Insult and injury: a narrative approach to understanding the emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services

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Abstract

Emotional and psychological abuse and neglect is poorly recognised in the lives of people with intellectual disability. While research into abuse and neglect has found this a longstanding and significant problem affecting the lives of people with intellectual disability, most of these studies have focused on physical and sexual abuse. For people with intellectual disability living in accommodation services, abuse can also be linked to the responses of compliance based services systems, in which a strong emphasis is placed on managerial and technical approaches to the development and operation of disability accommodation services.

Within this context, this research aimed to gather new insights about the experiences of emotional and psychological abuse of people with intellectual disability living in disability accommodation services. The study addressed three key research questions, namely:

- How do people with intellectual disability understand the experience of psychological and emotional abuse and neglect in disability accommodation services?
- What is the impact of that experience on them?
- What factors might predispose people to abuse, increase their risk and protect them against this form of abuse and neglect?

The study adopted a narrative approach and is based in the belief that the knowledge and truth about the issue is vested in those who have lived it, and those close to them. A new approach was developed for the study using narrative collage. Narrative collage involves putting the person with intellectual disability at the centre of the collage, and inviting other supporters into the research (with their agreement) to ‘bolster’ their narratives. Together, their stories build a collage of the person’s experience. It is fundamentally about gathering collective experience to develop new understanding.

Four people with intellectual disability and their supporters participated in the research in this way. Five family members participated in the research.
on behalf of their family member with high support needs. Narratives or stories of the experiences of nine people with intellectual disability in disability accommodation services grew from this involvement. A further sixteen people from policy and advocacy bodies participated in the research as key stakeholders, talking about systemic issues.

A framework for understanding emotional and psychological abuse and neglect was developed during the research, and used to group the abuse and neglect experiences into the following categories: caregiver privilege; degrading; isolating; minimising, justifying and blaming; neglecting; terrorising; withholding, misusing or delaying needed supports; and corrupting and exploiting.

The narratives revealed a total of 228 incidents of emotional and psychological abuse and neglect in participants’ ‘service lives’. All nine people experienced multiple forms of emotional and psychological abuse and neglect on multiple occasions. Results revealed that while some abuse was caused by the actions of malicious individuals, more commonly, abuse and neglect was caused by staff following service policies and routine practices that did not adequately respect people’s rights. The use and misuse of power and control emerged as a central theme in all experiences. The impact of this abuse and neglect on participant’s lives has been significant and is manifested through long standing issues with emotional and mental health, capacity to develop and maintain relationships, ability to trust, and cultural connections.

Despite this volume and range of abuse and neglect, people demonstrated great resilience in dealing with their abuse. All had strategies for managing their emotions and the distress that the abuse caused, and had moved on with life in important ways.

Four key issues emerged from this research which have particular importance for policy, practice and research, as they grow from the lived experience of people with intellectual disability. These problems concern

• the central place of systems in this form of abuse and neglect
• the cumulative impact of emotional and psychological abuse and neglect over time
• recognition of emotional and psychological abuse and neglect by people with intellectual disability, and
• the lack of moral authority accorded to people with intellectual disability in abuse acknowledgement and reporting.

The study concluded that approaches are needed that build capacity in people with intellectual disability and in those who support them to resist and deal with emotional and psychological abuse and neglect.
Statement of originality

This work has not previously been submitted for a degree or diploma in any university.

To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Signed:

Date:
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**Prologue**

The decision to undertake this research has been influenced by my experiences over the past twenty years as a disability service provider, individual and systemic advocate, and researcher in the disability field. During this time, I have witnessed (and sometimes, it must be acknowledged, participated in) interactions which I view to have been emotionally or psychologically abusive or neglectful. These may have been unintentionally abusive actions, but when considered through the eyes of the person using the service, I have little doubt they were received as abusive.

During the last decade, I have had the opportunity to develop some close relationships with research colleagues who have intellectual disability, and over time we have become friends. They have spoken with me in some depth about their experiences of living in accommodation services in the past, and about their experiences of what they consider emotional and psychological abuse and neglect.

I have reflected on these experiences with disquiet for several years, worried about the impact of this sort of abuse on people with intellectual disability, and been curious and concerned about why it has remained ‘under the radar’ in terms of recognition, response, and policy in the disability accommodation and support sector.

This research grew from a suspicion that emotional and psychological abuse and neglect was happening often, to many people with intellectual disability who live in accommodation services; that it was inadequately recognised; and that it was not responded to sufficiently well to either stop it or prevent it from happening. It is not intended as a theoretical treatise on abuse, but a living history of people’s experience which paints a picture of the subtlety, the frequency and the impact of this form of abuse on the lives of people with intellectual disability, and which makes an unapologetic call for change.
SECTION ONE: ESTABLISHING THE PROBLEM
Chapter one: Introduction

There’s so many different types of abuse, and it all comes down to the same thing. It’s making people nothing. And Fran was nothing. There was never anything nice said about her, everything was negative. And she had to put up with that, and we had to put up with that, until we all sort of believed it, almost.

- Amanda, Fran’s mother

1.1 Identifying the research need

Little is known about emotional and psychological abuse and neglect in the lives of people with intellectual disability. Few people with intellectual disability have been asked about their experiences and their memories of this abuse and neglect. The responses of still fewer have appeared in the research literature or influenced disability services policy.

The emotional and psychological abuse and neglect of people with intellectual disability in Australia remains largely un-investigated. Research with those who have experienced such abuse has not been conducted in Australia, and is also under-investigated in an international context (Saxton, 2009; Nosek, Clubb-Foley, Hughes & Howland 2001a; O’Callaghan & Murphy, 2003). A significant proportion of the existing research on the issue is situated either at a theoretical level or at an applied level which does not directly engage people with intellectual disability (Calderbank, 2000; White, Holland, Marsland & Oakes, 2003; Powers & Oschwald, 2004).

This study began from a premise that emotional and psychological abuse and neglect is an everyday occurrence in the lives of adults with intellectual disability who live in disability accommodation services. Interaction with a large number of staff, many of whom are casual workers, as well as co-residence with other people with disability who may
have significant challenging behaviour, and the depersonalising effects of group living all combine to make the likelihood of emotional and psychological abuse and neglect high for people living in these situations (Macfarlane, 1994; Swain, Heyman & Gilman, 1998; Powers, Curry, Oschwald, Saxton & Eckels, 2002).

The title of the thesis, *Insult and Injury*, is conceptually important to the research. The research is grounded in the belief that the insult, ignoring, belittling and humiliating which makes up a part of the service lives of some people with intellectual disability is neither trivial nor forgettable. It is every bit as injurious as other forms of maltreatment.

More broadly, abuse and neglect of people with intellectual disability living in disability accommodation services is recognised as a longstanding and significant problem, and is commonly held in the literature to affect a substantial proportion of people living in these circumstances (Sobsey 1994; Ticoll 1994; Conway, Bergin & Thornton, 1996). The research focus to date has been predominantly on the experiences of sexual and physical abuse and neglect. While it is critical that these crimes and wrongs are redressed, this focus of research and policy may have unintentionally shaped practice in disability services which further fails to recognise and address a chronic and commonly experienced form of maltreatment of people with intellectual disability (Packota, 2000).

Emotional and psychological abuse and neglect occurs within a policy context in which a strong emphasis is placed on managerial and technical approaches to the development and operation of disability accommodation services (Di Rita, Parmenter & Stancliffe, 2008; Clapton, 2008a; Clegg, 2008). The focus of such a system is that the act of management is viewed as more important than the subject of management – where the focus is on documenting service compliance to policy and procedures, and where responses to abuse are made on an individual basis, per incident of mistreatment. There is a discord between the responses of compliance based services systems and the abuse experiences of people with intellectual disability.
Within this environment, this study aims to gather insight about the experience of people with intellectual disability.

### 1.2 Aim of the research

This research seeks to understand the experience and impact of emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services.

The aim of the research is not to solve the ‘problem’, but to frame it in a new and important context – through giving voice to the people who experience the abuse.

Three key research questions are raised for resolution:

- **How do people with intellectual disability understand the experience of psychological and emotional abuse and neglect in disability accommodation services?**
- **What is the impact of that experience on them?**
- **What factors might predispose people to abuse, increase their risk and protect them against this form of abuse and neglect?**

The research also aims to add to the developing literature on ethical research with people with intellectual disability on sensitive issues, and seeks to create an expectation of change to address the issues raised by people’s experience of this form of abuse and neglect.

### 1.3 Structure of the thesis

In order to achieve this aim, several related activities occur within these pages. The thesis is divided into three primary sections – establishing the problem; presenting the results; and addressing the implications of the research for policy and practice. The first section establishes the problem
of emotional abuse and neglect in the lives of people with intellectual disability living in disability accommodation services, and details the research approach to its investigation. This is undertaken in the first three chapters of the thesis. A review of the literature comprises the following chapter, which details scholarship on the existing research in the area and the dominant themes and issues presented. It begins with an analysis of the contextual factors in play when emotional and psychological abuse and neglect occurs, focusing on constructions and conceptions of disability, culture, environment, power, gender and the multiple levels or sites of abuse. Existing research on the experience of this form of abuse and neglect is related, including its prevalence and relationship to institutional abuse. Research which has been conducted with people with intellectual disability is presented and analysed, and autobiographies by people with disability which include their abuse experiences add a new element to the literature review. The literature on the emotional and psychological abuse and neglect of other marginalised groups – children, older people and women - is reviewed. Definitions of emotional and psychological abuse and neglect from a range of scholars and policy contexts are drawn together.

This combined material is then used to develop a framework for more comprehensively understanding emotional and psychological abuse and neglect as it relates to people with intellectual disability living in disability accommodation services. This framework is carried forward in the thesis and later tested against the experiences of participants in the research.

The legislative and policy context of Australian disability services is described, and an analysis made of the policy responses of state disability departments to this form of abuse and neglect. The final section of the chapter reviews legal issues and possibilities for redress for people who have experienced this form of harm.

Chapter three explains the design of the research, and presents the conceptual approach, methodology and research method. The research is grounded in the belief that the knowledge and truth about the problem is
vested in the people who have experienced it. This gives rise to an ontological focus on lived realities (McClimens, 2004), and a concomitant perspectival epistemology (ibid; Conway, 1998), discussion of which is framed early in the chapter. The ontological and epistemological focus sets a framework for a narrative approach, and an analysis of the benefits and risks of critical and narrative research approaches is made.

Narrative collage has been crafted as a methodology which works to privilege the participation of people with intellectual disability while still welcoming the involvement of others who may have valuable contributions to make, and is laid out in the second section of the chapter. Narrative collage is fundamentally about gathering collective experience to develop new understanding. It is a methodology novel to disability studies, and builds from a small methodological base in other fields (Kephart, 2008; Kostera, 2006; Denzin, 2003). This approach to collection and analysis of collective narrative is described in detail.

The third section of chapter three details the research method, and describes the participants and the way in which they were recruited, the research tools, the use of advisory groups and consultation, and the interview processes. The final section in the chapter concerns ethical issues, and engages with issues concerning the involvement of people with intellectual disability in research of a possibly distressing nature, issues of informed consent, responding to information shared about criminal assaults, and the thorny issue of how much of the research results to share with participants.

The second section of the thesis addresses the results of the research across two chapters. Chapter four details the emotional and psychological abuse and neglect experienced by nine people with intellectual disability while living in a range of disability accommodation services. It builds a collage of their narratives, both individually and collectively.

The abuse and neglect experiences of participants are ordered in two ways – by typology, according to the abuse and neglect framework
developed in the literature review (Kovener, 2000), and according to the individual, systemic or structural nature of the abuse or neglect (Penhale, 1999). Accordingly, accounts are given of experiencing caregiver privilege; being degraded; being isolated; having abuse minimised, justified and being blamed for it; being neglected; being terrorised; having needed supports withheld, misused or delayed; and being corrupted or exploited. These categories are further organised according to the individual, systemic or structural strata in which the root of the abuse lies. The volume, range and frequency of other forms of abuse in the lives of participants is also raised.

Chapter five presents the results of the research which relate most explicitly to the central power and control element of the abuse and neglect framework. The largely negative experiences of participants in attempting to address abuse and neglect in their lives through making complaints are detailed. The responses of participants to their experiences of abuse and neglect, and their accounts which demonstrate the very significant impact of the abuse in the lives are also related. The final section in part one of this chapter involves the narratives of resistance and resilience shared by participants as they worked to reconcile their experiences and move on with their lives.

Part two of the chapter provides an account of the responses of key stakeholders who are engaged at a policy level with the abuse and neglect of people with intellectual disability. These policy, advocacy and complaints agents provided a systemic view of some of the features of emotional and psychological abuse and neglect. This section includes their thoughts about how to understand this form of abuse and neglect; their views on the impact of it on the lives of people with intellectual disability; its prevalence in disability services; how well recognised and how well responded to it is; the risk factors; strategies for protecting and safeguarding people with intellectual disability; preventing the abuse from occurring; and finally, how to influence change.
The third section of the thesis discusses the results of the study, analyses the implications of the results against existing research and literature in the field, and addresses implications for policy, practice and people with disability. In Chapter six the results of the research are discussed and analysed against the existing research and literature. A fundamental disparity is found between responses of the disability services system and the abuse experiences of people with intellectual disability.

The discussion opens with an analysis of the abuse experiences of participants, generating several meta themes which are common across the categories of emotional and psychological abuse and neglect. The impact of the abuse, and the resistance and resilience which people have drawn upon to combat this impact is considered and contextualises the abuse experiences – this is not a story of victimhood, but of survival. The discussion then moves through issues of recognising and identifying emotional and psychological abuse and neglect and some of the factors influencing the experience of it at a systemic level, to the frequently inadequate and ineffective responses of the disability services system. Several elements converge in the discussion, from which four new insights emerge. These concern the central place of systems in this form of abuse and neglect; the cumulative impact of the abuse on people’s lives and wellbeing; the recognition of emotional and psychological abuse and neglect by people with intellectual disability; and the lack of moral legitimacy which is accorded to people with intellectual disability in the recognition, acknowledgement and reporting of this maltreatment.

Chapter seven of the thesis draws out implications for the future. The considerable implications for both policy and practice which emerge from the demonstrated high volume and frequency of this abuse in the service lives of people with intellectual disability are presented. Implications for policy and practice around a lack of recognition of the central importance of systems and power relations in this type of abuse; the need for more sophisticated and better informed understandings of risk; and the need for broad scale cultural change in disability services are discussed. The role of evaluation and monitoring and the implications of change are also raised.
Practical alternatives for increasing and improving recognition and response to emotional and psychological abuse and neglect are offered. The need to respect the lived experience of people with intellectual disability, and the alliance of advocacy with practical strategies are offered as underpinning requirements.

Implications for the lives of people with intellectual disability within a system which takes a broader approach to protection are canvassed. The importance of education, training and support which goes beyond the procedural, for stakeholders at all levels, is viewed as being of key importance.

The lack of responsiveness to the recommendations of external inquiries is damning. There are significant implications for policy and practice in making broad systemic change in response to this significant body of demand. This is an important social problem, not a ‘disability land’ problem. Approaches are needed which build capacity at all levels.

The final chapter of the thesis offers some concluding thoughts. It connects the experiences of participants to imbalances of power and control at individual, systemic and structural levels through the key insights gained in the research – the central place of systems; the cumulative impact of the abuse; its recognition by people with intellectual disability; and the lack of moral authority accorded to them in its reporting.

These underpinning power imbalances combine with the lack of capacity of systems to recognise and redress the root causes of this maltreatment, failing people with intellectual disability in three fundamental ways. At the broadest level, there is no integrated approach to abuse prevention and response for people living in disability accommodation services. Second, an individualistic, procedural approach to abuse response has masked recognition of medium and long term impacts of emotional and psychological abuse on people’s lives. Third, at the level of daily service
provision, lack of recognition and awareness condemns people to routine indignity and abuse through the unthinking following of policy and procedure by workers which inadequately respects people’s rights.

The research concludes with a call to remain alive to the currency of ‘social death’ models of accommodation support, and to resist approaches which take authority from people and vest it in the system. The place of people with intellectual disability needs to be recast in order to alter the culture and practice of the service landscape to make it safer and more responsive.

### 1.4 Significance of the research

There is a demonstrated need for applied research which investigates the experience of emotional and psychological abuse and neglect of people with intellectual disability who have lived in funded disability accommodation services (Brown, 2004; Manthorpe & Stanley, 1999; Sobsey, 2000; 2002; Saxton et al, 2001).

This study will add significantly to the understanding of the experience of this abuse and neglect on people with intellectual disability living in a formal service environment in Australia. In giving voice to the experiences of people who have to date remained silent in Australian disability services, in a small way it brings a new perspective on the experience of abuse and neglect into the abuse debate which may invigorate what is currently a moribund fight for justice in the Australian disability political and policy climate (Public Advocate, 2005; Office of the Adult Guardian, 2008).

The results of the study may influence policy and practice at the level of systems change and in service provision contexts, both in Australia and overseas. They may also have use in systemic advocacy. The results have particular integrity, being grounded in the lived experience of people who
have lived through long years of emotional and psychological abuse and neglect in disability services.

In concluding this chapter, a brief discussion to clarify the use of particular contested terms may be in order at the outset of the thesis.

1.5 Contested language

The constructs ‘emotional and psychological’, ‘abuse and neglect’ and ‘intellectual disability’ are subject to ongoing and at times intense debate in the literature. Considerable heat and passion has been expended over the use and misuse of language, particularly around the way people with disability have been described - past and present. It may be useful in this introductory chapter to clarify the rationale behind the way these particular central terms are used in the study.

There is an ongoing debate in the literature about the value of continuing to use the term ‘abuse’, as it may serve to undermine and diminish the seriousness of the violence and crimes which are committed against people with disability (Brown, 2004; Sobsey, 1994; Women With Disability Australia, 2007). Sexual and physical assault, theft, fraud, chemical restraint, and false imprisonment are criminal acts, and should be named and treated as such when they appear in the lives of people with disability. However, there may be some abuses which are not as clearly criminal wrongs (although they may in some cases be civil wrongs) which may still benefit from being conceived of as abuses of the rights of people with disability. These include emotional and psychological abuse and neglect, institutional abuse and systemic abuse.

Conway argues that the term abuse draws on “ethical, sociological, psychological and philosophical understanding” (1994, p.15). A number of researchers talk about emotional and psychological abuse falling within a ‘grey area’ which is at the limits of legal behaviour (Conway, 1994; Chenoweth, 1995a), where the actions of the abuser are most certainly
abusive, but may not be criminal. In these situations, a more nuanced understanding or response may be needed – for example, how should we differentiate between a premeditated cruel action and one which was misguided but well intentioned, or one which was in compliance with service policy, but a service policy which did not respect the human rights of the people living in the service (MacFarlane, 1994)? As will be demonstrated, the subtleties of action and effect which are at play in some emotional and psychological abuse and neglect demand a complex response, which requires a way of referring to this maltreatment which is broad enough to encompass moral, ethical and legal wrong (Brown, 2004; Clapton, 2008b).

Further, the language used by different authors to describe emotional and psychological abuse and neglect is inconsistent, both within and across fields of study. Emotional abuse, psychological abuse, psychological maltreatment, verbal abuse, systemic abuse, indirect abuse and non physical contact abuse, are all terms used in the literature to refer to a similar group of experiences (McKinnon, 2008; O'Hagan, 1995; Sheehan, 2000; Sobsey, 1994; Conway, 1996; Howe, 2000; Packota, 2000; Bright, 1999). In this study, the terms emotional and psychological abuse and neglect are used. Significant distinctions will be made in the thesis between emotional and psychological harms, and as such, it is important not to conflate them. However, in this research, emotional and psychological abuse and neglect is considered a conceptually singular phenomenon. As will be discussed in due course, emotional and psychological abuses are understood in this study to occupy different points on a continuum of harm.

There is also an ongoing debate in Australia regarding language to refer to people with disability. Language surrounding disability is strongly influenced by the debates concerning the social and political positioning of disability in sociological contexts. Social model theorists and researchers in the UK predominantly use the term ‘disabled person’ to acknowledge the fundamentally social, political and structural processes of disablement (Oliver & Barnes, 1998; Goodley, 2003). In Australia, this terminology
does not have as strong a currency, and ‘person with disability’ is more frequently used. This is also the usual preference of self advocates, who prefer to be ‘person first’ (Self Advocacy Sydney, 2009; NSW CID, 2004). As such, the terminology preferred by self advocates in Australia, person with intellectual disability, is used in this thesis.

1.6 Summary

This chapter has introduced the research and outlined the approach of the thesis. Few people with intellectual disability have been asked about their experiences of emotional and psychological abuse and neglect. It may be an everyday occurrence in the lives of people living in disability accommodation services, and occurs within the context of a high prevalence of other abuses and neglect also suffered (Sobsey, 1994; Ticoll, 1994). Emotional and psychological abuse and neglect is happening in a policy context where the focus of services is predominantly on a compliance and managerial level (Clapton, 2008a; Di Rita et al., 2008), resulting in a discord between people’s experiences and service responses.

This research seeks to understand the experience and impact of emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services within this context. In order to do this, a review of the existing literature is undertaken in chapter two. The research design is explained in chapter three, and narrative collage as an innovative methodology detailed. The results of the study are laid out in chapter four and five, and discussed in chapter six, and the final chapters bring together implications of the research and concluding remarks.

The research is significant, as it responds to an identified need for applied research on the issue. It will add significantly to the field, and brings a new perspective to the abuse debate in political and policy terms. The
results may influence policy and practice in both systems change and service provision contexts.

Finally, language around the contested constructs of ‘emotional and psychological’, ‘abuse and neglect’ and ‘intellectual disability’ has been clarified.
Chapter two: Literature review

Tom   See I bought the meat to cook. Cause if I didn’t have Christmas dinner, at least I’d have the meat done. You understand what I’m saying?

Sally I do understand what you’re saying. Yeah, you’ve got to prepare ahead of time.

Tom   She said, ‘I haven’t got three hours or however long pork takes to cook’ - it takes a few hours. She said ‘I haven’t got time to sit here and watch it cook! I’ll take it home and I’ll bring it back’

Sally She’ll bring it back cooked?

Tom   And when I asked her about it, she said ‘oh, I had to throw it out to the dogs because it was slimy’.

2.1 Introduction

Research in this area largely considers either a range of abuses against people with a range of disabilities, or the sexual abuse of people with intellectual disability. There is a small body of literature directly addressing the problem of emotional and psychological abuse and neglect of people with disability, and a very limited literature addressing the emotional and psychological abuse of people with intellectual disability living in disability accommodation services.

Accordingly, in this chapter the existing research on emotional and psychological abuse and neglect of people with intellectual disability and people with other disabilities is reviewed and presented, and the dominant themes and issues presented. Part one of the chapter analyses the
contextual factors in play when emotional and psychological abuse occurs, focusing on constructions of disability, culture, environment, power, gender and the multiple levels or sites of abuse. Existing research on this form of maltreatment is reviewed in part two of the chapter, with a particular focus on research which has been conducted with people with intellectual disability, and including autobiographies and biographies of their abuse narratives. Following this analysis, the literature on the emotional and psychological abuse and neglect of other marginalised groups is presented – children, older people and women.

In part three of the chapter, definitions of this form of abuse and neglect from a range of sources are drawn together. From this combined material, a framework is developed for more comprehensively understanding emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services. This framework will be carried forward and tested against the experiences of participants in the research.

The legislative and policy context of Australian disability services is described, and an analysis made of the policy responses of the State disability department to this form of abuse and neglect in part four of the chapter. Part five, the concluding section of the chapter, reviews legal issues and possibilities for redress for people who have experienced such maltreatment.
Part one: Why is this happening?

2.2 Why is this happening?

This section presents some of the broader concerns which are raised in the literature about why this form of abuse occurs in the lives of people with intellectual disability, and why it continues to happen. A discussion about the contexts in which emotional and psychological abuse occurs, and views from the literature about how these contexts influence the recognition, response, protection and prevention of emotional and psychological abuse and neglect of people with intellectual disability is offered.

The aim here is not to find an answer to this vexed question, but rather to make explicit the link between these ‘higher order’ issues and the complex problem of emotional and psychological abuse and neglect of people with intellectual disability in disability accommodation services. This will be developed by drawing attention to the work of scholars who have engaged with this problem at a higher order or philosophical level.

2.2.1 Constructions of disability

Several theoretical understandings of the social, cultural and structural roles and places of people with intellectual disability were reviewed in this study. They share several features, most notably to do with the oppression, isolation and dehumanising of people with intellectual disability – all forces which substantially increase the conditions under which emotional and psychological abuse is likely to occur and recur.
Identity constructions - damaged identities

Hilde Lindemann Nelson’s (2001) work around damaged identities and narrative repair is used as an ontological foundation for this research, and it is also important in the literature review for applying its concepts to an understanding of the damage that is done to the identity of people with intellectual disability through emotional and psychological abuse.

Lindemann Nelson holds that personal identity is a lever which expands or contracts a person’s ability to exercise moral agency, according to the way in which they are identified by others, and the way in which they identify themselves. In the case of people who are identified by others as morally defective or lacking, certain actions are perceived as being appropriate or permissible which would not be so for people who are not so labelled, such as hospitalisation, humouring, or being treated with contempt, hostility – or being abused. Not only are actions available to others, but the self-identification of people as morally defective or lacking means they will mistrust their own capabilities, and treat themselves with suspicion or contempt, or exempt themselves from full responsibility for their actions, thus restricting their own moral agency.

Where an entire group are identified as morally defective or lacking (as in the case of people with intellectual disability), Lindemann Nelson talks of the construction of mandatory identities, where social expectations are set up about how group members are expected to behave, what they can know, what can be demanded of them, and to whom they are answerable. This is what she calls damaged identities. Individual identities are subsumed into a marginalised social group experience, and as Lindemann Nelson puts it:

The connection between identity and agency poses a serious problem when the members of a particular social group are compelled by the forces circulating in an abusive power system to bear the morally degrading identities required by that system (2001, p.x).

In the context of emotional and psychological abuse and neglect of people with intellectual disability, a morally compromised identity is constructed and maintained for service users by service management (through policies
which fail to adequately engage people’s human rights), service workers (through work practices which inadequately humanise people with disability), and people with intellectual disability themselves. This identity is likely to increase the risk of abuse occurring significantly, and may also contribute to the creation of a climate in which the response to such abuse is likely to be less than vigorous or rigorous, due to the increased vulnerabilities and decreased lack of protections accorded to people who are identified as service users.

Spatial and social constructions – ‘keeping people in their place’

Social geographers Kitchin (1998) and Hall (2004) argue that both spaces and social relations are organised to keep people with disability ‘in their place’ and to convey to people with disability that they are ‘out of place’ (Kitchin, 1998). According to this view, disability is spatially as well as socially constructed, and the rules which operate on a tacit as well as an overt level form structures which guide the operation of social and cultural practices. Kitchin states:

> These structures form, sustain and perpetuate the popular stereotypes which underlie many exclusionary practices and are enshrined within the maintenance of the dominant ideology (1998, p.352).

Hall (2004) contends that the social inclusion agenda has inadvertently excluded people with intellectual disability by establishing criteria for inclusion to which they either cannot or do not want to aspire, while at the same time marginalising the spaces and roles which they filled before the social inclusion agenda began. This leaves people with intellectual disability almost stateless – not included, yet neither left behind, and they are left particularly open to discrimination, rejection and abuse by individuals, groups and institutions.

The work of ethicist Clapton (2008b, 2003; Clapton & Fitzgerald, 1997) is ontologically and conceptually important to this research. She holds that:

> critical to any understanding of inclusion and exclusion in relation to people with intellectual disability is the exploration of the prevailing normative ethics which underpin notions of right and wrong, good and
bad, just and unjust, beneficent and malevolent... A belief in a state of normality which remains uncritically implicit, becomes contestable (2008b, p.10).

The normative ethics which have been applied to people with intellectual disability in relation to their experience of abuse and neglect have resulted in institutional practices in which abuse is not seen for what it is; where the abrading of the rights and dignity of people who use services is unrecognised; and where the usual moral concerns applied to other community members are suspended. It allows for the ‘othering’ of people with intellectual disability, discussed in the following section, the creation of what Clapton (2008b) terms a ‘discourse of disqualification’, in which people with intellectual disability are exempted from prevailing ethical considerations or perspectives, and the profound exclusion which results.

In response to this disqualification and exclusion, Clapton proposes a transformative ethic of inclusion – a call to a commitment to action which is flexible and dynamic, and which pays explicit attention to the structural and power relations affecting the inclusion and exclusion of people with intellectual disability. Rather than a binary ‘in-or-out’ model of inclusion, she contends that a ‘fabric of integrality’ is required – a socio-ethical fabric which is embracing of ‘the entirety of humanity and the diversity of persons’ (2008, p.205).

**Social constructionism – ‘othering’ and humanness**

Jones and Basser Marks (1999) describe the objective of the social constructionist approach to disability as being:

> to uncover the subtle societal factors which interplay with personal experience and together create, reinforce and potentially perpetuate the subordination of people with disabilities (p.3).

Social constructionists argue that the abuse of people with intellectual disability continues due to their extreme marginalisation and their positioning as ‘other’ or less human – that they have been categorised through cultural practices as being somehow fit for treatment which would be deemed inappropriate for someone without an intellectual disability.
(Taylor & Bogdan, 1989; Clegg, 1993; Clapton, 2008b). Lanoix (2005) claims that care is commodified in institutional environments, and that this objectifies the resident as a set of needs. This gives rise to a climate of ‘moral laissez faire’ in which abuse more easily occurs. Chenoweth writes:

> The capacity of institutions and service systems to dehumanise is a powerful precursor to cultures of institutional violence. This construction of the victim as non-human occurs in subtle yet powerful ways.... Once a person is dehumanised in this way, the usual constraints on abuse and violence become weakened and people are more likely to be verbally abused, beaten, sexually abused, tied up or locked up (1995b, p.40).

Nunkoosing (2000) holds that some explanations about intellectual disability are privileged over others – namely, that the knowledge of professionals and academics is privileged over that of people with intellectual disability themselves. In the context of abuse, the consequence of this is that the lived experience of the subtleties of emotional and psychological abuse by people with intellectual disability has been largely ignored in favour of the privileged professional explanations of abuse, which focus predominantly on sexual and physical abuse.

The constructions of people with intellectual disability as ‘other’, as damaged, as less than human, and as needing to be ‘kept in their place’ are powerful and dominant modes of social and cultural operation, and they have informed the development of the structures, including the disability services systems, within which people live today. As such, these constructions have direct relevance to this research, and to understanding the impact of emotional and psychological abuse and neglect in the lives of people with intellectual disability.

### 2.2.2 Conceptions of disability

A key to the way in which abuse and neglect of people with disability is viewed and responded to lies in the way shared understandings of
disability are operationalised. The conceptions of disability which underpin the development and application of disability service models directly influence the way in which abuse and neglect is understood and responded to and the degree to which people are protected from its occurrence. As Clapton and Fitzgerald point out:

> These models, or constructions of disability, have set the parameters for our response to people with disability. Through time, these models have become more sophisticated, yet their essence remains constant – otherness (1997, p.1).

**The medical model**

Historically, disability services were built and provided in response to the medical model of disability in many countries (Young, 2003; Johnson & Traustadottir, 2005). Large scale institutions were constructed to house and (re)habilitate people with disability. The intended purpose of such facilities was to treat the deficits of individuals, to house such people away from the community, and to provide care in a ‘professionalised’ environment, as it was considered that was preferable to a family environment. In practice, such institutions often did not fulfil these goals, or they did so partially, in an environment which was rife with abuse, overcrowding and impersonal care (Boxall, 2002; Johnson & Traustadottir, 2005; Young, 2003). This is argued particularly strongly in the histories of people with disability who have lived in these facilities (Bradley, 2008; Daisley, 2005; Pentland & Cincotta, 1995; Atkinson, 1997).

Harrison (2000) contends that the medical model emphasises the desirability of ‘normal’, and that this has been further endorsed by the normalisation movement and the general community, embedding the medical model into the community through a ‘personal tragedy’ view of people with disability. Consequently, although far fewer large scale institutions of past operate, a strong legacy remains in the perceptions that are maintained in the general community about the place and roles of people with intellectual disability (see also Clapton & Fitzgerald, 1997; Kitchin, 1998).
The devolution of large scale institutional facilities into group homes and smaller congregate settings has in some cases seen a shift to an inclusion oriented approach, where the individual needs, inclusion and active citizenship of people with disability are considered to be of paramount concern (Lord & Hutchinson, 2003; Mansell, 2006). However, it is also argued that the group home and disability community housing sector maintains a welfare or charity orientation to the housing and support of people with intellectual disability (Drake, 1996; Goggin & Newell, 2005). Within this paradigm, there remains an expectation that people should be grateful for the services they receive, and a perception that they have little control over or participation in the decisions about how the service is provided (Felce, 2000; MacArthur, 2003). For example, in a study of charities, authority and people with disability, Drake (1996) found that charities in the UK providing services to people with disability largely accorded with the views of the medical model, and that people with disability had little personal or political power, or opportunities for consumer participation, within the organisations.

It is argued persuasively in the literature that there are still many areas where the medical, or ‘personal tragedy’, and the welfare models of disability (where disability is seen to be a ‘problem’ which is located within the individual) are paramount in both the design and the implementation of services and social structures (Wills & Chenoweth, 2005; MacArthur, 2003; Goggin & Newell, 2005; Clear, 2000). When this is the case, services are welfare oriented or medicalised in approach, and seek to treat the symptom of the person’s lack of access or inclusion rather than to change the root cause of the problem. This leaves people with impairments the recipients of specialist services, rather than included through universal design principles and inclusive policies and practices (Ferguson & O’Brien, 2007; Taylor, 2001). In the case of abuse and neglect within disability services, this results in common responses which aim to protect clients, and address individual instances of abuse, but which arguably fail to consider abuse and neglect as a phenomenon affecting a whole population group, which is driven and influenced by
complex social, cultural and political forces (Brown, 2004; Marsland, Oakes & White, 2007).

**Normalisation and Social Role Valorisation**

The normalisation and social role valorisation movement has played a highly influential role in the conceptualising of people with disability and their relationship to services. Normalisation was first conceived by both Bengt Nirje in Scandinavia and Wolf Wolfensberger in the USA in the late 1960s and early 1970s. The essence of normalisation theory is to make available to people with intellectual disability the same patterns and conditions of everyday life in the same way as they are available to other members of the community (Perrin, 1999). It is argued that Nirje’s theory of normalisation drew from a focus on equality and human rights, while Wolfensberger’s, while maintaining a human rights concern, drew more on deviancy theory (Culham & Nind, 2003). Wolfensberger later developed the theory of social role valorisation (SRV) to extend, and perhaps supersede, his theory of normalisation. In SRV, according to Heal (1999), Wolfensberger urges human service workers to ‘pursue whatever avenues they might find to increase the valuation of people whose physical or mental deviance might engender devaluation’ (p.197).

Culham & Nind (2003) point out that normalisation and SRV have both been interpreted in several ways, resulting in numerous theories and definitions and cultural variations between countries. The movements, it is argued, represent a highly influential shift in the way services are provided to people with intellectual disability, in that they conceive of service recipients as community members and relationship holders, although the implementation of SRV is primarily through human service workers (Heal, 1999; Race, 1999). Normalisation is credited with influencing the devolution of large institutions, which has in turn directly influenced the abuse experiences of people with intellectual disability (Culham & Nind, 2003). Emerson, Hastings and McGill (1994) assert that normalisation and social role valorisation concepts were widely adopted and conveyed in disability services mission statements and job advertisements in the UK in the mid 1990s, but also found that the
ideology of the movement, while made explicit in mission statements and
the like, has:

been ineffectively translated into service activity [and]... may have had
some unhelpful consequences in generating confusion concerning staff
roles and devaluing the importance of effective staff management
procedures (p.168).

Critics of the normalisation and SRV movement argue that it is overly
ideological, controlled by services, that it relies upon the altering and
conforming of individuals with intellectual disability to social norms, that it
tends to be conservative and that it does not engage with the
fundamental power discourses which impact on the lives of people with
disability (Oliver, 1999; Ramcharan et al, 1997; Culham & Nind, 2003).
Adherents contend that SRV is a useful strategy, and should be one of
many that are used to improve the lives of people with intellectual
disability, who ‘can’t wait for the revolution to have their oppression
addressed’ (Race, 1999, p. 202), rather than getting caught up in the
continuing heated arguments about the merits or dangers of the theory.

The social model
A range of scholars have shifted the interpretation of disability from a
medicalised, ‘personal tragedy’ model or a welfare oriented charity based
perception towards social constructs that see society as a primary
causative factor in disability, due to the ways in which it oppresses
disabled people (Oliver, 1996; Thomas, 2004; Barton, 1996; Tregaskis,
2002). This has become known as the social model of disability. It is a
reinterpretation of disability which has changed the way in which disabled
people are viewed and the way in which they view themselves. The social
model, in essence, makes a distinction between impairment and disability.
Social model writers argue that disability is created by social, cultural and
political structures which act to exclude people with impairment. Disability
is thus a form of oppression (Abberley, 1997; Barnes, Mercer &
Shakespeare, 1999).
During the past decade, the social model has been increasingly influential, and increasingly critiqued. Feminist and psychoanalytic perspectives on disability which stress the cultural and social relations of disability appear in the literature in which recognition of issues of gender, race, and socio-economic status emerge – all of which have significant impact on the barriers or opportunities which impact on people with disability (Tregaskis, 2002; Morris, 1996). Recent debates suggest that the social model itself may be in danger of becoming an outdated ideology, and there is need for new and increasingly sophisticated understandings about disability which also take into account people’s experience of impairment, social relations and complex local and global social, cultural and political forces (Meekosha 2009; Shakespeare & Watson, 2002; Tregaskis & Goodley, 2005; Goggin & Newell, 2005).

It has also been argued in the literature that people with intellectual disability may not have been well served by the social model, which was first conceived in relation to people with physical impairments. Several scholars have written about the uncomfortable place of people with intellectual disability in social model theory (Goodley, 2001; Dowse, 2001; Chappell & Lawthom, 2001). Goodley’s ‘inclusive’ social model of disability explicitly discusses the social nature of the impairments of people with intellectual disability. He writes:

The ‘difference’ of people with learning difficulties, understood as being located in some biological deficit, individualises their very humanity; ripping them out of a social context, placing them in the realms of pathological curiosity... the social model of disability can only include people with learning difficulties when it recognises the social origins of ‘learning difficulties’ and ‘difference’ (2001, p.35).

Other criticism of the social model centres on its focus on the material conditions of equality, perhaps at the expense of day to day concerns for people with daily support needs due to intellectual disability. Scotch and Schriner (1997) argue that it is important not to rely solely on a focus on oppression and discrimination against people with disability. Were discrimination to disappear, there would still remain significant barriers
which prevent people with disability from being fully engaged and active citizens, and they contend that we risk trivialising frequent and often vicious stereotyping and exclusive practices by confusing them with the general incapacity of social systems to respond to individual variation. Harrison (2000) expresses the view that the social model does not address community attitudes, but rather dismisses them in favour of emphasis on structural and materialist concerns. His contention is that there is a need to address the social perception of what he terms ‘disability as detriment’ (p.167), and to do so using measures which go beyond disability awareness raising training.

While the conceptions of disability which shape the dominant social, structural and policy responses to people with intellectual disability in Australia have changed significantly over the past few decades, in many instances people with intellectual disability are still viewed as non-gendered, non-powerful, non-citizens (Sherry, 1999; Goggin & Newell, 2005), particularly inside the disability services framework. It is also important to note, as Brown identifies, that:

Although it is tempting to characterise the history of services as one long progression, all of these strands are recognisable within our current service systems (1994, p.128).

When there is a broad social acceptance of a group having less access to their rights and having difficulty in having those rights upheld, systems are seemingly allowed to develop which, mostly unintentionally, allow emotional and psychological abuse to thrive (McCarthy & Thompson, 1996).

### 2.2.3 Culture and environmental context

Abuse of people with disability who live in disability accommodation services happens within a particular cultural and environmental context. Vulnerability to abuse is discussed in the research by many authors. Some researchers present a view in the literature that the presence of disability itself may increase vulnerability, and include a focus on individual
vulnerabilities, such as the reliance on others to meet physical care needs, impairments which limit a person’s ability to recognise abuse, or residence in institutional settings (Nosek et al, 2001a; Sobsey, 1994). Others present a broader analysis of vulnerability, and discuss the structural, social and political circumstances which surround community and society responses to people with disability, arguing that it is these which in large part determine and increase the vulnerability of people with intellectual disability to abuse. These include poverty, unemployment and underemployment, inadequate housing, poor quality health care, exposure to domestic violence, and social stereotypes of vulnerability (Chenoweth, 1995b; Fawcett, 2008; WWDA, 2007; Nosek et al, 2001a). It should be noted that many authors include both individual and systemic factors in their analyses of vulnerability.

Exposure to large numbers of casual and agency staff, lack of control over which staff provide intimate care services, lack of control generally over day to day decisions and larger life decisions, organisational structures which focus strongly on systems management rather than individual support, poverty, unemployment and underemployment, lack of access to essential services, stigma and marginalisation, and discrimination all combine to increase the vulnerability and isolation of people with disability who live in disability accommodation services (Horne, Merz & Merz, 2001; Brown, 1999; 2004; Westcott & Cross, 1996; White et al, 2003). These factors may have a far more insidious and far reaching effect on vulnerability, and the way in which we respond to vulnerability, than does, for instance, a physical reliance on care or an intellectual reliance on support to manage finances.

Recent research by Marsland, Oakes and White (2007) sought to identify aspects of intellectual disability service cultures and environments which could act as early indicators that people with intellectual disability were at risk of abuse. They found that the behaviours, actions, attitudes and decisions of managers and staff, the behaviours of people with intellectual disability, isolation, service design, placement planning and
commissioning, and fundamental care and the quality of the environment were all critical in preventing a climate in which abuse could flourish.

### 2.2.4 The impact of power relations

Marsland, Oakes and White also found that power, choice and the organisational climate were significant issues, noting that:

- power is a significant construct underlying the issue of abuse. Specific issues relating to power have been associated with cultures of abuse. Where there are imbalances of power at any level within the care hierarchy, there is a risk that power will be used inappropriately, increasing the risk of abuse (2007, p.12).

It is argued that there is a serious imbalance of power structured into traditional disability services which perpetuates a climate which is ripe for abuse. Mandeville and Hanson contend that this power imbalance is pervasive and that it ‘permeates program policy, agency culture, professional practice, and the personal dynamics in paid relationships (2000, p.15). Ticoll (1994) details some of the ways in which people with disability are less powerful than those who abuse them. In some situations, people are reliant on perpetrators for physical, psychological or economic support or other necessities, they do not have control over the actions of others who have the potential to invade or disrupt their lives or well-being, and they lack credibility or ‘voice’ if they have the opportunity to make a complaint about their mistreatment.

According to the seminal work of Wardhaugh and Wilding on the corruption of care (1993), a number of organisational factors are in play which result in the conception of people using services as less than fully human – including the neutralisation of normal moral concerns, isolation, a failure of management and lack of accountability and an enclosure of the organisation from scrutiny. Failure to address the fundamental imbalance of power leaves people with intellectual disability vulnerable to the potential abuse of individuals and systems, as they have little recourse to change their own situations.
2.2.5 Gender and abuse

It is also important that analyses of violence and abuse do not overlook the importance of gender. Much of the literature on violence and disability concerns women with disability (see for example WWDA, 2007; Howe, 2000; Chenoweth, 1996; Curry, Hassounch-Phillips & Johnston-Silverberg, 2001). As Cockram notes:

Like women, men with disabilities also experience violence and abuse. However, it is important to attend to the significance of both gender and disability status when examining this critical issue. Meanings associated with gender roles such as wife and mother and the well-documented effects of gender discrimination in society significantly influence the abuse experienced by women with disabilities (2003, p.1).

It is important, however, to also consider the disempowered position of men with intellectual disability in disability services, particularly in their relationships with staff and management of those services.

The literature on emotional and psychological abuse of people with disability pays less attention to gender than does the literature and research on sexual and physical abuse. This may be because the material has a stronger concentration on abuse occurring within institutional and service oriented contexts, and thus people with disability are conceived more in the role of ‘clients’ or ‘residents’ than ‘men’ or ‘women’.

While gender is both relevant and important to any analysis of violence and abuse, it is overly simplistic to argue that one gender is more disempowered, or more discriminated than another in this context. Both men and women with intellectual disability are marginalised and isolated in disability accommodation services, and both are potentially victimised by emotional and psychological abuse and neglect. The technologies of that abuse may be different for women and men – there simply does not appear to be research which has considered this to date, indicating a need for studies which address these issues.
2.2.6 Models for understanding abuse

Several researchers present models of abuse which seek to understand the complex factors at play, and which go beyond the ‘bad apple’ conception of a single abuser who is acting out of malevolent intent within an otherwise wholly safe environment. These approaches share a view that there are multiple strata in which the preconditions for abuse are laid.

Penhale (1999) distinguishes three levels of institutional abuse: between individuals within the residential setting, abuse which arises due to the operational regime of the institution, and abuse which arises at a system level, caused by the broader structure of society. Penhale, in her work in the elder abuse field (Bennett, Kingston & Penhale, 1997), also talks of abuse as existing at three different structural levels – the macro (political) level, the mezzo (institutional) strata, and the micro (individual) level.

An alternative view is presented by Sobsey, who develops an integrated ecological model of abuse (1994) which draws from the work of Bronfenbrenner in the child abuse field. In essence, the model describes the interaction of culture, environment and relationships as core factors in the occurrence of abuse. His contention is that abusive incidents and relationships are influenced and made possible by power inequities, the modelling of abusive relations, the minimisation of counter-controls, and at the broadest cultural level, the provision of a rationale for power inequities in the lives of people with disability.

A third approach to understanding abuse is presented by Brown, who identifies three different frameworks for understanding abuse; according to the type of harm done, the relationship between the perpetrator and the client and/or their gender or position, and the context in which it occurs and the systems which need to be engaged to deal with it (2004, p.41-2). In this last typology, abuse falls into several categories, which have been listed in the table below:

<table>
<thead>
<tr>
<th>Abuse</th>
<th>Response needed</th>
</tr>
</thead>
</table>

33
<table>
<thead>
<tr>
<th>Ordinary crime in which the victim happens to be a vulnerable person</th>
<th>Goal to facilitate access to criminal justice system and mainstream agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuses which arise out of inequitable access to health care, benefits, housing and other service provision as a result (but also a cause of) discrimination and social exclusion</td>
<td>Requires monitoring through the collection of population wide statistics rather than documentation of individual complaints or incidents</td>
</tr>
<tr>
<td>Abuses which arise out of challenging needs and ethical dilemmas</td>
<td>Require formal, open and transparent decision-making, conducted on the basis of wide consultation, open to appeal and with the help of legal or citizen advocates</td>
</tr>
<tr>
<td>Abuses which arise out of professional or service relationships in which unequal power, institutional dynamics, poor training and low expectations conspire to produce rigid, depersonalising environments and callous or ignorant individual responses</td>
<td>These breaches of conduct and standards require action within the regulatory framework and by professional bodies</td>
</tr>
<tr>
<td>Deliberate and predatory abuse in which vulnerable people are groomed and targeted (for example by serial sexual offenders or in order to abuse financially), requiring concerted action not only on behalf of a current victim but also on behalf of future potential victims</td>
<td>These crimes are particularly morally abhorrent and justify prompt sharing of otherwise confidential information and interventions to screen the workforce</td>
</tr>
</tbody>
</table>

**Table 1:** Brown’s frameworks for understanding abuse and consequent responses required

This understanding of abuse is potentially very useful in seeking to understand emotional and psychological abuse and neglect of people with intellectual disability who live in disability accommodation services. However, abuse which has an institutional cause may be experienced by the individual in the same way as abuse which has a predatory cause – the behaviour of staff may be same in the case of emotional and psychological abuse, where the person is ignored, degraded or harassed.
It may be also be difficult to know in many cases, particularly where the person does not have conventional speech, whether the abuse they have experienced is institutional/systemic in nature or a result of the deliberate targeting of an individual person.

Each of the models presented here share the assertion that abuse occurs on multiple levels, in multiple contexts, and in interrelated ways. It is therefore a far more complex experience than can be adequately represented in a linear policy and procedural response to isolated incidents of abuse or neglect, so frequently used in disability services (as will be discussed later in this chapter).

This section of the chapter has presented some of the higher order or more philosophical arguments about why people with intellectual disability experience, and continue to experience, abuse and neglect. Dominant social constructions of disability and conceptions (or models) of disability have enormous influence on the cultural, social and structural places and roles in which people with intellectual disability are located, and this relates directly to their exposure to climates in which abuse is likely to occur.

The literature from the disability abuse field does not appear to delve into critical questions about why this form of abuse continues to be experienced by so many people with intellectual disability who live in disability accommodation services. It does, however, discuss reasons related to individual vulnerability and social and structural causes of violence and abuse which relate to this larger question. This gap may be due to the fact that much of the research in this field has been undertaken by practice based researchers or scholars with a practitioner history, including educators, social workers, psychologists and policy analysts. The review of the literature clearly shows that the abuse research landscape is both highly complex and very fragmented, and is compartmentalised into typologies of disability, abuse or marginalisation. There is an identifiable need for research which considers ‘higher order’ issues which are at play here, such as questions of citizenship, rights, humanness, and otherness.
Part two: The experience of emotional and psychological abuse and neglect

2.3 Emotional and psychological abuse and neglect of people with intellectual disability in the literature

Emotional and psychological abuse and neglect is experienced by people with intellectual disability living in disability accommodation services in many and varied ways (Jenkins & Davies, 2006; Brown, 2007; Ticoll, 1995; Horne et al., 2001; Page, Lane & Kempin, 2002):

- as a single incident
- as a pattern of behaviour (or an abusive relationship) from one individual abuser
- as the failure of an individual to provide essential emotional care
- as a series of single incidents carried out by a number of individuals
- as a series of patterns of behaviour (or abusive relationships) from a number of individuals at the same time
- as part of a behaviour management plan or treatment plan
- as a lifestyle caused by institutional routines and frameworks which influence the conduct of management, staff, and/or other residents.

Emotional and psychological abuse is poorly recognised and responded to in the lives of people with intellectual disability (Horne et al, 2001), apart from the small number of studies which directly ask people with disability about their experiences, where it features strongly as a common experience (see below for a detailed analysis of these studies). It is rarely seen as what Macfarlane describes as ‘subtle abuse in its often monotonous and sometimes threatening and cunning forms’ (1994, p.88). Few studies give attention to recovery, resistance and resilience of people
with disability in the face of this abuse and neglect – those exceptions are discussed in the following section of the chapter. As will be demonstrated in this chapter, government and service policy frameworks give little attention to addressing this form of abuse and neglect, and there are few avenues of legal redress for people who have suffered it.

### 2.3.1 Prevalence

There is little attempt to assess the prevalence of emotional and psychological abuse and neglect in the abuse literature. In any case, as will be discussed below, there are two considerably different positions on the prevalence of this form of abuse, which make any estimate extremely difficult.

Few studies give active consideration to the experience of emotional and psychological abuse and neglect. While most include it in the range of abuses experienced by people, it does not feature in discussion. Those writers who do give consideration to emotional and psychological abuse and neglect take two positions. The first assumes that the experience of emotional and psychological abuse is a separable category of abuse, and thus several studies cite figures for the experience of this form of abuse as a discrete phenomenon among people with a range of disabilities (eg. Nosek et al, 1998b; Saxton et al, 2001). The second, more dominant position states that as well as occurring on its own, emotional and psychological abuse underpins most other forms of abuse, and so is considerably more prevalent than has been recognised (Ticoll, 1994; Brown, 1999; Sobsey, 2000; Conway, 1994; Sheehan, 2000). Sobsey notes:

> Psychological abuse is the most complex form of abuse to objectively define or detect. It is also difficult to isolate from other forms of abuse because sexual abuse, neglect and even physical abuse all produce psychological harm, which can be the most devastating of all consequences (1994, p.33).
This is consistent with the literature from the child, elder and women’s abuse fields, as will be detailed further in this chapter. As well as being experienced as the sole form of abuse, emotional and psychological abuse is a precondition for a range of other mistreatments.

This study also draws from a body of work on the abuse of adults with intellectual disability which, while figures vary widely, is consistent in the assertion that all forms of abuse are experienced by many, or even most, people living in formal disability services (Sobsey, 1994; McCarthy & Thompson, 1996; Ticoll, 1994; Conway et al., 1996). Obtaining figures on the prevalence of abuse and neglect of people with disability, and people with intellectual disability, is problematic – studies use different methodologies, sampling, and definitions, making comparison difficult. No reliable prevalence figures are available. However, several researchers comment on a range of studies which show that people with disability are subjected to considerably higher rates of abuse and neglect than are people without disability (Sobsey, 1994; 2002; Brown, 1999; Calderbank, 2000; Conway et al., 1996; Nosek et al., 2001b). Figures range widely, but all point to a much higher than average experience of physical, sexual, and financial abuses. While some figures are available, the ranges between studies are so wide as to make comparison of very limited benefit. For this reason, figures are not included in this review.

Horne, Merz and Merz (2001) analyse the mental health consequences and social implications of the emotional and psychological abuse of people with disability. They contend that the prevalence of emotional abuse of people with disability is such that the impact of the trauma experienced by individuals also becomes part of a more widespread embedded social trauma. This is manifested through social and cultural practices which are largely unrecognised as potentially abusive, including those which have traditionally stigmatised and marginalised people with disability, such as institutionalisation, segregation, and isolation. This social trauma is addressed through social repression and denial, which allows abusive social and cultural practices to continue. Horne, Merz and Merz call for an increased social focus on the causes, rather than the symptomology of
abuse, and increased recognition of the impact of stigmatisation and marginalisation.

2.3.2 The place of institutional abuse

Institutional abuse is a relevant concept for this research, given that it focuses explicitly on people’s experiences in formal environments of care. Institutional abuse appears to have first been expressed as a serious issue of concern for people with disability in the early 1990s (Sobsey, 1994; Westcott, 1993; Ticoll, 1994; Chenoweth, 1995b). Two conceptions of institutional abuse have arisen. The first centres around place – the institution itself. The second centres around practices and cultures.

Sobsey defines institutional abuse as the “neglectful, psychological, physical or sexual abuse that takes place in the managed institutional care of human beings” (1994, p.90). He also contends that abuse in group homes and other community based supported accommodation environments should be considered institutional abuse if the nature of the relationship between the person being abused and the abuser is determined, at least in part, by the service system. For Sobsey, there are four factors which make institutional abuse unique - extreme power inequities between residents and staff; the collective nature of the abuse; the abuse is covered up, or the knowledge of it is not shared outside the institution; and there are clearly defined patterns of environmental influence (1994, p.91-93).

Brown understands institutional abuse to be:

not really a ‘type’ of abuse, or even just a ‘site’ of abuse, but a constellation of factors that interact to produce poor care, insensitive practice and to either provoke or condone individual or collective acts of cruelty (2007, p.2).

The sorts of practices which occur within this conception of institutional abuse include the development and maintenance of poor quality environments, oppressive routines, neglect of the needs, preferences and
aspirations of people living in the service, practices which are outside of community norms, individual and group cruelty, and negligence.

Institutional abuse is important for this research, in extending the understanding of the range and scope of behaviours that happen within the experience of emotional and psychological abuse and neglect. As is detailed elsewhere in this chapter, people with disability have a far more nuanced understanding of what constitutes abuse than does some of the academic and policy material, and institutional contexts may have an important part to play in unpacking emotional and psychological abuse and neglect in the formal service environments in which people live.

2.3.3 Research with people with intellectual disability about emotional and psychological abuse and neglect

A limited number of studies which directly ask people with intellectual disability about their abuse experiences were located in this study. This body of literature paints a clear picture of emotional and psychological abuse as a common experience in the lives of people with intellectual disability – so common that researchers reported it was not recognised by many people who participated in research to be treatment that was out of the ordinary. While small, this is an important body of work for this research. As Brown writes:

> The most complete picture comes from in-depth studies in which women [people] with learning disabilities have been interviewed directly about their experiences” (1994, p.43).

All of these studies clearly demonstrate that emotional and psychological abuse and neglect has a significant negative impact on the lives of people with intellectual disability, even when people are unable to name the abuse for what it is. The research canvassed in this section of the chapter discusses with people with intellectual disability their perceptions of abuse in broader frameworks than the more common paradigms of sexual and physical abuses.
For example, in the institutional context Malacrida asked 21 people with intellectual disability about their experiences of a time out room in an institution for ‘mental defectives’ in the UK. Using a standpoint epistemology and a narrative methodology, she found what she terms: a profoundly convincing personal and political argument against the institution’s routine and systemic violence, and ultimately, against institutionalisation itself (2005, p.535).

She notes that for most participants in the research, discussing their experiences was seen as an upsetting, but “necessary and important political and personal act” (ibid., p.524). People who participated in the research told of being humiliated, demeaned, physically assaulted, and dehumanised by staff in the process of being contained in the time out room of the institution.

Sequiera and Halstead (2002) reviewed the few studies which have included the views of people with intellectual disability about restraint and seclusion. They note that service users report strong negative feelings about restraint and seclusion, that it worsens their mental state, that it re-traumatises people with a history of abuse or rape, and that:

- they perceived those who are executing the physical intervention to be malevolent; as using the restraint to control or punish, as using unnecessary force or using physical intervention in an arbitrary way...
- [and] to be laughing or enjoying the experience (p.19).

Jones and Stenfert Krose (2006) also studied the views of service users with intellectual disability about physical restraint procedures in secure settings. They interviewed 10 people in depth, and report more mixed findings that Sequiera and Halstead. They were surprised to find an absence of emotional content in people’s responses to the questions, given the topic, and put this down to the routine place that restraint had in their lives. Participants had mixed views on whether staff enjoyed restraining them, and two participants described abusive practices. The authors caution that there may be a tendency for people with intellectual disability to be overly generous about the service they receive, and to
acquiesce to questions asked, and hence a need to take care in wording questions – they identify one of their questions as overly leading and possibly contributing to the unexpectedly positive findings of the study.

These studies highlight the importance of problematising the responses of staff and services to the ‘challenging behaviour’ that abused people may use to deal with the emotions called up by their experiences. Challenging behaviour is the term currently used in policy to describe ‘the behaviour displayed by a person with a disability that has the potential to harm themselves and those around them’. (Disability Services Queensland (DSQ), 2008a). It does, however, need to be acknowledged as a term of policy and service systems, not the language of people with disability.

Taking a broader approach to understanding abuse, the Roeher Institute (1995) conducted a large study in Canada with people with a range of disabilities, including people with intellectual disability. A narrative approach was taken, in order to tease out concerns that stories the Institute was hearing from people with disability did not reflect the definitions of abuse which were in common use in Canada. The aim of the study was to give people with disability a voice in naming violence and abuse. The researchers found that when people with disabilities were interviewed in depth about their understanding of violence and abuse, the impact of it on their lives, and how it made them feel, that:

> From that perspective, violence and abuse look somewhat different. In the experience of those with disabilities, it is not only the traditional acts of hitting, sexually assaulting or verbally abusing a person that are defined as violent. It is, in fact, a wide gamut of actions or lack of actions that create suffering or trauma. It is being pulled into an uncomfortable position. It is being isolated at home and not being allowed to go to school. It is being forced to eat food or being denied food. It is being given medication that takes away one’s sense of control. It is being left sitting on the toilet for long periods of time (p.ix).

Saxton, Curry, Powers, Maley, Eckels and Gross (2001) conducted a study with 72 women with physical and intellectual disability in the USA about
their perceptions of abuse they had experienced from personal assistance providers, both formal and informal. Only 7 of these women had intellectual disability. The researchers found that the personal assistance relationship, being carried out in the person’s home, was complex and boundaries were difficult for women to define and maintain, particularly around personal care. Overall, emotional abuse was the most highly reported form of abuse, taking forms including yelling and screaming, threats of abandonment, being ignored, threats to neglect children or pets, and violations of privacy. The authors report that the focus group approach provided a learning opportunity for many women, as the majority of participants did not recognise and define their own and other women’s experiences as abusive before discussing them with others. They state "The often subtle nature of the abuse resulted in women wondering if what they had experienced was intentional or unintentional" (p. 404).

Issues of recognition of abuse were also addressed by Collier, McGhie-Richmond, Odette and Pyne (2006) in a study where the authors worked with 26 people who use augmentative communication to address protective factors against sexual abuse. They found that while not all participants reported abuses, most of them expressed that they had "experienced or continued to experience a range of indignities and abuses in their lives" (p. 67). As with Saxton’s study, Collier and colleagues found that many of the people who participated in their study did not recognise abusive treatment to be so until they discussed it with others. They cite many instances of emotional and psychological abuse, including being threatened with the withdrawal of services, being subjected to degrading comments, being given the ‘silent treatment’ from their service providers and caregivers, being denied the right to personal autonomy and decision-making by service providers, and not being allowed to communicate by service providers.

Two studies were located which aimed to assess the traumatic impact of abuse on people with intellectual disability. O’Callaghan & Murphy (2003) included people with severe intellectual disability and their families in a study to measure post traumatic stress disorder in people who had
experienced abuse. Mitchell, Clegg & Furniss (2006) also interviewed people with intellectual disability to assess post traumatic stress disorder. Both of these studies found that the consequences for survivors of abuse were profound and long lasting.

While not including people with intellectual disability, two other pieces of research should be mentioned here, due to their similarity in approach to this study. Using a heuristic life narrative approach, Fitzerman’s doctoral thesis (1999) explored the experience of abuse with people with physical disability. Her central finding was that:

Subtle and emotional forms of abuse were experienced as common characteristics in everyday life. These forms of abuse were indicated to be represented by non-contact and contact form. Such acts were generally perceived as of a long duration, endemic in: social, familial, institutional and interpersonal constructs and detrimental to participants life’s [sic] circumstances. The implications of such abuse was seen to undermine their emotional and personal integrity, personal rights and self determination (1999, p.1)

Saxton, in her recent edited collection of narratives by people with disability about their experiences of abuse and neglect (2009), expresses concern that the internalising of messages of invalidation and powerlessness are one of the most insidious and little recognised aspects of abuse. These internalised messages not only impact on the self esteem and self worth of people, but open the door to further abuse.

There is a small but important literature which focuses on the resilience of people with intellectual disability in the face of maltreatment. Stefansdottir & Traustadottir (2006) present the stories of three women with intellectual disability who participated in a women’s history group, during which they talked about their experiences of living in a residential institution for people with disability. They found all three women actively used a variety of strategies to cope with their experiences of institutionalisation, and ‘fought to hold on to their human dignity, independence and sense of self-worth’ (p.66). Many times, these actions were interpreted by others as behaviour problems. The authors conclude that:
People with learning difficulties have historically been cast into many negative roles such as the role of the helpless eternal child or, even worse, as not human. It is therefore hard for many to relate to their common humanity and recognise their acts of resistance and resilience, even when it is openly expressed (2006, p.66).

In reviewing the existing research with people with intellectual disability about their abuse experiences, it is clear that their views add a very meaningful depth and breadth to the understanding of abuse that moves beyond physical domains and into the social and structural domains of society. It is perhaps in part because we have begun to address sexual and physical abuse, inappropriate accommodation and the physical and social exclusion of people with disability that more subtle and more pervasive forms of abuse can be aired and given serious consideration. An unmistakable need can be seen for research which explicitly seeks their thoughts and views on their experiences of emotional and psychological abuse and neglect to extend this small but important body of work.

2.3.4 Autobiographies by people with disability about emotional and psychological abuse and neglect

There is a small but growing Australian body of work by people with disability, or people close to them, about their experiences living in disability accommodation services, including their experiences of emotional and psychological abuse and neglect. These autobiographies are often hard to find, as they are frequently self published or published in small numbers - despite the absorbing stories contained within their pages they do not seem to have yet attracted a mainstream audience. Due to this difficulty, the focus of the literature review in this area was contained to Australian stories.

These works have an important place in this review, as the stories of people with disability are foundational to the research philosophy and have a central place in the approach of this research.
The autobiographies of people with intellectual disability are harder to locate than those of people with other disabilities. This may be because it is more difficult for people with intellectual disability to write their autobiography without a co-author, which brings with it a whole host of issues about ownership, financial capacity and time. A number of what Atkinson and Walmsley (1999) call ‘autobiographical fragments’ were located for this review. They are told in myriad ways – Robert Strike tells his story to a journalist in the mainstream media as an ambassador for an international day of people with disability (Bradley 2008), Doug Pentland tells his life history to a co-author and together they write a book (Pentland & Cincotta, 1995), Jane tells her story through video (Smith & Ward, 2007) and Robert Martin shares some of his past experiences as part of a conference plenary paper (2006a), which then forms the foundations of a journal article (2006b) and is also used in lobbying for the UN Convention on the Rights of Persons with Disabilities.

All of these stories share similar themes of isolation, oppression and lack of control over both minor and major areas of life when abuse happens. Each of the authors are looking back on their abuse experiences from a position of relative safety and power as respected self advocates and community members and through a lens of time passed. Some of the authors recognise emotional abuse. Robert Martin, for instance, says in his conference presentation that ‘the emotional abuse was the worst kind of all’ (2006a). Others understand abuse in more concrete terms, and talk about the bad treatment they received and its lasting impact.

For example, Jane’s video story contrasts life now with life in an institution and a community residential unit (in Smith & Ward, 2007). She tells of her early service experiences:

It was like a gaol, it was. And the nurses punished us, they did. And the punishment we got from the nurses, if we like wet ourselves or if we done something that we weren’t supposed to, the nurses would punish us and tell us to go in the corner, they would. Or go to bed early, they would, or go without food. Yes, sometimes I feel like swearing, do you
know what I mean, when it comes back? It brings back bad memories, it does. Good memories, sometimes, when you used to get away with things, not get caught.

Robert Strike, in describing his life in an institution for people with intellectual disability to a journalist for a major newspaper (Bradley, 2008, p.15), says:

It was tough, it was rough. When I was young I just watched people. I kept my mouth shut a lot, I was punished a lot, I was tied in a chair a lot ‘cause I had a big mouth.

Autobiographies by people with a range of other disabilities were also included in this review, and feature similarly abusive experiences. Without exception, all of the authors describe experiences of abuse and neglect in residential care. These experiences have had a significant impact on each of their lives. In all of their works, the authors talk about the subtle, monotonous abuses of their rights which rob them of their autonomy and their dignity, but which don’t breach the law. Several authors are repeatedly punished for complaining about these abuses. Meriel Stanger writes:

One particular nurse smacked me on my bottom for wetting the bed. I reported this nurse to the head of nursing in that department. The nurse later sought me out and gave me a hard time. I learnt after that. Make the complaint after you leave, not while you are still living there (2004, p.56).

Jan Daisley has published a two volume autobiography (2005; 2007). She chronicles time spent in a large residential institution after a catastrophic surgical accident left her with severe physical impairments, and then her move into the community into a series of group homes. Jan details a dismaying range of emotional, physical and financial abuses in her books. Many of these are the ‘drip, drip, drip’ of systemic abuse - staff who fail to turn up on time, or fail to turn up at all; rough handling; disrespectful comments. Jan’s ferocious drive and intellect - she completes two university degrees, sits on several boards of management and is politically active - do not appear to protect her from these experiences. After having
had two toes broken by a staff member pushing her shower chair into the
door jamb, and being told “not to be a wuss” (p.247), Jan writes:
people believe I can cope with anything, which is a load of hogwash. I
am like every other human being with feelings and emotions, but to
some, my dependence on a wheelchair and other people, negates my
human life and my ability to feel pain – likewise my psychological
capacity to handle the disempowerment, let alone recognise it, which is
one of my biggest bugbears... I had to be very careful with all I said and
did in case I was labelled as having a behaviour problem again (2007,
p.248).

There have been some well publicised exceptions to the small scale of
autobiographies by people with disability, such as Annie’s Coming Out
(Crossley & McDonald 1984), the story of Ann McDonald’s
institutionalisation and her ensuing legal fight to leave the facility, later
made into a movie. John Roarty’s Captives of Care (1981) described the
relationships between people living in an institution, the bleakness of
‘care’ there, and in the importance of resistance to the group in fighting
against the more extreme rigidity of imposed rules. This book was also
later made into a movie. Heather Rose’s both wrote and starred in the
movie Dance me to my Song (de Heer, 1998), which paints an intimate
picture of the emotional and physical abuse inflicted on Julia by her
support worker. Although the film was fictionalised, and not a
documentary, Heather has said in interviews that she drew from her lived
experience as a woman with severe cerebral palsy in writing the
screenplay.

These autobiographies together paint a picture of deprivation and ill
treatment. However, that is not their sole, or perhaps even primary
contribution. They are important voices of resistance, of personal growth,
and stories of people developing a degree of power over the structural
forces which contained them while they were abused. While resilience and
resistance are important themes in each of the works, they do also
highlight the differences in the lives of the authors and many people with
disability who remain living within the disability services system – it is no
coincidence that only one of these authors is still engaged in the disability services system.

### 2.4 Emotional and psychological abuse and neglect of other marginalised groups

The literature on abuse of other groups of people has a considerable amount to offer this study. The value of this material lies in the fact that research into the experiences of other groups, particularly children, is differently developed than the literature into abuse of people with intellectual disability. Consequently, models of understanding emotional and psychological abuse have developed and been considered in alternative ways.

Caution must be exercised in comparing the abuse experiences of people with intellectual disability with other groups who are marginalised. The life path and experiences of adults with intellectual disability who live in formal disability services is considerably different than that of children, women and elderly people (Stanley, Manthorpe & Penhale, 1999). Their experience of discrimination and marginalisation is different, and their historical experience of isolation and segregation is certainly different. However, there is value in drawing from these models and frameworks of understanding abuse to develop a more robust understanding of the features of emotional and psychological abuse and neglect of people with intellectual disability, particularly the focus on resilience from the women’s abuse field and the shared conception of the damage that emotional abuse does to children.

#### 2.4.1 Emotional and psychological abuse and neglect of children

There is a considerable literature addressing the emotional and psychological abuse of children, both in Australia and internationally. One
of the primary benefits of this literature when applied to people with intellectual disability is its focus on the development of clear definitions and criteria for identifying emotional and psychological abuse, and for the clarity which with some of this literature distinguishes between emotional and psychological abuse.

The child abuse literature appears to be fairly consistent with regards to definitions of emotional and psychological abuse. Several authors (Iwaniec, Larkin & Higgins, 2006; Tucci & Goddard, 2003) draw from the work of key researchers Garbarino, Guttman and Seely, (cited in Tucci & Goddard, 2003), Glaser (2002) and O’Hagan (1993) in identifying the critical elements of emotional and psychological abuse.

Drawing together the findings of these seminal writers, the key features of working definitions of emotional and psychological child abuse include:

- **Rejecting**: Behaviours which communicate or constitute abandonment of the child, such as refusal to show affection.
- **Isolating**: Preventing the child from participating in normal opportunities for social interaction.
- **Terrorising**: Threatening the child with severe or sinister punishment, or deliberately developing a climate of fear or threat.
- **Ignoring**: The caregiver is psychologically unavailable to the child and fails to respond to the child’s behaviour.
- **Corrupting**: Caregiver behaviour which encourages the child to develop false social values that reinforce antisocial or deviant behavioural patterns, such as aggression, criminal acts or substance abuse.

Glaser (2002, p.703-4) adds to these categories conditional parenting, insecure attachment, denigration and emotional unavailability.

There is agreement in the literature that the experience of emotional and psychological abuse is more common that usually recognised, and more commonly experienced than other forms of abuse (O'Hagan, 2003; Glaser, 2002; Tomison & Tucci, 1997; Iwaniec et al., 2006; National
Working Group on Child Protection and Disability, 2003). This is primarily due to the fact that emotional and psychological abuse generally underpins other forms of abuse (such as sexual and physical abuse), and also occurs without those other forms of abuse being present.

The child abuse literature contains a far stronger emphasis on the impact, outcomes and damage done to children by this form of abuse than does the literature in either the disability or elder fields. There is consensus in the literature that the impacts of emotional and psychological abuse and neglect on children can be severe, far reaching and have a myriad of consequences (Glaser, 2002; Kairys, Johnson et al., 2002; Veith 2004), all centring around the damage done to the child’s sense of self and their understanding of the ways in which they relate to the people and world around them.

A further division exists in the literature around the distinction between emotional and psychological abuse. The bulk of authors do not distinguish between emotional and psychological abuse, considering them to be the same thing. Child abuse theorists such as Glaser (2002) state that cognition and emotion are inseparable, and it is therefore unnecessary to make a distinction between emotional and psychological abuse. There is, however, a counter view, expressed by O’Hagan. O’Hagan (1993; 1995; 2006) has written extensively on the experience of emotional and psychological abuse and neglect in children. While acknowledging that the two are closely linked and entwined, he considers emotional abuse to be:

the sustained, repetitive, inappropriate emotional response to the child’s expression of emotion and its accompanying expressive behaviour (1993, p.28).

Psychological abuse is defined by O’Hagan as:

the sustained, repetitive, inappropriate behaviour which damages, or substantially reduces, the creative and developmental potential of crucially important mental faculties and mental processes of a child:
these include intelligence, memory, recognition, perception, attention, language and moral development (1993, p.33-34).

In effect, according to O’Hagan, emotional abuse will impact on children’s socialisation and social life, and impair their understanding of emotions in themselves and others. Psychological abuse will undermine the child’s attempts to understand the world around them, make it familiar and manageable, confuse and frighten them, and impair their confidence.

O’Hagan (1993), in his work on the impact of emotional abuse on children with disability, also draws on his own work and the work of others to state that these children may be at greater risk of being severely affected by their experiences of emotional and psychological abuse.

There are many views across the child protection field, and in concluding this section, which has focused on very specific behaviours which may make up this form of abuse, perhaps the views of an unnamed commentator, cited in Vieth (2004, p.2), are worth bearing in mind:

   Emotional abuse is, simply, all the rest, the excess within child abuse after physical abuse and sexual abuse are specifically defined. Any imaginative form of cruelty visited on a child that is not a beating or a sexual contact is psychological abuse.

2.4.2 Emotional and psychological abuse and neglect of older people

A considerable volume of work has been written on the issue of elder abuse, predominantly focusing on the domestic sphere, and the interaction between elders and carers (Slater, 2000; Biggs, Phillipson & Kingston, 1995; Bennett et al., 1997). A significant amount of this literature focuses on recognition of abuse and strategies to counter it. A small number of studies were located which have focused on gathering the views and experiences of older people who have been abused. Nandial and Wood point out the importance of studies which centre on those who have experienced abuse, noting that by focusing on the understandings of
abuse that people have gained from their experience of it, “we may identify possibilities for change that go beyond attempts to alter subversive actions in isolation” (1997, p.7).

Biggs, Phillipson and Kingston (1995) identify the need for a multi-layered approach to understanding the emotional and psychological abuse and neglect of older people – focusing on the individual situation, the organisational level, and the higher systems level at which interactions and understandings of power dynamics which surround caring relationships, and which takes the historic context into account. This has clear parallels with disability researcher’s analyses of the causative factors of abuse of people with disability (Sobsey, 1994; Westcott, 1993; Brown, 1994; White et al., 2003), as discussed earlier in this review.

Elder abuse writers appear to find more common ground with the women’s abuse and domestic violence literature, arising from a concern that elderly people and children occupy very different social, political and structural places in society. Several researchers have noted that both elder abuse and child abuse paradigms have been constructed by professionals, with the aim of protecting people and ‘solving’ the problem. They have not grown from a grass roots, feminist perspective, as has the domestic violence and women’s abuse literature (Bennett et al., 1997). Abuse of people with intellectual disability clearly falls into this category, and it is valid for this study to note that there is a need for grass roots involvement in defining, recognising and designing responses to abuse and neglect.

2.4.3 Emotional and psychological abuse and neglect of women

The literature on emotional and psychological abuse and neglect of women is almost wholly within the domestic sphere. The bulk of the literature relates to spouse abuse, or abuse within intimate relationships (eg.,
Champagne, 1999; Barile, 2002; Springtide Resources, 2000). Barling identifies this trend, noting that:

The small amount of literature published exclusively on emotional abuse is understandable given the lethal characteristics of physical abuse and the struggle of academics and professionals to develop a measurable and precise definition. However, the lack of a precise definition and a focus on treatment specifically for these women may be contributing to the trivialization of this phenomenon in our society (cited in Packota, 2000, p.4).

As with the elder abuse field, there is a considerable volume of material which focuses on the defining and understanding of emotional and psychological abuse, and strategies for women to firstly extract themselves from its grip, and secondly to recover from it. Here the literature differs from the other areas – the disability, child and elder abuse fields focus much more strongly on identifying potential impacts of abuse, and very little on how people can recover from the experience.

Packota proposes considering emotional and psychological abuse on a continuum. On one end are isolated hurtful behaviours that may occur in any relationship; at the other end is “pervasive, one-sided, severe psychological torture” (2000, p.4). McKinnon (2008) also subscribes to this view, and draws a useful distinction between emotional and psychological abuse in the domestic violence arena. She contends that there is significant overlap between verbal abuse, emotional abuse and psychological abuse, but that they are three categories of abuse. She argues that:

Emotional abuse almost always incorporates verbal abuse and psychological abuse almost always incorporates emotional abuse. Verbal abuse becomes emotional abuse when it continues over time and has the potential to negatively affect the target person’s emotional development and behaviour. Emotional abuse becomes psychological abuse when it continues over a prolonged period, incorporates a power differential and has the potential to erode the target person’s sense of self and social competence (2008, p.12).
In theory, distinctions between the forms of emotional and psychological abuse can be seen. In practice, it may not be as important to distinguish between them. Certainly, the bulk of researchers in the field have not felt the need to dwell on the distinction. However, McKinnon’s understanding of psychological abuse is very pertinent to an analysis of abuse of people with disability which draws on the use and relations of power (as is conducted in this chapter).

A distinction between emotional and psychological abuse, in which psychological abuse represents a deeper, longer term, power conflicted set of circumstances in which a person’s sense of self and social competence is threatened may be very useful to this research. It may help to understand how long term institutional practices help to create a ‘client’, and to create a set of circumstances in which the continued mistreatment of people with intellectual disability is almost inevitable.

### 2.4.4 Mandatory reporting of abuse and neglect

The question of mandatory reporting of emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services is a somewhat vexed one. Mathews and Kenny note:

> Law and policy concerning the detection and reporting of, and the responses to, abuse and neglect are theoretically and practically complex, and exist alongside political, economic, social and cultural forces in each society (2008, p.51).

While several benefits are identified in the literature, on balance, the view of many authors is that more vigorous and rigorous implementation of existing legislation and safeguards may be of greater benefit than mandatory reporting legislation, policy and practice.

In the USA, Canada and Australia, mandatory reporting of abuse and neglect is in place (albeit with variation in reporters and types of abuse reported) for child abuse and elder abuse. Some states in the US and
some Canadian provinces have mandatory reporting of abuse of people with intellectual disability, particularly those living in care facilities (Mathews & Kenny, 2008; Accessing Safety Initiative, 2006; Canadian Network for the Prevention of Elder Abuse, 2009). The benefits of these regimes are considered to be:

- to symbolically acknowledge the seriousness of abuse and increase awareness of both professionals and the community at large (Higgins et al., 2009)
- they may provide incentives for professionals to obtain information and to train staff about abuse (Macolini, 1995)
- they pre-empt moral dilemmas and impose a public duty on professionals, and a moral responsibility on community members, thus overcoming a reluctance to report abuse and neglect (Higgins et al., 2009; Macolini, 1995)
- more reporting enables the gathering of more comprehensive data on demographics and prevalence, which can be used in developing effective responses (Macolini, 1995).

However, there is considerable criticism of mandatory reporting regimes in the literature. Foremost among these is the concern that inadequate resourcing of mandatory reporting systems can result in people being worse off than they would be without the reporting structure, while making the community feel something is being done to address the problem. In a climate of limited resources, the funds used to operate a mandatory reporting system may reduce the number and range of community based services available to respond to the abuse identified (Higgins et al., 2009; Elder Abuse Prevention Unit, 2006; Macolini, 1995).

When resources become stretched, some child protection departments have raised that threshold of abuse which is recognised as triggering action. When reporters report abuse, they expect action. In the event that this does not happen, there is a risk that they will not report the next time they encounter someone who has experienced abuse (Higgins et al., 2009).
Elman (2005, p.6), in writing on sexual abuse of women with disability, points out that ‘context, public perception, and an appearance of official indifference matter’. However, mandatory reporting is not seen by a number of writers as a solution to indifference and invisibility (Higgins et al., 2009; Macolini, 1995; Mitchell & Buchele Ash, 2000). In part, the problem may be not so much the lack of legislation, but more the lack of understanding of existing legal and moral requirements of some service providers. It is argued, for example, that the duty of care obligations of service providers to their clients already require them to report and address abuse and neglect (Elder Abuse Prevention Unit, 2006). Mandatory reporters of abuse and neglect under existing schemes (such as doctors and teachers) have been identified as needing compulsory training in order to increase rates of reporting - another indication that the moral and legal responsibilities of both service providers and other associated professionals are not always taken up (Mitchell & Buchele Ash 2000). This is highly pertinent to the disability field, where the understanding of service providers of duty of care may be far from ideal.
Part three: Defining emotional and psychological abuse and neglect

2.5 Defining emotional and psychological abuse and neglect

Emotional and psychological abuse and neglect is difficult and complex to define, and remains a source of debate in the literature for many reasons (Penhale, 1999; Glaser, 2002; McKinnon, 2008). It is undoubtedly harder to identify than other forms of mistreatment. No injury can be seen, unless the person has also undergone physical or sexual assault. The impact of emotional and psychological abuse, while it can be severe, may be cumulative, reliant on a sustained attack on the person’s psyche (Iwaniec et al., 2006). Unlike sexual or physical assault, emotional and psychological abuse may be unintentional on the part of the abuser (as in the case of a staff member following an unnecessarily restrictive behaviour management plan). It is also difficult to isolate from other forms of abuse because other forms of abuse also include emotional or psychological harm (Sobsey, 1994; Kairys et al., 2002). Some authors argue that it is more strongly associated with the domain of omission whereas most other forms of abuse and assault reside within the domain of commission, or action – so neglect may have more complex role to play than in other abuse areas (Glaser, 2002; Sobsey, 1994).

2.5.1 Existing definitions of emotional and psychological abuse and neglect

A range of definitions of emotional and psychological abuse can be found within the disability literature and within both government and non-government policy and guideline documents. Often they are short and
non-specific in nature. This may be a reflection of the very difficult ethical and moral judgements that practitioners need to make in taking action when abuse is suspected (Brown, 1999). The fact that so many policy documents seem to share a definition may also reflect the fact that little attention has been paid to this form of abuse in the Australian disability sector to date.

2.5.1.1 Emotional and psychological abuse and neglect in policy

The Australian government has laid down the definitions of abuse and neglect which have been taken up by state governments and many non-government agencies. They are comprehensive and include definitions of emotional and psychological neglect, and also emotional neglect.

The Commonwealth, through the Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) was closely involved in the development of definitions of abuse and working towards solutions to the high rates of abuse of people with disability in disability services in the early 1990s. This focus appears to have dwindled with several restructures of administrative responsibility for programs and funding between departments and jurisdictions, and the Commonwealth presence on abuse and neglect is now primarily publicly represented through the funding of the Disability Abuse and Neglect Hotline (the Hotline).

The Hotline, a telephone response and referral agency, offers the following definition of emotional and psychological abuse and neglect:

Verbal assaults, threats of maltreatment, harassment, humiliation or intimidation, or failure to interact with a person or to acknowledge that person’s existence. This may also include denying cultural or religious needs and preferences (2009).

The Hotline also operates with a specific definition of emotional neglect. It breaks neglect into categories of physical, passive, wilful deprivation and emotional neglect. Emotional neglect is understood as:
the failure to provide the nurturance or stimulation needed for the social, intellectual and emotional growth or well being of an adult or child (2009).

Key government departments with a responsibility for preventing and responding to emotional and psychological abuse and neglect of people with intellectual disability in Australia operate under definitions almost identical to that of the Hotline. Disability Services Queensland (DSQ), the funding agency responsible for services in the state used by people involved in this research includes the same definitions of both emotional and psychological abuse and emotional neglect as does the Hotline. The establishment of an unambiguous definition of both emotional and psychological abuse and neglect in the Queensland government policy is useful for this research, as it provides a clear expectation of the treatment which the government deems unacceptable for people with intellectual disability receiving services – which will be seen in their testimonies to have been frequently experienced.

Overseas, the United Kingdom appears to operate under somewhat broader policy definitions, although still distinguishing between various types of abuse and neglect. For example, No Secrets, the UK government guidelines on protecting vulnerable adults from abuse and neglect (2000), includes the following definition of psychological abuse:

including emotional abuse, threats of harm or abandonment, deprivation of contract, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks (p.9).

In Safe Hands, the Welsh policy on abuse prevention, defines psychological abuse as “including threats of harm or abandonment, humiliation, verbal or racial abuse, isolation or withdrawal from services or supportive networks” (2000, p.15). This document does not include emotional neglect in its definition of neglect.
A series of other laws and policies from comparable overseas jurisdictions define abuse much more broadly, not breaking it down in component categories. For example, the Manitoba, Canada Vulnerable Persons Living with Mental Disability Act (1996) defines abuse as:

mistreatment, whether physical, sexual, mental, emotional, financial or a combination thereof, that is reasonably likely to cause death, or that causes or is reasonably likely to cause serious physical or psychological harm to a vulnerable person, or significant loss to his or her property (1 (1)).

The Act is primarily about guardianship and substitute decision making, but it also lays out the conditions for mandatory reporting of abuse by service providers and guardians and powers of investigation of the abuse allegation, and protective action including removal of the person to a safe place. This definition and framework is carried through into policy.

In California, the Lanterman Developmental Disabilities Services Act (1977) refers to abuse as it is defined in the California Penal Code, the Welfare and Institutions Code and the Federal Code – this linking to other pieces of legislation may be potentially useful to a person seeking to take legal action against an abuser. The Act also establishes a protection advocacy agency which is mandated to support and advocate for the rights of the victim.

Comparable overseas jurisdictions take a broader view of abuse policy than does Australia, placing it within a context of prevention, protection and multi-agency cooperation in responding to incidents. Australian high level abuse policy sets a framework of prevention, response and protection, but does not contain a multi-agency focus, having more a focus on containment and resolution of individual problems. It is helpful for this research that specific definitions are in play in the Australian policy context, in order to be able to assess the experience of people with disability living within disability services which are within the remit of those policies.
2.5.1.2 Emotional and psychological abuse in the disability abuse literature

Much of the disability literature includes reference to emotional and psychological abuse as one of many forms of abuse, and does not define it in any detail.

Women with Disabilities Australia, in their global review of violence against women with disabilities, draw from the work of many researchers to define emotional or psychological violence as:

the infliction of anguish, pain, or distress through verbal or non-verbal acts and/or behaviour. It results in harm to a person’s self-concept and mental well-being as a result of being subjected to behaviours such as verbal abuse, continual rejection, withdrawal of affection, physical or social isolation and harassment, or intimidation (2007, p.33).

Other definitions in the disability abuse literature include reference to lack of love and affection, corrupting, belittling, threats, verbal attacks, taunting and shouting which leads to the victim’s loss of confidence and self-esteem, and omissions of care that produce harm (Westcott, 1993; Ticoll, 1994; Nosek et al., 2001b; Conway, 1994). Saxton takes an interesting approach, and rejects an incident based notion of abuse. She and her colleagues at the World Institute on Disability state:

We regard abuse as a continuum of systematic mistreatment, extreme or subtle, the visible version of disability oppression (2009, p.3-4).

Nosek, Clubb Foley, and Howland define emotional abuse in their study as “being threatened, terrorised, corrupted, or severely rejected, isolated, ignored or verbally attacked” (2001a, p. 180). Ticoll (1994) writes at length about features of emotional and psychological abuse which have particular resonance in the lives of people with disability. These include threats by attendant care workers (this also appears strongly in the work of Powers et al., 2002), threats by social workers to remove children, threats of institutionalisation, verbal taunts from neighbours or strangers on the street, and lack of respect by caregivers. Ticoll quotes a
respondent in their study as saying ‘the climate of insult is present all the time, everyday’. (1994, p.13)

Several practice and policy manuals reviewed in the course of this study contain checklists of physical indicators and behavioural signs of abuse (Bhargava, 2006; Page et al., 2002; Disability Services Queensland, 2007b). There is a difficult balance between providing guidance for staff who may not perceive emotional or psychological harm without some assistance and narrowing the conception of emotional and psychological harm to such an extent that service recognition to it is formulaic and only occurs to particular instances of its occurrence. The work of Page, Lane and Kempin (2002) includes an analysis of the environmental and cultural causative factors of abuse and neglect, which places a checklist in a broader context. Without this context, there is a considerable danger that workers may not have the knowledge and skill needed to interpret behavioural or physical indicators of abuse effectively, or to take appropriate action if they do.

2.5.1.3 Emotional and psychological neglect in the disability abuse literature

Neglect is represented in two ways in the disability abuse literature. One conception is broadly as form of abuse (as is sexual abuse, physical abuse, financial abuse, and so on) which occurs in the lives of people with intellectual disability, not just in their emotional and psychological lives (Horne et al., 2001; Nosek et al., 2001a; Kovener, 2000; Ticoll, 1994). This is reflected in Australian policy and resource documents, and neglect is most often represented in ways similar to “a failure to provide the basic physical and emotional necessities of life” (DSQ 2007a, p.8) or “the failure to provide adequate support, food, shelter, clothing or hygienic living conditions” (Verick & Fullwood 1998, p. 10.6.1).

Davies and Jenkins (2006) argue that abuse literature has not fully engaged with a broader definition of neglect. Their research found that because acts of neglect stem from the activities of daily living, they are
less likely to be seen by visitors or inspectors. As well, they found practitioners to have a different attitude towards neglect, and a far lower recognition of it. Conway, Bergin and Thornton (1996) also consider neglect in some detail, and included questions around how neglect was conceived in a large scale national study of abuse and neglect in residential care. Their findings were that the majority of respondents saw that neglect was a type of abuse, but distinguished between unintentional and premeditated or deliberate neglect. Their analysis was that unintentional neglect had insufficient intentionality to be termed abuse.

The second conception of neglect in the disability literature is as a more specific form of emotional and psychological neglect (Sobsey, 1994; Conway et al., 1996; Manthorpe & Stanley, 1999; Page et al., 2002). The child abuse literature also consistently recognises emotional and/or psychological neglect (O’Hagan, 2006; Glaser, 2002; Iwaniec, 2006). The bulk of this material mentions emotional or psychological neglect as a category, without discussing its experience or impact.

Sobsey is one of the few writers who specifically discusses emotional neglect in the literature. He states that:

Neglect is perhaps the most insidious form of abuse; in extreme form it may be one of the most damaging... Emotional or developmental neglect occurs when an individual is deprived of basic human interactions required for the development of normal behaviour (1994, p.34).

There does not appear to be a robust literature engaging with the problem of emotional and psychological abuse and neglect of people with intellectual disability, particularly those living in disability accommodation services. This may be a fruitful area for further investigation, given earlier recognition by several authors of the prevalence of abuse in people’s lives (Sobsey, 1994; Ticoll, 1994; Conway et al., 1996).
2.5.2 A framework for understanding emotional and psychological abuse and neglect of people with intellectual disability who live in disability services

Drawing from the literature on abuse and neglect of people with disability, children, older people and women, a framework for understanding emotional and psychological abuse and neglect has been developed for this study. The framework provides detail on the possible range of abuses which could occur in this domain, and allows for the classification of those abuses into key theme areas. A tool for recognising some of the behaviours which occur in this sort of abuse and neglect has also been developed which visually represents some of the features of this form of abuse (Figure 1). It has been adapted by this researcher from the work of Kovener (2000).

![Power and control wheel](image_url)

**Figure 1:** Power and control wheel – adapted from Kovener, 2000
At the centre of the wheel is power and control. The key assumption of the framework is that the experience of emotional and psychological abuse and neglect in disability accommodation services is intimately connected to abuses of power and control. This assumption builds from the literature on power relations, and on conceptions and constructions of disability which influence service design and delivery (Marsland et al, 2007; Lindemann Nelson, 2001; Chenoweth, 1995b; Mandeville & Hanson, 2000). This body of work consistently holds that imbalances of power and control are inherent in disability services, and if unaddressed, create a climate in which abuse and neglect is likely to occur, as discussed earlier in section 2.2.4.

There are occasions in the lives of people with intellectual disability where it may be appropriate, and even necessary, that others take control – for example, where someone is in the grip of a seizure, or where a person is unable to understand the use of money. However, these individual actions of control need to occur within a broader framework that addresses the balance of power and control between ‘client’ and worker in order to minimise the risk of abuse and neglect. Assisting service providers to distinguish between necessary control and abusive control is an important endeavour.

Within this climate or systemic environment, the experience of emotional and psychological abuse is conceived as encompassing several characteristics. These characteristics, or themes, have been drawn from the child, women’s, elder and disability abuse literature (Tucci & Goddard, 2003; O’Hagan, 1995; Biggs et al.,1995; Champagne, 1999; Kovener, 2000). They are:

**Terrorising:** Coercing; threatening to hurt; frightening; intimidating; withholding basic support and rights; terminating relationship and leaving the person unattended; reporting non-compliance with a program; using more intrusive equipment; using consequences and punishments to gain compliant behaviour; pressuring the person to engage in fraud or other crimes.
**Corrupting/exploiting:** socialising a person into accepting ideas or behaviour which oppose legal standards; using a person for advantage or profit; training a person to serve the interests of the abuser.

**Caregiver privilege:** treating the person like a child or servant; making unilateral decisions; defining narrow, limiting roles and responsibilities; providing care in a way to accentuate the person’s dependence and vulnerability; giving an opinion as if it were the person’s opinion; denying the person the right to privacy; ignoring; discouraging; prohibiting the exercise of full capabilities.

**Isolating:** controlling access to friends, family and neighbours; controlling access to phone, TV, news; limiting employment possibilities because of caregiver schedule; discouraging contact with the case manager or advocate.

**Minimising, justifying and blaming:** denying or making light of abuse; denying physical and emotional pain; justifying rules that limit autonomy, dignity and relationships for program’s operational efficiency; excusing abuse as behaviour management; excusing abuse as caregiver stress; blaming the disability for the abuse; saying the person is not a ‘good reporter’ of abuse.

**Withholding, misusing or delaying needed supports:** using medication to sedate the person for agency convenience; ignoring equipment safety requirements; breaking or not fixing adaptive equipment; refusing to use or destroying communication devices; withdrawing care or equipment to immobilise the person; using equipment to torture the person.

**Degrading:** punishing or ridiculing; refusing to speak; ignoring requests; ignoring person; harassing; humiliating; ridiculing the person’s culture, traditions, religion; ridiculing personal tastes; enforcing a negative reinforcement or behaviour program the person doesn’t consent to.
Neglecting: failing to provide nurturance; failing to provide stimulation.

While the themes of degrading, terrorising, corrupting/exploiting, and isolating are common to all abused groups and environments, the themes of caregiver privilege, minimising, justifying and blaming and withholding, misusing and delaying needed supports are used here specifically in relation to the ‘care’ environment.

The child abuse literature also offers categories of rejecting and denying emotional responsiveness (Tucci & Goddard, 2003; O’Hagan, 1995). In the disability accommodation services setting, these have been incorporated into the concepts of caregiver privilege, and minimising, justifying and blaming. It should be noted, however, that this definition and model are specific to this environment.

Neglect is included in the wheel, but conceptually needs to be seen as an integral part of emotional and psychological abuse, where the omission of action may be as damaging as the commission of abusive action (as in the case of a person who does not learn to use a communication device due to lack of staff assistance to do so). Neglect can be seen in (at least) two ways, as a failure to provide nurturing or emotional support, and as a failure to provide stimulation.

It is intended that this framework for understanding emotional and psychological abuse and neglect be tested against the experiences of the people with intellectual disability who participate in the research. It is critical that a definition or framework has resonance with the lived experience of people with intellectual disability in order to accurately reflect the sorts of abuse that they endure. There are weighty cultural, environmental and organisational pressures brought to bear on the experience of abuse which influence both the way in which it is experienced and the way in which it is responded to. Some of these pressures influence the descriptions of abuse, and may result in
definitions of abuse which are dominated by a professionalised understanding of abuse, with service responses to allegations of assault uppermost in mind, rather than an understanding which is developed from lived experience. As Manthorpe notes in her work with people with intellectual disability about their perceptions of abuse:

listening to individual’s voices, however, reminds us that abuse is often subjective (1999, p.115).

Opinion on expansive definitions of abuse and neglect is divided in the literature. Some authors consider the range of abusive behaviours to be virtually inexhaustible, and contend that there is risk in developing a ‘checklist’ of abusive behaviours, particularly in the case of abuses which may not have tangible indicators (Conway et al, 1996; Brown, 1997; Veith, 2004). This may encourage formulaic responses - if a worker discovers that an abusive behaviour is not on the list, for example, then there is a risk they will not take action to end the abuse occurring in the life of the person with intellectual disability. As Brown maintains:

it is the identification of abuse within the context of a number of more or less closed interlocking systems that is problematical rather than the definition (1999, p.97).

There is also a body of research which builds a case that the disability sector focuses far more on responding to abuse once it has already occurred than on preventing it from occurring in the first place (White et al, 2003; Marsland et al, 2007; Page et al, 2002). In part, this may be due to a lack of capacity to recognise the more subtle signs of abuse. WWDA (2007) points out that any definition needs to incorporate the structural roots of violence so that analysis can be meaningful, and Bright cautions that:

Producing definitions, while useful to those whose work involves them in writing policies and procedures, may have the effect of disguising the routine indignity that many people may be exposed to day by day, throughout the day and possibly night time too (1999, p.128).

However, in order to better understand a comparatively under researched and little considered form of maltreatment, there is value in developing a
framework for understanding emotional and psychological abuse and neglect which goes into some detail in describing the sorts of behaviours and interactions which can occur when it is inflicted, and which is tested against the experiences of people who have experienced this sort of abuse and neglect. In a climate in which gross physical and sexual abuses of people with intellectual disability are often poorly responded to (Sobsey, 1994; Chenoweth, 1995b; Fawcett, 2008; Howe, 2000), there may be even less hope of subtle abuses being recognised and acted upon without clear and direct identification through definitions which have been developed with people who have lived through the experiences themselves.
Part four: Contextualising disability accommodation services

2.6 Disability services in Australia

This section of the chapter describes the way in which accommodation services for people with intellectual disability are organised in Australia, with a particular focus on Queensland, the state in which the study is conducted. The view of researchers on the relationship between service structures and abuse and neglect is considered, and relationships between some service models and a potential increase in the risk of abuse suggested. The legislative and policy responses to abuse and neglect in Australian and comparable overseas jurisdictions are detailed, and reports of inquiries into abuse and neglect in disability services which have been conducted in Australia are noted. Finally, research on training and education about abuse and neglect for management, workers, and people with intellectual disability is considered.

2.6.1 Accommodation services context

Structure of services
According to the latest available figures, 3% of the total Australian population in 2003, or 588,700 people, had intellectual disability. Approximately 67,000 people used accommodation support services or lived in institutions, group homes, boarding houses or other supported accommodation types in that year (AIHW, 2006, p.29). Approximately 15% of this population used accommodation support services in Queensland.

Accommodation services which support people with intellectual disability in Australia take three main forms – institutional settings, which include
segregated institutions, hostels and boarding houses (in which approximately 5,000 people resided across Australia in 2003); group homes, which support 4 – 6 people to live together in a shared household with staff support (in which around 11,000 people lived across Australia); and alternative accommodation types, such as smaller group living, and individual supported living (in which about another 17,000 people with intellectual disability live across Australia) (AIHW, 2006, p. 29). All three forms share some level of staff support, which in the case of boarding houses is often extremely limited. All except private hostels and boarding houses receive government funding.

In 2003 in Queensland, 4,933 people received accommodation support (support hours in rented or owned accommodation); 935 people lived in residential institutions; 903 resided in group homes; and 3,228 lived in other accommodation types in which they received support. In summary, 10,000 Queenslanders with disability were in close contact with funded staff in a residential context, the bulk of them people with cognitive disability (AIHW 2006, p.29).

Government funding to disability services is organised through the Commonwealth/State/Territory Disability Agreement (CSTDA), in which the Commonwealth Government takes primary responsibility for the organisation of funding of employment services, and the States take primary responsibility for the operation of funding of accommodation, respite and community access services. In 2003, accommodation services received $1,638 million in funding across Australia (AIHW, 2006).

**Quality of service provision**

The literature shows a high degree of consistency around the features of effective approaches to accommodation and support for people with intellectual disability. They are fundamentally linked to a focus on the individual, and to supporting and facilitating the connection of the person in a range of relationships and with a range of communities of their choosing.
MacArthur (2003, p. 26-29) identifies some of the features of current good practice in daily living support organisations as being flexible service structures with flexible staffing, operating with flattened management structures. They separate the provision of housing and support, operate within flexible provision of housing, and are not locked into bricks and mortar. Individual clients have freedom to move around the service structure according to their need and preference, and they are encouraged and supported to use other personal supports and to access generic services.

Additionally, a range of researchers identify features of effective approaches as recognising and responding to:

- the importance of the relationships people have with family, friends and community, and working in a way that respects and resources these relationships (Fisher et al., 2007a; O’Brien, 1993; Felce, 2000).
- decision making and authority which is vested in people with intellectual disability and their families and supporters (Epstein-Frisch, Van Dam & Chenoweth, 2007)
- the need for the preferences and demonstrated enjoyment of people with disability to dictate their living arrangements (Cummins & Lau, 2003; Felce, 2000)
- the need for skilled and well trained staff (Fisher et al., 2007a; Mansell et al., 2007)
- a strong focus on planning – not just about service activities, but about things needed to live a good life. Part of planning relates to service activities, but only as far as how they contribute to a higher goal. (MacArthur, 2003)
- choice by people with disability exercised over both day to day and large scale issues (Finlay, Walton & Antaki, 2008)
- engagement in ongoing domestic and personal activities (Emerson, 2004)
- the importance of ordinary patterns of living (MacArthur, 2003)
- the need for multiple strategies to promote and facilitate the inclusion of people with disability in the community (Bigby, 2004)
- support of good health
change over time – in the way people are supported, the amount of support, where support is provided, and how it’s provided (Goggin & Newell, 2005).

Empirical studies on the quality of service provision to people with intellectual disability have shown that community living models have, in many cases, not delivered on the promise of a fully included and valued life in the community. The quality of life of people living in group homes has been consistently demonstrated to be superior to that of people living in institutions, but not as high as for people living in more individualised arrangements (Emerson, 2004; Bigby, 2004; Stancliffe & Keane, 2000). However, studies also note that there is a high degree of variation within models of supported accommodation – to the extent that a well run institution may provide better quality of life than a poorly run group home. As Felce notes:

The high variation in outcomes between ostensibly similar examples of community housing services implies that there is not yet a complete understanding of the factors which are necessary within the design and operation of services for a decent quality of life to result (2000, p.35).

This lack of definitive evidence makes it harder to differentiate between good and poor quality options for funding and government endorsement. In a climate where cost is of increasing importance to governments, the lack of hard data on the superior performance of a particular model over others means there is considerable risk that governments will make cost effectiveness their primary consideration in funding new services for people with intellectual disability (Mansell, 2006; DiRita et al., 2008).

2.6.2 Relationship of service structures to abuse and neglect

It is argued by some authors that there has been a fairly pragmatic and linear movement between legislation, policy and practice in disability services. This linear shift fails to give adequate space to reflect on the issues surrounding the ‘big picture’ of abuse and neglect, such as culture,
environment and the impact of funding rules and regimes. The result of this approach is a service framework which has significantly improved in terms of its acknowledgement of the categories of abuse and neglect. However, it is questionable whether the incidence, experience and responses to abuse and neglect have been affected by these changes (Burgess, 1997; Robinson & Chenoweth, 2005).

Page, Lane & Kempin found in a national review of abuse prevention strategies in Australian disability services that development of abuse prevention within state departments:

has typically been reactive, following major service reviews or investigations that have identified systemic and extreme abuse. There does not appear to be a consistent approach to identifying, examining and learning from patterns of abuse and violence across the broad range of service types and experiences of people with a disability (2002, p.84).

The inclusion of abuse and neglect in policy and procedure for services is essential so that staff and management may have consistent ways to respond to its occurrence. However, the policy focus does give rise to a situation where abuse and neglect may be considered primarily policy issues for services to address, rather than potentially criminal issues for justice agencies to respond to. The inclusion in a policy set may lead workers and managers to treat abuse and neglect as behaviour management or staff management or as programmatic problems (Brown, 1994; Sobsey, 1994; 2000).

Other organisational factors also impact on the experience of emotional and psychological abuse and the recognition and response to it, including social isolation of residents, due in part to ineffective planning and support from service providers, (Mandeville & Hanson, 2000) and the increasing casualisation of the workforce. The increasing number of casual staff in particular has serious implications for the recognition and response to patterns of abuse and neglect, as there are a dearth of long term moral witnesses to note the cumulative effect of this maltreatment (Clapton 2008b; Brown, 1999).
White, Holland, Marsland and Oakes note this trend in their research, recognising that:

while at a theoretical level there is a recognition of the diverse causes of abuse, popular explanations appear to give little attention to the broader context of care, instead emphasising the role of the individual (2003, p.8).

The tendency to respond to abuse and neglect only on an individual level and to treat symptoms rather than causes of abuse is well recognised in the literature. The failure of organisations to proactively address risk, and broader systemic concerns about power and its misuse, social constructions of disability, and the ambivalence of social attitudes to people with intellectual disability are all key in understanding the phenomenon of abuse and neglect (Nosek et al., 2001a; Calderbank, 2000; Penhale, 1999; McCarthy & Thompson, 1996; Chenoweth, 1995b).

The history of accommodation services has been one in which control and decision making has been vested in the staff and management who work in the services. As Brown writes:

The life history of many of the adults with intellectual disability who live in these services is one of institutionalisation, poor medical and health treatment, poor nutrition and education, and non-existent support to redress issues of justice such as rape, assault, and theft of possessions (1997, p.28).

This may not be a current experience for people, but it creates a particular context and history which affects their current experiences. This mode of operation has shifted to some extent, with more innovative services working to create environments in which the choices and decisions of service users are facilitated and respected. However, these choices and decisions are most often at the level of ‘vegemite or peanut butter’, and very rarely centre around important decisions such as who to share your home with, which staff will be employed in the service, or how funding should be prioritised (Ryan, 1996; Robinson, 2002).
Over the past five years, there is evidence that government agencies in Australia have developed stronger policy frameworks for responding to abuse and neglect. They have in several states implemented a working with vulnerable people criminal history check for prospective staff. In some instances staff training has increased. However, no evidence could be found in this review which indicated a significant policy or funding response to the underpinning recommendations of government commissioned reports, such as the large scale review by Page, Lane & Kempin (2002), undertaken on contract for the National Disability Administrators group (made up of the State disability departmental heads). The fundamental finding of this large report was the need for primary prevention of abuse through the development of inclusive communities, advocacy, building individual resilience and family supports and intervention.

There are currently concerning signs in several Australian states that larger models of supported accommodation are being developed by government, with a view to housing groups of people with intellectual disability in clusters of groups together (PWD, 2009; DSQ, 2007; DADHC, 2006). There is a strong body of evidence against the congregation of people in groups when the routines, structures and operation of the group are determined by staff and managers, spanning the quality of life, cost and abuse fields (Emerson, 2004; Stancliffe & Keane, 2000; Rioux, Crawford, Ticoll & Each 1997; Malacrida, 2005; Marsland et al., 2007).

2.6.3 Legislative responses to abuse and neglect

Funded accommodation services in Australia are subject to the State Disability Services Acts (which are slightly different across the country, but enacted in all states and territories). The enactment of the Commonwealth Disability Services Act (1986) heralded a new mode of operation for disability services in Australia, and was the first legislation to include acknowledgement of the rights of people with disability and a
recognition of the need for better organisation of funding and operation of services. The development of Disability Services legislation in each state was a requirement in order for the States to receive significant funds from the Commonwealth as part of the Commonwealth State Disability Agreement, proving a significant incentive for States to enact legislation. This Agreement saw the State governments take primary responsibility for the funding and operation of accommodation services for people with disability.

In Queensland, the *Disability Services Act* was first enacted in 1992 and was amended in 2006, after a contentious consultation process. A stronger and different focus on abuse and neglect was included in the Act. The previous Act did not include a specific reference to abuse, and the current Act includes the specific principle “People with a disability have the right to live lives free from abuse, neglect or exploitation” (p.20). The new Act also provides for the introduction of a quality assurance and certification process, based on the Disability Services Standards; increased powers for the state disability services department to enter non government funded services to monitor and investigate complaints; and criminal history checks for staff working in services funded by the department (DSQ, 2008b).

A significant change to the new Act is the addition of a substantial section on the use of restrictive practices, including containment and seclusion, mechanical, chemical and physical restraint. While the aim of this is to provide uniformity in approach on the part of staff and managers, the legislation was received critically by the disability advocacy community, which expressed grave concerns about the lack of alternative supports mandated to prevent the need for restrictive practices to manage people’s challenging behaviour more constructively, the lack of appeal mechanisms for people with disability and their advocates, and an overwhelming concern that restrictive practices will be used to manage difficult people in a climate of understaffing and under-resourcing (QDN, 2007). This is of particular relevance to people who are likely to have experienced emotional and psychological abuse and neglect and to be re-traumatised.
by unnecessary restraint (Sequiera & Halstead, 2002; Jones and Stenfert Krose, 2006).

### 2.6.4 Policy responses to abuse and neglect

**Funded services**

Fyson and Kitson identify a failure of disability policy makers to make the necessary connections between what they term two ‘parallel agendas’ (2007, p.429) – the desire to promote choice and independence for people with intellectual disability on one hand, and on the other the need to protect them from abuse and neglect. They argue that this failure can be seen in two ways. It may result in increased risk to more independent people through ignoring the reality of the risk in their lives that comes with having control vested in others who provide support. Conversely, people may be overly controlled through risk management approaches which ineffectively acknowledge their right to self determination in an effort to keep them safe.

**Disability Services Standards**

The state departments responsible for providing accommodation and support to people with intellectual disability are required to adhere to the spirit and content of the Disability Services Standards in each state or territory, which are a policy and practice interpretation of the Disability Services Acts. In all states and territories, a Standard is included around the right of people to be free from abuse and neglect, in the same standard as the protection of human rights. Other Standards relate to domains including decision making and choice, individual needs, valued status, complaints, family relationships, service management, and privacy and confidentiality.

The Disability Services Standards are also the tool which most funded service providers use as their guide in developing policy and procedures for service operation. In Queensland, Standard 9, *Protection of Legal and*
Human Rights and Freedom from Abuse and Neglect, has the stated aim of “upholding the legal and human rights of each person with a disability and taking action to prevent and/or respond to allegations of abuse and neglect” (2008b, p.3). The indicators which service providers need to meet include having policies and practices protecting the rights of service users which are consistent with legislation and human rights instruments; support for service users to exercise their legal and human rights; policies and practices that demonstrate prevention of abuse and neglect; procedures for critical incident management in the case of allegations of abuse or neglect; and a documented improvement plan detailing strategies for protecting services users from abuse or neglect (2008b, p.11).

Abuse and neglect policy and procedures
Disability Services Queensland (DSQ), the Government department responsible for the funding and monitoring of funded disability service providers has policy and procedure guidelines on abuse and neglect which are readily available (DSQ, 2007a). The stated intention of the policy document is to establish and promote standard practice across the disability sector by providing a framework document. DSQ also funded the development of an information booklet which is designed to accompany the policy and procedures document. The policy discusses the role of the Department, management and staff in prevention and response to allegations of abuse (2007b). Procedure guidelines are provided to give service providers clear information to guide the development of their own service specific policies and procedures. The information booklet consists largely of a checklist of indicators of various forms of abuse, a checklist for services in developing policy and procedures, contact numbers for further information, and a glossary of terms.

Funded non government organisations tend to take their cue from the Disability Services Standards and Quality Assurance manuals laid down by governments in writing their abuse and neglect policies. Policies generally follow the same framework – a general statement about preventing abuse from occurring; reacting appropriately to allegations of abuse; protecting
complainants from further abuse; training for staff (and sometimes clients); and protecting services from allegations of mismanagement of complaints through detailed procedures (eg, Wesley Mission Disability Services, 2003; McCall Gardens Community, 2000).

Service monitoring
The State Disability Services Acts also specify monitoring of services to ensure compliance with the Act. This is interpreted a little differently in each state, although each state has applied a quality assurance framework of some description. At the time of writing, Queensland is part way through a compliance audit process of all services, in which services need to demonstrate to auditors that they meet the Disability Services Standards in their documentation and practice. The audit process is based on assessment of the evidence of policy and procedure, and meeting with service provider representatives and some family and client representatives. In New South Wales, a version of the same process applies, although there is no engagement with service users or family members and auditors are Departmental employees. In a Victoria, the department is shifting to a self assessment model, with verification by a third party (DHS, 2009).

Common to all of these approaches is a focus on compliance to a predetermined set of guidelines and regulations. Compliance mechanisms such as these rely heavily on audit and regulation to monitor specific elements which have been identified as markers of quality in service provision. Clegg, in her work on holding services to account, points out that audit is a very different process from evaluation, and one which does not aim to search for knowledge about the operations and drivers of service. She writes, "Audit investigates adherence to government policy" (2008, p.581). This is necessary to create a benchmark level of service quality, but is a missed opportunity for opening debate about how to improve supports and the effectiveness of supports, and does not focus on the measurement of individual outcomes for people who use the service, or in this case, their protection from abuse.
One of the perhaps unintended results of applying a managerial approach to human services is a service structure which prioritises the management of systems over the meeting of individual need (Di Rita et al., 2008). It gives rise to a culture in which compliance to statutory standards, and monitoring of administrative tasks and functions are of primary importance (Goggin & Newell, 2005), and one in which the act of management is more important that the subject of management – as seen in the ‘content free’ management which has so frustrated human services practitioners over the past decade (Wills & Chenoweth, 2005).

In the case of preventing, recognising and responding to emotional and psychological abuse and neglect of people using services, a compliance based approach may be unlikely to uncover the more subtle abuses which appear in people’s everyday lives, due to its concentration on the measurement of the existence of policy and procedure, at the expense of measuring individual satisfaction with the quality of service provision.

Community Visitors
The establishment of the Official Community Visitor program, which is part of the Attorney General’s Department in the Queensland Government, is a monitoring and protection strategy which in part acts to remove the onus of complaint from people with intellectual disability, who may be unable to raise issues of abuse due to capacity, lack of recognition, or fear. Community Visitors maintain a regular visiting schedule to funded services, and identify and raise issues of concern at a high level for resolution. They can raise both individual and systemic issues. The Office of the Community Visitor also feeds into other systemic agencies such as the Public Advocate and the Office of the Adult Guardian, ensuring systemic issues are raised in those quarters.

Boarding houses and hostels
There are far fewer protections for people with intellectual disability living in the private accommodation sector than in the funded sector in Australia. The private sector is comprised largely of boarding houses and hostels, where a significant number of people share rooms and space.
People living in boarding houses receive bed and basic housekeeping for their rent, and people living in hostels receive bed, meals and basic housekeeping services. The sector in Queensland has undergone regulation over the last five years (Department of Housing, 2004; Fisher et al., 2007b), driven by fire safety concerns, which has somewhat standardised the sector and also resulted in the closure of a considerable number of facilities. However, it remains a marginal existence for people with intellectual disability, where they are often at considerable risk from other residents (Young, 2003; Allen Consulting Group, 2003; QAI, 2003). There are many people with disability living in the private accommodation sector in the state. One study (Fisher et al., 2007b) found that people living in private residential facilities could be between 1.5 and 2.5 more likely to have a disability than people living in private households. Further, they were less likely to have informal carers or family members to support them. This study found that:

Their vulnerabilities and support needs are likely to be complex in two respects. First, many experience multiple vulnerabilities. Second, they are as a rule living in environments that add to their vulnerability in terms of the risk to safety from other people living in the facility (Fisher et al, 2007b, p.iv)

The policy response of government to regulate the private hostel and boarding house sector in Queensland is contentious. The advocacy and tenancy sectors responded with anger and frustration to regulation as it relates to people with intellectual disability and mental illness, who are often highly vulnerable to other residents, such as people leaving prison, who make up a significant proportion of the boarding house population. The view of the advocacy sector was that regulation was propping up an unviable and unethical industry (QAI, 2003). For people with significant support needs, the private for profit accommodation sector is not an appropriate housing option – there is little incentive for owners to provide higher levels of care, as more care equates to lower profits. There is no policy or practice requirements, and limited ‘visitability’ of facilities by government agencies (Fisher et al., 2007b; Allen Consulting Group, 2003).
2.6.5 Inquiries into abuse and neglect

In several states, there have been inquiries into situations where allegations of extreme abuses have been made, mostly in large scale institutional services. In Queensland there have been three judicial inquiries into abuse of people with intellectual disability living in accommodation services since 2000. Two of these inquiries concern the same institution, the Basil Stafford Centre. The first inquiry, the Stewart Inquiry (1995) found that the abuses were so pervasive that there was little alternative but to recommend the closure of the institution at the earliest opportunity. Among the findings were that:

An insidious culture existed at the Centre. This culture promoted the occurrence of client abuse and gross neglect, and the harassment or intimidation of staff members who reported or could have reported such occurrences, by other staff members. This culture provided the climate, and thus the opportunity, for acts of official misconduct to take place and minimised the likelihood of both the act and the offender being detected. The situation existing at the Centre had the effect of discouraging, to the point of stifling, the reporting of such acts of official misconduct. The situation cannot be explained away as arising from the actions of a few individual ‘bad apples’ (1995, p.xii).

Prior to the release of this report, the Director General of the Department informed the judicial commission that the Centre would be closed within three to four years. Despite this clear central finding, and this public undertaking on the part of government, four years later, the Centre was still operating, and a second inquiry was held into allegations of abuse in the same facility. The Carter Inquiry (2000) discusses the reduction in the number of residents living in the Centre (from 111 to 69), and the intention of management to further reduce this over time to approximately 25 people. Despite identifying poor management and negative staff attitudes as significant problems, the inquiry concludes that the Centre is a viable concern and should remain open in a reduced capacity. It promotes vigilance in the community based Adult Living Service, the group home based service to which many people had moved,
giving caution about the risk of the culture of abuse moving into this system.

At the time of writing, it is proposed that new villas will be built on the grounds of the old Centre to contain people who require secure housing due to challenging behaviour. It seems that the risks of abuse and neglect for people due to isolation and institutionalisation are not abating with time and knowledge of alternatives.

A further inquiry into abuses in accommodation services is highly relevant for this research. It concerns the care provided to a group of people with multiple disabilities living in a private accommodation hostel in a regional area. The operators of the facility were receiving funding from the state disability services department for providing accommodation and support for some of the people living in the facility, and the department were referring people, including children with disability, to the facility for four years after family members of residents began lodging serious complaints (Waters, 2004). Details of horrific abuses were revealed by family members and former staff to a Commonwealth parliamentary inquiry (House of Representatives Standing Committee on Legal and Constitutional Affairs, 2004):

> The behavioural management was unreal. They were often denied food and had cold showers. They held someone down to cut their fingernails, using half-a-dozen people, until their fingers bled. Buckets of water were thrown over them. They had chillies put in their mouths... They were deprived of sleep. There was emotional and physical abuse. There was hitting residents with a broom handle and a fly swat. There was intimidation and harassment and there was extreme verbal abuse. Residents were often locked in their bedrooms and were often publicly humiliated in front of other people. The treatment for head lice was fly spray. The residents were often tied to chairs and toilet seats (2004, p.96-7)

Four staff members of the facility were committed to stand trial on multiple charges including torture, assault and deprivation of liberty (ABC News, 2007). This inquiry is of particular interest, as the people living in
the facility were in the same position as some of the people who participated in this research, in that they flowed in and out of the funded accommodation system, and had to resort to the private accommodation sector when funded accommodation was not available, or not desirable to them.

Benbow (2008) notes this trend overseas, identifying the failure of human services systems to learn from inquiries in the UK. This topic also connects closely to the work of Wardhaugh and Wilding (1993) on the corruption of care, to White and associates (2003), and Marsland and colleagues (2007), all of whom identify systemic power relations and means of engagement which preclude or make difficult the resolution of abuse and neglect, as discussed earlier in the chapter.

### 2.6.6 Training and education about abuse and neglect

The need for training and education of management, of workers, and for people who live in disability services about abuse is represented in the literature in a number of different ways. However, this literature concerns abuse generally – no literature concerning education and training about emotional and psychological abuse and neglect was located in this study. Given the likely prevalence of this form of abuse, and the subtlety of some of the experiences described in the existing literature, a need for education and training about this form of abuse and neglect is clear.

At one level, some authors represent the need for training for disability services staff and other professionals in recognising the signs of abuse, better responding to these signs, consistency in following policy, and increasing the vigour and concern with which people who have been abused are supported through a process of recovering from their ordeal (Bhargava, 2006; Page et al., 2002; Conway et al., 1996; The Roeher Institute, 1992).
A majority of the literature presents the issue of education and training at a more complex level, advocating for the need for education which goes beyond procedural responses to a deeper understanding of the factors which increase the risk of abuse occurring, strategies to minimise its occurrence and protective approaches. These are advocated by a series of researchers, including Marsland et al (2007), Ticoll (1994), Bruder, Stenfert Kroese & Bland, (2005), and WWDA (2007). White, Holland, Marsland and Oakes (2003), for example, identify staff training and competence as a critical aspect of service cultures and environments which can either protect against or promote abuse. They situate this need within an analysis of other aspects, however, including management, staff deployment and support, staff attitudes, behaviour and boundaries, power choice and organisational climate, isolation, and service conditions, design and placement planning. Jenkins & Davies (2006), in their research with practitioners around abuse, found that neglect in many cases did not meet workers self-identified ‘thresholds for actions’ in hypothetical abuse situations. They raise a series of implications for action which arise out of this research, one of which is training, but argue for training and education as part of a suite of responses, reflecting the need for multi-level responses to a complex problem.

Education for people with intellectual disability is discussed in the literature, both in terms of what may be termed protective behaviours training (Page et al., 2002; Conway et al., 1996) and in a more global context of personal empowerment (Johnson & Traustadottir, 2005). The self advocacy literature, and academics who have worked with the self advocacy movement (Goodley, 2000; Dowse, 2001) write holistically about the benefits of knowledge for personal empowerment and the way that this may flow into all areas of a person’s life. A number of researchers also discuss the impact of informal peer education in raising the concept of emotional and psychological abuse and neglect as abuse in the eyes of people with intellectual disability, who previously had not understood their experiences to be abusive (Collier et al., 2006; Saxton et al., 2001).
Further to this, some researchers and scholars identify a need for a reconceptualisation of the way in which abuse is understood – and for training and education to then accompany a new paradigm which is more centred around an understanding of abuse which better grasps the significance of social, cultural and structural factors. The work of Brown (2004), Penhale (1999), and Sobsey (2004), referred to in section 2.2.6 above, is critical here.

A managerial, procedurally driven, approach to responding to the abuse and neglect of people with intellectual disability seems to characterise the policy response of services in the Australian context at the current time. There appears to be little responsiveness to the recommendations of commissions of inquiry into abuse in residential facilities. Legislation, policies and procedures in Queensland are predominantly focused on responding to individual instances of abuse, and on providing clarity on the circumstances in which people may be restrained. While it is of course essential that individual cases of assault, injury or abuse are dealt with effectively and with compassion, there is little evidence that legislation and policy is also focused on changing environments and interpersonal dynamics which may allow abusive cultures to develop and be sustained.
Part five: Legal issues in responding to emotional and psychological abuse and neglect

2.7 Legal responses to abuse and neglect of people with intellectual disability in disability services

This final section of the chapter considers the legal protections which are in place at international, national, state and local levels for people with intellectual disability who experience emotional and psychological abuse in disability accommodation services. As will be seen, there are few robust protections of their rights. There are two main approaches to legal responses – a human rights approach, and a legal redress approach.

2.7.1 UN Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) changes the context of the way in which abuse of people with intellectual disability in accommodation services can be understood. Prior to the ratification of the Convention in 2008, government and service understandings of abuse have largely been linear, procedurally oriented, and focused on the resolution of individual instances of wrongdoing. In the main, they still remain so, but the entry of the Convention into the lexicon of the disability and legal community may herald a change in ethos and language over time.
The UNCRP puts the experiences of people with intellectual disability into a citizenship framework, where expectations are that they will have the same rights, and the same expectation that their rights will be enacted, as other members of the community, regardless of the resource limitations or other historical limitations of the disability services sector which have previously limited the responses of inquiries into abuse of the rights of people living in accommodation services.

All of the articles in the Convention could relate to the experience of emotional and psychological abuse and neglect in some measure. The Convention recognises in the preamble “the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms” (c), and the counter to these freedoms is the fundamental interrelatedness of abuses. However, some specific articles have particular relevance, including:

- Article 13 - Access to justice
- Article 14 – Liberty and security of the person
- Article 15 – Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16 – Freedom from exploitation, violence and abuse
- Article 17 – Protecting the integrity of the person

Many of the articles are fairly straightforward in their explanation, while some, such as Article 16, provide more detailed requirements of State Parties which have ratified the convention. Article 16, Freedom from exploitation, violence and abuse, details the need for States Parties to take all appropriate legislative, administrative, social, educational and other measures to protect people with disability from abuse; to prevent abuse from occurring through assistance, support, education and effective monitoring of facilities and programmes; to promote the support and recovery of victims; and to appropriately respond to the occurrence of abuse, violence or exploitation.

However, as an international human rights instrument, ‘reasonably available’ domestic remedies must be exhausted before a person (or their
representative) is able to take action against a government for a breach of their rights. In practice, this is a very substantial barrier to legal action in the abuse context, where the standard of proof in legal actions is such that people with intellectual disability are rarely successful in prosecuting their assailants, due to the private environment in which abuse is usually carried out and the difficulties which many people with intellectual disability may have in relating their experiences.

At the time of writing, Australia had recently announced its intention to sign the CRPD Optional Protocol, which establishes an international complaints mechanism for breaches of the treaty in member states. Under this mechanism, were a complaint to be upheld against Australia, the treaty body decision has a ‘persuasive’ effect – that is, it is not enforceable by legal means. If the Convention were recognised within Australian law, its capacity for enforcement would depend on the rights and remedies explicitly conferred within that legislation. This is a key issue in the recent Australian debates around a Bill of Rights (French, 2009c; Fogerty, 2009).

A number of projects are underway which aim to operationalise the articles of the Convention, and to bring them to life for people with intellectual disability and those who support them. For example, a project developed by Queensland Advocacy Incorporated (2009) is currently seeking to measure the extent to which the rights laid out in the Convention are enjoyed in everyday life for people with disability living in Queensland. Projects such as this may bring the ethos of the Convention into the lives of people with intellectual disability without the need for international legal action to protect their rights.

A recent report by the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (Nowak, 2008) expresses particular concern about this frequent experience by people with disability. The report states:

in many cases such practices, when perpetrated against persons with disabilities, remain invisible or are being justified, and are not recognized
For an act, or an omission of action, to constitute torture, there are four elements within the Convention against Torture which need to be satisfied. These are severe pain or suffering, intent, purpose and State involvement. Purpose must be related to obtaining information or confession. The critical element here is the alternative limb ‘or based on discrimination’. If the act of torture occurs because of disability or impairment, it arguably does not matter what the purpose is – this limb broadens the torture test (French, 2009c). Acts which fall short of this definition may constitute cruel, inhuman or degrading treatment or punishment under Article 16 of the Convention against Torture. The Convention on the Rights of Persons with Disabilities complements other human rights instruments on the prohibition of torture and ill treatment and providing further guidance on issues of choice and decision making, legal capacity, and informed consent to medical treatment. Applying the torture and ill-treatment framework to people with disabilities means that:

Under international law, and the Convention against Torture in particular, States have the obligation to criminalize acts of torture, prosecute perpetrators, impose penalties appropriate to the gravity of the offence and provide reparation to victims. By recognizing and reframing violence and abuse perpetrated against persons with disabilities as torture or other cruel, inhuman or degrading treatment or punishment, victims and advocates can be afforded stronger legal protection and redress for violations of human rights (p.10).

### 2.7.2 Legal redress for emotional and psychological abuse and neglect

As one legal academic points out:

You don’t want to bring in the legal system if you can avoid it. It is clumsy, slow, stressful, expensive, and you hardly ever get the outcome you expected (Mathews, 2009).
However, legal redress should be open to people with intellectual disability in the same way that it is for other people in the community who have had their rights breached.

Legal avenues do not appear to offer an easy way forward for people with intellectual disability to get redress for emotionally and psychologically abusive treatment they receive in disability accommodation services. Many of the behaviours which occur within emotional and psychological abuse are not perceived at law to be criminal, unless they occur in concert with other criminal acts such as rape, physical assault or theft, in which case they may be treated as causing nervous shock, pain and suffering, and adverse impacts, although only in limited (and usually extreme) circumstances (French, 2009c, Gibney, 2009).

2.7.2.1 Criminal law

There is a very limited criminal law response to this form of abuse and neglect in the Australian context, and there are also some serious barriers to the representation of cases of emotional and psychological abuse and neglect in civil law. According to legal practitioners in two states (Gibney, 2009; Fogerty, 2009), it is rare for emotional and psychological abuse to be represented in legal cases in a criminal context.

State Criminal Codes and Acts each contain several Sections which could conceivably apply to people with intellectual disability experiencing significant emotional and psychological abuse and neglect. For example, within the Queensland Code are Sections addressing the crimes of torture, threats and robbery, and the misdemeanours of duty to provide necessaries, failure to supply necessaries, negligent acts causing harm and deprivation of liberty (2008). The Code also includes provision for conspiracy to commit crime and other offences, and accessories after the fact to offences which could apply to groups of staff who participate in abusive regimes.
Criminal cases must be brought to court within a three year period, unless specific exemptions can be gained from the court to have the matter heard outside this time frame. The standard of proof in criminal cases is high, requiring strong evidence which meets the legal test of ‘beyond reasonable doubt’, which in the case of emotional and psychological abuse in isolated disability accommodation services is likely to be difficult to obtain. Sheehan (2000; 2006), in studies of emotional harm presentations in children’s court hearings, notes that criminal hearings rely upon individual instances of harm as evidence, rather than relationships which are harmful, and that there is also a heavy reliance on physical evidence of injury. The standard of proof required in civil actions is lower, the test there being ‘the balance of probabilities’.

**2.7.2.2 Civil law**

Civil law offers possibilities for actions under the laws of torts. The most commonly used of these is negligence, although there is not a large volume of civil actions involving people with intellectual disability (Gibney, 2009). In negligence actions, it must be proven that a duty of care was owed to the person by the service provider, that there was a breach of the duty of care, that harm occurred, that the harm was foreseeable, and that the harm was a result of the breach of the duty of care (Fogerty, 2009). Other less commonly used torts in civil law which may present possibilities for legal redress in this situation are assault and battery, and false imprisonment (French, 2009b).

There are, however, several barriers to civil action. The greatest difficulty in torts litigation is ‘material damage’, or the need to quantify the loss suffered by the person in tangible terms. Many people with intellectual disability are not in employment so there is no loss of income; most don’t receive subsequent treatment for their abuse or assault, or there is not cost to the treatment they receive; and policy responses to abuse and assault rarely contain a resource component on an individual level (such as moving a person to another living environment) (French, 2009c). Proving financial and functional loss is difficult when emotional and
psychological abuse and neglect remains so poorly recognised and understood, particularly in people with high support needs and limited communication.

In almost every instance, the person taking the action will be an individual against an organisation and their insurance company. The requirements of funding of disability services require insurances which include vicarious liability, in which the organisation takes legal responsibility for the (non-criminal) actions of their workers. This results in a very inequitable balance between the individual and a battalion of lawyers and insurance managers. A further significant barrier is that, if the action does not succeed, costs will be awarded against the person and they stand to lose all assets and may be declared bankrupt. Civil cases are also generally focused on financial compensation, which may not be the primary motivation for the person.

The courts will sometimes extend time limitations on legal actions, where there are compelling reasons why the action is commenced out of time. In Queensland however, there have been several cases where the Queensland government has used the *Limitations of Actions Act* (1974) and *Personal Injuries Proceedings Act* (2002) to prevent people with historical child abuse claims from taking action in courts against the government, due to the passage of time. Victims of abuse are unlikely to be able to lodge their claims within the statutory period of time, particularly when they experience lengthy abuse (Mathews, 2004). The defendant has the discretion to call into action the time limitations – in these cases, Mathews argues, the moral responsibility of the government to compensate victims of abuse in its case was subsumed by the financial and public relations concerns of current administration (ibid).

### 2.7.2.3 Discrimination law

The Australian Human Rights Commission (AHRC) oversees the application of federal legislation in the area of human rights, including the *Disability Discrimination Act* (1992). The Act includes provisions for protection
against harassment for people with disability in the contexts of employment, education, and the provision of goods and services. In this latter respect (Section 37), the Act states:

It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to harass another person who:

(a) wants to acquire the goods or services or to make use of the facilities; and

(b) has a disability;

in relation to the disability.

The Act allows for complaints of disability discrimination in specialist disability accommodation services, but such claims typically fail at the litigation stage because there is no comparator (French, 2009c) - it is difficult to show that needs have not been met due to disability when the service is set up for the purpose of meeting the needs of people with disability. However, the Disability Discrimination Commissioner of the AHRC reports that the Commission has received complaints of harassment in relation to emotional and psychological abuse and neglect, although not as many as they would have expected (Innes, 2009). None of these have been clearly argued at either the Federal Court or Federal Magistrate’s Court, which prevents an analysis of the issues brought forward within the complaints. The complaints were resolved at conciliation conferences.

At a state level, the State Anti Discrimination Commissions and Boards implements the State Anti Discrimination legislation. The Acts operate within the a similar framework as does the Commonwealth Disability Discrimination Act, although accepting complaints from a wider group of people. Tribunals hear cases which are not settled through a conciliation process.

The strength of the AHRC and State Anti Discrimination Board/Commission frameworks lie in their conciliation approaches, and the low threshold of evidence they require in order to accept a complaint. There are no costs to making a complaint (although there are costs if the
matter is terminated and proceeds to the Federal Court for adjudication), and the Commissions have principles about equity between each side to try and ensure that service providers and complainants are evenly represented in conciliation hearings. There is a one year time limit to bring a complaint, although time can be extended in certain circumstances. The focus of harassment cases is the harm which has resulted from an action or series of actions, or the failure to act – so the behaviours are the focus, rather than the abuse experience. This highlights the differences between the language of the law and the language of abuse which come into play at all levels in the legal system.

If the complainant has the goal of wanting an apology for the treatment they have suffered, a change in service policy, or to contribute to service training, then the conciliation processes available through the Discrimination legislation may be a useful legal remedy. Small amounts of financial compensation are also paid in some circumstances, according to the ‘bargain’ of the parties involved in the complaint resolution. The fundamental premise of both the AHRC and Anti Discrimination frameworks, however, is that the wrong done was on the basis of an inappropriate response to the existence of disability. While it is almost impossible to extricate disability from this complex mix, a question is raised about whether there is a risk that linking the abuse to disability discrimination may inadvertently drive a policy response when a criminal or civil response may be more appropriate.

2.7.2.4 Compensation

Victims Compensation Schemes are in operation in each state of Australia, and at a Commonwealth level. The extent to which emotional deprivation and abuse or psychological injury can be claimed under these schemes is not clear in all cases, but does not seem open without strong advocacy. Most schemes have an emphasis on compensation for injuries as a result of violent assault or domestic violence, and focus on physical injury or psychological injury arising from experiences of extreme nature (such as kidnapping). The NSW Victims of Crime website does, however, explicitly
recognise the specific heightened vulnerability of people with disability to ‘crimes such as physical, sexual, emotional or psychological abuse and/or neglect’ (Lawlink NSW, 2008).

In Queensland, victims compensation is made under the *Criminal Offence Victims Act* (1995). It requires that the offender be convicted of the offence against you, or that you make an application for the government to make an ex gratia payment, in the event that the offender is unable to be located, is of ‘unsound mind’, or a minor. This scheme is currently being reformed, and a new victims financial assistance and service scheme is due to be introduced in late 2009 with the aim of increasing the speed and coordination of response to victims of crime. However, the scheme does not appear to be open to compensating victims of emotional and psychological abuse and neglect, noting that eligibility is limited to those who ‘can claim compensation if you suffered a physical injury or mental or nervous shock or the adverse effects of a sexual offence’ (Department of Justice and Attorney General 2009).

A final legal avenue which has opened for some people in the recent past is access to financial compensation through redress schemes. A key recommendation of the Forde Inquiry (1999) into abuse of children in state funded institutions was that compensation be offered to survivors of institutional abuse in Queensland facilities. After a lengthy delay, the Queensland government initiated a redress scheme for people who lived in institutional facilities as children and experienced abuse. The scheme is tiered, with payments made according to a rated severity of abuse experienced. Access to the scheme was promoted through mainstream media and the Department of Communities website. This may not have been a broad enough marketing strategy to reach people with intellectual disability who do not read or write, or who require easy English materials (Mathews, 2009). Despite findings of systemic abuse of a similar breadth and depth in disability institutions in Queensland and other states of Australia (Carter, 2000; Stewart, 1995; Burdekin, 1993), no similar schemes have been implemented for people with disability to date.
Tasmania and West Australia have also implemented redress schemes for victims of child abuse and neglect in state sanctioned care. South Australia is currently considering a redress scheme in response to a recommendation from an inquiry into abuse of children in state sanctioned care (WA Government, 2009; ABC, 2009a; Mathews, 2004). There is no consistency between schemes, or equity between states, and there are no schemes in other Australian states. Of concern is a recent development in West Australia, where the government have decided, in light of higher than expected applications by survivors of childhood abuse in state funded institutions, to halve compensation payments to eligible applicants (ABC, 2009b). Overseas, several provincial governments in Canada have established compensation schemes, and the Irish government has also established a compensation scheme to acknowledge and apologise for the abuse suffered by children in state care (Mathews, 2004).

International human rights instruments, criminal law, civil law and discrimination law remain the primary legal avenues open to people with intellectual disability. However, the literature and legal experts are united in the opinion that legal avenues do not offer an easy way forward for people with intellectual disability to gain redress for wrongs done to them for emotional and psychological abuse. There are very significant barriers in the legal systems which are tested to the limit by people with intellectual disability, and which may preclude even their access to the system, much less a successful outcome.

### 2.8 Conclusion

The review of the literature clearly has shown that the abuse research landscape is complex, fragmented and compartmentalised into typologies of disability, abuse or marginalisation. There is a need for research which considers 'higher order' issues which are at play here, such as questions of citizenship, rights, humanness, and otherness. Dominant social constructions of disability and conceptions (or models) of disability have enormous influence on the cultural, social and structural places and roles
in which people with intellectual disability are located, and this is related directly to their exposure to climates and environments in which abuse is likely to occur.

The policy and legislative frameworks presently in place do not appear to well support a nuanced or a multi-faceted approach to responding to the emotional and psychological abuse and neglect of people with intellectual disability. Neither do legal avenues provide an easy way forward for people to have their rights upheld.

In reviewing the existing research with people with intellectual disability about their abuse experiences, it is clear that their views add a very meaningful depth and breadth to the understanding of abuse that moves beyond physical domains and into the social and structural domains of society. The autobiographies of people with disability strengthen this view, and have also added an important new element. Their stories introduce voices of resistance, personal growth and empowerment. An unmistakable need can be seen for research which explicitly seeks the thoughts and views of people with intellectual disability on their experiences of emotional and psychological abuse and neglect to extend this small but important body of work.

The literature on abuse of other groups of people has made a considerable contribution to this study, although caution must be exercised in comparing the abuse experiences of people with intellectual disability with other groups who are marginalised. However, there is value in drawing from these models and frameworks of understanding abuse to develop a more robust understanding of the features of emotional and psychological abuse and neglect of people with intellectual disability.

A framework for understanding emotional and psychological abuse as it affects people with intellectual disability has been developed in the chapter, building from this body of work, and will be tested with participants in the research. It is critical that a definition or framework has resonance with the lived experience of people with intellectual disability in
order to accurately reflect the sorts of abuse that they endure. There are weighty cultural, environmental and organisational pressures brought to bear on the experience of abuse which influence both the way in which it is experienced and the way in which it is responded to.

2.9 Summary

This chapter has reviewed the existing research on emotional and psychological abuse and neglect of people with intellectual disability and people with other disabilities, and presented the dominant themes and issues.

The foundation for this analysis is laid in part one of the chapter with a discussion of the contextual factors which are in play when abuse occurs in the lives of people with intellectual disability. Why does it happen, and continue to occur in the lives of people with intellectual disability with such regularity? Issues of constructions and conceptions of disability, culture, environment, power, multiple levels or sites of abuse are debated in this section.

Part two addressed the experience of emotional and psychological abuse and neglect. The literature on the emotional and psychological abuse and neglect of people with intellectual disability has been detailed first. The prevalence of this form of abuse is considered, as is the relationship with institutional abuse. Research which has been conducted with people with intellectual disability about emotional and psychological abuse and neglect is analysed. Autobiographies by people with intellectual disability about their experiences of emotional and psychological abuse and neglect conclude this section.

Research on the emotional and psychological abuse and neglect of women, children and older people has also been canvassed in this review, and is also presented in this part of the chapter. This combined material is analysed with a view to developing a framework for more
comprehensively understanding this form of abuse as it relates to people with intellectual disability living in disability accommodation services.

A definition and framework for understanding this form of abuse has been developed in part three of the chapter, building from the research and understanding of scholars from the range of abuse fields.

Some context for the operation of the disability services structure in Australia is provided in part four of the chapter, along with an analysis of the policy responses of state disability departments to the experience of emotional and psychological abuse and neglect by clients of disability services. A brief analysis of policy responses has also been made with comparable international jurisdictions.

In part five of the chapter, the legal issues concerning emotional and psychological abuse, at local, state, federal and international levels are reviewed, and the current possible avenues for redress for people who have experienced this sort of abuse considered.

Key conclusions from the literature review conclude the chapter. They reveal that the research landscape is complex, fragmented and compartmentalised. A need is identified for research into ‘higher order’ issues affecting the experience of abuse, such as otherness, and the denial of citizenship and rights, which take account of social constructions of disability. Existing legislative and policy frameworks are not found to offer a nuanced or multi-faceted response to abuse and neglect. Neither do legal avenues appear to offer an easy solution. The contributions of people with intellectual disability through autobiography and biography indicate a clear need for further research which includes their lived experience, particularly around resistance and resilience. Any frameworks for better understanding emotional and psychological abuse and neglect need to have resonance with people’s lived experience.
The following chapter builds from these key outcomes of the literature review, and details the conceptual and methodological approach taken in designing the research.
Chapter three: Research design

Sally  
Do you still live at the place where the bad things happened?

Ann  
No. But they’re still in my head.

3.1 Introduction

This chapter develops the design of the research. Part one begins by outlining the conceptual framework which contains the ontological and epistemological assumptions that underpin the research approach. These focus strongly on the lived experience of people with intellectual disability, and demand a methodology that privileges this experience. A rationale for the selection of the methodology for the study is provided, and an innovative narrative methodology - narrative collage – is detailed in part two of the chapter.

The research method is laid out in part three, and the design of research tools and strategies, recruitment of participants, advice sought and received, and the interview process are described here in detail.

Ethical issues which arose in the design of the study are addressed in part four of the chapter. These include the historical exclusion of people with intellectual disability from abuse research, issues of consent, reporting of criminal activity and the thorny question of how much detail of the research findings to share with participants are discussed at this point. The chapter concludes with a canvassing of the limitations of the study.
3.1.1 Narrative style of the thesis

It is traditional for researchers to remove themselves from the written landscape and to focus upon the actions taken and the results found in the writing of the thesis. However, the researcher in narrative research has a clear and present role as a participant in the research (Reissman, 2008; Owens, 2007), and it seemed injudicious to hide this behind language which failed to describe the twists and turns, struggles and pleasures which were uncovered during a lengthy research process. What seemed more important was to strive to balance my place in the research with that much more important place of the people who shared with me their experiences. Consequently, the methodology chapter of the thesis talks explicitly about my approach to the research and how it influences the ontological and epistemological approach of the research; my engagement in the research process; and the changes I made to the research method and the way they were applied. The results chapter focuses far more strongly on the lived experiences of participants, and allows the strength and power of those experiences to speak for themselves. The implications and conclusions chapter blends the two sets of experience and reflection.

In adopting this approach, I was influenced by the work of several researchers around representation and reflexivity in qualitative research (Mantzoukas, 2004; Richardson, 2000; Ellis & Bochner, 2000), and also by the work of Owen (2007) and Goodley (1996; 2001) in narrative research with people with intellectual disability. Owen condenses this approach, in writing:

meaning is jointly constructed in the space between the researcher and the respondent, with the researcher becoming part of the process being studied (2007, p. 310).

Mantzoukas (2004), in his work on representation within qualitative inquiry, claims that non-positivist paradigms insist on representation of the researcher, and that to hide this in the research text is both insincere and ‘fundamentally out of line with the rules, convictions and models
commonly agreed within those paradigms’ (p. 1002). He also makes a
direct link between the epistemological and ontological assumptions of the
researcher and who or what is represented in the research – that the way
in which the research conceptualises the research and relationship
between researcher and participants regulates the outcomes of the
research to a large degree.
Part one: Conceptual approach

The ontological and epistemological position of the research is grounded in the belief that the knowledge and truth about the issue under question is vested in the people who have experienced it, and in the people close to them. Their narratives, in both singular and collage form, hold an authoritative position in the research. McClimens (2004) calls this an ontological focus on lived realities. She cites Humphries' concern that:

there is a risk in academic debate that preoccupation with the philosophical aspects of any discipline can obscure the lived realities which constitute the substance of the theoretical arguments (1998, p.12). (2004, p.72)

This approach privileges the lived experience of people with intellectual disability, who historically have not been well served by more traditional ontological approaches. Several disability theorists argue that the dominant ontology of disability is inherently negative (Hughes, 2006; 2007; Kumari Campbell, 2005; Shakespeare, 1997b), where disability is always located on the negative side of the binary construction of normalcy, and where ability is seen as congruent with human worth – in effect, where people with disability are always ‘othered’. Hughes argues convincingly for the development of a critical social ontology of disability that “problematises non-disablement and exposes the invalidating representations of disabled people’s lives that lie at the heart of our disabling culture” (2006, p.i).

An ontological focus on exposing the invalidating representations of the lives of people with intellectual disability requires a concomitant focus on revealing and illuminating narrative representations in which people are central actors who have a position of authority with respect to their narratives and the research. Knowledge constructed from the position of privileged ontology, through the ontological focus on lived realities
(McClimens, 2004) allows for the development of a perspectival epistemology (ibid; Conway, 1998).

A perspectival epistemology relies upon trust in the knowledge of the people who have lived the experience. As Conway writes, it:

> encourages a maximal expression of affective investment in the world – a chorus of radically situated ‘voices’ – and thus stands 180 degrees removed from the traditional epistemological goal of disinterested, disaffected contemplation (1998, p.25).

Perspectivism, however, in its Nietzschian roots, does not rely upon one view and discard others as irrelevant. Rather, it emphasises a specific view, and other perspectives make up the background (Dick, 2007). I have also been influenced here by the work of Harding around standpoint theory, in which an epistemic privilege is accorded to the standpoint of marginalised research participants (Harding, 2004; Falmagne, 1998; Conway, 1998).

In order to maintain an ontological focus on lived realities, and a perspectival standpoint epistemological approach, there was a need to be creative in developing a methodological approach which privileged the involvement of people with intellectual disability, but which did not exclude others who may have something to contribute. After much searching, narrative collage was assembled as an ethically workable methodology which could enable people with intellectual disability to maintain centre stage, while valuing and including the participation of those who supported them and who had valuable contributions to make. The use of narrative collage has at times resulted in a richness of material which is greater than the sum of its parts – perhaps a new interpretation of Nietzsche’s statement:

> The more affects we allow to speak about one thing, the more eyes, different eyes, we can use to observe one thing, the more complete will our ‘concept’ of this thing, our ‘objectivity’ be. (cited in Conway, 1998, p. 255)
The development and use of narrative collage is discussed in detail in the following methodology section of this chapter.

The work of Hilde Lindemann Nelson (2001) around counter stories and their role in narrative repair of damaged identities is also ontologically important to this research. Nelson’s central argument is that personal identity is a lever which expands or contracts a person’s capacity to exercise moral agency. The way in which we are identified by others determines the way in which they act towards us. In the case of people who are identified by others as morally defective or lacking, treatment such as humouring, hospitalising, or being treated with hostility or suspicion commonly ensues, and this restricts a person’s freedom to act. It also affects a person’s self-identity, and thus moral agency. Nelson says that "Identities mark certain people as candidates for certain treatments, and within abusive group relations these treatments are seldom benign" (p. xi). Where an entire group are identified as morally defective or lacking (as in the case of people with intellectual disability), Nelson talks of the construction of mandatory identities, where social expectations are set up about how group members are expected to behave, what they can know, what can be demanded of them, and to whom they are answerable. This is what she calls damaged identities.

Nelson argues that because identities are constructed and damaged narratively, they can be repaired through narrative means. This is done through the counterstory – a narrative which develops group members as fully developed moral agents. The counterstory is designed to act in two ways. First, in altering the perception of the dominant group of the subgroup, and assisting them to seeing the subgroup as worthy of moral respect. Second, the counterstory aims to alter the person’s self perception and increase their resilience.

Similar concepts to Nelson’s counterstory are also represented in the work of other theorists. For example, Goodley (2001) presents four inclusive epistemologies of impairment, including ‘impairment, as storied’. He discusses the importance of narrative in epistemological understandings of
impairment, with particular reference to its possibilities to assist people with intellectual disability to develop identities which are not mired in victimhood and passivity. Goodley talks about the capacity of narrative to offer opportunities for resistance and resilience at an epistemological level for people with intellectual disability.

The importance of resistance and resilience in narrative is taken up at both an epistemological and a methodological level in this research. At an epistemological level, the acts of resistance and resilience which appear in the narratives are conceived of as a key response to the invalidating representations of people’s lives which is being addressed by the research at an ontological level. At a methodological level, the research is designed to maximise the possibility for people to make meaningful connections with family or other supporters during the research process, so at the end of it end they are together, rather than separately thinking about their experience of discussing a potentially distressing subject at length.

In summary, both the ontological and epistemological foci centre on the expert knowledge of the people who have the lived experience of the issue under question – the experience of emotional and psychological abuse and neglect. The ontological focus of the research centres on their lived realities and on the development of new ways of representing previously invalidating representations of people’s lives. The epistemological focus of the research is perspectival, and takes a partisan, standpoint approach which privileges the participation and role of people with intellectual disability in the research, and which focuses on both their experiences of the phenomenon of abuse and neglect and also their strategies for dealing with it – the counterstories they have developed to repair their damaged identities, in Nelson’s terms, or the tools of resistance they have used to avoid becoming victims.
Part two: Methodology

This section provides a short discussion of the methodologies considered in developing the research. It then details the methodology assembled for the project, narrative collage, before a discussion of some of the issues in analysing narrative texts which needed to be considered.

3.2 Selection of methodological approach

The methodology literature provides guidance on several possible ways to approach the research questions. Both critical theory and narrative approaches were of particular interest in the formative stages of the research, and both approaches were reviewed for their conceptual and practical ‘fit’ with my fairly participatory practice history; with the subject matter and its potential to cause distress to participants; and with the stated aim of the research to create an expectation of change.

3.2.1 Critical theory

Harvey describes critical social research as having a primary core in which knowledge is structured by existing sets of social relations – that it cannot be factually understood as true or false, but is conditional on the understanding and interpretation of the agents involved in the process. He sees the aim of a critical methodology as being to “provide knowledge which engages the prevailing social structures. These social structures are seen by critical social researchers, in one way or another, as oppressive structures.” (cited in May, 1993, p.28). Crucially, critical forms of research call current ideology into question, and initiate action, in the cause of social justice (Crotty, 1998). The critical ontology relies upon the premise that knowledge is mediated through a complex set of political, social and structural relations – it is constructed, negotiated and renegotiated continually, according to the context in which the knowledge is being
gained and the power relations which are in operation (Sim & Van Loon, 2001).

The highly politicised nature of critical theory and critical research was initially an attractive feature of the approach. On reflection, and after reading further into narrative approaches, however, a concern arose that a critical approach may encourage assumptions about the circumstances and the stories of the people I was planning to work with. Did they feel oppressed? Were they looking for, or in need of, empowerment? Might their narratives present a whole different story? My suspicion was that there was a story about disempowerment to be told, and the literature supported that. However, it was pre-emptive to assume that, firstly, that was what the narratives would be, and secondly, that that was all the narratives would be. The cautioning of disability studies scholars against the representation of people with disability purely as victims of oppression without fortitude and strategies of resilience (Atkinson, 2004; Goodley, 1996) was also influential.

Fine, Weis and Wong (2000), in considering representations and social responsibilities in qualitative research, pose a series of questions for researchers to consider in designing and conducting research so that it does not further marginalise participants, and so that researchers consider their roles in contributing to socially responsible and methodologically solid research. One of their questions is around ensuring that the voices of participants are situated in context, and another around the use of multiple methods, so that different kind of analyses can be constructed to illuminate issues in different ways. They argue that researchers need to take a real responsibility for ensuring that the lived experiences of people who participate in their research are treated with integrity and respect. I hoped a narrative approach might offer a way to do this in the context of my research.
3.2.2 Narrative approaches

Elliot (2005) argues that a common theme runs through all narrative approaches. They share an interest in people’s lived experiences, and the temporal nature of those experiences; a desire to empower research participants and to encourage their contribution in identifying the most pertinent themes in an area of the research; an interest in process and change over time; an interest in self and representations of self; and an awareness of the active role of the researcher as narrator.

Elliot also distinguishes between first order and second order narratives. First order narratives are those stories that people tell about themselves and their experiences. They can be understood as ‘in some senses constitutive of individual identities’ (2005, p.12). Second order narratives are the accounts researchers develop to make sense of other people’s experiences and the social world. These second order narratives use individuals as units of analysis, or as parts of what Richardson terms a collective story (cited in Elliot, 2005).

This concept may be not be so easily defined when carrying out narrative research with people with intellectual disability, due to the difficulties of clear agency that some people have. Booth and Booth (1996) address some of the challenges in doing narrative research with people with intellectual disability - specifically inarticulateness, unresponsiveness, a concrete frame of reference, and difficulties with the concept of time. All of these issues combine to make the delivery of an independent narrative which contains all the features of a standard story – that it is temporal, meaningful and social (Elliot, 1995) – somewhat less likely to occur without intervention from the researcher.

Owens (2007) discusses the importance of the research context in which narratives are developed with people with intellectual disability, and the fluidity between first order and second order narratives when strategies such as frequent iterations are used with people who have limited communication skills due to disability.
Voice of the researcher in the research

The researcher is commonly viewed as a narrator or a co-narrator in narrative approaches (Elliot, 1995; Richardson, 2000; Liamputtong & Ezzy, 2005). In research with people with intellectual disability, whose voices may be less easily heard, less traditionally voiced, and less authoritative in society, the voice of the narrative researcher is thrown into greater relief.

Several researchers (Booth & Booth, 1996; Owens, 2007; Goodley, 1996) are of the view that creative and thoughtful strategies are needed which may blur the traditional boundaries of narrative ‘ownership’, but which maintain respectful and fair ways of researching which treat participants with integrity. Owens sees the quality of narrative research with people with intellectual disability as being dependent in part on the skill of the researcher in extracting and interpreting meaning from the narratives of participants. Goodley contends that:

To acknowledge the pen of the researcher in the writing of life histories does not detract from the potency of the narrative, rather it excavates many issues of power that are often submerged amongst the rhetoric of ‘empowerment’. (2006, p. 340)

The relationship between the key participants and the researcher is complex. While the research is entirely dependent on their contribution, expertise and authority, having access to all of the narratives means that a level of privilege is accorded to the researcher which is not shared with any of the participants – it is only the researcher who undertakes the thematic analysis, pulls out the common threads, and makes links between the narratives. While a summary of key experiences was shared with all participants, this only went part of the way to redressing this vexed issue.

Atkinson and Walmsley (1999) point out some of the limitations of narrative research, as opposed to auto/biographical research which
provides longer term and greater breadth of opportunity for people with intellectual disability to narrate and research their ordinary life experiences, rather than the extraordinary experiences which are more often of interest to researchers. They write of autobiographical accounts, or fragmented autobiographies. While conveying less breadth and depth than auto/biographies which tell people’s life history, they see a use for fragmented accounts. They write; ‘It is possible to deploy a set of biographical and auto/biographical fragments to tell a story, to make a case, and to present some accounts which might otherwise not be heard.’ (1999, p.215). However, the limitation they point out is that fragmented autobiographies focus on what is different about people’s lives, the things that make them marginalised and devalued, rather than the ordinary life experiences that people would focus on themselves as part of a life history approach. They are performative accounts.

Empowerment and narrative research
A number of researchers contend that narrative research methodologies have the capacity to empower participants, due to the enhanced opportunities for increasing their knowledge and understanding about the world, assisting them to validate their lives and giving voice (Atkinson & Walmsley, 1999; Bruce, 2008; Ewick & Silbey, 1995). Montalbano-Phelps (2004), in her work on the transformative power of women relating narratives on their abusive experiences, argues that narrating abusive experiences can be empowering on a personal level for women when the narrator is willing and able to narrate, the context of the telling is right, and the teller-listener interaction is appropriately supportive. On a methodological level, she asserts that the narration of abuse narratives has transformative possibilities, both through the change of the individual narrator from victim towards survivor, and in the development of a shared body of narrative work on the issue of abuse.

Atkinson (2004), in discussing life history research with people with intellectual disability, points out that narrative methodologies make people the experts in their own lives, and that this is an empowering thing, particularly for people who have been marginalised and diminished in
many ways throughout their lives. She maintains that life history research assists people to validate their life experiences, and that helps them in developing a strong sense of self and reconciling life experiences. Goodley (1996) takes this same approach, valorising the central place of the person in the research process. Owens (2007) views narrative methods as having a role in ‘liberating’ the voices of people with intellectual disability who would otherwise remain silent in research processes.

A valuable caution, however, about unthinking claims to empowerment for participants in narrative research is made by Andrews (cited in Reissman, 2008). She argues that the claim of empowerment rests on the healing power of storytelling, and that a series of questions need to be asked in order to ensure that this process is in fact occurring. The questions she poses are:

Who benefits from the work? Is a ‘speaking self’ the same as a ‘healing self’? How are stories going to be received by differently situated audiences? Will they be heard as the author intended? How will a narrator view the investigator’s representation later, particularly if her life has moved on? (2008, p.199).

**Narrative and agency**

A number of researchers highlight problems in ascribing agency to people with intellectual disability who may not understand the processes with which they are engaged. It is argued that policy initiatives and research approaches based on models of liberal citizenship which require individuals to exercise voice and demonstrate independent capacity may fail to adequately consider people’s needs for care, security and wellbeing (Redley and Weinberg, 2007; Young & Quibell, 2000). A different approach for people with what Kittay (2001) refers to as ‘attenuated agency’ was crafted for this study, drawing on the knowledge of family members and advocates close to people with high support needs.

Those participants who have not directly taken part in the study are nonetheless critical to its conduct. While their experiences are included through proxy accounts – the narratives of their family members and
advocates – they were personally unaware of the research. No claims could be made to individual empowerment for people with high support needs, although the experience of participating in the research may have been beneficial for family members in similar ways as for people with intellectual disability, as detailed above.

3.3 Narrative collage

It is commonly held that multiple layers of meaning, analysis and reading are possible within a narrative approach (Reissman, 2008; Elliot, 2005; Liamputtong & Ezzy, 2005). It was important that the integrity of the individual narratives of the people who had shared sometimes painful experiences were given the space and recognition that they deserved, particularly as some people had waited a long time for a receptive space in which to air their experiences. These stories, on an individual level, hold an important and irreducible meaning. However, there are also some shared elements of people’s stories which may offer a new understanding of this form of abuse and neglect which may assist in recognising and responding to it when people live in disability services. This seemed to require a different sort of analysis.

A fundamental dilemma also arose in the research design, in trying to determine how to make sense of both the range and nature of abuses experienced by a group of people (and what this may mean for all people living in disability services), while still remaining alive to the meaning and worth in the individual stories of each person who was involved in the research. In order to do this, two methodological approaches have been used. The primary approach which has been applied to the research is one of narrative collage, and a more traditional narrative research methodology is also used to maintain and sustain the integrity of the individual narratives and to keep their broader context.
Narrative collage was crafted as a response to the ontological and epistemological demands of the research, which required that people with intellectual disability have a privileged position in the research, but that others close to them who may have valuable input and support to offer be welcomed into the research too.

The key to narrative collage as a research method lies in the assemblage of its component parts. Each constituent part tells a story, but the sum of the parts together make something that is new and conveys a theme or meaning that none of the component parts suggests so well alone. Kephart, a poet and author, says:

The repetition of images builds symbols and motifs. Although a collage is comprised of small narratives, its cumulative total is more a thesis or emotional statement than a traditional story (2008, p.1).

Narrative collage does not have a strong presence in the methodology literature. It is represented in the performance ethnography (Denzin, 2003) and organisational studies (Kostera, 2006) fields, and perhaps most strongly in the field of critical literature studies (Kephart, 2008). Common to all fields in understanding narrative collage is that it is about gathering collective experience to develop new understanding. This was particularly engaging, and offered the possibility of developing a shared conception of some of the features of this form of abuse, which may assist in understanding it better. Kostera (2006, p.14) frames narrative collage in the following way:

The point with composing a collage out of the collected stories is to find a collective level in the invention. It is a kind of inter-subjective reality

There were many advantages in working with people who were happy to share information between each other, although in some instances they were interviewed separately, according to their preference. I was asking people about their ‘service lives’, which in some cases went back decades – it would no doubt be helpful to have some assistance with dates and places, among other historical reminders. There was also a clear need for a process which was supportive in the event of people becoming
distressed, given that the topic was likely to be upsetting for people to talk about at length.

Narrative collage is not reliant on timeline, in the way that more traditional narrative research is. This changes the focus away from a list history approach, to a focus more strongly on events. Fortunately, this was in keeping with the preference of research participants, who were wanting to talk about events which had had a major impact on them, due to the distressing and sometimes traumatic nature of their experience. However, there is a risk that a focus on abuse events will lead to a depiction of participants purely as victims, and there was a need to guard against this.

3.4 Analysis of narratives

Aside from the assemblage of experiences, the narrative collage approach has several commonalities with narrative research approaches used by researchers who have written about their experiences working with people with intellectual disability (Atkinson, 2004; Owens, 2007; Goodley, 1996), as detailed above.

The approach taken in this research is an attempt to overcome the limitations of time passed, history, power, inarticulateness, and ability to generalise that combine to impact on the capacity of people with intellectual disability to talk about their experiences, particularly experiences that are negative (Booth & Booth, 1996; Montalbano-Phelps, 2004; Goodley, 1996). The approach seeks to understand how individuals are impacted by their experiences. It is also a methodological effort to understand the impact of emotional and psychological abuse and neglect on people with intellectual disability in a more systemic way, by applying a series of different ‘filters’ over the narrative collages of people’s abuses which may uncover some of the shared features of their experiences that highlight failures of the disability services systems which are set up to support people with intellectual disability. In seeking this understanding, it
is hoped that some ideas for changing the ways in which people with intellectual disability are supported to live their lives so they are safer, more fulfilled and more in control of their lives may emerge.

It is very important, however, that an approach such as narrative collage does not strip the narratives of people with intellectual disability and those who support them of their context. Were they to be broken into shards, it would be easy for this methodological approach to portray a group of people as victims of oppression who have little strength, fortitude or positive characteristics from which to draw. Each narrative is important in and of itself, and must be analysed from that point, as well as in combination with the voices of others who have been in a similar position.

Consequently, there are conceptually two levels to this approach of narrative collage – first, it operates as a research method, and second, also as a methodology. At the level of participants, the collage effect can be viewed in the multiple perspectives which are gathered around each person with intellectual disability to form a narrative collage of their abuse experiences. At the analysis level, narrative collage is used methodologically, and forms an umbrella under which both holistic and thematic (or categorical) analysis of the individual narratives sit. It is in many ways a blend of Elliot’s (2005) first order and second order narratives.

I was influenced by the work of Ewick and Silbey (1995) around subversive stories in narrative research, and their contention that: subversive stories do not aggregate to the general, do not collect particulars as examples of a common phenomenon or rule; rather, subversive stories recount particular experiences as rooted in and part of an encompassing cultural, material, and political world that extends beyond the local... Subversive stories are narratives that employ the connection between the particular and general by locating the individual within social organisation. (1995, p.219-220)
‘Classical’ narrative analysis privileges holistic analysis of narrative – that is, it does not advocate the breaking down of narrative into themes or codes, due to the risk of dislocating material from its context (Elliot, 2005; Reissman, 2008). Many theorists argue, as do Webster & Mertova (2007), that narrative inquiry is valuable because it attempts to capture the whole story, and hence it frames the human experience in a different way and allows an analytical examination of the underlying assumptions and insights that the story illustrates that would not be available in more dislocated research materials.

However, several researchers agree that in some cases, it can be done. Leiblich, Tuval-Mashiach & Zilber (1998) divide narrative analysis into holistic and categorical approaches. They offer a matrix of holistic and categorical form and content, and suggest a combination of both approaches is possible. Reissman, one of the leading theorists in the narrative research field, writes:

While useful for making general statements across many subjects, category-centred approaches eliminate the sequential and structural features that are the hallmarks of narrative. Honoring [sic] individual agency and intention is difficult when cases are pooled to make general statements. I believe, however, that category-centred models of research (such as inductive thematic coding, grounded theory, ethnography and other qualitative strategies) can be combined with close analysis of individual cases. Each approach provides a different way of knowing a phenomenon, and each leads to unique insights (2008, p.12).

The narratives will be taken apart and analysed thematically in the research, in order to try and understand what makes up this sort of abuse and neglect. However, this thematic analysis will occur after a holistic presentation and analysis of the individual narratives of people with intellectual disability. The thematic analysis will not extract the narratives from the meaning of the whole - the extracts will still remain connected to the holistic experience of the person. It is essential that the presentation of the experience of each individual weaves the story so that the discrete experiences have separate power, but so that the impact of multiple
abuses over time can be viewed. This is a critical issue for the methodology – and determines how the data is laid out. The separateness of the incidents is important, because in and of themselves they are important as individual wrongs. However, the cumulative effect of them is another level of wrong that was done to people, and needs to be seen to be so.

There are three sets of material in the research. The first is the narrative collages. The core narratives of people with intellectual disability are buttressed by narratives from family members, individual advocates and a disability support worker who added their perspectives about the person’s experiences – hence the term ‘narrative collage’. The second set of material comprises narratives from family members who act as agents for their family members who have high support needs due to intellectual disability, and who are unable to participate in this sort of research on their own behalf. The third set of material is in-depth, semi-structured interview responses from key policy stakeholders in the disability services field. These are not considered narratives, but more what Reissman (2008, p.4) calls ‘question and answer exchanges’.
Part three: Research method

3.5 Sources of research material

Material has been gathered from three key sources and is used in the research.

The primary research material is comprised of the four narrative collages of people with intellectual disability and their support people, and the five narratives of family members of people with high support needs. This material is about the lived experience of nine people with intellectual disability over their ‘service lives’.

Sixteen key individuals in the disability field, primarily policy and complaints management agency representatives also contributed to the research through in-depth, semi-structured interviews. Their interviews were transcribed, and this material focuses more broadly on issues of prevalence, recognition, response, prevention and protection against abuse.

Comparative critical policy analysis of state, national and international research and policy responses to the issues raised by emotional and psychological abuse and neglect of marginalised groups has also been undertaken to inform the analysis of the narrative and interview material.

3.6 Design of research tools

An interview series was designed to gather information in the most supportive and sensitive way possible, with high regard for the levels of distress the research could cause participants. This structure draws on the work of several researchers, around both the construction of interview
series (Seidman, 1998) and around the experience of relating abuse narratives (Montalbano-Phelps, 2004; Mitchell et al., 2006).

The research tools which were designed to inform the way in which the research was conducted included:

- Standard information and consent forms
- Easy English information and consent forms
- A screening questionnaire to ensure participants with intellectual disability were not living in the environment in which the abuse they were describing was occurring; were not in a therapeutic relationship about their abusive experiences; and consented for me to talk to a supporter about their perspective of the abuse
- A three stage interview series, with semi-structured interview prompts (see below for details)
- A definition of emotional and psychological abuse and neglect handout
- A project flyer for recruiting family members

The research tools are attached at appendices one - seven.

The interview schedules were designed following the work of Seidman (1998, p.11), whose three-interview structure is designed to allow the interviewer and participant to “plumb the experience and to place it in context”. The first interview sets the scene of the participant’s experience. The second allows participants to reconstruct the details of their experience within the context in which it had occurred. The third is intended to encourage them to reflect on the meaning their experience holds for them. The use, and subsequent adaptation, of the research tools is described in the section 'the interview process’, below.

The design of the interview series and schedules to prompt conversations (indeed, the whole project design) was submitted to and approved by the University Human Research Ethics Committee.
3.7 Recruitment of participants

Participants in the study were recruited using purposive, or ‘snowball’, sampling. This method of sampling is useful in cases where the aim is to seek out participants who are most likely to have experienced the process under study (Denzin & Lincoln, 2000), and where a small group of people will form the basis of the study. Snowball sampling was used as a method which "identifies cases of interest from people who know people who know what cases are information-rich" (Kuzel & Patton, cited in Miles & Huberman 1994, p.28).

Using this method, nine ‘core’ participants with intellectual disability were recruited to the study. Ann, Tom, Jim and Craig participated in their own right, using narrative collage (detailed below). The family members of Diwata, Jill, Fran, Jenny and Dan participated on behalf of their family member, due to their high support needs, which precluded them being involved in the research themselves. An introduction to each person in the research will be made in the opening of the next chapter, which presents their experiences.

Several ethical issues were raised by the topic of the research which dictated the need to tread carefully in recruiting participants with intellectual disability – such as the likelihood of the topic causing distress; the risk of retribution from services if someone talked about a current experience of abuse; and the need for informed consent about participation in the research (see the discussion on ethical issues, below, for a fuller discussion). Consequently, a decision was made to include two sets of gatekeepers in the recruitment process. Advocacy agencies were asked to be the first set of gatekeepers, and to make contact with the family or other supporters of people who they thought might be interested in being involved in the research, and to talk with them about the research. If the family member or supporter thought the person would be interested, they would then speak with the person about the research. The family member or supporter thus became the second gatekeeper.
This process was designed to minimise the risk of people with intellectual
disability agreeing to take part in the research without understanding the
implications of it, and becoming distressed partway through the research
process. This is particularly so, given that it is hard to describe the
subtleties of emotional and psychological abuse without ‘leading’ people
with intellectual disability. It was also designed to reinforce the consent of
the person with intellectual disability, as the family member or supporter
was asked in their consent form to indicate that they believed that the
person was able to understand what the research was about, and to
consent to being involved in it. However, I did have some misgivings
about whether the inclusion of two gatekeepers was paternalistic or overly
protective, and perhaps did not allow people with intellectual disability
who may have liked to have been in the research the dignity of choosing
for themselves.

The data set shows that all four people who participated in the narrative
collage interviews came to the study through the same advocacy provider
gatekeeper. This is a result of one of the ethical requirements of the
research - that people no longer lived in the service in which the abuse
had taken place. There is limited movement of people with intellectual
disability between disability accommodation services. It also proved
difficult to get agreement from residential services to promote the
research to their residents. The advocacy agency had maintained contact
with people who used their services over several years, and they were
obliging in contacting inactive clients to gauge interest in participation in
the study. Consequently, each person in the study had received assistance
from an advocate in changing services or for similar concerns at some
point (not necessarily in relation to the abuse they spoke about in this
study). Surprisingly, given the large number of services they had lived in,
none of the nine total participants with intellectual disability shared
service histories.

Issues of geography also influenced the research design, as some options
were not available due to the distance of the research participants from
the researcher (I lived in a small regional village in another state). It was
not possible to build a small group which met many times, for instance. Location, however, did act to protect participants from accidental meeting with the researcher in a small community after the research.

The recruitment of family members of people who have high support needs was also conducted through advocacy agencies. This was a much more straightforward process, with families who were interested in the research agreeing to have their phone numbers passed on me so contact could be made. This form of recruitment did result in a set of family participants who are all particularly strong advocates for their family members, a feature which needs to be taken into account in the analysis of their narratives.

Recruitment of policy stakeholders was completed through analysis of the Queensland government policy, complaints response and advocacy sectors. Representative agencies for each of the primary areas within disability services were contacted, and in all cases agreed to participate. Participants within agencies were identified based on their individual expert knowledge or their position in the organisation.

It was very important that the research did not get waylaid by some of the inevitable justifications that the service sector provides for the experiences that people with intellectual disability have in services, such as staff shortages due to resource limitations, a lack of capacity to develop better models of supported accommodation due to political will and resourcing, and so on. These are true, and I have no wish to demonise the service sector (see literature review for a discussion of these issues). However, the service sector (staff, managers, non government organisations and the government departments who manage them) has a strong and loud voice, and many places in which to use its voice. People who use services have a small and frequently silenced voice on many issues. They are rarely heard about contentious issues, and never heard about this issue of emotional and psychological abuse and neglect. It was critical that the research looked, as much as was possible, at the issue through the eyes of the people who had experienced it.
Consequently, representatives of the service sector were not included in the research.

### 3.8 Advisory groups and consultation – people with intellectual disability and advocates

At the beginning of the fieldwork stage of the research, consultation was held on two separate occasions with two people with intellectual disability who have expert knowledge about research and about abuse experiences. These two people have worked on participatory research projects in the past with several researchers, including me, and they both kindly agreed to advise me on the appropriateness of the research topic, the intended approach of the interview structure and way in which the questions were worded. Their feedback was that:

- The topic was an important one, and one that they did not think people had had their say about before
- I needed to be careful not to upset people
- I needed to ask questions really clearly
- I needed to make some changes to the words that I had used in my questions
- I needed to make sure the research did something – that it was used to make change

Adjustments to the interview materials were made in response to their feedback, and consideration of their broader feedback informed the methodological approach of the research.

At the outset of the fieldwork phase of the research, an advisory group of advocates and key individuals in the disability rights movement in Queensland was also initiated. Members of the group were determined based on previous work related contact and referral from other advocates. It was largely through these consultation group members that participants in the study were located.
The group generously provided advice about the appropriateness of the research; the likelihood of attracting participants; risks in the intended research approach; ensuring informed consent; and potential strategies to attract people who may be interested in being involved in the research. Their feedback was that:

- the research was important and relevant
- it would be very difficult to find participants
- it was important that participants were not put at risk of retribution by service providers, so the strategy of limiting participation to people who could talk about their experience in past services was essential
- it was important to balance people’s right to participation in the research with their right to be protected from distress they might not be able to anticipate. With this in mind, the strategy of using two gatekeepers, advocacy agencies and family members, was considered useful
- serious consideration should be given to expanding the participant group to include family members, due to both the difficulty in attracting enough participants with intellectual disability, and because the large bulk of people living in funded accommodation services are people with high and complex support needs who are unable to participate in this sort of research on their own behalf

This advice was extremely valuable, and proved more and more useful as the fieldwork stage of the research progressed. The recommendation of the reference group to open the participant group to include family members was not initially taken up, as one of the over-riding concerns in the development of the research was about the lack of centrality of people with intellectual disability in research about abuse.

### 3.9 Amendments to the research design

After several months of recruiting, it became clear that the potential pool of participants with intellectual disability was small, and it was not likely that more than four people who had lived in state funded disability
accommodation services were going to be attracted to the study. There are likely to be several reasons for this, most particularly the limitations placed on the recruitment of participants in order to minimise the risk of undue distress. These included people having to have left the service in which the abuse had occurred; people being willing to talk about it; people having the capacity to talk about it; and people not being in a therapeutic relationship about their abuse experiences. For people with intellectual disability in this state, there is very limited availability of funded accommodation and support, and within that, very little movement is available, and almost none across services. It is very unlikely that people would be able to move between services, as their needs would not be highly prioritised for government funding, being deemed as already receiving services. It is also recognised that people with intellectual disability may have difficulty with memory (Booth & Booth 1996), and the research recruitment process was asking people to go back in time if they had left the place in which the abuse had occurred some time ago.

The method of the study was amended to respond to three factors - the low numbers of participants to date; the range of accommodation settings from which they came (funded, private and children’s homes); and the fact that the original method did not include the voices of people with high support needs due to their intellectual disability. A decision was taken to include family members of people with high and/or complex support needs in the research, in order to ensure that the stories of those people would also have a voice. Accordingly, five family members of people with high support needs were recruited to the study, who provided the perspectives of people who were unable to participate directly in the research due to the nature of their disability. This proved to be a very positive development in the research, and the narratives of Jill, Diwata, Jenny, Fran, and Dan’s family members have added a great deal of depth and breadth to the research.

However, in order to maintain a ratio of participation in which the voices of those who found it hardest to participate were privileged, family members participated in one individual interview, and people with
intellectual disability were involved in up to three individual interviews, as well as other incidental meetings.

The early research design also included a final group interview to be held with each key participant and those who have also been interviewed in their social network. The intent of this final interview was to focus on the participant’s plans for the future, and so to leave the participants and their supporters in a position where they were each aware of the possibly painful abuse stories which had been shared, and were hopefully working together towards positive action for the future. This final meeting did not happen for any participants, for several reasons. First, and most importantly, it quickly became clear that it was overly presumptuous to assume that people and their family and supporters did not already have well established ways of sustaining and nurturing each other, and that they needed direction on this. Second, the circumstances of each of the participants made these meetings impractical. Jim and Tom’s mothers both live a long distance away, and visit irregularly. Ann’s sister also lives quite a long way from her, although they are in more frequent contact. Craig has no family support, and expressed no desire for closer contact with his advocate. Finally, some participants had so little positive future vision and opportunity that the idea of a meeting devoted to pursuing this issue would be fruitless and possibly painful for them.

### 3.10 The interview process

#### 3.10.1 People with disability and their supporters

The interview series was designed to include the development of rapport and some level of relationship between the researcher and participants, through the introduction of a face to face meeting prior to the interviews themselves starting. This meeting was held with participants at their homes (according to their preference), and used for them and I to introduce ourselves to each other, for me to tell them a little bit about the
research, and for us to get a sense of whether we felt we would like to work together. The meeting was used by me to ‘screen’ participants for their appropriateness for inclusion in the research, through asking questions about whether they had experienced bad treatment at somewhere they lived, whether they still lived in that place, whether they were receiving counselling about that treatment, and so on. This schedule is contained in appendix three. If people met the criteria for inclusion in the study, we then moved on to talk through the easy English consent form. In practice, Ann, Tom and Jim provided a lot of information about their experiences in the screening meeting, despite that not being its purpose. This was recorded and used in their narratives, with their permission.

A series of individual in-depth, semi-structured interviews were conducted with each participant in order to construct their narratives. The interviews were all conducted at people’s homes, in accordance with their expressed preference of home as a comfortable and private place to talk. Each interview was preceded by social talk and tea or coffee, and I brought morning or afternoon tea to each interview, which we usually had after the interview.

The original intention was to collect the narratives from people through a set series of three semi-structured interviews. This built from Seidman’s (1998) three phase interview structure, in which the first interview sets the scene, the second interview allows participants to reconstruct details of the experience, and the final interview encourages them to reflect on the meaning of the experience.

The first interview, therefore, it was hoped, would centre around a focused history of the person’s experience living in formal disability services; the second interview would focus on drawing out details of the abusive experiences the person has had in that context; and the final interview would concentrate on drawing out their reflections on the meaning of the experiences.
When the interview guide was piloted, it became clear that this format was overly rigid, as the experience of the abuse was tied up closely with the chronological history of the person’s accommodation placement. This later proved true for all of the participants in the research. It was too difficult for some people to firstly provide a chronological history of the places in which they had lived, particularly those people who had lived in many different places, as Ann, Tom and Jim have, and to then jump back again to discuss the things that happened in those places the following week. They wanted to talk about the things that happened in those places at the time they first raised them as somewhere they lived. It became clear that constructing a chronology was a job for the researcher outside of the interview, not for the participants inside the interview. It was more profitable for both of us to allow the interview to proceed more fluidly and to capitalise on their flow of memory about the sorts of experiences they had in each place in which they lived.

Consequently, the interview guide was used as a prompt for the researcher to make sure that all the broad elements of the research had been covered, but the ordering of the questions or topics was much more led by participants. The first interviews were for all participants the ones in which they gave a history of the places in which they had lived, and told about much of the abuse they had experienced. The second interviews for Ann, Tom and Jim were held a week after the first. I came prepared with the transcripts of the first interviews, and with a summary of their history of accommodation services, and a list of those abuse experiences that I hoped to talk about further.

This approach proved fairly successful for Ann and Jim. They both willingly answered questions about different services, and gave more detail on several incidents of abuse that they had touched upon in the prior interview. They also both raised new instances of abuse that they had been thinking about during the week, knowing I was coming back to talk with them again. It worked somewhat less well with Tom, although this was influenced by the fact that he had a support worker present at this
interview who was disinterested in his experiences, affecting his focus on
the interview.

Craig participated in only one interview, as he had thought about his
situation at great length prior to our meeting. He had talked about his
situation with many other people before coming in contact with this
research, and his participation was more practised, although no less
valuable, because of this. Craig was also labelled as having intellectual
disability and other disabilities as a child, although he does not now
identify himself as having intellectual disability. His advocate feels that
much of the impact of Craig’s disability can be put down to deprivation. As
his childhood was lived under the label of intellectual disability, I felt it
reasonable to include his story in the research, as his lived experience is
comparable to his compatriots.

None of the four completed a third formal interview. During the first
meeting and the first and second interviews, it became clear that it was
difficult for people to reflect on the meaning of their abuse experiences. In
several instances, they did not even realise the experiences were abusive,
although they expressed their view that they were ‘wrong’. It was clear
that an interview which was devoted to reflecting on the impact of the
experiences was not going to work. The other question which was
scheduled for the third interview, about what was in the future, was
brought forward into the second interview, as a concluding, and hopefully
more uplifting, topic on which to finish the interviews.

The incidental conversation which happened at the beginning and end of
the interviews was very important for the research process. I quickly
developed a technique of laughingly turning on the tape recorder quickly
once I arrived to catch the important words, as a number of times people
had been waiting to tell me about incidents they had been thinking about
since our last meeting, and they didn’t wait until the interview was
properly started. Similarly, I left the tape recorder running while we had a
cup of tea at the end of the interview, making sure that people knew
when I turned it off as I left, so I could check if they didn’t want anything
they had said to be excluded from the tape. A number of abusive experiences were related this way, and they were experiences that people did not identify as abusive, but saw rather as something that made them feel sad or upset.

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<thead>
<tr>
<th>Screening meeting</th>
<th>Interview one</th>
<th>Interview two</th>
<th>Supporter interview</th>
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<tr>
<td>Ann</td>
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<td>Gemma</td>
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<td>Jim</td>
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<td>Wendy</td>
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<td>Tom</td>
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<td>Craig</td>
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**Table 2: Interview schedule with participants at the centre of narrative collages**

The narratives of each primary participant are supported by in-depth, semi-structured interviews with people in their intimate support network - family members, advocates or in one case a close support worker. The interviews with supporters were conducted individually, at places nominated by each person as comfortable and private. One interview was conducted by phone, due to distance. Another interview was conducted with an advocate who knew all four people.

It was important that people in the support network were clearly informed of the purpose of their involvement – that they were adding a viewpoint to the person’s narrative, rather than being interviewed for their own narrative (although this is inevitable to a degree). The design of the information material provided to these participants, the screening process used, and the interview guides (see appendix four) all provide information to guide these participants in their role as supporters, as people who are adding another perspective to the abusive experiences of the key participants. Their participation is on a different basis to the family members of people with high and/or complex support needs, who are representing the story of their family member, rather than supplementing it – an important distinction.
### 3.10.2 Family members

Initial contact was made with family members through the advocacy agencies described as the gatekeepers above. Once families had indicated their provisional interest in being involved in the research to the advocacy agencies and agreed to have their contact details passed on, I contacted them by phone, and discussed the research with them. In each case, the family members agreed to participate in an interview, and a time and place was agreed.

Interviews were conducted with family members either in their homes or in coffee shops, according to their preference. A short list of guide questions was used (see appendix four), which prompted families to talk about the history of their family member’s accommodation placements, and asked them to think about the sort of treatment they received while there, abusive treatment, the impact of abuse, complaints and the response to them, and positive experiences. Interviews were conducted informally, over tea or coffee.

The interviews were transcribed, and a copy of the transcript offered to family members for review.

### 3.10.3 Key stakeholders

Interviews with key stakeholders were held in their offices, at a time of their choosing. These interviews were straightforward from the perspective of key stakeholders, as they had all participated in similar activities before. A short list of questions to structure the interview was sent to stakeholders ahead of time, in order to assist them to focus their thoughts prior to the interview (attached at appendix four). These questions were used to give structure the interview, but did not dominate the discussion, which in several cases diverged from the interview schedule. The interviews were tape recorded and later transcribed, and either a copy of the transcript or a summary of the discussion was sent to participants, according to their preference.
3.11 Feedback to participants

At the conclusion of each interview, the preference of each participant for receiving feedback about their personal contribution and about the research more broadly was discussed. In accordance with the preference of participants, several processes of iteration and feedback were put in place. These encompassed:

- Sending the transcript of the interview for detailed review and amendment
- Sending the interview on CD for people to keep as a record
- Sending the transcript of the interview for people to keep as a record
- Sending a summary of issues discussed in the interview
- Phoning to talk about the issues raised when the transcript was received
- Sending a summary of the broader research findings
- Meeting with people to talk about the broader research findings

These final two points require some discussion. The initial research design contained a more elaborate strategy for engaging with participants about the research outcomes at the end of the research process. It included offering group meetings with interested participants to talk through the summary results, in the assumption that people may be interested in collective action to address issues of abuse in their lives, and may gather support from the experiences of others. It became apparent after the fieldwork that this strategy was impractical. Due to distance, little support was available to participants with intellectual disability to prepare for and resolve issues after such a meeting, which may stir up feelings of anxiety and distress.

Consequently, the scope of this goal was reduced, and people were sent either an easy English or standard English version of a summary of the primary results of the research (attached at appendix seven). Due to the personal and confronting nature of the material for people with intellectual disability, they were contacted by phone prior to it being sent, and offered a meeting to go through the document together if they preferred.
3.12 Data analysis

There were two levels of wrong which appear to be occurring in the lives of participants – individual incidents of harm, and an accumulative lack of action to redress these gathering injustices. Two forms of narrative analysis appeared to be required to give effective accounting of these. Data analysis was completed using holistic narrative analysis and also thematic analysis of the narrative collage material and the more traditional narratives of family participants and interviews with key stakeholders.

Holistic narrative analysis is an attempt to consider the meaning of each narrative collage, or narrative in the case of people with higher support needs, in relation to the greater ‘story’ of emotional and psychological abuse and neglect of people with intellectual disability in disability services (Ewick & Silbey, 1995; Atkinson, 2004). It does so, however, by aiming to consider each person’s story as a whole, as well as in its constituent parts. Smith and Sparkes describe the holistic analysis process thus:

a [holistic] narrative analyst turns a story told into a story to be formally analysed, extrapolates some sort of theoretical propositions from it and transfers these results by telling them in the form of a realist tale. (2008, p.21)

Thematic analysis has also been used in order to adequately represent the strong themes emerging from the data about the individual harms which have occurred in the lives of people with intellectual disability (Reissman, 2008; Elliot, 2005). The intention of this combined approach is to reflect both the individual and collective nature of the experience of emotional and psychological abuse and neglect in the lives of people with intellectual disability.

Narrative collages were developed for each of the four people with intellectual disability who had supporters who participated in the research as ‘buttresses’. These collages focus primarily on the experiences, thoughts and views of the person, but include the perspectives of those
other supporters on the person’s experiences. They are long and detailed documents, and unfortunately space precludes them being contained in this thesis. However, a segment of Ann’s narrative collage is included at appendix eight to give a flavour of the approach.

Neither have full narratives of the more traditional narratives been shared here. First, the length of the narratives of each person is such that the sheer weight of information is unmanageable without thematic analysis in order to make some sense of the shared experiences. Second, the disability community in Queensland is one in which many people are easily identified. People who participated in this study moved between services, and most people lived in what are now quite notorious services. They are in several cases easily recognisable, and care needs to be taken to minimise the risk of them being identified by a reader of the thesis. Consequently, identifying details have been altered – names have been changed, as have the names of their family and supporters, the workers who engaged with them, the names of the services in which they lived, and the names of the places in which the services were located. The location of the research within the state has also been left undisclosed.

Fragmented biographies (Atkinson & Walmsley, 1999) were developed for all nine participants with intellectual disability. These are short narratives which develop a picture of the person and how they fit into their world. They seek to paint a picture of the person as bigger than their abuse experience. It is both ethically and methodologically important that they are conceived of in this way. They are included at the outset of the following chapter.

Following this process, a thematic analysis of the narratives of each of the nine sets of interviews was completed, working from the transcripts which had been coded using NVIVO software (Reissman, 2008; Elliot, 2005). The themes which emerged from this analysis were then analysed against the framework of emotional and psychological abuse and neglect developed in the literature, and schematised according to their inception in the individual, systemic or structural domain (Penhale et al., 1999).
This process of thematic analysis resulted in a catalogue of individual wrongs done to people and a series of other emerging themes which centred on shared experiences. The shared experiences around impact of the abuse, resilience, experience of complaint making and so forth which were flagged in the thematic analysis were taken forward and analysed against the holistic narratives (Smith & Sparkes, 2008; Ewick & Silbey, 1995). The fragmented biographies and holistic narratives were also used in considering the impact of actions of the disability services system on the lives of people with intellectual disability more broadly around emotional and psychological abuse and neglect recognition, response and prevention.

In practice, this approach moved across holistic and thematic analysis, at times quite fluidly. The holistic narrative approach provided the context of people’s lives, essential to understanding who they were, and why their participation was important to the research – the bones of the research. Thematic analysis drilled down for the detail of the experiences of abuse and neglect which put the meat on the bones of the research.
Part four: Ethical issues

A series of ethical issues arose in the design of the research which required resolution in order to proceed. These included the history of exclusion of people with intellectual disability from research of this nature; consent; disclosure of criminal offences; and a more complex philosophical issue around the sharing of research findings with participants.

3.13 Exclusion of people with intellectual disability from abuse research

There is a history of excluding people with intellectual disability from directly participating in research on troublesome issues. A robust literature exists on the issue of the involvement of people with disability in research which affects their lives. The shared contention of this work is that research is strengthened both in terms of the quality and type of data obtained and the ethics of the study when a participatory approach is adopted (Shakespeare, 1997a; Rioux et al., 1997; Balcazar et al., 1998). A number of writers, particularly from the UK, have considered the principles and practicalities of involving people with intellectual or learning disabilities in research as partners, as advisors, and as participants (Atkinson, 2004; Tregaskis & Goodley, 2005; Chappell, 2000), and this study draws directly from this material.

The capacity of people with intellectual disability to consent to participating in research of this nature is a clear issue of ethical concern. This study builds from a body of literature which gives theoretical consideration and from practical research findings about the assessment of capacity and the development of strategies to increase that capacity (Dye, Hendy, Hare & Burton, 2004; Rioux et al., 1997; Swain et al., 1998). Clegg (2004) and Clapton (2003; 2008b) both discuss a
hermeneutic approach to ethics as critical to the production of research in this context. The project design is based around a hermeneutic understanding of ethics, with particular emphasis on the creation of an ethical environment. This ensures that the individual consent of participants is not the only mechanism to ensure the fairness of the research process.

Significant ethical issues arise in considering research which includes interviewing victims of abuse about their experience. These are compounded for people with intellectual disability, due to their difficulties in having insight into the possible personal repercussions of involvement in such research. The research design attempted to address these issues through:

• the structure of the interview series
• heeding the advice from the reference groups
• ensuring participants are not currently experiencing the abuse under discussion
• encouraging people to have a support person with them in the interview for moral support if they like
• ensuring they are not currently in a therapeutic relationship regarding the abuse
• through the identification of a specialist counsellor who is skilled in working with people with intellectual disability and families, who participants can see at no cost to them if they are distressed by the research.

3.14 Consent

Of the people with intellectual disability who were involved in the research, all were able to give their informed consent to participating in the study. Fortunately, the situation did not arise where it was hard to determine whether or not someone understood the consent process. A partially foreseen difficulty, however, was that people were not interested in the consent process, and I found it hard to keep their attention focused
on the (admittedly rather dry) easy English consent form all the way to the end. As the purpose of the research had been discussed with people by the time we were going through the consent process, they were justifiably far more interested in talking about their experiences than they were in signing a university form. The consent process was also complicated by the fact that I needed to explain that I would like to also talk with a family member or other supporter, and why I’d like their consent to do that.

It had been anticipated that separating the screening meeting and first interview would assist in dealing with the consent process, as well as allowing people time to develop some rapport with me, and to prepare themselves to talk about possibly difficult issues. Everyone except Jim were eager to start sharing their stories of their experiences while living in disability services, which they had ready for me.

At the beginning and end of each meeting, I reiterated the key points of the consent process – that people were at liberty to change their mind about participating, that they could change their mind about being involved later, and that they could change their mind about having certain bits of their stories included. I also checked in at the beginning and end of each meeting about people’s emotional state, and reminded them of the availability of the free counsellor if they were feeling upset by anything we were discussing.

I was very aware of the potential of the research to distress people with intellectual disability and family members and other supporters. The discretionary funds available to PhD students through the university were set aside for the use of participants if they were distressed by the research, so they could see a counsellor who specialised in working with people with intellectual disability who have experienced trauma at no cost (the counsellor was contacted and agreeable to being involved in this way). People who were in a therapeutic relationship about their experiences of abuse were also excluded in the research at the earliest
stage – advocacy providers, the first gatekeepers, were asked not to make contact with anyone they knew was not emotionally well.

In terms of minimising distress and risk to participants, it was important that the research only included people who had left the abusive situation. The stories of reprisal from services for making complaints and difficulty in dealing with service providers which emerged in the narratives supported this decision. It did, however, impose a limitation on the methodology of the research, in that it requires people with difficulties with memory to rely on memories of their past experiences. However, all of the participants had a large volume of vivid experiences which they related – the trauma of some of the experiences may mitigate against the effects of time on memory.

3.15 Disclosure of criminal activity

The potential disclosure of other forms of abuse which is a criminal activity, such as assault, theft, or sexual assault was a genuine concern. The concern lay both in addressing people’s need for justice, and also that they might not realise mention of previous assaults would start a chain of events they might not anticipate.

The research addressed this concern in discussing this with participants as part of the consent process in clear terms - that if they talked about something happening to them that was against the law, I may need to get help for them from someone like the police, but I would not do anything about it without talking to them first. In the event, while a large number of abuses were related, no assaults which were actionable were disclosed, as they were either non-specific, long-ago historical or being dealt with through other advocacy and legal channels.
3.16 How much to share with participants?

A broader ethical issue is also raised by the analysis of the material that participants in the research have shared. Some of the themes which have emerged are around issues such as loneliness, isolation, disempowerment and damage to relationships. The commitment to share the research findings with participants is in keeping with a participatory methodology. However, questions are raised about how ethical it is to share findings of this nature with participants. There is limited, if any, benefit in discussing results about people’s personal circumstances over which they are powerless to make change. While it is straightforward to share results which lay the blame for abuse on the disability services system, results which may be personally hurtful are another question entirely.
Part five: Limitations to the study

3.17 Limitations

There are a number of significant limitations to the study which must be acknowledged.

This is a small scale study, involving only nine people with intellectual disability at its core. The research was conducted within a defined geographical area, and consequently, no rural participants were involved. It is not possible to generalise beyond the experiences of the participants, although it is possible to note that their lives are not exceptional in terms of the pattern of services they have used and the paths they have followed.

The scale of the study also meant that a decision had to be made after several months to stop recruiting for participants with intellectual disability, and to instead recruit family members of people with high support needs. While this had significant benefits, and enabled the voice of these people to be heard by proxy, it did mean that fewer people with intellectual disability have a direct voice in the research. Challenges arose in ensuring their voices were heard amidst the more eloquent voices of family members and key stakeholders. Although the methodology aimed to address these, the challenges remained in the writing process.

There is an absent voice in the research, which is that of direct support workers. This was a deliberate methodological decision in order to ensure that the lived experience of people with intellectual disability remained the primary focus of the research. It was also necessary due to the scope of the research. It should be acknowledged, however, that one side of the story remains untold, and that support workers no doubt have an interesting and complex tale to tell about this abuse.
Finally, the study was conducted by only one researcher. The role of both supervisors in the research process was invaluable, in offering constructive advice, critique and analysis of the data. There would, however, have been considerable benefit in a team of at least two field researchers to ‘combine forces’ to winnow data, generate themes and discuss emerging ideas.

3.18 Summary

This chapter has detailed the conceptual, methodological and practical approach to the research project.

The ontological and epistemological approach of the research is presented in part one of the chapter. It is grounded in the belief that the knowledge and truth about this issue is vested in those who have lived it, and in those close to them. This ontological focus on lived realities (McClimens, 2004) privileges the lived experience of people with intellectual disability, and requires a perspectival epistemology that trusts in the validity of this lived experience (Falmagne, 1998; Conway, 1998).

This conceptual foundation calls out for a methodology that privileges the involvement of people with intellectual disability, but which welcomes the involvement of others who have something to offer in a collaborative spirit. Part two of the chapter detailed narrative collage, which has been used as a methodology which offers an innovative approach to gathering rich and dense data on this lived experience of abuse. It is a little known methodology, seemingly unused in disability studies, but which links to the broader canon of narrative method (Denzin, 2003; Elliot, 2005; Owens, 2007).

The research method is noted in part three of the chapter, with the sources of research material; research tools; recruitment of participants;
use of advisory groups; amendments to the research design; the interview process; and data analysis each detailed.

Part four of the chapter raised ethical issues which were addressed in the design of the research, including overcoming the common exclusion of people with intellectual disability from research about abuse and neglect, issues of consent to involvement in the research, and dealing with the potential disclosure of criminal activity. A further ethical question is raised, but not resolved, regarding how much of the research results to share with participants, when some of the systemic outcomes may be personally distressing, but beyond the power of participants to change.

The final section of the chapter addressed the limitations to the study, and recognised its smallness of sample and scale, defined geographical area, recruitment issues, the absent voice of service providers and the challenges which arose in ensuring the voice of people with intellectual disability is heard in the research.

The following chapter presents the outcomes of this research method, the results of the study.
SECTION TWO: RESULTS OF THE RESEARCH
Chapter four:
The experience of emotional and psychological abuse and neglect - individual, systemic and structural

And the police took her back [after being left alone at a fair]. Then, they took her back to the house, and they phoned the [institution] doctor, they wanted to make sure that she hadn’t been molested or whatever, you know, that she’d not come to any physical harm. And the doctor said that she was finishing her shift in 20 minutes, and she didn’t have time to come down and examine her, and that they’d have to wait until the next doctor. When the next doctor came on, he said he’d have to do his rounds, and he wouldn’t be finished until 9 o’clock, and by that time she’d be asleep. And they wouldn’t come down and make sure that she was alright.

- Ivy, Jill’s mother

This chapter details the emotional and psychological abuse experienced by nine people with intellectual disability who lived in funded disability services.

In keeping with the methodological approach of the study, the chapter focuses on the lived experience of people with intellectual disability. It builds a collage of their narratives, both individually and collectively. Their experiences are gathered and presented by typology, according to the abuse framework developed in the earlier literature review chapter.
(Kovener, 2000). Detailed accounts are given of experiencing caregiver privilege; being degraded; being isolated; having abuse minimised, justified and being blamed for it; being neglected; being terrorised; having needed supports withheld, misused or delayed; and being corrupted or exploited. Additional forms of abuse experienced by participants are also presented.

Each subsection has also been presented to reflect the individual, systemic or structural nature of the abuse people experienced (Penhale et al., 1999), in order to provide a framework for analysis in the next chapter.

### 4.1 The narratives

This section introduces the reader to each person with disability whose experiences are central to the study, and presents the narratives of each of these key participants.

The narratives of Ann, Jim, Tom and Craig form the core of the narrative collage. They all provided a great deal of information about their experiences in our meetings together. The family members Ivy, Datu, Rose, Amanda and Patrick provided the information which form the narratives of their family members - Jill, Diwata, Jenny, Fran and Dan. They were unable to participate in the study, as they have high support needs due to their intellectual disability (or acquired brain injury in Dan’s case). The research design chapter details the process of developing the narratives.

It was difficult to bring such richness of detail down to a ‘biographical fragment’ (Atkinson & Walmsley, 1999, p.215). However, each narrative presented below does serve to provide an introduction to each of the people who were involved in the research. Importantly, they also paint a picture of people as more than victims of abuse – this is critical to both people’s self conception and to the ontological approach of the research,
in its aim to confront the dominant negative conception of people with disability.

Ann
Ann is in her early 40s, and lives alone in a small house. She enjoys being involved in craft and art groups, dancing, hydrotherapy and shopping. She receives support each day from a new innovative support service. Ann has been living here for about two years. She is a person who has intellectual disability, physical disability and psychiatric disability.

Before moving here, Ann spent the previous 10 years living in a series of boarding houses and hostels, a privately run group home, two nursing homes, and two psychiatric institutions. She experienced a wide range of abuses in many of the facilities, including physical, sexual, emotional and psychological, chemical and financial abuse and neglect. Her experiences in one facility are the subject of current legal action. Ann had an accident in a hostel and broke her hip, and finished up in a nursing home for a time, which appeared to be a catalyst for her leaving the boarding house sector. Her sister worked with an advocacy agency to find Ann her current support arrangement. Some of Ann’s abuses are the subject of current legal action against the owners of one of the facilities in which she lived.

Tom
Tom is a vibrant and engaging man who lives with his dog in a Department of Housing unit in a block of twelve units. He is happy with his unit, but has a lot of trouble with his neighbours. He gets support each day from an innovative disability support service which he is involved in managing. Tom is in his late 30s, and he has physical and intellectual disability.

Before he lived here, Tom lived in many places, including in two residential institutions, two group homes, at least three privately run hostels, and on his own with paid support in three locations. He has had a
Jim lives alone in a duplex unit in the suburbs, although his Mum visits from the country and stays for several weeks at a time. He gets daily support from a large disability services organisation. Jim is in his early 40s, and he has intellectual disability and physical disability.

Jim has lived in residential care since he was a young child. He first moved out of his family home into a residential institution at four years old, where he lived until 18. After that, he lived in several group homes and shared accommodation settings, before moving into his current home. He has experienced a lot of abuse and neglect in different services. He used to enjoy working in an art workshop locally, but after it closed down a couple of years ago, he stays home most days, unless he’s going shopping.

Craig lives alone in the suburbs. He is a hard working man in his mid 40s, who also is very involved with advocacy issues and giving talks to community groups. Craig has physical disability, and was in the past labelled as having intellectual disability, although he’s not sure that he in fact does.

Craig was placed in residential care as a baby. He lived in a residential institution throughout his childhood, leaving at eighteen. He then lived in several share arrangements, before moving into his current home. Craig is Aboriginal, and was brought up not knowing that he was Aboriginal until he was a teenager. His experience of emotional and psychological abuse is cultural as well as individual.
Jill
Jill is a lady in her mid 40s, who lives alone in a small block of units. Her mother lives in a unit in the same complex, and they spend a lot of time together. Jill and her mother Ivy have a very close and loving relationship.

Jill has very high support needs due to her intellectual disability, and needs people to support her 24 hours a day. When she was 15, Jill moved into a large residential institution. She lived there for 22 years, until moving into her current home 10 years ago. In the institution, Ivy says Jill experienced many abuses. Ivy knew about some of these at the time, and others she found about when she obtained Jill’s file after Jill left the institution. Jill is not able to speak, and so could not tell anyone about her experiences, good or bad. During her time in the institution Ivy talks about times when Jill’s health was very poorly managed, and when she was seriously neglected.

Jill’s experiences in the community have also been very difficult, due to poorly trained service providers, ill-matched co-residents, and under-resourcing. Her current situation works very well for her, but at a substantial cost to Ivy, who in her mid 70s is spending at least 50 hours a week supporting Jill due to a shortfall in funding.

Dan
Dan lives in a Department of Housing house, which he shares half the week with his brother Patrick, and half the week with paid staff. He has been living here for 18 months. Dan had a football accident when he was 23, which resulted in him acquiring a brain injury and physical disability.

After his accident, Dan lived with his mum and dad for five years, until their health deteriorated. He then moved to a Department of Health funded long stay rehabilitation centre, where he lived for 14 years. Patrick says that Dan was not emotionally or psychologically sustained or nurtured at all while he lived in the centre, and that he experienced a lot of abuse and neglect while he lived there.
**Diwata**
Diwata lives at home with her dad. She is currently a student at TAFE, and enjoys spending time shopping and with her family, especially her nieces and nephews. Diwata has just turned 21, and she has intellectual disability. Diwata’s family come from Thailand.

Diwata lived in residential care as a child, when she went to special school in a regional city away from her family. Her Dad brought her home because she was so unhappy, but it was hard for him to bring her home because the service resisted. He feels that she had some abusive treatment while she was living in care.

**Jenny**
Jenny lives in the same house as other people with disability, although they don’t share support. She has a close relationship with her mum, Rose, who she sees regularly and who is intimately involved in her life. Jenny is in her mid 20s, and she has intellectual and psychiatric disability.

Jenny first lived in residential services when she was fourteen. Since then, she has lived in a range of large hostel style, group home and shared arrangements. Her mother has been very active in seeking out innovative support options for Jenny, and the emotional and psychological abuse that Jenny has experienced has been very distressing for them both.

**Fran**
Fran lives on her own in a house in the suburbs. She leads a busy life, going to several social activities and exercise classes during the week. Fran is 28, and she has autism and intellectual disability.

Fran moved into a residential institution at the age of six. She stayed there until she was 18, when she moved into her current home as part of the Institutional Reform process. Her mother Amanda worked extremely hard to put together a support arrangement which she felt would support Fran well, and which would allow her to live a decent life – something Amanda did not feel she had been able to live until then. Fran experienced
a range of abuses when she was living in the institution, and Amanda feels her life has changed dramatically since she moved into her own home and her family manages her supports.

### 4.2 Experiences of emotional and psychological abuse and neglect

This section relates the experiences of emotional and psychological abuse and neglect shared in the interviews by people with intellectual disability, family members, and other supporters. These are ordered using the typology of the abuse and neglect framework which was developed in chapter two (reproduced below).

![Power and control wheel – adapted from Kovener, 2000](image)

Detailed descriptions of each category of abuse can be revisited in section 2.5.2, and can also be found at appendix six. This approach allows the experiences of participants to be detailed within a framework which supports analysis in the following chapter.
4.2.1 **Overview of the abuse experiences**

A brief consideration of the volume of abuse that participants have faced may assist in situating their narratives in a broader context. While this is a qualitative piece of research, including this quantitative representation opens an alternative view of the nature of the abuse experienced which may not be seen through the narratives alone. Further, as Silverman notes in his discussion of reliability and validity:

> simple counting techniques can offer a means to survey the whole corpus of data ordinarily lost in intensive, qualitative research. Instead of taking the researcher’s word for it, the reader has a chance to gain a sense of the flavour of the data as a whole (1993, p.163).

The table below presents a cumulative total of the number and range of emotional and psychological abuses which were related by people with intellectual disability and their family members and supporters. The abuse they described is spread over the time in which they have used services, which for all participants except Diwata was at least 10 years. In the case of five of the nine participants, they had lived in disability services from the time they were young children.
<table>
<thead>
<tr>
<th>Type of abuse</th>
<th>Number of references to the abuse in the interview data</th>
<th>Number of participants experiencing this form of abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver privilege</td>
<td>53</td>
<td>9</td>
</tr>
<tr>
<td>Degrading</td>
<td>34</td>
<td>9</td>
</tr>
<tr>
<td>Isolating</td>
<td>29</td>
<td>9</td>
</tr>
<tr>
<td>Minimising, justifying and blaming</td>
<td>35</td>
<td>9</td>
</tr>
<tr>
<td>Neglecting</td>
<td>25</td>
<td>8</td>
</tr>
<tr>
<td>Terrorising</td>
<td>36</td>
<td>7</td>
</tr>
<tr>
<td>Withholding, misusing or delaying needed supports</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Corrupting/exploiting</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3: Volume of emotional and psychological abuse and neglect related by participants (ordered by frequency of experience among participants)

It is also worth noting that some things were just too hard for people to talk about. There were several incidents which family members decided, on reviewing the transcripts, that they would prefer to keep private, as they were too painful to include. There were also some places people perhaps weren’t ready to go - a number of people had ‘false starts’ in conversation, where they did not complete thoughts or sentences about abuse experiences, and were obviously uncomfortable. There is little doubt that there was more abuse and neglect in people’s lives than is presented here.

The remainder of the chapter is devoted to the narratives of participants concerning their abuse and neglect experiences. They are discussed within the categories of emotional and psychological abuse, and are ordered according to the frequency with which they were experienced by
participants. At the end of each section is a summary table, highlighting the key features of the abuse and neglect experiences. The first of these is caregiver privilege.

### 4.2.2 Caregiver privilege

All people with intellectual disability who participated in, or who were the subject of the research experienced emotional and psychological abuse which falls into the category of caregiver privilege. It was the most commonly reported category of abuse related in the interviews, with 53 separate episodes of abuse noted across the nine participants with intellectual disability.

**Caregiver privilege at the individual level**

Some of the experiences people described were about how individual staff members exercised caregiver privilege over them, or about the abusive relationship they had with a particular staff member.

*Staff acting to protect their own interests*

Ann had an accident in a hostel, and fell over a blanket left on the floor and broke her hip. The owner of the hostel moved her to another property she owned after Ann was discharged from hospital, in order to recuperate. Ann was of the view that the owner of the facility moved her in order to make sure she didn’t take legal action against her (it should be noted that the owner’s actions happened in the context of a significant amount of other abuse, much of it caused by staff, which occurred in the hostel).

*Being forced into the passive ‘client’ role*

Tom talked about how his current support worker ruined his Christmas dinner. He had bought a piece of pork to roast for his Christmas meal. He asked his support worker for help to cook it. He told the story:
Tom  She said, ‘I haven’t got three hours or however long pork takes to cook’- it takes a few hours. She said ‘I haven’t got time to sit here and watch it cook! I’ll take it home and I’ll bring it back’

Sally  She’ll bring it back cooked?

Tom  And when I asked her about it, she said ‘oh, I had to throw it out to the dogs because it was slimy’.

Sally  But you’d only just bought it, had you?

Tom  She cooked it and left it sitting out.

Tom ended up going to a church group for Christmas lunch. The worker was not disciplined, despite Tom complaining to the service coordinator, and Tom was not recompensed for the meat. Tom has asked the same worker not to remove paperwork from the house. She has taken it home regardless to complete it. She has also taken Tom’s house key from the key safe to get more keys cut, despite him not wanting workers to have keys to his home.

Caregiver privilege at the systemic level

Much more common in the narratives were people’s stories of abusive experiences which were caused by staff following service policies and routine practices that did not adequately respect their rights. These practices, procedures and policies seemed to focus much less on the needs of individuals and much more on the convenience of the system. There are several key areas in which caregiver privilege was experienced by people who were involved in the research – in how personalised their care was, the level of control and decision making they were able to exercise, the relationships with support workers they had, and in the action taken when they complained about unfair treatment.

Being a cog in the wheel

The way that clothing and services were provided en masse to several people in the research was depersonalising, limiting and sometimes degrading. While it no doubt made it easier for the facilities to function, it
had the effect of increasing people’s dependence, limiting their capacity, and painting them to staff, families and other residents as not worthy of the respect of personalised service.

Craig remembered the way that clothing and services were provided when he was growing up, living in an institution for children with disability. Staff used to pick clothing off a shelf in a clothing room for children, and dentists, doctors and physios all came in to the institution. Patrick remembered buying Dan a new shirt, and bringing him home for a weekend to discover that a staff member had written his name on the shirt on the outside of it in permanent marker. When Patrick raised this, no-one at the rehab hospital was ‘interested in changing that or anything’.

Amanda remembers Fran’s bowel movements being tracked, along with all other residents of her section of the institution, on a chart on the wall. Jim remembered staff going off on coffee breaks together when he lived in a medium sized residential facility as a teenager, and leaving the ‘clients’ on their own for a while. When asked whether things used to happen when they were on their own, Jim said people used to cry and make a lot of noise, so much that he couldn’t watch TV. He remembers this happening as a matter of routine.

Rose felt so strongly about the poor quality of care in the service that Jenny was living in as teenager that she felt she could not go away on a holiday. Jenny used a respite service which was bad for similar reasons. Rose said:

*it was just like a churn out. Nobody took any care of the washing, it was just all thrown in together, nobody had anything personal, everybody sat down, they didn’t give a stuff what you were eating. It was revolting.*

**Fighting for control**

Having control over the decisions, large and small, which make up a lifestyle was expressed by almost everyone in the research to be important to them. Being treated as a child and having decisions made for
you was a particularly strong concern for Tom and Jim. Getting information from staff about health, accommodation changes, and major incidents in the lives of people with high support needs like Jill, Rose, Dan and Fran was a major problem for their families.

Tom remembers living in a group home where he had no say in who he lived with. When someone died, another resident was moved in without any consultation with other residents. Tom felt this was unfair. In his current living arrangement, he is able to decide who will support him, although in observing his relationship with his support workers over our three meetings, his stated control and his actual control of the relationships are very different, and the support workers do not display a great deal of respect for him.

As an adult, in his current service, Jim feels like he gets the chance to make little choices, but not big ones. For example, he recently did not want to employ a support worker he met, as he thought she looked like a drug addict. However, he felt he didn't have any option but to say yes, due to pressure by the service to take her on. Wendy also talks about phoning Jim, and that often he will be having a ‘snack’ dinner, like spaghetti on toast. She feels that he often eats what is convenient for staff, rather than what is healthy for him.

At several points when Fran was a child, the institution proposed that there would be major changes in her care, with minimal notice and no consultation. For example, one change proposed was that only one staff member would be rostered between two cottages at night to support ten residents with high support needs, including someone who had uncontrolled epilepsy. After strong protest, this was overturned – however, it was part of a pattern of action where changes which were not in Fran’s best interests were initiated a number of times without consultation or prior agreement.
**Narrow conceptions of personhood**

Rose was concerned that Jenny might be depressed. She expressed this concern to Jenny’s current support workers, saying that she is worried that Jenny may be low because she’s not going anywhere exciting. Their response to her was that her life is better than many other people with intellectual disability, so there is no cause to worry.

**Increasing dependence**

Some people talked about experiences of care in which they, or their family member, became more dependent as a result of the actions of the service, rather than better supported to live their life.

Patrick used to spend time with Dan at the rehab hospital, trying to stimulate him. He felt that the staff resented him ‘revving’ Dan up, and would have preferred him not to be stimulated. Patrick says:

> you know, one of the nurses said ‘oh, it’s alright for you, you come out here and spend a couple of hours’ – it was more like six hours – ‘and then go away and leave him and we have to deal with the [sic]’. Because I would take him out walking along the fence and all sorts of other stuff to try and stimulate him. And you know, ‘you’re doing this and we’ve got to deal with the consequences’. And I said ‘well, that’s what you actually get paid for’.

At one point, Jenny was living in a service in which people had individualised supports, singly or in groups of two. A new manager could not see the rationale behind this, and changed the orientation of the service, so it became a standard group home model. Fortunately, Jenny had portability of funding, but the disruption of what was a workable arrangement had a significant cost.

**Breaking the rules**

Several people recalled receiving inappropriate or even offensive responses when they protested about treatment which they felt was unfair – responses which emphasised the power of the organisation over the people who lived in it.
Jim remembered being put to bed at seven o’clock through his teen years by staff, despite not being tired. After he complained, he was put to bed later, although he says staff ‘weren’t nice about it’, and there was obviously a cost to making the complaint. Patrick also recalls Dan being put to bed at six o’clock in the evening, and staff expressing their dissatisfaction about the fact that he used to yell out through the night – due, Patrick feels, to the fact that he had had enough sleep by about midnight.

When Diwata moved to a regional town several hours from her family, the service took rental properties which were on short leases. Every three months, she and the other children were required to move into new premises. This happened three times in succession. Every time Datu visited her or took her home for a short time, on her return Diwata would get very upset. Datu decided to bring Diwata home, and was taken to court by the service over what they said were unpaid fees – strongly disputed by Datu. The result of this court action was that Diwata’s financial affairs are now managed by the Public Trustee, and Datu has to account for all her spending. Datu felt that ‘Just like, I’m losing the right for my daughter’.

**Caregiver privilege at the structural level**

At the broadest level, caregiver privilege can be seen in the way that programs of supported accommodation are implemented in Queensland, particularly in the lack of choice and self-determination afforded to people with disability in their accommodation and support arrangements.

Ivy felt that conditions for people with intellectual disability haven’t improved very much with the program of devolution of institutions. She said:

*From what I see of it, people have been moved into mini institutions all over the community now. They’re in three person and four person households all round the community, and living in*
more or less the same conditions they lived in [institution]. So I really don’t think they’ve done good service to the exercise. I think that they caused a lot of upset to a lot of people for no good reason.

The table below summarises the key features of the abuse of caregiver privilege experienced by participants, dividing the themes which emerged from the results into individual, systemic and structural domains.

**Caregiver Privilege**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staff acting to protect their own interests</td>
<td>• Being a cog in the wheel</td>
<td>• Accommodation and support system is unresponsive to personal choice and self-determination</td>
</tr>
<tr>
<td>• Being forced into the passive 'client' role to meet worker convenience</td>
<td>• Fighting for control over decisions</td>
<td>• Accommodation and support system defaults to institutional practices, whether institution or group home</td>
</tr>
<tr>
<td></td>
<td>• Narrow conceptions of personhood</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Care provided in a way that increased dependence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Being punished for 'breaking the rules'</td>
<td></td>
</tr>
</tbody>
</table>

Table 4 Summary of caregiver privilege

**4.2.3 Degrading**

Degrading was a frequently reported form of emotional and psychological abuse and neglect. It was the second most highly featured category of maltreatment in the research. All nine participants shared memories of degrading experiences, and 34 individual incidents of degrading abuse and neglect were described during the interviews.

**Degrading at the individual level**

Here, examples of degrading which were not linked to organisational or structural causes were primarily instances of punishment, where staff had
taken it upon themselves to impose harsh punishments for perceived infractions, or dehumanisation.

Both Diwata and Jim were physically punished as children. Diwata was smacked by a staff member, her dad thinks because they couldn’t agree on something. Jim was put to bed without dinner in one facility, and smacked by another staff member when his stoma bag came off during the day. While the smacking constitutes physical abuse, Jim’s strongest recollection is the humiliation.

Ann recalled the treatment she received from the owner of the hostel when she fell and broke her hip:

\[\text{Sally} \quad \text{When you had the accident, you got taken to the hospital, you told me.} \]

\[\text{Ann} \quad \text{Frank piggy backed me. They were all laughing about it in the dining room.} \]

Craig remembered the routine when he returned to the institution from visits to his family in a rural area:

\[\text{Craig} \quad \text{You know, and, um, I used to have my head shaven.} \]

\[\text{Sally} \quad \text{When you came back?} \]

\[\text{Craig} \quad \text{Yeah. The staff used to shave my hair. And that used to be humiliating in front of the kids.} \]

**Degrading at the systemic level**

As with caregiver privilege, it was far more common that experiences of degrading shared by participants in the research had their roots in the systems driving organisations and services. Where the results in degrading may differ from caregiver privilege is that at least four participants identified the diffuse and pervasive nature of degradation as deeply affecting people in the long term.
The snowball effect
Amanda, in talking about Fran’s cumulative experiences in disability services, said:

There’s so many different types of abuse, and it all comes down to the same thing. It’s making people nothing. And Fran was nothing. There was never anything nice said about her, everything was negative. And she had to put up with that, and we had to put up with that, until we all sort of believed it, almost.

Gemma, Ann’s current support worker, in talking about Ann’s long history of abusive experiences in boarding houses, hostels, psychiatric institutions and nursing homes, said:

the thing that was like the base ground, what I thought was degrading and neglecting was the huge assumption that you could just do that on a day to day basis. That was the basis of these people’s life … [these things] are just really pervasive, you know?

This understanding of degradation as a daily experience at some points in the lives of people with intellectual disability was also put forward by Rose and Patrick.

Punitive service cultures and practices
Punishment as a practice of services was a clear theme, and one which Jim in particular talked about a lot. Jim recalls being punished at the institution where he lived, by being locked up. He was locked in a room, he thinks for a long time. He doesn’t remember doing anything wrong, and thinks that this was what they did to everybody, but wasn’t sure.

Another time, at the same place, Jim was put out into the playground with other residents as a punishment, and the gate closed so they couldn’t get back in. He said he was put there because staff ‘didn’t want to listen to me or things like that’ when he made a complaint about something.

Routine procedures which thoughtlessly humiliate people
Some of the practices which people with intellectual disability and their family members found humiliating and undignified may not have been done with the intention of making them feel this way. For instance, the fact that Fran’s bowel movements were recorded on the wall, in full view of anyone coming into the ward was no doubt conceived as a measure to aid the management of her health. When Tom lived in a boarding house in the inner city, he had a room on the first floor. The boarding house did not have wheelchair access, and he could only get in or out of the building if other residents carried him.

The degrading impact of poor physical care
The quality of physical care provided to people who also have physical support needs has a clear link to this category of abuse. The lack of physical care provided to Ann in the hostel was also degrading. She described one night where she was unable to get to bed herself, due to her physical disability. Other residents dragged her down the corridor and laid her on the floor next to her bed, where she stayed all night.

Ridiculing and belittling
The most frequent descriptions of degrading were comments, actions and practices which belittled and ridiculed people living in disability services. Some of these were almost ‘throw away’ comments, although the impact of them has stayed with people and their family members, in some cases for many years.

For instance, Patrick described a meeting he had with the management of Dan’s rehab unit about his care. He recalled:

> And I said to her, 'Brenda James’, I said, 'why is it that Dan gets no therapy?’ And she gave me a very condescending laugh, 'oh, well it wouldn’t be worthwhile, would it?’

Ann found the owner of the hostel in which she had one of her accidents, particularly embarrassing and shaming. She described many occasions when she was degraded by this woman, who routinely shouted at residents, ‘grounded’ them if they committed any minor transgression,
refused to allow them to take phone calls, and restricted access to family members. Ann felt that the injury caused by her accident was compounded by the indignity of the way in which she was treated by the owners of the hostel and other residents.

When Jim was living in a group home, he had his two sisters over to visit one evening. His housemate was having noisy sex with a blow up sex doll, to their great embarrassment. When Jim complained about this to the Coordinator of the service, her response was that it was up to him (the co-resident), it was not Jim’s business.

*Degrading of lifestyle*
One of most diffuse ways in which degrading was represented in the narratives was in the way that people’s lifestyles were affected by the imposition of service structures.

Rose, for example, struggled to reconcile the difference in Jenny’s lifestyle after she began living in a large disability service with how their family lived before she moved. She said:

*Jenny’s life was herded into a bus to go to school, herded there to go home, and you stayed there all the time. It was terrible! This was a girl who was used to getting on a plane and thinking ‘Oooh, it’s school holidays. Why don’t we all go to Singapore?’, or ‘why don’t we drive to Ayers Rock?’ This is a girl who had been around the world twice, and there she was in this dump. And it was awful, and her life was ratshit. And I knew that, but I couldn’t take her home, because I couldn’t manage her.*

*Degradation at the structural level*

The impact of government policy at the broadest level can be exemplified in this study particularly strongly in the degradation of one participant’s culture. The intersection of disability policy and Indigenous policy of the
day resulted in an alienating and shaming childhood and adolescence for Craig, one in which his sense of self was eroded on several fronts.

Cultural degradation
Craig’s experience as a child was one in which he was degraded on both personal and structural levels for his indigenous status. As a young child growing up in an institution, Craig did not know he was Aboriginal, and was confused by taunts and insults by other children that he was ‘black’ and ‘different’. He recalled:

And I said to them, ‘how can I be different’ Ah, because I said to them, you know, ‘I’m just the same as you, in a wheelchair, so what’s the difference?’, you know, and they just said ‘you’re black’. You know, that got me thinking. Mm.

Craig talked to the principal of his school, who told him he was Aboriginal. To be told this way was painful and affecting. Craig said:

No one told me about it. Not even a member of the Aboriginal race told me that I was Aboriginal. I was told that I was Aboriginal by a non Aboriginal person. Mm.

As an adult, Craig obtained his files through Freedom of Information, and gained access to a thick folder of both useful and painful information about his past. He is referred to as ‘an inmate’ in parts of his file. His birth family is referred to in ways that portray them as less than human. It is also clear that he came to the institution as a baby from a situation of high risk.

Craig did return home to his birth family periodically for visits throughout his childhood. In keeping with government policy of the time, Aboriginal people were required to obtain permission from the government to travel. Craig’s grandmother, with whom he stayed, was required to submit to an inspection of her home, and of the other grandchildren for nits and scabies prior to Craig coming to visit. Looking into the files, the language used in an official letter of permission to travel gives an indication of the cultural degrading that has affected Craig deeply:
'Replying to your letter dated 29th, you are advised that settlement matron and welfare officer inspected Agnes Z’s home today. They report that it was clean, as was the yard. They also examined the heads of Agnes Z’s children and report that they were clean.’

Craig remembered coming back to the institution from these visits, and routinely having his head shaved, which he used to find humiliating in front of the other children.

In reflecting on his past, Craig said:

*When I go through all this stuff, it’s about emotional issues... Everything they’re saying is emotionally, is emotionally abusive.*

He felt that the actions of the system, rather than individuals, have had a big impact on his life, and this impact is felt mainly through the fact that Craig feels uncomfortable with Aboriginal people. He said:

*Because, even though I don’t show it, I hide it, I still don’t feel comfortable with Aboriginal people, because I haven’t grown up with them. You know, even though I’m an Aboriginal myself, I just don’t feel comfortable.*

The following table summarises key features of degrading abuse and neglect which were experienced by participants in the research.
### Degrading

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Punishment for perceived infractions of rules</td>
<td>• The snowball effect of degradation of time</td>
<td>• Cultural degradation</td>
</tr>
<tr>
<td>• Humiliation</td>
<td>• Punitive service cultures and practices</td>
<td>• Loss of identity</td>
</tr>
<tr>
<td></td>
<td>• Routine procedures which thoughtlessly humiliate people</td>
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<td></td>
<td>• The degrading impact of poor physical care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Practices and policies of responding to complaints and abuse which ridicule and belittle</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Service structures which degrade lifestyle</td>
<td></td>
</tr>
</tbody>
</table>

Table 5 Summary of degrading

#### 4.2.4 Isolating

As with caregiver privilege and degrading, isolating was a form of abuse which all nine participants in the research had experienced. 29 separate experiences of this form of abuse and neglect were contained in their narratives.
Isolating at the individual level

The narratives of isolation which appeared at the individual level involved particular staff who took action to prevent people from having access to family, friends or community, or who in one case took malicious action to isolate people by damaging the relationships that they had with others.

Jenny shared a home for a time with another young man. Jenny’s mother Rose remembered them as being very attached to one another, but over time this relationship eroded, Rose feels due to the intentional action of some male staff members in the house who wanted to move Jenny on. These staff made anti-female comments and, Rose thinks, incited Jenny’s co-resident to develop an anti-female perspective which impacted most heavily on Jenny and also on female staff. Ultimately, Jenny was subject to physical violence from her housemate, and also to two years of the emotional and psychological effects of being denigrated with anti-female comments such as ‘bloody women’ from both male staff and her housemate.

Isolating at the systemic level

Stories of abuse at the systemic level primarily concerned service practices and policies which had the effect of isolating people with intellectual disability. In some cases, people were physically isolated, in others, socially and emotionally isolated. Service policies and practices which damaged relationships between people living in disability services and their families were described which left people isolated. A strong theme emerged concerning policies and practices which isolated people by excluding their families and other supporters.

Physical isolation

Physical isolation was described in a range of ways by participants. Ann, for instance, refers to being locked into the hostel in which she once lived, so no-one could get out. When Tom was living a particular hostel, he was housed on the first floor, with no wheelchair access to get in or out of the
building. The only way he could get in or out was if someone else would carry him, and his electric chair, up or down the stairs.

Medication and the misuse of disability equipment physically isolated Dan. With Dan’s move into a wheelchair came an increasing control of his movements by staff within the facility in which he lived. His brother Patrick recalls that at the same time Dan moved into the wheelchair, he also stopped going to a singing group he was part of. He also remembers being told of Dan’s wheelchair being removed when he was in bed, so he could not leave the room. Patrick had had previous arguments with staff over their dissatisfaction with Dan’s active nature, and their wish that he would be more compliant and less active, and he suspects that Dan’s medication was increased at least partially to limit his movement.

Social and emotional isolation
Relationships with support workers were discussed by everyone who participated in the research. Discussion of elements of these relationships is spread throughout this chapter, as the impact of these relationships, both positive and negative, is enormous. In terms of isolation, though, relationships with support workers were most commonly expressed in terms of controls over interactions and relationships between people and workers, as Jim’s story poignantly illustrates.

Jim firmly expressed his view that he is not allowed to be friendly with carers who support him in his home, and he felt bitter about his experience of being penalised for feeling friendly towards workers:

Jim  You can’t do that.
Sally  You can’t do what?
Jim  Be, be friendly with carers.
Sally  Be friendly with them?
Jim  A couple of carers I did. One carer I got in trouble with, took me to see a psychologist.
Sally  A psychologist? So, the carer took you to a psychologist?
Jim  No, arranged for me.
Sally  Arranged for you to go to a psychologist?
Jim    Yeah. I was being friendly with her.
Sally  So, they said because you were being friendly with
       her, you had to go to the psychologist?
Jim    Yeah.

The organisation responsible for providing support to Jim had deemed his
attachment to a support worker to be inappropriate, and organised the
visit to the psychologist. Jim lives alone, does not work, and has little
social activity in his week. Support workers are sometimes the only people
he sees in his week. His views expressed above regarding support workers
leave him profoundly isolated.

Amanda said that the whole experience of living in an institution was
isolating for her daughter, because ‘no-one knew Fran’. The combination
of high staff turnover, low staff to resident ratios, an institutional
environment and Fran’s high support needs resulted in a living
environment in which Amanda felt Fran was not well known by anyone
where she lived.

Ann also talked about feeling very isolated and lonely when she lived in a
hostel. She used to frequently pack her bags and leave to go somewhere
else. She used to go to her mental health case worker for help, who would
return her to the hostel – this happened, Ann thinks, between eight and
ten times. Ann said:

   I couldn’t make any friends there, cause they were too busy
   fighting and squabbling with each other.

Service policies which damage relationships and isolate people with
intellectual disability
The imposition of rules and regulations was felt by some family
participants to actively damage the relationship between them and their
sibling, son or daughter.

At one point, Patrick brought Dan home for an extended period. He had
made an agreement with the main nurse manager for the district that
Dan’s bed costs would be covered while he was at home. Patrick received a bill for Dan’s bed costs for the entire period he’d been at home, and when he contacted the service, assuming there had been an error, was told that the agreement he’d made was with an individual who had gone on leave, there was no agreement, and the bill was to be paid. Patrick recalled:

*I said ‘well, OK, that’s fine, he’ll be back tomorrow.’ And from then on, I probably went once a week, sometimes even once a fortnight, for eighteen months. And I had a meeting with them, and we had reviews, which were a laugh. At one of the reviews I sat there and told their physios and nurse managers and whatever you have there, ‘you know, I find it really sad that I can’t come to visit someone I love because I can’t deal with the institution where he lives.’ And I mean it wasn’t engineered, looking back, it wasn’t engineered, I was very emotional about it. Yeah, and I think they sort of saw that.*

Rose remembered how difficult it was for her to go and have dinner with Jenny at the hostel in which she was living as a teenager. She recalls being the only parent who came to have dinner, and that staff ‘didn’t quite know what to do with me’. She described staff at this place telling her, and other parents, about successes they’d had with residents, but in a way that seemed like they were able to do something parents had failed to do with their children – something Rose strongly felt induced feelings of guilt and inadequacy in parents.

*Policies and practices of excluding families which isolate people with intellectual disability*

All family participants related experiences where they had been excluded from involvement in the lives of their family members. They felt, without exception, that this was unacceptable, in many cases abusive, and that it contributed to the patchwork of negative experiences they themselves had had, as well as those experienced by their family member.
Rose talked about the shared experiences of other mothers she knows through a support group, and how service policy impacts on the degree to which they feel able to advocate for their child when they are being ill treated. Rose said:

*You want to advocate for your child cause he’s going to hospital, with his head split open every six weeks, but the service says ‘no, you can’t, the other mothers don’t want anyone going to the house without an appointment’. So no mothers go to the house.*

Rose also talked about the signs of isolating Jenny from her family which she is seeing happening in Jenny’s current living environment. She gave examples of things like not having a consultation about buying clothes before going out to buy them, not giving her information when she asks for it, and discouraging contact with Jenny’s case manager. She feels that some staff see her role in Jenny’s life as peripheral, and that a year ago, this wasn’t the case.

Datu said that he could see that his daughter Diwata was very unhappy living in the service she was living in, about three hours away from her family. After she told Datu that one of the staff was ‘smacking’ her, he decided that he was going to bring her home. The service convinced him to leave her there for one more year, to stay at school. Datu now regrets this decision, because Diwata was so distressed by living there, and so isolated from her family.

Ivy, Jill’s mother, became very involved in managing Jill’s health when she had a serious health problem which was not addressed by the institution in which she lived, despite repeated attempts by Ivy to get them to take action. She took Jill to see specialists outside the institution medical structure to resolve her problem, and remembers that, as a consequence:

*I was very unpopular. I’m still a bit unpopular… no, they didn’t like that at all. They used to come up with all sorts of reasons why they hadn’t done things, or things had happened, and it was always my fault, you know. It was always the way I’d spoken to the staff or the way I’d spoken to the manager.*
Wendy, Jim’s mother, recollected a brief period that Jim spent at what is now a notorious institution as a young child. While he was only there a fortnight, the first time she went to see him, she was so shocked at his physical condition and surroundings that she brought him home again. However, it wasn’t easy to visit Jim. Wendy remembers ‘You had to go through a pretty strict procedure to get into the place, too’.

### Isolating at the structural level

At the broadest level, people with intellectual disability experience isolation as emotional and psychological abuse when it pervades their lives, characterising large parts of their existence, moving well beyond the disability services regime. Two participants in this study experienced this sort of abuse – Jim and Craig.

Ivy’s view that the move from institutions into group home accommodation has not necessarily afforded people with intellectual disability a less isolated lifestyle – rather, that they live a similar lifestyle in smaller groupings (expressed earlier in this chapter) can perhaps be seen in Jim’s routine.

Jim said he doesn’t talk to his neighbours, and that he doesn’t see his friends very often. He used to work, but the art workshop closed down, and his health needs were increasing to the point where he was finding work difficult. His mum comes and stays a couple of times a year, for a few weeks at a time. Jim is the view that he is not allowed to be friendly with support workers (detailed above), although they are the main people he sees in the week.

Craig’s experience of isolation as a form of emotional and psychological abuse and neglect is a cultural one. Craig was removed from his family as a baby, and taken to the city for medical treatment. He was subsequently placed in an institution for children with disability, and as he puts it:

> Um, as far as I know was that, I didn’t see my family for seventeen years, grew up white.
He experienced profound isolation from his family, his culture and his cultural traditions, not even finding out that he was Aboriginal until he was well into his teenage years.

The summary below provides a snapshot of the identified features of isolating as a form of emotional and psychological abuse and neglect.

**Isolating**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Preventing access to family and friends</td>
<td>• Physical isolation to increase staff convenience</td>
<td>• Social and physical isolation from community</td>
</tr>
<tr>
<td>• Maliciously damaging relationship with housemate and friend</td>
<td>• Control over relationships and lack of meaningful relationships resulting in social and emotional isolation</td>
<td>• Cultural isolation</td>
</tr>
</tbody>
</table>

| | Systemic | Structural |
| | • Service policies which damage relationships and isolate people with intellectual disability | • Social and physical isolation from community |
| | • Policies and practices of excluding families which isolate people with intellectual disability | • Cultural isolation |
| | • Delegitimising of family relationships | |

Table 6 Summary of isolating

### 4.2.5 Minimising, justifying and blaming

All nine people with intellectual disability involved in the study had experienced this form of abuse and neglect, and 35 separate incidents were related in the narratives. Themes which emerged in this category centred around either denial, justification or excuse. The first of these concerned a failure to acknowledge abuse, assault or injury by staff and
services, or making light of it by not reporting it to family members, and also denying the physical and emotional pain of injury and abuses that people had experienced. The second theme of justification involved the imposition or following of rules which limit autonomy, dignity and relationships for the sake of the efficiency of the operation of the service. Finally, the third theme to emerge here was around excusing abuse as behaviour management.

At the broadest level, there are a further two themes which have relevance to the study concerning cultural abuse and the ‘boxing’ of people with intellectual disability into categories that they do not fit in order to meet programmatic or funding guidelines.

**Minimising, justifying and blaming at the individual level**

It is difficult to separate the individual from the systemic with regard to people being treated as ‘poor reporters’ of abuse. While Ann’s experience is a clear example of abuse on the part of an individual worker, it can also be viewed as a signal of an under resourced community housing and support sector.

Ann used to find the constant fighting between residents at the hostel where she lived, distressing and upsetting. She used to leave, and go and see her Andrew, her mental health case worker, seeking another alternative to living at the hostel. In her interview, Ann remembered:

* Sally  Did you talk to Andrew about it [specific abuse problem Ann had raised]?
* Ann  Yeah, but he just rang them and, he just got the wrong side of the story. He just used to put me in the car and take me back.
* Sally  Right. And so after he called them, he didn’t think that you were telling the truth?
* Ann  Mmm. Manipulative.
* Sally  Is that what he said?
* Ann  Mmm.
Ann was treated as a ‘poor reporter’ of abuse, and her case worker’s approach to her reports of ill treatment was to alert the abusers to her complaints, and then return her unsupported to the environment in which the problems had occurred. Ann’s abuses were eventually substantiated by her advocate and sister, and some of them were the grounds of legal action against the owners of the facility which is ongoing at the time of writing.

**Minimising, justifying and blaming at the systemic level**

As with other categories of emotional and psychological abuse, systemically rooted action is behind most of the incidents that participants shared in their narratives. These included the failure to acknowledge injury or assault, blaming the person’s disability for the abuse, denying their pain, excusing abuse as behaviour management, and enforcing rules which limit dignity for the sake of efficiency.

*Not acknowledging, or making light of, injury or assault*

The lack of proper acknowledgement of injuries and possible assaults on people with high support needs, who were unable to say what had happened to them, was of great concern to family members who participated in the research.

Amanda recalled several times in Fran’s younger years when she was concerned about physical injuries Fran sustained which were not adequately explained. She described a climate of frequent concern by she and her husband for Fran’s wellbeing, where injuries were not reported to them, and where they had no proof of what she called their ‘niggles’ that things weren’t right.

Over the years, Fran had two lots of stitches. Amanda said she does fall frequently, and bangs into things often, so the injuries may well have been accidental, but the causes were not detailed by the institution staff. Once, Fran came to school from the institution with a bruise on her cheek about the size of a tennis ball. In Fran’s communication book between
school and the institution, the institution staff had written only that there was bruising. The institution did not contact Fran’s family to let them know she had been injured, and did not contact the school to explain the injury. Fran said:

\[
\text{Now, it could have been done by another resident. The bruise on the cheek, how did that happen? You just don't know. And they could have acknowledged that it happened, don't try and say that it didn’t happen!}
\]

Amanda took Fran to her own doctor, and Fran’s dad photographed the injuries. After a complaint to the state Ombudsman, the institution apologised for the way they had handled this incident, but Amanda felt little change occurred as a result of the complaint.

Jill was left by workers at the regional country show, who returned to the institution with other residents, leaving her sitting on a wall in the showground. Jill is unable to stand on her own, and remained sitting on the wall until ambulance officers, who were fortunately located in a nearby tent, became concerned about the length of time she had been sitting there alone. When she was returned to the institution by the police, around seven o’clock that night, she still had not been noticed missing by staff. After she was returned to her unit on the grounds of the institution, staff phoned the institution doctor, wanting to check that Jill hadn’t been sexually assaulted or physically harmed. Ivy said:

\[
\text{And the doctor said that she was finishing her shift in 20 minutes, and she didn’t have time to come down and examine her, and that they’d have to wait until the next doctor. When the next doctor came on, he said he’d have to do his rounds, and he wouldn’t be finished until 9 o’clock, and by that time she’d be asleep. And they wouldn’t come down and make sure that she was alright.}
\]

Ivy was not notified of any of this, but discovered it all ten years later, on obtaining Jill’s file through Freedom of Information legislation when Jill moved out of the institution.

When Jim shared a house with another resident who had challenging behaviour, staff and coordinators routinely told him that the other man
had more problems than he did, and that Jim needed to be understanding. When the other man threatened Jim, banged the door near Jim’s head and shouted at him, Jim rang the supervisor for help, as there were no staff at the house with them in the evenings. He was told that he would have to ignore him, and that the other man couldn’t help it. Jim said the service did not do anything that helped him to feel safe while he was living with this person. When Jim complained about another co-resident having loud sex with a blow up sex doll in his bedroom while Jim’s sisters were visiting, he was told that there was nothing they could do, it was the private business of the man, and Jim would just have to put up with it.

When Jenny and Rose were in a medical environment, a nurse broke confidentiality and told them that four non-verbal residents from the institution where Jenny was living had been brought in to the sexual assault unit over the past month. Rose was horrified, and got together with another parent, and they went to the director of disability services for the state at that time. He acknowledged that the assaults were occurring, and told Rose and the other mother that they knew the assailant, had removed him, and would be putting him back on duty in the institution when things had ‘died down’. Rose said she was then told that she could buy a new wardrobe for Jenny, something she had been agitating to do for some time.

**Blaming the person’s disability for the abuse**

Despite the fact that people who participated in this study lived in specialist disability accommodation services, it was sometimes their disability which was blamed for the abuse which occurred in their lives. This was the case for both Jill’s chemical abuse, and Dan’s challenging behaviour.

Ivy feels that Jill was placed on epilepsy medication after having one large seizure as a reaction to an overdose of a combination of three other drugs, and may not have epilepsy. Two of these drugs were the strong psychotropics Melleril and Mogadon. The other drug was to control dribbling, about which Ivy says:
The dribbling doesn’t bother Jill, it only bothered the workers, because they had to keep changing her apron, you know.

When Jill left the institution, Ivy, in consultation with Jill’s doctor, weaned her off all medication except for a small dose of the anti epileptic medication, with no ill effect. She is now in good health and takes half the dose of Epilim she was taking in the institution, and no other medication – Ivy questions whether any of the other drugs were needed by Jill at all.

When Dan first moved into the rehab facility, his brother Patrick felt that he wouldn’t have thought of himself as a ‘patient’, and that he would have found the place ‘pretty creepy’. Dan had an incident early on in his stay there, and the manager asked his family to come and take him home, due to his behaviour. Patrick refused, and the facility sent Dan to the psychiatric ward at the local hospital, who assessed him and returned him to the institution. Patrick says their diagnosis was ‘he doesn’t have a psychiatric problem, he has behavioural problems. This is what you do’.

The service promoted itself as a centre of excellence for people with acquired brain injury, but refused to accept responsibility for supporting Dan with challenging behaviour.

Denying physical and emotional pain

The denial of both physical and emotional pain by services and workers can be both physically abusive and also emotionally and psychologically abusive.

Jenny fell and broke her wrist. After treatment in hospital, where both her mum and support worker were present, she was taken home by her support worker, with instructions to take painkillers four hourly. The support worker did not provide the painkillers, saying later to Rose they were not necessary. Jenny is unable to indicate verbally whether she is in pain or not.

Jim remembered being taken on an outing in a bus one day with a group, and getting his foot badly burnt on the exhaust pipe of the bus. Jim requires support to move onto and off a bus, as he uses a wheelchair and
has no use of his legs. The service took Jim straight to hospital for treatment, but Jim said that ‘I got in big trouble for it’ when his foot was burnt, despite the fact that he had no control over where his feet were placed, and in fact could not feel the burn occurring.

To Ivy’s sorrow, she only discovered through reading Jill’s file after she had left the institution that when she first entered the facility, Jill was in a state of severe emotional distress. Ivy recalled:

\[I \text{ kept phoning and I was getting ‘oh no, she’s doing well’, but when you read the file you see how upset she was, that’s why she was on all the Melleril and all the rest of it, because she was so distressed.}\]

Excusing abuse as behaviour management
The use of behaviour management strategies which people did not adequately understand the rationale behind was an experience shared by several participants. Jim, Craig, and Ann all shared the view that being locked up or hit were experiences that are standard, happened to most people, and that they were not sure why they happened to them. This form of behaviour management is an obvious physical abuse, and also has clear emotional and psychological consequences.

Jim remembered being locked up several times when he lived in an institution as a child. Once, he was locked in a playground with some other residents, after he had complained about something. He felt this was a punishment for complaining. Another time, he was locked in a cupboard, but he doesn’t know why this happened. On a third occasion, Jim remembered being locked in a room for a long time, although he doesn’t remember having done anything wrong. He thought they probably did it to everyone who lived there, but wasn’t sure - it was a long time ago.

When Jim was a teenager, he lived in a hostel that housed ten teenagers with disability. He used to be put to bed at seven o’clock, which he complained about as being too early. After he complained, Jim said:
Jim They make it hard.
Sally How did they make it hard?
Jim They didn’t talk to me nice and treat me nice.

After he made the complaint, Jim was put to bed later, but staff completed the task in such a way that it was an unpleasant experience for Jim.

Datu also recalled Diwata telling him that she was ‘smacked’ by a worker at the house where she lived, he thinks when they ‘couldn’t agree or something’.

Enforcing rules that limit autonomy, dignity and relationships for the sake of service efficiency

Some of the policies of services which are intended to provide choice and to increase the level of self determination of people with intellectual disability are operationalised in such a way that the opposite occurs. For example, over the weeks that Jim was meeting with me to tell his story, he was also interviewing prospective support workers. He said that he did not feel able to say no, if he didn’t like the person. He did tell the coordinator of the service that he did not want one person to work with him, but was overruled by her, saying that they were finding it so hard to find support workers, he would have to give her a try. Wendy, Jim’s mother, also raised this, saying that Jim doesn’t really get to choose his own staff, although he is supposed to.

Jim’s firm belief that he is not allowed to have a cordial relationship with support workers is a disheartening example of the justification of rules which limit relationships for the sake of the operational efficiency of the service program. It also blames Jim for the development of a relationship which may possibly have grown beyond a usual support worker/client relationship, if it was not handled appropriately by the support worker. Rose found Jenny’s entry into residential care very confronting. The regimentation that came with living in a large group was very difficult for both Jenny and her mother to deal with. Jenny’s autonomy and dignity were subsumed by the rules and timetable of the hostel in which she was
living, and Rose felt that she spent the bulk of her life being ‘herded’ between school and the hostel. The routines of dining together in a large group, mass laundry, large TV rooms and lack of privacy were a stark contrast to Jenny’s family life, and one that was difficult to adapt to.

Patrick recalls numerous occasions when he was told ‘that’s the way it is, that’s the rules’ in response to questions about why his brother could not have a particular therapy, be put to bed later, have more stimulation in his day or similar issues. His response was to say:

> And I always say, ‘well, I don’t give a shit about the rules, this is a human being you’re talking about here’.

**Minimising, justifying and blaming at the structural level**

At the broader level, Patrick talked about how difficult he had found it to deal with bureaucracies, and get them to envisage Dan as a person. He said:

> I talk about the box syndrome...You know, I talk about them having boxes, and saying ‘well, you’ve got to get in that box’. ‘Oh, I’m sorry, my arms and legs are hanging out’. ‘That’s ok, we’ll cut them off and put them in the box, but you’ve got to get in the box.’ Everything’s about, and this is going back to Dan, when things got really bad for him, getting him into the wheelchair. That was about their convenience, it was never about his, never about his. Except where those good souls would try and make a difference. But from a systemic point of view, it was never about him, it was just about keeping the body alive. It’s a numerical process, run by accountants. It’s so sad.

In terms of cultural abuse, Craig’s experience is a prime example of emotional and psychological abuse in which relationships, autonomy and dignity have been severely limited for the sake of the efficiency of the operation of a program. Craig, and his family, could not travel without express permission from the government. He could not visit family without his grandmother’s home and family members being inspected for
cleanliness by a government matron prior to his visiting, and him being shaved in case of lice infestation on his return to the institution. Craig’s relationship with his own culture, as well as with his family, is damaged as a result of these experiences, which contain a mixture of protection and abuse.

The summary below describes the primary themes of the abuse experience of minimising, justifying and blaming which emerged from the narratives of participants.

**Minimising, justifying and blaming**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
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<tbody>
<tr>
<td>• Being treated as a 'poor reporter' of abuse</td>
<td>• Not acknowledging, or making light of, injury or assault&lt;br&gt;• Blaming the person’s disability for the abuse&lt;br&gt;• Denying physical and emotional pain&lt;br&gt;• Excusing abuse as behaviour management&lt;br&gt;• Enforcing rules which limit autonomy, dignity and relationships for the sake of service efficiency</td>
<td>• The 'box syndrome’&lt;br&gt;• Enforcing rules which limit autonomy, dignity and relationships for the sake of program efficiency</td>
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Table 7 Summary of minimising, justifying, and blaming

### 4.2.6 Neglecting

It is difficult to isolate emotional and psychological neglect from abuse experiences, as many abusive experiences contain a neglectful component. It is a category which is pervasive, insidious and difficult to pin down. However, the thematic analysis identified that eight of the nine participants with intellectual disability in this study experienced emotional...
and psychological neglect which was distinct from other abuse, in addition to neglect which accompanied other abuse. 25 separate incidents of emotional and psychological neglect were identified, across a number of themes. These included the failure to maintain a nurturing environment, failure to maintain a stimulating environment, the impact of under-resourcing, the connection between physical and emotional neglect and compounding neglect.

**Neglecting at the systemic level**

*Under-resourcing*

The chronic under-resourcing of disability services, particularly the large residential institutions of the past, cannot help but contribute directly to the emotional and psychological neglect of people who live in them. Low staffing ratios, high levels of client need, and high staff turnover combine to create an impersonal living environment in which it is unlikely that nurturing relationships and stimulating programs will thrive.

At one point, management at the institution in which Fran lived proposed to cut staffing on the night shift, to the point where one staff member would staff two villas housing ten residents, all of whom were under eighteen years old. All of the residents had high support needs, and one had uncontrolled epilepsy which required a high level of monitoring. After vigorous opposition from families, this change did not occur. Amanda said:

*Can you imagine if I went out at night, and left my kids on their own? Community Services would be down on me like a ton of bricks!... But that was the sort of thing that happened, that made you feel like they didn’t really care about our kids.*

Amanda talked about the difficulties that staff were faced with in the environment of the institution, which contributed directly to the quality of care which was available to Fran and others living there. One staff
A member was allocated to look after six people, all of whom had high and complex support needs. Amanda said:

So you had one person looking after six, so they could never be any more than minded. So you had six children heading in different directions – how can they have anything but neglect?

Amanda gave some concrete examples of this neglect. One time, a worker told another parent she was responsible for the care of twelve children on her own between the end of school and dinner time, all of whom required assistance with personal care, feeding and behaviour. Fran received stitches a couple of times, due to injuries received when she fell because there weren’t enough staff around to care for her. She fell in the bathroom when someone was having a bath and the floor was wet – but she was in the bathroom because there was only one staff member, and in order to bathe the other person and also supervise Fran, both of them needed to be in the bathroom. This has implications both for the privacy of the person being bathed and for Fran’s dignity. These are situations where individual staff members seemed to be making the best of a bad situation, but were unable to overcome the limitations of inadequate resources.

Amanda recalled the whole experience of living in the institution as being very isolating for Fran, as ‘no-one knew Fran’. It is difficult to see how this failure to have anyone who really knows your preferences, your sense of humour, or your tastes in food makes it possible to nurture a person.

Ivy also remembered the understaffing as a contributory factor in the emotional neglect of Jill. As with Fran, Jill lived with a ratio of one staff member to six residents. Ivy recalled:

no matter how much the parents suggested that more staff should be available, that was completely ignored. Actually one of the ministers said that if they increase staff, they found that staff pay more attention to each other than they do to the residents [laughs]. So, that was the attitude to the staffing of the villas.
Failure to maintain a nurturing environment

In order to sustain emotional and psychological health and wellbeing, a nurturing home environment is important for all people, but perhaps even more so for people with significant support needs due to their intellectual disability. In several cases, however, this was not the case for people who participated in the research. The failure to provide a nurturing environment is emotionally and psychologically abusive – giving people no ‘safe harbour’ to build their emotional reserves.

After Jill left the institution and moved into her own home, she was supported by a non-government service. The service received extra funding for one month, in the transition period, and as soon as this period was over, they started to say that there was not enough funding to support Jill and her co-tenant. Ivy felt that workers were not experienced or well trained in supporting people with high support needs such as Jill’s, and staff turnover was high. Ivy gave the example of one worker who was recruited who couldn’t bear the sight of faeces, and who used to vomit every time she had to assist the two ladies with their personal care. The service pulled out of their contract to provide support within a matter of weeks, and took the co-tenant with them to another house, leaving Jill stranded.

Ivy and Jill’s advocate were in a series of meetings with senior managers at the state disability department to try and resolve the situation, where Ivy was given a sheet of paper with instructions about how she must conduct herself when dealing with service providers. The service provider was not penalised, despite a series of episodes of apparent mismanagement, including failure to adequately staff and manage the house within the budget they tendered for, allowing Jill to almost swallow a large piece of kitchen sponge, and poor management of her health. While this is not directly emotional and psychological neglect, the result of this situation was that Ivy was highly stressed, and Jill was subject to a series of casual workers for the next few months until the situation was resolved – resulting in Jill living in an unstable environment which she found stressful and distressing, and where she was not nurtured in the
way that she requires in order to maintain her fragile health and wellbeing.

Craig recalled his living arrangements growing up. He slept in a dormitory with anywhere up to twenty others. Personal belongings were kept in a pigeonhole, and when he was a little older, a metal locker with a drawer. Craig had no photos or other items to make things personal.

Craig also found out as an adult that his mother never signed release papers, which prevented him from being adopted and meant that he remained living in the institution until he turned eighteen. He remembered meeting a family who wanted to adopt him when he was around five years old, and also another family a little later who was interested in him. This was an enormous loss to him.

Tom was at great pains to make sure that I was aware that he did the hiring and firing of staff in his current living arrangement. His support worker on the day that we met for one interview was a young man who over the course of two hours slept on the sofa, played music through his headphones, went outside to smoke, and sprawled on a chair, answering Tom’s repeated questions of ‘we’re friends, aren’t we?’ in monosyllables, with his eyes closed. The previous week, this man’s grandmother, also a support worker, had arrived to start work while I was with Tom. She entered the house without knocking, did not say hello, and started going through some papers behind Tom, who was sitting in his wheelchair and did not seem to have seen her.

*Failure to maintain a stimulating environment*

Accompanying the need for a nurturing environment is the need for stimulation. The lack of emotional and psychological stimulation in the lives of some participants was stark, and painted a bleak picture of lives half lived.

Patrick found the fact that Dan was placed in the rehab facility at all to be emotionally and psychologically neglectful, and even worse that he lived
on the hospital side of the facility, which had two wings, a hospital side for people with more severe injury and a rehabilitation side. He felt that, as a young man who was fit and healthy in so many ways, he should not have spent so many years in the company of people who had been so severely brain injured that they were, in his words, ‘vegetative’. He said:

So, there was a lot of neglect, I think in that time he’d just roam the corridors, you know, his ‘peek a boo, skiddly on doo’ chant just became stronger and stronger. He used to use it to comfort himself, very softly and quietly...

If Patrick didn’t go and visit Dan, he felt that nothing would happen for him. At one point, Patrick said he was going to see Dan every day, out of concern for his emotional and physical wellbeing. He acknowledged that staff were overworked, and that a lot of the people who lived in the facility needed a high level of care that wasn’t possible for staff to provide. He felt strongly, though, that some people were better able to deal with the institutional environment, but Dan was not able to ‘shut it off and deal with it’. At one point, it became too difficult for Patrick to visit, and he stopped going to see Dan for a time, instead arranging for other people to go and read to him and so on. He said of that time:

I reckon in the 18 months that I talked about, when I backed off, I reckon the only things they did for him were to feed him and shower him. And that’s my, I mean, I wasn’t there, but that’s my reading of what happened.

Jim experiences a different sort of isolation. He doesn’t talk to his neighbours, he doesn’t go to work, and he rarely goes out socially. Mainly, Jim stays home alone and watches TV. He doesn’t feel able to be friendly to support workers, as detailed earlier in the chapter. It does not appear that Jim receives any structured assistance to overcome this isolation, despite receiving funded support.

Connection between physical and emotional neglect
Tom’s mum, Penny, makes the connection between physical neglect and emotional neglect. She remembered going to see Tom for holidays, and
spending days cleaning his house, as it was in such a filthy state when she arrived. She said, for example, the griller tray was cemented to the oven because it hadn’t been cleaned for a long time. Penny said workers do not provide food which is to Tom’s tastes, and she feels he has little choice in what he eats. Tom likes to feel that he has some choice and control over who works with him, and what they do, but Penny’s view is that:

‘You’d think Tom was working for them, rather than those workers working for him’

While Jill was having a lot of casual staff, Ivy suspects she had some sort of choking episode, which has resulted in her not being able to eat at all for days. She is still not able to chew any food at all, and now has pureed food. According to Ivy, speech pathologists say this is common after someone has a severe choking episode, as it is so frightening.

Lack of adequate concern for wellbeing
When Jill was left at the regional show on her own (detailed above), the refusal of the institution doctors to check on her return that she hadn’t come to physical harm, despite repeated requests, is indicative of a lack of concern for wellbeing that was demonstrated in several instances.

Ann, Jim, Fran, and Dan also experienced preventable injuries. The responses to their injuries varied, but in all case were less than vigorous or concerned. Jim, for instance, recalled being ‘in trouble’ when his leg was badly burned on a bus exhaust, despite the fact that he uses a wheelchair and a staff member would have had to move the chair so his leg was against the exhaust.

Compounding neglect
Ann’s memory of seeking help from her mental health case worker to escape the regular fights and other abuses happening at the hostel is an example of compounding emotional and psychological neglect. Already living in an environment in which her openly stated need for emotional nurturing and sustenance (‘friends’) is deprived, Ann’s seeking of support from an external source is a good strategy. To be not only labelled
‘manipulative’, but to also have your concerns flagged to the people who have perpetrated some of the abuse before being returned to the environment in which it took place, time and time again, is both neglectful and abusive.

Gemma, Ann’s support worker, is of the view that neglect was at the foundation of the way that the hostel operated. This was at a physical level, but also at an emotional and psychological level, and played out in the snide verbal asides, ongoing withholding of contact from Ann’s sister (of the threat of it), the terrorising at a physical and emotional level which happened on multiple occasions, and the physical maltreatment. Gemma said:

But the thing that was like the base ground, what I thought was degrading and neglecting was the huge assumption that you could just do that on a day to day basis. That was the basis of these people’s life.

Neglecting at the structural level

Patrick raised the difficult subject of the impact on the lives of family members of improving the lives of people with disability. To a greater or lesser degree, one of the reasons that the family members in the study have participated in it is because they have made some major decisions which put the abuse in the past because they have stepped outside the traditional disability service structure. However, while this has undoubted benefits in the lives of people with disability, this also has significant costs in terms of energy, time and resources on families. Patrick said:

It’s just, it horrifies me that we can do this to each other, you know? I mean, I look back on this, and for years I’ve struggled with this, and I used to think ‘why did you save him, if you’re not going to support him?’

The table below presents the summary features of neglect as a form of emotional and psychological abuse in the lives of participants in the study.
Neglecting

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
</table>
| ▪ Betrayal of ‘care’ in interpersonal interactions | ▪ Under-resourcing increasing the risk of abuse and neglect  
▪ Failure to maintain a nurturing environment  
▪ Failure to maintain a stimulating environment  
▪ Connection between physical and emotional neglect  
▪ Lack of adequate concern for wellbeing  
▪ Compounding neglect – neglectful and abusive responses to attempts to address neglect | ▪ Impact on family members of sustaining decent quality of life for person  
▪ Lack of community insight into damage caused by neglect of people with intellectual disability |

Table 8 Summary of neglecting

4.2.7 Terrorising

Eight of the nine people with intellectual disability in the study had experienced terrorising. Ann, Jim and Tom shared multiple experiences of being terrorised in their narratives, and all five family participants talked about their knowledge of experiences their family members had been through. 36 separate experiences of being terrorised were related in total. Several themes emerged within these experiences, including the use of punishment to gain compliance, being intimidated, and being threatened. It is interesting to note that almost all abuse within this category is themed within the systemic level, with few experiences categorised at either the individual or structural levels.
Terrorising at the individual level

Intimidation and control
Rose described a pattern of behaviour by a staff member who supported Jenny which she was concerned about. Jenny broke her wrist when she fell out of bed while staying at her mum’s house. They went to the hospital, and the support worker met them there. When the hospital staff did not follow the protocol for treating Jenny that Rose had recently completed with the specialist disability clinic (attached to the hospital), both Jenny and Rose became agitated. When Jenny began hitting and kicking, Rose began to use the strategy she had worked out with the clinic previously to calm Jenny and contain the situation. The support worker told Jenny to ‘stop it’, and she did. This is not Jenny’s usual pattern, and she has a long history of complex challenging behaviour. Rose was very concerned that Jenny stopped out of fear of the support worker.

Later that day, Rose drove Jenny to her house. Jenny couldn’t get out of the car without help, and Rose asked the support worker to wait while she went around to the other side of the car, so she could push from one side, while the support worker steadied Jenny from the front. Rose said the support worker instead ‘yanked Jenny out, literally yanked her!’ That night, the support worker did not give Jenny the prescribed dose of pain relief medication for her broken arm, saying later to Rose that it was not necessary, even though Jenny is not able to say whether she is in pain.

Rose later found out that the staff member reported Rose to the manager of the service, saying she was disruptive and rude to the hospital staff. She has also complained to the service manager about Rose before, saying that her involvement in Jenny’s life is stressful for workers. Rose felt that she had no option to respond. She has seen this support worker treat Jenny roughly, but has no evidence of assault or physical abuse. She said:

*I’ve got no way of proving that, and if I even said it, that would be harassment.*
Terrorising at the systemic level

Intimidation
Being intimidated was almost a ‘feature’ experience of this form of abuse, and it underpins many of the other elements of the category.

Ivy recalled things getting very bad at the institution where Jill lived towards the end of her time there. The government had put in place a devolution program, and was encouraging parents to move their adult children from the institution into group homes. This was challenging for some parents, particularly those people who had been strongly encouraged to place their sons or daughters in the institution years before, on the grounds that it was a safe and permanent solution for them. Ivy was engaged in a robust fight with the government for adequate funding for Jill to live with only one co-resident, not in a group environment. She also remembered an alarming conversation with another mother. Ivy said:

things got so bad at the centre, and I would say deliberately so, because they wanted us to want our people out. One mother told me she was told that in time to come, there would only be very violent men living at [institution], and she had a daughter. So that was some encouragement to move your daughter out of there!

When Ann lived in the psychiatric institution for a year, she recalled the time out room with anxiety. She said several times, ‘You only had to look out the window to go into time out!’ She remembered it as being extremely cold, and the worst part about being in the institution – a place to be scared of.

Jim remembered being locked up, when he lived in the institution. He doesn’t know why he was locked up, and thinks it was something that probably happened to everyone.
**Living in a state of fear**

Some experiences were so constant that they amounted to a continual state of fear at some points in people’s lives.

Ann described an environment at the hostel where physical violence from staff to residents, and between residents, was frequent. She related several incidents of physical assault, including being hit by other residents, being hit by staff, being prevented from leaving the premises by other residents acting on the instructions of staff, and being threatened with physical violence by staff. She said *'I was frightened there every day. That’s why I used to take off and go and see Andrew.’* Andrew, Ann’s mental health case manager, used to return Ann to the hostel, unsupported, after notifying the owners of her complaints.

Gemma said that the legal action against the owners of the hostel which Ann is involved in, with a lot of encouragement and support from her advocate and sister, brings her both a measure of relief and a great deal of anxiety. Ann was also one of subjects of a prominent television documentary program about the quality of care in the facility which aimed to expose some of the abusive practices. She showed me this program, and was at the same time proud and nervous about her participation.

Amanda recalled an incident which eloquently described the longstanding emotional and psychological impact of abuse. She remembered the day when she realised that it was likely that Fran had been physically assaulted in the past, and that the assault had left its mark on her emotionally. Fran had left the institution, and was living in her own home. Amanda and Fran’s support workers used to try to encourage Fran to work out her frustration by punching into their hands. Amanda said:

> And one day, I remember, I held my hands up, and I must have looked threatening, and the look on her face! She was absolutely terrified. And so that said to me, I can’t prove anything, but that says to me that she was physically abused.
Rose recalled the staff campaign of turning Jenny’s friend and co-resident Ian against her, and against other female staff, by encouraging him to use anti-female language such as ‘bloody women’, to denigrate women in general as an example of terrorising.

**Being threatened**

Physical and emotional threat was experienced by several participants in the research. This is closely linked to intimidating and frightening.

Jim had personal possessions stolen on numerous occasions, by both workers and co-residents. A worker stole Jim’s collection of two dollar coins from his bedroom. One co-resident who stole from Jim threatened him when Jim complained about the theft. He threatened to tell the police about Jim complaining about him. Jim was very frightened by this man, and very relieved when he eventually moved to another house. The service took little action to redress the problem, Jim recalled.

Ann also related the experience of being threatened by a worker at the hostel, when she had been physically assaulted earlier that day. She had decided at lunch time that she’d had enough, and she was going to ‘take off’ and go home to her family home. Another resident knocked her over to prevent her leaving, bruising her. She went back to her room, and lay down. Her sister called, and the weekend supervisor let her take the call as a favour (usually, Ann was expected to walk down to the public phone box in the street). Ann remembered the supervisor standing over her and saying ‘don’t you dare say anything’ before handing over the phone, and then staying in the room for the length of the phone call. She said did not feel able to tell her sister what had happened, but that she felt her sister knew something was not right, ‘from my voice’.

**Threats escalating to assault**

Sometimes, threats escalated to actual assault, leaving people with intellectual disability injured and vulnerable in several ways.
One particular incident Ann recalled involved being pushed down the stairs at a boarding house she lived in previous to the hostel in which most of the abuse she discussed occurred. Ann had been on the phone to her mother, and the phone had cut out. She asked the staff member for more money for the pay phone, but was told to wait, as the staff member was giving out medicine. Ann objected to waiting, and in the resulting argument, the staff member pushed her down the stairs. Ann was physically injured in the fall, and it appears she was also evicted from the hostel for fighting, as she left immediately for another hostel, not of her choosing.

On another occasion at the hostel, Peter, the owner, came into Ann’s bedroom and accused her of tipping coffee over a table. Ann said he dragged her to the top of the stairs, and held her over the stairwell, threatening to throw her down the stairs. Ann said:

*He said, ‘you’d better watch your step, or I’ll be ringing your sister’... He was so strong, he could really hurt you.*

**Coercion**

In some cases, it was not clear to people whether their rights had been abused or not.

A support worker took Jim’s best shoes to give to her boyfriend. Wendy considers this theft, but Jim wasn’t sure. The worker seems to have talked Jim into giving her the shoes, as Jim didn’t wear them often, as he rarely goes anywhere that he needs to dress up. Wendy complained, and the worker gave back the shoes, but Wendy said they were ‘well and truly worn’ by then. The worker was not disciplined, to Wendy’s knowledge, beyond being spoken to by the manager.

**Using punishment to gain compliance**

The use of physical and emotional punishments to gain compliance incites fear in the person receiving the punishment, and aims to ensure that they will not use the behaviour in future. However, in some of the instances
related below, the link between the person’s behaviour and the punishment are tenuous at best.

When Jim was young, he remembered a particular night nurse hitting him every time his stoma bag came off, and making him put it back on himself. At another facility, he was put to bed without dinner if came home from school and his stoma bag had come loose. Jim said at one stage this was happening every second day – a failure by staff to place it correctly in the morning would be the most likely cause of this.

Ann’s co-residents also used to share the same sorts of experiences. Ann related the story of a roommate who had epilepsy, who was punished for having seizures. She said:

And if she had been good and hadn’t had a fit all week, she could go away for the weekend to her boyfriend’s. I had to hold her tongue to make sure she wouldn’t get in trouble for having a fit. If I had’ve let it go and she had that fit, no weekend leave.

Datu said that every time he visited Diwata at the group home where she was living, she was upset. Whenever he took her home for a break, she would cry all the way back (a three hour trip). He said:

\textit{Datu} \quad she doesn’t stop. She just feels sad and things.

\textit{Sally} \quad Oh.

\textit{Datu} \quad And I’ve got no choice, cause it’s for her, it’s good for her, to learn things. She learned, but not too good.

\textit{Sally} \quad Why do you think she was feeling sad?

\textit{Datu} \quad She hate the place. [firmly]

\textit{Sally} \quad Do you know why?

\textit{Datu} \quad Oh, probably cause some people who look after her, you know, they’re not treating her so good, something like that. I don’t know, but so far, that’s what I know. She’s not very happy, and every time she says one of the ladies, like, give her a smack, things like that. I don’t know.
**Withholding basic support and rights**

Basic support and rights were withheld from people in a number of different ways, resulting in them going without fundamental requirements for periods of time, and going through a great deal of stress.

Tom was receiving a certain amount of hours of support each week from a non-government service provider. He attended a review meeting, at which he heard them say they would continue their service. He said he then received a letter saying *'bye bye mate, you’ve got to leave’*, as he was too hard to manage. He was not referred to a new service provider, and he and his mother had to go back to the government funder to renegotiate his hours of support as a matter of urgency. For a period of several months, Tom was in a difficult position, with inadequate support hours and having to use casual and agency staff.

After Ann was released from hospital once her broken hip was stabilised, the owner of the hostel moved her to a group home she owned in another suburb. Here, Ann remembered being bedridden, and lying in her own urine. She recalled being given a poor diet of only fruit, in order to make her lost weight, and said that the staff who worked there were not nice people who spoke roughly to her most of the time. After a period living here, Ann was admitted to another hospital with bedsores and sores on her feet.

The table below presents summary information about the key features of terrorising as a form of emotional and psychological abuse and neglect, as expressed by participants.
**Terrorising**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
</table>
| • Intimidation and control by an individual staff member (acting outside of a policy framework) | • Intimidation  
• Living in a state of fear  
• Being threatened  
• Threats escalating to assault  
• Coercion  
• Using punishment to gain compliance  
• Withholding basic support and rights | |

Table 9 Summary of terrorising

4.2.8 Withholding, misusing or delaying needed supports

This form of abuse had been experienced by five participants in the study. 11 separate incidents were described which related to the withholding, misusing or delaying of needed disability related supports. The themes which emerged were around chemical restraint, the refusal of needed equipment, and the withdrawal of needed equipment to immobilise the person.

It should be noted that several other incidents of this sort of abuse were described by participants which had happened to people they knew, and while they are not detailed here, they may give an indication that this form of abuse could be more common that first thought.

Withholding, misusing or delaying needed supports at the individual level

Tom had hurt his leg, and called his mother for advice. She suggested that he go to the hospital and get it checked. The support worker who was working with Tom that day said 'oh, I’m going home in a minute, I haven’t got time to take you there’, and pulled all the wires out of Tom’s electric
chair, so he was unable to go. The worker left, leaving Tom lying on the
floor, unable to leave the house. Tom said:

He was training to be a doctor! And I told him his bedside
manner... Sucked big time!

Tom’s mum, Penny, said that the worker left the organisation, but was not
disciplined, as far as she was aware.

Withholding, misusing or delaying needed supports at the
systemic level

Chemical restraint
Jill and Dan both experienced over-medication and its serious
consequences. Their stories are alarming, and have both physical and
emotional abuse components.

When Jill lived in the institution, her weight dropped to alarmingly low
levels – 25kg at the lowest point. Her mother, Ivy, feels this was due to
overmedication and a combination of heavy duty drugs which may have
not been necessary. She said:

I always said she lived a life of misery and neglect, because your
weight doesn’t drop to 25 kilograms if you’re being well cared for,
does it?

Jill was placed on high doses of Epilim, an epilepsy medication, which was
increased shortly before she left the institution, despite her showing no
apparent need. The increase in medication caused Jill to stop eating. She
was originally placed on this medication after having a large seizure, Ivy
felt as a reaction to an overdose of a combination of three other drugs,
rather than as an indication of true epilepsy. Two of these drugs were the
strong psychotropics Melleril and Mogadon, which Jill was first prescribed
to deal with her emotional distress at being admitted to the institution.
When Jill left the institution, Ivy, in consultation with Jill’s new doctor,
weaned her off all medication except for a small dose of the anti epileptic
medication, with no ill effect, and now questions whether it was ever
necessary.
When Dan first moved into the rehab hospital, he used to walk independently, although he would have falls. He used to push other residents around the facility in their wheelchairs. Patrick recalled that:

*With the change of management, came a much stronger drug regime, and all of a sudden he was falling over all the time, so we’ve got to put him in a wheelchair. And in amongst this he was also part of a singing group that they had there. So he was so drugged out of his brain that he couldn’t participate in that any more.*

Patrick obtained a copy of Dan’s medical records, and found that Dan was on extremely high doses of Dilantin, Epilim and Tegretol, all at the same time, apparently an unusually high volume and combination of drugs. When he questioned the staff about Dan’s lack of coordination and mental functioning, he said:

*and that was the other thing they would say, ’Oh, it’s just natural deterioration’. Oh, well how come he naturally un-deteriorates [off the medication]?*

**Refusing to provide needed equipment**

The use of the term ‘equipment’ here refers to any service or equipment which a person may need as a consequence of their disability. These are examples where there is not simply a failure to provide equipment, but an active refusal on the part of staff and services to provide equipment which would assist people to live more comfortably or safely.

Ivy is of the view that Jill’s weight loss was also due to a refusal on the part of the institution to puree Jill’s food. Jill has a swallowing disorder which makes it very difficult for her to eat. After leaving the institution, Ivy suspects Jill had a choking incident when being fed by a support worker at home, after which she stopped eating altogether. After Ivy began pureeining all her food, Jill finally began eating again, and has now regained weight and is much healthier.
When Tom lived in a hostel in the inner city, he lived up a flight of stairs. The hostel did not have wheelchair access, and Tom could only get in or out of the building if other residents or the owner or staff were prepared to carry him and his electric wheelchair up or down the stairs.

The assumptions that were made about Dan were very frustrating to Patrick, as he found them to be limiting and demeaning. The refusal of the manager of the facility to provide therapy to Dan, saying that it would not be ‘worthwhile’, mentioned earlier in the chapter is also a clear example of emotional and psychological abuse in this category.

When Ann was coming out of the shower, she tripped over a rug and fell and broke her hip. Instead of seeking appropriate medical attention, and calling an ambulance, the brother of the owner of the hostel in which she lived piggy backed her to his car, and drove her to casualty.

_Withdrawing equipment to immobilise the person_
Three participants had experienced the deliberate removal of their wheelchairs in order to prevent them from moving around their homes and communities.

Patrick used to pay a lady to go and read to Dan, when he couldn’t visit himself. One day, when she arrived, she found Dan in his room, where he had been put ‘like a naughty boy’, and his wheelchair taken away as a punishment. She wrote a letter outlining the circumstances, which Patrick took to the Health Minister, but unfortunately little was achieved.

Jim was punished by staff in two different facilities when his stoma bag came off. In one institution, he was smacked as a young child by a night nurse whenever his bag came off. In another hostel, he was put to bed without dinner whenever he came home from school and his bag had come off. Once Jim had been put to bed, he could not reach his wheelchair and get into it on his own, so he had to remain in bed until staff would get him up the following morning.
The table below contains the summative primary themes which emerged from the results in this area of withholding, misusing or delaying needed supports.

**Withholding, misusing or delaying needed supports**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Withdrawing equipment to immobilise the person</td>
<td>• Chemical restraint</td>
<td></td>
</tr>
<tr>
<td>• Refusing to provide needed equipment</td>
<td>• Withdrawing equipment to immobilise the person</td>
<td></td>
</tr>
</tbody>
</table>

Table 10 Summary of withholding, misusing or delaying needed supports

### 4.2.9 Corrupting and exploiting

Stories which related to four experiences of corrupting or exploiting abuse were shared by participants, centring on three different people with intellectual disability. This represents a small, but important theme in the study, centring around the misuse of power by workers to require people living in services to behave in ways that they ordinarily would not – either by being manipulated into malicious political staff campaigns, living routines that minimise staff workload, working as staff would (or should), or listening to confessions they rather would not.

#### Corrupting and exploiting at the individual level

Jim talked about his difficulties with a worker who was engaged to take him to and from TAFE, where he was going to learn literacy and computer skills. He said he had trouble with the worker, because she talked at great length and in great detail about her personal money troubles, and also unburdened herself to him about the recent death of her mother. While this is not abusive by itself, Jim was very uncomfortable with the conversation, and he gave the impression that it continued for several
weeks. The inappropriateness of the worker using Jim as a ‘listening ear’ when his communication impairment and his lack of assertiveness dictate that he would almost certainly be unable to ask her not to talk about these issues, certainly in the level of detail which she did, changes the context of the interaction, making it an exploitative interaction due to the intensity and the one-sidedness of the communication, and Jim’s inability to end or leave the conversation.

Ann was sexually assaulted when she was in a private psychiatric hospital. Gemma says that she had some longstanding emotional damage as a result of this abuse, and feels that she bears responsibility for the assaults, as they took place as part of a twisted relationship that the male nurse instigated with Ann.

**Corrupting and exploiting at the systemic level**

Rose felt that Jenny’s friend and co-resident Ian was corrupted by male staff who worked in the group home that they shared. As she understood it, Jenny was also victimised by the exploitation of her friend. Rose felt strongly that these staff (who worked with both Rose and Ian) wanted to move Jenny on, as she was not easy to work with due to her support needs. She said they instigated a malicious, and subtle, campaign of turning Ian against Jenny, and against other female staff, by encouraging him to use anti-female language such as ‘bloody women’, to denigrate women in general, and other actions which damaged the relationship between Jenny and Ian to the point where Jenny was eventually the victim of physical violence by Ian. Not only was the longstanding relationship between Jenny and Ian damaged beyond repair, but Rose was concerned that Ian’s conception of women was badly damaged, and his relationship with female staff difficult. Jenny was subjected to two years of the emotional and psychological effects of being denigrated and put down by both her friend and staff who were paid to support them, and she ultimately left the accommodation service as a response to what Rose found to be an intolerable situation.
On a lower, but more chronic, level Rose talked about the way that she sometimes saw staff manage Jenny in several of the places in which she has lived, by:

> getting Jenny to be quiet, or to go to her room, or to do stuff that they want done, so it makes their job easier

Tom lived for about eighteen months in a group home with people who had higher support needs than he. He paints a vivid picture of a lifestyle where he undertook a large proportion of household tasks, including assisting other residents to get dressed (despite having a significant physical impairment himself), teaching household tasks to other residents, and cooking meals for the group. He said staff did some tasks, but also watched a lot of TV. Tom remembered one day when he hit breaking point:

> Tom Yeah. One day I forgot that I put a chicken in the convection microwave, and when I went back there, it had broken it.

> Sally Oh no!

> Tom And it was, how can I watch and look after these lot and do that at the same time?

> Sally And what did they [staff] say?

> Tom Oh, you can do it, you know how to cook.

Tom’s mum, Penny, also raised this point, saying independently of Tom that in some of the places that Tom has lived, ‘You’d think Tom was working for them, rather than those workers working for him’.

The table below contains a summary of the abuse experienced in the category of corrupting and exploiting, as related by participants in their narratives.
Corrupting and exploiting

<table>
<thead>
<tr>
<th>Individual</th>
<th>Systemic</th>
<th>Structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Workers emotionally offloading to residents</td>
<td>- Intentionally damaging relationships between co-residents</td>
<td>- Blurred roles and responsibilities</td>
</tr>
<tr>
<td>- Sexually exploitative relationships</td>
<td>- Requiring residents to complete staff duties</td>
<td></td>
</tr>
</tbody>
</table>

Table 11 Summary of corrupting and exploiting

4.3 Other forms of abuse experienced

A high volume of other forms of abuse and neglect were also described by people in the course of their narratives. The table below details these abuses.
<table>
<thead>
<tr>
<th>Type of abuse/crime</th>
<th>Number of references in the interview data</th>
<th>Number of participants experiencing this form of abuse/crime</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical neglect</td>
<td>26</td>
<td>8</td>
</tr>
<tr>
<td>Negligence (inattentive care resulting in harm)</td>
<td>20</td>
<td>7</td>
</tr>
<tr>
<td>Incompatibility with co-residents resulting in harm</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Financial abuse</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Failure to adequately maintain health</td>
<td>16</td>
<td>5</td>
</tr>
<tr>
<td>Physical assault</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Witnessing abuse/assault of others</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Assault by co-residents*</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Chemical restraint</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>False imprisonment</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Inadequate staffing resulting in harm</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Theft</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Injury with unknown cause</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Sexual assault</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

**Table 12: Other forms of abuse (ordered by frequency of experience)**

* note – this total is included in physical assault, but also included as a separate category, to show the experience of assault by co-residents experienced by a significant number of participants.
There is overlap between these abuses and the emotional and psychological abuse and neglect detailed above. Where participants talked about the emotional or psychological component to the abuse (for example, ‘he feels like he can’t trust men now’), the incidents have also been included in the emotional and psychological abuse categories. It is difficult to separate the causes, experience and effects of abuse and neglect, as many (if not all) forms of abuse and neglect have an emotional and psychological component. For this reason, statistical comparison is not helpful. However, what can be clearly seen from the table is that a high volume of abuses have been experienced by this small group of people.

While this study does not focus on abuses other than emotional and psychological, it would be remiss not to include mention of these other forms of maltreatment. Some of the abuses which are not fully detailed in the discussion of emotional and psychological abuse and neglect, but which have significant implications for the emotional health and wellbeing of participants include sexual and physical assault, witnessing the assault of others, and false imprisonment in particular.

### 4.3.1 Abuses at the individual level

The abuses related by participants which were situated in the individual domain were primarily those caused by other residents. This was mostly physical assault, and was linked in several instances to systemic failures to house co-residents more appropriately so that their needs were better matched, or to respond to earlier complaints about the behaviour of violent co-residents. In the case of Fran and Jill, some injuries they received in the institution were of unknown origin, and their families assume they were received either by accident or from another resident. Three people had their possessions stolen by support workers. Two participants were sexually assaulted by workers in services.
4.3.2 Abuses at the systemic level

Abuses with systemic cause were strongly linked to support workers and management of services. People with high support needs came to harm in several cases due to the failure of workers to maintain adequate care standards. The health of five participants was damaged due to the failure of their services to provide adequate health care.

Six of the nine participants experienced financial mismanagement, in some cases of significant amounts of funds. False imprisonment was an experience related by three participants, where the link between the punishment of exclusionary time out and the misdeed was unclear in their minds. Chemical restraint was a long term experience for three participants.

4.3.3 Abuses at the structural level

The inability of participants to move away from co-residents who had threatened them, or who they were frightened of, before or after they were assaulted is indicative of a structural abuse. The harm that resulted to people from assaults by co-residents can be seen in part as a result of the structure of the disability services system which houses groups of people with diverse support needs together without recourse to moving if the need arises.

Physical neglect was experienced by eight of the nine participants. This was expressed through the presence of preventable illnesses and injuries, such as scabies and underweight, provision of poor quality food, poor medical care, and unhygienic home conditions. Participants described people with high support needs living with staffing ratios of 1:6, and at times even 1:12. This is linked to the fact that three participants came to harm directly as a result of inadequate staffing levels. Under-resourcing was described by several family participants as chronic, and of great concern to them. The failure to provide adequate staff to support people with high support needs provided conditions ripe for abuse to occur.
4.4 Summary

This chapter shed light on an aspect of people’s lived experience about which little is known, and painted a picture of the frequency, volume and subtlety of emotional and psychological abuse in the lives of participants. It provided a detailed account of the experiences of nine people with intellectual disability who were living in disability services at the time their abuse occurred. Their experiences of emotional and psychological abuse and neglect were framed according to the schema developed in the literature review, and organised in the appropriate individual, systemic or structural strata. Other forms of abuse related by participants were also detailed.

The following chapter presents the responses of participants to the experiences of abuse and neglect, and the effect that they feel that it has had on their lives. Chapter five also provides an account of the responses of key stakeholders to systemic concerns around this form of maltreatment.
Chapter five: Responses to abuse and neglect - power and control

And I said to her, ‘Brenda James’, I said, ‘why is it that Dan gets no therapy?’ And she gave me a very condescending laugh, ‘oh, well, it wouldn’t be worthwhile, would it?’.

- Patrick, Dan’s brother

Chapter five presents the second part of the results. This material relates directly to the central power and control node of the emotional and psychological abuse and neglect framework, within which all of the abuse experiences have been structured. Part one of the chapter details the responses of participants to the experiences of abuse and neglect which were presented in the previous chapter and the effect they relate it has had on their lives. Their experiences in complaining about abuse are presented. The impact of abuse on the lives of people with intellectual disability and family members and the emotional consequence of the abuse is detailed. A description of the resilience of people in dealing with their experiences concludes the section.

Part two of the chapter provides an account of the responses of key stakeholders who are engaged at a policy level with the abuse and neglect of people with intellectual disability. These policy, advocacy and complaints agents provided a systemic view of some of the features of emotional and psychological abuse and neglect. This section includes their thoughts about how to understand this form of abuse and neglect; their views on the impact of it on the lives of people with intellectual disability; its prevalence in disability services; how well recognised and how well responded to it is; the risk factors; strategies for protecting and
safeguarding people with intellectual disability; preventing the abuse from occurring; and finally, how to influence change.
Part one: Responses of participants to emotional and psychological abuse and neglect

The responses of participants to their experiences of emotional and psychological abuse and neglect were explicitly connected to the central dynamic of power and control which is at the core of the abuse and neglect framework. In this section, they describe their experiences of making complaints about the maltreatment they experienced; the impact of the abuse on their lives; and the strategies they have used to counter the effects of the abuse and neglect.

5.1 Complaints

All nine participants had made multiple complaints over the time they have been engaged with disability services.

Complaints are of interest to this study in two contexts. First, the subject matter of the complaint may directly concern emotional and psychological abuse and neglect. Participants didn’t identify their complaints as being about emotional and psychological abuse, although many of the experiences people shared related to abusive incidents. Second, the experience of making a complaint was at times itself an abusive event, depending on the way in which it was responded to and addressed. This happened with some frequency.

People did not complain about frivolous issues. There was a shared understanding that it took courage and a certain summoning of emotional strength to make a complaint, and it was not something people did lightly. It seemed that it was only when situations became intolerable that people
made complaints – when their safety was threatened, their family member was injured, or they could see serious misconduct had occurred.

People contacted a range of different bodies for support with complaints. The first port of call for all participants who made complaints was the service, but in numerous cases the problems which were raised were not resolved at this point.

Making a complaint was far from a guarantee that things would change for the better for people who participated in this study. Eight of the nine participants had experienced punitive outcomes when they had made complaints. They viewed complaining as a ‘necessary evil’, highly stressful and not guaranteed of a good outcome.

5.1.1 Complaints at the individual level

All of the nine people with intellectual disability who were involved in the study had individual advocates at points in their lives who had assisted them or their family members to make complaints about various matters. This is reflective of the recruitment process for the study, which used advocacy agencies as ‘gatekeepers’, rather than the availability of advocacy for people with intellectual disability in this state. Their history of advocacy may mean that the people who have participated in this study are more likely to have made complaints, to have taken action to change the situations of themselves or their family member, or to speak up about their situation than others in a similar position.

Jim didn’t tell his mother about his ill treatment, which she found very distressing at the time of the interviews. He did talk to his sisters about it, but found that, as children themselves, they weren’t very interested.

Ann used to complain to her mental health case worker about the threats, assaults and verbal violence she lived with on an ongoing basis. She said he used to call the hostel, ‘get their side of the story’, and then return her
there, unsupported. Alerting Ann’s abusers to her complaints and then leaving her to face their displeasure at her complaining was both unethical and abusive. Ann was also phoning and writing letters to her sister at the same time, telling her about what was happening. Her sister made contact with an advocacy agency, and together over time they helped Ann find a better living situation.

### 5.1.2 Complaints at the systemic level

The responses of support workers, managers and services to complaints fall into several clear themes. These centre around the appropriateness of the response to complaints. A minority of responses were positive and effective. More common were inappropriate and punitive responses, and a lack of response to complaints.

*Making positive change by complaining*

One participant had a purely positive view of making a complaint. Tom had a good experience of complaining, when he made a complaint to the state disability department complaints service about the worker who took the wires out of his wheelchair and left him lying on the floor. Tom said ‘*they changed all their laws because of what I told them!*’, and he is proud of speaking up.

*Inappropriate responses to complaints*

Family members in particular noted that the service system was set up in such a way that it did not respond to complaints effectively or sensitively. For example, as a child Fran came to school from the institution with a large bruise on her cheek, with the only explanation a note in her communication book saying she had a bruise. The institution did not contact Fran’s family to let them know she had been injured, and did not contact the school to explain the injury. They eventually apologised, but only after an inquiry by the state Ombudsman, to whom Fran’s family had complained.
Ivy said she became very unpopular with both staff and management of the institution because she complained about serious problems with their management of Jill’s health and wellbeing. Amanda was of the view that many people she had come in contact with were worse off after complaining to the state disability department about abuse.

**Punitive responses to complaints**

Tom used to talk to his mother on the phone about problems with his service providers. She would call the service and complain on his behalf, but felt that Tom would be penalised as a result, and that the service would promise change, but do little.

Jim described several occasions when things had gone wrong for him. After complaining about being put to bed early, and about other residents making so much noise that he couldn’t watch TV, Jim said that staff made things hard. While he did get put to bed later, he remembered they *'They didn’t talk to me nice and treat me nice’*, and he was ignored about the noise complaints. When Jim was living in a group home with three other men, he had many times when he didn’t feel safe, particularly at night time. They did not have staff rostered on to support them at night, and Jim found the other men frightening. One of the men had schizophrenia and problems with violence, and Jim was threatened by him several times. When he sought help from the service coordinator, using the pager service, he was told that the man had more problems than Jim, and he would have to ignore it. Jim said the service did not help him to feel safe in the two years he was living in this situation.

**Lack of response to complaints**

Jim is of the view that people don’t do anything when you complain, and that it’s not fair. He said maybe things have changed, but then changed his mind, and said that people still won’t listen. He said *'people at the top don’t want to know, some people’*.  

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Early on in Dan’s residence in the rehab hospital, Patrick wrestled with whether to stay silent or to speak up about concerns he had about Dan’s treatment. He said:

*So I just opened my mouth, whenever I saw something I didn’t like, I just opened my mouth, and I guess I became a bit of a thorn in their side, and an annoyance to them.*

However, Patrick did not feel that this action ultimately made a difference to the treatment that Dan received.

### 5.1.3 Complaints at the structural level

Family members told of the long and difficult process of creating a safer life for their family member. This involved many complaints and arguments with services and government departments. It also required staunch advocacy and a refusal to accept the amount and type of funding and accommodation offered, which was in some cases insufficient to meet people’s needs once they had left the institutional environment. People with intellectual disability saw problems and resolutions in a much more linear way than did family members – as problem and solution, rather than a path to a particular end point.

Sometimes the problems which underlay the subject of complaints were beyond the ability of support staff to solve – for example, in the cases of Jill, Dan and Fran, their family members saw that their need was to move from an institutionalised environment which failed to meet their needs in many ways.

Some people with intellectual disability and family members took more formal action to address these underlying problems. Jill’s family had approached their local parliamentary member for assistance, and had also taken legal action against the funding government department for a failing to provide sufficient funding to adequately support Jill in her current living arrangement. Patrick made representations to the Minister for Health, ultimately responsible for living conditions in the facility in which Dan...
lived, about his abuses. Craig was considering participating in a compensation scheme for children who had been abused in care which had recently been introduced as the result of an inquiry into child abuse in institutions.

5.2 Impact of the abuse

The remaining section of part one of the chapter addresses significant issues from the narratives about the way the abuse impacted on the lives of participants. These include the impact of the abuse on participant’s lives; their experiences of making complaints; and the resilience, emotions and coping strategies drawn upon in dealing with the abuse and neglect over time.

As with the experiences in the emotional and psychological abuse and neglect framework, these have been conceptualised in terms of their individual, systemic or structural basis.

Without doubt, the abuse in the lives of participants in this study has had a significant impact. This is manifested in many ways – through people’s emotions, their mental health, their capacity to develop and maintain healthy relationships and their cultural connections. A theme of resistance runs through the narratives – people are not passive victims to the service system. That they are able to participate in this study may be due in large part to the fact that their abuse is (in most cases) historical.

5.2.1 Impact at the individual level

Amanda eloquently described how Fran continues to sometimes be overcome by her emotions, she thinks in response to her experiences of abuse. She said:

*And sometimes Fran will just cry. And Fran’s not a crier. She’ll start crying, and workers have said to me, ‘Why? She was happy a minute ago, and then she just crumpled up and started to cry’.*
And I said, ‘all I can think is that she’s remembering things’. Something’s brought something back. All we can do is sit next to her and hold her hand and tell her she’s safe and she’s not going to be left with this alone.

Ann’s support worker, Gemma, sees the long term impact of the abuse on Ann as being damage to her capacity to develop and sustain relationships. Gemma said:

But, you know, a lot of her way of thinking about herself is institutionalised, you know, that she really looks towards institutions as being where she’s going to get friendship, or where she’s going to get her needs met, really.

Jim’s firm view that he is not ‘allowed’ to have any cordial or friendly relationship with support workers has resulted in severe isolation, given he does not work and has a limited social life. He spends most of his time alone, and says he is not happy.

Craig’s divorcing from his cultural roots has left him uncomfortable around Aboriginal people as an adult. This is a profound impact on his sense of belonging to a family, culture and long tradition.

Rose saw Jenny’s entry into the disability services system as the ‘end of her healthy psychological life’. Jenny acquired a psychiatric disability in the first thirty bed hostel, Rose feels as a reaction to her experiences there. Rose thinks the impact of the culture of the service in which Jenny now lives, where going for coffee is considered an ‘outing’, contributes to Jenny’s depression and lack of purpose.

The impact of the abuse on people with intellectual disability was seen by family members to be ameliorated in some cases by the actions of individual staff. Some staff in services took a protective role with particular people, which brought families some peace of mind. Jill had a particular support worker who looked out for her, who worked with her for many years. When Fran was eighteen, the institution management
proposed that she be moved to a unit with a group of women in their forties. A support worker lobbied hard on her behalf for this not to happen, and she remained with peers her own age. Patrick recognised the efforts of ‘those good souls’ who would try to make a difference to Dan’s life. However, while family members were grateful for these individual actions, they saw them as making little difference to the overall outcomes.

5.2.2 Impact at the systemic and structural level

The number and range of abuses and poor quality of care which Jill, Fran, Ann, Dan and Jenny experienced prompted their families to go to great lengths to secure better accommodation and support options for them. Ann and Jill’s families have taken legal action on their behalf to redress the injustice of their circumstances. Fran, Jill and Dan’s families fought long and hard with government departments to secure funding so that their family members could live in more appropriate and individualised supported accommodation.

However, on a daily basis, the family members of Jill, Fran, Diwata and Dan spend hours caring for their loved relatives. Repeatedly, they told the story of having to make a choice between tolerating poor treatment, abuse and low standards of care for their relative, or creating new options. The creation of new options has resulted in greatly increased safety and new opportunities for people with intellectual disability, but at some significant cost to family members.

Ivy recalled being told by social workers that Jill would be better going into an institution when she was young, as she and her father would not be able to care for her when they were elderly, and Jill would find it harder to adjust to an institution if she went into one at an older age. Now Jill is 47, Ivy 74, and Ivy spends at least 50 hours each week supporting her to live in supported accommodation, due to a shortfall in funding. The only way Ivy would be relieved of this work would be for Jill to move into group accommodation, and for Ivy to lose control of key parts of Jill’s
support which she sees as central to the quality of her life. At the time of writing Ivy was battling with the government department through legal avenues, seeking further funding to support Jill adequately in her current living arrangement.

Patrick lives half his week with Dan, and half at his own home. He finds his life extremely stressful, and doesn’t know how long he can sustain this way of living. Datu can’t see a way forward for Diwata if she can’t learn independent living skills. He worries that she will have to go back into a group home when he dies, and does not see this as a good option. Amanda feels grateful for the support of a circle of supporters who specifically provide support to Fran, and who have made a long term commitment to her.

5.3 Resilience

Many emotions were called up for people in discussing such a personal and confronting topic. People with intellectual disability and family members revealed a range of different methods they had used to manage the very difficult situations they had to address, and the emotions they were sometimes dealing with.

5.3.1 Resilience at the individual level

Putting experiences into a context

Participants with intellectual disability also talked (with prompting) about some positive experiences in their ‘service lives’, against which their experiences of abuse and neglect were balanced. Craig, who grew up in an institution, talked about his relationships with other children, and memories of some kindly staff. He also remembered being taken home for weekends by one staff member for a time. Ann recalled birthday celebrations, and watching sport on television with a weekend staff person who ‘understood how I felt’. Jim enjoyed outings away from the places he lived most of all.
Guilt
Amanda talked about the residual guilt she still feels about Fran living in the institution. She said:

I just think, you know, what damage has been done to you, Fran, that we don’t know about? And that’s very hard for me.

Rose also talked about her feelings of guilt. She said:

I’ve gone through huge amounts of guilt. I always feel totally helpless that I can’t make her life what I believe to be good enough.

Pain
Jim thinks that his experiences have made him a different person, and that ‘You know probably what to expect now’. Given that Jim showed little hope of anyone listening to him if he had a problem, and while he said he wasn’t happy, had no plans for changes in his future, this may be a bleak outlook. When his mum suggested that it ‘toughened him up a bit’, Jim agreed.

Jim hadn’t spoken to his mother, Wendy, about any of the abuse he had experienced while it was happening. Jim chose to have Wendy in the room while he was interviewed, and she found it very confronting to hear his story. Later, when she was interviewed alone, she said:

Wendy I feel like I’ve been asleep. I feel like, you know, I didn’t know anything like this was, I s’pose, and I wouldn’t have been – I don’t know, you don’t think of these things at the time!

Sally No, no you don’t.

Wendy You know, I didn’t know anything about it then [very quietly].

Living in the present
Others preferred to try not to think about the past, and focus on the present. Ann, in looking back on her experiences, said she now feels
lucky. ‘That I’ve got this house. And my new car. And I’ve got these nice ladies coming here and looking after me’. She still has dreams about the past, but then she tells herself about how good things are now. Ann talked about enjoying her arts program, where they have drums where you can ‘drum out your frustration’. She also remembered going for very long walks, to get some space, and also to try and feel closer to her mother, who had died some years before.

Patrick said ‘Um, I guess there’s a mountain of stuff in here, that I try to switch off from, these days’.

Craig obtained his file from the institution where he grew up a few years ago. He said ‘as I grew older, I wanted to find out who I was, and where I came from’. Craig was also looking to the future for comfort. His plans included ‘Making sure that people like myself never have to go through that’.

5.3.2 Resilience at the systemic and structural level

Difficulty taking action on abuse
The lack of hard evidence of emotional and psychological abuse made it difficult for families to take action when they suspected something was not right. Amanda’s comment is reflective of several participant’s views:

But there was nothing there, and we kind of, cause we were going through such a bad time [with other family issues]. I always used to call it ‘putting Fran on the back burner’...And I hated having to it, but for your own sanity, you kind of just had to.

Practical action
Some participants found practical actions helpful. Rose used to work hard on fund raising committees to buy buses for the hostel Jenny lived in, even though she strongly disagreed with congregate living and mass outings. She said:
So, I did all that kind of crap to have some kind of sense of control, and to get the staff to like me, because to me, she would be safer.

Great resilience was demonstrated on the part of both people with intellectual and family members. People with intellectual disability showed their resilience in simply living through the range and volume of abuses they described, and continuing to find pleasure in their daily lives. Family participants demonstrated their resilience in their consistent and long fought battles with services and government departments to create a better living environment for their family member. It took several years for Dan, Jill, Amanda, Ann and Jenny to each move into a responsive, individualised home environment. Amanda’s perspective of Fran is indicative of several participants’ experiences. She said:

*Fran is a leader. She has survived horrific experiences in a horrific institution, and now she’s thriving – because she has a decent life. She might not know she’s a leader, but she is a leader.*
Part two: Responses of key stakeholders to systemic issues

Sixteen people from a range of policy perspectives participated in ten individual and small group interviews, in order to develop a picture of the view in the state disability community about how this form of abuse and neglect is understood, how prevalent it is felt to be, how well it is recognised and responded to, and ideas for how it could be better prevented and people protected against it. They were predominantly people with a longstanding history of working in the disability, both directly with people with intellectual and other disability and in the policy and advocacy contexts.

The government and funded non-government disability sector in this state is small, particularly in the area of abuse, and individual participants and agencies easily identifiable. For this reason, participants are referred to as representatives of systemic policy and advocacy agencies, service provision organisations, and complaints agencies, rather than their more identifiable organisational links. Individual advocates with longstanding experience also participated in this part of the research. It should be noted that, while a cross section of agencies which deal with abuse and neglect are represented here, people in these organisations were approached on the basis of their individual knowledge, background and skill.

The discussion here follows the themes addressed in each interview – namely, the understanding and definition of the abuse; its impact; its prevalence; how well it is recognised; how well it is responded to in the sector; risk factors which may increase the likelihood of its occurrence; prevention strategies; and ideas for safeguarding and protecting people with intellectual disability and influencing change.
5.4 Understanding this form of abuse and neglect

Key stakeholders had a nuanced understanding of this form of abuse and neglect, and drew on both their direct support and policy experience to share their insights. They also offered a range of perspectives around the way emotional and psychological abuse and neglect was defined, and how definitions were used. Themes which emerged from this part of the interviews centred around the subtlety of this form of abuse and neglect, the influence of culture and power and issues of defining this abuse and neglect.

Stakeholders who had worked with hundreds of people with intellectual disability talked about the subtle nature of emotional and psychological abuse, and how it was not understood as abuse. Individual advocates recalled many examples of abuses disguised as policy, such as Therese’s memory of the rule within an institution that any new resident who showed grief or tears could not have visitors until they stopped, as it was seen as better for them to get over the grieving process before seeing their family, or Kate’s current experience of volunteer work in a large residential setting where all residents are fed pureed food, which is all mixed together, despite some people being able to chew food, and all being able to enjoy different flavours.

Lived experience and personal perception
Heather, who has a long history in service provision and policy development, contended that service providers are not able to fully understand the experience of emotional and psychological abuse and neglect, because they don’t have the life experience of living with an intellectual disability in this society. The best they can do is to sit beside people and say ‘this is my perspective. What is yours?’, and ‘what do we need to do to move forward?’.

Brian, a systemic policy and advocacy officer, expressed the view that:
it’s probably a slippery thing. Cause emotional stuff is more subtle than a slap or, you know, sexual assault...what one person might consider to be emotional assault or psychological, another person might not.

He went on to say that this subtlety may be particularly difficult for people with intellectual or cognitive disability, who may not understand why the abuse has upset them, and that there is an increased likelihood that the frustration that comes from this would be expressed through challenging behaviour.

The influence of culture and power

Therese’s view of emotional and psychological abuse was that it usually happens over a long period of time, and that it is part of fabric of the system that people live in. Their lack of normative life experiences means that people have little to compare their experiences to, and it is difficult for them to understand that their treatment may be abusive. Her experience was that people develop particular ways of responding to this treatment, however, and these anti-social behaviours are then treated as a problem. This then gives rise to different ways of treating people, ways in which they are treated as not quite human. Therese said:

they’re placed in situations where they’re, the expectations of how they live and what happens to them are very different to what happens for other people. And it’s not until they have a different experience that they really understand that they have been abused and neglected.

Representatives of systemic policy and advocacy bodies shared the view of individual advocates that emotional and psychological abuse and neglect was fundamentally linked to the culture of services. Leanne said:

I think that there’s a culture. I think the culture, that people within the culture don’t accept it exists. When you’re outside it you can see that it exists, and that it’s powerful.

For Zoe, an individual advocate, the abuse of power and trust was integral to an understanding of emotional and psychological abuse and neglect.
This was supported by comments by others from systemic policy and advocacy bodies. Rachael, a service provider and leader in the field, described this as an exaggeration of the power imbalance that exists between workers and clients, and stressed its ongoing and growing nature. The series of incidences together influence the construction of people’s identity, and determine how they act in a situation. She said:

Like people would describe feeling small, and not listened to, not being heard. Or they have a disagreement, and feel the disagreement was not being an equal playing field, it escalated into something else where they were blamed disproportionately.

Defining abuse and neglect
Polly was a representative of a systemic policy and advocacy body, but her understanding of emotional and psychological abuse was also built from her earlier experience as a service provider. She conceived of it as quite subtle in many cases, and involving behaviours such as treating people as objects, not respecting their basic humanity and right to dignity, and ignoring their emotional needs and the need for connection. She recalled instances of seeing people speaking to and treating people with disability roughly, threatening people, taking away treasured possessions or activities without reason, ridiculing people, and denying people opportunities to develop self-esteem and the experience of achievement because the worker wants to get things done. Polly also felt that:

some people are quite resilient to that, and some are not, and some people will internalize it to a greater degree and it affects their life experience to a greater degree. And it’s very hard to identify unless you are spending a lot of time with people.

Heather, who has a long history in both service provision and disability services policy, understood emotional and psychological abuse as any behaviour or action that is inconsistent with treating someone as a valued person and as someone with dignity. Others identified some unusual features of this form of abuse. Charlie, an individual advocate, talked about some very subtle put-downs that people experienced, such as the friendly banter that frequently exists between staff, but often not between
staff and residents. Robyn, a systemic advocate, raised the failure of services to support people with intellectual disability through their grief in times of loss, such as the death of family members.

A systemic policy and advocacy body which is charged with protecting people with disability from abuse and neglect did not use a definition of emotional and psychological abuse in their practice, or perceive a need for it, as they saw their role as to ‘enquire into function’. Neither did a systemic advocacy program which spent a lot of time in disability services, considering their role to be to look at individual issues and then consider whether abuse or neglect might explain the circumstances – it was felt more appropriate to use the broadest definition possible of ‘abuse, neglect or exploitation’. Leanne, the representative of this organisation, was at pains to point out that this did not mean ignoring indicators of emotional or psychological abuse, but that it was not the role of an individual advocate to assess this, rather to identify issues of concern and raise the alert for further investigation.

Emotional and psychological neglect was raised as an issue of concern by several stakeholders. Polly argued that neglect was a form of abuse, and that most people living in disability services were emotionally neglected. She defined this neglect as ‘failure to treat the person’s aspirations, goals and dreams, and on the other side of that of course would be their sorrows and hurts’. The sorts of failures to act that she saw were in the isolation of residents, the lack of assistance provided to people to have meaningful relationships with others, the lack of assistance to be able to communicate with others, the neglect of health, and responding to a person’s frustration and anger without respecting the cause of it, so that the person’s frustration increases. She pointed out that with a ratio of one staff member to five residents in a group home, it is not possible to achieve these things. Others identified the failure of the service system to stimulate people with disability, and particularly those with autism, as neglect.
The multifaceted understanding of stakeholders about this form of abuse and neglect was both complex and sophisticated. The cultural, interpersonal and inter-relational aspects raised highlight the complex nature of this form of maltreatment, and raise questions about the benefits of sharing understandings of emotional and psychological abuse and neglect.

### 5.5 Impact

The impact of emotional and psychological abuse on people with intellectual disability was seen by stakeholders to be profound. The subtlety of comments made by workers, both verbally and in progress notes, combined with the difficulties that people have in identifying such abuses and raising them as concerns, was seen to result in an abrading or degrading of the person’s psyche – what Adam, a representative of a systemic policy and advocacy body, referred to as a ‘wearing effect’. Carol, his colleague, put it this way:

> They are already disabled, and they become infinitely more disabled... they are unable to self-actuate because at a fundamental level they are being hurt, in their very heart and inner lives, which people don’t see, and they don’t address. So, I think that the impact’s huge.

Leanne, a representative of a systemic advocacy program, talked about the concerning trend of residents isolating themselves in their bedrooms in response to violence between residents and what they termed ‘staffing arrangements’. She and others also identified a lack of recognition on the part of staff that witnessing violence was in itself emotionally and psychologically damaging. Robyn, from another agency, also talked about the range of abuses which can accompany inappropriate matching of co-residents. Leanne said:
So, while no-one comes up to [us] and says 'I’m being emotionally abused’, certainly the [advocates] visiting sites are affected by what they see. It’s the impact of what people are hearing and seeing, on each other.

Individual advocates provided many examples of emotional and psychological abuse and neglect which had occurred in the lives of people they supported. Therese’s view that 'they talk about it still, so it obviously affects them still’ was representative of the attitude of all four individual advocates about the impact of the abuse. Complaints services commented that the abuse increased anxiety, sometimes dramatically, in people who may already have difficulties managing anxiety.

The impact for families was also raised, both in terms of the emotional strain of being concerned for the safety of their family member, but also in terms of the delicate balance that needs to be maintained with services, so that they don’t become ‘troublesome’ parents, who complain too much, because that will have implications for their son or daughter once complaints and monitoring agencies have gone.

Another strong theme which emerged here was around the cauterising or cutting off of relationships between people with intellectual disability and support workers by services, where the decision is made by management to move a staff member on to another house, because a resident is becoming attached to them. Several key stakeholders raised this as a concerning feature of service provision, and one which they saw as emotionally and psychologically abusive. Several examples were given where staff had been moved, and residents were not even provided with the opportunity to say goodbye to them. It is a difficult relationship to navigate, as there is a need for some boundaries. However, the grief caused by poor management of such important relationships is abusive and cruel, and was seen to have a sometimes devastating impact on residents. The poverty of the emotional lives of people who live solely within disability services was starkly pointed out by Dagmar, in saying 'It must be horrible to have no-one who loves you’.
Heather was troubled by the fact that people with disability she knew hadn’t reacted to and fought against emotional and psychological abuse, when she would have expected them to, out of fear of a loss of service. She had watched them trade off their dignity and their right to be free from abuse in order to receive a service. She said:

*So, when I look at those people, who are among probably the least vulnerable of people with disabilities, and if that’s their experience, and that’s the impact for them, then I hate to think what it means for others.*

### 5.6 Prevalence

The shared contention of all stakeholders was that the rate of emotional and psychological abuse and neglect experienced by people living in disability accommodation services was high, certainly far higher than any existing figures would show, and in Heather’s words ‘*prevalent enough to warrant significantly more comprehensive services than we currently have*’.

The complaints referral service advised that in their 2007 annual report, psychological abuse accounted for 27% of all abuses notified to their service nationally. The manager said these figures may not be very reliable, given that systemic abuse is also highly rated in their figures, and their reported difficulty in determining whether abuse is primarily emotional/psychological or systemic in cause.

Carol, representing a systemic policy and advocacy body, said that their agency is of the view that the level of emotional and psychological abuse of people with intellectual disability is quite high. She talked about the difficulties in looking at changes in a person’s behaviour to gauge emotional or psychological abuse, particularly when people were not able to tell their own story, to try and overcome conflicting stories about what had occurred. She concluded:
So, because it is such a difficult area to prove, I think we see a massive under-reporting of it on the ground, because our ability to respond to it in an appropriate way is very limited.

Leanne, who represented a systemic policy and advocacy body which spent a lot of time in disability services, said that the level of emotional and psychological abuse and neglect in those services was ‘extreme’. She argued that people come to accept it, and that it becomes acceptable because over time, the lack of resources and training and independent scrutiny mean that a certain level of emotionally abusive and neglect practice can become the norm. She said:

And so it’s, it doesn’t strike people as being unusual or strange or unacceptable, because that’s just the way it is. And that’s the biggest problem, I think, and the reason why it’s so prevalent. I think it’s massively under-reported because that’s just the way it is. There’s a level of acceptance in the funding.

5.7 Recognition

Stakeholders discussed recognition of emotional and psychological abuse and neglect in differing ways. Complaints response agencies detailed their processes for receiving and acknowledging complaints about abuse, while policy and advocacy bodies and individual advocates talked about systemic issues they had encountered in disability services concerning the way that emotional and psychological abuse and neglect is recognised among workers and managers, and by people with intellectual disability themselves. These centred around recognition by workers and recognition by the service system.

Overlaying the discussions about recognition was acknowledgement by most stakeholders that many people with intellectual disability may not realise that what is happening to them is in fact abuse.
Lack of recognition by workers

When Charlie worked for a large disability service, he was involved in the development of their abuse policy. It included emotional abuse and neglect, but he said it was rarely reported, as workers did not observe or identify it sufficiently well to report it.

Other stakeholders also raised the issue of staff at times not recognising emotional and psychological abuse, and the example was given of staff not understanding the impact on residents of witnessing violence between other residents. Zoe discussed the ease with which workers could be drawn into cultures which were disrespectful and abusive, giving an example from her own practice in which she became acclimatised to quite dehumanised conditions in an institution within a short period of visiting there, and relating how difficult she found it to keep normalising her view of what is appropriate behaviour in that context.

Polly, representing the view of her systemic policy and advocacy agency, argued that emotional and psychological abuse and neglect may be perceived as part of a person’s disability by someone who does not know them well, and overlooked.

Lack of recognition by the service system

Heather had worked extensively with service providers in recent times, and found that they were having to focus heavily on viability concerns, leaving few of them ‘comfortable with just basic survival, [so they] can lift their sights a bit and look a bit at the bigger picture’.

Charlie also talked about the frustrations of a system which fails to consider people holistically, instead concentrating on vacancy management and funding imperatives which constrict options. He viewed the increasing corporatisation of disability services as having a significant impact of recognition of emotional and psychological abuse and neglect, and saw the increased focus on managerial approaches, occupational health and safety and workplace standards, and the concomitant drive to
make best financial use of limited resources resulting in a concentration on the physical environment, at the expense of the emotional one.

Polly and her colleagues also discussed their view that neglect is not on the agenda of the disability services system at all, unless it is extreme, almost to the point of death. This was supported by the views of individual advocates, who contended that sexual and physical crimes and abuses, being much more easily identifiable, receive far greater attention, even within their own organisations.

Examples were also provided of policy at a high level which failed to consider the potentially abusive implications on people with intellectual disability. Therese recalled attending a consultation about the development of state-wide policy on abuse, neglect and assault. The draft policy did not include recognition of assault from one resident to another. She also recalled arguing over domestic violence policy with the state Housing Department, who have a policy that no-one should have to tolerate domestic violence. This policy does not extend to resident to resident assault in group homes.

**Complaints**

Complaints agencies discussed their systems for recording complaints about emotional and psychological abuse and neglect. In both cases, they are allocated a particular ‘box’ in a data base, sometimes multiple categories, depending on the particular situation. One agency participating in the research was a referral agency, and stressed that recognition of particular forms of abuse did not change the action they took, which remained the same in all cases. However, the recognition of particular forms of abuse is reflected in their annual reports and other public material, which helps establish prevalence. The other agency was a resolution and prevention body, and matched particular portions of complaints against a matrix of definitions developed from the state government Disability Services Standards. These are fairly general on abuse, using a broad definition, although the operational policy guidelines used by the agency include emotional abuse. This agency raised a
difference in recognition between themselves and the other agency, which centred around systemic and emotional abuse.

The referral complaints agency recognised abuse which had at its root organisationally or policy driven causes as systemic abuse (and as other forms of abuse at the same time too, depending on the circumstance). Examples given were all residents of a group home being put into their pyjamas by seven o’clock, or all residents having to eat the same menu without choice. The prevention and response complaints agency did not include recognition of systemic abuse in its policy, and would instead record these sorts of experiences as examples of emotional abuse, contending that regardless of the intention of the service, the experience for the client is still emotionally abusive. However, some of the examples they provided indicated a preference to address issues as questions of lack of choice or failure to have individual needs addressed, rather than questions of possible abuse. The agency indicated that they would classify the allegation into the category in which they were most likely to get a clear cut recommendation for change at the end of an investigation process.

5.8 Response

Stakeholders provided perspectives on a range of responses which were given to people when they experienced emotional and psychological abuse, which covered a continuum from effective and appropriate concern through to bizarre reactions which amplified the impact of the initial abuse. Complaints agencies detailed their processes for responding to complaints about this form of maltreatment, and the sorts of outcomes which people could commonly expect in these situations.

*The impact of policy on responses to abuse*

Systemic policy and advocacy agencies discussed the response which they sometimes received from services regarding concerns about abuse, that ‘we’re fine, we’ve got a policy to cover that’. They expressed concern that
the link between having the policy and implementing the policy did not appear to be made in some cases, nor did the necessary accompanying actions such as training staff, informing clients and families of the policy, and so on.

When Charlie worked for a large disability service provider, the most frequently reported abuses in that organisation were physical assaults. While it was not identified as such, Charlie saw a strong current of emotional and psychological abuse also running through these reports. When a pattern of incidents was identified, a person would sometimes be moved to another house, using the vacancy management system. Charlie felt that most of these would not have occurred if more appropriate accommodation and an emotional and psychological support framework had been in place.

Fears were expressed by several stakeholders that new restrictive practices legislation would give the ‘green light’ to services to use behaviour management strategies such as restraint, exclusionary time out and sedative medication far more frequently in response to challenging behaviour by residents. Their concern arose from two points – that the restrictive practices may cause emotional harm, and that the challenging behaviour may be in response to emotional or other abuse, and restrictive practices a most inappropriate response to it.

Double standards
The standards of protection which were offered to staff and to residents when faced with violent residents in some cases differed widely. Individual advocates raised examples of instances where when staff had been assaulted by residents, they received counselling, stress leave and double up shifts. When residents were assaulted by the same resident, they did not receive anything. Therese said:

They even employed an extra worker in, I think they’ve got an extra worker in five houses in [government run service], just to support the staff, because the houses were so abusive, and yet the abuse was usually targeted to another person with a disability.
Criminal history checks are conducted on staff, but no similar checks on clients, and very vulnerable people with intellectual disability may have to live in the same house as someone with a strong history of violence. This also cuts the other way, with some people labelled as extremely challenging due to a single incident which occurred years ago, which follows them, out of context, and taints their associations with staff and fellow residents through house after house.

Responses of complaints agencies
The complaints bodies responded to complaints about emotional and psychological abuse and neglect in differing ways. The referral agency took details from individual complaints, and referred the matter to agencies in each state for resolution. The resolution and prevention agency took complaints either verbally or in writing, and then broke them into what they called ‘workable chunks’, allocated a risk level to the allegation, and conducted an investigation into the veracity of the complaint.

From here, the aim of the agency was to resolve the complaint in a collaborative manner, and to ultimately reconcile the client and service. It should be noted that complaints about criminal matters are referred on to another agency. Three reports are generated from complaints, at the client, operational and strategic levels. The first contains recommendations aimed at resolving the specific complaint, the second contains issues pertinent to the local support system, such as training or regional support, and the strategic report relates to whole of program concerns for the state.

In response to questions about how the agency responds to the subtlety of emotional and psychological abuse, and the lack ‘hard evidence’ of this abuse, Andrea and Dagmar pointed to the perceived benefit for the complainant of having the worker realise that their actions were seen to be abusive, even though it cannot be proven that they were so. They also said they often recommended staff training, and also for letters of
acknowledgement and apology for the distress caused to be sent to the
person on occasion. Dagmar said:

So sometimes, the best that we can achieve is to give the person
that lodged the complaint a full and thorough explanation of what
really did happen. Maybe because information hadn’t been kept, or
hadn’t been provided back, and where you don’t have information,
you tend to fill in the gaps for yourself, and then you’re going off
on assumptions. So, most of the complaints are really about a
breakdown in communication.

5.9 Risk factors

Systemic policy and advocacy bodies saw the risk of emotional and
psychological abuse and neglect being increased by a number of factors,
including the history of violence in some services, the impact of the
environment of under resourcing, the staffing arrangements, lack of
knowledge and understanding of people, and abuse between residents.
Leanne’s view was that the combination of factors was ‘just like a
flourishing little hot bed for it to happen’.

The place of services in people’s lives was seen to be important in terms
of risk. The lack of relationships external to services – informal
relationships, friendships and family connections – was viewed as a
significant risk factor for emotional and psychological abuse and neglect
by most key stakeholders. Complaints agencies reported receiving few
complaints from people with intellectual disability, saying they received
most of their complaints from family members, advocates or other
representatives of people with intellectual disability.

Intentionality of abuse
The majority of key stakeholder participants were at pains to point out
their view that the bulk of emotionally and psychologically abusive and
neglectful acts were not carried out with malicious intent. Rather, they
were seen to more often be the result of unthinking application of rules
and policies, or making choices in the heat of a stressful moment which, on reflection, were not good choices. However, systemic responses to these instances at times promulgate disrespectful values and set up frameworks which fail to respect the rights of residents. Charlie gave a cogent example of this, in relating the experience of support worker who was untrained and unsupported in a group home. Her support of a man was handled poorly, and he became loud and aggressive. The worker was hit, and in the heat of the moment, she hit him back. While Charlie did not condone this action, he understood it, and placed it in a context of her lack of training, support and guidance. However, she was not disciplined, but moved to another house, and provided with self protective behaviours training. No action was taken on behalf of the resident.

Polly talked about the dysfunctionality she had witnessed in professional teams during her work history, and how this creates a situation of risk for people with intellectual disability. The power conflicts which she saw arise on a number of occasions played out in a range of ways, including resistance to involving families in the lives of the person with intellectual disability. She recalled support teams trying to limit the involvement of families to birthday and Christmas parties and other token occasions, rather than inviting them to be involved in individual planning meetings, weekend activities, or routinely seeking their engagement.

*Risk increased by broad disability policy*

The funding imperative which forces the shared housing of people with intellectual disability was seen by some stakeholders to be a risk factor for emotional and psychological abuse and neglect. In this state, there has long been a practice of capping funding at sixty five hours per week per person. If a person requires more support than this, they need to pool their funds with another person, and share support by living together. In practice, this frequently results in three or four people sharing a group home, with little recourse for movement in or out, as each resident is dependent on the funds of the others. Vacancies in group homes are managed on a data base by the state disability department, and individual advocates noted that people with significant intellectual disability are in
their experience the most likely to be co-housed with people with severe challenging behaviour, as they have someone else making their decisions. They don’t have the problem solving skills to keep themselves safe, to navigate relationships, or to move to another living situation if unhappy.

The introduction of new legislation on the use of restrictive behaviour management practices such as restraint and seclusion had recently occurred at the time of interview, and was fresh in people’s minds. Both individual advocates and systemic policy and advocacy bodies expressed concerns about the link between restrictive practices and emotional and psychological abuse, particularly the fact that legislation providing clarity around the use of these techniques may also condone and legitimise their use. This is even more strongly the case in this state, where safeguards are seen to be weak. In a climate of under-resourcing and under-skilling of workers, it was viewed as likely that restrictive practices will be used more often than ideal, and they will no doubt have a strong emotional and psychological impact.

Charlie saw the failure of the service system to link people with intellectual disability to workers who knew them well and who could support them emotionally as neglectful and abusive. The high rates of casual staffing used in the field mean that people are frequently supported by strangers in their daily lives, including for their intimate personal care and emotional needs. Charlie said:

> And that’s such the vulnerability of people with disabilities, is that they are ultimately vulnerable to the person who walks through the door for the next eight hours. And it shouldn’t be, they should be able to expect a standard of, quality of, reflective practice, and that just doesn’t happen.

The increasing compliance culture of the service system was seen by some stakeholders to be a risk factor for abuse. Rachael expressed it well, in saying:
I think we’ve created an environment where individuals working in the system, whether they be paid or unpaid, are less inclined to trust their own judgement than they are to check what rule applies here. I think that’s a dangerous thing for people.

One representative of a systemic policy and advocacy body argued that the government funding agency responsible for the accommodation and support of people with intellectual disability in this state needed to face some hard truths. With hundreds, if not thousands of people waiting for services, and budgets which are significantly short of where they need to be in order to support existing clientele, the department is forced into a harm minimisation approach in the way they manage clients. Brian asserted that:

what we need is some recognition that this forces some deliberate risks, let’s work on identifying those, let’s put in place some strategies to minimize the harm. In saying that I’m not advocating that people should be lumped together in bad situations with tenants they’re not compatible with, but the reality is that, in the current context, they will be. So, being pragmatic and realizing well, that’s the world we live in at this point in time, what can we do to minimize the harm that comes to people?

5.10 Protection and Safeguards

A number of stakeholders raised the fact that before it can be addressed, there is a need for acknowledgement of the fact that emotional and psychological abuse and neglect is happening to people with intellectual disability in disability services. This needs to happen at the broadest social level, as well as within disability services. There was seen to be little public demand for emotional and psychological abuse and neglect to be addressed. Although there is a certain level of abhorrence around sexual assault of people with disability, as Carol put it:

as for the rest, it’s so far under the radar that there’s no leverage externally to say, you know, hang on a minute.
Adam linked safeguards with the need for clear and unambiguous definitions of emotional and psychological abuse and neglect, which leave people in no doubt about what constitutes such maltreatment – saying that the need for protection from this form of abuse would reduce with an increased knowledge about what constitutes it, given that it is perpetrated out of ignorance rather than malice in many instances.

International human rights instruments were viewed by some stakeholders as a useful framework within which to gauge the degree to which the lives of people with intellectual disability living in disability accommodation services met basic human rights standards.

Protection from retaliation and retribution for making a complaint about abuse was raised as an area which is currently not well addressed. Within current quality assurance systems, service providers are required to ensure that residents are protected from retribution if they make a complaint, but according to systemic policy and advocacy bodies, those mechanisms are flimsy. Brian expressed his lack of confidence that these mechanisms would protect people against emotional and psychological abuse and neglect, saying ‘There’s a thousand ways to emotionally abuse someone, and most of them quite subtle’.

Relationships external to services
Stakeholders consistently put forward the view that one of the strongest safeguards for people with intellectual disability lay in keeping them connected in their relationships, and that relationships with people who know you well and value you as an individual have a powerful protective function. A key role for service providers was seen as supporting and developing these relationships, in this context as a safeguarding measure against abuse.

Several stakeholders identified the need for substantially more independent advocacy support for people with intellectual disability in order to address emotional and psychological abuse and neglect in their
lives. In addition to ongoing advocacy, they saw a need for independent support for people to make complaints, and to walk alongside them throughout the complaints process. The current systems offer little ongoing support – one purely by phone, and the other with limited contact. The barriers for people with intellectual disability to make complaints themselves are high, and complaints agencies reported receiving few complaints directly from them. Rachael pointed out that in order for advocacy support to be effective, resources need to be in place to allow for quick resolution of problems, in a non adversarial way, to best meet the needs of all parties. Heather’s belief was that ‘the prevalence is such that we should feel very embarrassed about the level of support we offer’.

Community based and individualised environments
Key stakeholders were consistent in their responses that individually oriented, community based living arrangements were protective for people with intellectual disability. Their increased presence in their community, and the larger number of incidental relationships they formed while going about their daily lives, form natural safeguards against abuse. Some individual advocates also saw small, family driven, holistic services which viewed the person as a more than a client were a strong protective agent.

Scrutiny of services
Several stakeholders identified a need for better valuing of external scrutiny, and for checks and balances which address this culture, and draw the attention of workers and managers to the effects of cultural influences which subtly degrade and disrespect the rights of residents. In order for this to be effective, a shift needs to occur to allow for reflective learning and understanding of relationships, interactions and values – and a focus predominantly on residents, rather than service management.

The resolution and prevention complaints body representative, Andrea, talked about the role their agency played in leveraging change in services through recommending changes as a result of involvement in compliance auditing processes. Some of these recommendations were around training
for staff, ensuring that staff were aware of particular policies and procedures, and so on. There is also some capacity for the agency to recommend increased resources, where systemic practices are the root cause of people’s abuse.

In answer to questions about how they reach the parts of the service system that perform the worst, Andrea said they relied on the accumulation of complaints and reports from multiple sources to identify problem areas, including complaints from neighbours and members of the public, the outcomes of quality assurance compliance audits, and Community Visitor monitoring visits. They are working to improve their information sharing practices to increase the chances of finding out about poor practice which may be hiding abuse.

Disability Services Queensland (DSQ) is both a funder and a provider of services, and also has a formal role in scrutinising both DSQ and non-government DSQ funded services. The complaints and monitoring function is administratively separated from service provision, but reports to senior management who maintain overall responsibility for the operation of the Department. These multiple roles were raised by stakeholders as complex and at times contradictory.

*Training, education and support for workers*
Training and education was raised by stakeholders as an important tool in protecting people from abuse and neglect. Training and education was discussed on several levels, including attitudes and values based education, rights based training, and practice based training. Complaints bodies conduct training, and also recommend training and education as primary outcomes of complaints resolution processes. This training is geared to particular issues, such as how to make a complaint, behaviour management or individual planning. They viewed this training as important for both complaint response and also as a tool in their prevention role. One of the systemic policy and advocacy bodies identified the need for training and support for families to identify emotional and psychological abuse, or perhaps more supportively, to identify the signs
that their family member is satisfied, and what action to take if they don’t believe their family member is happy in their home.

The need for better support and supervision of direct support workers was raised by a systemic policy and advocacy body. This was couched not in terms of monitoring and checking of performance, but rather encouragement, mentoring and facilitating their performance. This builds on the view of several stakeholders that much of the abuse which occurs in disability services happens out of ignorance or blind following of rules, rather than malicious intent. Heather said:

*If it’s something that you, if you come into a workplace and you see it as accepted practice, and you’re not as discerning as you would be in other circumstances, and you just don’t see it. And if somebody is able to work with you in a way that is non-judgemental, and that they can support you to see that, and that’s a process of growth and people need support to do that.*

_Protective qualities of workers_

Rachael saw the focus of service provision as being predominantly on physical care and recreation. She identified a need for emotionally mature workers who focus on working with people to develop and support their emotional capacity, and suggested that this was an area where workers needed to be better recognised and paid. While training is vital, it can only go so far in teaching emotional maturity, and workers need to come to a job with a certain amount of maturity in order to be able to adequately support people without resorting to power plays and games of ownership and ‘who knows you best’ which lead to emotional and psychological abuse and neglect. This was supported by comments by workers in a systemic policy and advocacy agency, who noted that some of the comments made by staff about residents that they had viewed in progress notes over time were reflective of very poor attitudes and a fundamental lack of respect which opened the door to emotional abuse.

Individual advocates expressed the view that it was essential for individual workers to take responsibility for their own behaviour in order for real
safeguarding to occur. Heather expressed the view that a legislative framework needs to be in place, and clarity of expectations around standards, but:

that real safeguarding comes from individuals being, taking responsibility for their own behaviour, and the heavier, the bigger the stick that’s held up to people, the less they take control and responsibility for their own behaviour, because you’ve shifted the control and the responsibility externally.

5.11 Prevention

The development and maintenance of relationships which were not reliant on the service system was raised by most stakeholders as an important factor in preventing abuse from occurring. Such relationships included friendships, family relationships and ongoing, personal advocacy relationships, such as citizen advocacy style programs.

The need for education and training for workers was also raised as an important prevention strategy. Rachael pinpointed the limitations of the competency based training in this area, arguing that it does not teach workers the process work about how you get people to talk about emotions, or how a worker might adapt their technique to work with people with particular emotional needs, such as people with autism or acquired brain injury. Charlie identified values based education for direct support workers as critical, so that they can make decisions which are grounded in a framework which is based around the rights and needs of people with disability. He said:

And if you can enculturate that into people who at the coal face delivering support, because that’s where the rubber hits the road, then that would be the most significant, broad impact you could have. So long as those values work with the relative structures they’re getting from the service.
Some of the physical structures of services in this state remain anchored in the past. While large groups of people are housed together, it is very difficult to make changes that will dramatically improve people’s quality of life. Kate, when asked how abuse could be prevented at the institution where she works, said ‘Nothing could make [institution] better. Not while you have seventy people living together’.

### 5.12 Influencing change

Key stakeholders were in a position to influence change, and one of the questions they were asked concerned this role, and how they could act to influence the rates at which people experienced emotional and psychological abuse.

Individual advocates felt that there was a need to acknowledge, on the broadest level, that the lives of people with intellectual disability who live in disability services were lived in such a way that they were ripe for abuses. As Zoe phrased it:

*nowhere else do people who are unrelated live in a group home, where their tenancy is decided by the government, in a lot of cases, or the service deliverer. And they live there for their life. And until that is adequately acknowledged, and what that does to people, it’s…*

One systemic policy and advocacy body related a success story which they felt demonstrated the benefit of developing relationships over time, and the power of incremental change. In this instance, a relationship was established with a resistant service in which many allegations of abuse had been over a long time. Instead of a confrontational approach, the agency took an approach of working alongside support workers for an extended period, using a process of facilitating, supporting and advising them on several issues such as re-engaging people with their families. Brian commented that this worked quite positively, and proved that ‘there
are times for coming in with the big stick, and there are times for coming in with a different approach’.

Changing the dominant culture of the disability services system was recognised as being a highly challenging, complex and difficult undertaking. It was seen to necessitate tackling industrial issues, HR issues, occupational health and safety, and a myriad of other concerns relating to the working environment. There were seen to be roles for external people to facilitate and encourage culture shift, but stakeholders were also of the view that:

If you’re doing all that externally, you still need people on the inside, and that’s the hard job. You get leaders in pockets actually doing the hard work of confronting the culture. Because you can do it all from out here, you can plan it and have that strategy, but it has to happen from the inside.

The importance of having multiple points of intervention to make change to people’s experience of emotional and psychological abuse and neglect was raised by a systemic policy and advocacy body. While much of this abuse has systemic roots, this group cautioned that individual people should not be forgotten, and assumed to be passive victims of a systemic problem. It must also be acknowledged that a risk exists that people who are already entrenched in a systemically abusive system will be further abused if they try to challenge that abuse. With care, however, it was felt that people with intellectual disability should undoubtedly be provided with skill development opportunities to learn protective skills and strategies. There was also a need identified for different education strategies for people who have experienced abuse, people who have not, and people who have not yet entered the disability services system.

The complaints bodies were of the view that they worked to influence change on both a case by case basis and at a strategic level. The referral body had limited capacity to influence change, apart from ensuring referrals were taken up by referral agencies. It presented regular summaries of data to its funding body, but was precluded in its funding
agreement from using data derived from its operations for analytic purposes, so did not publicly present or promote findings about prevalence or trends. The resolution and prevention agency argued that their conciliation approach enabled them to resolve a high proportion of complaints, as they required a low standard of proof, and could recommend any course of action that they felt would be helpful or useful to the person, the organisation or the system. In addition, they had a systemic role of preventing abuse and neglect, which they addressed through identifying trends in reporting, initiating training and education, and communicating issues of concern at a senior management regional and state management level to leverage change on abuse issues.

The contributions of key stakeholders provide a different perspective of emotional and psychological abuse and neglect. Their systemic viewpoint opens for consideration broader issues of understanding, impact, recognition and response, risk factors, safeguarding, and prevention.

5.13 Summary

This chapter presented the responses of participants to the abuse and neglect in their lives, and the responses of key stakeholders to systemic issues around this form of maltreatment.

Part one of the chapter related how people described the long term impact, the experience of attempting to make and resolve complaints, and their strategies of resilience in dealing with maltreatment.

Part two of the chapter presented the responses of key stakeholders, who gave a systemic perspective on emotional and psychological abuse and neglect, including their thoughts on how they understand it, its prevalence, how well services recognise and respond, how people can be protected, and strategies for prevention and influencing change.

The following chapter discusses the implications of these results.
SECTION THREE: DISCUSSION AND IMPLICATIONS OF THE RESEARCH
Chapter six: Discussion

*Sally*  And so, while that was going on, were you
telling people the things that were happening,
when he [another resident] grabbed you?

*Jim*  Yes! They didn’t want to know.

*Sally*  They didn’t want to know.

*Jim*  Cause they all go to one side.

*Sally*  Beg your pardon?

*Jim*  On one side.

*Sally*  They all went on one side? On the other fellow’s
side?

*Jim*  No, the service.

*Sally*  The service’s side? Oh.

This chapter discusses the results of the study, and analyses the results against existing research and literature in the field. The discussion is organised around the abuse experiences of participants, moving through issues of recognising and identifying emotional and psychological abuse and neglect, and some of the factors influencing the experience of it, to the responses by the disability services system. Several elements converge in the discussion, from which some key findings emerge. These themes emerged from a deeper analysis of the results against other research.

Four new insights emerged from the analysis, and are presented after this systemic discussion. These concern the central place of systems; the recognition of emotional and psychological abuse and neglect by people with intellectual disability; the cumulative impact of the abuse; and the lack of moral authority accorded to people with intellectual disability in recognising, acknowledging and reporting the abuse.
The chapter must, however, be prefaced by the recognition of a centrally important feature which emerges from the results and the literature, and which underpins the discussion. The use and misuse of power and control is ubiquitous in this experience. It provides the context within which individual experiences occur, the preconditions for interpersonal interactions, and the framework for both systemic and structural injustices (Marsland et al., 2007; Wardhaugh & Wilding, 1993; Mandeville & Hanson, 2000). The results of the research, as they have unfolded in the last two chapters, progressively reveal the centrality of power relations in this form of abuse and neglect. The critical role of power and control in understanding emotional and psychological abuse and neglect forms a foundational building block for the forthcoming discussion and implications chapters of the research.

6.1 The experience of emotional and psychological abuse and neglect

The experiences of emotional and psychological abuse and neglect shared by individuals, families and supporters both confirm and significantly extend the understanding of this form of abuse in the literature. Participants’ experiences were themed against the abuse wheel framework developed in the literature review (Kovener, 2000). They were also categorised according to the origin of the abuse in the individual, systemic or structural domain (Penhale, 1999). The use of the two frameworks together enables the development of an analysis which provides both a detailed picture of the individual lived experience of the abuse, and also allows consideration of the individual, systemic or structural domain in which the abuse is rooted. Conclusions can be drawn from this dual framework for strategies for change to prevent and better respond to this form of abuse and neglect which are at the same time grounded in the lived experience of people with intellectual disability and have utility in the policy context.
The experiences of abuse and neglect of participants in this study confirm and extend the abuse wheel framework. As outlined in the previous chapter, each of the categories of abuse and neglect were experienced by a number of people with intellectual disability, and in all categories but one, they had experienced multiple occasions of abuse and neglect. The categories had resonance with the lived experience of people with intellectual disability and with family members – they understood the behaviours contained within the definitions and related them to their own experiences. Key stakeholders critiqued the framework, and added some sub-themes, which fit within the existing categories of emotional and psychological abuse and neglect contained in the framework.

Some new behaviours and actions emerged through this combination of lived experience and critique which had not, to date, featured in the literature on emotional and psychological abuse and neglect. These included:

- taking away treasured possessions or activities without reason
- denying people opportunities to develop self-esteem and the experience of achievement because the worker wants to get things done
- failing to support people through grief and loss
- maintaining differential relationships (eg having no easy ‘banter’ with residents, as with co-workers), and
- responding to a person’s frustration and anger without respecting the cause of it, so that the person’s frustration increases.

### 6.1.1 Experience of abuse and neglect

The level of emotional and psychological abuse and neglect in the lives of participants in the study was expected to be high (McFarlane, 1994; Sobsey, 1994; Conway et al., 1996). However, the volume, range and frequency of abuses and neglect that people with intellectual disability, families and supporters described was significantly greater than anticipated. A total of 228 incidents of emotional and psychological abuse and neglect in the ‘service lives’ of nine people with intellectual disability
were related by participants during the research. There are no statistics with which to compare these figures, abuse research being well known for unreliability with regard to prevalence figures (Brown, 2004; Ticoll, 1995; WWDA 2007).

Many of these were stand alone experiences, where emotional or psychological maltreatment was the sole abuse or neglect. A significant number of the abuses were, however, either part of, or associated with other types of abuse, such as sexual and physical assault, theft and false imprisonment. This accords with the dominant position of the disability abuse literature, which holds that emotional abuse, as well as being experienced alone, underpins the experience of other forms of abuse (Sobsey, 2000; Brown, 1999; Ticoll, 1994).

All nine participants with intellectual disability experienced multiple forms of emotional and psychological abuse and neglect on multiple occasions. As detailed in the previous chapter, they were all subjected to abuse of caregiver privilege, degrading, isolating, and minimising, justifying and blaming. Eight of the nine had experience of emotional neglect, and seven had been terrorised. Five people had experience of having needed disability related supports withheld, misused or delayed, and three people were emotionally corrupted or exploited.

Across this range of abuse and neglect, a number of themes emerge which apply to all or most of the categories of emotional and psychological abuse and neglect. These themes emerged through meta analysis of the themes presented in the results in the previous two chapters and the existing research and literature. They are discussed in the following section of the chapter.

The diffuse and pervasive nature of the abuse
The climate which was created by the multiple abuse experiences coloured the world of the nine participants, and is central to understanding their experiences of emotional and psychological abuse and neglect. The abuse they experienced was in many cases diffuse and pervasive, and spread
into all areas of their lives. This can be seen particularly clearly in the neglect of the emotional and psychological wellbeing of participants and the failure of services to provide emotional support, nurturance and stimulation to them. It also featured strongly in the experiences of degrading that participants related, where their personal preferences, family structures, and cultural connections were ridiculed, belittled and disrespected.

This theme adds to a small existing literature which recognises the creation of a climate of insult and the significant impact of ongoing, routine abuse in the lives of people with disability (Brown, 2004; Horne et al., 2001; Macfarlane, 1994; Roeher Institute, 1995; Sobsey, 1994). Much of the existing literature contains a focus on abuse incidents, and a primary focus on sexual and physical abuse and neglect of people with disability (Conway et al., 1996; Collier et al., 2006; Sequiera & Halstead, 2002). Emotional and psychological abuse and neglect is almost a ‘second tier’ abuse in these studies, which do not recognise its pervasive and cumulative effects.

Damage done by thoughtless following of policy and practice by staff
A considerable amount of the abuse people experienced was due to staff ‘following the rules’, when the rules impacted on the dignity, autonomy and relationships of people living in the services. Fundamentally, this related to staff prioritising the benefit of the service system over the benefit of the individuals within it. This abuse included actions by staff which damaged relationships between people with intellectual disability and families, by making families feel unwelcome in services; and thoughtless humiliating practices, such as Tom’s living with such poor physical access that he had to rely on other residents to carry them in or out of the building. Policies were also enforced in such a way that their intent was skewed. Jim’s belief, for example, that he is not allowed to have a cordial relationship with any support worker who comes to his house, after being chastised by the service management for becoming friendly with a worker, has resulted in ongoing uncomfortableness,
degradation and isolation in his interactions with support staff, sometimes the only people he sees in a week.

Consideration of some of the reasons staff may ‘follow the rules’ to the detriment of people living in services is given later in the chapter. However, reasons for the unthinking following of policy and established practice include the dominant bio-medical conceptions of disability which frame service provision (Clapton & Fitzgerald, 1997); managerial systems of care (Di Rita et al., 2008); low resourcing; and technically oriented and procedurally driven staff training which fails to adequately humanise people with intellectual disability (White et al., 2003). All of these combine to create a culture in which the following of procedural process is accorded higher priority than responding to individual harms.

The abusive impact of poor quality care
The quality of care provided to people with intellectual disability had clear ramifications for their emotional and psychological wellbeing. Ann’s recollection of the humiliation of being dragged down the corridor to her room by other residents and left on the floor overnight when she couldn’t get herself into bed unassisted is a clear example of these practices. The experiences of being degraded, humiliated and shamed, and blaming the person’s disability for the abuse were particularly strongly related to institutional approaches to care. These approaches centred on practices of workers and managers, rather than facilities, and although many of the practices did occur within large residential facilities they were also experienced in group homes and small shared and individual settings.

There is a clear link here to the literature on institutional abuse, particularly the work of Brown (2007) and Sobsey (1994) in recognising the inequities of power between staff and residents, the collective nature of some of the abuse, the denial or covering up of the abuse, and the tacit or explicit condoning of poor practice which allows abusive and neglectful acts to continue.
Fighting for control

Having control over decisions, small and large, was a recurring problem for participants. People with intellectual disability frequently described having their decision making control taken away by support workers. Families had serious problems getting access to information or having input into decisions about their family members health, wellbeing and in several cases, harms done to them. Family members also described active processes of discrediting and delegitimising of their role and relationships by services and staff. The lack of control over both small and large scale issues connected directly to emotional abuses of caregiver privilege, withholding of needed supports and corrupting.

This theme connects directly to the literature on power relations, which holds that there is a serious imbalance of power structured into traditional disability services which perpetuates a climate which is ripe for abuse (Mandeville & Hanson, 2000; Wardhaugh & Wilding, 1993; Marsland et al., 2007).

Punishment

Punishment was a major theme in the research. People with intellectual disability were punished for their behaviour, both to encourage future compliance to rules, and for complaining about the quality of their care. Punishment was a standard practice of a number of services, and three participants with intellectual disability recalled with fear their experiences in time out rooms. A number of family members were very aware of the subtle punishment that was meted out to their family members if they complained too vigorously about their treatment, and felt they had to tread a careful line. This is also connected to the literature on power relations, detailed above.

Damage to relationships

Service policies and practices damaged the relationships between people with intellectual disability and those who were important in their lives. Less commonly, relationships were deliberately damaged by the actions of individual support workers. This happened in several ways. People were
isolated from their families by policies and procedures which served to make families feel unwelcome in services. Service managers failed to report harms which occurred to people, resulting in them not receiving emotional support from family or other supporters when they were in pain or trauma. Families and people with intellectual disability were not consulted about major changes in services, resulting in conflict.

These actions occurred within a broader cultural context, where social policy of the past had encouraged the dislocation of people with intellectual disability from their families and communities, promoting a model where services took sole responsibility for people’s care (Johnson & Traustadottir, 2005). Despite the more recent policy and rhetoric around consumer engagement, individual planning, and the importance of family relationships (DSQ, 2008), the results of this study show that in practice there has been an inadequate shift between the two paradigms.

*Lack of adequate concern*

A lack of appropriate concern for the harm experienced by people with intellectual disability was frequently expressed. With the exception of key caring individual staff members, participants universally recalled that responses of support workers and managers in services to the harm they experienced were less than vigorous. All family participants related instances of injuries or harms which were not reported to them by services – in some cases these were of a very serious nature. People with intellectual disability felt that support workers and managers, in the main, were not interested in hearing about the abuses they had experienced, and took little action to address it. Participants made comments like ‘they ignore me’, ‘they don’t want to listen to me’, and one person was called ‘manipulative’ for reporting the abuse she experienced. These responses compounded the initial abuse experienced by people with intellectual disability, and had a substantial impact on their emotional and psychological wellbeing, both in the short and long term.
Living in a state of fear

Living with the threat of violence from co-residents, and not feeling vigorously protected by staff was a way of life for all but one participant who had shared accommodation with groups of people with intellectual disability. Being intimidated, threatened and terrorised by staff and managers was also a lived reality for seven of the nine participants. At times these threats of violence from both other residents and from workers and managers escalated to physical assault. For several participants, these experiences were so constant that they amounted to a continual state of fear at some points in their lives.

The level of fear and intimidation felt by people who have been through these experiences does not carry through into the academic literature. The impact of the experience on the lives of people with intellectual disability is diluted when their words are not heard on the page. Those studies which include the voice of people who have been restrained, secluded or otherwise experienced abuse, neglect, or trauma have great power due to their immediacy and the authority of the voice of participants (Malacrida, 2005; Saxton et al., 2001; Collier et al., 2006; Mitchell et al., 2006).

Withholding basic support and rights

Basic support and rights were withheld from people in a number of different ways, resulting in them going without fundamental requirements for periods of time, and going through a great deal of stress and trauma. This included appropriate foods, emergency medical care, therapies and funding for adequate levels of accommodation and support. People with high support needs particularly suffered for the lack of basic supports, and their family members were frustrated and distraught by the long processes of lobbying and fighting for funding with bureaucratic and obstructive government agencies.
The individual nature of protection / the failure of systemic abuse response mechanisms

Several participants talked about key individual staff who had worked with them at points in their lives, and who had played a protective role. These people had all taken a personal interest and built a relationship over time. In the institutional environment, these staff played protective roles for both Jill and Fran, preventing Fran from moving to an inappropriate ward, and taking action to address Jill’s serious health problems. In the private accommodation arena, Ann recalled the protective role played by a staff member who was instrumental in having another worker sacked who had pushed Ann down the stairs. Only one participant with intellectual disability, and no family members, talked about any protective function in services or systems acting to protect them or to respond effectively to their abuse. On the contrary, their experience of complaint mechanisms and policies around abuse was largely negative. This is discussed in more detail below.

All participants in this study had support from an advocate in addressing the consequences of their abuse on their lives. This advocacy support was very important for all of them in addressing the situations in which the abuse was occurring. Without independent, skilled support, people may not have left the situations in which they were living, and may have continued to be abused – in fact, Jim, Tom and Jenny, who continue to live in more ‘traditional’ service models, still have ongoing problems in dealing with workers, choice and control over life issues.

The academic disability abuse literature appears silent on the subject of ‘champions’ within institutional cultures which are unsupportive in addressing abuse. Several autobiographies by people with disability raise the importance of allies in addressing abuse (Pentland & Cincotta, 1995; Martin, 2006; Daisley, 2005; 2007). This may be a fruitful area for further investigation.

The volume, range and frequency of emotional and psychological abuse and neglect experienced by participants in this study was such that it has
been an unavoidable and inevitable part of their service lives. Eight of the
nine people with intellectual disability have experienced it across a range
of services, different service types, and over many years. It has continued
across different policy regimes and institutional or organisational
structures, and continued despite the presence of safeguards such as
Community Visitor schemes. Discussing the experience of abuse and
neglect also raises questions about why this abuse is so endemic, and the
impact of it on people with intellectual disability. These are addressed in
the following sections of the chapter.

6.1.2 Impact of the abuse and neglect

Participants in the study felt the abuse experiences have had a significant
and lasting impact on their lives. This manifested in many ways – through
people’s emotions, their mental health, their capacity to develop and
maintain healthy relationships and their cultural connections. It is not
possible in this study to distinguish whether or not abuse was the cause
of, or consequence of, negative outcomes in the lives of participants. As
their narratives show, participants were complex people, with complex
histories, relationships and needs. Some of these characteristics may have
had the effect of making people more vulnerable to abuse, or
exacerbating the effects of abuse or neglect. Nonetheless, the perceived
impact of abuse and neglect related by participants is of critical
importance – it is their lived reality.

The abuse and neglect that is described occurs across a continuum,
ranging from subtle to extreme actions. The most ‘extreme’ abuses,
however, may not be the ones which have had the most impact on the
person - it may be one particular instance, a chain of behaviour from a
particular abuser, or the collage of small insults and hurts over time
coming from a range of people which all participants experienced.

Participants in the study showed a considerable range of emotions in
discussing the impact of the abuse on their lives. Some of the abuses
which left lasting pain might be not be considered critical incidents by services, but certainly seemed to have had an enduring and significant impact on the person. Other abuses which were at a level which should trigger investigations in services, or criminal charges, did not seem to cause as much distress to participants – perhaps because they were better acknowledged and addressed at the time. For some people, it was the fact that their concerns were repeatedly degraded and ignored by managers which caused their distress and which they said was as or more abusive to them than the original incident about which they were complaining.

Key stakeholders identified some impacts of emotional and psychological abuse which may not be visible to casual visitors, investigators or auditors. They expressed concern that this abuse, and its considerable impact, would continue unrecognised by outsiders due to the subtle signs of the impact on people with intellectual disability. These included people isolating themselves or removing themselves from painful situations; the ‘wearing effect’ of continual small abuses that people can’t express to other outsiders; increasing anxiety; abrading and degrading of psyche and confidence; damaging of burgeoning relationships (moving staff if residents start to develop a relationship of trust or reliance with them); and trading off dignity for security of service.

There was also a flow-on impact on family members. All family members expressed the view that they were not able to rely on the disability services system to provide care and support for their family member to live free from abuse. They said, in fact, that it proved to them it could not, or would not, provide safe service – evidenced by the number and range of harms which occurred to their family members.

The difficulty for family members lay in the binary position into which they felt forced. In order to remove their family member from a situation which they viewed as inherently unsafe and unsatisfactory, they were required to make some considerable sacrifices to their own quality of life. Ivy, Datu, Patrick and Amanda and her ex-husband all currently spend well
over thirty hours every week (frequently more) directly supporting their family member, to make up for shortfalls in funding in their current supported accommodation arrangements. Rose also spends considerable time, and is working hard to try and find another option for Jenny, where she can be better supported.

Horne, Merz and Merz (2001) contend that the prevalence of emotional and psychological abuse and neglect of people with disability is such that the impact of the trauma experienced by individuals also becomes part of a more widespread embedded social trauma. Families are caught up in this wider social trauma. Segregation, isolation and institutionalisation have been traditional approaches to managing disability within the historically dominant bio-medical, individualistic paradigm of disability. It is consistently held in the literature that the propensity of these practices to cause emotional abuse and neglect has been largely unrecognised (Clapton, 2008b; Brown, 1999; Johnson & Traustadottir, 2005). Where families have rejected these approaches as causing damage and harm to their family member, they are left with few if any alternative approaches within a disability services system which remains dominated by this conceptual approach.

It is argued by Horne, Merz and Merz that responses to abuse which involve social repression and denial allow abusive social and cultural practices to continue. In this study, the central place of systems in the emotional and psychological abuse and neglect of people with intellectual disability, discussed later in the chapter, confirms the multiple layers of traumatic impact caused by this abuse.

The clear and significant negative impact of emotional and psychological abuse related by participants in this study confirms and extends the small literature in the field. Much of the literature focuses on detection, response and prevention, with little focus on impact. The results of this study accord with the few studies which focus on the impact of abuse on people with intellectual disability (O’Callaghan & Murphy, 2003; Mitchell et al., 2006). These studies found the consequences to be profound and long
lasting, and made links to post traumatic stress disorder. The emphasis in the child abuse impact literature on the damage done to the child’s sense of self and their understanding of the ways in which they relate to the people and world around them also has parallels in this study (Glaser, 2002; Kairys et al., 2002; Veith, 2004). However, there are clear differences in the experiences of participants, as adults, and care needs to be taken not to conflate them.

### 6.1.3 Resistance and resilience

Great resilience was demonstrated on the part of both people with intellectual disability and family members. People with intellectual disability showed their resilience in simply living through the range and volume of abuses they described, and continuing to find pleasure in their daily lives. Family participants demonstrated their resilience in their consistent and long fought battles with services and government departments to create a better living environment for their family member. It took several years for Dan, Jill, Amanda, Ann and Jenny to each move into a more responsive, individualised home environment. Amanda’s perspective of Fran is indicative of that of several participants. She said:

> Fran is a leader. She has survived horrific experiences in a horrific institution, and now she’s thriving – because she has a decent life. She might not know she’s a leader, but she is a leader.

A theme of resistance runs through the narratives – people are not passive victims to their experiences of abuse in the disability services system. Participants drew on many different strategies and methods to ‘get through’ the difficult periods in their lives.

People with intellectual disability tried to keep their experiences in some sort of context by focusing on the good times they had over the years, and the positive relationships with some individual staff and co-residents. They also worked to live in the present and look to the future, which was
sometimes hard. For example, Jim felt his experiences had taught him what to expect from services, but had toughened him up a bit, so he felt a little better equipped to deal with potential problems. Craig worked in an area where he could make change to try and make sure other people did not have the same experiences he had. Ann used focused strategies to remind herself that when she had dreams about her past abuse, that it was in the past - she counted what she viewed as her good fortunes one by one to drive the bad memories away.

Family members struggled with guilt and pain over the abuse that their family member had undergone. The lack of hard evidence had often made it hard for them to take action, and they channelled their concern into practical action, fundraising for services, completing informal physical therapy with their family member, or contributing to parent support groups.

The ways in which people have resisted and reconciled the abuse in their lives are important – both to their individual stories, and to the research. Lindemann Nelson (2001) argues that because identities are constructed and damaged narratively, they can be repaired through narrative means. This is done through the counterstory. A counterstory is a narrative which develops group members as fully developed moral agents. The counterstory in this context allows people to present themselves as fully formed, moral agents, who have shown strength and resilience in the face of adversity. They are worthy of moral respect by others, and themselves.

This can seen vividly in Tom’s experience of having his wheelchair damaged by a support worker to prevent him going to the doctor. His no doubt frightening experience of being dominated and controlled was related as an anecdote about how he had complained successfully about poor treatment, finishing with his comment about the skills of the worker, who was training to be a doctor, ‘I told him his bedside manner... Sucked big time!’ For Tom, this was an example about how he stood up for himself and resisted mistreatment. At an epistemological level, the
counterstories of resistance and resilience which appear in the narratives are a key response to the invalidating representations of people's lives.

That people were able to participate in this study may be due in part to the fact that their abuse is in most cases historical. They are living in safer and more individualised situations now, and can talk about their experiences with the filters of time passed and distance. This was also the case in the biographies and autobiographies located in the literature review (see, for example, Pentland & Cincotta, 1995; Martin, 2006; Bradley, 2008). In the case of research on such a potentially disturbing topic, the potential for causing distress may need to be balanced against the methodological difficulties caused by asking people with intellectual disability to recollect past events (Booth & Booth, 1996; Owens, 2007).

It is noteworthy that most disability abuse literature reviewed did not include a significant focus on recovery, focusing more on understanding, defining and responding to abuse (Saxton et al., 2001; Ticoll, 1994; Page et al., 2003; Sobsey, 2000; Conway et al., 1996). In an environment in which so much abuse and assault against people with disability goes unrecognised and unaddressed, this is a priority. However, it may be useful to draw from the women’s and children’s abuse fields in their focus on recovery and resilience, particularly for this abuse and neglect, which is so pervasive and longstanding (Glaser, 2002; Kairys et al., 2002; Packota, 2000; McKinnon, 2008). A need for research which focuses on recovery and resilience of people with intellectual disability who have experienced abuse can be clearly identified.

6.1.4 Understanding why this happens

The constructions of people with intellectual disability as ‘other’, as damaged, as less than human, and as needing to be ‘kept in their place’ are powerful and dominant modes of social and cultural operation (Lanoix, 2005; Chenoweth, 1995; Kitchin, 1998), and they have informed the
development of the structures, including the disability services systems, within which people live.

The theoretical understandings of the social, cultural and structural roles and places of people with intellectual disability reviewed in this study hold that people are oppressed, isolated and dehumanised on fundamental levels (Lindemann Nelson, 2001; Hall, 2004; Clapton, 2008b; Nunkoosing, 2000). The results of the study confirm this clearly. Lindemann Nelson’s concept of damaged identities is very relevant to the experiences of participants in this research. She contends that where an entire group are identified as morally defective or lacking (as in the case of people with intellectual disability), mandatory identities are constructed, where social expectations are set up about how group members are expected to behave, what they can know, what can be demanded of them, and to whom they are answerable. This is what she calls damaged identities. Individual identities are subsumed into a marginalised social group experience.

The long history of emotional and psychological abuse and neglect which each of the participants in the study have experienced is indicative of their conceptual position as what Clapton terms ‘profoundly irrelevant’ (2003, p.541). This is reflected in the study in the focus of the service system on the ‘resident’ or ‘client’ category in which people are placed. Residents are different to citizens, and are treated differently. They are subject to policies and procedures which govern the way in which they live their lives (Lanoix, 2005). They also depend on the vagaries of an under-resourced disability services system to provide staff to support them to live in artificially constructed households.

In the lives of participants in the study, this situation sets up a marginalised social group experience and creates a morally compromised identity. When combined with the failure of policies and practices to recognise, effectively respond to, protect and safeguard against emotional and psychological abuse and neglect in their lives, emotional and psychological abuse and neglect is virtually assured. Further, holding
people in the ‘resident’ frame may also contribute to a climate in which the response to abuse by service workers and managers is less likely to be vigorous and concerned.

The conception of people with intellectual disability as damaged, Needy Others (Clapton, 2003) is pervasive, and influences the way in which policy and practice responds to their experience of abuse and neglect – particularly subtle abuses which have been normalised within service provision. The identities of people with intellectual disability are damaged by the responses of the service system to their shared experience of chronic, pervasive emotional and psychological abuse and neglect (Lindemann Nelson, 2001) – responses which are lacking in adequate concern, overly procedural and system oriented. A mandatory identity is constructed through this dominant response, in which expectations are set up about how residents with intellectual disability in accommodation services are expected to behave, what they can know, what can be demanded of them, and to whom they are answerable. Residents are expected to be compliant; they are expected not to know about their right to complain about emotional and psychological abuse and neglect, or to understand it (some staff may not recognise it themselves); they are expected to endure it as a sometimes routine part of receiving service (in its more subtle forms); and they are answerable to any staff member, permanent or casual, benign or malign.

There is a complex interplay of factors which create a climate in which abuse occurs with such regularity, as will be discussed in the following sections of the chapter.

6.2 Influencing factors

A number of factors influence the experience of emotional and psychological abuse by people with intellectual disability in disability accommodation services. This section of the chapter focuses on discussion
of factors which may predispose, increase risk or protect against the experience of this form of abuse and neglect.

### 6.2.1 Predisposing factors

The way in which legislation, funding and policy for accommodation support for people with intellectual disability is conceptualised, operationalised, and manipulated forms a matrix within which disability services operate. This forms a culture or environment which may predispose people with intellectual disability to experience emotional and psychological abuse and neglect. Several factors are at play here, including the focus of and adherence to legislation; the way in which it is interpreted into policy; policy prioritisation; and resource allocation.

*Failure to adhere to disability services legislation*

The experiences of participants in this study demonstrate a fundamental failure of the disability services sector to adhere to either the spirit or the letter of the Commonwealth or State *Disability Services Acts* (1986; 2002; 2006). The State Act (under which accommodation services are funded) and its accompanying practice standards include explicit statements that people with disability have the same human rights as others, and that people with disability have the right to live lives free from abuse, neglect and exploitation. It also requires that people receive services in a ‘safe, accessible built environment appropriate to their needs’, and can ‘pursue grievances about services without fear of the services being discontinued or recrimination from service providers’ (DSA, 2006). The Standard on ‘protection of legal and human rights and freedom from abuse and neglect’ stipulates that services ‘take a pro-active duty-of-care approach to the prevention of abuse and neglect of service users’ (DSQ, 2008).

For none of the nine participants with intellectual disability were these conditions consistently met. The large degree to which systemic factors played a part in their continued abuse and neglect means that the
government, as funders and managers of the service system, must bear responsibility for this maltreatment.

**Emphasis of legislation**
The tone or primary focus of legislation set up to frame disability services has also changed in Australian states over the past decade. In the state in which the research took place, the Act now focuses far less on statements of rights, and far more strongly on regulation of services. The review and amendment of the State Act in 2006 included a large new section on the monitoring and regulation of services, and a diminution of focus on the rights of all citizens with disability in the state. For example, advocates who participated in the study reported a significant growth in the use of restrictive practices after the introduction of guidelines for the use of such in the 2006 Act. The Act provides little protection for clients, and significant protections against prosecution for staff in the event of adverse outcomes for residents – giving a ‘green light’ for restrictive practices, advocates feared. Legislation on the same issue in other states is framed quite differently, giving greater protection to residents.

**Policy interpretations of legislation which fail to respond adequately to the experience of abuse and neglect**
Little evidence is found in the literature that legislation and policy is focused on changing the environments and interpersonal dynamics in disability services which may allow abusive cultures to develop and be sustained (Marsland et al., 2007; Wardhaugh & Wilding, 1993). This is also reflected in the strong focus on managerial approaches and compliance measures by the disability service system which was found in this study.

In more recent years, adherence to the Act has been assessed through the quality assurance framework, which measures compliance against a set of Disability Services Standards. This is done through audits of policy and procedures, and some interviews with key stakeholders over two days per service. There is a body of literature to show, however, that compliance based audit approaches are unlikely to uncover the more
subtle abuses which feature in the daily lives of people with intellectual
disability, due to their focus on measuring the existence of policy and
procedure, at the expense of individual outcomes and alternative
measures of service quality (Goggin & Newell, 2005; DiRita et al., 2008;
Wills & Chenoweth, 2007).

It seems unlikely that current mechanisms to measure the actions of
services to protect their clients against abuse and neglect will be effective
in strengthening protection or building resilience at either an individual or
service level. The focus is primarily on recognising the existence of policy
and procedure. The heavy reliance on a compliance based quality
assurance regime for measuring quality is also likely to result in
measurement of the way services respond to the occurrence of abuse
which is formulaic and based on individual instances, with no recognition
of trends of abuse.

Funder/provider/scrutiniser role conflicts
The multiple roles of the government department responsible for disability
services are also problematic in terms of managing an appropriate,
effective and consistent response to emotional and psychological abuse
and neglect at a government level. Disability Services Queensland is
dually responsible for funding and providing services to people with
intellectual disability, and also for monitoring and dealing with complaints
against disability services, both their own and those non-government
organisations they fund to provide services. While administratively
separated, senior managers retain responsibility for the operations of the
entire department. It should be acknowledged that criminal allegations
are referred to the Crime and Misconduct Commission, but few allegations
of emotional and psychological abuse and neglect are likely to fall into this
category.

There are fundamental conflicts of role in a government department
scrutinising the actions of its own staff in the case of allegations of abuse
and neglect. There are also difficulties with a funding agency acting as a
scrutiniser of the behaviour of agencies it funds, beyond their compliance to contracts of funding.

Resource allocation
Financial resources have always been a key concern for the disability sector, both historically and currently. The lack of allocation of adequate resources to support the populations of people with intellectual disability in any Australian state (AIHW, 2006) mean that governments have to make difficult decisions about the best use of limited resources. In the process, some important protections for people with intellectual disability are not ‘funded into’ the dominant funding structure for disability services. In fact, there are indications that proposals for some new congregate models of supported accommodation favoured by governments may increase the risk of abuse to people with intellectual disability (Emerson, 2004; Fisher et al., 2007a; MacArthur, 2003). One group of key stakeholders in this study viewed the funding imperatives of government as in many ways a harm minimisation approach.

Policy prioritisation
Similar to the allocation of funds, the comparative importance placed on policy priorities has implications for the experience of emotional and psychological abuse. Policy makers know this form of abuse occurs. However, it is not prioritised against other policy imperatives such as vacancy management, dealing with behavioural issues, early intervention and so on. The choices being made at policy levels about which issues to address have the consequence of neglecting to attend adequately to the emotional and psychological abuse and neglect of people with intellectual disability.

At the level of lived experience, this may result in people with intellectual disability being exposed to risky situations on a daily basis. Sharing tenancies with other people with challenging behaviour, an increasing focus by government on group living, and resource allocation which is insufficient to allow individualised supported accommodation options for people with high support needs are all indicators of policy prioritisation
which provides conditions ripe for emotional and psychological abuse. All participants in this study had experienced abuse and neglect which was caused or exacerbated by these factors.

Underpinning each of these factors is a key ontological assumption about disability which heavily (and to many invisibly) influences the way the service system operates. While the epistemologies of service provision have changed, the fundamental ontological assumptions which underpin it have not been challenged (Clapton, 2008b). This gives rise to a elemental discord between the stated aims and the practices within the service system. There has been a shift in legislative and monitoring frameworks which frame the operation of government and service policy in the disability services sector over time. People with disability, historically viewed as devoid of rights, are now viewed as rights holders (Harrison, 2000). However, because the fundamental negative ontological assumptions about disability, discussed in chapter two, have not been attended to, rights often remain inaccessible to people with intellectual disability living in disability accommodation services (Hughes, 2006; Kumari Campbell, 2005). People can only claim their rights under certain conditions - they need to know they have rights, they may need support to access them, and barriers to accessing rights need to be removed. Clapton writes:

Rights have been commanded by people with disability, and supported by policy makers and social planners, but with little attention to the fragility of their claims and their implied guarantee to affect change. Disability rights are seen as desirable, but their often ineffectiveness ignored. They are seen as a source of power for political change, but their moral value and situatedness receives little attention (2008b, p.122).

6.2.2 Risk factors

In addition to factors which predispose people with intellectual disability to experiencing emotional and psychological abuse and neglect, there are a number of factors which increase the risk of this abuse occurring in their lives. These include enforced co-residency; the lack of change at a high
policy level; the way in which legislation may not always act protectively; and the lack of protection for residents in the private accommodation sector.

*Enforced co-residency*

Several participants in the study had experienced multiple abuses which were due to the enforced sharing of group homes and large residential institutions. In these cases, people had not had the opportunity to meet their co-residents prior to moving in together, had no option to move out, and had few or no protections against the abuse or assaults, even when they complained. Being required to share a home with people with whom you don’t get on sets the stage for negative experiences under any circumstances, and when people had additional intellectual disability and associated impairments (several co-residents that participants talked of also had mental illness), the situation worsened considerably.

There is a high degree of consistency in the literature around the features of effective approaches to accommodation and support for people with intellectual disability. They are fundamentally linked to a focus on the individual, and to supporting and facilitating the connection of the person in a range of relationships and with a range of communities of their choosing (MacArthur, 2003; Fisher et al., 2007a; O’Brien, 1993; Felce, 2000; Mansell et al., 2007). Several authors also identify enforced co-residency (Sobsey, 1994; Chenoweth, 1995) and a ‘vacancy management’ approach to housing of people with intellectual disability (Mansell et al., 2007; Goggin & Newell, 2005) as risk factors for abuse.

In addition to being emotionally and psychologically abused by co-residents, the experience of living in an uncomfortable and sometimes dangerous environment is itself emotionally and psychologically abusive and neglectful. The ongoing tension and interpersonal difficulties, and the failure of the services to address these, created a climate of discontent for some participants and distress for others.

*Understanding not translated into action for change*
A well developed literature exists on systemic risk factors for the abuse and neglect of people with disability. These include the behaviours, actions, attitudes and decisions of managers and staff; the behaviours of people with intellectual disability; the neutralisation of normal moral concerns, and a lack of accountability. Further, a lack of scrutiny of the organisation; isolation; poor service design, placement planning and commissioning and quality of physical care and environment combine to increase risk (Marsland et al., 2007; Wardhaugh & Wilding, 1993).

Key stakeholders who participated in the study amply demonstrated that there is a sound understanding of this form of abuse and neglect among a selection of senior policy analysts, lobbyists and advocates, both within and outside government. While none of the participants in the study were directly engaged in making government policy, they were in a position to influence it. However, there is little evidence of this knowledge being translated into practice or policy. This raises critical questions about why these well placed stakeholders are not having impact in this area, and the barriers in translating knowledge into change.

At a government level, ministers and senior bureaucrats were made aware of the abuse that several participants were experiencing, by the lobbying actions of family members. Yet responses from government to families to resolve the abusive situations were glacially slow, and not responsive to the urgency of the need of people to be safe. While the families of Jill, Fran, Jenny and Dan eventually received funding to support their family member in a more individualised way, the path to receiving the funding was rocky and littered with obstacles. Three of the four still do not have sufficient funding to cover the week’s support, and rely on family support or enforced co-residency to stretch the funding – which none of them find a satisfactory or sustainable outcome.

*Legislation may not always be protective*

The restrictive practices guidelines mentioned above are an example of legislation which may not act to protect people with intellectual disability from emotional and psychological abuse and neglect. While the intent of
the legislation is to set guidelines for the use of restrictive practices, the weakness of the legislation and its focus on the protection of staff from prosecution in the event of negative outcomes for people being restrained result in legislation which is viewed by many advocates as endorsing the use of restrictive practices such as restraint and seclusion. Key stakeholders expressed concern that restrictive practices may exacerbate abuse, if the origin of the person’s challenging behaviour is caused by abuse and this is not understood by workers at the outset.

**Lack of protections for people living in boarding houses and hostels**

People with intellectual disability living in the private residential sector - in boarding houses and hostels run for profit - do not have the same level of protection as do people living in funded services. They have no entitlement to services, few tenancy rights, and pay a high percentage of their pension to the owner in rent and board. They frequently live in a marginal environment with a mobile population which includes a high proportion of newly released prisoners and people with mental illness – a sometimes volatile and frequently risky mix of residents. When mistreated, there are few avenues for people with intellectual disability to turn to – there are small number of tenancy advisory services, and some access to disability advocacy services in Queensland. During legislative and policy reform of the sector, advocates lobbied for the exclusion of people with intellectual disability from boarding houses and hostels, due to the risks posed to them by the environment (QAI, 2003).

### 6.2.3 Protective factors

A number of factors were also identified which may protect people with intellectual disability against emotional and psychological abuse and neglect. These include the involved presence of engaged family or other supporters in their lives, and having an active and connected presence in the community, with relationships with people outside the disability sector.
The importance of supporters

Having active, engaged family or supporters is strongly represented in the literature as a critical protective factor against emotional and psychological abuse and neglect (Ramcharan et al., 2007; Felce, 2000; O’Brien, 1993). The staunch support and advocacy provided by parents and siblings for the participants in this study changed the path of their lives. Two participants had limited contact with family members for a time – they experienced years of abuse in large institutions and boarding houses and hostels respectively. When their family members re-engaged more closely with them, and connected them with a very effective advocate, large scale changes began to occur in their lives.

In the experience of participants in this study, the backing of family or other supporters such as advocates or an engaged support worker was a key factor in bringing services to account when abuse occurred. The outcomes for participants who had ‘strategic complainers’ supporting them, as compared to those who complained on their own behalf, were markedly different, and more successful.

Supporters were also a crucial component in safeguarding and developing safe environments, particularly for people with high support needs. Family members’ long term lobbying and vision for a better life for their family member directly resulted in significant change for several participants. Without their resolute support, it is likely that they would remain residents in group homes or large accommodation groupings, where they would be at considerably higher risk of emotional and psychological abuse and neglect.

There is an important role for disability service providers to play here in supporting, maintaining, developing, and sustaining these relationships.

The value of community and of unpaid relationships

Being engaged in the local community and having relationships with people outside disability services is protective. There is a significant body of literature which establishes the protective nature of being a recognised
member of a local community, with relationships with people who are not paid to spend time with you (Mansell, 2006; Fisher et al., 2007a; Felce, 2000). While many participants in this study remained fairly isolated from community relationships, they were in several cases less isolated than they had been while they were being abused. Fran (and Amanda’s) experience of a circle of support was particularly demonstrative of the protective nature of these relationships.

Both of these protective factors are about minimising the importance of formal disability services in the lives of people with intellectual disability. Meeting daily support needs are of course of great importance, but historical and to some extent current service approaches which place services as the central focus of people’s lives allow for the growth of conditions in which abuse and neglect can flourish, and where there are few independent watching eyes to observe and prevent it (MacArthur, 2003; Bigby, 2004). When relationships and interactions with other community members have pre-eminent importance, and the role of disability services is to facilitate that greater purpose, a more coherent function and form for support services becomes evident.

6.3 Responses by the disability services system

This section of the chapter discusses responses by the disability services system to the experience of emotional and psychological abuse and neglect. It focuses particularly on systemic responses such policy and procedure platforms, quality assurance frameworks, and complaint mechanisms – these are the key measures implemented by the service system to address the problem. Discussion of the service system response is divided here according to the order in which it is experienced, and so recognition of the abuse, response to it, and complaints about it after the event are addressed in turn.
6.3.1 Recognition of emotional and psychological abuse and neglect

The definitions of emotional and psychological abuse and neglect in operation by State government, and also by complaints agencies, set an expectation for what people with disability should be able to expect service providers to recognise as ill treatment. These definitions, detailed in the literature review, are almost identical across agencies.

The clarity of definitions of emotional and psychological abuse and neglect should (with training) enable service providers to identify interpersonal interactions which are abusive. The State-wide policy within which these definitions sit is broad in scope, and includes a focus on pro-active strategies and frameworks to ensure that abuse and neglect is recognised and addressed at an early stage. These include recognition of the heightened vulnerability to abuse and neglect that social and physical isolation brings; the need for systems to identify and prevent abuse, neglect and exploitation; and the requirement that early intervention approaches for identifying abuse and neglect take particular note of known risk situations, both systemic and individual (DSQ, 2007a). The policy also has a focus on professional development and staff training around recognition and response. While this represents the current policy position, it is not a radical departure from previous policy. The previous government policy on abuse took a more procedural approach, and focused more strongly on responding to incidents of abuse. It did, however, also include recognition of the need for preventative action, including improving service quality and creating a culture of openness and best practice in the disability sector (DSQ, 2003).

Broad scale information dissemination about abuse and neglect by State government which was located in the review took three strands – legislation and practice standards, an information booklet and complaints based training. The DSQ policy document on abuse and neglect is linked to an information booklet about abuse and neglect. This was designed to accompany the policy and procedures documents. The second platform of
information dissemination is the Standard on ‘protection of legal and human rights and freedom from abuse and neglect’ which forms one of the Disability Services Standards to which services must comply (DSQ, 2008b). Finally, complaints bodies conduct training, and also recommend training and education around particular issues as primary outcomes of complaints resolution processes.

**Effectiveness of information dissemination in the experience of participants**

Despite the existence of policy and information dissemination strategies, recognition of emotional and psychological abuse and neglect was problematic in the experience of participants in this study.

There were three key reasons for this. Staff were seen by many family and key stakeholder participants in the research to be frequently lacking in the appropriate training and skills to recognise this form of abuse, particularly in its more subtle expression. Second, key stakeholders also consistently viewed staff as often working within environments where a certain amount of abusive practice is normalised. This was particularly the case with ‘low grade’ emotional and psychological abuse and neglect. Where staff lacked the professional and personal capacity to recognise it on an individual level, the system did not provide the cues to recognise and counter the abuse or neglect.

The third factor affecting recognition concerns the impact of the quality assurance systems currently in operation in the state in which the research took place. There are many positive elements to the framework, including the monitoring of a level of service practice and the expectation of a raising of quality of service provision. However, there is also a significant cost to this framework in terms of abuse recognition.

At a systems level, the managerial and corporate ethos which drives the quality assurance model used in the state may have a negative impact on individual responses to experiences of harm. Key stakeholders expressed concern that the focus of services was directed to the management of
systems, rather than the support of individuals by the requirements of quality assurance. Monitoring and assessment exercises focus heavily on measuring the existence of policy, rather than the implementation of it. This was also seen to increase risk. This is consistent with the literature, which finds that a compliance based approach may be unlikely to uncover the more subtle abuses which appear in people’s everyday lives, due to its concentration on the measurement of the existence of policy and procedure, at the expense of measuring individual satisfaction with the quality of service provision (di Rita et al., 2008; Clegg, 2008; Wills & Chenoweth, 2007). In recent times, financial viability concerns for many non government services, and the increasing focus on contract based performance and competitive tendering of services have added to this pressure (Clapton, 2008a).

There is a presumed understanding of disability which is drawn upon in developing quality assurance frameworks, and this conceptual model determines the actions, responses and techniques considered appropriate for use. These frameworks draw uncritically on the dominant bio-medical, or psycho-social model of disability, which views the ‘problem’ of disability as residing within the individual. They seek to treat the symptom of the person’s lack of access or inclusion, rather than to change the root cause of the problem, leaving people the recipients of specialist services, rather than included through universal design and broad socially inclusive policies and practices (Wills & Chenoweth, 2005; MacArthur, 2003; Goggin & Newell, 2005; Clear, 2000). In technical contract approaches, people with intellectual disability are reduced to ‘instrumental worth’ rather than having moral ‘intrinsic’ worth (Clapton 2008a). The dominant quality assurance frameworks of the Queensland disability services sector are thus a technical response to the ‘problem’ of disability, rather than a moral response to the exclusion of a group of people from society and culture.

The ‘benchmarking’ of a quality of service through quality assurance processes which fail to recognise abuse, particularly subtle ongoing abuse and neglect, runs a very real risk of endorsing and confirming the
practices which gave rise to the abuse in the first place. At the least, it is unlikely to adequately address either the cause, recognition or response to abuse and neglect under these conditions.

### 6.3.2 System responses to emotional and psychological abuse and neglect

A managerial, procedurally driven, ‘top-down’ culture heavily influenced the responses of the disability services system to the emotional and psychological abuse and neglect of participants in this study. This dominated the way in which bureaucracies, service managers and support workers responded to reports of harm and complaints about ill treatment. Implicit within this is a relinquishment of moral responsibility on the part of individual workers and managers (Marsland et al., 2007).

It was rare that participants received prompt and concerned responses from service management regarding their abuse experiences. In fact, family members related a significant number of incidents in which serious abuses were not reported to them by services – these only came to light through file notes obtained by people with disability and family members using Freedom of Information legislation some years later. The positive responses to abuse in the lives of participants - complaints which had been settled, situations of risk which had been resolved and funding which had been allocated – were largely due to the pressures placed by family members and individual advocates on senior government managers over time, and to some key individual support staff. No participants with intellectual disability or family members expressed confidence in the disability services system to respond effectively to their abuse. Key stakeholders were also highly critical of the service sector’s response. Key stakeholders provided a wealth of further examples of emotional and psychological abuse and neglect. As with the participants in this study, systemic factors were also at the root of the abuse in many of these examples.
The failure of services to respond effectively or appropriately to reports of emotional and psychological abuse connects with the lack of adequate recognition of abuse, as discussed above. In some cases, service managers were working at balancing the needs of a number of co-residents, all of whom had complex support needs, in a climate of under resourcing and a shortage of staff. To respond to Jim’s complaints of physical and emotional threats by a co-resident by saying that he has greater needs, and that Jim simply needs to try and be understanding, for example, fails to address both the abuse he had experienced from the co-resident, and also the underlying systemic factors which had caused the abusive situation to arise. If four men with complex needs had not been living together in a shared situation which was not of their choosing, the abuse would not have occurred in the first place. It is an exemplar of a management system which responds to the ‘problem’ of disability without due regard for the moral or educative components, as detailed in the section above. Such focus on technical management diminishes people with intellectual disability as humans and as moral agents with intrinsic worth.

Systemic abuse is clearly present in the double standards used by services in their differing responses to staff and residents who are assaulted or abused. Key stakeholders described staff being frequently transferred to another facility, provided with counselling or stress leave, and in severe cases, receiving financial compensation for the assaults the experienced. Residents most frequently received little or no action in response to assault or abuse from co-residents beyond incident management. This double standard compounds the original injury, and is potentially emotional and psychologically abusive, or at the very least neglectful. Key stakeholders argued that a level of systemic emotional and psychological abuse and neglect becomes the norm in many services, to the point where, according to one, ‘there’s a level of acceptance in the funding’.

As discussed earlier in the chapter, there is a notable failure of the disability services system in this State to adhere to the spirit and the letter of disability legislation in this area. Services have not acted
sufficiently well to protect people with intellectual disability from emotional and psychological abuse and neglect or to respond effectively when it occurs. Both the range, volume and frequency of abuse experienced by participants and the views of key stakeholders in this study are amply demonstrative of this failure. There has been a lack of due diligence on the part of government, policy makers, and service management to ensure that the services which are set up to support people do not fact damage them.

The government policy statement on abuse, neglect and exploitation states:

DSQ is committed to preventing and responding to the abuse, neglect and exploitation of people with a disability both in its provided and funded services. In instances where the abuse, neglect and exploitation of clients does occur, DSQ will respond to the abuse, neglect and exploitation of people with a disability within both its provided and funded non-government services.

The human rights principles of the Disability Services Act 2006 include the principle that people with a disability have the same human rights as other members of society and should be empowered to exercise their rights. This is best achieved through an integrated approach that targets the cultural, environmental and interpersonal causes of abuse, neglect and exploitation. (DSQ, 2007a, p.1)

Despite this explicit recognition of the social, cultural and environmental causes of abuse and neglect, little evidence of action to address these has appeared in this study. Competing policy priorities, resource allocations and managerial approaches to quality assurance may have mitigated any integrated approach for people living in disability accommodation services. The policy and procedure framework appears to respond primarily to individual incidents of abuse and neglect, and to treat the symptoms rather than systemic causes of abuse. It is inadequate to deal with the complexity of the experience.
These broad policy statements show some evidence of a shift in ideology, moving towards an acceptance of social perspectives on disability in the acknowledgement of the causative role of cultural, environmental and interpersonal factors (Tregaskis & Goodley, 2005). In practice, however, the dominant policy and practice response of the service system to the emotional and psychological abuse and neglect of people with intellectual disability remains firmly within the deficit or individual approach to disability (Brown, 2004; Marsland et al., 2007). It focuses on the problem contained within the individual, resolution at the individual level, and has devoted limited energy and resources to prevention and protection from maltreatment.

The tendency of the service system to respond to abuse and neglect only on an individual level and to treat symptoms rather than causes of abuse is strongly represented in the literature. The failure of organisations to proactively address risk, and broader systemic concerns about power and its misuse, social constructions of disability, and the ambivalence of social attitudes to people with intellectual disability are all key in recognising and addressing abuse and neglect (Nosek et al., 2001a; Chenoweth, 1995; Penhale, 1999; McCarthy & Thompson, 1996). It appears that these links were not made by either staff or service management in the experience of participants in this study.

It is argued in the literature that the pragmatic and linear movement between legislation, policy and practice in disability services fails to give adequate space to reflect on the issues surrounding the ‘big picture’ of abuse and neglect, such as culture, environment and the impact of funding rules and regimes (Burgess, 1997; Robinson & Chenoweth, 2005). This results in a service system which has significantly improved in terms of its acknowledgement of the categories of abuse and neglect, but which may have changed far less in its responses. Each of the models of abuse presented in the literature review (Penhale, 1999; Sobsey, 1994; Brown, 2004) share the assertion that abuse occurs on multiple levels, in multiple contexts, and in interrelated ways. It is a far more complex experience
than can be adequately represented in a linear policy and procedural response to isolated individual incidents of abuse or neglect.

There is a demonstrated lack of response by government to the findings of judicial and parliamentary inquiries into abuse in accommodation facilities for people with intellectual disability in this state over the past fifteen years (Stewart, 1995; Carter, 2000; House of Representatives, 2004). One institution is at the time of writing undergoing some redevelopment after closing for a time - despite two judicial inquiries, the earlier one finding a corrupt culture which was ‘irredeemable’ and strongly recommending closure as soon as possible (Stewart, 1995). Criminal charges were laid against workers and the owners of one private facility following one parliamentary inquiry. However, no systemic changes have been pursued to ensure the safety of other vulnerable adults living in similar facilities. There is also a notable lack of significant policy or funding response to the underpinning recommendations of large scale government commissioned reports, such as the abuse review by Page, Lane & Kempin (2002), undertaken on contract for the National Disability Administrators group (made up of the State disability departmental heads). The fundamental finding of this large report was the need for primary prevention of abuse through the development of inclusive communities, advocacy, building individual resilience and family supports and intervention.

The question of civil liability also arises around the failure of the service system to protect people from emotional and psychological abuse and neglect. The dominant structure of the disability services system may make it difficult, or even impossible for individual support workers to meet their duty of care requirements to their clients, resulting in them being legally negligent in their duty if their clients experience harm as a result of abuse of systemic cause. This does not appear to have been tested, due to the substantial barriers for people with intellectual disability in taking legal action on emotional and psychological abuse and neglect (Mathews, 2004; Gibney, 2009).
It is unlikely, in this climate, that mandatory reporting of abuse and neglect would adequately address injustice and ameliorate conditions for people with intellectual disability living with emotional and psychological abuse in disability services. The literature is divided on whether mandatory reporting regimes in other jurisdictions fill the gap left by service providers and other professionals who lack moral, policy and practice grounding in addressing abuse and neglect (Higgins et al., 2009; French et al., 2009; Macolini, 1995; Mathews & Kenny, 2008). Such regimes can raise awareness, force higher reporting of abuse and neglect, and remove moral ‘greyness’ from decisions about whether or not to report abuse (Macolini, 1995). The risks, however, are that their cost can drain limited resources from community based responses to abuse and neglect, and they can become quickly overwhelmed with the volume of abuse and neglect notifications (Higgins et al., 2009).

Importantly, it is identified in the literature that the duty of care obligations on service providers already require them to actively address abuse and neglect in the lives of people they work to support (Elder Abuse Prevention Unit, 2006). The lack of understanding of existing legal and moral requirements by some service providers, and the failure to apply these, may be a more profitable path to pursue. More vigorous and rigorous implementation of existing legislation and safeguards is likely to be of greater benefit to people with intellectual disability in the fight against abuse than the development of a mandatory reporting regime.

The individualised nature of the response of the disability services system to the experience of abuse, and its failure to translate policy goals into practice means that there is little change to the status quo for people with intellectual disability. The high rates at which they experience abuse and neglect are unlikely to change without a distinct increase in the rates and effectiveness of recognition and response to abuse and neglect at all levels in the service system – from prevention through to protection from further abuse or neglect. The safety of their services is unlikely to change without large scale, intensive, culturally driven effort. People with intellectual disability also have little capacity to make changes to their
own circumstances, due to the enormous power imbalance between themselves and all other strata of the service structure (support workers, managers, organisations and government). This can be seen clearly in the following section, which discusses complaints about abuse and neglect.

### 6.3.3 Complaints and redress

Complaints did not, by and large, result in an improvement in the life circumstances of people with intellectual disability. People with intellectual disability who complained on their own behalf were more often penalised for speaking out, often subtly. They did not generally have good experiences of complaining, and described their complaints being ignored or minimised (with one exception). Family members, while they did not enjoy the experience, persisted with complaints, were able to take them higher and further, and demanded different outcomes to people with intellectual disability. They sometimes complained with a view to long term change, such as funding allocations for individualised support. Family members talked about damaged relationships with services once they complained, being ‘unpopular’, feeling uncomfortable, and the difficulty of complaining to an unresponsive bureaucracy.

Barriers for people with intellectual disability in making complaints were high. When complaining internally about abuse within disability services, the experiences of several participants show that retribution or punishment from staff for speaking out about unfair or abusive treatment was common. Mechanisms to prevent retaliation or retribution were rudimentary and were seen as unlikely to be effective in protecting people from subtle retribution. As one key stakeholder put it when expressing his concerns about the lack of vigour in these protection mechanisms:

‘There’s a thousand ways to emotionally abuse someone, and most of them quite subtle’.

External complaint agencies accepted complaints in a manner which required access to phone or writing, and the ability to structure a
complaint coherently. No ongoing support was available with the complaint process – there was no advocate to walk beside a person through the process and provide moral support, unless they were fortunate enough to obtain advocacy support through a funded disability advocacy service. Complaints mechanisms without advocacy support are unlikely to adequately deal with power imbalances in this kind of subtle, ongoing, insidious abuse (French et al., 2009). Access to Official Community Visitors mitigates this to an extent, although resources are low, and visiting not frequent.

External complaints regimes were bureaucratic, and quite regimented in some ways. At a state level, complaint intake was structured according to Disability Services Standards. At a national level, it was focused on the experience of abuse or neglect. The focus of both bodies was on individual complaint resolution through conciliation. Issues of serious or criminal misconduct were referred to other bodies for investigation. The state body was also mandated to have some strategic focus on prevention and education, and the national body had an education role only. However, there was little evidence in this study of systemic action to recognise and address pervasive cultural elements of emotional and psychological abuse which may emerge through individual complaints in either body, apart from reporting to senior management on emerging trends in complaints.

Complaint responses which have a conciliation approach have mixed outcomes. Some key stakeholders viewed benefits to people with intellectual disability in receiving an apology, and saw that workers may benefit from seeing that their actions were hurtful and negative, and that they may modify their behaviour in future. However, several concerns are raised in the literature that a conciliation approach may at times feed into the power imbalances which are strongly in play in the lives of people living in formal service environments. This may appear as a lack of rigour in investigation and prosecution where the complainant has intellectual disability (particularly when they are not supported by a strong advocate), and in a continuation of the focus on this abuse at a purely individual
level, when so much of it is rooted in systemic policies and practices (Wardhaugh & Wilding, 1993; Mandeville & Hanson, 2000; Ticoll, 1994).

Some questions were also raised about how often emotional and psychological abuse is actually recognised in the conciliation process. Complaints agencies at a state level showed a preference for pragmatically cataloguing complaints about issues which could be termed emotional and psychological abuse as other problems to aid quick resolution. Accordingly, examples were given of issues which were abuses, but termed choice issues, or privacy issues. Individual resolution is of course important, but this has implications for recognising, understanding and addressing this abuse in disability services. It fails to consider the influence and role(s) played by systemic and structural factors. This approach also undermines the authority of the person with intellectual disability, and calls into question the legitimacy and relevance of their knowledge (Clapton, 2008b). This is a key finding of the research, and will be discussed further in this chapter.

Legal avenues do not appear to offer an easy way forward for people with intellectual disability to address emotional and psychological harm in this area. Many of the behaviours which make up emotional and psychological abuse are not criminal wrongs, and it may be that we need to draw upon moral, ethical and rights-based frameworks to understand and address it. Two participants had initiated legal action. Although emotional and psychological abuse and neglect was not the subject of the action, it had a contributory role. There are very significant barriers in the legal system, which may preclude access to it in the first place, even before the question of a successful outcome is raised. However, the legal system is largely untested in this area, and a successful legal case against the disability service system could prove a powerful lobbying tool for change.
6.4 **New insights into the problem**

The discussion in the chapter to this point has focused on the shared abuse and neglect experiences of people with intellectual disability, the influencing factors which have created and maintained the climate in which their abuse and neglect took place, and the responses of the service system to emotional and psychological abuse and neglect.

Within and across each of these areas, four key issues emerge which have particular resonance and importance. These problems cut to the heart of the experience of emotional and psychological abuse and neglect. They have been experienced by all participants in the study. They have implications for policy and for practice in disability services, and beyond. Most importantly, they offer new insight into the lived experience of people with intellectual disability, and provide valuable information about both the ways in which they have experienced chronic, ongoing maltreatment, and the ways they understand it.

These four key problems concern the central place of systems; the cumulative impact of emotional and psychological abuse and neglect; recognition of emotional and psychological abuse and neglect by people with intellectual disability; and the lack of authority of people with intellectual disability in abuse acknowledgement and reporting.

**6.4.1 The central place of systems**

Participants experienced some abuses which were based in predominantly individual interactions. However, substantially more frequent were their experiences of abuses and neglect which had at their root systemic factors, such as policy directives, unthinking following of rules, or humiliating institutional practices. People also experienced abuses which were caused by structural factors, or broad social policy and practice. In many instances these systemically and structurally rooted practices resulted in subtle, monotonous abuses which routinely degraded and
belittled participants in the study. In and of themselves, these were probably not issues over which people would make a formal complaint, but together they blended into a collage of negative and abusive experiences.

The range, extent and volume of these experiences created a climate in which an expectation of ill treatment was set. A failure of services to respond with concern, haste and vigour was described again and again by all participants. Where abuse was responded to by services, it was done on the basis of an individual incident. No participant had experience of their abuse being considered by service providers as part of a pattern or trend in their lives. It is clear that emotional and psychological abuse and neglect has been present throughout the ‘service lives’ of all of the participants in the study, and that it has shaped their experiences and impacted on their self concept and self worth.

Many researchers in the child, women’s and elder abuse literature contend that emotional and psychological abuse is reliant on a sustained attack on the person by an individual abuser (Iwaniec, 2006; Tucci & Goddard, 2003; Packota, 2000). The results of this study demonstrate that the sustained nature of the abuse which does such damage may also be provided by the environment or service relationship or the staff/client relationship, not the relationship between two individuals. There was comparatively little intentional abuse by an individual ‘reliant on a sustained attack on the person’s psyche’ (Iwaniec et al., 2006), except in some isolated instances.

Over time, many of the people in the study did not have long term relationships with support workers – staff came and went regularly in their lives. However, the bulk of the mistreatment people experienced was categorised as being of systemic cause. The disability services system provided and maintained the conditions under which abuse was more likely to occur, and failed to respond appropriately when it did happen. The individual actions of abusive behaviour from workers and co-residents in many cases need to be situated inside this environment to be
understood. The sustained nature of emotional and psychological abuse and neglect which the literature requires was provided by the structural conditions of the service system.

The relationship between emotional and psychological abuse and neglect and institutional abuse is important here. Brown considers institutional abuse to be:

*not really a ‘type’ of abuse, or even just a ‘site’ of abuse, but a constellation of factors that interact to produce poor care, insensitive practice and to either provoke or condone individual or collective acts of cruelty* (2007, p.2).

Sobsey (1994) includes extreme power inequities, the collective nature of the abuse, covering up of the abuse, and clearly defined patterns of environmental influence as criteria for institutional abuse.

Many of the features of institutional abuse as defined by these prominent authors have been experienced by participants in this study. However, they have also experienced more personal, intimate insults and hurts in addition to those of systemic cause. Institutional abuse is highly relevant to understanding emotional and psychological abuse and neglect, but does not provide the entire answer to its experience or cause.

### 6.4.2 The cumulative impact of emotional and psychological abuse and neglect

The cumulative impact of long term emotional and psychological abuse and neglect was striking in the lives of participants. It played a major role in how they currently live their lives, the relationships they are able to maintain, their capacity to trust others and their ongoing emotional health.

The creation of a climate in which ill treatment is expected, as discussed above, allowed for the generation of a collage of small and large insults and injuries over time. As each new experience occurred, another piece was glued into the collage.
These experiences have had a significant cumulative impact on the self esteem, self concept, and self worth of participants. Most of the people with intellectual disability who participated in the study themselves were at the time of writing very socially isolated, had difficulties forming and sustaining equitable relationships with others, and some of them struggled with mental health issues. They found it difficult to trust people, and were often suspicious of the motives of others, such as new service providers. People with higher support needs were also isolated, but less so, due to their family involvement. Several had mental health concerns, and showed indications of ongoing stress and distress which their families felt was due to their abusive experiences.

This concept of cumulative impact is critical in interpreting the difference between emotional and psychological abuse and neglect. The mainstream view from the child abuse and women’s abuse fields are that there is little difference between emotional and psychological abuse, as both relate to cognition. A minority of writers from the women’s abuse (McKinnon, 2008) and child abuse (O’Hagan, 2003) fields argue that emotional and psychological abuse and neglect are in fact distinct. In this conception, psychological abuse is seen as a deeper, longer term, power conflicted form of emotional abuse in which a person’s sense of self and social competence is threatened.

Accepting the cumulative impact of ongoing emotional abuse of people with intellectual disability in disability services means that individual incidents should not be the only measurement of abuse and neglect. A series of individual incidents of emotional abuse or neglect, together with inappropriate and inadequate system responses over time, may comprise psychological abuse or neglect and cause lasting damage to the person. This may occur within one facility or across a number of different services, and within one set of relationships or across many staff relationships. One experience of abuse or neglect may be enough to comprise psychological abuse, if it is distressing enough to the person. A series of subtle, low
grade, routine behaviours that are not recognised by services, but are seen by people with intellectual disability and families as degrading, insulting and disrespectful may also comprise psychological abuse.

This sort of abuse also needs to be understood beyond individual incidents, in terms of the ‘service histories’ and life histories of people with intellectual disability – the neglect and abuse in their pathway through many services, inappropriate services, unresponsive services; and the failures of the service system to identify their abuse and respond to it. Emotional and psychological abuse and neglect is present not only in interpersonal interactions, but also in the failings of the disability services system to protect people’s safety and to provide them with a stimulating and nurturing home environment. Ann’s path, for instance, through many boarding houses, hostels and funded programs, is one in which little responsibility for her emotional and psychological wellbeing (in the face of known abuses) was taken by either the disability, mental health or criminal justice systems.

Policy frameworks and systems management approaches (such as quality assurance systems) which inadequately recognise personal experience in favour of a focus on the measurement of the existence of policy and procedure may also play a contributory role here. The strong focus on measuring policy and procedure, and the concomitant weak focus on understanding personal experience, directs the attention of disability services to compliance measures. It minimises the time they have available to address issues of interpersonal abuse and emotional neglect which they may not even fully understand, due to their sometimes subtle nature. This allows abuse and neglect to remain unaddressed in the lives of people with intellectual disability, its impact accumulating more rapidly.
6.4.3 Recognition of emotional and psychological abuse and neglect by people with intellectual disability

People with intellectual disability were able to express very strongly that what had happened to them was something that they had not liked, and that they felt offended and violated about the things they had experienced. While they did not, with the exception of Craig, have a language for emotional and psychological abuse and neglect, they had a ‘moral’ awareness that wrong had been done to them on an emotional and psychological level. For example, Jim remembered ‘not nice things’ and that ‘they make it hard…they didn’t talk to me nice and treat me nice’ when he complained. Ann recalled that an abuser in one place she lived ‘hurt them by being nasty to them’, and remembered being ‘threatened’.

The subtlety of some abuses, particularly those which are systemic in root cause, led participants with intellectual disability and also some family members to be unsure of whether they had in fact experienced abuse. Some of the abuse that occurred within relationships did not appear to be recognised as abuse by either the abuser or the person being abused. However, participants were overwhelmingly clear in the perception that these were wrong actions that resulted in harm and hurt to them.

The existing research around recognition located in the review found that women with physical and intellectual disability did not, in many cases, recognise abuses until they discussed it with others who had experienced the same treatment (Saxton et al., 2001; Collier et al., 2006). The outcome of this study is somewhat different – while people did not have the words to name the abuse, they most certainly had a strong awareness that wrong had been done to them.
6.4.4 Lack of moral authority accorded to people with intellectual disability in abuse recognition, acknowledgement and reporting

People with intellectual disability most often did not have an authoritative place in the acknowledgement and reporting of abuse and neglect in this study. Several incidents were related by participants when they were not believed about their experiences of a range of abuses. For example, when Ann told her case worker about being assaulted, he called and notified her abusers that she had complained, and then drove her back to the facility and left her there, numerous times. She was told she was ‘manipulative’ for complaining about the treatment she received – including abuses which caused lasting physical disability and which are now the subject of legal action.

There were a significant number of instances where people complained about ill treatment and were punished, either directly or indirectly, for speaking out. Sometimes this retribution was direct, and sometimes very subtle – being put to bed at a more appropriate hour after complaining about being put to bed very early, but staff being curt and uncaring while completing the task; or being told that someone else has greater problems, and you need to be more understanding of their needs when complaining about threats from another resident.

People with intellectual disability who participated in this study were frequently not treated as having legitimacy by the service system – their voice was seen as needing to be interpreted by staff, complaints agencies, or sometimes families or advocates. The response of a complaints body to a question about how they resolve complaints which involve questions of subtle abuse which are difficult to prove was indicative of this view:

So sometimes, the best that we can achieve is to give the person that lodged the complaint a full and thorough explanation of what really did happen. [my emphasis]
The knowledge of people with intellectual disability was at times treated as ‘irrelevant’, or they were treated as ‘irrelevant persons’ (Clapton, 2003). Their moral authority was called into question - both explicitly in the way that the choice lies with services, staff and managers about whether or not to respond to people’s reports of maltreatment, and tacitly in the way that reporting systems for abuse and other complaints are developed and implemented.

The failure to recognise the moral authority of people with intellectual disability fits within a social constructionist approach to abuse, which holds that abuse continues due to the extreme marginalisation and the positioning of people with disability as ‘other’ or as less than human (Jones & Basser-Marks, 1999). This allows the development and maintenance of cultural and structural practices which are seen as appropriate for people with intellectual disability, but which would not be seen as appropriate for people without intellectual disability (Taylor & Bogdan, 1989; Clegg, 1993).

These practices are consistent with Nunkoosing’s (2000) contention that some explanations about intellectual disability are privileged over others. The knowledge of professionals and academics is privileged over that of people with intellectual disability themselves. In the context of abuse, the consequence of this is that the lived experience of the subtleties of emotional and psychological abuse by people with intellectual disability has been largely ignored in favour of the privileged professional explanations of abuse, which focus predominantly on identifying and responding to individual occurrences of abuse in which physical harm has been sustained and on controlling the conditions under which abuse may occur (Chenoweth, 1995; MacFarlane, 1994).

Using the work of ethicist Clapton (2008b), detailed earlier in chapter three, it can be seen that people with intellectual disability are straddling both profound exclusion and technical inclusion. They are subject to what Clapton calls ‘conceptual conflicts’, living within a utilitarian approach which focuses on the greater good for the greater number (drawing from
individualistic personal tragedy models of disability) while at the same time exposed to legislation, quality assurance and policy frameworks which espouse rights. This is evidenced in the unsatisfactory policy rhetoric regarding their right to protection against abuse and neglect which is not backed up with practical support and resources to make meaningful change in people’s lives.

6.5 Conclusion

There is a fundamental disparity between the responses of the disability services system and the abuse experiences of people with intellectual disability in this study. System responses are primarily geared to discrete instances of abuse or assault, which can be addressed and resolved on an individual basis. The experience of participants in the study is that the abuse they experienced is caused primarily by the interaction of poorly trained and supported workers with systemic factors such as managerial culture, resource shortages, policy priorities which downgrade the importance of individual support, and institutional practices. The causes of their abuse are complex, and require much more complex and well considered strategies to resolve than have been delivered to date.

6.6 Summary

This chapter has discussed the experiences of emotional and psychological abuse and neglect shared by participants in the study, focusing particularly on those which crossed over several categories of abuse or neglect and which had strong impact on the lives of people with intellectual disability. The themes which emerged centre around the diffuse and pervasive nature of the abuse; the damage done to people by thoughtless following of policy and practice by staff; the damage done to their relationships through abuse; the abusive impact of poor quality care and the withholding of basic support and rights; punishment and control;
threat and fear; a lack of appropriate concern about harm suffered, and the failure of systemic abuse response mechanisms to protect people.

While people demonstrated great resilience in dealing with their abusive experiences, the impact of this abuse and neglect has been significant and lasting. It has manifested in many ways, including people’s emotional and mental health, their capacity to develop and maintain relationships, their ability to trust, and their cultural connections.

A series of factors influence the experience of this abuse and neglect. They may predispose, increase risk or protect against the experience of emotional and psychological abuse and neglect. Factors which may predispose abusive conditions include the way in which legislation, funding and policy for accommodation support is conceptualised, funded and implemented. These have been discussed in section two of the chapter. Also discussed are risk factors which may increase the likelihood that people with intellectual disability will be exposed to emotional and psychological abuse and neglect, including enforced co-residency, unresponsiveness at a high policy level, and the lack of protection for residents in the private residential sector. A number of protective factors were also identified which may act to positively support people – these included the involved presence of engaged family or other supporters, and having an active community presence and relationships.

The third section of the chapter addressed the responses of the disability services system to emotional and psychological abuse and neglect. It was characterised by a top down, managerial, procedurally driven culture, which dominated the way in which people with intellectual disability experienced responses to their reports of abuse and neglect. Quality assurance processes which focus on recognising policy at the individual response level, with minimal focus on prevention and cultural change, appeared to strongly influence the service system. Complaints systems did not, in most cases, result in improvements in the life circumstances of participants in the study.
Four key issues emerged from the discussion which have distinct resonance. They have particular importance for practice and research as they grow from the lived experience of people with intellectual disability. These problems concern the central place of systems; the cumulative impact of emotional and psychological abuse and neglect; recognition of emotional and psychological abuse and neglect by people with intellectual disability; and the lack of moral authority accorded to people with intellectual disability in abuse acknowledgement and reporting.

The following chapter addresses the implications of the research for policy and practice, and for the lives of people with intellectual disability.
...when things got really bad for him, getting him into the wheelchair. That was about their convenience, it was never about his, never about him. Except where those good souls would try and make a difference. But from a systemic point of view, it was never about him, it was just about keeping the body alive. It’s a numerical process, run by accountants. It’s so sad.

- Patrick, Dan’s brother

7.1 Introduction

Emotional and psychological abuse and neglect is in many ways inextricably linked to other forms of abuse – both in the way it is experienced and in the way it is addressed by the service system. This influences the way that it is conceptualised, recognised, and responded to in policy and practice. It is the ‘poor relation’ to sexual and physical abuse and neglect. Critical questions are in play around how the experience and impact of this chronic and pervasive abuse and neglect can be better recognised, responded to and prevented.

A range of policy and practice responses are required to meet short, medium and long term agendas for change. There are first, second and third order implications for policy and practice detailed below. Some require resources or political will. Others can take effect immediately. Still others will never take effect unless a series of preceding steps have been implemented.
This chapter considers implications of this study for the future for people with intellectual disability, for policy and practice in disability accommodation services, and for research.

### 7.2 Acknowledging barriers to change

Substantial barriers to action appear to be in place. Key stakeholders, for example, were individuals who were well placed to influence change. They were people with a great deal of knowledge, skill and history. Their understanding of emotional and psychological abuse and neglect was sophisticated and nuanced. They indicated that they were not met with hostility by senior bureaucrats on issues of abuse and neglect – on the contrary, senior policy makers and managers were also concerned about the maltreatment of people with intellectual disability. Yet this knowledge, skill and concern has not translated into successful action to stop abuse from occurring.

### 7.3 Making use of definitions and understandings of emotional and psychological abuse and neglect

Understandings of emotional and psychological abuse and neglect have been further advanced in this study, through testing the abuse and neglect wheel against the lived experience of people with intellectual disability. This approach has brought together two sets of historically separate material – the experiences of research participants and academic definitions of phenomena. With the addition of the individual/systemic/structural framework (Penhale, 1999), this combined material stands to be a useful tool to both policy and practice. The wheel may prove a useful training tool to assist disability support workers, managers, family members and others supports such as advocates to better understand the actions which may occur in this form of abuse and neglect. It is important that they are also provided with an analysis of the
role of systems and social structures in this abuse and neglect. An adapted form may be of use to people with intellectual disability in training and education. A more complex construction of emotional and psychological abuse and neglect can inform the development of policy for disability accommodation services. This may assist policy makers to recognise, and hence to reflect in policy, both the potential range of actions which can occur, and the central place of systems and social structures in this form of abuse and neglect.

7.4 Implications of the abuse experience

The high volume, range and frequency of emotional and psychological abuse and neglect in the lives of participants in the study was both alarming and distressing. The results of this research with nine people can only be generalised with caution. However, the participants in this study had very similar ‘service lives’ to many other people with intellectual disability. Between them, participants in the study had experience of a wide range of services, service types, and interaction with hundreds, perhaps thousands of staff over the years. It would be surprising to discover that other people in the service system did not share similar experiences. The results are consistent with the literature on other forms of abuse, which, while varying in range and methodology, consistently show a high prevalence of abuse and neglect (Sobsey, 1994; McCarthy & Thompson, 1996; Ticoll, 1994; Conway et al., 1996). The implications for people with intellectual disability from this study are that this form of abuse and neglect may be endemic in their lives. The practice of support workers needs to understand this, and be sensitive to it, respecting the fact that people who have lived in disability services for long periods are likely to have experience of emotional and psychological abuse and neglect.

The cumulative impact of this experience has implications for the individual participants in the research, for policy, and for practice. For people with intellectual disability, there are long term implications for their
capacity to form and maintain relationships, their mental and emotional health, their social isolation and their capacity to trust. While people demonstrated determined resilience in the face of distressing abuse experiences, and the ways in which they have moved on in their lives have enabled them to put some of the abuse behind them, the impact remains significant and long standing.

The policy implications of recognising the cumulative impact of this abuse and neglect are considerable. Prevention and safeguarding against the experience of emotional and psychological abuse and neglect become even more important. A more nuanced response to people with intellectual disability is needed, which is able to respond to the needs of both people who have lived within the service system for some time (who are highly likely to have been abused and neglected), and to proactively support people entering the system, to prevent them experiencing abuse and neglect.

### 7.5 Better understanding the risk

The risk of emotional and psychological abuse and neglect happening to people with intellectual disability was found in this study to be increased by several systemic factors, such as enforced co-residency, understanding which was not translated into change at policy levels, and the slowness of response of senior bureaucrats to notifications of serious abuse and neglect. In the study, little evidence of action to prevent or safeguard, or to manage risk effectively was found. There are serious implications for governments in addressing issues of safeguarding, risk and prevention of this abuse and neglect. As the knowledge about this form of maltreatment builds, along with the body of work on protective factors, it becomes more incumbent on governments to proactively address issues of protection from and prevention of emotional and psychological abuse and neglect.

There is a need for the disability services system to develop measures to identify and act on the risk of abuse, before having to respond to its
occurrence. As discussed in chapter six, elements of disability services culture and environments are known to act to increase or decrease the risk of abuse occurring in the lives of people who live in them (Marsland et al., 2007; Wardhaugh & Wilding, 1993). This study has confirmed and reinforced previous research on systemic risk.

Service based change needs to centre on an increased focus on prevention and addressing risk, more effective recognition and response to the experience of emotional and psychological abuse and neglect and broadening approaches to service monitoring and evaluation. This should be standard risk management practice.

Significant resources need to be allocated for the effective development and implementation of integrated approaches that target social, environmental and interpersonal causes of abuse, and which respect the moral agency of people with intellectual disability. They require skilled drivers and implementers. Until this is the case, it is difficult to see how substantial systemic change will occur.

### 7.6 The place of power and systems

The experiences of participants in this study show that this abuse and neglect was diffuse and pervasive, and was intimately connected to power relations. The lack of power of people with intellectual disability in both their interactions with staff, and in their living environment more broadly, meant that they had effectively no recourse to change their situations. A lack of adequate concern for harm they experienced, and the poor quality of care in several facilities, combined with the thoughtless following of policy and procedure by staff resulted in chronic emotional and psychological abuse and neglect. Against this, systemic protection of people’s rights were weak, and their experiences of protection centred around those key individual workers who took on a personal protective role.
Existing responses have been largely oriented to individual incidents of harm (usually physical or sexual). Little acknowledgement of the subtle, insidious and systemic nature and impact of emotional and psychological abuse and neglect has been indicated in legislative, policy and practice frameworks in play in the disability services sector.

The central place of systems in the experience of this abuse and neglect indicates that the bulk of the responsibility, and the work, in responding to this form of abuse and neglect lies with the service sector. No participant had experience of their abuse being considered by service providers as part of a pattern or trend in their lives. It is clear that emotional and psychological abuse and neglect has been present throughout the ‘service lives’ of all of the participants in the study, and that it has shaped their experiences and impacted on their self concept and self worth. The ‘sustained’ element of attack which many researchers see as integral in emotional and psychological abuse and neglect (Iwaniec, 2006; Tucci & Goddard, 2003) may be provided for people living in disability accommodation services not by a malevolent individual, but by the service environment or service relationship. The range, extent and volume of these experiences created a climate in which an expectation of ill treatment was set.

The measurement of individual incidents of harm should not be the only appropriate measure of emotional and psychological abuse and neglect. There is a need for measures which recognise patterns of abuse or neglect over time, and across services and service types, to identify when people are experiencing ongoing harm and neglect. They need to focus on the person, not on the measurement of systems. In this light, government, senior managers and service line managers all need to take key roles in recognising, responding to and acting to prevent emotional and psychological abuse and neglect. Further, these actions need to be conceived very differently to the responses in the service sector to date.

However, the lack of personal and systemic power that people with intellectual disability had in this study may be perpetuated without due
attention to redress the power relations at play in emotional and psychological abuse and neglect. There is a need to focus on building individual resilience in people with intellectual disability who are likely to experience abuse and neglect. The qualities of resistance and resilience shown by participants in this study were key to their moving on with their lives after abuse and neglect, and to balancing the substantial impacts of the abuse and neglect on their lives and wellbeing. However, a focus on teaching skills of resilience needs to occur within a broader context, in which structural and systemic factors affecting the abuse and neglect of people with intellectual disability are actively being addressed. It is tragic to teach people to recover better from inevitable abuse.

### 7.7 The need for cultural change

The need for cultural change was recognised by participants at all levels of the study. People with intellectual disability identified the need for support workers and managers who were more responsive to their experiences; families argued for a service system which supported informal family relationships, rather than replacing them, and which allowed control by the person and those who were close to them; and key stakeholders saw the need for recognition of the role of the current service structure in providing the conditions in which abuse and neglect is highly prevalent. They also stressed the importance of developing strong moral frameworks in individual support workers, so that workers become an effective resource to people in times of abuse or mistreatment. It was recognised that changing the culture of the disability services system was both complex and difficult. Strategies which had been used successfully to influence cultural change included a focus on relationship building and incremental change; having multiple points of intervention; focusing on both individual and systemic levels; and redeveloping funding and service provision approaches to be more person centred.
7.8 Respecting the value of lived experience

While the disability services system, complaints systems and quality assurance systems were lacking in their recognition of and response to emotional and psychological abuse and neglect, people with intellectual disability were in no doubt that wrong was being done to them.

The knowledge of people with intellectual disability about their lives was in many instances treated as irrelevant and lacking in moral authority by service workers and managers, and they were conceived as lacking in capacity to make judgements about moral wrongs, particularly abuse and neglect. This resulted in them living with abusive situations, particularly when the abuse stemmed from co-residents. In several instances, this seems most likely to have occurred because workers and line managers had little if any capacity themselves to make changes to the living situations of the people who were in conflict. However, their responses of negating and denying the validity and relevance of the abuse reports of participants in this study were morally, ethically and legally wrong. Such responses are driven by scarce resourcing, policy priorities which include enforced co-residency and vacancy management and procedurally based staff training.

These responses allow the development of cultural and structural practices which are seen as appropriate for people with intellectual disability, but not for others (Taylor & Bogdan, 1989; Clegg, 1993) – institutionalisation, isolation and segregation in their modern forms.

The implications of this are far reaching for people with intellectual disability. The creation of alternate cultural and structural practices for people, based on their experience of disability, allows for the experience of an alternate life, in which it is far likelier that a person will experience abuse and neglect, as the factors which protect against abuse and neglect are less likely to be present. Out of this understanding come implications for policy and practice. The factors which may act to protect people from the experience of abuse and neglect – being embedded in community and
having relationships – are not features of created service environments. They are features that a high quality service environment seeks to nurture, but which are too frequently lacking in the lives of people with intellectual disability.

Responses to abuse have been professionally designed and controlled. There is a need for grass roots involvement in defining, recognising and designing responses to abuse and neglect. To date, there are few research, policy, practice guidelines or education resources about emotional and psychological abuse and neglect which build directly from the lived experience of people with intellectual disability. The place of people with intellectual disability in the abuse landscape needs to be rethought. As well as being victims of this, they are survivors of it. They have important stories to tell, and we have important things to learn from their survival experiences.

The way in which the disability services system has included people with intellectual disability in policy processes also needs work. The structure of formal consultation processes are often exclusive of lived experience - reliant on literacy, engagement with government officials and offices, and jargon. It is incumbent on policy makers to gather knowledge and make adaptation into the language of policy, rather than expecting people with intellectual disability to make that leap.

### 7.9 More effective recognition and response to abuse and neglect

Complaints, in the main, did not result in an improvement in the lives circumstances of people with intellectual disability who participated in this study. Reporting structures for dealing with emotional and psychological abuse and neglect were almost entirely ineffective in resolving abuses in the lives of participants in this study. Their reliance on complaints being initiated by very disempowered people in order to identify abuse; the scope for subtle (and not so subtle) retribution by service providers for
complaining about abuse and neglect; and the failure of some complaints staff to recognise emotional and psychological maltreatment are all examples of a system which inadequately recognised the limitations placed on people who were frequently institutionalised by the impact of service practices and policies. This calls out for a new approach. Official Community Visitors schemes, which operate in several Australian states, offer a useful mechanism for the entry of an independent agent into the service environment. It is critical that such schemes visit frequently enough to view routine practices; that Visitors are available privately for people to speak with; and most importantly, are directly linked to an independent, specialist watchdog agency with powers of investigation and prosecution.

Currently, Visitor Schemes sit within justice agencies, such as the NSW Ombudsman’s office, Queensland Department of Justice and Attorney General, and Victorian Public Advocates Office. French, Dardel and Price-Kelly (2009) argue that although independent of the services operations of government, these regimes operate as ‘culturally interior to government’ (p. 28). They tend to privilege public administration over individual rights, and Ombudsman’s offices in particular are principally concerned with policy adequacy and compliance. French and colleagues recommend that, as part of a national approach to the detection, reporting, investigation and prosecution of abuse, neglect and exploitation management, ‘an independent, specialist watchdog agency capable of developing and implementing an activist, human rights oriented approach to its jurisdiction be developed’ (p28). While this refers to NSW, it is equally applicable to any Australian state.

Such a body would link to a currently proposed national abuse prevention and response agency (French et al., 2009). This would have royal commission equivalent powers, and a mandate to receive and investigation notifications and complaints relating to abuse and neglect; the power to remove or order the removal of a ‘vulnerable adult’ from a situation of unreasonable risk; power to make compulsory requests for emergency and ongoing assistance from relevant Government agencies to
ensure the safety of the person; the ability to undertake own motion inquiries into systemic issues relating to abuse, neglect and exploitation and publicly report on the findings of these; the ability to develop and publish policy recommendations, guidelines, and standards to promote service quality improvement and educational programmes; and the obligation to collect and publicly report data (p 26).

The current District Inspector scheme which operates under the *Mental Health (Compulsory Care and Treatment) Act* 1992 in New Zealand also offers a useful model. Inspectors are charged with assisting people being assessed or treated under that act, and also people with intellectual disability living in group homes, by providing information and support to ensure their rights are upheld. They have powers to remove people from situations of undue risk, to require services to ensure an accused abuser does not work with a person who has alleged they have abused them until the complaint is resolved, and have positions of seniority and gravitas in the health and disability system in New Zealand (Ministry of Health, 2003; Bell, personal communication).

The Welsh government, in reviewing their abuse guidance policy *In Safe Hands* (2000), set up an adult protection project group. The remit of this group is to review the effectiveness of present policies and legislation, standards, work streams, incident reporting and information systems. They are required to assess and report where improvements can be made across government, and make recommendations based on evidence from existing research, as well as identifying the need for further research (Parry, 2008). Such an approach would have great merit in the Queensland context, where, as discussed in chapter six, the approach to emotional and psychological abuse and neglect (and abuse and neglect of people with intellectual disability more generally) is characterised by a procedural, individualistic response to isolated instances of abuse and a managerial ethos, both within and across areas of government and non government service provision.
The development of a robust, proactive and strategic abuse prevention and response agency would be a central feature in combating the myriad problems besetting the current service system. The legacies of historical policy and practice, combined with low policy prioritisation and unevenly implemented policy frameworks have combined to result in a patchy response to the abuse and neglect of people with intellectual disability. In some instances, this response appears to be driven more by personal feeling on the part of key individuals than well designed and comprehensively implemented policy and practice.

Abuse prevention and response schemes need to operate in concert with approaches to service monitoring and evaluation which proactively guard against abuse and neglect. This is addressed further in section 7.11, below.

### 7.10 Advocacy

Individual advocacy support is needed, both in order for people to make complaints about their experiences of abuse, and for ongoing independent support. It is essential that people with intellectual disability have someone to walk beside them through the process of addressing emotional and psychological abuse in their lives. The institutional, systemic nature of much of the abuse also calls out for a systemic advocacy response to protect the rights of all people with intellectual disability living in disability accommodation services. The key findings of this research, particularly the central place of systems, the cumulative impact, and the lack of authority of people with intellectual disability in reporting the abuse combine to make people highly vulnerable to the actions of the service system, and almost completely powerless to change their own circumstances.

The unresponsiveness of the disability services sector to experiences of abuse and neglect was in part responsible for the moves of five participants in this study into alternative forms of accommodation. In
most cases, the family members of these participants were required to make considerable sacrifices of their own quality of life in order to make up for shortfalls in funding so that their family member could live a safer and more fulfilling life. The conceptual approach of the disability services system remains, despite the existence of policy rhetoric in the social model vein, firmly ensconced in the bio-medical model (Clapton & Fitzgerald, 1997). Although some individualised programs have begun (and some participants in the study have experience of these), it is largely resistant to more innovative models of individualised funding, true person centred planning, or family directed service provision which is fully funded. There is a big difference between partially-funded individual supports and fully-funded individual supports. Families and people with intellectual disability should not be having to make choices between abusive service or inadequate amounts of better quality service. This is, in fact, a form of systemic abuse, and compounds the impact of the original abuse on their lives.

7.11 Approaches to service evaluation and monitoring

The matrix of legislation, funding and policy in the state disability services arena forms a cultural environment which predisposes people with intellectual disability to emotional and psychological abuse and neglect in several ways. The fundamental failure of the sector to adhere to the spirit and the letter of either the Commonwealth or State Disability Services Acts (1986; 2002; 2006) sets the foundation. At a high level, the existing policy documents of government contain broad, pro-active strategies to recognise and address abuse and neglect at an early stage, and include recognition of some of the social and environmental factors influencing its heightened experience by people with disability. However, there is little evidence of a translation of this policy into practical action. Accompanying procedures remain focused on response to individual incidents of harm. The state wide information resource is highly procedural, focusing on indicators of abuse, service quality assurance requirements, and individual
assault response service contact details. The experiences of participants
did not reflect its successful dissemination.

Over time, the focus of the service system in complying with legislation
has moved to quality assurance mechanisms. These managerial
compliance systems are unlikely to be effective in uncovering more subtle
abuses, strengthening protection or building resilience against abuse and
neglect at either an individual or service level, due to their focus on
measuring the existence of policy and procedure, at the expense of
individual outcomes and alternative measures of service quality (DiRita et
al., 2008; Wills & Chenoweth, 2007). The ‘benchmarking’ of a quality of
service through quality assurance processes which fail to recognise abuse,
particularly subtle ongoing abuse and neglect, runs a very real risk of
endorsing and confirming the practices which gave rise to the abuse in the
first place. At the least, it is unlikely to adequately address either the
cause, recognition or response to abuse and neglect under these
conditions.

The approach taken by the disability services system to monitoring of
service quality does not at present adequately encompass an
understanding of the systemic causes of abuse and neglect. Nor does it
allow for the in-depth, qualitative analysis and evaluation which would
enable services to reflect on their practice and grow from the experience
(Clegg, 2008; Di Rita et al., 2008). There is a need to encourage and
foster reflective learning in services and the service system, replacing or
at least augmenting the current heavy focus on compliance to standards.
Current practices in place in Queensland complaint services, where
individual complaints which have potential strategic implications are
included in a trend report to senior management have merit, and could be
built into a whole-of-system monitoring process. The lived experience of
people with intellectual disability needs to form a significant component of
any such framework.

The allocation of limited resources is a key concern for government and
the sector. However, in the process, some important protections for
people with intellectual disability are not ‘funded into’ the dominant funding structure for disability services. Policy prioritisation at a high government level also impacts significantly on the experience of emotional and psychological abuse and neglect. Choices made at senior policy levels of government about which issues to address have the consequence of neglecting to attend adequately to the emotional and psychological abuse and neglect of people with intellectual disability.

The lack of vigorous and concerned responses at a systemic level to the experience of emotional and psychological abuse and neglect found in this study has significant implications for policy and practice in the disability services sector, and of course for people with disability themselves. There is a conspicuous lack of sanctions for breaches of legislation; a failure on the part of government to enforce the requirements of disability services legislation and policy; and soft or non-existent penalties for services which do not meet minimum standards under quality assurance measures – these are all indicators of a policy regime which fails to give due weight to the experience of abuse and neglect.

7.12 Better understanding protection

The protective factors identified in this study are consistent with those found in the literature – the importance of active, engaged supporters in your life, and the value of community and unpaid relationships (MacArthur, 2003; Bigby, 2004). The implications for policy and practice here are clear. Relationships protect people. Policy and practice in disability services needs to be geared to the development of supports which engage people in their communities as citizens, in a range of roles and relationships. However, the control which is vested by others in the lives of people with intellectual disability (often expressed through support) needs to be honestly acknowledged, and safeguards put in place to maximise protective features while protecting against the reality that a certain level of vulnerability to abuse will always be present in the lives of...
some people with intellectual disability. Fyson and Kitson put it well in writing:

The pretence that such support does not also include an element of control leaves a dangerous gap in which abusers may find an all too comfortable niche (2007, p.434)

This point is about recognising that developing policy responses to abuse and neglect go well beyond the development of policies and procedures titled ‘responding to abuse and neglect’. Responding to abuse and neglect in the lives of people with intellectual disability needs to be a consideration in the development, implementation and review of all legislation, policies, procedures and operational frameworks of disability services. Prevention is more about the creation of positive pathways and alternatives for people with intellectual disability to develop fulfilling and sustaining lives than the closing off of opportunities for abusers to abuse.

The lack of protections for people living in the private boarding house and hostel sector resulted in many abuses over time for several participants in this study. As services are owned and operated by private individuals, few protections are in place for residents, apart from a broad physical safety monitoring of premises scheme. It is imperative that strong protections for residents in this marginal environments are put in place. This is a difficult policy question for government, as it is situated in a climate of unmet need for services, a diminishing private service sector, and constrained resources. However, the private boarding house and hostel sector is comprised of a sometimes volatile mix of people with mental illness, intellectual disability, multiple disability, ex-prisoners, and homeless people (Fisher et al., 2007b). It is a highly vulnerable population, and people with intellectual disability and multiple disability are among the most vulnerable to emotional and psychological abuse and neglect.

Attitudes to the reporting of the experience of abuse and neglect appeared in this research as an issue which also has implications for both policy and practice. The experience of family members was, in all cases, that they
found out about some abuses of their family member after the event. Some people discovered gross abuses had occurred years after the event through reading file notes they had obtained through Freedom of Information legislation. Others were informed by service providers who had contact with their family member in other parts of their lives. Service providers, and services, do not own the information about their clients. They have a duty, both legally and morally, to inform the family members of people with high support needs of their abuse and injuries, in order that they might advocate for their redress, provide support to them and protect them from further abuse. For people with greater capacity to make their own decisions about informing family or other supporters, a range of power and control issues were in play which impacted on their ability to tell people what was happening in their lives. At times these were direct threats, but at other times, people simply had no access to their supporters, or had no language to describe their experiences in a way that would make people take action. These are both policy and training issues, and need to be addressed at broad policy setting, state-wide training and at service operations levels.

7.13 Education, training and support

This study found little systematic education and training about abuse and neglect was in place. No training on a state wide level, and no compulsory training, was located in the review. No stand alone training resources about emotional and psychological abuse and neglect were located.

Training, education and support is needed on all levels – for workers in their practice, their attitudes and values and their professional development; for service managers; for policy makers and senior bureaucrats. Key stakeholders and the literature are in parallel in insisting that this must go beyond procedural responses to a deeper understanding of the factors which increase risk, strategies to reduce the occurrence of abuse, and protective approaches (Page et al., 2002; Conway et al., 1996). Education and training needs to connect to an understanding of
abuse which better grasps the significance and influence of social and cultural factors (Brown, 2004; Penhale, 1999). Professional training and education is conceptually ad hoc and incongruent, with a mix of paradigms, management approaches and philosophies influencing both shorter professional development courses and university degrees. The influence of positivist conceptual paradigms and functionalist, therapeutic individualistic models is clearly evident. There is a need for a far stronger sociological approach to people with intellectual disability to underpin professional development and university education which is undertaken by developing senior managers.

Education and support of a different kind is needed for people with intellectual disability who use services; for family members and supporters; and for advocates. People with intellectual disability need education about self protective behaviour and about personal empowerment. Approaches to education need to be tailored to the lived experience of participants, and to be alive to the likely possibility of those participants having experienced abuse (Montalbano-Phelps, 2004). Peer education may be a useful approach, particularly in raising the concept of emotional and psychological abuse and neglect with people with intellectual disability who may not have previously understood that their maltreatment had a name (Collier et al., 2006; Saxton et al., 2001). Family members and advocates need to be able to recognise abuse, particularly in people who have high support needs, and to know how to take action against it and support the person.

7.14 Broad systemic change in response to external recommendations

The demonstrated lack of response by government to the findings of a series of judicial and parliamentary inquiries into abuse in accommodation facilities for people with intellectual disability in this state is damning (Stewart, 1995; Carter, 2000; House of Representatives, 2004). There is little evidence of systemic change being pursued to ensure the safety of
vulnerable adults living in similar facilities. Similarly, there is little significant funding or policy response to the underpinning recommendations of large scale government commissioned reports, such as the abuse review by Page, Lane & Kempin (2002), undertaken on contract for the National Disability Administrators group (made up of the State disability departmental heads). The fundamental finding of this large report was the need for primary prevention of abuse through the development of inclusive communities, advocacy, building individual resilience and family supports and intervention.

Over time, inquiries, reports and research have built a consistent demand for a framework which offers alternatives to the current approaches to preventing and responding to abuse and neglect of people with intellectual disability. Yet there is little response from the disability policy and service sector, which continues to operate largely unchanged. The addition of overarching policy statements which give lip service to the social model have little meaning when they are not supported with resources, training and education and practical action to give meaning in the lives of people living in those services.

The question of legal liability for the experience of emotional and psychological abuse and neglect remains to be tested. It is clear that the government, services and workers owe their clients a duty of care. To test whether this duty has been breached at law would be a most interesting question, and one which would be potentially worthwhile. It may be a very useful strategy in pursuing policy change, as legal compulsion may provide incentive for change in a way that exposure of the wrong of abuse and encouragement to make change has not.

In many ways it is impossible to extricate emotional and psychological abuse and neglect from other forms of abuse and neglect, particularly in considering the implications of research for policy. The issue of mandatory reporting of abuse and neglect of people with intellectual disability is one such area. The literature is divided on the benefits and disadvantages of mandatory reporting in other jurisdictions (Macolini, 1995. French et al.,
The most fundamental question about mandatory reporting concerns whether it would fill the gap left by service providers and other professionals who lack moral, policy and practice grounding in addressing abuse and neglect (Higgins et al., 2009). This gap, as seen in the disability services arena, is considerable. There are benefits in the raising of awareness, increase in reporting rates, and removal of ‘moral greyness’ in making decisions about whether or not to report. However, without substantial resourcing for taking reports, responding, and removing people from risk where needed, and for thoughtful and attitudinally based training and education for all stakeholders, such a system will only document the status quo.

### 7.15 Sorry – the hardest word?

In the child abuse domain, the abuse and neglect of children in institutional care has been responded to in several Australian states and other comparable international jurisdictions with formal acknowledgement of the wrong done to young residents, apologies by state governments, and schemes of compensation (Forde, 1999; Redress WA, 2009; Mathews, 2004). Despite findings of systemic abuse of a similar breadth and depth in disability institutions in Queensland, NSW, and other states of Australia (Carter, 2000; Stewart, 1995; Burdekin, 1993), no similar schemes have been implemented for people with disability to date. The profound ‘othering’ of people with intellectual disability at a cultural and structural level (Jones & Basser-Marks, 1999) may provide the conditions under which such people are not seen as worthy contenders for compensation or apology, or even where institutional practices are not viewed as abusive or neglectful (particularly in the case of more subtle or structural abuse).

This study has demonstrated that wrong has been done, on a profound level. The research clearly shows that people with intellectual disability experience abuse and neglect at significantly higher levels than other people in the community; that their experiences are responded to with comparatively little concern and vigour; and that this abuse and neglect
blights their lives. It builds from a body of literature that consistently supports these results in a broader abuse sphere.

At the very least, an honest accounting needs to be taken of the lived experiences of abuse and neglect of people with intellectual disability, particularly those people who have dwelt in institutional environments and navigated the services system for years. An apology is due to those people - for the abuse and neglect they have experienced at the hands of malevolent individuals, for the maltreatment which was the result of poorly executed policy and procedure, and for the failure of the disability services system to protect and safeguard the rights of people living within it to a safe and fulfilling existence.

Such an apology must occur at a judicial level, as with the Forde inquiry into child abuse in Queensland institutions (1999), to ensure gravitas, legal weight, and the capacity to make recommendations to government which have financial obligation, such as schemes of compensation.

**7.16 Further research**

The review of the literature clearly shows that the abuse research landscape is complex and fragmented, and is compartmentalised into typologies of disability, abuse or marginalisation. A significant proportion of the scholarship in this literature is normative, and builds on already excluding or problematic concepts of disability, abuse or otherness and technically questionable practices, contributing further to the exclusion of people with intellectual disability from full citizenship and moral authority. There is an identifiable need for research which considers 'higher order' issues which are at play here, such as questions of the denial of citizenship, rights, humanness, and otherness.

An unmistakable need can be seen for further research which explicitly seeks the thoughts and views of people with intellectual disability on their experiences of emotional and psychological abuse and neglect to extend
the small but important body of work which has been conducted to date (refer, for example, to Brown, 1994; Malacrida, 2005; Sequira & Halstead, 2002; McCarthy, 2003). This study adds the voices of nine people to the cohort. However, there are many absent voices – people living with mental illness, people with higher support needs, people who have not yet entered the services system – from whom much could be valuably learnt.

Narrative collage, the methodological approach used in the research, may hold possibilities for engaging people with significant support needs due to intellectual disability in research on a range of issues. The strength of the approach lay particularly in its privileging of the participation of the person with intellectual disability; being able to rely on supporters for the information about timelines and other historical facts sometimes so difficult for people with intellectual disability to remember (allowing the focus of the person to remain on their narrative); and the natural way in which the research process left the person and their supporters together for mutual support at its conclusion. Its effectiveness in this instance in supporting people with considerable abilities to participate in research of a distressing nature has implications for research in other areas – other forms of abuse and neglect are obvious, but other potential research topics which spring to mind include grief and loss, isolation and the experience of medical intervention. There may also be considerable merit in testing the methodology with people with higher support needs on broader issues, such as their experience of community inclusion, where the ethical issues around consent may be less complex, due to the risk of distress to participants being lower.

7.17 Taking the fight outside service land

Finally, this thesis treats emotional and psychological abuse and neglect as a problem within the disability services system. The study considers the experiences of people who live within that system. However, it must be recognised there is little acknowledgement or understanding of emotional and psychological abuse and neglect at a public or broader
community level, and no demand for it to stop. There is a need to step outside of the disability services arena with this issue and to create a level of awareness in the broader community of the frequency, range and volume with which abuse and neglect is experienced. From this, action can be taken to raise community expectations that people with intellectual disability should be able to exercise their right to live free from abuse and neglect.

7.18 Summary: the need for capacity building

Approaches are needed which build capacity to resist and deal with emotional and psychological abuse and neglect in people with intellectual disability and in those who support them at all levels – family members and advocates, service support workers and managers. Such approaches need to acknowledge the individual, systemic and structural levels at which emotional and psychological abuse and neglect operates, be based upon sound and ethical research, and be grounded in the lived experience of people with intellectual disability.

Underpinning all three levels is the need for the creation and sustenance of protective factors – community based, individualised supported lifestyles with multiple relationships with unpaid people – demonstrated in the literature, and confirmed in this study to safeguard people against the experience of emotional and psychological abuse and neglect (Fisher et al., 2007a; O'Brien, 1993; Felce, 2000).

The importance of individualised, well developed policy and practice guidelines for services which are informed by the lived experience of people with intellectual disability should not be underestimated in a capacity building approach. While it is critical that workers and managers are provided with education and training that equips them to make moral decisions, rather than to follow procedural pathways, a framework needs to be in place which supports those individual responses and provides a context for them.
At an individual level, a capacity building approach to addressing emotional and psychological abuse and neglect needs to give priority to developing the individual resilience of people with intellectual disability and those who support them so they can better resist the subtle, pervasive and cumulative impacts of this maltreatment. Skill needs to be built in workers, managers, family members and advocates to better recognise this abuse and neglect and to support people through it. Education and training needs to be provided that goes beyond the procedural to develop attitudes and values that support change and growth. Advocacy needs to be resourced and sustained, on both crisis and ongoing bases, to ensure that people have someone to walk beside them through the difficult process of addressing emotional and psychological abuse in their lives. Finally, it is essential that support services are in place and used by people with intellectual disability who have experienced emotional and psychological abuse and neglect.

At a systemic level, capacity needs to be developed in service management, Government departments, Ministers, policy makers, analysts and lobbyists to more effectively address the legislative, policy and procedural responses to abuse and neglect of people with intellectual disability. Many of the existing responses remain at the technical level, and are missing moral and educative components. The disability services system needs to move beyond compliance frameworks to ensure protection and upholding of the rights of people with intellectual disability to safety and freedom from abuse and neglect. To do this, the priority of the policy focus on abuse and neglect prevention needs to be increased. This research confirms a body of work that clearly tells us that much abuse is systemically caused (Brown, 2004; Sobsey, 1994; Penhale, 1999), and the service system needs to respond to this evidence by investing seriously in energy and resources to investigate and respond to this. There is a dearth of knowledge about this area, and a small research base. Systemic advocacy which is funded and untied, and which can act without fear or favour, can support this aim.
At a structural level, the abuse landscape is highly fragmented, into types of abuse, types of victim, types of crime. There is a need for a concentration on ‘higher order’ issues which are at play here, such as questions of citizenship, rights, humanness, and otherness to develop more informed responses to specific problems, such as the experience of emotional and psychological abuse and neglect.

Responses to emotional and psychological abuse in disability services have been to date been professionally designed and controlled. There is a need for ‘grass roots’ involvement of people with intellectual disability and their supporters in defining, recognising and designing responses to this abuse and neglect.

Finally, in the broader community, there is little or no recognition of the volume and impact of these harms against people with intellectual disability. This is not a ‘disability land’ problem – it is a social problem that should be broad enough to acknowledge all humanity.
Chapter eight: Concluding remarks

You know, it doesn’t matter what abuse, what type of abuse, someone has to suffer, if no-one makes it better, if no-one says sorry that something went wrong, because no-one is going to say to you, ‘I’m sorry this happened’. And sometimes Fran will just cry. And Fran’s not a cryer. She’ll start crying, and workers have said to me, ‘Why? She was happy a minute ago, and then she just crumpled up and started to cry’. And I said, ‘all I can think is that she’s remembering things’. Something’s brought something back. All we can do is sit next to her and hold her hand and tell her she’s safe and she’s not going to be left with this alone.

- Amanda, Fran’s mother

This final chapter offers some concluding remarks, with which to draw the thesis to a close.

Together, the nine narratives of people with intellectual disability form a complex and confronting collage of emotional and psychological abuse and neglect – a collage of insult and injury, but also one of strength, fortitude and resilience in the face of hardship. There is more to this than a victim story. People are much more than their abuse experiences – their narratives reflect this. However, their experiences of emotional and psychological abuse and neglect have without doubt changed them, and for several, altered their life courses. The impact felt by this insult and injury, although grossly under-recognised by the disability services system, can hardly be understated. These are stories that we need to hear, to learn from.

The narrative collage approach allowed for the development of multiple pictures of the worlds of participants and their experiences of emotional
and psychological abuse and neglect. These experiences, framed through the emotional and psychological abuse and neglect framework, have shown that this form of maltreatment is complex and multifaceted. At the core of them are relations of power and control, which influence and implicate the actions and behaviours of abusers at individual, systemic and structural levels.

Connected to power relations are the key insights from the research concerning the central place of systems in this form of abuse and neglect; the cumulative impact of the abuse; the recognition of the abuse by people who experience it; and the lack of moral authority accorded to people with intellectual disability in the reporting of their own abuse. These underpinning power imbalances at multiple levels, in combination with systems failures to recognise and redress the root causes of maltreatment, result in policy and administrative structures which have failed to adequately respond to the emotional and psychological abuse of people with intellectual disability in three primary ways.

First, competing policy priorities, resource allocations and managerial approaches to quality assurance have mitigated any integrated approach to abuse prevention and response for people living in disability accommodation services at the broadest level. Second, in the middle tier, an individualistic, procedural approach to abuse response has masked recognition of the medium and long term nature and impacts of much emotional and psychological abuse in the lives of people with intellectual disability. The third tier, at the level of daily service provision, is where the lack of recognition and understanding of the phenomenon of emotional and psychological abuse and neglect is played out in routine actions which fail to adequately acknowledge the moral worth and respect of people for whom service is provided – not only through intentionally abusive actions, but most commonly through unthinking following of policy and procedure, through workers ‘following the rules’.

An indubitable part of the history of people with disability is social death models – the institutionalisation, isolation and segregation which has been
a part of the lives of many people with intellectual disability (Young, 2003; Johnson & Traustadottir, 2005). These practices are sadly far from gone, and continue within different arrangements of brick and mortar (Harrison, 2000; Ferguson & O’Brien, 2007). A call is made in these closing remarks to dispute any moral integrity granted to models which continue to take authority from people with intellectual disability and those close to them, and vest it in the system (Horne et al. 2001). We need to contribute to change which builds from the lived experience of people with intellectual disability around subtle abuse and neglect in order to have any hope of understanding how to reframe services in such a way that they do not continue to abuse.

The marginalised social group experience and conceptual positioning of people with intellectual disability as ‘profoundly irrelevant’ (Clapton, 2003) results in damaged and morally compromised identities for people with intellectual disability (Lindemann Nelson, 2001). When combined with the policy and administrative failures outlined above, this is a highly vulnerable state. Lindemann Nelson (2001) holds that it is just this situation that creates mandatory identities, within which expectations are set about the ‘resident’ category which perpetuate abuse and neglect.

The place of people with intellectual disability needs to be recast. Their rightful place is not as recipients of policy and practice, but as determinants and recipients. Their authority in recognising and reporting abuse and neglect in their lives needs to be accorded the respect it deserves. Their families and advocates, especially for those people with high support needs, also have an important role to play as allies in altering the culture and practice of the service landscape to make it safer and more responsive.

These nine people are a small group, but their stories are similar to many hundreds of others in their state, and to many thousands of their contemporaries across the country. It is likely that there are many, many other stories like these. These lives matter. We have to be ashamed of what has happened here. Who is going to bear that shame?
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Appendices

Appendix 1: Information and consent form – easy English

Emotional Abuse and Neglect: The experience of people with intellectual disability who live in services

Information about this research for people with intellectual disability

Who is doing the research?
My name is Sally Robinson. I am a student at Griffith University. I am doing this research for my uni degree.

If you need to contact me, my phone number is 0410 484 405, and my email address is Sally.Robinson2@student.griffith.edu.au

This research is being supervised by Professor Lesley Chenoweth at Griffith University. Her phone number is
(07) 3382 1485, and her email address is l.chenoweth@griffith.edu.au.

What is this research about?
My research is about the bad treatment that people with intellectual disability sometimes get when they live in group homes or institutions.

I want to know about the sort of treatment you got when you lived in a group home or institution.

I also would like to know what makes things worse, and what sorts of things help make things better.

If you say it’s OK, I will also be talking to your family, your advocate and another person who has supported you while you were living there.

I will also be talking to other advocates and government people about how they think bad treatment could be stopped.

Why is this important?
Lots of people have been treated badly when they live at a service. This is a big thing for them.
There hasn’t been any research yet that asks people with intellectual disability what they think about this bad treatment. This research might help other people, so they don’t get bad treatment at services.

**What does the research want to do?**

This research wants to:

- Find out what it’s like if you are treated badly when you live in a service
- Find out what makes bad treatment happen
- Find out what could have stopped the bad treatment from happening in the first place
- Do the research in a way that includes people with intellectual disability, and tell other people how they can do it too
- Tell other people about what the research finds out, so we can stop it happening as much

**What are you being asked to do?**

- I would like to meet with you up to four times in total (two or three times in private and one time in a group). We will talk about what it was like living at the service. Each meeting will probably take about one hour.
- If you would like to, you are welcome to have someone come to the interviews with you as a
support person – you don’t have to do this if you don’t want to.

· You can change your mind about being interviewed at any time – you don’t have to finish an interview if you change your mind

· I also want to meet with your family, advocate or other person who supports you once, so I can ask them what they think about the bad treatment you had.

· After we have our three private meetings, I would also like to meet with you together with your family, advocate or other person who supports you. At that meeting, I’d like to talk about what you are going to do in the future.

Who will be in the research?
The research will be with people who have lived in group homes or institutions in the past – not now. It will also be with the key people who support you. This may be your family, friends or advocate.

I want to make sure that this research does not upset people who are in it. There are some people who won’t be in the research. They are:

· People who are getting help from a counsellor about their bad treatment
People who are not able to give consent to being in the research
People who are still living at the place where they had the bad treatment

The good and bad parts of being in the research
You won’t get any direct good things from being in this research (like money). You will get the chance to tell me about what has happened to you at the group home or institution you lived at. You will be helping me to find out how we can make things better for other people who have had bad treatment too.

The main bad thing that could happen if you agree to talk to me about the bad treatment you have had is that it might make you feel upset. You might feel sad or angry about it.

You can bring someone to the interviews with you to give you support, if you would like to. If talking about these things with me does make you feel upset, there is a counsellor called Christine who you can talk to. She can help you to feel better. Her phone number is at the bottom of the next page.

Keeping your information private
When we talk, I would like to record what you say with a tape recorder. This is to help me remember everything you say. After I go, I will listen to the tape and write down the things you have said. Once I’ve written things down, I will throw the tape away. If you want, I can read the notes for you, to tell you again what you have said.

I will make up a name for you, and use that name in my notes instead of your real name. This is to make sure no-one knows it’s you who told me these things.

I will keep all the written notes locked up, so no-one else can read them.

If you tell me about something that has happened to you that is against the law, I may need to talk to someone about it, like the police, to get help for you. I will not talk to anyone else without talking to you about it first.

*Meeting your costs*

I will meet with you at your home, or another place if you like. I’ll come at a time that suits you. If you come to meet me somewhere else and it costs you money to get there, I will give you the money, so it doesn’t cost you anything.

*Changing your mind about being involved*
You can change your mind about talking to me. You can decide not to be in this research at any time. I will not be upset with you if you don’t want to keep being in it.

*Telling you what I find out*

After I have finished talking to you and everyone else in the research, I will find out a lot about bad treatment. If you want, I will tell you what everyone has said about the bad treatment they have had. You can come to a meeting with other people to find out what you have all said. If you don’t want to do that, I can come to you and tell you on your own.

*Feeling OK*

If talking about these things with me does make you feel upset, there is a counsellor called Christine Douglas who you can talk to. She can help you to feel better. Christine has worked with lots of people who have intellectual disability before. She can also help you find a counsellor who you can see for a longer time if you need to. Her phone number is 3357 8086.

*Questions?*

If you have any further questions about the research, please ask me. You can contact me by phone on 0410 484 405, or by email at Sally.Robinson2@student.griffith.edu.au
Concerns

If you think I have not treated you fairly, you can call my boss at the University. Her name is Lesley Chenoweth, and her phone number is 3382 1485. You can also call the Ethics Manager at the university on 3875 5585.
Expression of consent for people with intellectual disability

My name is Sally Robinson. I am undertaking this research for my PhD study at Griffith University.

My study is called ‘Emotional Abuse and Neglect: The experience of people with intellectual disability who live in disability services’.

This form asks you to agree to:

- Talk to me two or three times on your own (or with a support person if you like). Each time we will talk for about one hour.
- Talk to me once in a group interview, with your family member and anyone else you think should be there.

By signing this form, you are agreeing that you understand the information sheet I read through with you, and that you know

- you are agreeing to meet with me two or three times on your own (or with a support person) and once in a group interview;
- you have been able to ask questions, and I have answered them OK;
- the risks in being in the research;
- you won’t get any money or other benefit from being in the research;
- you don’t have to be in the research – it’s your choice;
- any expenses you have in being the research will be paid by Sally;
- If you tell Sally about a crime that happened to you, she may need to tell someone (like the police) about it.
• if you have more questions I can ask Sally;
• you can change your mind and stop being in the research at any time, and no-one will be upset with you;
• if you have any problems with Sally or the interviews, you can call Sally’s boss, Lesley Chenoweth at Griffith Uni on 3382 1485. You can also call the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3875 5585 (or email him at researchethics@griffith.edu.au) if you think the research isn’t being fair to you or other people; and
• you agree to be in the project.

Name:

Signature:

Date:
Appendix 2: Information and consent form – families and supporters

Emotional and Psychological Abuse and Neglect: The experience of people with intellectual disability who use formal disability services

Information for Participants: Family Members and Supporters

Who is conducting the research?
My name is Sally Robinson. I am a PhD student in the school of Human Services at Griffith University, and am undertaking this research for my PhD study. My contact details are (02) 6689 5207 or Sally.Robinson2@student.griffith.edu.au
This research is being supervised by Professor Lesley Chenoweth at Griffith University. Her phone number is (07) 3382 1485, and her email address is l.chenoweth@griffith.edu.au.

What is this research about?
This research aims to identify and describe the quality of the emotional and psychological experiences of people who have lived in formal disability services. I am gathering the perspectives of people with intellectual disability who have lived in disability services, and family members or other support people who know the person well.

I will also be talking about how emotional and psychological abuse and neglect are managed in government and policy with key agencies and individuals in the disability field.
This study has been approved by the Griffith University Human Research Ethics Committee.

Why is this issue important?
The reading I have done indicates that abuse and neglect of people with intellectual disability is an issue which affects a significant number of people, and one which has a dramatic impact on people living in accommodation support services.

No in-depth research which includes interviews with people who have experienced emotional and psychological abuse and neglect appears in the literature. This study will add significantly to the understanding of the experience of this abuse and neglect on a vulnerable group. It may influence policy and practice in the disability field, both in Australia and overseas.

Aims of the research
This research seeks to:
- define and investigate the experience and impact of psychological and emotional abuse and neglect of adults with intellectual disability living in funded specialist disability services
- explore and investigate the causes and risk factors
- identify preventative measures which may have stopped the person experiencing such abuse and/or neglect
- add to the developing literature on ethical research with people with intellectual disability on sensitive issues
- provide research which demonstrates the impact of the issue on the participant group, and which creates an expectation of change in the
wake of public recognition of the responsibility to address this form of abuse and neglect.

What are you being asked to do?
I would like to meet with you for one individual interview, in which we will discuss the experience and impact of the emotional and/or psychological treatment that your family member or friend has had while living in a disability service. This interview will probably last between 30 minutes and 90 minutes.

The basis of selection of participants for the research
The study will include people who have previously lived in funded disability services, and the key people who support them. This may include family members, friends or advocates.

I want to ensure that this research does not cause distress to people who are involved in it. The following groups of people will not be included in the research:
- People who are currently in a therapeutic relationship about the experience of the abuse
- People who are not able to consent to participating in the research (to avoid unduly distressing people who may not fully understand why they are being involved in this study)
- People who are currently living the place where they have experienced the abuse (to ensure people are not in fear of punishment or ill treatment by their current service provider)

Benefits and risks of being involved
This research may provide some benefits to you, although there are no direct benefits. The benefits include the opportunity to tell a story which has had significant impact on you, the opportunity to contribute to research which may make things better for other people living in disability services, and the opportunity to participate in research which is adding new knowledge to research and practice in the area.
There are certain risks to your participation in the research which need to be clearly outlined. It is possible that elements of the research may be personally distressing to you.

If you feel in any way distressed following your participation in this research, a counsellor who is experienced in working with people with intellectual disability and their families is available for no cost to you (her details are below).

It is possible that participants in the research may disclose experiences which involve illegal or criminal activities which have not been prosecuted. In this instance, the researcher may need seek further guidance from both her supervisor and the Ethics Office of the University and/or to provide information to authorities to ensure criminal activity is appropriately responded to. There is a possibility that the researcher’s notes may be subpoenaed in the event of court action.

Confidentiality of the information you provide
Our interviews will be tape recorded, and a transcript made of the tape recording. The tape will be destroyed after the transcription is made. If you would like, the transcription can be provided to you so you can check it is an accurate reflection of your words. The transcripts will not include your full name. The material gathered will be coded (a number will be allocated to each participant, and used to identify each person), and the code will be stored separately from the transcripts. They will be kept securely, in a locked filing cabinet, and on a password protected, non-networked computer.

All efforts will be made to ensure no identifying details are retained in the information on which the analysis of findings is made. Pseudonyms and changed place names will used for any data which is used for publication.

Reimbursement of your costs
I will meet with you at a time and place that is suitable to you. If you incur any costs in participating in the project (such as travel expenses), these will be reimbursed.

**Changing your mind about being involved**
Your decision to participate in this research is completely voluntary. At any point in the research, including during interviews, you can change your mind about being involved, and withdraw your consent.

**Feedback to participants**
On completion of the research, a summary of the overall findings will be sent to you, if you would like to know the outcome of the study. A meeting will also be held for those participants who wish to come, at which the summary findings will be talked through.

**Debriefing**
If you have been distressed at any point by your participation in this research, a specialist counsellor, Christine Douglas from InnerWorks Counselling, is available to assist you. She is experienced in working with people with intellectual disability and their families and supporters. This counselling is available to you at no cost. Christine can also refer you on to longer term counselling and support services if they are needed. Her number is 3357 8086.

**Your privacy**
The conduct of this research involves the collection, access and / or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at [www.gu.edu.au/ua/aa/vc/pp](http://www.gu.edu.au/ua/aa/vc/pp) or telephone (07) 3875 5585.
Conflict of interest
Over the past five years, the researcher has been involved in funded research for various government departments in Queensland. This research is not connected to any previous research in this context.

Questions?
If you have any further questions about the research, please ask me. I can be contacted by phone on 02 6689 5207, or by email at Sally.Robinson2@student.griffith.edu.au

Concerns about ethical conduct
If you have any concern about the ethical conduct of the project, or my conduct as a researcher, please contact my supervisor, Professor Lesley Chenoweth, on 07 3382 1485 (or l.chenoweth@griffith.edu.au). You can also contact the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University on phone 07 3875 5585 or by email at research-ethics@griffith.edu.au.
Expression of consent: family members and supporters

My name is Sally Robinson. I am undertaking this research for my PhD study at Griffith University.

My study is called 'Emotional and Psychological Abuse and Neglect: The experience of people with intellectual disability who use formal disability services'.

This form asks you to consent to the following participation in the research:

- Participation in an individual interview, which will last between 30 and 90 minutes

By signing below, I confirm that I have read and understood the information package and in particular that:

- I understand that my involvement in this research will include participation in one individual interview;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that any costs of participating in the research will be reimbursed;
- I understand that if I have any additional questions I can contact the researcher;
• I understand that I am free to withdraw at any time, without comment or penalty;
• I understand that I can contact the research supervisor, Prof Lesley Chenoweth on 07 3382 1485 (or l.chenoweth@griffith.edu.au) or the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3875 5585 (or researchethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and
• I agree to participate in the project.

Name:

Signature:

Date:
Appendix 3: Screening questionnaires

Screening Questionnaire: Key participants

I want to find out about how well you were treated in the disability service where you used to live [use name of service if possible].

I would like to talk to you and also to your family or advocate or friend about what it was like for you.

The questions I am going to ask you are to make sure that you understand what’s involved in being in this research. They are also to make sure that I don’t include anyone who is going to find it very upsetting. There are some rules about who I am allowed to include in the research.

1. Have you had bad treatment at a place where you live? [prompts if necessary: talking to you in a way that’s not nice; being ignored]
2. Do you still live at the place where those things happened?
3. Do you have anything to do with that place anymore?
4. Is it OK to talk to me about that time?
5. Is it OK with you if I talk to [parent/advocate] about this too?
6. Do you go to a counsellor to talk about that time? Have you ever been?
7. I would like to come and talk to you two or maybe three times about that time. I would also like to come and talk to [your family/advocate] once about what they think about it. Is that OK?
8. As well as us meeting privately, I would to meet with you and [parent/advocate] together in a group interview. This meeting is not to tell them your private information. It is to talk with all of you about how you got over that bad time.
Is that OK?

9. Who do you think I should talk to about that time in your life?

**Screening Questionnaire: Family members/carers**

This research aims to identify and describe the quality of the emotional and psychological experiences of people who have lived in formal disability services. I am gathering the perspectives of people with intellectual disability who have lived in disability services, and family members or other support people who know the person well.

I want to make sure that people know what they are agreeing to be involved in, and that I don’t include people who are likely to find the research very distressing. I can’t include some people who do not fit the research criteria.

1. Has [your son/daughter/person you care for] experienced emotional or psychologically abusive or neglectful treatment at a disability accommodation service [use form of accommodation, provided by family gatekeeper - for example, group home]?
2. Do you think they would be willing to talk to me about that experience?
3. Are you willing to talk to me about their experience?
4. Do you think they will be happy for you to talk to me about that experience?
5. Does [the person] still use the service where the bad/abusive treatment occurred?
6. Does the person, or you, still have a relationship with the service in which the treatment happened?
7. Does the person, or you, go to counselling/talk to anyone formally about the experience? Have they ever been?
8. I would like to come and talk to the person up to three times about their experience. I would also like to come and talk to you once
individually about your views of their experience. Are you willing for that to happen?

9. Additionally, I would like to meet with you, the person, and any other relevant support person [advocate, etc] together in a group interview. The group interview is not to share information conveyed in private in the individual interviews. It is to talk with all of you about how you come to terms with the experience and move on. Are you willing for that to happen?

10. Who do you think I should talk to about that time in [person’s] life?
Appendix 4: Interview questions – people with intellectual disability, families and key stakeholders

Interview 1: Key Participants

Aims:
- To find out the pattern and key experiences of the person’s life – abbreviated life history.
- To get a sense of where it will be best to focus discussion of abusive treatment in the next interview

General recollections
- [base on information collected in screening interview – eg number of service lived in]
- Where do you live now?
- Do you like it there?
- What do you like/not like there?
- Can you tell me about other places you have lived?
  [Chronologically if possible – or from most recent to least recent]

Specific service
- Can you remember what it was like at [place of residence]?
- What did you like there?
- Where there things you didn’t like?
- What were they?
- How did staff talk to you?
- Did you like the way they talked to you?
- How did other people treat you?

Emotional and psychological treatment
- Were there times you weren’t happy at [place of residence]?
• Why weren’t you happy there?
• Were you able to talk to anyone about feeling unhappy? [who? Their response?]

*Routines of house* (to gauge how influential the person was on the routines, and how much they were consulted on the way the house operated)
• Did the staff do a lot of paperwork?
• What do you think they wrote down?
• Did they ever tell you what they wrote?
• Who decided when you had a shower?
• Who decided when it was time for dinner?
• Who decided what you ate for dinner?
• Did you all sit together for dinner?
• Did you talk at the dinner table?
• What did people talk about?
• Did you go in the car with staff?
• Did you sit in the front or back?
• Did you talk in the car? What sort of things did you talk about?

*Fun stuff.*
Next time, we will talk more about the treatment you had at X that you weren’t happy with. Is that OK with you?

**Interview 2: Key Participants**

Aim: to gather in-depth data on emotionally and/or psychologically abusive experiences.

*Note: Frame this interview after first one conducted, so can pick up on elements likely to be fruitful from short life history in interview 1. Go through key incidents or patterns one at a time.*

*Depending on participant, this may be done in one interview, or it may be necessary to return for another interview.*
Do you remember when I came to talk to you before and you told me
about some of the difficult things that had happened in your life?

**Could you tell me a bit more about X?**

*Tell me a bit about what it was like when x happened to you*
- What do you remember about it?
- Can you remember what you did? What made you do that?
- Can you remember what you thought?
- Can you remember how you felt? What made you feel that way?
- How many times did it happen to you?

*Can you remember who was the first person you told about what
had happened to you?*
- What was it like when you told them? What did you want to happen?
- When did you tell them?
- Was it the same day it happened, a few days later, or a long time later?
- If long time ago – what stopped you from talking about it?
- What do you think should have happened?

*What do you think about x now?*
- What thoughts do you have about it?
- Have you though about it in the last week? Where were you? Who were you with?
- What do you do if thoughts about x pop into your head?

*Do you have any pictures in your head about x?*
- What are they?

*How does x affect you physically in your body?*
- Do you feel it in your body? Where do you feel it?
- How is your sleeping?
- Do you have any problems sleeping? What problems do you have?
• Do you have any dreams at night?
• Do you remember any of your dreams? What were they about?

**How do you feel when you think about x?**
• What do you do when you feel like that?
• Who notices when you feel that way?
• How can they tell you are feeling like that?

**What’s it like talking about x now?**
• How do you feel when I ask you these questions?

*Meaning of the event to their life*

**When x happened what did you think would happen to you?**
• What made you think that?

**How has x affected your life?**
• How has your life changed since x happened to you?
• Have you noticed any changed in yourself?
• Have you noticed any changes in other people?
• If your mum/dad or husband/wife were in the room what would they say?
• Has x stopped you doing anything? What did it stop you doing?

**Has it changed your relationship with your family? In what ways?**
• Has it changed your relationship with your boyfriend/girlfriend or friends? In what ways?

**Can you tell about something good that happened while you were living there?**
• What was it?
• Who did you do it with?
• What did you like about it?
• Have you done it again since then?
• Would you like to?
Family/advocate/friend interview

1. General recollections
   a) Can you give me a summary of [person’s] life? How long have you been involved in their life?

2. Work through definition of emotional and psychological abuse and neglect.
   a) Do you feel that [person] ever experienced this sort of treatment? Can you tell me more about that?
   b) Do you feel that other people living in the house also experienced this sort of treatment?

3. For each of the specific instances mentioned above:
   Were you aware of any occasions when [person] wasn’t treated well by the service[s]?
   Can you tell me about those times?
   What sort of impact do you feel this treatment had on [person]?
   How did you know it was having an impact [behaviour changed, person told you, etc]?
   Were those changes temporary, or has there been a continuing impact? If so, what is the impact?
   Did you feel able to take any action [eg, complain]?
   What happened if you did?
   What do you think should have happened?

4. Positive experiences
   What sorts of treatment did you know X received that they, or you, found supportive?
   What was good about these experiences?
Appendix 5: Information flyer for recruiting participants

Research Project

Emotional support in disability services:
emotional and psychological treatment of people with intellectual disability who live in group homes and other residential services

- Are you a family member or carer for someone who lives, or has lived, in a group home or other formal accommodation service?
- Do you have comments to make on how well you think they were treated when they lived in that place?
- Do you think they would be interested in being involved in a research project about their experiences?

What's the research about?
I am a student at Griffith University who is doing PhD study about emotional and psychological abuse and neglect. I am looking particularly at the experiences of people with intellectual disability who have lived in disability services, and their families and other supporters.

This research aims to identify and describe the quality of the emotional and psychological experiences of people who have lived in formal disability services, and to look at what makes it worse and what can help prevent poor treatment. I am gathering the perspectives of people with intellectual disability who have lived in
disability services, and family members or other support people who know the person well.

**What’s involved?**

I would like to come and talk more about the project with you and the person for whom you care.

If you agree to be involved, the project will involve:

- The person themselves talking with me about their experiences on four separate occasions (three times individually, and once at a group interview)
- Talking with me yourself about the person’s experiences on two occasions (once individually and once in a group interview)
- Meeting in a group interview with me, the person themselves, family and/or carers and anyone else who you think would be important to include.

**If you are willing to find out more about being involved in the project, please call Sally Robinson on 0410 484 405.**

Thank you for your help
Appendix 6: Definition of emotional and psychological abuse and neglect handout for family and key stakeholder participants

Defining emotional and psychological abuse and neglect

A. Terrorising:
   - Coercing
   - threatening to hurt
   - frightening
   - intimidating
   - withholding basic support and rights
   - terminating relationship and leaving the person unattended
   - reporting non-compliance with a program
   - using more intrusive equipment
• using consequences and punishments to gain compliant behaviour
• pressuring the person to engage in fraud or other crimes

B. **Corrupting/exploiting:**
• socialising a person into accepting ideas or behaviour which oppose legal standards
• using a person for advantage or profit
• training a person to serve the interests of the abuser

C. **Caregiver privilege:**
• treating the person like a child or servant
• making unilateral decisions
• defining narrow, limiting roles and responsibilities
• providing care in a way to accentuate the person’s dependence and vulnerability
• giving an opinion as if it were the person’s opinion
• denying the person the right to privacy
• ignoring
• discouraging
• prohibiting the exercise of full capabilities

D. **Isolating:**
• controlling access to friends, family and neighbours
• controlling access to phone, TV, news
• limiting employment possibilities because of caregiver schedule
• discouraging contact with the case manager or advocate

E. **Minimising, justifying and blaming:**
• denying or making light of abuse
• denying physical and emotional pain
• justifying rules that limit autonomy, dignity and relationships for program’s operational efficiency
• excusing abuse as behaviour management
• excusing abuse as caregiver stress
• blaming the disability for the abuse
• saying the person is not a ‘good reporter’ of abuse
F. **Withholding, misusing or delaying needed supports:**
   - using medication to sedate the person for agency convenience
   - ignoring equipment safety requirements
   - breaking or not fixing adaptive equipment
   - refusing to use or destroying communication devices
   - withdrawing care or equipment to immobilise the person
   - using equipment to torture the person

G. **Degrading:**
   - punishing or ridiculing
   - refusing to speak
   - ignoring requests
   - ignoring person
   - harassing
   - humiliating
   - ridiculing the person’s culture, traditions, religion
   - ridiculing personal tastes
   - enforcing a negative reinforcement or behaviour program the person doesn’t consent to

H. **Neglecting:**
   - failing to provide nurturance
   - failing to provide stimulation
Appendix 7: Summary of research findings for participants

Insult and injury: a narrative approach to understanding the experience of emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services

Research project summary outcomes

This PhD research aimed to understand the experience and impact of emotional and psychological abuse and neglect on people with intellectual disability living in disability accommodation services. It was completed by Sally Robinson from Griffith University.

Background: existing research and policy

There has been little research about emotional and psychological abuse and neglect of people with intellectual disability to date. Research which has been done shows that it is poorly recognised and responded to in the lives of people with intellectual disability(1), apart from a small number of studies which directly ask people with disability about their experiences, where it features strongly as a common experience (2).

Emotional and psychological abuse and neglect is happening to people in a policy environment where the focus of many services is directed towards management and compliance to government quality standards (3). Government and service policy frameworks give little attention to addressing this form of abuse and neglect, and there are few avenues of

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legal redress for people who have suffered it. Responses are highly procedural, there is little training for workers, and understanding of more subtle abuse and neglect is poor. This results in a disparity between people’s experiences and service responses to their abuse.

The research approach
This study is based in the belief that the knowledge and truth about the issue is vested in those who have lived it, and those close to them. It used a method called narrative collage to find out these experiences. Narrative collage involves putting the person with intellectual disability at the centre of the collage, and inviting other supporters into the research (with their agreement) to ‘bolster’ their narratives. Together, their stories build a collage of the person’s experience.

Four people with intellectual disability and their supporters participated in the research in this way. Five family members participated in the research on behalf of their family member with high support needs. Narratives or stories of the experiences of nine people with intellectual disability in disability accommodation services grew from this involvement. A further sixteen people from policy and advocacy bodies participated in the research as key stakeholders, talking about systemic issues.

Results of the research
A framework for understanding emotional and psychological abuse and neglect was developed during the research (4), and used to group the abuse and neglect experiences into the following categories:

4 Kovener (2000)
The stories of the nine people with intellectual disability revealed a total of 228 incidents of emotional and psychological abuse and neglect in their ‘service lives’. All nine people experienced multiple forms of emotional and psychological abuse and neglect on multiple occasions.

Some abuse was caused by the actions of malicious individuals. However, much more common was abuse and neglect which was caused by staff following service policies and routine practices that did not adequately respect people’s rights. These practices, procedures and policies seemed to focus much less on the needs of individuals and much more on the convenience of the system. Some abuse and neglect had even broader roots in the social structure (such as abuse with a racial or cultural component).

Across this range of abuse and neglect, a number of themes emerged which applied to all or most of the categories of emotional and psychological abuse and neglect, and which had strong impact on people’s lives. The themes centred around:

- the diffuse and pervasive nature of the abuse
- the damage done to people by thoughtless following of policy and practice by staff
• the damage done to their relationships with family and friends through the abuse
• the abusive impact of poor quality care and the withholding of basic support and rights
• the emotional and psychological impact of punishment and control
• the emotional and psychological impact of threat and fear
• a lack of appropriate concern from services about harm suffered, and
• the failure of systemic abuse response mechanisms to protect people.

Resilience and the impact of the abuse and neglect
Despite this volume and range of abuse and neglect, people demonstrated great resilience and recovery from their abusive experiences. They all had strategies they used to manage their emotions and the distress that the abuse caused, and had moved on with life in important ways.

However, the impact of this abuse and neglect on their lives has been significant and lasting. It has manifested in several ways, including some people’s emotional and mental health, their capacity to develop and maintain relationships, their ability to trust, and their cultural connections.

Systemic issues
The disability services system was characterised by a top down, managerial, procedurally driven culture, which dominated the way in which people with intellectual disability experienced responses to their reports of abuse and neglect. For example, the use of complaints systems did not, in most cases, result in improvements in the life circumstances of participants in the study.

A series of factors influence the experience of this abuse and neglect. They may predispose, increase risk or protect against the experience of emotional and psychological abuse and neglect.

Predisposing factors include the way in which legislation, funding and policy for accommodation support is conceptualised, funded and implemented. Quality assurance processes which focus on recognising
policy at the individual response level, with minimal focus on prevention and cultural change, appear to strongly influence the service system.

Risk factors which may increase the likelihood that people with intellectual will be exposed to emotional and psychological abuse and neglect were evident, including enforced co-residency, unresponsiveness at a high policy level, and the lack of protection for residents in the private residential sector.

A number of protective factors were also identified which may act to positively support people. These included the involved presence of engaged family or other supporters, and having an active community presence and relationships.

**New insights from this research**

Four key issues emerged from this research which have particular importance for policy, practice and research, as they grow from the lived experience of people with intellectual disability. These problems concern

- the central place of systems in this form of abuse and neglect
- the cumulative impact of emotional and psychological abuse and neglect over time
- recognition of emotional and psychological abuse and neglect by people with intellectual disability, and
- the lack of authority accorded to people with intellectual disability in abuse acknowledgement and reporting.

**Into the future**

Approaches are needed which build capacity in people with intellectual disability and in those who support them to resist and deal with emotional and psychological abuse and neglect. Such approaches need to acknowledge the range of levels at which emotional and psychological abuse and neglect operates, be based on sound and ethical research, and be grounded in the lived experience of people with intellectual disability.

At an individual level, a capacity building approach needs to
• develop the individual resilience of people with intellectual disability and those who support them
• build skill in workers, managers, family members and advocates to better recognise this abuse and neglect and support people through it
• provide education and training that goes beyond the procedural to develop attitudes and values that support change and growth
• resource and sustain advocacy, both crisis and ongoing
• ensure support services are in place and used by people with intellectual disability who have been abused or neglected.

At a systemic level, many of the existing responses remain at the technical level, and are missing the moral and educative components.
• the priority of the policy focus on abuse and neglect prevention needs to be increased
• capacity needs to be developed in service management, Government departments, Ministers, policy makers, analysts and lobbyists
• the disability services system needs to move beyond compliance frameworks to better protect and uphold the rights of people with intellectual disability to be safe and free from abuse and neglect
• the service system needs to invest seriously in energy and resources to investigate and respond to the evidence that systems are responsible for much emotional and psychological abuse and neglect
• there is a need for systemic advocacy which is funded and untied, and which can act without fear or favour

At a structural level, the abuse landscape is highly fragmented, into types of abuse, types of victim, and types of crime.
• There is a need for a concentration on ‘higher order’ issues which influence abuse and neglect, such as questions of citizenship, rights, humanness, and otherness
• responses to abuse have been professionally designed and controlled. There is a need for ‘grass roots’ involvement of people with intellectual disability and their supporters in defining, recognising and designing responses to abuse and neglect
in the broader community, there is little or no recognition of the volume and impact of harms against people with cognitive disability. This is not a 'disability land’ problem – it is a social problem.

Underpinning all three levels is the need for the creation and sustenance of protective factors – community based, individualised supported lifestyles with multiple relationships with unpaid people – demonstrated in the literature, and confirmed in this study to safeguard people against the experience of emotional and psychological abuse and neglect (5).

References

### Appendix 8: Excerpt from Ann’s narrative collage

<table>
<thead>
<tr>
<th>Ann’s narrative</th>
<th>Supporter’s perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>From Dover, Ann was taken to hospital, where she spend a considerable amount of</td>
<td>Yeah, when she had the injury, it was, you know, totally</td>
</tr>
<tr>
<td>time, due to a badly broken hip. After she was released from hospital, the</td>
<td>neglectful. It was their negligence.</td>
</tr>
<tr>
<td>owner of the hostel took her to a privately run group home in an outer suburb</td>
<td></td>
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<tr>
<td>to live for a time.</td>
<td>And I’m pretty sure she was kicked, also, at that time.</td>
</tr>
<tr>
<td>S And then after Dover? You lived in a house at Banksia?</td>
<td>So because she does things that, sort of, maybe weren’t the</td>
</tr>
<tr>
<td>A And they [Kerry?] wanted to be closer to me, and wanted to help me walk on</td>
<td>best, she feels guilty about being [indistinguishable -</td>
</tr>
<tr>
<td>my own.</td>
<td>abused].</td>
</tr>
<tr>
<td>S Oh, ok, she lived at Banksia, did she?</td>
<td></td>
</tr>
<tr>
<td>A She ran one of the hostels up there.</td>
<td></td>
</tr>
<tr>
<td>S Oh, so Dover was at Banksia?</td>
<td></td>
</tr>
<tr>
<td>A No, Dover was in [another suburb].</td>
<td></td>
</tr>
<tr>
<td>S Right.</td>
<td></td>
</tr>
<tr>
<td>A Banksia was a house.</td>
<td></td>
</tr>
<tr>
<td>S Was that after you had your accident?</td>
<td></td>
</tr>
<tr>
<td>A Yeah. She left me laying in bed, with my panty pads all wet and sodden.</td>
<td></td>
</tr>
<tr>
<td>S Oh, did she?</td>
<td></td>
</tr>
<tr>
<td>A She wanted to help me walk all the time. You know?</td>
<td></td>
</tr>
<tr>
<td>S Yeah.</td>
<td></td>
</tr>
<tr>
<td>A That was because they were liable.</td>
<td></td>
</tr>
<tr>
<td>S</td>
<td>Yeah. Because you’d had your accident there, and she was worried about that?</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>A</td>
<td>Yeah, from having that, she went off to Banksia.</td>
</tr>
<tr>
<td>S</td>
<td>So, from Dover you went to Banksia?</td>
</tr>
<tr>
<td>A</td>
<td>Yeah.</td>
</tr>
<tr>
<td>S</td>
<td>And then you went to nursing home after that?</td>
</tr>
<tr>
<td>A</td>
<td>Yeah.</td>
</tr>
<tr>
<td>S</td>
<td>And did you share with other people at Banksia?</td>
</tr>
<tr>
<td>A</td>
<td>Yeah. I couldn’t sleep at all, they used to have the radio on the middle of the night.</td>
</tr>
<tr>
<td>S</td>
<td>You did, or someone else did?</td>
</tr>
<tr>
<td>A</td>
<td>No, they did. And I looked through, I couldn’t find my bag anywhere. And someone just walked in and took all my stuff.</td>
</tr>
<tr>
<td>S</td>
<td>And did you stay there a long time?</td>
</tr>
<tr>
<td>A</td>
<td>No, cause Sarah and [her husband] got me out. She’s a good sister.</td>
</tr>
<tr>
<td>S</td>
<td>Oh, that’s good.</td>
</tr>
<tr>
<td>A</td>
<td>Um, and then I was, and then I was admitted to [suburb] general [hospital], cause I had sores on my feet, bedsores and everything.</td>
</tr>
<tr>
<td>S</td>
<td>Oh, gosh, did you? Oh. So, you spent a lot of time lying in bed, at that house?</td>
</tr>
<tr>
<td>A</td>
<td>Yeah. They wouldn’t feed me or anything, they’d only give me fruit and stuff, to make me lose weight.</td>
</tr>
<tr>
<td>S</td>
<td>So they didn’t give you proper meals? And were there people there all the time to look after you?</td>
</tr>
</tbody>
</table>
A: Yeah, and they weren’t very nice.
S: Weren’t they. What was not nice about them?
A: Maoris. Dark people.
S: How did they speak to you?
A: Oh, roughly. Most of the time.
S: That mustn’t have been a very nice time, Ann.
A: No.
S: So, how long do you reckon that went on for, that house?
A: Oh, I was in [suburb] General for a long time. Sarah and [husband] came down to see me anyway.
S: Oh, that’s good.
A: It wasn’t too bad. My behaviour wasn’t too bad.
S: Well, you were under a lot of pressure, by the sound of it.
A: Yeah, I know!
S: Yeah, yeah. It would be hard for anyone to keep their behaviour tip top, I reckon, in those sort of conditions.
A: Yeah, being swished around all those places. I didn’t know it I was Arthur or Martha!

I know Ann will sometimes sort of beat up some things, but I don’t think she really talks about it. It’s funny, you know, sometimes she’ll exaggerate something, but won’t talk about it, because it was dreadful.

Ann left the house at Banksia to go into hospital for a range of health problems, including conditions caused by ill treatment at Banksia, such as bedsores. From the hospital, she went briefly to a psychiatric clinic, and after a dispute there she remembers being taken to a large psychiatric institution, where she spent the next year.
And so, after the second nursing home, where did you go then?

Green clinic.

Green clinic?

Yeah, cause that’s when I started getting sick.

So, when you went to Green clinic, did you stay there for a long time?

No, no, I went off my head and the police came and got me.

Oh, so only for a little while. A few days, or a few weeks?

A few days. I didn’t last long. Cause they didn’t believe that I had top cover, for a single room, that’s what it was over.

I was going off one day, and the police came and got me, and took me out to Meadow Lea [psych institution].

From Green clinic?

Mmm, mm. it was night-time too.

Oh, that must have been scary.

It was. That was not a very good night.

No, I bet.

And I still remember it.

I reckon it would be something that would be hard to forget.

Yeah.

But the thing that was like the base ground, what I thought was degrading and neglecting was the huge assumption that you could just do that on a day to day basis. That was the basis of these people’s life. And that might be my emotional, that makes me really angry, I suppose. Um, but I think they definitely terrorised her too. But I suppose I find that this is like a basis of everything, it underlies everything. And it’s probably what makes me really cross.