The Hidden Abuse of Disabled People Residing in the Community: An Exploratory Study

prepared for

Tairawhiti Community Voice

TAIRAWHITI
COMMUNITY
VOICE

by

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Kaitiaki Research and Evaluation

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Foreword

Hutia te rito o te harakeke

Kei hea to Komako e ko

Ki mai ki ahau

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Te Tangata, he tangata, he tangata e

If the centre shoot of the flax is ripped out (the flax dies),

Where will the bellbird sing?

If you were to ask me what is the most important thing in the world?

I would reply, it is people, it is people, it is people.

This research project has been inspired by truly amazing people. It began with one woman's story which highlighted for me the complex matrix of enablers that allow for the abuse of vulnerable adults. Her story caused me to question; are adults who are dependent on others for their care more likely to be abused? Are there adequate protections against abuse available for people who rely on domestic and non-domestic relationships for their day-to-day wellbeing? Why does New Zealand law not protect vulnerable adults in the same way that it protects our children?

To find answers to these and other questions, we needed to identify the personal, familial, structural and institutional barriers to ending abuse. We needed to learn about the circumstances that create opportunities for the exploitation and abuse of vulnerable adults (and in particular, those living with disabilities, degenerative neurological diseases or traumatic brain injury).

I am very grateful to Michael Roguski who has produced this work for Tairawhiti Community Voice. The knowledge this research provides holds us all to account for the abuses which have been highlighted. It is now over to us to act upon the recommendations in order to make Tairawhiti a safer home for everyone. To achieve this, we have a lot of work ahead.

I offer my sincere thanks to each of the research participants. The gift of your story illuminates the challenges ahead in order for our community to keep each of you and many others safe. Our community owes each of you a huge debt of gratitude. I sincerely hope we can bring about robust changes that will end the suffering of all people and bring some sense of peace and justice to all of those who have suffered abuse.

Leslynne Jackson
Tairawhiti Community Voice

Acknowledgements

EXECUTIVE SUMMARY

In early 2012 Tairawhiti Community Voice commissioned Kaitiaki Research and Evaluation to undertake research to:

- increase their understanding of the multidimensional nature in which abuse manifests in relation to disabled people

- identify individual and structural barriers that prevent disabled people from voicing and extracting themselves from abusive environments.

In the first instance, the study was inspired by a growing awareness of the abuse of disabled people living in the New Zealand community. Next, while international research has highlighted that disabled people are vulnerable to an array of abuse by family members and those outside of the family charged with their provision of care (Hague, Thiara, Magowan & Mullender, 2008; Saxton, Curry, Powers, Maley, Eckels and Gross, 2001), no such research has been conducted in New Zealand.

In response, the current research was designed to meet the following specific objectives:

- understand the nature of abuse experienced by disabled people who require high levels of support by family/whānau members and other parties involved in their day-to-day care

- identify the individual, societal and structural barriers that assist in the continuation of abuse

- explore the barriers faced by disabled people in voicing abuse

- identify the systematic structures that maintain the abuse of disabled people and inform how Tairawhiti Community Voice can advocate for the safety and well-being of these people

- provide an evidence base from which interventions can be developed to help identify and prevent abuse.

Approach

The study used a combination of case study and participatory research methodologies. Case study methodology enables an in-depth exploration of disability-related abuse, from multiple perspectives, within designated geographic areas. Participatory research was employed because it is underscored by stakeholder:

- design of the research process

- review and validation of the emerging research findings

- ownership of the results (Cornwall and Jewkes, 1995).

Participatory methodology was reflected in an *initial community stakeholder workshop*. The workshop aimed to clarify the research objectives and engage stakeholder agreement to use snowballing methods to recruit potential participants. The majority of participants from the initial workshop, alongside a selection of interviewees who indicated an interest in the research findings, participated in a *key findings workshop*. The workshop sought clarification and endorsement from participants about the key research findings. Finally, these findings were tested with a variety of national stakeholders (i.e. representing disabled, police and legal perspectives) from different locations around New Zealand.

Forty-four individuals participated in a combination of individual, small group and focus group interviews. The majority of participants (n=35) were recruited from in or around Gisborne/Tairawhiti. The remaining nine participants were recruited from other New Zealand locations because of their knowledge of disability issues across New Zealand.

Of the 35 Gisborne/Tairawhiti participants, 10 were disabled and a further 10 were family/whānau members of a disabled person. With half of the interviews, a support person or advocate nominated by the participant was present. Interviews lasted between 45 and 90 minutes and were audio recorded with participants consent. To safeguard participant anonymity, type of disability, ethnicity, gender and age are not reported.

The remaining 11 Gisborne/Tairawhiti participants were selected because of their professional responsibility, their experience with the disability sector and/or a history of witnessing or working alongside disabled people who had been abused. The majority of these professionally aligned participants participated in a combination of individual, small group and focus group interviews. Individual and small group interviews lasted up to two hours. Focus groups ranged between one and three hours.

Types of Abuse

Participants discussed having experienced abuse in residential services, institutions, home-based environments and in the community.

- **Residential services –** abuse within residential settings occurred through either a staff member or client associated with the organisation. This type of abuse assumes the victim is a resident of a residential service. Residential services include specialised residences, usually designed for up to six residents, with 24-hour care worker supervision. The types of services include nursing homes, specialist residences for people who have experienced a brain injury (including stroke), mental health, intellectual disabilities and homes for people in need of care.

- **Institutional settings –** institutional abuse occurred through staff associated with an organisation. Most commonly, participants referred to hospitals as a primary site for institutional abuse. This type of abuse assumes the victim was temporarily placed in the institution.

- **Home-based environments –** abuse within the home occurred through home-based care workers, landlords and the individual's partner or family/whānau. Managers of homecare service organisations were also discussed as facilitating abuse by failing to appropriately action reports of abuse.

- **Community settings –** abuse in community settings was referred to as either occurring opportunistically by someone unknown to the victim or, for example, in the case of financial abuse, through local businesses and neighbours.

Similar to previously identified forms of abuse, participants described experiencing psychological/emotional, financial, physical and sexual abuse (Otkay and Tompkins, 2004; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006). Relatively new to the literature are forms of abuse, termed here, as silencing, locked-in and dehumanising processes and treatment.

Structures Maintaining the Status Quo

A number of structural issues were identified as maintaining the status quo; specifically:

- a low level of societal awareness of disability abuse

- a variety of silencing processes

- a lack of appropriate monitoring

- poor management practice of a variety of disability-related residences and services

- inadequate reporting options

- existing legislation, and powers emerging from legislation, are inadequate. This is especially problematic in that the disabled individual does not receive adequate protection during an investigation of abuse.

Of note, while the various issues are presented and discussed separately, they are generally interrelated and do not occur discretely.

1. Low levels of disability awareness

Low levels of societal awareness about disability-related issues, specific vulnerabilities and the abuse of the disabled were discussed as primary barriers that maintain the status quo. Specifically, low levels of disability awareness were seen as providing a foundation to each of the remaining barriers.

The pervasiveness of abuse and inequitable treatment of disabled people was attributed to deep-seated societal attitudes and beliefs which position disabled people as second class citizens. On one level disabled people's second-class status is reflected in abled bodied bias in the development of architecture, access and societal representation. On a deeper level, however, disabled people share an insidious history of eugenics and societal maltreatment, most recently witnessed in Nazi Germany, which reflects a willingness, on a societal level, to make disabled people expendable.

Given the pervasiveness of negative societal attitudes towards the disabled, participants stressed that the use of terms such as the *social model of disability* can fail to portray the lived reality of social exclusion, bias and maltreatment and the second class status of the disabled. Consequently, there were demands for a clear re-branding of disability-related abuse to give it equal footing to that of inequitable treatment of other marginalised groups.

2. Silencing

Multiple reports were provided of disabled people, and/or those associated with them, being pressured to refrain from reporting incidents of abuse. In other situations, individuals' complaints of abuse were ignored by a third party. This process, albeit how subtle or deliberate, is termed here as silencing and manifested in terms of:

- **the disabled person** – silencing occurred amongst disabled participants in terms of the following –

  - pressure to not report abuse. Often this pressure occurred subtly through a conditioning process whereby individuals reported learning to be silent about their abuse through one or more of the following –

    - negative experiences resulting from past complaints

    - fear of retribution

    - a concern that removal of a care worker or a family/whānau member would result in solitude and a lack of care

  - instances when the disabled individual believed they were somehow deserving of abuse

  - a normalisation process whereby the individual has become so accustomed to ill-treatment that abusive behaviours are accepted as either normal or not worthy of an official report

  - difficulties some disabled people experienced communicating. This generally involved non-verbal individuals and individuals with limited understanding and the inability to complain.

- **negation** – numerous accounts were offered where a complaint of abuse was negated on the grounds that the disabled person's testimony lacked veracity. This generally involved:

  - some form of disparagement of the individual complainant

  - questioning the degree of truth underpinning a complaint on the basis of the individual having been diagnosed, at some point, with a mental illness

- **collusion** – collusion refers to a conspiratorial agreement to deny an abusive incident. Rather than an explicit attempt to negate the individual's abuse, collusion was reported to manifest when witnesses believed they should protect parties from statutory "*interference"* or to protect the individual perpetrator's or organisation's reputation. It should be stressed that collusion was not limited to organisations. Numerous examples were documented where a family/whānau had colluded with the disabled person in an effort to protect the perpetrator from prosecution.

3. Monitoring of service provision-related abuse

Participants unanimously regarded residential and home-based provision of care services as insufficiently monitored and stated that the lack of monitoring of the provision of care was the most common issue that maintains disabled people's vulnerability to abuse.

In each case of residential and home-based abuse through a care worker, a lack of monitoring was identified in terms of the quality of service provided, the individual client and family/whānau satisfaction and presence of abuse. Further, no participant was aware of a government agency adequately auditing or overseeing complaints made by clients of residential or home-based services.

Of note, there is no monitoring provision for disabled people who reside in their own or a family/whānau member's home and are not in receipt of paid service provision. As such, disabled people who are home-based and not in receipt of paid care services are placed in an extremely vulnerable position because any incidence of abuse can go unidentified.

4. Poor management practice and a lack of professional standards

Services in Gisborne/Tairawhiti were generally described as reflecting:

- **low levels of professionalism** – most commonly, concerns about poor management practice focused on the lack of professional standards demonstrated by many managers of residential and home-based services. The lack of standards was traced to a sector that often lacked formal training and exposure to best practice

- **a lack of appropriately trained staff** – a lack of adequate training and professional development led to what was commonly perceived as underperforming services. This was a concern because a lack of commitment to the provision of high quality services was viewed as compromising clients' safety

- **nepotistic hiring and staff management practices** – related to the lack of adherence to professional standards were questionable hiring practices. Services were criticised for not carrying out criminal history and last employer reference checks and hiring individuals with undemonstrated skill or aptitude. In part, poor hiring practices were traced to nepotism. The lack of staff with requisite skills and temperament was explained in terms of the low wages commanded by support workers.

Concern was raised about the failure of many services to place their clients' safety as paramount and multiple examples were given of processes that re-victimised the disabled individual. It was, however, acknowledged that Gisborne/Tairawhiti, as a provincial

centre, has a limited skilled workforce. This may impact on what participants referred to as a *"low calibre"* pool of care workers and supervisory staff.

5. Reporting

Reporting abuse was discussed on two levels: first- and second-stage reporting. First-stage reporting refers to the initial disclosure of actual or suspected abuse and can be reported by the abused individual or someone associated with the disabled person. First-stage reporting barriers generally involve a silencing process (as discussed above). Second-stage reporting refers to the action taken by the person or persons who received the initial complaint. Second stage reporting barriers include insufficiently actioning a complaint or investigation and a failure to protect victims during and after an investigation.

The following specific reporting barriers were identified:

- **service organisations -** a number of reporting gaps were identified. A large number of participants reported a high level of dissatisfaction over the way in which complaints made to service organisations were managed. Further, disabled participants discussed being placed in untenable positions, as a punishment, after a complaint was made. Threats or actual loss of rights, privileges and safety meant that participants reported extreme reluctance in making a future complaint

- **barriers to engaging with police -** the ability of the police to prosecute an alleged perpetrator was restricted by difficulties associated with obtaining evidence that would be considered sufficient to meet necessary evidential thresholds. This was especially true in situations of emotional and psychological abuse where participants felt helpless because of a lack of 'hard' evidence or due to confusion about whether they had a case to pursue under different legislation. Because of past negative experiences with some frontline officers it was common for participants to be extremely reluctant to seek police assistance. Negative experiences included reports being negated because of the individual's disability, a lack of knowledge of disability issues and demonstrations of prejudice towards disabled people.

- **insufficient protection -** in all situations where a complaint was made to the police and/or the Health and Disability Commission, the allegedly abused individual remained in the residence or home during the investigative period. Further, in the majority of cases there was insufficient evidence to arrest or remove the perpetrator from the residence. This placed the complainant at considerable risk of retribution, whether emotional or physical

6. Service fragmentation

A proliferation of fragmented and segregated health and disability services were associated with:

- **a lack of awareness and understanding about what health and disability services exist in the community –** because of a lack of awareness of various services potential referral bodies stated that they had a high degree of uncertainty about referral options. The lack of certainty created a concern that many disabled people and their families' needs go unmet. Further, non-government organisations, Work and Income and the police participants had a high degree of uncertainty about the quality of care provided and the efforts expended to ensure service clients are protected. Finally, a lack of service awareness was raised as a concern as disabled clients can be so isolated that abuse can go undetected by members of the wider community

- **competitive funding arrangements –** service privatisation and contractual requirements have resulted in a lack of inter-service collaboration. Further, a lack of inter-service collaboration and restricted eligibility criteria was attributed to the

competitive environment. Such restrictions have countered holistic service provision efforts. Specifically, individuals with high and complex needs and/or those within family/whānau systems, fail to receive holistic service provision. Rather than an integrated case management system designed to meet the holistic needs of the disabled individual, and where pertinent families, the current funding system is generally geared to the purchase of specific tasks or activities.

7. Legislation

One factor identified as maintaining the status quo is the lack of consensus surrounding definitions of abuse; inherently there is no one definition of abuse that can be universally applied across the various manifestations of abuse reported by disabled participants, their family/whānau members and/or community stakeholders.

Further, a degree of uncertainty exists in the applicability of different legislation that potentially applies to the protection of disabled people from abuse. There is also uncertainty about the level of protection afforded to disabled people if the perpetrator is providing care in a residential setting, for example whether this is excluded by definition of a domestic relationship under Section 4 of the Domestic Violence Act. Significantly, locked-in abuse is not included within existing statutory definitions of abuse.

One critique of the Crimes Act is that offences under the Act are treated as discrete breaches of the law and the various offences under the Crimes Act have not been developed as extensively as the Domestic Violence Act. As such, the Crimes Act lacks the drivers for detection, investigation, prosecution and protection that are central to the Domestic Violence Act.

A second critique of the Crimes Act centres on the lack of protection afforded to disabled people. Evidentiary requirements, in relation to the abuse of the disabled under the Crimes Act, were viewed as unnecessarily high and were reported to deter disclosing abuse.

Thirdly, the Protection of Personal Property and Rights Act (PPPR) is critiqued, particularly, because of:

- a lack of criteria guiding enquiry into the suitability of a welfare guardian to meet the potentially complex and diverse needs of an incapacitated person

- the absence of any specific requirements placed on a welfare guardian to account for the on-going care and wellbeing of an incapacitated person.

1 INTRODUCTION

In early 2012, Tairawhiti Community Voice commissioned Kaitiaki Research and Evaluation to undertake research to:

▪ increase their understanding of the multidimensional nature in which abuse manifests in relation to disabled people

▪ identify individual and structural barriers that prevent disabled people from voicing and extracting themselves from abusive environments.

In the first instance, the study was inspired by a growing awareness of the abuse of disabled people living in the New Zealand community. Next, while international research has highlighted that disabled people are vulnerable to an array of abuse by family/whānau members and those outside of the family/whānau charged with their provision of care (Hague, Thiara, Magowan & Mullender, 2008; Saxton, Curry, Powers, Maley, Eckels & Gross, 2001), no such research has been conducted in New Zealand. As a consequence, Tairawhiti Community Voice members, comprising non-government and government representatives, identified that a substantial gap in knowledge was hindering appropriate and informed responses from agencies working with disabled people in the community.

In response, the current research was designed to meet the following specific objectives:

▪ understand the nature of abuse experienced by disabled people who require high levels of support by family/whānau members and other parties involved in their day-to-day care

▪ identify the individual, societal and structural barriers that assist in the continuation of abuse

▪ explore the barriers faced by disabled people in voicing abuse

▪ identify the systematic structures that maintain the abuse of disabled people and inform how Tairawhiti Community Voice can advocate for the safety and well-being of these people

▪ provide an evidence base from which interventions can be developed to help identify and prevent abuse.

The stages of the research included:

▪ a review of the literature to –

– increase understanding of the dynamics of abuse of disabled people

– review methodologies that have been used to study this issue

– identify gaps in knowledge

– identify policy and research implications

– provide an evidence-base to ensure that this research builds on and contributes to previous research in this area

▪ key informant semi-structured interviews with Tairawhiti Community Voice members, Tairawhiti Abuse Intervention Network (TAIN) staff , disabled adults

residing in New Zealand's East Coast, family/whānau members of disabled people and legal representatives working for disabled people

- key informant interviews with national organisations that are positioned to provide a national overview of the abuse of disabled people.

2 LITERATURE REVIEW: WHAT IS KNOWN ABOUT THE ABUSE OF DISABLED PEOPLE

No New Zealand specific research-related literature pertaining to the abuse of disabled people residing in the community was identified. However, while no in-depth research has been conducted in New Zealand, there is a growing awareness of abuse against people who, due to old age or physical and cognitive impairments, can no longer manage their own affairs. In part, the growing awareness can be attributed to organisations such as the Disabled Persons Assembly and the Disability Clothesline Project who make the eradication of abuse of disabled people a central focus.[1] In addition, the growing awareness of abuse can be understood in light of the large New Zealand disabled population. For example, as of 19th of May 2011 Accident Compensation Corporation (ACC) had 2884 clients with moderate to severe or severe brain injuries. Of these, 1290 required attendant care of more than 56 hours per week (ACC, personal communication, May 19, 2011).

In response to the growing awareness of disability-related abuse a booklet, funded by the It's Not OK campaign to highlight the issue of domestic violence and disability, was recently developed by the Auckland Domestic Violence and Disability Group. The booklet, *Domestic Violence and Disabled People*, provides information for disabled people to help them identify if they are in an abusive relationship and how they can access help (Auckland Domestic Violence and Disability Group, 2011). The booklet acknowledges many of the issues highlighted by overseas research surrounding the fears associated with voicing abuse such as fear of losing care, being institutionalised, not being able to communicate with services and a lack of adequate transport and means to access support (Auckland Domestic Violence and Disability Group, 2011). Family violence agencies in New Zealand, such as Women's Refuge, also provide information on their website regarding violence and disability. According to their website, Women's Refuge provides assistance to abused disabled women and have a relay service so that women with hearing and speech issues may access their services (Women's Refuge, 2012).

Given the dearth of New Zealand disability-related abuse literature, this review focuses solely on international literature. The review includes literature from Australia, Malawi, the United Kingdom, the United States and Canada.

The review is presented in a number of sections. These include:

- prevalence of the abuse of disabled people

- perpetrators of abuse

- types of abuse experienced

- factors that intensify abuse

- disabled people's experiences in accessing services

- policy implications and suggestions to improve services that have resulted from these studies are also explored.

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[1] For more information, please refer to www.disabilityclothesline.org.nz

2.1 Prevalence and risk

As the current review focuses primarily on applied research studies that generally included participants who had all experienced abuse, prevalence information was not always reported. However, a small number of the studies did explore the prevalence of abuse amongst the disabled population and others also utilised a comparison group of a non-disabled sample as well. The findings of these studies are discussed in this section.

In a study that looked at the facilitators and barriers faced by disabled women when disclosing abuse, Curry, Renker, Robinson-Whelen, Hughes, Swank, Oschwald and Powers (2011) explored what specific factors aided or hindered disclosure of abuse. Of their 305 disabled female participants, 276 had suffered some form of interpersonal violence in their lifetime (90%). Oktay and Tompkins (2004) examined rates of abuse by personal assistance providers in a group of 84 disabled people who received some sort of care from personal assistance providers. The majority of the participants were men (n = 60), who comprised 71% of the sample and 24 women (29% of the sample). The participants were questioned regarding maltreatment from their primary personal assistance providers and other personal assistance providers. Thirty percent of the sample indicated that they had suffered abuse at the hands of their primary personal assistance provider and 61% disclosed some form of abuse at the hands of other personal assistance providers.

A comparison study by Young, Nosek, Howland, Chanpong and Rintala (1997) examined the prevalence and types of abuse experienced by physically disabled women and non-disabled women in the United States. In the first phase of their study, 31 women with physical disabilities were interviewed on issues surrounding sexuality. Twenty-five of the thirty-one participants (80.6%) indicated that they had experienced some form of abuse and, in total, 55 separate incidents of abuse were reported. Following the initial qualitative phase, 439 disabled and 421 non-disabled women were surveyed about a raft of sexuality-related issues (Young et al., 1997). Of the physically disabled women who were surveyed, 272 (62.0%) reported some form of abuse (a similar figure of 62.2% was reported for non-disabled women) (Young et al., 1997).

A study by Martin, Ray, Sotres-Alvarez, Kupper, Marocco, Dickens, Scandlin and Gizlice (2006) also used a comparison group of non-disabled women to investigate if women's disability status was linked to the risk of being subjected to physical or sexual assault within the past year. The study used data collected from the North Carolina Behavioural Risk Factor Surveillance System. In total, 5,326 women participated in the study. A total of 3,883 women surveyed had no disability and the remaining 1443 non-institutionalised women identified as having some form of disability (self-identified disability, cognitive impairment, activity limitation or use of equipment) (Martin et al., 2006). A multivariate analysis indicated that disabled women were not at a significantly greater risk of physical assault than non-disabled women (2.0% of disabled women reported physical assault, n= 29, compared to 2.3% of non-disabled women, n= 89). However, disabled women were at a much greater risk of sexual assault than non-disabled women with more than four times the odds of experiencing sexual assault in the last year compared to non-disabled women, with 2.1% of disabled women (30 women) experiencing some form of sexual assault in the past year, compared to 0.6% of non-disabled women (23 women). Amongst the disabled women surveyed those with cognitive impairments were identified as being the most likely to experience sexual assault (Martin et al., 2006).

A study by Brownridge (2006) highlighted that women with disabilities have a higher risk of experiencing violence than women without disabilities. Brownridge (2006) surveyed 7,027 Canadian women about family violence.[2] Of the women in the study, 1,092 (15.5%) were disabled (5,935 were not disabled). Brownridge (2006) reported that women with disabilities

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[2] All participants were heterosexual and were either married or living in common law relationships.

were 1.4 to 1.9 times more likely to experience the threat of assault with a fist or other object; to be pushed, grabbed, or shoved in a way that could hurt; and to be slapped. The major differences between the disabled and non-disabled participants were presented within the more harmful forms of violence, as women with disabilities were twice as likely to report being beaten and kicked, bit or hit with a fist. In regards to sexual assault, disabled women were three times more likely to be subjected to threats of sexual assault or actual sexual assault. The results of the Brownridge's (2006) study revealed that disabled women reported more physical violence in both a one-year and five-year timeframe; however, the difference was only statistically significant with the five-year time frame. Overall, Brownridge (2006) reported that disabled women had a 40% higher risk of being exposed to violence in the five years preceding the study than their non-disabled counterparts.

Research by Sobsey and Doe (1991) looked specifically at the sexual abuse of disabled individuals. Over a two year period 162 reports of the sexual abuse of a disabled person were collected from sexual treatment centres and disability advocacy groups. All reports were sourced from either Canada or the United States and the study had no age limitations (Sobsey & Doe, 1991). The majority of victims were women, with reports coming from 132 women and 30 men. The majority of victims had an intellectual impairment (114 people), 33 indicated a mobility problem, 21 a hearing impairment, 17 a psychological impairment, seven a visual impairment, six a neurological impairment, three were autistic and two had a learning disability. In the appraisal of their findings, the authors concluded that disabled individuals were at a 78% greater risk of being abused purely due to their relationship with the "disability service system" (Sobsey & Doe, 1991, p. 249). They supported this claim by outlining that while the majority of sexual abuse happened in the home (51.9%), 36.7% took place in spaces that were linked to their disability. Abuse was also likely to happen in group homes (6.3%), institutions (12.7%), hospitals (3.2%), vehicles used for transportation (10.1%) and other places related to the individual's disability (4.4%).

2.2 Perpetrators

Characteristics of perpetrators who abused disabled people varied across the literature. In the first ever nationwide study of disabled women and domestic violence in the United Kingdom, Hague, Thiara, Magowan and Mullender (2008) explored the different forms of violence experienced by disabled women, as well as the type and adequacy of available services, avenues of response and sought recommendations from disabled people to improve services. Hague et al. (2008) interviewed 30 abused disabled women between the ages of 20 and 70 years, who reported a range of sensory or physical impairments. All the women lived within the community and not institutions, hospitals or residential homes.[3] Participants were questioned about the types of violence they had experienced, who had committed these acts, the length of the abuse, their experience of gaining help, the response they received following their request and their views on good practice and what advice they would give to other disabled women in the same situation. Hague et al. (2008) reported that the majority of women were abused by their intimate partner, with 25 women (83%) abused by their male partner, and two by their female partner (7%). However, five women disclosed abuse by family members (17%) and three women (10%) reported abuse by their personal assistance providers (Hague et al., 2008)[4].

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[3] Hague et al. (2008) strove to recruit disabled women from ethnic minorities and those within lesbian relationships. However, due to difficulties with recruiting in general, the majority of the participants identified as white (20 of the 30 women) and 27 were in heterosexual relationships, with two participants indicating that they were lesbian and one bisexual.

[4] Due the fact that some women had often been abused by more than one person, the total number of perpetrators totals greater than the 30 participants.

Emotional abuse was reported by 227 of the 439 physically disabled women in the American study by Young et al. (1997). The perpetrators of this form of abuse were most commonly husbands or live-in partners (n = 58, 25.5%), mothers (n = 49, 20.5%) and fathers (n = 42, 17.8%). Of the 155 physically disabled women who reported physical abuse, husbands or live-in partners were the most common perpetrators, accounting for 17.3% (n=27) of this type of abuse. Young et al. (1997) stated that when it came to sexual abuse, strangers were the most common perpetrators. Of the 175 physically disabled women who reported sexual abuse, 10.5 % (18) disclosed that the abuser was a stranger (Young et al., 1997).

A study undertaken in the state of Victoria, Australia, by the Office of the Public Advocate (OPA) (2010) investigated violence against people with cognitive impairments. This study involved the review of 86 cases that involved allegations of violence (OPA, 2010).[5] The 86 cases were held by 14 different guardians who met with the researchers and case summaries were written based on their recollections. The guardians were asked to check details against their records and alter any information accordingly. Across the 86 case studies, there were allegations made by 66 women and 22 men, who ranged in age from 16 to 100 plus, with intellectual impairment being the most commonly reported disability (n = 41). The alleged perpetrators of the abuse were overwhelmingly partners or relatives (64 cases, 74%). Four cases involved abuse by co-residents (5%) and nine by staff members (10%) (OPA, 2010). In 30 of the cases abuse was carried out by the individual's personal assistance provider (35%) and in 19 (22%) of the cases the abusers were a parent or partner's parent. Intimate partner violence was also common, present in 33 of the 86 cases (30 women and three men, 38%) and in 21 of these 33 (64%) cases multiple forms of abuse were experienced.

In regards to who were the most common perpetrators of sexual violence, Sobsey and Doe (1991) reported that the majority of offenders were male, as 147 of the 162 victims (91%) indicated abuse by a male and only 15 reported a female abuser (9%). Perpetrators included family members (16.8%, 27 cases), neighbours/friends (15.2%, 25 cases), paid other service providers (e.g. babysitters) (8%, 13 cases), a stranger (8.2%, 13 cases), dating companion (3.8%, six cases) and step-family member (2.2%, four cases). In the remaining 44% of cases, the authors noted that the relationship to the offender was directly linked to the person's disability (Sobsey & Doe, 1991). For instance, the authors detailed how in 45 cases (27.7%) abusers were disability service providers (personal care attendants, residential care staff and/or medical professionals), transportation providers in nine cases (5.4%), foster parents in seven cases (4.3%) and other disabled individuals in 11 of the cases (6.5%).

The characteristics of personal assistance perpetrators were explored by Otkay and Tompkins (2004). In a study of 84 people with disabilities, the authors found that male personal assistance providers were significantly more likely to mistreat those in their care than female personal assistance providers (Otkay & Tompkins, 2004). Of the twenty participants whose primary assistance provider was male, 53% reported abuse (n = 10), compared to only 24% of the 64 participants who indicated a female primary assistance provider (n = 15). Although personal assistance providers of a younger age were reported to be more likely to abuse, no age-related significant differences were found. Otkay and Tompkins (2004) reported that family members who were the primary personal assistance provider were least likely to be abusive, as only four of the 24 participants (17%) who had a family member as the main personal assistance provider reported abuse. The authors reported that personal assistance providers from agencies were most likely to abuse, as 16 of the 38 participants (41%) with providers from an agency reported abuse; although, this difference was not statistically significant (Otkay & Tompkins, 2004).

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[5] Of note, the study did not require the acts of violence reported to be substantiated as one of the aims of the study was to highlight the barriers that face disabled people in reporting violence against them.

2.3 Period of abuse

Only two studies have explored how long people with disabilities endure abuse. Hague et al. (2008) reported that the length of abuse suffered by their participants ranged from one to twenty-two years, and women with greater care needs reported near life-long abuse. Young et al. (1997) also indicated that women with physical disabilities suffered abuse for a longer duration than their non-disabled counterparts. Abuse (emotional, physical and sexual abuse) was experienced on average for 7.4 years by physically disabled participants, greater than the 5.6 year period of abuse suffered by non-disabled participants.

A study by Cockram (2003) investigated domestic violence experienced by disabled people in Western Australia. A survey was sent to 231 agencies that were considered to have contact with abused disabled women and one of the questions asked about the length of time that clients had experienced abuse. The period of time ranged from up to six months to more than six years, with 419 women (65%) of women living with violence for up to two years, 125 women (18%) between two-to-six years and 165 women (23%) more than six years.

2.4 Types of abuse

Diverse types of abuse were reported by participants across the studies. The abuse experienced by disabled participants differed from the types of abuse experienced by non-disabled women. Participants reported abuse that was linked to their disability, such as humiliation, destruction of specialised equipment, manipulation of equipment and sexual abuse traded for care. The types of abuse experienced by the disabled participants are explored below and Table 1 outlines the specific examples of abuse experienced.

In regards to the types of domestic violence reported by disabled women, Hague et al. (2008) revealed that 17 participants (57%) had disclosed experiencing physical, emotional and sexual abuse, 10 (33%) experienced physical and emotional abuse, and three (10%) only emotional abuse. Physical violence was often coupled with severe emotional abuse and degradation that was frequently tied to the individual's disability. The authors noted that compared to non-disabled women, disabled women reported a higher rate of emotional abuse and humiliation (Hague et al., 2008). Sexual violence was also commonly reported by participants in Hague's et al. (2008) study, with coercion, rape and reports of forced sexual relations. Neglect and isolation by primary caregivers who were family members or intimate partners was common. Participants disclosed financial abuse, with instances of intimate partners completely controlling finances or using allowances to buy alcohol and/or drugs. Further, many women discussed how they were made to feel bad about not contributing to the household earnings (Hague et al., 2008). In describing the abuse suffered by disabled women, one participant stated:

> Severely disabled women are often quite abused anyway throughout their lives. And it's
> not obvious abuse, it's not violence particularly, it's quite passive and people can abuse
> that very easily. It's a very easy thing to abuse (Hague et al., 2008, p.31).

An Australian study by Cockram (2003) also focussed on experiences of family violence and interviewed 32 disabled women who had suffered domestic violence. Fifteen women had physical disabilities, eight intellectual or cognitive impairments, seven psychiatric impairments and two reported sensory impairments. In a semi-structured interview the women were asked to share their experiences of violence and how they coped. The women revealed threats and actual physical abuse, sexual abuse, as well as emotional, social and financial abuse (Cockram, 2003). Another Australian study by OPA (2010) also highlighted a range of abuse: physical, sexual, emotional, psychological, as well as violence related to disability, financial abuse and neglect (OPA, 2010). The most frequent form of reported violence experienced by both the men and women in the case summaries was physical violence: 18 of the 20 (90%) male cases and 34 out of the 66 (52%) women reported having suffered

physical violence (OPA, 2010). Sexual violence was also experienced by a large minority of the women, as 30 of the 66 (45%) cases involved some form of sexual abuse, alongside two male cases (10%) (OPA, 2010). As with other studies, the OPA (2010) cases involved more than one type of violence, as 50 (58%) of the cases included more than one type of abuse.

Focussing specifically on personal assistance provider abuse, of the 25 women who reported abuse by a primary personal assistance provider, Otkay and Tompkins (2004) noted that 15 experienced verbal abuse (60%), nine physical abuse (36%), eight theft (32%), seven extortion (28%), five neglect (20%), four poor care (16%) and three sexual abuse (12%). Of the 51 participants who suffered abuse by another personal assistance provider, verbal abuse and theft were most common, reported by 24 disabled participants (47%), followed by neglect (22 participants, 43%), poor care (18 participants, 35%), extortion (13 participants, 25%), physical abuse (eight participants, 16%) and sexual abuse (seven participants, 14%) (Otkay & Tompkins, 2004). Although only three participants in Hague et al (2008) reported abuse by a personal assistance provider, the authors commented that it is thought to be a common occurrence amongst disabled women. In regards to the types of abuse committed by personal assistance providers, Hague et al. (2008) reported that abuse by personal assistance providers was more commonly non-physical, such as financial abuse and invasions of privacy.

Abuse by personal assistance providers was explored by Saxton, Curry, Powers, Maley, Eckels and Gross (2001), in which female participants reported actual or threatened physical harm, sexual, emotional (most common) and financial abuse. Other forms of abuse considered to be specific to disabled women were also disclosed (Saxton et al., 2001). Disabled women described abuse that was directly linked to special equipment or medications, for example denying access to or damaging specialised equipment and inhibiting or forcing medication. Participants also revealed other incidents of abuse unique to their disability. One participant, due to a lack of mobility and her reliance on her personal assistance provider, described feeling trapped:

> *"She'd come in there and she'd have like some major catastrophe in her life and sit there and talk forever…I couldn't get a word in edgewise…I just couldn't take it…" (Saxton et al., 2001, p. 404).*

Other incidents considered to be specific to those with disabilities included neglect by personal assistance providers, such as not adequately fulfilling duties or working under the influence of alcohol or drugs (Saxton et al., 2001). Following the Saxton et al. (2001) study, Saxton, Curry, McNeff, Limont, Powers and Benson (2006) conducted similar research with 78 disabled male participants aged 20 to 65 years. The majority of participants indicated that they had a mobility disability (54 participants), while 13 indicated a cognitive disability and seven participants had a visual disability. A number of men also indicated the presence of multiple disabilities such as hearing problems and speech impairments (Saxton et al., 2006). The study found that disabled men were subjected to many of the same abusive situations as disabled women. Physical abuse, sexual abuse and neglect were disclosed, financial abuse was common, as was emotional abuse. Sexual abuse encompassed undesired sexual advances and coercion to participate in undesired sexual acts (Saxton et al., 2006).

Research by Sobsey and Doe (1991) looked specifically at sexual abuse of disabled individuals. The types of sexual abuse suffered varied, with 51.3% (86 victims) reporting vaginal or anal penetration and 41.4% (67 victims) touching or masturbation. Other kinds of abuse included oral-genital contact, coerced sexual acts with another victim or the abuser. The mean number of incidents across the victims was 1.52, with many victims subjected to more than one sexual abuse incident (Sobsey & Doe, 1991). One incident of abuse was reported by 33 people (20.4%), 33 people also indicated that they had been abused in a range of between two to ten times; and almost half of the reports (80 people, 49.6%) indicated ten plus incidents of sexual abuse. The remaining 16 reports detailed the abuse as repeated (9.7%). The authors revealed that the abuse caused not only physical harm in

46.7% of cases, but also had emotional, social and behavioural consequences for the victims (Sobsey & Doe, 1991).

Table 1: Types of Abuse Experienced by Disabled People	
Type of Abuse	**Examples of abuse**
Psychological/Verbal/Emotional abuse	Verbal aggression; threats; threats to children and pets; being ignored; breaches of privacy (Cockram, 2003; Young et al., 1997) Isolation; threats to take children away; turning children against her, intrusion, domination, humiliation (Hague et al., 2008) Not following care instructions (Otkay & Tompkins, 2004)
Physical abuse	Being pushed down stairs; special equipment being thrown across room or cut up; petrol bombs or bricks thrown through window; stabbing; strangulation: being dragged by hair (Hague et al., 2008) Hitting, slapping, punching, rough handling (Cockram, 2003; Otkay & Tompkins; 2004)
Financial abuse	Theft (Hague et al., 2008; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006) Denial of funds, taking control of finances, not paying for required prescriptions (Hague et al., 2008) Extortion (Otkay & Tompkins, 2004) Personal assistance providers showing up late, but receiving full pay (Saxton et al., 2001)
Neglect	Failure to check skin properly which results in bedsores; urinary infections due to not checking leg bag or not providing enough hydration, rushing checks (Otkay & Tompkins; 2004) Turning up to work late (Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006) Arriving to work under the influence of drugs or alcohol (Saxton et al., 2001; Saxton et al., 2006) Not providing specialised equipment or medication (Cockram, 2003)
Poor care	Poor care technique resulting in bedsores, urinary infections, bruises, falls. Infections from poor sterilisation of equipment and burns from being put into bath water that was too hot (Otkay & Tompkins, 2004)
Sexual abuse	Rape; sexual assault; forced sex (Cockram, 2003; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006; Sobsey & Doe, 1991; Young et al., 1997) Care that depended on sex (Hague et al., 2008) Inappropriate touching; coerced oral sex (Otkay & Tompkins, 2004; Sobsey & Doe, 1991; Young et al., 1997) Duped into sex by partners (Kvam & Braathen, 2006)

2.5 Key factors in the manifestation and maintenance of abuse

A number of key factors have been identified as contributing to the manifestation and maintenance of abuse. Oktay and Tompkin (2004) indicated that length of service was a factor in abuse by personal assistance providers and maltreatment was more common when the provider had only been caring for the disabled person for a short period of time. Workload was also a factor and personal assistance providers who worked the most hours were more likely to be abusive (Oktay & Tompkins, 2004).

The participants of Saxton et al. (2001) highlighted the socialisation of disabled women as a factor that was supportive in sustaining abuse. Disabled women are not socialised to take charge in relationships. The disabled person is the employer and according to Saxton et al. (2001) the person who should be in control of the relationship. However, due to socialisation, disabled women are often unsure about how to handle and control the employer-employee situation (Saxton et al., 2001). According to Saxton et al. (2001), the imbalance of power was particularly great in situations where the personal assistance provider was a relative or partner. One woman cynically described problems in trying to take control of her situation:

> *"Ok, this is it, I'm going to do whatever I can to change this marriage. And by the way, can you bring my scooter to me so I can leave you?" (Saxton et al., 2001, p. 402).*

The authors noted that disabled women's dependence on a spouse as a personal assistance provider can bolster the cycle of domestic abuse and impede leaving an abusive situation (Saxton et al., 2001; Hague et al., 2008). The reliance on a partner for not only financial/emotional needs and mobility can also greatly influence the power balance within a relationship (Saxton et al., 2001).

The requirement of greater levels of care was also a factor that increased the likelihood of abuse. Participants requiring higher care levels disclosed abuse by more than one perpetrator or intimate partner (Young et al., 1997). Young et al. (1997) found that their participants' disabilities meant that they could not escape abusive situations because of a lack of adaptive equipment. The authors also noted that the use of personal assistance providers often meant that they were more vulnerable to abuse Young et al., 1997). Martin et al., (2006) also reported that participants with cognitive impairments were more likely to suffer from sexual assault. Perhaps another factor in the manifestation of abuse is the type of disability. It may also play a part in helping maintain the abuse, as a participant in Cockram (2003) explained how her disability meant that she often had trouble remembering facts and this was used against her by her partner to stop her voicing the abuse (Cockram, 2003).

Brownridge (2006) also considered other factors (education, age, employment and ethnicity) that may increase the chances of disabled women experiencing violence from their partner. The only statistically significant finding was the relationship between age and disability, with older disabled women reporting higher levels of violence than younger disabled women (Brownridge, 2006). Of note, although not significant partners of disabled women were 2.5 times more likely to behave in a patriarchal and dominating manner than partners of non-disabled women. They were also 1.5 times more likely to engage in "sexually proprietary behaviors" (Brownridge, 2006, p. 818). These behaviours, according to Brownridge (2006), mean that disabled women are at a greater risk of violence than their non-disabled counterparts.

2.6 Barriers and facilitators to disclosing abuse

Research participants, across the studies, revealed a number of barriers to disclosing abuse. Hague et al. (2008) found that an individual's disability not only exacerbated the abuse, but also made leaving the situation harder. Further, seeking help was made more difficult if a

women was not able to access funding due to immigration status or if English was not a first language (Hague et al., 2008).

The most commonly reported barriers and facilitators are outlined in Tables 2 and 3 respectively. It should be noted, that barriers were more commonly discussed in studies than facilitators.

Table 2: Barriers to Voicing of Abuse
▪ Discriminatory societal attitudes towards disabled people (Cockram, 2003; Hague et al., 2008; Kvam & Braathen, 2006; Saxton et al., 2001; Saxton et al., 2006)
▪ Lack of accessible services and accommodation (Cockram, 2003; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006)
▪ Fear of losing personal assistance provider (Curry et al, 2011; Hague et al., 2008; Saxton et al., 2001)
▪ Fear of institutionalisation (Cockram, 2003; Hague et al., 2008; Saxton et al., 2001)
▪ Fear of losing children due to lack of personal assistance provider (Curry et al., 2011; Hague et al., 2008; Saxton et al., 2001)
▪ Abuse of a disabled person will not be taken seriously/believed (Cockram, 2003; Curry et al., 2011; Hague et al., 2001; Saxton et al., 2001; Saxton et al., 2006)
▪ Abuse of women in a lesbian relationship would not be believed due to the fact that women are not viewed as abusive by society (Hague et al., 2008)
▪ Police lack of knowledge, understanding and training (Cockram. 2003; Hague et al., 2001; Saxton et al., 2001)
▪ Domestic services lack of knowledge and training (Cockram, 2003; Hague et al., 2008)
▪ Lack of awareness that the experience was abusive (Curry et al., 2011; Hague et al, 2008; Saxton et al., 2001)
▪ Blaming yourself for the abuse (Cockram, 2003; Hague et al., 2008; Kvam & Braathe, 2006; Saxton et al., 2001; Saxton et al., 2006)
▪ Embarrassent /shame (Curry et al, 2011 ; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006)
▪ Past negative experiences when reporting abuse (Cockram, 2003; Curry et al., 2011; Hague et al., 2008)
▪ The fact that professionals (medical/agencies) did not ask about the possibility of abuse (Hague et al., 2008)
▪ Fear of being alone/not finding another partner (Cockram, 2003; Hague et al., 2008)
▪ Societal attitudes towards the noble and self sacrificing personal assistance provider, who could not possibly be abusive (Hague et al., 2008)
▪ Lack of attention given to the issue of abuse in the disabled community (Saxton et al., 2006)
▪ The systematic barrier of the power imbalance between disabled services agencies and disabled people which does not support the disclosure of abuse (Saxton et al., 2006)
▪ Post-separation violence – harassment of disabled people and their family members (Hague et al., 2008)

The 276 female victims of violence in Curry et al., (2011) were asked to rate seven facilitator items and nine barrier items on a Likert scale, with 1 indicating strongly agree to 5 which represented strongly disagree (Curry et al., 2011). In addition to the barriers from Curry et al., (2011) listed in Table 2, 96 women were also afraid of what might happen if they reported

the abuse to the police, 67 women feared death or injury and almost one in five women (51) reported a belief that nothing could be done to change the situation (Curry et al., 2011). Curry et al. (2011) also reported that participants who had been subjected to higher incidences of abuse in the past year and those with the most dangerous abusers were more likely to agree with the barriers. However, these women were no less likely to report abuse (Curry et al., 2011). Another finding highlighted by the authors is the fact that women who identified as cognitively disabled disclosed more barriers and less facilitators, which indicates that those working within the disability field need to ensure that cognitively disabled women are offered a secure environment in which they can comfortably disclose abuse (Curry et al., 2011).

Curry et al. (2011) identified that the most commonly agreed facilitator item was "My loved ones (e.g. children and pets) would be protected if I report abuse" with 229 (83%) of the women strongly agreeing or agreeing with it. Two hundred and twenty-five of the women (82%) also strongly agreed/agreed that they would receive the emotional support needed if they reported the abuse, so this was a major facilitator as well. Other high rating facilitators included the knowledge that they would have accessible and necessary services (e.g. transportation, shelter and support) and 222 women strongly agreed/agreed with this. A large majority (221 women) also indicated that a facilitator was the knowledge that they would be respected and believed if they disclosed the abuse and 219 would be confident disclosing abuse if they knew their privacy would be respected. Another facilitator was the fact that women would be safer if they reported the abuse (215 women), with fewer women (141) indicating that the fact that their needs and wishes would be respected was a facilitator.

In exploring facilitators to leaving an abusive situation, Hague et al. (2008) questioned participants about what factors aided their escape. Factors that helped in the decision to leave included an intensification of abuse, assistance from a support agency, fear for their children's safety and simply just gaining the courage to leave. The authors explained how it often took the women many years to leave an abusive relationship (Hague et al., 2008). All participants reported having used various strategies to cope with the abuse. Most commonly reported were attempts to alter their own and the abuser's behaviour; becoming submissive and completely withdrawing from society (Hague et al., 2008). Leaving the abusive relationship was the only way to escape violence for the majority of women in Cockram's (2003) study. The participants disclosed that escalating violence and fear for their and their children's safety or a boost in confidence motivated them to leave the relationship (Cockram, 2003).

Table 3: Facilitators to Voicing of Abuse
▪ Reporting the abuse would result in protection for their children/pets/other loved ones (Curry et al., 2011)
▪ Assistance from a support agency (Hague et al., 2008)
▪ Fear for their children's lives (Cockram, 2003; Hague et al., 2008)
▪ Gaining the courage to leave (Cockram, 2003; Hague et al., 2008)
▪ Escalation in abuse (Cockram, 2003; Curry et al., 2011; Hague et al., 2008)
▪ The knowledge that they would have accessible and required services if they reported abuse (Curry et al., 2011)
▪ The knowledge that they would received emotional support (Curry et al., 2011)
▪ Knowledge that they would be respected and believed (Curry et al., 2011)
▪ The knowledge that they their privacy would be respected (Curry et al., 2011)
▪ Disclosing abuse would mean that they were safe (Curry et al., 2011)

2.7 Recommendations for providing improved services to abused disable people

Hague et al. (2008) asked participants to provide recommendations for good practice for service providers, the statutory sector and strategic development.

2.7.1 Service provider recommendations

According to the participants, domestic violence agencies need to ensure that their refuges are accessible, that their services are transferable, in the event that a victim needs to move areas to escape violence, and that there are sufficient levels of support for disabled women. Participants also stressed that every domestic violence organisation needs a dedicated disability worker and every disability organisation needs a domestic violence worker. Not only did agencies need to take into account the physical needs of disabled women, but also the multiple and complex needs that are associated with different impairments. Not only was access to buildings, via ramps, necessary but other small adaptations such as accessible information technology, resources in large print for blind people and flashing alarms for deaf people. Participants urged domestic violence agencies to connect with abused disabled women in the community to raise awareness of domestic violence. The need for agencies to become more aware of the possibility of personal assistance provider violence was voiced and the participants also drew attention to the need for the collection of data on disabled women with whom the agencies work. Further, any new strategies or training schemes require disabled women's representation in all stages and disabled women need to be more involved at a managerial level across domestic violence agencies (Hague et al., 2008).

2.7.2 Statutory recommendations

Recommendations for the statutory sector include the 'mainstreaming' of domestic abuse of disabled women, not simply a separate aside within policy, but an integral part of policy. Further, service provision and guidance needs to empower disabled women and give disabled women as much control as possible. Other suggestions included the need for training of staff in the statutory sector, the creation of partnerships and networks between agencies working with abused disabled women and the establishment and advertisement of facilities that can house abused disabled women. The participants also argued that the criteria to gain access to services needs to be inclusive of abused disabled women (Hague et al., 2008). The statutory sector also needs to ensure that ensure that disabled women play a central part in any decisions or changes.

2.7.3 Strategic development recommendations

Strategic development recommendations included, amongst others, domestic violence frameworks that cater to disabled women's experience of abuse and these frameworks need to be included in all relevant national and local performance indicators for agencies. Government reports on domestic violence need to specifically include disabled women and domestic violence against disabled women need to be recorded at national and local levels (Hague et al., 2008).

Saxton et al. (2001) recommended a number of strategies to deal with personal assistance provider abuse. Their participants suggested that personal assistance employers should be educated in their legal rights and obligations, that there should be an increased awareness of disabled women's rights to access women's shelters and domestic violence services; they also voiced the need for support groups for disabled women who had experienced abuse. The women also proposed that disabled women receive training and support in their recruitment and vetting of potential personal assistance providers and also that they need to more aware of their responsibilities as employers. The women also expressed the need for better police training, to ensure that officers can appropriately deal with issues associated

with the abuse of disabled women. The male participants of Saxton et al. (2006) also noted that there needed to be raised awareness surrounding the abuse of disabled men to help them cope with the violence in their lives.

The Victorian Women with Disabilities Network Advocacy Information Service produced recommendations to help improve family violence services to disabled women (Healey et al., 2008).[6] Key recommendations included the need for a human rights approach as part of a three-way strategy in which issues faced by disabled women are incorporated into all areas of domestic violence services. The establishment of strategies that would serve as 'good practice' and the expansion of specialist disability and domestic violence bodies were also recommended (Healey et al., 2008). Another key recommendation was the need for disabled women to be fully involved in the decision-making process and represented in key local and national forums. Accommodation (including emergency accommodation) needs to be accessible and long-term accommodation affordable to disabled women. Services also need to provide intensive case management when working with disabled women (Healey et al., 2008). Other key recommendations included the need for data collection, cross-sector collaboration and capacity building, the availability of accessible information and communication. It was recommended that family violence sector standards, codes and guidelines include disabled women at all levels and ensure they are accessible to disabled women. Further disability training for sector staff, more monitoring, research and evaluation to bolster knowledge surrounding violence experienced by disabled women and changes on a national level were recommended, with this including better resourcing, monitoring programmes, research and an involvement of disabled women in national-level strategy and decision-making (Healy et al., 2008).

2.8 Similarities and differences across the studies

The studies discussed above share many similarities. All of the studies revealed that disabled people are subjected to a range of abusive situations, many of which are also experienced by non-disabled people. However, disabled people appeared to be at risk of suffering from abuse that is directed at their disability or abuse that utilised their impairment in a way that makes the violence unique to the disabled population (Cockram, 2003; Hague et al., 2008; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006; Young et al., 1997). In regards to the types of violence under the review, three studies chose to look specifically at domestic violence (Brownridge, 2006; Cockram, 2003; Hague et al., 2008) while Sobsey and Doe (1991) examined sexual abuse only.

In regards to the characteristics of the disabled populations, the majority of studies chose to look solely at abuse suffered by disabled women (Brownridge, 2006; Cockram, 2003; Curry et al., 2011; Hague et al., 2008; Kvam & Braathen, 2006; Saxton et al., 2001; Young et al., 2007), while some chose samples of mixed gender (Otkay & Tompkins, 2004; OPA, 2010) and Saxton et al. (2006) had only male participants. Some studies also chose to look at disabled people with specific impairments, such as OPA (2010) who focussed on those individuals with cognitive disabilities, Young et al. (1997) who looked at women with physical disabilities and Hague et al. (2008) who investigated women with physical and sensory disabilities. The other studies did not stipulate a specific population of disabled people and included a diverse range of disabilities (Brownridge, 2006; Cockram, 2003; Curry et al., 2011; Kvam & Braathen, 2006; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006; Sobsey & Doe, 1991). The samples in the majority of studies were not ethnically diverse, despite the specific efforts of such studies as Hague et al. (2008) to be so. The majority of the participants in many studies identified as white or European (Curry et al., 2011; Hague et al., 2008; Saxton et al., 2006; Young et al., 1997), however, Cockram (2003) and Saxton et

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[6] Recommendations arose out of consultations with representatives from government agencies, universities, family violence organisations and disability organisations.

al. (2001) had more ethnically diverse samples. Kvam and Braathen (2006), Sobsey and Doe (1991) and Otkay and Tompkins (2004) did not report on the ethnicity of their samples. In regards to age, with the exception of OPA (2010) and Sobsey and Doe (1991) who included cases of people under the age of 18, the other studies utilised an adult population, covering a range of ages (Brownridge, 2006; Cockram, 2003; Curry et al., 2011; Hague et al., 2008; Kvam & Braathen, 2006; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006).

In examining who was responsible for the abuse suffered by disabled people (i.e. whether the abuser was a partner, personal assistance provider or both), men were overwhelmingly more likely to be the abuser (Brownridge, 2006; Cockram, 2003; Curry et al., 2011; Hague et al., 2008; Kvam and Braathen, 2006; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006; Sobsey & Doe, 1991). In the majority of the studies intimate partners and family members were the perpetrators of violence (Cockram, 2003; Hague et al., 2008; OPA, 2013; Sobsey & Doe, 1991; Young et al., 1997). Sobsey and Doe (1991) also reported that neighbours/friends, other service providers and strangers could be responsible for sexual abuse of disabled people. Abuse by personal assistance providers was also highlighted by Hague et al. (2008), Otkay and Tompkins (2004), Saxton et al. (2001) and Saxton et al. (2006). The OPA (2010) case study review also reported abuse by partner's parents.

The barriers and facilitators that were discussed by participants were very similar across the studies. Societal attitudes towards disabled people were a common barrier highlighted by participants (Cockram, 2003; Hague et al., 2008; Kvam & Braathen, 2006; Saxton et al., 2001; Saxton et al., 2006), as well as lack of accessible services and accommodation (Cockram, 2003; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006). The notion that abuse of a disabled person would not be taken seriously and/or believed was also a barrier (Cockram, 2003; Curry et al., 2011; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006). The men in Saxton et al. (2006) offered some additional barriers specific to disabled men and highlighted the fact that societal attitudes towards disability was not the only societal barrier that they had to overcome. In addition to this was a lack of acknowledgement in general surrounding the fact that men can suffer abuse (Saxton et al., 2006). Men were also more likely to assume that there was no help available; simply putting up with the abuse and more men blamed themselves for the situation they found themselves in than women (Saxton et al., 2006). Men were also more likely to view systemic barriers as abusive in themselves. Overall, Saxton et al. (2006) surmised that disabled men and women have very similar experiences of abuse; however, men may find it more difficult to voice this abuse due to the machismo derived societal expectations and a lack of awareness surrounding men as victims of violence.

2.9 Summary

The abuse of disabled people has received little attention from researchers, although this picture is slowly improving. The reviews findings indicate that disabled people experience not only common forms of abuse but are also exposed to disability specific abuse and also experience abuse for longer periods of time than non-disabled people (Cockram, 2003; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006).

The most important findings from the international literature indicate that:

▪ compared to non-disabled women, disabled women are more likely to be subjected to physical and sexual abuse, have experienced greater levels of violence and suffered abuse for a longer period of time (Brownridge, 2006; Cockram, 2003; Hague et al., 2008; Sobsey & Doe, 1991; Young et al., 1997)

▪ as well as being exposed to commonly recognised forms of violence, disabled women are also vulnerable to disability-specific forms of abuse, such as neglect by personal

assistance providers and abuse of medications (Hague et al., 2008; Otkay & Tompkins, 2004; Saxton et al., 2001; Saxton et al., 2006)

- there are inadequate service provisions available to disabled women who experience abuse (Hague et al., 2008; Healey et al., 2008)

- societal attitudes towards disabled people and power imbalances in relationships with partners, personal assistance providers and agencies have been identified as barriers that help maintain abuse (Cockram, 2003; Hague et al, 2008; Saxton et al., 2001; Saxton et al., 2006).

Many gaps in disability-related knowledge exist. The bulk of the literature that investigated abuse and disability focussed on disabled women (Brownridge, 2006; Cockram, 2003; Curry et al., 2011, Hague et al., 2008; Kvam & Braathen, 2006; Saxton et al., 2001; Young et al., 2007). The study on abuse by personal assistance providers conducted by Saxton et al., (2006) used an exclusively male sample, which showed that disabled men's experience of personal assistance abuse was not wholly different to women's, however, to provide a full picture of the experience of abuse, more studies need to try to incorporate a larger proportion of men into their sample. A lack of male research participants could be because of the domestic violence focus in past research or perhaps the fact that it may be more difficult to recruit disabled males.

There is also a lack of knowledge about disabled non-white populations. The majority of studies have included samples that mostly comprised white or European participants. As discussed, the United Kingdom study by Hague et al. (2008) endeavoured to include black, minority ethic and refugee communities in their study, but only a third of their sample identified as such, while Cockram's (2003) Australian study and a study in Texas (Nosek et al., 2006) did include ethnically diverse samples. Despite this, much more research needs to be done to investigate the abuse of disabled people from ethnic minorities and any specific barriers and facilitators to voicing abuse. Studies have also failed to include the experiences of disabled lesbian woman and gay men: we have no knowledge of their experiences of violence and their access to services, an area that could benefit from greater focus.

Whether or not an individual's type of disability increases the likelihood of an individual being abused is an unknown. Martin et al. (2006) did, however, note that their cognitively disabled participants reported more sexual abuse. Curry et al. (2011) also reported that the participants in their study who indicated a cognitive impairment also identified more barriers than facilitators in voicing their abuse. In a study that did not specifically look at abuse, but changes in aggression following a traumatic brain injury (TBI), Kim (2002) reported that a TBI can result in cognitive difficulties in understanding or remembering a dangerous situation that could result in physical or sexual violence. Kim (2002) also noted that those who had suffered TBI can at times have difficulties keeping their anger under control, which may result in others using physical means or inappropriate medication to deal with them (Kim, 2002). It could be that individuals with certain types of impairments are at greater risk than others, but this cannot be confirmed due to lack of research in this area, which is another area that could benefit from more research.

Disabled people who report abuse have expressed that there are many barriers to them accessing services that can help them escape abuse, with a lack of accessibility, training and awareness of services available (Hague et al. 2008). Large gaps in knowledge still exist in how both family violence organisations, disability services and other agencies/professionals who come into contact with disabled people can improve the way they interact with the disabled community to increase awareness and help identify at risk disabled individuals.

3 APPROACH

The study used a combination of case study and participatory research methodologies. Case study methodology enables an in-depth exploration of disability-related abuse, from multiple perspectives, within designated geographic areas. Participatory research was employed because it is underscored by stakeholder:

- design of the research process

- review and validation of the emerging research findings

- ownership of the results (Cornwall and Jewkes, 1995).

Participatory methodology was reflected in an *initial community stakeholder workshop*. The workshop aimed to clarify the research objectives and engage stakeholder agreement to use snowballing methods to recruit potential participants. The majority of participants from the initial workshop, alongside a selection of interviewees who indicated an interest in the research findings, participated in a *key findings workshop*. The workshop sought clarification and endorsement from participants about the key research findings. Finally, these findings were tested with a variety of national stakeholders (i.e. representing disabled, police and legal perspectives) from different locations around New Zealand.

Because the abuse of disabled people is commonly hidden, the study drew on qualitative research methods only; namely, individual and small group semi-structured interviews and focus groups. Semi-structured interviews and focus groups explored:

- the nature of abuse experienced by disabled people who require high levels of support by family members and other parties involved in their day-to-day care

- individual, societal and structural barriers that assist in the continuation of abuse

- barriers faced by disabled people in voicing abuse

- the systemic structures that maintain the abuse of disabled people and inform how Tairawhiti Community Voice can advocate for the safety and well-being of these people

- suggested interventions to identify and prevent abuse.

3.1 Definitions

A great deal of debate surrounds definitions of disability. However, disability-related definitions fall into two primary definitional categories.[7] These are as follows:

- the medical model of disability wholly places the emphasis on medical dysfunction and the individual's pathology (Hague, Thiara, Magowan & Mullender, 2008). It has been argued that this model propagates the idea that it is disabled people who need to adjust

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[7] A third model, the biopsychosocial model of disability has been recently described. This model is early in its development and has been proposed to complement, and not extend or improve on, the social model of disability. The biopyschosocial model was developed from the World Health Organisation's 2001 International Classification of Functioning, Disability and Health and views disability "as indicative of human variation". (Healey et al. 2008, p. 31). In defining disability, this model takes into account factors such as ageing populations the high numbers of disabled individuals amongst the world's poor, lack of access to precautionary measures and treatments and the development of new disabilities which are related to socioeconomic and other lifestyle factors (Healey et al., 2008).

to fit into society and it disempowers disabled people, as the control lies in the hands of the medical profession and not with the disabled (Shakespeare, 1998)

- the social model of disability forwards that it is not the medical condition itself which is wholly disabling, but societal conventions, attitudes and behaviours (Healey, Howe, Humphreys, Jennings and Julian, 2008). Disability is the result of not only an individual impairment, but also the way in which society and the environment interact with disabled people (Shakespeare, Gillespie-Sells & Davies, 1998). The social model of disability emerged from the disability people's movement of the 1960's and 1970's as a challenge to the dominant medical model. This model acknowledges the social context and highlights the fact that societal attitudes are equally as disabling as medical impairments (Barnes, 1998).

The current research grounds itself within the social model of disability because this model takes into account both medical impairment and society's disabling attitudes towards disabled people. The terms used in this study are in accordance with those used and promoted by disabled activists in New Zealand such as "disabled persons", "people with disabilities" and "people with impairments" (Hague et al., 2008).

3.2 Participants

Forty-four individuals participated in a combination of individual, small group and focus group interviews. The majority of participants (n=35) were recruited from in or around Gisborne/Tairawhiti. The remaining nine participants were recruited from other New Zealand locations and on the basis of their knowledge of disability issues from a national, rather than a local, perspective. The combination of local and national perspectives ensured people's rich lived experiences were gathered as well as perspectives on a variety of structural barriers and facilitators.

Of the 35 Gisborne/Tairawhiti participants, 10 were disabled and a further 10 were family members of a disabled person. With half of the interviews, a support person or advocate nominated by the participant was present. Interviews lasted between 45 and 90 minutes and were audio recorded with participants consent. To safeguard participant anonymity, type of disability, ethnicity, gender and age are not reported.

The remaining 11 Gisborne/Tairawhiti participants were selected because of their professional responsibility, their experience with the disability sector and/or a history of witnessing or working alongside disabled people who had been abused. The majority of these professionally aligned participants participated in a combination of individual, small group and focus group interviews. Individual and small group interviews lasted up to two hours. Focus groups ranged between one and three hours.

Table 4: Participant Characteristics (n = 44)		
Locations	**Participants**	**n**
Gisborne/Tairawhiti	Disabled individuals	10
	Family members	10
	Residential managers (past and present) and care workers	4
	Community stakeholders (including social workers, Work and Income, nurses, allied health professionals, social service agencies and disability organisations, local government representatives, NZ Police and community advocates)	11
Nationally representatives/ stakeholders	NZ Police	3
	Disability advocate	4
	Legal representative	1
	Social work representative	1
Total		**44**

3.3 Participant recruitment

Potential participants, disabled people and family/whānau members of someone who is disabled, were initially approached by a Tairawhiti Community Voice social service, advocate or a member of the initial stakeholder workshop and asked if they would like to participate in the research. Potential participants were provided with an information sheet and asked to contact the principal researcher should they have questions about the research and/or if they would like to signal their desire to participate. In addition, the local newspaper reported on the study. Three participants made contact with the principal researcher through this medium.

Professionally allied Gisborne/Tairawhiti participants were recruited through a snowballing methodology. Similarly, participants with a nationwide structural perspective were also recruited through snowballing.

3.4 Data Analysis

Interview data were analysed to identify patterns and themes relating to the research objectives and wider contextual issues. A process of constant comparative analysis was used. Throughout the process, emerging findings were consistently tested to determine the extent to which they are common across participants. The constant comparative method meant comparing:

- different individual and stakeholder perspectives
- data from interviews with supporting documentation

- analysis from interviews and observations with best practice literature
- data across programmes and services.

In practice, this meant that information was defined and categorised through a continual review of interviews, fieldwork notes and regular discussions/fieldwork reviews with the research team. As a result, emerging patterns were continually tested through the interview and observation process as well as an exploration of new questions that arose as an outcome of preceding interviews. This process of constant comparative analysis provided an opportunity to explore, in greater depth, reasons underlying emerging patterns.

3.5 Ethical considerations

An application for ethical approval for the study was submitted to Auckland University of Technology Human Ethics Committee detailing procedures for fully informing those being asked to take part in interviews about the research, obtaining informed consent, providing feedback at the conclusion of the study and procedures for storing and maintaining the confidentiality of information. Ethics approval was granted in July 2012 (*AUTEC Reference number 12/135*).

The provisions of the Privacy Act 1993 with respect to confidentiality and methods of obtaining, storing and destroying information were adhered to in this study.

3.6 Limitations

The study's research findings are based on the perspectives and experiences of 44 participants only. While best efforts were made to interview a diverse range of participants the research is limited to the experiences of the individuals who took part in this study.

4 CONTEXTUALISING ABUSE

One challenge associated with accurately identifying and describing all forms of abuse reported by participants is that abuse can become normalised as an outcome of prolonged exposure. In this sense, the very nature of abuse can result in its desensitisation. Such a reaction was common in many of the interviews carried out with abused individuals. Typically, only extreme examples of abuse were initially communicated. For example, it was common for participants to relate accounts of severe beatings or situations where the individual had been in fear of their life. As such, less extreme cases, such as financial or verbal abuse, were generally not discussed unless the topic was raised by the interviewer. The following excerpt, from my research diary, is illustrative.

> *I had spent an hour interviewing X and it was only at the close of the interview I mentioned, in passing, that it was great that he had not encountered financial abuse as it had not arisen during the interview. In reply, X shook his head and stated, "I have had heaps of financial abuse. I reported it [to managers at the homecare agency] but nothing happened. I used to leave my wallet in the drawer thinking that they [care worker] won't go in there. I trusted their professionalism. But I was naïve. People should not take it let alone go into my drawers. I think they think that disabled people don't know. That we are idiots" (Roguski, Diary extract, 10 August 2012).*

A similar normalisation process was evident in some family/whānau members who participated in interviews. Similar to disabled participants, it was common for abuse-focused discussion to centre on extreme examples of abuse as some family/whānau representatives engaged in a process that negated the abusive nature of various behaviours. Chapter 5 discusses this form of abuse in relation to silencing. Finally, a process of normalisation was identified as more commonly occurring amongst those who had experienced a disability from birth or early childhood. Participants who developed a disability in adulthood appeared to be better positioned to identify acts as abusive and be more willing or able to want to make a complaint. Such willingness was attributed to those with an adult-onset disability; having experienced the inherent rights afforded the able-bodied.

4.1 Types of abuse

Participants' discussed having experienced abuse in residential services, institutions, home-based environments and in the community.

▪ **Residential services –** abuse within residential settings occurred through either a staff member or client associated with the organisation. Residential services include specialised residences, usually designed for up to six residents, with 24-hour care worker supervision. The types of services include nursing homes, specialist residences for people who have experienced a brain injury (including stroke), mental health, intellectual disabilities and homes for people in need of intellectual care.

▪ **Institutional settings –** institutional abuse occurred through staff associated with an organisation. Most commonly, participants referred to hospitals and schools as common sites of institutional abuse.

▪ **Home-based environments –** abuse within the home occurred through home-based care workers, landlords and the individual's partner or family/whānau. Managers of homecare service organisations were also discussed as facilitating abuse by failing to appropriately action reports of abuse.

▪ **Community settings –** abuse in community settings was referred to as either occurring opportunistically by someone unknown to the victim or, for example, in the case of financial abuse, through local businesses and neighbours.

Multiple forms of abuse were identified. Further, it was common for participants to report abusive histories that involved having experienced abuse in multiple settings (for instance community, home and residential) and from multiple perpetrators.

Similar to previously identified forms of abuse, participants described experiencing psychological/emotional, financial, physical and sexual abuse (Otkay and Tompkins, 2004; Hague et al., 2008; Saxton et al., 2001; Saxton et al., 2006). Relatively new to literature are forms of abuse, termed here, as silencing, locked-in and dehumanising processes and treatment.

4.1.1 Financial abuse

Financial abuse occurred across residential, home and community settings, however, those commonly reported as financially exploiting disabled people were residential and home-based care workers, landlords, family/whānau members and partners.

Those in receipt of home-based care services and those residing in a residential service provided multiple accounts of money and goods (such as food and clothes) either being stolen or extorted.

> *I had a client ask me to talk to a couple of staff members who would borrow money off her and pay it back in drips and drabs, if at all. Nine times out of ten they wouldn't pay it back. The thing is, the client felt powerless. She was vulnerable to the staffs' bullying (Manager, Residential Service)*

> *I have had lots of money stolen by care workers. Personal items have gone missing. Food and clothes. I think they think they can take food from me because I find it hard to get down to the kitchen (Disabled participant)*

> *What is always interesting is where clients' money goes. Clients always had some form of income yet they never seemed to have enough money. In fact they had very little money. So where does the money go? (Residential care worker)*

> *I have had to dismiss a number of staff because of financial abuse. There have been occasions where staff members have taken our clients' debit cards and ran up charges (Manager, Residential Service)*

> *I had another staff member who would take the client shopping and ask the client to buy her a packet of cigarettes, saying that "She [the care worker] had been kind to her [the client] that week and she needed a reward". So the client would buy her a packet knowing that if she didn't she wouldn't get a ride home (Manager, Residential Service)*

Less common were accounts of opportunistic extortion or theft whereby disabled people were intimidated and forced to give money. Two examples were given of neighbours taking goods and money from a disabled person and there were a number of accounts of local high school students threatening people in wheel chairs and/or mobility scooters for money. The threat being:

> *If you do not give us money we will throw you out of your chair (Disabled participant)*

Finally, a number of local businesses were reported to exploit those with disability. This was especially cited in relation to landlords who would exploit those with brain injuries and audiology services where the hard of hearing, especially the elderly, reported having been encouraged to purchase expensive hearing aids rather than cheaper versions best suited to the individual's needs.

Rather than financial gain as a primary motivation for financially abusing the disabled, a number of participants traced financial abuse to malicious intent; that disabled people, because of their inherent vulnerabilities, are easily targeted.

4.1.2 Physical abuse

Physical abuse was reported as occurring in all but institutional settings. Those commonly reported as physically abusing disabled people were residential and home-based care workers, other disabled individuals residing in residential services, family/whānau members and partners, and youth within community settings. Physical abuse included being kicked, stabbed, slapped, punched and being thrown out of wheel chairs and mobility scooters.

A number of antecedents to the physical abuse were identified. In one case, a partner's on-going physical abuse of her husband was traced to her frustration and anger over her husband having had an affair. As such, the physical abuse was regarded as a deserved punishment. Care workers were described as having physically assaulted disabled participants as a punishment for having made a complaint. In other situations, physical abuse was framed as occurring because care workers and family/whānau members were frustrated with the on-going level of care the disabled person required and, in place of appropriate coping strategies, physically transferred their frustrations onto the disabled individual.

> *In my teens my mother used to beat the hell out of me. I would be black and blue. There was one time when she caught me smoking with a bunch of friends and she beat me terribly. This was the 80s when it was still okay to hit your children. But this was so much more than a hiding. I became quite suicidal as a result. She was my only support person and beating me was the ultimate source of betrayal (Disabled participant)*

Other examples appear purely malicious. In these situations care workers and youth from local high schools were reported as gaining sadistic pleasure from having power over the disabled and delighting in removing the individual's means of mobility.

> *Kids do horrible things to me. If I am on my [mobility] scooter they get smart or they throw things (Disabled participant)*

4.1.3 Emotional and psychological abuse

Emotional and psychological abuse includes a broad range of strategies that demean and intimidate the individual through non-physical means. These included verbal disparagement and inaction, including neglect. Notably, emotional and psychological abuse manifested in two forms:

a)   extreme and overtly intimidating behaviour, and

b)   in the guise of social acceptability.

Multiple extreme and overtly intimidating examples of emotional and psychological abuse were offered. These were generally associated with home and residential environments, although cases of bullying and overt intimidation were reported in a number of workplaces. Perpetrators included residential and home-based care workers, family/whānau members and partners, and employers and work colleagues. Examples included yelling and screaming, forcing individuals to sit in corners, placing food beyond the reach of the disabled individual, threatening cessation of care and leaving the physically disabled in a confined area for prolonged periods of time (up to four hours). Examples of confinement included being left on a toilet, in bed and in a chair where the individual risked falling off. Also common were threats of assault and abled bodied individuals standing over the physically disabled as an act of intimidation. The following example was offered by a participant who described how a care worker would consistently remind them about their need for support. The participant interpreted the constant discussion of their vulnerabilities as a threat, with the insinuation that the removal of support would result in the disabled individual's heightened vulnerability.

I had one care worker who would whisper in my ear, "Do you know how lucky you are to have me". It was a threat (Disabled participant)

A manager who recently took over the running of a residential service provided the following example of extreme manifestations of psychological abuse. The account details the type of abuse that the manager witnessed and then remedied over the first year of management.

When I came here, emotional and psychological abuse was prevalent. It is not nearly as common now and the staff know that I simply won't accept it. The things I encountered were clients being bullied, demeaned, being spoken to in all sorts of ways you wouldn't believe. They would be sworn at and literally made to sit in corners. One day a client came to the door and a staff member said, "What the fuck do you want?" And that was a senior member of staff so junior staff members saw that as accepted practice. The abuse was pervasive. Every single client got it. We had numerous incidents of self-harm, of parts of the building being destroyed, all as an outcome of emotional and psychological abuse. Clients would attack one another, damage windows and put holes in walls. The place was institutionalised. The carers were not carers they were jailers. Clients just sat in corners and no rehab happened. It was bedlam (Manager, Residential Service)

Similar to the physical abuse discussed above, a reoccurring antecedent to emotional and psychological abuse was a family/whānau member or care worker's stress. In this sense the emotional and psychological abuse acted as a coping mechanism whereby frustrations in the perpetrators' lives were transferred to the disabled individual.

One of the main problems with your caregivers is that they take their problems out on you. If they have problems they come here and take it out on me. It makes me feel scared and powerless (Disabled participant)

Participants offered a number of examples of abuse that had sufficient semblance of social acceptability to avoid detection. Common to these incidents was that they occurred in public contexts and workplaces. Perpetrators included staff and employers.

No one minds a little good natured jibbing but people will use a loss of a physical limb to be nasty. They get away with it because they say it's a joke. Tradesmen are the worst (Manager, Disability NGO)

When I developed my disability my employer treated me as a liability. Something unclean. He wanted to get rid of me even though my billable hours were higher than anyone else's. He would do all sorts of things to show me I wasn't welcome. He made me keep a record of my activities on a 15-minute basis. That would be fine but he didn't make anyone else do it (Disabled participant)

Employers never cease to amaze me how cruel they can be. They will do anything to take advantage (Manager, Disability NGO)

My employer wanted me to leave. I was treated like a leper. Obstacles were placed in the way of the wheelchair access bathrooms on my floor so I had to hold on for ages but the problem is that part of my condition is a lack of control of my bladder (Disabled participant)

4.1.4 Sexual abuse

Sexual abuse was reported as occurring in residential and home settings. Perpetrators included family/whānau and partners and, in the case of residential settings, other clients and care workers.

Two forms of sexual abuse were identified. Firstly, a number of participants reported having been sexually abused by family/whānau members. Participants related a sense of extreme violation and a heightened sense of vulnerability. Because of their physical disabilities, they had not been able to avoid the perpetrator and were, thus, unable to escape. As one participant stated, *"I was a sitting duck"*. Importantly, participants cited sexual abuse as the first lesson in being silenced and learning not to complain for fear of retribution and an inability to escape.

Abuse within residential services was also raised. Within this context, care workers and clients were cited as perpetrators. In one residential service, the staff were described as facilitating the abuse as they *"had an open door policy on the girls"*. This meant that clients, who were characterised as having impeded impulse control, were not prevented from entering the women's bedrooms and forcing the women to have sex.

4.1.5 Locked-in abuse

Locked-in abuse encompasses situations in which a disabled individual's mobility and/or ability to communicate are removed. As a consequence, the individual is so restricted that they are isolated and completely reliant on another party. This form of abuse was reported as occurring in home and residential settings. The degree of impact of locked-in abuse was positively correlated to the degree of physical disability and the restrictions placed on the individual.

Multiple examples of locked-in abuse were offered. Examples included having exits from the property blocked or removed (such as wheelchair access or the perpetrator refusing to transport the individual). Consequently, the disabled individual was wholly reliant on the perpetrator to permit mobility. Next, a non-verbal participant with multiple disabilities described a sense of helplessness when his computer was removed and he had no other means of communication. Finally, a physically disabled individual described having had her telephone removed. This meant that she had no means of external communication.

Associated with being locked-in is an acute awareness that the disabled person is completely reliant on a third party and was described as *"completely humiliating and disempowering"*.

4.1.6 Dehumanising processes and treatment

Rather than abuse that directly harms an individual, a series of dehumanising processes and treatment of the disabled people were commonly cited by disabled participants, community advocates and family/whānau members. Dehumanising processes and treatment encompasses situations where the disabled individual is so objectified that their personal choice and voice are invalidated. As such the disabled individual is not afforded the same rights as abled bodied individuals. Inherently the disabled individual is made invisible. While these processes and treatment may, arguably, exist outside a technical definition of abuse, they are included here because of their prevalence and impact. Further, such processes are relevant to a discussion of abuse as they continually position the disabled as second-class citizens. Dehumanising processes and treatment were reported as occurring across all sectors of society and manifested in terms of the removal of an individual's rights, social exclusion and invisibility.

Removal of personal rights

Participants offered many examples of having their rights removed. The removal of personal rights was discussed broadly and included being forced to undergo humiliating procedures whilst in hospital, the removal of the right to engage in consensual sexual activity and the right to have children. In each example, participants attributed perpetrators' behaviour to general disregard of the disabled person's rights and the lack of choice afforded to disabled people.

The following example involves a participant's account of being hospitalised and what she felt was a form of rape when a tampon was forcibly inserted against her will. This account is included here as a form of dehumanising processes and treatment because the participant strongly believed the action of hospital staff reflected their perceptions of her as a disabled individual: objectified to the point that she was not afforded the same rights as an able-bodied individual.

> *In my view I was raped by the hospital system. I started menstruating when I was nine and I happened to be in hospital because my father needed some respite from looking after me. So what happened was that I was almost hogtied on the floor of the hospital. I was screaming. They held me down as a nurse inserted a full-length tampon. I was totally humiliated. They thought it was the best approach but I felt completely exposed and disempowered. Absolutely vulnerable. In hindsight I have no idea why they didn't give me a sanitary pad. Why in god's name force a tampon into me (Disabled participant)*

Next, participants discussed being judged in terms of their sexuality and their right to have sex. In numerous examples, barriers were erected to prevent sexual activity. The assumption underlying these efforts is that disabled people do not deserve or are not entitled to consensual sexual expression.

> *There was an account of Dora and Eric who were residents in a residential facility. Eric was 50 years old and Dora 40. The couple had only recently started a relationship and were looking forward to having dinner together on Friday next but they said that their date might be have to be cancelled as the manager [manager of the residential service] had said that they needed to have a staff member present to chaperon them. Eric and Dora said that this was because the manager did not want them to have sex. So I asked them, "How often do you think the manager has sex a week?" They said that they it was none of their business. And I said, "Exactly, so what makes it the manager's business if you have sex" (Community advocate)*

Another account was described by a staff member who had supported two clients' decision to engage in a consensual sexual relationship.

> *There was this one time when Jason had just gotten back from his girlfriends and there was a little bit of dried sperm on the front of his pants. He was completely reliant on us to undress and wash him and we always did it in pairs. You know, two of us at the same time. Well, on this occasion my colleague was appalled that he had had sex and she refused to change him or help me wash him. She said that it was disgusting and that she wasn't going to be part of it. I never really understood her reaction (Residential care worker)*

Other examples of societal efforts to remove disabled people's rights were raised in regards to childbearing.

> *When I told my family I was pregnant I got full on negativity from my mum, my sisters and cousins. They had big opinions. My mother almost disowned me. She had been told by health professionals that I wouldn't live long so she created a list of things that I wasn't*

allowed to do. Daggers were out. "It could compromise my health". They said that I would die. But the thing is that it was my right. Just being human gives you the right. I got really mind-fucked by them. In the end I became really suicidal. What should have been the happiest time in my life ended up sending me into a tailspin (Disabled participant)

In addition, a number of day-to-day examples were offered whereby the individual's rights were removed. Most common were situations where decisions were made on behalf of the disabled individual.

It will be 10pm at night and I will be watching television in my room and she [the care worker] comes into my room and just turns it off. Like, hey, I am watching the bloody TV. She just says something like, "It is time to go to bed". If I wasn't disabled would I be able to watch the TV. Bloody hell I would. So what right does she have to make decisions for me (Disabled participant)

Caregivers don't listen to what I want. I get upset because people make decisions for me (Disabled participant)

I asked my mother to write a note for me, telling the caregivers what I wanted. She put it on the fridge. "I would like a cup of tea at 10am and another at 3pm. I like my steak cooked medium-rare". They never made me a cup of tea at 10am, they made it when it suited them and they cooked my meat the way they like theirs cooked. I had to eat it. They said, "Who are you to demand something from me" (Disabled participant)

I was living in a residential service. The other clients and I had decorated the house with all our personal belongings. We developed a scheme and went to great efforts to make sure it felt like a home. As Maori, we also decided that we wanted a karakia on the wall. We had photos of people who were dear to us. A new manager came in and ordered that I take all my pictures off of the walls. They made us put away photos of our loved one's who have passed on. In their place the new manager put up her own pictures and knick-knacks. The thing is, it was the residents' home. It's not the manager's home. She doesn't live there. It was our right to have our own possessions there (Disabled participant)

Finally, it was common for disabled people to be punished through the removal of their personal property. What is disturbing about this form of abuse is that the disabled individual has been so objectified that the removal of personal property is not seen as theft by the perpetrator, but was often reframed as social good.

I worked in one place where they would take TVs and radios off residents as a form of punishment. It was awful. The poor residents would get so upset. We are talking about people who are non-verbal who have little in their life and the little they have has been taken away. It was just pure abuse (Community advocate)

Social exclusion

A second aspect of dehumanising processes and treatment is social exclusion. While subtle, the lack of societal inclusion was reported as leaving many disabled people isolated and external to mainstream society. Further, loneliness was common. Typically, participants attempted to understand social exclusion as a result of negative societal attitudes towards disability.

Disabled participants commonly shared long histories of being socially excluded with accounts of people staring or simply ignoring them. This was especially difficult when participants were at school as they often felt as though they were treated as a novelty, for example being in a wheelchair, but not fully included or treated as equal.

> *People are scared of me. But I don't care (Disabled participant)*

> *I experienced a lot of rejection from my peers at school. They kept me at arms length. I have a lot of associates but not one true friend (Disabled participant)*

Social exclusion was also discussed in terms of architecture and access to businesses. The following example is useful in highlighting the often, at best, superficial provision of accessibility. As a consequence, the lack of accessible access severely restricts the disabled.

> *I had a complaint the other day about our local supermarket. They have disability car parks but no one is monitoring them so it is almost impossible for disabled people to find parking. I spoke to the local council and they said that it is private land so they can't ask the parking wardens to patrol the area. Then I spoke to the managers at supermarket and they did not have the resources to monitor it. In the end, it just shows the supermarket's lack of commitment to the needs of disabled people (Community advocate)*

Of note, those who developed a disability later in life were less likely to experience the heightened levels of social exclusion reported by those born with a disability.

Being made invisible

Invisibility is related to social exclusion. Invisibility occurs when the individual is not afforded the right of being acknowledged. This was commonly reported in regards to participants' experiences of voicing complaints, service receipt and not being given the same courtesy as abled bodied individuals.

Multiple disabled participants and their support people described situations where questions and behaviour would be directed to their abled bodied companions rather than themselves.

> *One situation, just recently, my mother took me into a dairy. So we are at the cashier. I am in my wheelchair and my mother is standing behind me. I handed over the money and the checkout girl reached past me and gave the change to my mother. I mean what the fuck? (Disabled participant)*

Next, participants described a number of occasions when they felt their opinion was devalued or ignored.

> *Back in school there were a number of circumstances where I felt unheard. One occasion involved PE [Physical Education]. The PE teacher had an expectation that I could walk around the school field [with crutches]. He said that it would be good for me. It was excruciatingly painful and it was screwing up my hips really fast. I told them I was in pain. He ignored me. As a result it has left my hips completely damaged (Disabled participant)*

> *My baby girl was born premature and we were at the doctors one day and the nurse insisted on giving her a vaccination. I was pleading, please no, she is premature, you shouldn't be giving her the vaccinations yet. I don't want you to do it. She ignored me. I just couldn't believe that she would do that (Disabled participant)*

> *I worked in a supportive service for people with traumatic brain injury. The clients were always put down. The clients weren't listened to. They were given no choices. Rather it was, "Do what we think is best for you" (Residential care worker)*

Experiences of invisibility were strongly voiced in relation to difficulties in making complaints about a service. The majority of disabled people reported either feeling as though their complaints were not taken seriously, or that their complaints were ignored.

I sent and email to the CEO of X [homecare service] and asked if he could look into some issues I was having with my care workers. I told him that I had raised the issue with two of his managers but they hadn't done anything. It has been six months and I still haven't heard back (Disabled participant)

There was this one time when my colleague and I stopped off at a café to get a bite of lunch. So we lined up and my colleague ordered her food. I waited and the girl behind the counter took someone else's order. I waited a bit more and then someone else was served. I thought, "Maybe she can't see me". Like I'm in a wheelchair. So I said, "Excuse me, could I order something" and she bloody well ignored me. Anyway I asked to speak to her manager. I didn't get any traction until I threatened to go to the head office. Only then did I get an apology (Disabled participant)

I stayed at a motel recently and I got really terrible service. I had asked for a wheelchair accessible space, you know a room spacious enough for a wheelchair, wheelchair shower access etc. When I got there it wasn't accessible. There were steps. When I said that I had asked for an accessible room the guy said, "Well I can always carry you". It was late at night and they refused to change my room, they didn't even bring me a chair to sit on in the shower. So I left the next morning. When I got home I rang the owners and complained. Basically they said that I was an angry cripple and there was nothing wrong with the room or the way the reception staff had treated me (Disabled participant)

The dehumanising nature of social disability was commonly referred to in regards to relatively recent policy decisions that prevent consumers in receipt of home-based care from receiving services from a family/whānau member. While this may have been established to prevent familial abuse it was reported as removing the individual's choice and placed the individual at risk of abuse from non-family/whānau caregivers.

I was getting physically abused by my care worker. That is why my mum moved back from Whangarei to come to Gisborne to be my primary caregiver. But my mother had to leave X [homecare service] because they changed the rules and said that they would no longer employ her (Disabled participant)

X [homecare service] wouldn't hire my mother as a caregiver. They said they can't hire a family member as a principal caregiver. The thing is people target people with disabilities for money. With my family it has been proven that they are more trustworthy, reliable and helpful. It is non-family members that have abused me. I just wish I had some choice in the matter (Disabled participant)

5 STRUCTURES MAINTAINING THE STATUS QUO

A number of structural issues were identified as maintaining the status quo; specifically:

- a low level of societal awareness of disability abuse
- a variety of silencing processes
- a lack of appropriate monitoring
- poor management practice of a variety of disability-related residences and services
- inadequate reporting options
- existing legislation, and powers emerging from legislation, are inadequate or unclear. This is especially problematic in that the disabled individual does not receive adequate protection during an investigation of abuse.

These issues are outlined in Figure 5.1 and are discussed throughout the chapter.

Of note, while the various issues are presented and discussed separately, they are generally interrelated and do not occur discretely. They are presented individually for ease and clarity of discussion.

Figure 5.1: Abuse of the Disabled: Structures Maintaining the Status Quo
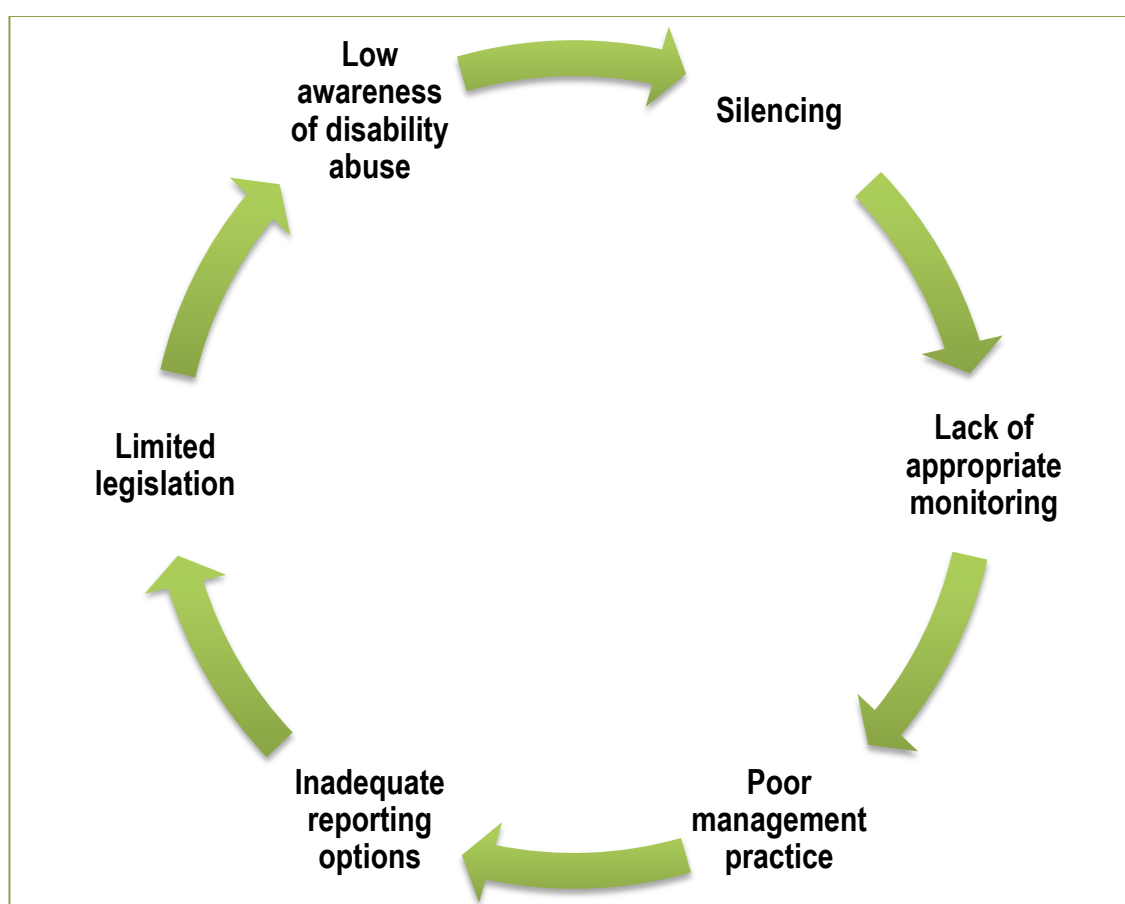
5.1 Low levels of disability-related awareness

Low levels of societal awareness about disability-related issues, specific vulnerabilities and the abuse of the disabled were discussed as a primary barrier to maintaining the status quo. Specifically, low levels of disability awareness were seen as providing a foundation to each of the remaining barriers.

As previously discussed, the social model of disability positions many of the difficulties encountered by disabled people as emerging at a societal level rather than the level of impairment. This was aptly captured by the Union of the Physically Impaired Against Segregation and the Disability Alliance (UPIAS) in the 1976 release of the Fundamental Principles of Disability:

> *. . . In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976, p. 22).*

The definition is useful in that it reflects key elements discussed by many of the current study's participants; namely, it stresses that disabled people are socially oppressed and differentiates between impairments and socially derived oppression. What the definition lacks, however, is an explicit statement of the way in which disabled people's second-class status can be reflected in negative attitudes and behaviours on a day-to-day basis.

> *If you are bent or broken you are not a real person (Disabled participant)*

A number of examples of abusive situations were gathered that provide some indication of normalised discrimination of the disabled. Disability-focused humour, interpreted as socially condoned ridicule of the disabled, was commonly cited. Next, disabled and able-bodied participants related many instances where able-bodied individuals reported heightened levels of visceral discomfort when confronted by the disabled and that this discomfort may act to condone abuse.

> *Even though I have been working in the area of disability for years my partner physically can't cope being around disabled people. For instance, if we were at a party where there were some disabled people I would go up talk just like I would talk to anyone else. My husband would be physically uncomfortable. He would feel it viscerally. He just wouldn't cope (Social worker)*

> *We are seen as scary. So it is like, if you are scared then it is okay to act against the thing that scares you (Disability advocate)*

> *We are dealing with fear and that fear turns into discrimination (Disabled participant)*

Other indications of normalised disability-related abuse include the failure, of a third party, to intervene or report abuse to a statutory authority. The lack of intervention was believed to reflect a combination of deep-seated ignorance of what encapsulates abuse and socially endorsed attitudes and behaviours that perpetuate abuse.

Participants stressed that the socially endorsed alienation of the disabled should be appreciated as a dominant discourse that positions the disabled as undeserving of the rights

afforded able-bodied individuals. As such, cases of abuse are not social aberrations but a reflection of societal norms.

Three types of societally endorsed alienation of disabled people were discussed as casting disabled people as second-class citizens. Most commonly, disabled people's social exclusion was evidenced through inaccessible architectural design and structure. Next, disabled advocates stressed that contemporary attitudes and treatment of the disabled can be located throughout history; the most recent of which was Nazis Germany's experimentation on the disabled prior to World War II.

> *The abuse of the disabled is insidious. Just look at what happened with six million Jews under the Nazis regime. They also experimented and killed three quarters of a million disabled people. Those attitudes are so ingrained. It comes from the deserving and the undeserving belief system. -They see us as broken and so they don't think we deserve the same rights as the able-bodied (Disability advocate)*

Finally, the abuse of disabled people, normalised through a variety of professional justifications (such as needing to restrain, train or correct individuals) was commonly raised.

> *I have had to dismiss staff for roughly treating clients; grabbing them by the arm and pulling them across the floor and leaving bruises. I have had staff physically slap and restrain clients. Before I came here it was accepted because clients were classed as behaviourally challenged and needed to be restrained. There was the belief that clients needed to be dealt with forcibly. We have a no restraint policy now and we just don't have the same anger issues from the clients. If you treat people with respect there is no need for physical restraint (Manager, Residential Service)*

Given the pervasiveness of negative societal attitudes towards the disabled, participants stressed that the use of terms such as the *social model of disability* can fail to portray the lived reality of social exclusion, bias and maltreatment and second class status of the disabled. Consequently, there were demands for a clear re-branding of disability-related abuse to give it equal footing to that of inequitable treatment of other marginalised groups.

> *Society does not understand that the way negative attitudes and behaviour towards the disabled is no different to racism, homophobia and anti-Semitism. These negative attitudes mean that the abuse of the disabled is permitted on a broad scale. It is not surprising that it [abuse] is not reported, that staff, police and the courts fail to act appropriately (National disability advocate)*

One of the primary outcomes of negative attitudes towards the disabled is the normalised inequitable provision of services, building and parking considerations and legal protections. Such inequities act to socially exclude the disabled which risks incidents of abuse going undetected.

Summary

Low levels of societal awareness about disability-related issues, specific vulnerabilities and the abuse of the disabled were discussed as a primary barrier to maintaining the status quo. Specifically, low levels of disability awareness were seen as providing a foundation to each of the remaining barriers.

The pervasiveness of abuse and inequitable treatment of disabled people was attributed to deep-seated societal attitudes and beliefs which position disabled people as second class citizens. On one level disabled people's second class status is reflected in abled bodied bias in the development of architecture, access and societal representation. On a deeper level, however, disabled people share an insidious history of eugenics and societal maltreatment, most recently witnessed in Nazi Germany. This history was discussed as reflecting a willingness, on a societal level, to make disabled people expendable.

Given the pervasiveness of negative societal attitudes towards the disabled, participants stressed that the use of terms such as the *social model of disability* can fail to portray the lived reality of social exclusion, bias and maltreatment and second class status of the disabled. Consequently, there were demands for a clear re-branding of disability-related abuse to give it equal footing to that of inequitable treatment of other marginalised groups.

5.2 Silencing

Multiple reports were provided of disabled people, and/or those associated with them, being pressured to refrain from reporting incidents of abuse. In other situations, complaints of abuse were ignored by a third party. This process, albeit how subtle or deliberate, is termed here as silencing. Silencing manifested in a number of ways and are discussed below.

5.2.1 The disabled person

Disabled participants most commonly reported incidents of silencing when they felt pressured to not report abuse. Often this pressure occurred subtly through a conditioning process whereby individuals reported learning to be silent about their abuse through one or more of the following:

▪ negative experiences resulting from past complaints

▪ fear of retribution

▪ a concern that removal of a care worker or a family/whānau member would result in solitude and a lack of care.

Another outcome of a socialisation process were instances when the disabled individual believed they were somehow deserving of abuse. For example, one individual in question felt that his disability placed his family/whānau caregivers with an unnecessary strain and reported understanding if they had to slap him in frustration. Another example of an individual reportedly deserving abuse involved a disabled man whose wife would physically assault him as a punishment for having had an affair.

Silencing also arose through a normalisation process whereby the individual became so accustomed to ill-treatment that abusive behaviours were accepted as either normal or not worthy of an official report. The following excerpt is taken from an interview with a disabled person

Community advocate	*Do you see being ignored as abuse?*
Disabled participant	*No, I didn't see it like that.*
Community advocate	*Now that we have talked about it how do you view it?*
Disabled participant	*You get so used to it happening to you that you get used to it. And sometimes people snap. You try and tell them something and they yell and scream at you. So over time you learn not to rock the boat. Most times you just keep your mouth closed. So things have to be really bad before you say anything. That is why I need a support person*

Normalisation of abuse was also discussed by the Health and Disability Advocate who recounted incidents of silencing having occurred because many disabled individuals are not aware of their rights.

Another difficulty is that most consumers don't know that they even have these rights (Health and Disability Advocate)

Finally, silencing was reported because of difficulties some disabled people experienced communicating. This generally involved non-verbal individuals and individuals with limited understanding and the inability to complain.

5.2.2 Negation

Numerous accounts were offered where a complaint of abuse was negated on the grounds that the disabled person's testimony lacked veracity. Generally, this involved some form of disparagement of the individual complainant.

> *No one wants to take responsibility. For example, when I challenged a staff member about some suspected financial abuse, the first response I got from the staff member was, "Oh don't listen to her. She is daft. She just makes all that stuff up." And I got that from six people when I was trying to investigate the complaint. And so what happens is that staff will start to gang-up together and say, "Oh, she says that all the time. She's daft". We are talking about a client who has had a stroke but is quite cognitively aware. She definitely isn't daft. She knows what is going on. It had been going on for years and she was too frightened to tell anyone because she would have had to face their recriminations (Manager, Residential Service)*

> *What you hear is, "Oh, she's just a fucking liar" (Manager, Residential Service)*

On other occasions the complainant's strength of character was questioned. This was reported as most commonly occurring when individuals possessed a mental health diagnosis. The following account was offered by a care worker from another New Zealand location. The account mirrors numerous examples offered by Gisborne/Tairawhiti participants.

> *I was working at a physical disability support service. There was one service for men and one mixed. There were rumours going around that something was happening at the other house but no one knew. A woman who got around on a mobility scooter visited me. She said that she was scared and was sleeping under her bed at night. I told the manager and he just brushed it off, "Oh that is her mental illness". So straight away there was no belief. I think it was two to three weeks later that the client went down to the river and poured accelerant over herself and set herself on fire. There was an enquiry but I was never called to give evidence. There was no consequence higher up. It was like finding the weakest link. This woman could be alive if they heard what she was saying (Residential care worker)*

Disabled participants reported that such negation had resulted in a decision to avoid any future reporting of abuse.

5.2.3 Collusion

Similar to negation, numerous accounts of collusion were documented. Collusion is referred to here as a conspiratorial agreement to deny an abusive incident. Collusion was reported as occurring across the following parties:

- non-government organisations
- residential services, including managers and care workers
- parents and extended family/whānau members
- the disabled person themselves.

Rather than an explicit attempt to negate the individual's abuse, collusion was reported to manifest when witnesses believed they should protect parties from statutory "*interference*" or to protect the individual perpetrator or organisation's reputation. The following example reflects an attempt to collude because of fear of a loss of funding.

> *When I first started this job I discovered some abuse at another residential service when a manager of a local NGO brought it to my attention but said, "Don't bring my name into it. We are funded by them. A lot of our clients come from those two homes (Allied health professional)*

While ultimately linked to funding, the following examples illustrate organisational collusion in an effort to avoid attention from statutory bodies.

> *Institutionalised clients and managers try and keep the abuse in-house. There needs to be a shift so people can step outside the institution and ask for help. It is far better being transparent and have nothing to hide (Residential care worker)*

> *It is about keeping the services seemingly squeaky clean. If the police or the Disability Health Commission got involved then that would make them look bad (Residential care worker)*

It should be stressed that collusion was not limited to organisations. Numerous examples were documented where a family/whānau had colluded with the disabled person in an effort to protect the perpetrator from prosecution.

Summary

Multiple reports were provided of disabled people, and/or those associated with them, being pressured to refrain from reporting incidents of abuse. In other situations, individuals' complaints of abuse were ignored by a third party. This process, albeit how subtle or deliberate, is termed here as silencing and manifested in terms of:

- **the disabled person** – silencing occurred amongst disabled participants in terms of –
  - being pressured to not report abuse. Often this pressure occurred subtly through a conditioning process whereby individuals reported learning to be silent about their abuse through one or more of the following –
    - negative experiences resulting from past complaints
    - fear of retribution
    - a concern that removal of a care worker or a family/whānau member would result in solitude and a lack of care.
  - instances when the disabled individual believed they were somehow deserving of abuse
  - a normalisation process whereby the individual has become so accustomed to ill-treatment that abusive behaviours are accepted as either normal or not worthy of an official report
  - difficulties some disabled people experienced communicating. This generally involved non-verbal individuals and individuals with limited understanding and the inability to complain.

- **negation –** numerous accounts were offered where a complaint of abuse was negated on the grounds that the disabled person's testimony lacked veracity. This generally involved –
  - some form of disparagement of the individual complainant
  - questioning the degree of truth underpinning a complaint on the basis of the individual's having been diagnosed, at some point, with a mental illness

- **collusion –** collusion refers to a conspiratorial agreement to deny an abusive incident. Rather than an explicit attempt to negate the individual's abuse,

collusion was reported to manifest when witnesses believed they should protect parties from statutory *"interference"* or to protect the individual perpetrator or organisation's reputation. It should be stressed that collusion was not limited to organisations. Numerous examples were documented where a family/whānau had colluded with the disabled person in an effort to protect the perpetrator from prosecution.

5.3 Monitoring of service provision-related abuse

Participants unanimously regarded residential and home-based provision of care services as insufficiently monitored and stated that the lack of monitoring of the provision of care was the most common issue that maintains disabled people's vulnerability to abuse.

In each case of residential and home-based abuse through a care worker, a lack of monitoring was identified in terms of the:

- quality of service provided
- individual client and/or family/whānau satisfaction
- presence of abuse.

Further, no participant was aware of a government agency adequately auditing or overseeing complaints made by clients of residential or home-based services.

The need for monitoring was raised on two levels. First, in recognition of disabled people's vulnerability there is a need to ensure that the disabled person is not being harmed in anyway. Many residential and home-based care services purported to monitor client satisfaction through one or more of the following:

- an annual satisfaction postal survey
- random client and family/whānau satisfaction surveys
- home and residential service site visits where management meet with clients and discuss their levels of satisfaction.

However, the monitoring processes were heavily criticised because they place the onus on the disabled client to make a complaint. In doing so, the monitoring practices maintained the status quo as many disabled participants stated clients would not make a complaint because of fear of reprisals or a belief that they would not be believed. The following is taken from an interview with a disabled participant who discussed the costs of complaining about a home-based care worker.

I had someone come into my home three times a week and clean. She wasn't doing a very good job so I rang up X [home support service] and asked for someone else. They said that that was fine but that the cleaner would need to work out her two-week notice. It was awful, the cleaner would come in and stomp around, she would use her physical presence to intimate me and things would be left in my way so I ended up falling over four times. She was punishing me for making a complaint (Disabled participant)

The monitoring processes were also criticised because they lacked rigour and were perceived as providing a superficial image of professionalism rather than a focused attempt to monitor client satisfaction and safety. Specific criticisms associated with existing monitoring processes included:

- disabled participants doubted service commitment to protecting clients and ensuring client satisfaction because client-generated complaints had repeatedly had no response from service management. As a consequence attempts to monitor client satisfaction and safety were viewed as perfunctory only

> *I have never met a manager from X [home support service]. When I enrolled with them they promised me that a manager would visit me once a month. I have been with them for 12-months now and I have made many complaints but I have had no contact (Disabled participant)*

- multiple reports that, despite the various services' intention, clients were not surveyed annually

- participants unanimously agreed that surveying was an inappropriate means of gauging client satisfaction. Dissatisfaction was based on the following –

    - current administration of surveys assumes service clients had adequate eyesight and sufficient psychomotor coordination to complete the instrument

    - a reluctance to honestly complete the survey as reports of care worker dissatisfaction required the survey respondent to provide the care worker's name. Such naming requirements were perceived to breach anonymity and placed the respondent at risk of either organisational or care worker retaliation

    - monitoring surveys and/or face-to-face interviews should be carried out by an independent reviewer. This would afford greater client protection

    - regular contact and an in-depth assessment is required to identify dissatisfaction and abuse. Surveying neither provides an in-depth assessment nor a time sensitive process; as an inordinate amount of time can elapse before the abuse is identified.

It should be noted that there is no monitoring provision for disabled people who reside in their own or a family/whānau member's home and are not in receipt of paid service provision. As such, disabled people who are home-based and not in receipt of paid care services are placed in an extremely vulnerable position because any incidence of abuse can go unidentified.

Summary

Participants unanimously regarded residential and home-based provision of care services as insufficiently monitored and stated that the lack of monitoring of the provision of care was the most common issue that maintains disabled people's vulnerability to abuse.

In each case of residential and home-based abuse through a care worker, a lack of monitoring was identified in terms of the quality of service provided, the individual client and family/whānau satisfaction and presence of abuse. Further, no participant was aware of a government agency adequately auditing or overseeing complaints made by clients of residential or home-based services.

There is no monitoring provision for disabled people who reside in their own or a family/whānau member's home and are not in receipt of paid service provision. As such, disabled people who are home-based and not in receipt of paid care services are placed in an extremely vulnerable position because any incidence of abuse can go unidentified.

5.4 Poor management practice and lack professional services

Poor management practice and a lack of professional services were discussed as a factor maintaining the status quo; specifically, some services in Gisborne/Tairawhiti were described as reflecting:

▪ low levels of professionalism

▪ a lack of appropriately trained staff

▪ nepotistic hiring and staff management practices.

Most commonly, concerns about poor management practice focused on the lack of professional standards demonstrated by some managers of residential and home-based services. The lack of standards was traced to a sector that often lacked formal training and exposure to best practice.

> *The managers are often not that well trained. They often come from the support base. They only know what they have been exposed to which often is not much. The coordinators support the status quo because that is all they know (Disability advocate)*

Participants assumed that a lack of adequate training and professional development led to what was commonly perceived as underperforming services. This was a concern because a lack of commitment to the provision of high quality services was viewed as compromising clients' safety.

> *One of my main concerns is the lack of professionalism in our services and I question the level of commitment to the consumers that they are being funded to work with. Really it is a concern that we have a lot of services in our community that underperform. I look at our health and disability services, how the hell did different people get their management jobs. I have concerns about the quality of staff that are employed to work with our client groups (Allied health professional)*

Specific concerns centred on the failure of some services to place their clients' safety as paramount and multiple examples were given of processes that re-victimised the disabled individual.

> *We have cowboys and cowgirls out there who are ruining people's lives. They are re-victimising people (Local government representative)*

> *I was working a mixed house that provided supportive services. One of the men had a history of inappropriate touching and started to prey on one of the weaker females in the house. He was caught and the police were called but they decided not to press charges. He was not taken out of the house and the victim was continually re-victimised. We tried to press charges as this was the only way he would get a higher level of help. They brought in a psychologist but it was just skirting around the edges and making things look nice. Things were put in place, like the supervisor had to leave their door open for a sleep over and an alarm was put on his door. But that wasn't sufficient. The victim is still living in the house and was continually re-traumatised (Residential care worker)*

Related to the lack of adherence to professional standards were questionable hiring practices. Some services were criticised for not carrying out criminal history and last employer reference checks and hiring individuals with undemonstrated skill or aptitude. In part, poor hiring practices were traced to nepotism.

> *What strikes me about certain organisations is the nepotism. Because they hire family, people are frightened to challenge. When I came here I was shocked by how it is a closed shop. Organisations were hiring cousins, sisters and brothers. So if I challenged*

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someone then their relation would get back at me. I think it is still quite endemic in the care system in Gisborne. You have certain family members who recruit certain family members and it becomes too hard to discipline or dismiss someone so it all goes into the too hard basket (Manager, Residential Service)

Further, the lack of staff with requisite skills and temperament was explained in terms of the low wages commanded by support workers.

The government pay support people a pittance. People who provide care to our most vulnerable. If the government provided a decent wage they could get a higher calibre of person (Disabled participant)

We now have a proliferation of agencies who deliver care in the home. We know for the most part those people are lowly paid and not trained in the field of disability and are not able to recognise it (Manager, Social Service agency)

Because these people are so marginalised, and often have not had the best of lives, they don't know what is right or wrong. Support workers are so unsupported and so marginalised themselves they operate on a simple level of we love you or we don't. They thought it was ok to play with the person's hair. Their boundaries are often askew (National disability advocate)

It was, however, acknowledged that Gisborne/Tairawhiti, as a provincial centre, has a limited skilled workforce. This may impact on what participants referred to as a *"low calibre"* pool of care workers and supervisory staff.

The problem in Gisborne is that we don't have the skilled workforce (Manager, Residential Service)

Finally, a lack of adherence to professional standards was discussed in reference to an inadequate provision of staff training. This impacted on care workers ability to identify abusive behaviour and appropriately respond to the needs of the individual.

Entering into the support field, there is often training to enter the field but the area missing is what you should do when a client talks about or reveals a form of abuse. It just isn't taken seriously enough (Residential care worker)

Summary

Poor management practice and a lack of professional services were discussed as a factor maintaining the status quo; specifically, some services in Gisborne/Tairawhiti were described as reflecting:

- **low levels of professionalism –** most commonly, concerns about poor management practice focused on the lack of professional standards demonstrated by many managers of residential and home-based services. The lack of standards was traced to a sector that often lacked formal training and exposure to best practice

- **a lack of appropriately trained staff –** a lack of adequate training and professional development led to what was commonly perceived as underperforming services. This was a concern because a lack of commitment to the provision of high quality services was viewed as compromising clients' safety

- **nepotistic hiring and staff management practices –** related to the lack of adherence to professional standards were questionable hiring practices. Some services were criticised for not carrying out criminal history and last employer reference checks and hiring individuals with undemonstrated skill or aptitude. In part, poor hiring practices were traced to nepotism. The lack of staff with requisite skills and temperament was explained in terms of the low wages commanded by support workers.

Concern was raised about the failure of some services to place their clients' safety as paramount and multiple examples were given of processes that re-victimised the disabled individual. It was, however, acknowledged that Gisborne/Tairawhiti, as a provincial centre, has a limited skilled workforce. This may impact on what participants referred to as a *"low calibre"* pool of care workers and supervisory staff.

5.5 Reporting

Problems associated with reporting suspected or actual abuse were raised as a major factor maintaining the status quo.

Reporting abuse was discussed on two levels: first- and second-stage reporting. First-stage reporting refers to the initial disclosure of actual or suspected abuse and can be reported by the abused individual or someone associated with the disabled person. First-stage reporting barriers generally involve a silencing process (as discussed above). Second-stage reporting refers to the action taken by the person or persons who received the initial complaint. Second stage reporting barriers include insufficiently actioning a complaint or investigation and a failure to protect victims during and after an investigation.

This section discusses reporting barriers in reference to service organisations and statutory bodies. The degree to which first or second stage reporting barriers manifested differed.

5.5.1 Service organisations

Second-stage reporting issues were most commonly discussed in reference to service organisations. Of concern, none of the disabled participants who had made a complaint to a residential or a home-based service were satisfied with the way in which their complaints had been managed. Disabled and advocate participants' dissatisfaction with the way in which service organisations dealt with complaints was discussed in terms of managerial inaction and punishment.

Managerial inaction

A large number of participants reported a high level of dissatisfaction with the way in which complaints were inadequately managed. Multiple examples were offered whereby managers, either residential and/or home-based care organisations, had not responded to client complaints. Complaints had been made through email, telephone calls, voice mail messages and letters.

> *I wrote email after email about it to the manager [care workers stealing money and food] but I have never heard back. They [care workers] aren't supervised and the managers don't come to your home to check up and see how you are doing (Disabled participant)*

The majority of complaints did not detail abuse but asked for a meeting with senior management to discuss issues. It was through senior managements' lack of response to these requests that disabled clients reported developing perceptions that the organisation would not intervene in the event of a disclosure of abuse.

Punishment

Disabled participants discussed being placed in untenable positions, as a punishment, after a complaint was made. Threats or actual loss of rights, privileges and safety meant that participants reported extreme reluctance in making a future complaint.

> *I wasn't happy with my X's [homecare worker] attention to detail. Lovely lady but I needed the bathroom floor cleaned really well because I have slipped over a number of times. Anyway, I asked the agency for a new care worker. They said that the caregiver would need to work out a two-week notice period. It was awful, she [care worker] wasn't happy. She would come in here all grumpy like. I felt really unsafe. Some malicious stuff*

happened and I ended up falling over and really hurting myself. It was awful (Disabled participant)

Managerial inaction and/or punishment for making complaints were discussed as arising out of the following:

- inequitable attribution of rights – some disabled individuals' complaints were not appropriately actioned because staff and/or management did not afford disabled people the right of complaint

    The biggest barrier is the understanding of staff that it is a valid a complaint. They [managers and staff] don't understand that a client should complain and why they are a complainant and the actual validity of the complaint (Manager, Residential Service)

- failure to appreciate disabled people's vulnerability to abuse – across participant representatives attention was repeatedly drawn to senior managements' failure to ensure services occur within an environment that is responsive to disability-related vulnerabilities

    You know what shocks me is that I have been going into different residential services for years and training staff on consumers' rights. There was one service that I have been training people for the last three years. Just recently, at the end of a training, one of the care workers turned to me and said, "Oh I get it now. They are vulnerable so we have to be patient with them". I just couldn't believe it. There is just a deep seated response to treat people with disability as objects and a lack of understanding of their right to a full life (Community advocate)

    A failure to appreciate many disabled people's vulnerability was reflected in a failure of management to protect residents by removing a staff member who had a known history of violent abuse.

    I am really concerned about the residents at his new home. They are non-verbal and they have the most difficult needs to manage. Management gave assurances that he would never be doing sleep overs and that he would be supervised at all times but that isn't good enough. Why do they continue to employ someone who they know has a history of violent abuse (Community advocate)

- dehumanising view of disabled people – disabled people's reports of abuse were negated or simply not believed. This reflected an entrenched negation of disabled people's voices and experience

    You might be in a wheel chair, you know, that is your only impairment. Like you have all your cognitive faculties. But they won't take your seriously. They have literally said, "You are mental so why should I believe you" (Disabled participant)

- lack of adherence to best practice – three examples of alleged physical abuse were gathered where service management had not notified the police and, consequently, a formal investigation had not been carried out. Rather, service management had carried out an internal investigation. Due to staff collusion, however, management reported that they were unable to gather sufficient evidence to be able to either reprimand the staff members in question or escalate the complaint to a police matter. At issue, managers lacked clarity around when they should report an alleged case of abuse to the police.

    There was one time with a non-verbal man in a residential home. There was a lot of suspicion about the case because the man had severe bruising around his groin area. He was so blackened that he couldn't pee. He was hospitalised for quite a long time. The care worker said that she had left the man sitting on the toilet to go and fetch an

incontinence pad. The care worker said she was gone for 10 seconds only and said that when she came back the client had fallen off the toilet onto a pipe. Of course there was a lot of suspicion because the bruising was so terrible. It looked as though the poor man had been kicked severely and repeatedly in the groin. The poor man still resides in the same place (Allied health professional)

- lack of professionalism – as previously discussed, a lack of professionalism in conjunction with nepotism prevented appropriate complaint procedures being followed.

  Manager had two incident reports written about his behaviour and they were submitted to the organisation. But the organisation was corrupt. There are two managers in the organisation and he is related to one of them. So the consumer's complaint did not go anywhere (Community advocate)

5.5.2 Statutory agencies

The New Zealand Police and the Health and Disability Commission were identified as the primary statutory agencies where a report of suspected or known abuse could be made. However, a number of factors emerged from the interviews that dissuade disabled people from reporting abuse.

New Zealand Police

A number of first stage reporting barriers were raised in reference to the New Zealand Police; factors that hindered the initial report of abuse being made to the police. These police specific reporting barriers included: socially learned avoidance, previous negative experiences with the police, evidentiary requirements and risks to the victim.

a) Socially learned avoidance

Disabled participants reported that many disabled people avoid seeking police intervention because they have learnt, through social conditioning, that their opinions and experiences are inconsequential.

Disabled people have so much experience of not being listened to they don't see police as a possible conduit (Disability advocate)

Through a process of conditioning many people won't go to the police. They assume they will receive an inadequate response (Disabled participant)

b) Previous negative experiences with the police

Across disabled and able-bodied participants, a mixture of positive and negative past experiences with police were discussed. Positive interactions appeared to reflect an individual police person's knowledge of victimology and disability-related issues and involved the police ensuring the complainant felt safe during the investigative interview, contacting support people and adopting an empathic and supportive investigative demeanour. In contrast, experiences were described as negative when participants, both disabled and able-bodied, felt that best efforts had not been made in an investigation. Poor practice was attributed to:

- an assumption that disabled complainants are not regarded as a reliable witnesses. This was especially true in situations where someone had a known mental illness and situations where the individual is non-verbal

  The languaging is, "You are not a reliable witness". I have heard that hundreds of times (Allied health professional)

- a lack of knowledge about disabilities and the vulnerabilities experienced by disabled people. This often manifested as an impatience with disabled people's efforts to

communicate and the police erroneously assuming that the support people (such as care workers or family/whānau members) can assist with the communication. The assumption that a third party should be used to help with communications ignores the fact that the person may be the perpetrator

> *If there is any sort of communication issue or speech impairment there is a high chance that the police will go to the support worker for interpretation. Yet that might be the person who is carrying out the abuse (Disability advocate)*

- disabled people's complaints of abuse being negated

> *The police just don't take disabled people's complaints seriously (Residential care worker)*

> *We had a client who was physically assaulting staff and clients and the cops would be called up and they would say, "What do you want us to do? He is fucking mental" (Manager, Residential Service)*

- a noticeable discomfort around disabled people.

> *He [the policeman] was yelling at me. Sure, I realise that I don't speak clearly [use computer for communication] but that does not mean that I am deaf. He just looked terrified. Really uncomfortable. He couldn't wait to leave (Disabled participant)*

> *When I worked in mental health the police were a real barrier to people getting the help they need. If not trained in the area of disability the police generally fear disabled people (Disability advocate)*

As a consequence, those who had poor experiences with the police stated that they would only reluctantly contact the police in the future and preferred to address any complaints through internal mechanisms.

> *I have no faith in the police at all (Manager, Residential Service)*

c) Evidentiary requirements

Police participants related that, while they would investigate all reports of abuse, their ability to prosecute was dependent upon the strength of evidence. However, disabled and community advocate participants stressed that the very nature of a disability often precludes disabled people from being able to provide the requisite information/evidence. This can be understood in light of victims not being able to verbally convey what has taken place, the covert nature of much abuse and a lack of witness corroboration.

> *The nature of abuse for disabled people is often unique. How can you prove that someone left sitting for 10 hours is abuse? How can you prove that someone who has been left sitting on the toilet for hour after hour is abuse (National Disability Advocate)*

> *The police don't look at how abuse manifests for disabled people. How do you prove that what the disabled person has been experiencing is abuse? The police would not have a clue about what is going on. The expectation of what is okay is really low (Disabled participant)*

> *And the reason for that is simple. If they go to court without that evidence they are going to lose anyway. And that is why they give up (Legal representative)*

In cases of emotional and psychological abuse, it appears that insufficient action may be taken because the Domestic Violence Act is regarded as the main route to protect against emotional abuse and neglect. There is also uncertainty in the interpretation of the Act as to whether the Domestic Violence Act applies in cases where the perpetrator was an in-home caregiver, support worker or another occupant of a shared residence. Section 3 of the

Domestic Violence Act requires that a domestic relationship exist between the applicant and respondent. Section 4 defines a domestic relationship as including situations where the parties ordinarily share a household or where they have or have had a close personal relationship. Given these stipulations, it is reasonable to interpret the Act as, generally, excluding those in an employer/employee relationship, such as care workers, from the definition of a domestic relationship.

> *I don't think the police know what to do with a complaint of psychological abuse from a disabled person who is not in a relationship with the perpetrator. What Act does that fall under? (National Disability Advocate)*

Despite police assurances that best efforts would be made to obtain evidence, the majority of disabled participants stated that they would only seek police intervention in extreme situations and attributed this decision to poor past experiences, either their own or someone's in their network. The inability to secure sufficient evidence often left participants feeling isolated and vulnerable to retribution.

Participants also stated that they would not seek police intervention because much of the abuse they had experienced was psychological and emotional and they had little faith in the police being able to intervene, sufficiently, in those situations.

> *A fair number of us know that the chances of it getting beyond a complaint are minimal, so we ask ourselves, if it is worth it (National Disability Advocate)*

d) Risk to the victim

While previous negative experiences with the police and the burden of gathering sufficient evidence was cited as dissuading many disabled participants from seeking police intervention, the greatest barrier to reporting abuse was the risk that the act of reporting posed to the victim. Participants discussed how they or others in their network had been placed at-risk after they had made a complaint of abuse to the police. In each situation, they had assumed that measures would be taken to protect the victim during and after the investigation.

In all situations where a complaint was made to the police the allegedly abused individual remained in the residence or home during the investigative period. Further, in the majority of cases there was insufficient evidence to arrest or remove the perpetrator from the residence. This placed the complainant at considerable risk of retribution.

> *Complaining to the police needs a clear and immediately available support network. This is not always available to socially isolated individuals who may not be sure of trusting to paid supports (Disabled spokesperson)*

Further, no provision was made to protect the complainant while investigations were carried out. Central to this weakness is that there is no agency charged with the early identification and investigation of abuse pertaining to disabled people. As such, abused disabled people are vulnerable to retaliation during an investigation.

Health and Disability Commission

The Health and Disability Commission was created under The Health and Disability Commissioner Act and it was enacted in October 1994. The Office of the Commissioner's role is to promote and protect the rights of health and disability services consumers, and facilitate the fair, simple, speedy and efficient resolution of complaints. This is achieved through a nationwide network of independent advocates.

It is acknowledged that the Health and Disability Commission was designed to empower consumers and assist in complaints about health and disability-related service delivery and receipt. In this sense the Commission was not developed as a point of early intervention. The

Commission is, however, acknowledged as an important line of statutory reporting as it is a possible point of disclosure.

In Gisborne/Tairawhiti, complaints are generally channelled through the local advocate who has established a strong presence in the community through running staff and consumer training on disability people's rights, visits to residential care facilities, health and disability providers and close networks throughout the community.

> *I like to describe my role as "just a vehicle that enables a Consumer to complain about the service they have used and are not happy with". The role is confined (Health and Disability Advocate)*

A number of restrictions limit the powers of the Commission and the role of advocates. As such, the Commission is a limited reporting source. First, complaints are restricted to those in receipt of health and/or disability-related services. This focus reflects the breach of rights under which the Act came about. As such, the Commission has no role in abusive situations that occur outside of a health and/or disability service, such as in a home, inequitable service provision in school settings or abuse that occurs in the wider community. This restriction extends to government agencies such as Accident Compensation Corporation, Housing New Zealand and Work and Income. Next, while any individual can make a complaint, the advocate can only action the complaint if the consumer of the health or disability service in question agrees. In practice, collusion and/or a process of silencing can result in a complaint being rescinded at any point. In this sense, the advocate is reactive and their role ends once the complaint is withdrawn. This is reinforced by the advocates being prohibited from investigating complaints.

Another limitation of the Commission's role and responsibilities is that those not in receipt of health and/or disability services, such as those residing in the home without a paid care worker, are especially vulnerable as there is no oversight of the individual's wellbeing. While those residing in a residence or in receipt of a formalised service may be monitored to some degree, there are many disabled individuals whose wellbeing is not monitored because of a lack of oversight, either formal or informal.

> *First someone has to identify it. Someone would have to see it and report it as there is no one to monitor it. Also, people don't even recognise it. Next, people just can't be bothered with it. They would rather be pissing about having hui. I will give you an example, "I called down to the X [NGO] one day. So we went in, and there is a big hall, and the person who runs it comes over to me and says, "The meeting is upstairs so I hope you don't mind walking up these stairs. You're not a retard are you?" And that was the X [NGO] Coordinator. So if she has that attitude how is she treating her clients (Manager, Residential Service)*

Summary

Problems associated with reporting suspected or actual abuse were raised as a major factor maintaining the status quo. The following specific reporting barriers were identified:

- **service organisations -** a number of reporting gaps were identified. A large number of participants reported dissatisfaction over the way in which complaints made to service organisations were managed. Further, disabled participants discussed being placed in untenable positions, as a punishment, after a complaint was made. Threats or actual loss of rights, privileges and safety meant that participants reported extreme reluctance in making a future complaint

- **barriers to engaging with police -** the ability of the police to prosecute an alleged perpetrator was restricted by difficulties associated with obtaining evidence that would be considered sufficient to meet necessary evidential thresholds. This was especially true in situations of emotional and psychological abuse where participants felt

helpless because of a lack of 'hard' evidence or due to confusion about whether they had a case to pursue under different legislation

Because of past negative experiences with some frontline officers it was common for participants to be extremely reluctant to seek police assistance. Negative experiences included reports being negated by the individual's disability, a lack of knowledge of disability issues and demonstrations of prejudice towards disabled people.

▪ **insufficient protection -** in all situations where a complaint was made to the police and/or the Health and Disability Commission the allegedly abused individual remained in the residence or home during the investigative period. Further, in the majority of cases there was insufficient evidence to arrest or remove the perpetrator from the residence. This placed the complainant at considerable risk of retribution, whether emotional or physical.

▪ **gap -** those not in receipt of health and/or disability services, such as those residing in the home without a paid care worker, are especially vulnerable as there is no, or limited, oversight of the individual. While those residing in a residence or in receipt of a formalised service may be monitored to some degree, there are many disabled individuals whose wellbeing is not monitored because there is no one around. Further, there is no provision for the safety of the complainant while an investigation is undertaken. Finally, there is no agency charged with the early identification, investigation and protection of the disabled.

5.6 Service fragmentation

A combination of diverse and segregated health and disability services was raised as a primary contribution to disabled people's abuse.

> *All of this [abuse of the disabled] happens because the services are fragmented. When you have this [fragmented services] this is what it leads to (Local government representative)*

The following specific outcomes of service fragmentation were identified: insufficient awareness and competitive funding arrangements.

5.6.1 Insufficient awareness

Participants from non-government organisations, police and the health and the disability sector continually affirmed that a proliferation of segregated health and disability agencies has resulted in a lack of community-wide awareness of what services exist.

Three concerns were raised in relation to a lack of service awareness. First, referral agencies, such as the police, lacked clarity about which agencies they could refer an individual. Similarly, disabled individuals and their families related that they do not know how best to access services. The lack of certainty created a concern that many disabled people and their families' needs go unmet.

> *I have a battle raising awareness about the services that exist out there. Most disabled people don't know what exists or how to access the various services (Health and Disability Commission Advocate)*

Next, all participating non-government organisations, Work and Income and the police reported a high degree of uncertainty about the quality of care provided and the degree to which organisations safeguard their disabled clients. The lack of certainty contributed to an unwillingness to refer or connect an individual to a service as referral risked being construed as an endorsement of quality.

Finally, a lack of service awareness was raised in terms of the risk that clients of a particular service may be so isolated that abuse can go undetected.

5.6.2 Competitive funding arrangements

Service privatisation and contractual requirements were discussed as contributing to the diversity of services and, perhaps more importantly, to a lack of inter-service collaboration. The government funding model, it was argued, prevents inter-service collaboration as it creates a competitive environment and service streams of restricted eligibility.

> *I have three immediate concerns about fragmented services and why problems exist. I believe the government funding model does not allow for collaboration across sectors. Disability, aged and family services cannot necessarily align because they are funded through different bodies. So my family service funded by CYF cannot align with the disability service funded through the District Health Board. We have different funders so we have different criteria. Actually marrying them up is bloody near impossible. Next is gatekeeping. "If our client goes over there, they might not come back to us and we might not meet our contracted volumes and then we will lose our jobs". Third, "but we like the way we do it. We don't understand how them over there do it so we're not going to send our clients over there" (Manager, Social Service agency)*

> *The point I am trying to make. Health services will bump people over to social services. And social services will bump people over to health services. People are like footballs bouncing around. "No that is a health need". "Oh no that is a social service need". "Oh no we don't do that" (Manager, Social Service agency)*

Arising out of the competitive funding model's task or activity focus was a concern that the referral mechanisms, to ensure continuity of care, are sorely lacking in Gisborne/Tairawhiti and has contributed to an inadequate transition between secondary and primary care. This was perceived to result in hospital patients failing to receive appropriate and/or the full entitlement of services upon discharge.

> *The transition between secondary and primary care is nil and negligible and there are a lot of people falling through the cracks simply because of funding and where it sits (Manager, Disability Service)*

Inadequate transition was reported to result in non-receipt of care, and ultimately, service isolation.[8]

> *At the moment I am having an argument with the DHB about the chronic care contract. Certain diagnoses don't fit. There are no clear pathways for certain people with certain disabilities. Stroke and muscular skeletal disease is another one. Like Joe Blow might have a major CVA [cerebrovascular accident] and is hospitalised and receives in-hospital rehabilitation for four weeks and then that is it. They are discharged without any follow-up rehab (Manager, Disability Service)*

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[8] The failure to appropriately transition people from secondary to primary health was reported as negatively impacting on their recovery and resulted in permanent disability. "There has been a major breakdown between key parties and so there has been a major breakdown in referrals. As a result we aren't receiving referrals upon discharge. Rather, people end up coming to us months down the track and it means we have missed rehabilitation opportunities because too much time has gone by. So someone who had a stroke is permanently damaged whereas if they had come to us earlier they would be in a much better position. They only get to us as a last resort. . . stick them in a residence" (Manager, Social Service agency)

Finally, concern about the lack of holistic service provision was raised. Specifically, participants asserted that one outcome of the competitive funding arrangement is that services can become siloed and individuals with high and complex needs, and/or those within family/whānau systems, fail to receive holistic service provision. Rather than an integrated case management system designed to meet the holistic needs of the disabled individual, and where pertinent families, the current funding system is generally geared to the purchase of specific tasks or activities.

> *A disabled person is not given a unique system of care unique to their needs. Rather services are discordant. They will have to go to physiotherapy for their rehabilitation in one place, the X for home-based care, Y for something else etc. Caregivers are task focused. They get someone out of bed in the morning or they clean the house a few hours a week. There is no provision for them to actually meet and discuss the emerging needs of the client. As an outcome of these disparate services, there are a few people, if anyone, who views the individual as a whole. It is not holistic service provision. Gaps exist and it is in these gaps that abuse can occur and go undetected (Manager, Social Service agency)*

One outcome of service segregation is that disabled individuals can become isolated and, consequently, be placed at risk as there is a lack of integrated multidisciplinary oversight which could act as an early identification of abuse.

Summary

A proliferation of fragmented and segregated health and disability services were associated with:

- **a lack of awareness and understanding about what health and disability services exist in the community –** because of a lack of awareness of various services potential referral bodies stated that they had a high degree of uncertainty about referral options. The lack of certainty created a concern that many disabled people and their families' needs go unmet. Further, non-government organisations, Work and Income and the police participants had a high degree of uncertainty about the quality of care provided and the efforts expended to ensure service clients are protected. Finally, a lack of service awareness was raised as a concern as disabled clients can be so isolated that abuse can go undetected by members of the wider community

- **competitive funding arrangements –** service privatisation and contractual requirements have resulted in a lack of inter-service collaboration. Further, a lack of inter-service collaboration and restricted eligibility criteria was attributed to the competitive environment. Such restrictions have countered holistic service provision efforts. Specifically, individuals with high and complex needs, and/or those within family/whānau systems, fail to receive holistic service provision. Rather than an integrated case management system designed to meet the holistic needs of the disabled individual, and where pertinent families, the current funding system is generally geared to the purchase of specific tasks or activities.

5.7 Legislation

Community advocate and non-government agency participants raised a number of concerns about a lack of protection afforded to disabled people under existing legislation. Inherently, legislation was perceived as providing protection for able-bodied individuals and, in many situations, excluded the unique experiences and needs of the disabled. Given that legislation was cited as creating a barrier to disabled peoples protection under the law, it is included here as a factor that acts to maintain the status quo.

This section reviews legislation that provides some protection to disabled individuals. This includes:

- The Domestic Violence Act (1989)

- Crimes Act (1961)

- The Personal Property and Rights Act 1988 (PPPR Act).

5.7.1 Domestic Violence Act (1995)

The Domestic Violence Act aims to reduce and prevent violence in domestic relationships through the provision of legal protection for victims; namely Protection Orders.

The Act defines domestic violence as:

- physical abuse

- sexual abuse

- psychological abuse (including intimidation, harassment, damage to property, threats of physical abuse, sexual abuse or psychological abuse and in relation to a child).

The Domestic Violence Act attempts to holistically address abuse occurring within the context of a domestic relationship. The holistic provisions are guided by an overarching philosophy that recognises domestic violence as an unacceptable behaviour and provides sufficient legal protection for victims (Section 5). Because the Act was designed to protect individuals within a domestic violence relationship, the Act incorporated a set of objects, which are aimed to safeguard the victim (i.e. Protection Orders) and act as a secondary prevention (such as the requirement for perpetrators to attend non-violence programmes). Further, the emphasis placed on the eradication of domestic violence has resulted in the development of specific domestic violence police training programmes. Further, police responsiveness is captured through extensive administration requirements which are monitored as measure of adherence to best practice.

While the Domestic Violence Act, arguably, provides the most encompassing definition of abuse found in New Zealand legislation, the Act only applies to abuse experienced in domestic relationships. Section 4 of the Act defines a domestic relationship as including situations where the parties ordinarily share a household or where they have or have had a close personal relationship. As discussed previously, it is reasonable to interpret the Act as, generally, excluding those in an employer/employee relationship, such as care workers, from the definition of a domestic relationship. As such, it is not clear whether the Act adequately protects disabled people experiencing abuse in home-care / live-in support situations. There appears to be an uncertainty about the legal protection available to disabled people experiencing such abuse, and particularly emotional and psychological abuse.

Police Safety Orders

Police Safety Orders (PSOs) were introduced by the Domestic Violence Amendment Act 2009 and provided the New Zealand Police with the power to issue and serve PSOs from 1 July 2010. PSOs contain two important features. First, PSOs provide the Police with the power to remove a person ('bound person') from a residence and require that person to vacate any land or building for up to five days. Second, PSOs may be issued by the Police without the consent of the victim.

The concern about the applicability of Protection Orders under the Domestic Violence Act (1995) equally applies to Police Safety Orders (PSOs). These can only be issued in the context of a domestic relationship as defined by Section 4 of the Domestic Violence Act.

While PSOs have been positively received at a community level, disabled participants raised concern that the removal of the perpetrator potentially places the disabled individual at

considerable risk. Given that perpetrators are often caregivers, some disabled participants related that they would be placed in an untenable position, in the short-term, because the removal of a caregiver would mean that their basic needs would be compromised. The significance of this risk, coupled with a long-term need for familial support, meant that participants were wary of contacting the Police as their choice on how to best handle a situation could be removed and would risk jeopardising their limited existing support.

5.7.2 Crimes Act (1961)

The Crimes Act criminalises a series of crimes against the person. These include theft (Section 219) common assault (Section 196), sexual violation (Section 128), the sexual exploitation of person with significant impairment (Section 138), failure to provide a standard of care (Standard of care applicable to persons under legal duties or performing unlawful acts, Section 150a), neglect and the failure to protect from injury (Section 151) and the ill-treatment or neglect of a vulnerable adult (Section 195). In addition it is a criminal offence to threaten to destroy property (Section 307), engage in threatening acts (Section 308) or threaten to kill or do grievous bodily harm (Section 306).

On one hand, the Crimes Act provides for the protection of disabled individuals from family/whānau members, partners, caregivers/care workers and staff members of any hospital, institution or residence where the disabled individual resides. Further, sections of the Act provide safeguards against physical abuse, sexual abuse and financial abuse. Some protections are also made against psychological and emotional abuse, although the Act focuses on written threats and makes no provision for psychological taunts and nonverbal means of intimidation. On the other hand, because abuse, such as locked-in, psychological and emotional abuse, can manifest so insidiously there is generally insufficient evidence to prosecute.

One critique of the Crimes Act, offered by participants, is that offences under the Act are treated as discrete breaches of the law. Whereas the Domestic Violence Act has an overarching philosophy to protect people in a domestic relationship from violence, the various offences under the Crimes Act were not developed to address the holistic needs of an abused individual and, as such, lack the extensive provisions of the Domestic Violence Act. As a consequence, the Crimes Act is viewed as lacking the drivers for detection, investigation, prosecution and protection that are central to the Domestic Violence Act.

A second critique of the Crimes Act centres on a perception that evidentiary requirements, in relation to the abuse of the disabled under the Crimes Act, are unnecessarily high and were reported to deter disclosing abuse. For instance, disabled and family/whānau participants often stated that they would not report abuse to the police as they were concerned that the police would find that there was insufficient evidence and that a disclosure of abuse would result in the perpetrator retaliating in some form. As a consequence, the majority of disabled participants reported that they would only contact the police in extreme cases of abuse as many forms of abuse, including physical, generally did not provide the police with sufficient proof. Reluctance to report abuse also needs to be understood in light of fears associated with going through a criminal court proceeding as it was felt that they would not be sufficiently supported during the court proceeding and feared that their mental acuity and strength of character would be brought into question.

Amendment to the Crimes Act, Section 195A

In September 2011, Section 195A of the Crimes Act was amended in an effort to combat collusion or failure to report a risk of death, grievous bodily harm or sexual assault of a vulnerable child or adult. The amendment applies to:

a) a member of the same household as the victim, or

b) a person who is a staff member of any hospital, institution, or residence where the victim resides.

Importantly, the amendment applies to those who have frequent contact with a vulnerable adult and are closely connected with a household. In this sense, it could be reasonable to include neighbours and care workers, who have frequent contact and are closely connected with the household, within the duty to report.

Three issues were identified with the amendment. First, the amendment focuses on severe physical aspects of abuse only. As such the legal protection for vulnerable adults from psychological and emotional abuse remains limited, alongside, locked-in, financial and dehumanising abuse.

> *The spirit behind the Act is to stop collusion but the Act focuses on severe forms of abuse*
> *such as the risk of death, sexual assault and grievous bodily harm. So the gap is that if*
> *there is insufficient evidence or if it is a type of abuse that falls outside of that stipulated*
> *under the Act, such as emotional and psychological abuse, then there is no provision*
> *under the Act (Legal representative)*

Next, some confusion surrounds reporting. Rather than requiring past incidents of grievous bodily harm and sexual assault to be reported, one interpretation of the amendment is that it frames reporting in terms of future risk of abuse. As such, participants were unsure about the duty to report when there had been one previous occurrence of the stipulated abuse only. Finally, of all participants interviewed, only the Health and Disability Advocate had knowledge of the amendment.

5.7.3 The Personal Property and Rights Act (1988)

The Protection of Personal Property and Rights Act 1988 (PPPR) exists to provide personal and property protection for those members of society who, for various reasons, are not capable of looking after their own affairs. The Act can apply to those with mental health issues, those who have suffered a traumatic brain injury or stroke which has impaired their mental ability, people with intellectual disabilities or those suffering from dementia (New Zealand Family Courts, 2011). The Act, through the Family Court, allows an individual to appoint an enduring power of attorney or, if the person is incapable of doing so, their relatives or other people can apply under the PPPR Act for a Personal Order to ensure the wellbeing and care of that person. The PPPR Act also allows people to request that the Family Court appoint a welfare guardian or property manager who would be responsible for making decisions on behalf of someone deemed incapable of doing so. The New Zealand Family Courts (2011) states that the Family Court's two goals, when making decisions under the PPPR Act, are to:

> *cause the least possible interference in a person's life…(and) to enable and encourage*
> *the person to use and develop whatever capacity they do have, as much as possible*
> *(New Zealand Family Courts, 2011, p. 5).*

There are a range of Personal Orders that the Family Court can make and these include:

- arrangements for a person's care

- ensuring medical services are provided

- the appointment of someone to look after minor property or monetary affairs

- the appointment of an individual to represent the individual or to manage their affairs

- requiring someone to pay the incapacitated person for work they have completed or ruling on a person's right to travel outside of New Zealand or placing conditions on their leaving (New Zealand Family Courts, 2011).

Some community advocate participants expressed concern regarding the PPPR Act in relation to the absence of the need for the person appointed by the Court to ensure that the

protected person is free from abuse and neglect. Except for a three-yearly review, there is no robust accountability process requiring a welfare guardian to regularly account for the wellbeing of the incapacitated person and to report on the level and nature of care provided. Further, solicitors representing the Protected Person are not required to have any specific training in disability issues. Nor are they required to carry out an assessment of the individual's wellbeing and possible exposure to abuse.

A further concern relates to the level of enquiry that is undertaken regarding the suitability of a welfare guardian and the extent of their ability to care for the incapacitated person's needs. While the Court must be satisfied that the welfare guardian is capable of carrying out their duties, the Court's assessment is made outside of any formalised criteria. As such there are no specific criteria relevant to assessing the extent to which a welfare guardian is able to ensure the wellbeing and care for a person with complex needs and whether, for example, that guardian would be able to identify if abuse was occurring and have the knowledge and skills to respond appropriately.

Whilst there is a need for a medical certificate to be completed by a general practitioner or other specialist, there is no requirement for the solicitor to engage with or consult any organisation providing services to the incapacitated person or to consult with the relevant medical practitioners or specialists to eliminate any possibility that family/whānau violence or other types of abuse or neglect is occurring. At the present time the Court relies on the solicitor appointed to act for the Protected Person to consult with the person and other relevant persons. The level of consultation is driven by a fee for service and true representation of the Protected Person's situation is dependent upon the willingness of the solicitor to undertake the range of tasks which would be necessary to gain a true picture of the situation.

As discussed, there is no requirement for a welfare guardian and/or property manager, appointed by the Court under the PPPR Act, to regularly account for the on-going safety, health and wellbeing of the protected person. There is however a requirement for a property manager to annually submit financial accounts to the Court, which are reviewed by the Public Trust. The fee for this service is paid from the funds of the protected person. Therefore, it is entirely possible that Personal Orders could be made without awareness of whether family/whānau violence or abuse or neglect is occurring.

Other concerns raised by participants related to the difficulties of obtaining information in relation to the protections available under the Act without paying for legal advice, and if appointed under the Act, the lack of readily accessible information or advice to inform or support the appointed role. Cost was identified as a barrier to taking action under the Act.

5.8 Summary

One factor identified as maintaining the status quo is the lack of consensus surrounding definitions of abuse; inherently there is no one definition of abuse that can be universally applied across the various manifestations of abuse reported by disabled participants, their family/whānau members and/or community stakeholders.

Further, a certain degree of uncertainty exists in the applicability of different legislation that potentially applies to the protection of disabled people from abuse. There is also uncertainty about the level of protection afforded to disabled people if the perpetrator is providing care in a residential setting, for example whether this is excluded by definition of a domestic relationship under Section 4 of the Domestic Violence Act. Significantly, locked-in abuse is not included within existing statutory definitions of abuse.

One critique of the Crimes Act is that offences under the Act are treated as discrete breaches to the law and the various offences under the Crimes Act were not developed with the same extensiveness as the Domestic Violence Act. As such, the Crimes Act lacks the drivers for

detection, investigation, prosecution and protection that are central to the Domestic Violence Act.

A second critique of the Crimes Act centres on the lack of protection afforded to disabled people. Evidentiary requirements, in relation to the abuse of the disabled under the Crimes Act, were viewed as unnecessarily high and were reported to deter disclosing abuse.

Thirdly, the Protection of Personal Property and Rights Act (PPPR) is critiqued, particularly, because of:

- a lack of criteria guiding enquiry into the suitability of a welfare guardian to meet the potentially complex and diverse needs of an incapacitated person
- the absence of any specific requirements placed on a welfare guardian to account for the on-going care and wellbeing of an incapacitated person.

6 COMMUNITY DERIVED RECOMMENDATIONS

The previous section identified a number of factors that act to maintain the status quo. This chapter addresses participant derived responses to each of the presenting issues. The discussion is framed in terms of:

- prevention

- professional standards

- service coordination

- early identification and intervention.

6.1 Prevention

Negative social attitudes towards the disabled, combined with low levels of awareness about disability-related issues, were identified as providing a foundation for the insufficient detection and reporting of the abuse of the disabled. Low levels of disability awareness have created a foundation from which abusive behaviour is not consistently monitored and corrected by societal standards. Participants strongly recommended that there is a need for extensive community education about the disabled. Further, education should focus on:

- awareness raising and removing stigma and fear of the disabled

- the types of abuse experienced by disabled individuals

- vulnerabilities associated with disability that place them in untenable positions

- the need to report abuse, a zero tolerance, and how to report abuse.

It is acknowledged that the police may need specialised training to be better positioned to respond to reports of abuse.

6.2 Professional standards

Two issues were raised pertaining to a lack of professional standards associated with the provision of disability-related services. First, participants unanimously regarded residential and home-based provision of care services as poorly monitored and stated that the lack of monitoring of the provision of care was the most common issue that maintains disabled people's vulnerability to abuse. Existing services' efforts to monitor disabled clients' satisfaction and the existence of harm or abuse were, in the main, unsatisfactory. Services were perceived to lack independence and objectivity in their efforts to monitor client satisfaction and possible experiences of harm.

Next, poor management practice and a lack of professional services were traced to a concern that client's safety could be compromised. Specifically, services in Gisborne/Tairawhiti were generally described as reflecting:

- low levels of professionalism

- a lack of appropriately trained staff

- nepotistic hiring and staff management practices within residential and home-based services.

Disabled participants, along with family/whānau and community advocates, strongly recommended the development of an independent client satisfaction monitoring system. It was recommended that the service monitoring system:

- inclusively monitor disabled individuals' experiences as well as the experiences and perceptions of significant others

- monitor staff and management responsiveness to client and whānau concerns and complaints

- incorporate a variety of mechanisms that assist disabled individuals accurately report levels of satisfaction and exposure to harm (for example, developing methods that take into account eye sight and hearing impairment).

Because poor management practices and under performing services were generally traced to a combination of a lack of formal training and exposure to best practice, participants from each participant group advocated for the implementation of management and care worker employment standards. Specifically, contracts for service should require staff and management to demonstrate:

- the attainment of relevant educational standards

- demonstrated knowledge of disabled people's experiences and particular vulnerabilities.

Further, service management should be required to demonstrate a commitment to:

- maintaining disabled people's safety

- ensuring an understanding of the unique needs of disabled people underpin the organisational culture

- staff training in being able to identify signs of abuse and how to report suspicions or disclosures

- the avoidance of nepotism

- extensive and thorough hiring practices (including previous employer reference checks and review of criminal histories)

- regular training on the identification and reporting of abuse

- proactively investigating complaints of abuse and/or harm

- ensuring that staff consistently demonstrate positive attitudes and behaviours towards clients

- the eradication of harm and the provision of client safety

    It is critical that anyone who establishes themselves as a disability service is accredited in terms of the profound nature of disability. Services need to demonstrate an understanding of, and provision to account for, disabled peoples vulnerability. At the least staff need to be well versed in the way that abuse can manifest, knowing how to recognise abuse and channels to report suspicion. Also, management need to demonstrate a commitment to maintaining the disabled person's safety (Community advocate)

Outstanding issues that maintain the status quo, and impacting on professionalism and monitoring, include:

- the cost associated with attracting staff with the requisite skills, knowledge and temperament

- no monitoring provision for the disabled who reside in their own or a family/whānau member's home and are not in receipt of paid service provision. As such, disabled

people who are home-based and not in receipt of paid care services are placed in an extremely vulnerable position because any incidence of abuse can go unidentified.

6.3 Service coordination

A proliferation of fragmented and segregated health and disability services were associated with a lack of awareness and understanding about what health and disability services exist in the community.[9] As a result, various potential referral bodies stated that they had a high degree of uncertainty about referral options. Further, non-government organisations, Work and Income and the police participants had a high degree of uncertainty about the quality of care provided and the efforts expended to ensure service clients are protected. Finally, low levels of service awareness was raised as a concern that disabled clients can be so isolated that abuse can go undetected.

Importantly, in part, service fragmentation was traced to competitive funding arrangements which were reported to encourage territorial service provision and a lack of inter-service collaboration. Further, restricted eligibility criteria was also attributed to a competitive funding environment. Such restrictions were reported to counter holistic service provision efforts. Specifically, individuals with high and complex needs and/or those within family/whānau systems, fail to receive holistic service provision. Rather than an integrated case management system designed to meet the holistic needs of the disabled individual, and where pertinent families, the current funding system is generally geared to the purchase of specific tasks or activities.

Community stakeholders suggested that the issue of low service awareness, gaps in service delivery and a lack of interagency collaboration could be ameliorated through the introduction of dedicated disability community-based social workers.

> *There needs to be a point of contact for different services. So we are aware of what they do. So we know that we are working with the right person (Police representative)*

Disability community social workers would:

- act as a point of contact for service identification and referral

- ensure that referrals are geared to holistic service provision

- advocate for the individual's full entitlement

- act as a one possible reporting contact for suspected or known abuse

- advise best course of action when an individual chooses to report an abusive incident(s)

- provide community-based education on disability issues

- provide a follow-up mechanism to ensure clients are receiving their full entitlements.

Importantly, providing a follow-up mechanism is linked to the professional standards discussion above. Participants stressed that community-based disability specialist social workers would be best placed to meet with clients and ensure all their needs are met and that the service that they are provided meets appropriate standards.

Importantly, participants stressed eligibility criteria associated with accessing dedicated disability community-based social workers needs to be broadly defined, as existing social work structures often preclude the provision of social work assistance.

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[9] Participants acknowledged that the Citizens' Advice Bureau has historically provided referral advice to disabled individuals and their significant others. The advice, however, has lacked consistency as it has relied on the individual volunteer's knowledge.

It is the criteria as well. I have people who have come to my office that I am not permitted to help given the way in which my role has been defined and I have had to say, "Sorry, but I can't really help you because this isn't a complaint about a service you are using". And I say, "What you need is a social worker". Well, you know it is going to be difficult, because there is this social worker but they don't meet their criteria and there is this social worker but they don't meet their criteria. So what we need is a community social workers and lots of them (Health and Disability Advocate)

6.4 Early identification and intervention

A number of factors were identified, at a legislative and central government level, that maintain the status quo. First, there is no one definition of abuse that can be universally applied to disability-relevant situations. Rather, relevant definitions are restricted to the Crimes Act and the Domestic Violence Act but arguably do not include all relevant perpetrators (for instance, employees, such as care workers, under Section 4 of the Domestic Violence Act). Next, the various offences under the Crimes Act were not developed with the same extensiveness as the Domestic Violence Act and, as such, lack the drivers for detection, investigation, prosecution and protection that are central to the Domestic Violence Act. It can be argued that a perception that evidentiary requirements, in relation to the abuse of the disabled under the Crimes Act, are unnecessarily high and were reported to deter disclosing abuse. Another gap under the current legislation and police investigation practices is a lack of protection of the alleged victim while an investigation is carried out. This was especially noted in situations that fall outside of the provisions of the Domestic Violence Act.

In light of the barriers to the reporting of experienced or suspected abuse and a lack of protection afforded to the alleged victim, participants strongly suggested a need for the establishment of a statutory agency, based on a similar model of Child, Youth and Family, with the statutory responsibility to investigate allegations of abuse while affording alleged victims protection during the investigative period. Further, participants suggested that a statutory agency is required to protect vulnerable adults and specifically include the disabled and the elderly.

Under the CYFA [Child, Youth and Family Act], if the risk to the child is such CYF [Child, Youth and Family] have the powers to remove the child. We need an agency, with similar powers, to protect the needs of disabled people. Such an agency needs the power to investigate allegations of abuse, keeping in mind that abuse needs to encompass the widest definitions, it would have the power to remove the disabled person or the alleged perpetrator, the power to call a conference and the power to impose an Order to secure the child (Manager, Social Service agency)

The impetus for the development of a statutory agency arose from a community forum discussion. Child, Youth and Family was discussed as a possible model because of its focus on the protection of vulnerable children and young people. The need for a similar statutory agency was raised in light of the:

▪ prevalence of abuse towards the disabled and the elderly

▪ pervasive negative societal attitudes towards the disabled and elderly

▪ lack of existing legislative protections afforded the disabled and elderly.

CYF [Child, Youth and Family] is there to protect young people and children. Such protections reflect a particular emphasis society provides for vulnerable children. Disabled people do not receive the same care and protection and we need legislation to make sure things change (Community advocate)

> *The problem with the current legislation is that there is no provision to protect the disabled person during an investigation into the allegation of abuse. We need something like CYF [Child, Youth and Family] (Allied health professional)*

> *There is no agency charged with the early identification, investigation and protection of the disabled (Community advocate)*

- need for appropriate development and implementation of ancillary agencies' (such as the NZ Police) policies and training.

Participants noted that the establishment of a suitable statutory agency would require:

- extensive consultation with disabled individuals, service providers and the police

- a review and alignment of existing legislative definitions of abuse to ensure that the experiences of disabled people are sufficiently included (such as including care workers/caregivers)

> *Under the Domestic Violence Act, it is really clear, what they define as domestic violence does not match with disabled people living in a residential setting. Any violence or abuse is challenged under employment law. The domestic nature is the concept that needs to be tweaked. Because support workers coming into our home is not seen as domestic (National Disability Advocate)*

- the development and enactment of legislation specific to the protection of vulnerable adults (including the disabled) that relies on a balance of probabilities as an underpinning legal standard.

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