you think the barriers are to collaborative work, policy and service development to address the abuse of disabled people
2. What you think would be a useful way forward to bridge the current communication gap between sectors to enable the issue of violence to be constructively addressed
3. What you think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused
4. What opportunities you have engaged with to learn more about the other sector and what has enabled or hindered this
5. If you have ever been asked to do any work to investigate possible service provision or other work in this area, or if any work has been carried out by your agency?

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 9. Network coordinator invitation and information sheet

for the disability, sexual/domestic violence and human rights sectors

Date:

Dear XX

My name is Debbie Hager. I am a Doctor of Philosophy (PhD) student at the University of Auckland, in the department of Social and Community Health, School of Population Health. I am writing to request your help in engaging your network members in my research.

I am doing research to understand how the disability sector and the domestic and sexual violence sectors understand the ideas, theories, models and beliefs that underpin their own work and also that of the other sector. I have attached an outline of the questions below.

The research is not investigating lived experience of abuse and/or disability or related service provision. It is looking at the underlying ideas, theories and/or models that support work in the sexual/domestic violence sectors and in the disability sector. I would also like to gather any written material that supports or further clarifies the issues that we will be talking about – any models, principles, literature or policies that could be shared with me.

Please will you distribute copies of the invitation letter and participant information sheet to the members of your network and ask that anyone who is interested to contact me directly (so that you don't have to do any organising for me). Please ring me if there is anything you'd like to discuss about the process or the research. You are, of course, welcome to participate in the research.

I would like to conduct focus groups or interviews between October 2013 and March 2014. They will take about one to one and a half hours. I will audio record the interviews and focus groups. All personal and identifying information will remain confidential in any verbal or written information prepared from and about the results

of the interviews and focus groups. I will not identify the networks that participate in the research as the sector is small and this could lead to the identification of individuals.

The themes and key concepts from the research will be used for my PhD thesis, shared at conferences and in papers and will also be shared with the Domestic Violence and Disability Working Group (DVD), the Disability Coalition Against Violence (DCAV) and representatives of the various sectors for feedback and to check credibility. Everyone who participates in the research will be invited to participate in this process.

Thank you very much for your time and help in making this study possible. If you have any questions or want to know more please phone me or email me. Debbie Hager, Tel. 373-7999 extn. 89208, Email: d.hager@auckland.ac.nz. My supervisors are:

Dr. Jennifer Hand Tel. 09 373-7999 extn. 87645 Email: j.hand@auckland.ac.nz	Associate Professor Elsie Ho Head of Department Tel. 09 3737-999 extn 86097 Email: e.ho@auckland.ac.nz
---	---

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 3737599 extn. 83711.

The questions I will be asking relate to the following areas.

1. How people understand the sector they work in – how they would explain their area of work (i.e. sexual/domestic violence or disability) to someone with no prior knowledge
2. How they understand the related issue (i.e. domestic and sexual violence for those in the disability field)
3. What they think the issues are at the intersection of disability and domestic and sexual violence
4. From these answers we will identify the ideas, principles, theories, models or beliefs that their work is based on, how they understand these and how they use them in their work
5. We will examine any principles, theories, models or beliefs that they identify or discuss for the other sector and their understanding of these

Then we will talk about:

1. What they think the barriers are to collaborative work, policy and service development to address the abuse of disabled people
2. What they think would be a useful way forward to bridge the current communication gap between sectors to enable the issue of violence to be constructively addressed
3. What they think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused
4. What opportunities they have engaged with to learn more about the other sector and what has enabled or hindered this
5. If they have ever been asked to do any work to investigate possible service provision or other work in this area, or if any work has been carried out by your agency?

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 10. Focus group participant information sheet

for the disability, sexual/domestic violence and human rights sectors

The University of
Auckland
Private Bag 92010
Auckland
New Zealand

Project title: Domestic and sexual violence and disability. Understanding paradigms and creating congruence to prevent violence against disabled women

Researcher: Debbie Hager

Kia Ora.

I am a PhD student at the University of Auckland, in the department of Social and Community Health, School of Population Health. I am doing research to develop a theoretical structure to guide policy and service development to meet the needs of disabled women, to prevent abuse and respond constructively when it occurs. **The research is not investigating lived experience of abuse and/or disability or related service provision.** It is looking at the underlying ideas, theories and/or models that support work in the sexual/domestic violence sectors and in the disability sector. I would also like to gather any written material that supports or further clarifies the issues that we will be talking about – any models, principles, literature or policies that you could share with me. (The questions are attached at the end of this information).

You are being invited to participate in this research because of your knowledge and experience in relation to the research topic. I will provide interpreters if this will facilitate your involvement.

I would like to conduct the focus groups/interviews between October 2013 and March 2014. Focus groups will take between one to one and a half hours. I will advise you where the focus groups will be held/we can discuss where you would like the interviews to take place. The discussions will be audio-recorded. After the initial focus group I may want to contact you again just to clarify or follow up information you have given me. I am not making either the transcripts or the recordings available to participants or employers.

A professional will transcribe the focus group/interview recordings. This person will sign a confidentiality agreement to protect your privacy. Also, I will assign a code name to be used with the information. The audio material will be owned by me and will be stored securely on University of Auckland machines for 6 years then all

forms of data (digital voice recorder, electronic data and copies of the transcripts) will be destroyed & permanently erased from electronic storage.

During the focus group you do not have to answer all the questions and you can stop participating at any time, however, you are not able to withdraw material. I will do all I can to keep any personal information that you provide in a focus group/interview confidential and your name and identifying details will not be used when the results of the interviews are written up. You are urged to keep material that you hear discussed in the focus group confidential. Only the other people in the focus group will know that you have participated and what you have said, however, due to the nature of focus groups, I cannot guarantee confidentiality. Choosing to participate or not will have no consequence for your employment or for your future participation in sector networks.

The material that I gain from this research will be used in my PhD and will be shared in reports, papers and conference presentations. No personal details will be available or linked to any of the reported material. A meeting will be held in each participating town at which the themes and key concepts from the research transcripts will be verbally shared with the Domestic Violence and Disability Working Group (DVD), the Disability Coalition Against Violence (DCAV) and interview and focus group participants for feedback and to check credibility.. At this stage, a summary of the findings will be available for participants. This will enable discussion about my findings and the opportunity for different perspectives and points of view to be included in the final conclusions. Once the research is completed, findings will be made available to DVD and DCAV and other interested groups and individuals for advocacy purposes. No personal details will be available or linked to any of the reported material at any stage of this process. The rights to publication and ownership of the material will remain with me.

If you want to participate in a focus group/interview please let me know by phoning me on 09 3737599 x 89208. If I am not available please leave me a message with your name and phone number so I can get back to you or email me at d.hager@auckland.ac.nz. Once you have made contact I will phone or email you to discuss the research and tell you the date and time for the focus group/interview.

While this research is asking about ideas, theories and models, you may have personal or family experience of sexual or domestic violence. If, after the focus group/interview, you feel that you would like support and/or counselling about the issues that have been raised I have organised for local, appropriate professional services to be available for you and I will be able to provide you with contact information about this service. This service may require the payment of appropriate fees. Please note that:

- taking part in this study is voluntary (your choice) and that you can stop participating at any time during the focus group
- I will provide interpreters if required
- you are urged to keep the material discussed in the focus group confidential, however, because of the nature of focus groups, I cannot guarantee confidentiality
- all attempts will be made to keep personal information you provide in the focus group confidential and your name and identifying details will not be used when the results of the focus groups are written up or reported in any context.
- The focus group/interview will be recorded
- The recordings will be transcribed
- The consent forms will be stored separately from the data and these and all recorded and other material will be destroyed after 6 years
- The employer/network facilitator has given an assurance that there will be no consequence for your employment/ongoing participation in the network
- Information is available if you require ongoing support after the focus group
- The questions that I will be asking are outlined at the end of this sheet.

Thank you very much for your time and help in making this study possible. If you have any questions or wish to know more please phone me at work or email me.

Debbie Hager Social and Community Health School of Population Health The University of Auckland	Tel. 09 373-7599 extn. 89208 Email: d.hager@auckland.ac.nz
--	---

My supervisors are:

Dr. Jennifer Hand Tel. 09 373-7599 extn. 87645 Email: j.hand@auckland.ac.nz Senior lecturer Social and Community Health School of Population Health University of Auckland	Associate Professor Elsie Ho Tel. 09 3737-599 extn 86097 Email: e.ho@auckland.ac.nz Head of Department Social and Community Health School of Population Health University of Auckland
--	---

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Ethics Committee, The University of Auckland,

Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 3737599 extn. 83711.

The questions I will be asking relate to the following areas:

1. How you understand the sector you work in – how you would explain your area of work (i.e. sexual/domestic violence or disability) to someone with no prior knowledge
2. How you understand the related issue (i.e. domestic and sexual violence for those in the disability field)
3. What you think the issues are at the intersection of disability and domestic and sexual violence
4. From these answers we will identify the ideas, principles, theories, models or beliefs that your work is based on, how you understand these and how you use them in your work
5. We will examine any principles, theories, models or beliefs that you identify or discuss for the other sector and your understanding of these

Then we will talk about:

1. What you think the barriers are to collaborative work, policy and service development to address the abuse of disabled people
2. What you think would be a useful way forward to bridge the current communication gap between sectors to enable the issue of violence to be constructively addressed
3. What you think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused
4. What opportunities you have engaged with to learn more about the other sector and what has enabled or hindered this
5. If you have ever been asked to do any work to investigate possible service provision or other work in this area, or if any work has been carried out by your agency?

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years, Reference Number 9896

Appendix 11. Transcription/interpreter confidentiality agreement

Project Title: Domestic and sexual violence and disability. Understanding paradigms and creating congruence to prevent violence against disabled women

Researcher: Deborah Hager

Supervisors: Assoc Prof. Elsie Ho & Dr Jennifer Hand

Transcriber/Interpreter:

I agree to assist in the transcription/interpretation of the interview material/audio-recordings for the above research project. I understand that the information contained in the interviews/audio-recordings is confidential and must not be disclosed to, or discussed with, anyone other than the researcher and her supervisors.

I agree to keep the anonymity of the research participants.

Name: _____

Signature: _____

Date: _____

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN
PARTICIPANTS ETHICS COMMITTEE ON 26-Jul-2013 for (3) years,
Reference Number 9896

Appendix 12. Interview schedule – key informant and focus groups

Updated February 2014

1. Think about the perfect person to work in (DV SV, Disability). You're writing the job description – what do you write for the knowledge and values that a woman /person needs to have for the position? What does she need to know? What values does she need to have?
2. I don't know what (DV/SV/Disability) is. Please explain it to me as a layperson. Don't tell me what you do – tell me what (DV/SV/Disability) is.
3. What motivates you to work in this field? – what really excites you about your job? What makes you get up in the morning and go to work?
4. When you're doing your work, what outcomes do you want? What's the best outcome that could occur? (Listen for key words – prompt for what they mean to the participant - i.e. what does safe mean?)
5. Now – back to me and my need to understand. Think about how you understand (the related issue) and explain (the related issue) to me.
6. Do you think that these issues overlap? (if yes) In what way? (Prompt) How do you think these issues relate to each other?
 - a) (If no) Can you explain more to me about how you see this?
7. What values and ideas underpin your work? I've heard you mention – can you tell me more about this.... What other ideas? Values?
8. Are there particular models of practice or theories that you use in your work or that help you understand your work. I've heard you mention – can you tell me more about this.... Any other models? Theories? Could you explain this to me more....
9. Do you have any written material about the (model or theory) that I could have a copy of?
10. Do you know anything about the values, ideas, theories or models that are used in (the related fields)? Can you tell me about these? You mentioned...can you explain this more....
11. I'm doing this work because of the high rates of abuse of disabled people. What do you think are the barriers to the domestic and sexual violence and the disability sectors working together to address this?
 - What barriers are there in your sector?
 - What barriers are there from the other sector?
 - What attitudinal barriers are there? (How do you think they think about domestic violence/SV/Disability?)
12. How do you see yourself in relation to the (other sector)? Are the two lots of workers and aims similar or different? What are the similarities? What are the differences?

13. Explain to me what you think the problems of working with a disabled/abused woman would be?
14. Why isn't the abuse of disabled people being taken seriously?
15. Do you think that societal myths and misunderstandings about disability/feminism prevent people engaging with the issue? What sort of myths/misunderstandings would this be?
16. Is there something about one sector working with crisis and one working more routinely?
17. When I say feminism/disability, what images does it conjure up in your mind?
18. What do you think would be a useful way to bridge the barriers?
19. Are there ideas, models, values etc. that the sectors have in common that could be used to start conversations between the sectors?
20. Do you think a human rights approach would work? Have you ever used this in your work?
21. What do you think would be useful strategies to prevent violence against disabled people and to provide constructive services to those who are abused?

Now some quick questions about your own agency...

22. Have you ever been asked /asked any of your staff to do any work to investigate possible cross-sector service provision or other work in this area? Has any work on this been carried out by your agency?
23. Does your organisation have any policies or practices to respond to allegations of abuse from disabled people? (If yes). How and why were these developed? Do they work in practice? Who did you work with to develop them? Who do you partner with to respond?
24. What opportunities have been offered to you to find out more about (the related sectors?) Have you been able to attend this training/other opportunity? How did you find it? Was it useful? Did it increase your knowledge? If you couldn't attend/participate, what prevented you taking up this opportunity?
25. Do you think there should be more cross-sector training? What would enable you and other staff to participate in this?

Appendix 13. Search terms, data bases and sources of literature

Data bases: for example	Search terms: for example
<ul style="list-style-type: none"> • PsycINFO • Scopus • Google Scholar • International bibliography of social sciences • Academic search premier • Proquest • Sociology abstracts • Sage Journals online • Gender studies data base • Gender watch • Australian family and society abstracts data base • Pubmed 	<ul style="list-style-type: none"> • Disabil* • Disability • Disabled • Disability/violence • Domestic/family violence • Sexual violence • Abuse • Violence against women • Models and theories • Paradigms/woman • Disability and domestic violence • Women and disability • Disabled women • Women/aging/old • Best practice/practice guidelines
Topic specific sites: for example	
<ul style="list-style-type: none"> • ANROWS – Australian national research organisation for women’s safety • NZ family violence clearing house • Women’s Aid • UK disability archive, Leeds • Donald Beasley Institute (NZ) • CCS Disability library (NZ) • People First (NZ) • Te Puna – national library of NZ • Specific journals – e.g. Violence Against Women, Disability and 	<ul style="list-style-type: none"> • Feminist disability theory • Attitudes/perceptions/beliefs • Health promotion • Human rights • Exclusion/stigma/discrimination/myths/ disability • Intersectionality • Feminist/qualitative methodology • Feminist disability • Vulnerability

<p>society</p> <ul style="list-style-type: none"> • NZ Human Rights Commission • NZ Govt Family Violence Unit • GOVT websites and related ministry libraries (MOH, MSD, Justice) 	<ul style="list-style-type: none"> • Vulnerable/disability/women
<p>Additionally I sought literature from:</p>	<p>People/organisations directly approached for information</p>
<p>Academics who write about disability:</p> <ul style="list-style-type: none"> • Missy Morton – Otago University • Debbie Espiner – University of Auckland • Debbie Payne – AUT • Martin Sullivan – Massey University <p>New Zealand Disability Support Network - the peak body for the owners/managers of disability organisations</p> <p>I talked to Disabled People’s Organisations (DPOs) – NGO and for profit service providers</p> <p>The Donald Beasley Institute for research about people with intellectual disability</p> <p>The CCS Disability library</p> <p>The Human Rights Commission</p> <p>I was referred to literature and reports by people I talked to</p> <p>I asked the various activists if they knew of grey literature and research that I hadn’t uncovered.</p> <p>I did three Official Information Act (OIA) requests to discover information about police, disability and Ministry of Social Development policies.</p>	<p>Human Rights Commissioners</p> <p>Age Concern, elder abuse coordinator</p> <p>Auckland Disability Law</p> <p>Northern regional domestic violence portfolio manager, MoH.</p> <p>Te Pou</p> <p>Office of Disability Issues</p> <p>Various domestic and sexual violence sector service providers</p> <p>Ministry of Women’s Affairs</p>

Appendix 14. New Zealand literature about violence against disabled people

Note: This is not all of the New Zealand literature used in the thesis. This is the literature that has reference to violence against disabled people.

- Appleton-Dyer, S. & Soupen, A. (2017). *Rapid review of the Waitematā safeguarding adults from abuse (SAFA) pilot report for the Waitematā Police*. Auckland, New Zealand: Synergia.
- Barnett, H. (2015). *Report to the Special Rapporteur on the rights of persons with disabilities. United Nations Geneva*. Wellington, New Zealand: Disabled People's Assembly New Zealand.
- Briggs, F., & Hawkins, R. (2005). Personal safety issues in the lives of children with learning disabilities. *Children Australia*, 30(2), 19–27.
- Cranson, H. (2010). *Diversity report 2009 – 2010*. Wellington, New Zealand: National Collective of Independent Women's Refuges.
- Disability Coalition Against Violence. (2010). *Discussion document to the Taskforce for Action on Violence Within Families, Taskforce meeting 11 August, 2010*. Christchurch, New Zealand: Author.
- Disabled Women's Support Group. (1987). *Women with Disabilities. Report of a consultation meeting of women with disabilities, convened by the Ministry of Women's Affairs*. South, Central Auckland and Wellington, New Zealand: Disabled Women's Support Group and DPA.
- Domestic Violence and Disability Working Group. (2010). *Domestic violence and disabled people*. Wellington, New Zealand: It's Not OK Campaign, Ministry of Social Development.
- Hager, D. (2001). *He drove me mad: The relationship between domestic violence and mental illness*. (Unpublished master's thesis). Auckland, New Zealand: University of Auckland.
- Hager, D. (2011). *Finding safety: Provision of specialised domestic violence and refuge services for women who currently find it difficult to access mainstream services*. Homeworks Trust. Retrieved from www.homeworkstrust.org.nz

- Hager, M., & Hager, D. (2013). *Independence/dependence. Integrating concepts for a future disability inclusive feminism*. Wellington, New Zealand: Unpublished conference paper. Women's Study Association Conference.
- Hickey, H. (2007). *Claiming spaces: Maori (indigenous persons) with disabilities, making the invalid valid*. Hamilton, New Zealand: University of Waikato MPRU Maori Pacific Psychology Symposium, November 2007.
- Justice and Electoral Select Committee. (2017). *Family and whanau violence legislation Bill: As reported from the Justice and Electoral Select committee*. Wellington, New Zealand: New Zealand Government
- McRae, J. (2014). *Becoming a person: The biography of Robert Martin. How an intellectually disabled man helped change the world*. Nelson, New Zealand: Craig Potton Publishing.
- Ministry of Health. (2001). *The New Zealand Disability Strategy: Making a world of difference. Whakanui Oranga*. Wellington, New Zealand: Author.
- Morton, M., & Munford, R. (1998). Re/presenting difference: Women and intellectual handicap. In R. Du Plessis, & L. Alice (Eds.), *Feminist thought in Aotearoa/New Zealand* (pp. 164-171). Auckland, New Zealand: Oxford University Press.
- New Zealand Family Violence Unit & Hager, D. (2013). *Evidence brief: Issues and opportunities for addressing family violence within the disability sector*. Prepared for the Taskforce on Family Violence. Wellington, New Zealand: NZ Family Violence Unit, Ministry of Social Development.
- Office of Disability Issues, (2014). *The Disability Action Plan 2014-2018*. Wellington, New Zealand: Author.
- Office for Disability Issues, (2015). *The Disability Action Plan 2014-2018: Update 2015*. Wellington, New Zealand: Author.
- People First in Partnership. (2012). *'Keeping safe feeling safe' project: Disability related hate crime – People First focus group (2012) findings*. Auckland, New Zealand: Author.
- Roguski, M. (2013). *The hidden abuse of disabled people residing in the community: An exploratory study*. Gisborne, New Zealand: Tairawhiti Community Voice.

Van Eden, K. (2013). *Putting people first: A review of Disability Support Services performance and quality management processes for purchased provider services*. Wellington, New Zealand: Ministry of Health.

Wilson, D., & Webber, M. (2014). *The people's report: The people's inquiry into addressing child abuse and domestic violence. Section one: Honouring their stories, their lives*. Auckland, New Zealand: Glenn Inquiry.