

Towards
quality and
safety in
disability
services:
Confronting the
'corruption of
care'

SA Health & Community Services Complaints Commissioner - focus on disability services

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A strategic policy and practice framework to guide the HCSCC's contribution to the prevention and redress of rights denial and violence affecting people living with a disability

We can use a framework like a travel map. We can read a map, because others before us have come up with common symbols ...A map also shows us that there may be different paths that can be taken to get to the same place. A framework can help us decide and explain route we are taking...With a conceptual framework, we can explain why we would try this or that path, based on the experiences of others, and on what we ourselves would like to explore or discover. (healthy women, healthy communities)

Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.

Eleanor Roosevelt 1948

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.

The fundamental conditions and resources for health are:

- peace,
- shelter,
- education,
- food,
- income,
- a stable eco-system,
- sustainable resources,
- social justice, and equity.

Improvement in health requires a secure foundation in these basic prerequisites.

Ottawa Charter for Health Promotion 1986

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Dedication

This report is dedicated to:

The countless, often unknown, people living with disability who have, in solidarity with others without freedom, sought to make all places where services are offered non-violent and respectful. They have advanced a vision of a life rich with relationships, rights and opportunities that calls all like-minded people into action.

Their families, friends and associates who, out of love, not a sense of burden, have defended the right to live in community, free from harsh treatment as valued citizens, urging services to do their best and communities to embrace all.

The professionals, service workers and managers who have followed this vision and this expectation, always valuing, always open to learn, always celebrating new ways that services can support without controlling and empower without abandoning.

The advocates, rights defenders, policy makers and researchers who have been undaunted in their commitment to speak truth to power.

The community members who have stepped forward to open their lives to people with disability, especially those who have lived for too long with shame, fear and loneliness.

It is all these people who fund our strengths, our hopes, our memories and our dreams. It is they who assure us that quality service is possible.

Preface 6

Human services, especially those upon which people rely for large parts of their lives, over the long term, must deal with an ambivalent history and present.

It is here that lives have been transformed and people learned to love themselves, living free from the shame and stigma that can so often arise from dependence on medical and human services. They have been deeply known by those charged with offering services. Their lives have been built on a vision of their living well, in their own way, surrounded by those who love and care.

In the mid 1980s disability policies and services in Australia embraced this more positive vision of the role of services to provide personalised support, to fulfil rights and to stay out of the way so the person (and where appropriate, their family) could get on with life. That optimism has continued to guide those with good intentions and excellent skills and to stay focused on the reforms that refresh and rebuild the commitment of hope-filled human services professionals, workers and managers.

They have stayed close to the stories of the lives of people with disability, hearing their aspirations, their fears, heeding their directions and learning innovative ways of working. They are creative, self aware and self critical. They are open to the insights of those who rely on them for support and to the feedback from committed colleagues. They can explain what they are doing; they are unafraid to ask questions; and to take their time to work out the best way forward.

They have been able to build service providing organisations that stay close to their values; that never give up asking and learning; that act humbly in the face of suffering and boldly in response to hope. Even while they know that no system is perfect, the organisation and all those connected with it keep focused on the good for each person. Their organisations are questing and alive, as well as distressed when things go wrong.

And go wrong they do.

Human services professionals, workers and managers must also deal with the shadows of the history and present in their work. The goal displacement that elevates the system's needs and demotes the needs of service recipients. The confusion that renames violence 'therapy', rights denial 'protection' and harshness 'care'. A present born from a history that allowed people with disability, labelled as cripples, imbeciles and lunatics, to be gathered up and sequestered in what poet Adrienne Rich called 'places freighted with human suffering'.

Places/spaces that, to this day, carry the hallmarks of violence, oppression and trauma. Places that, while looking different, even homely, leave people stranded from community life and — those who work with them anxious and prone to authoritarianism in order to deal with the stresses of incompatible group living, poor skills, low support from management and forgotten values and restricted vision.

Towards quality and safety: Confronting the 'corruption of care' acknowledges this ambivalent history and addresses those people and places that lie within the shadow, in order to free all those reliant on services from the threat of further rights denial and violence.

The report advocates the mobilisation of those who have a strong record of enlightened service provision in order to fulfil the systems change mandate of the South Australian Health and Community Services Complaint Commissioner, which is to address, in a range of ways, the shadow in human services that distorts good intention into destructive act.

Introduction and methodology

Introduction: starting with commitment to ensure rights protection and redress

This document proposes a strategic policy and practice framework for the South Australian Health and Community Services Commissioner (HCSCC) to advance work in the prevention and redress of rights denial and violence in the lives of people with disability, especially those who are reliant of community and other services.

The project, commissioned by the HCSCC and authored by Lorna Hallahan from Flinders University (see Appendix#1), has been developed in light of a combination of sustained commitment and emerging concern, responsibly acted upon and arising from:

- A consistently lower-than-expected complaints rate with associated high reports of fear of retribution for individuals and families who 'dare' to complain.
- A view based on anecdotal evidence, analysis of presenting complaints and the literature – that low complaints rates do not necessarily reflect a high satisfaction with health and community services, in particular those with disabled service users.
- Growing evidence about and shifting conceptualizations of: the dynamics of risk and protection; heightened vulnerability; and a widening conceptualization of rights denial and violence, including abuse, neglect, oppression and restriction.

Building on the considerable commitment of the HCSCC to rights protection and redress at individual and systemic levels (the mandated capacity to deal with complaints added to the capacity to monitor and report complaints trends and to make recommendations about safety and quality in community and health services), this project aims to rigorously explore these understandings in order to establish a sound evidence base and related conceptual framework for systematic policy development and planning and programming.

Following this brief introduction and explanation of the methodology and the parameters of a Strategic Policy and Practice Framework, the document is divided into two main parts, bolstered by 3 appendices and a set of references.

Part #1 Rationale: Evidence and Insights documents the background to need for the HCSCC to revisit the current strategy based on rights protection through complaints handling and a limited program of sector education. As a detailed knowledge review that establishes the need for vigilance and action in this arena Part #1 argues that abuse and neglect are most constructively seen as rights denial and violence.

This section follows with a detailed response to questions arising from Carol Bacchi's (2009) 'Policy Analysis: what is the problem represented to be?' Bacchi's approach (known as WPR) helps us see *the corruption of care* (Martin, 1984: Wardhaugh and Wildling 1993; Cambridge, 1999) of those who face heightened vulnerability (in part because of the nature of their impairments) as a multi-layered and intricate set of relationships – in both public and private spheres. A complex and intense set of relationships shaped by: strong historical forces; unequal power differentials; competing sets of duties and interests; as well as persistent and promising forces of resistance to practices that produce rights denial, threat and violence.

Part #2 Toward non-violent services in non-violent communities, applies Watzlawick's concept of first and second order change (1974) to develop a way into planning for further action. Based on the knowledge and understandings produced in Part #1 it restates the vision of the HCSCC, its values base and commitment to ethically defensible practice. It then begins the process of developing what is policy pertinent and do-able...

The starting point for this project therefore lies in frustration about being unable to secure a safe future for many people with disability reliant on human services despite sustained effort over many years, specifically with the HCSCC over 7 years. Rather than allowing this concern to stifle further attempts to understand and respond to rights denial and violence, the HCSCC has acted responsibly to fulfill its legislated mandate to make services safer for those reliant upon them and to respond to wider systemic issues that contribute to the corruption of care.

We can act on a shared concern to work towards the flourishing of all vulnerable people, supporting them in their struggles for personal fulfilment and to work for: social civility (in which individuals treat each other with respect and regard); social decency (in which the society's institutions uplift and honour our citizens); and social justice (in which all people are treated fairly, free from discrimination and oppression and achieve access to economic and social resources.)

Project methodology: WPR Policy analysis

A critique does not consist in saying that things aren't good the way they are. It consists in seeing on what type of assumptions, of familiar notions, of established unexamined ways of thinking the accepted practices are based (Foucault, 1994,456)

Writing in 2007 Carol Bacchi advanced an explanation of a problem representation approach to policy analysis that, in subsequent work, has become known simply as WPR. She says:

A "what's the problem represented to be?" approach to policy analysis produces a methodology to identify the problem representations implicit in policies and policy proposals, and to reflect on their ethical implications...a problem representation approach is an analytic method for scrutinizing the deep-seated assumptions and preconceptions that underpin particular policy directions. The intent is to point out "on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practices that we accept rest" (Foucault 1981 in Pálsson and Rabinow 2006, 91). (Bacchi, 2007, 16,17; see also Bacchi, 2009)

This approach gives us an entry point into scrutinizing assumptions about people with disability and their vulnerability to violence. Taking this approach we will come to see that the assumption of solely intrinsic vulnerability in some groups of adults reliant on human services contributes to and does not protect them from the possibility of rights denial and violence arising from the corruption of care. Furthermore, the assumption that such people are 'empowered consumers' of services rather than 'crucially reliant upon' services contributes to an overestimation of the capacity for complaints about service provision to drive significant change either for individual complainants (or their representative) or across the service sector (as test cases).

Testing these assumptions and positing alternative understandings does not leave a safeguarding mechanism such as the HCSCC without purview and purpose. Conversely this approach has the potential to open up opportunities for action, mandated by the Health and Community Services Complaints Act [SA 2004] and within current resources.

Within the WPR methodology, which starts at asking the question 'what is the problem?', this document also employs the research briefing approach developed and modified by the Social Care Institute of Excellence in the UK (SCIE, 2000, 2003, 2009). This approach accepts that

research in areas such as human services is often scattered and of mixed quality. This is a field in which 'the gold standard' cannot apply as the research relies on trying to make sense of — real world situations, not carefully designed experimental findings. Therefore the SCIE has designed a rigorous and accountable approach that draws together a systematic search of the peer reviewed and other relevant literature, and applying a series of quality tests, namely:

- Transparency are the reasons for it clear?
- Accuracy is it honestly based on relevant evidence?
- Purposivity is the method used suitable for the aims of the work?
- Utility does it provide answers to the questions it set?
- Propriety is it legal and ethical?
- Accessibility can you understand it?
- Specificity does it meet the quality standards already used for this type of knowledge? (SCIE, 2003)

The SCIE model also argues:

A RB is a **critical** account of research reports published on a topic. This means that key concepts and issues are subject to critical analysis, showing for example their origins, debates about definition, and about the relevant statistics, and demonstrating the application of SCIE's value base. (SCIE, 2009, 2)

Part #1, Rationale – evidence and insights applies this approach. Multiple searches have been carried out through the Flinders University Library search tools of the major data bases. Search terms include: adult protection; disability and rights; disability and violence; intellectual disability and abuse; sexual assaults; corruption of care; risk assessment; public health; health promotion; iatrogenic services; child protection; complaints; trauma informed services: Sanctuary model; and violence prevention.

The parameters of a strategic policy and practice framework

Most policy and practice frameworks link an agency's strategic plan, policy and practice, with its mission, vision, and agency values. They aim to be a consistent and articulated conceptual map to guide coherent decision-making about cases and wider agency actions. Their clear purpose is to preserve a link between *philosophy and intention* and *action and outcomes*. They also serve additional purposes including:

- A structured approach to interpret, analyse, organise and explain data gathered through practice reflection, literature surveys and research projects
- The basis for thinking about what we do and about what it means, influenced by research and theory
- A set of assumptions, values, and definitions under which we carry out the agency's interventions
- A logical progression of ideas and questions with some concepts having primacy
- A set of coherent ideas or concepts organized in a manner that makes them easy to communicate to others

In order to carry out these purposes this framework 'Towards quality and safety: Confronting the corruption of care' aims to be:

- Research derived and practice informed
- Theoretically sound and ethically defensible
- Vision driven and values based
- Policy pertinent and do-able

Part# 1 Rationale: Evidence and Insights addresses the requirement for 'Towards quality and safety: Confronting the Corruption of Care' to be research derived and practice informed, and therefore establishes a well grounded knowledge base for planning and action. It applies the WPR model to problematise current understandings of abuse in services and to expand insights that can deepen a theory of change.

Part #2 Strategic action toward non-violent communities, non-violent services addresses vision, values, pertinence and do-ability. It concludes with recommendations for strategic action.

Part #1 RATIONALE: evidence and insights

1.0 Gathering our evidence

A detailed knowledge review of rights denial, abuse, neglect and oppressive and restrictive practices in disability services, looking at: definitions, prevalence, factors and dynamics in risk and protection; and context in terms of current and future responses

We have acknowledged that good things happen in human services driven by strong vision, excellent values-based leadership, and a capacity to deal swiftly and effectively with practice that goes awry. Many services have responded to complaints about service provision with openness, a willingness to make reparation to the person or persons affected and a desire to ensure that the same poor service is not replicated. These services become exemplary, not necessarily because they always get things right, but because they face up to the times that those who rely on them are harmed.

The HCSCC must however also deal with services that are slow to respond to complaints, intimidate complainants and are resistant to making the necessary changes. It is these services that become the focus of concerns within rights protecting bodies and reflected in the literature about established patterns of neglect and harm.

1.1 Definitional issues: Is it care? Is it abuse? Or is it violence and rights denial?

The terminology in this policy conversation about abuse and neglect in disability services and community settings is scattered, loaded with multiple meanings and at times used to soften the nature and impact of oppressive and assaultive behaviour.

A graphic (and immediately relevant for HCSCC) example of this renaming process is evident within the discussion about restraints and seclusion, increasingly called 'restrictive practices'.

Williams' (2010) overview of mechanical restraints in the US from 1999 to 2009 shows a decline over the period, especially following a pivotal report about 142 fatalities arising from the use of physical restraints. There is however a simultaneous concern about increasing use of psychotropic medications as restraints. This is indicated by a growing awareness of drug restraints being seen as the 'chemical strait-jacket' or 'drug cosh' used in group homes and other congregate settings. This understanding, advanced by users and services and some professional allies, challenges the rationale for medical interventions to 'calm the person down' and renames them as restrictive and oppressive practices aimed at keeping the peace and limiting the person's agency (and, at times, sexual expression). A single search of multiple data bases through the Flinders University Library yielded over two thousand items, many of a

medical nature defending and explaining the use of chemical restraints while a larger proportion advocated against the practice and in favour of the development of peaceful, – restraint free ways of working with people (for example Jones, 2001; Hughes, R et al, 2009; Donley et al, 2011).

Feminist writers in this field stress that labelling such practices (as well as those less contested such physical and sexual assault) as rights denial, abuse, neglect, and maltreatment deemphasies the violent aspects of the relationship (Nixon, 2009). They advocate a deliberate naming of these practices and settings as violence (see Curry et al, 2009). This is consistent with feminist understandings of domestic violence and community violence, stressing that violence understood thus includes harassment, bullying, mockery, derision, belittlement as well as denial of activities and rights through to direct physical and/or sexual assault. What happens to people with disability is no less violent because it is not always an intimate relationship. Curry et al advocate adopting the WHO definition of violence (against women) as it is sufficiently comprehensive as to not confine violence to a single relationship and set of acts and is able to incorporate those acts and events that prevail within families, services and communities.

For the purposes of clarity and comprehensiveness, this report also adopts the same approach with the removal of the sex specificity. The reference to gender-based violence can be replaced with dependency-based:

Therefore, the United Nations definition of violence against women:

'any act of gender-based violence that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.'

Becomes:

'any act of dependency-based violence that results in, or is likely to result in, physical, sexual of mental harm to service recipients, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life.'

Multiple international reports stress rights denial in many countries. A recent report, Global Mental Health 6: Human rights violations of people with mental and psychosocial disabilities:

an unresolved global crisis by Natalie Drew and others, published in The Lancet in late 2011 highlights poor and inhumane treatment in 'facilities' especially in relation to failure to support exercise of legal capacity and use of restraints as 2 of the 3 most pressing issues in rights denial in low to middle income countries. (The third is discrimination in employment). Although some physical conditions may be better in the Australian system and the choices of care settings much wider, with more people effectively contributing to planning their support and recovery, the May 2012 UNCRPD Shadow report by the non-government sector in Australia concluded in section 24:

Our consultations revealed evidence of widespread abuse, inhumane treatment and neglect, particularly in relation to people with cognitive and psychosocial disability and people with dementia. Medical model solutions and approaches, behaviour management regimes and significant levels of human rights ignorance by disability and medical professionals all contribute to the abuse and inhumane treatment experienced by people with disability. Significant concerns are also raised about the poor treatment and neglect of people placed in immigration detention centres who experience psychosocial disability as a result of human rights abuses and mistreatment.(5)

The relevant recommendations for action of the Shadow Report Working Group are addressed below in Part# 2.

Some authors (e.g. Johnson, 2011) contend that the term 'abuse' is often poorly understood, too broadly defined and too identified with actions carried out by a range of persons, and argue that 'harm' as an outcome be substituted. This paper however strives for consistency with other emerging work in this field (see Hughes et al, 2012 below) and with the feminist perspective explored here. Therefore, *Towards quality and safety: Confronting the corruption of care* refers to abuse, maltreatment, neglect, physical and sexual assault and undue use of restraints as **violence**. It links it further into **rights denial** which may have elements of violence contained within it but may also be observable in itself, especially around limited access to resources, denial of opportunities and supported life in the community, systemic discrimination and restriction of the right to exercise capacity.

1.2 Prevalence and incidence: What is the nature and extent of rights denial and violence?

A recent meta-study and systematic review, conducted by Hughes et al, (April 2012) and funded by the WHO Department of Violence and Injury Prevention and Disability finds little robust data and research but is able to arrive at a sound conclusion that:

Adults with disabilities are at a higher risk of violence than are non-disabled adults, and those with mental illnesses could be particularly vulnerable. However, available studies have methodological weaknesses and gaps exist in

the types of disability and violence they address. Robust studies are absent for most regions of the world, particularly low-income and middle-income countries — (1621).

The authors note that the majority of studies relate to people living with mental illness with some significance in linking intellectual disability and exposure to violence over the last 12 months. They could not however find any usable studies of violence against adults with intellectual disability in 'institutional settings' (including group homes) even though it is a widely held view (based largely on case study evidence) that these people are more vulnerable than other groups in these settings and those without disability (p.1627). So, addressing the question of an apparent increasing incidence of violence against the 15% of people with disability worldwide they have this to say:

People with disabilities seem to be at an increased risk of interpersonal violence because of several factors: exclusion from education and employment, the need for personal assistance with daily living, reduced physical and emotional defences, communication barriers that hamper the reporting of violence, societal stigma, and discrimination. Furthermore, rising numbers of media reports emphasise cases of physical violence, sexual abuse, and hate crime inflicted on individuals with disabilities in homes, institutions, communities, and other settings. However, whether this increase indicates a rising prevalence of violence against individuals with disabilities, more consistent reporting to authorities, or greater media coverage than previously is unclear. (p.1621, number references included in original)

The authors, advocating for as detailed an understanding as possible to responding to this violence against people with disability, call for a public health approach which is explored in Part#2 of this report. Here we are concerned with capturing a sufficiently robust understanding of these issues to safely build a coherent and strategic response.

Disability activists and advocates have long expressed concern for service users who are abused and neglected by those who are employed to provide care and support. It is difficult to quantify the extent of this 'corruption of care' (Cambridge et al 1999, 2011) when low recognition of abusive behaviour (Johnson, 2011), perceived low reporting of incidents and low substantiations (Cambridge, et al 1999, 2011) indicate a higher incidence than numbers dealt with by formal complaints bodies. In Australia, data are old, patchy, difficult to synthesise and analyse. There is however, a consensus of concern (evidenced by presentations at *Everybody's Business* a 2011 national conference about safeguarding including attempts to make sense of these imprecise data; and expert discussions contributing to the development of National Disability Insurance Scheme policy) among a wide range of academics and human rights practitioners, funding bodies and service providers. This view, that abuse and neglect, in a range of forms, remains a pressing problem for policy makers and others committed to rights protection and the safety of adults considered to be in heightened vulnerability, also drives the concerns of the SA HCSCC.

Cambridge opens his 1999 article, *The first hit, with* the irrefutable claim that our work should proceed on the premise that the abuse of people with learning disabilities is 'morally indefensible' (1999, 285). Still publishing with colleagues 12 years later he regretfully has to record that concerns about abuse have not abated. In the 2011 study he analyses adult protection data from 2 areas in the UK, focusing on a sample of 397 cases of alleged sexual abuse of adults with intellectual disability from about 2000 to 2005. The profile of the sample showed 63% living in 'residential settings' and the balance with families. 74% of the cases analysed related to multiple forms of abuse where sexual abuse was one component. The researchers say that this picture mirrors other studies in the intellectual disability field (p.121). This builds on earlier work carried out by Bailey (1997) who analysed 2 studies in search of some incidence. He concludes that, despite considerable methodological problems, definitional contraindications and low self report, it is safe to conclude that people with intellectual disability are more vulnerable to sexual abuse than the general population.

Australia does not hold such a comprehensive data set as we do not operate a national approach to adult protection, such as *No Secrets*, the UK model. Cambridge and his colleagues stress however that the systems of service provision and the underlying assumptions about adult protection are roughly consistent across the UK, US, Europe, Australia and New Zealand (p.118). This finding is reinforced by the Murray and Powell (2008) comprehensive study of sexual assaults of adults with disability in Australia. As well as acknowledging that arriving at any consistent prevalence is virtually impossible given significant deficits in data collection (both by the ABS and through crimes reports), they confidently concluded higher levels of victimisation. They go onto state:

Existing data also indicates that adult men and women with a disability do not experience equivalent risk of victimisation of sexual violence. Consistent with patterns of sexual assault generally; there is a gendered aspect to sexual violence that is perpetrated against adults with a disability. Australian and international research indicates that it is predominantly women with a disability who continue to be the victims (Brownlie et al., 2007; French, 2007; Women with Disabilities Australia, 2007a,b).(Murray and Powell, 4)

Further studies in the USA and UK suggest that abuse occurs more often in environments characterized by institutional modes of care, especially for those people labelled as presenting with 'challenging' behaviour, low expressive language and poor relationship networks beyond the service (Joyce, 2003; Sabat et al,2004; Kelly, 2010). Joyce's 2003 audit of allegations made by 26 individuals (24 of whom were women) referred to a psychologist to assess the viability of allegations of abuse (sexual and physical) concluded that:

The present study suggests that abuse can and does occur in a range of settings and with a range of perpetrators, and that living in the community does not protect against abuse. A range of perpetrators was identified in this study, but as has been shown in other studies, the majority of perpetrators were not strangers or casual

acquaintances (Furey, 1994; Sobsey, 1994). Families often express anxiety about the vulnerability of their relative in relation to the general public, but the investigations - undertaken in the present study suggest that people with ID remain particularly vulnerable to abuse by those close to them (612).

A sobering element of this study stresses that none of the cases resulted in prosecutions of the alleged offenders (on the basis that the person with intellectual disability was judged to be incapable of giving evidence in court) and that in a couple of instances at least no changes were made in the service environment. Where family members were thought to have harmed their member with intellectual disability monitoring processes were put in place.

Looking to the future of a more market approach to disability services delivery we are also reminded of the potential for interpersonal violence to occur in people's homes (not group home settings) as evidenced by the recent multi-method quantitative study carried out in the UK by researchers connected to Violence Against Women Research Group (now the Gender and Violence Research Centre) at the University of Bristol and the Centre for the Study of Safety and Well-being at the University of Warwick. The group found high levels of domestic violence affecting women with disability and a lack of adequate resources to respond appropriately (Hague et al, 2011). They also inquired into paid support worker rights denial and abuse and found that dependency and dominance were key features in many of these relationships (p.157).

This suggests that we cannot rely solely on service systems delivery reform to reduce and remove violence from the lives of people who are reliant on services. Such an approach would be overly optimistic and possibly hubristic. Central to this understanding is an exploration of 'clienthood'. In brief, according to Wolfensberger and Thomas (1994):

One of the main points we make in this delineation of the client role is that the meaning and valuation of this role varies widely, depending on the kind of clientage at issue. For instance, being the client of an expensive hairdresser or a high-powered financial lawyer or stockbroker can be a valued client role—but being the client of the human service system usually is not. Even being a client of the generic hospital system is not exactly a valued role, and most people are anxious to escape it as soon as they can. Particularly devalued is what one might call a "career client role," i.e., being in chronic human service clientage in a major way, and possibly for the rest of one's life (p4).

The relatively small number of relevant studies analysed here demonstrates the lack of sustained peer reviewed evidence building about violence and rights denial in the lives of people with disability and other vulnerable adults. By contrast there is a richer seam of research to investigate in child protection with quite well established understandings of the nature and extent of child abuse in countries such as Australia. This finding arising from the present knowledge review is bolstered by Kennedy's similar finding. She points out that:

'the public profile and breadth and depth of tragedy in the human services shadow world is strangely underrepresented in academic and other commentary, which is primarily targeted at an internal audience. ...the professional and scholarly commentary on misadventure and malpractice in the human services is minimal in Australia and only slightly more extensive overseas.' (2009, 6)

The following sections build on learnings from the child protection field as well as evidence from the field of intellectual disability.

1.3 How do we know what is happening and when?

- Complaints
- Related behaviours
- Self report of workers
- Whistle-blowing
- Evidence of nonviolent setting
- Bullying of staff
- Increase in self harm

It is clear from the studies explored above that for both intrinsic and extrinsic reasons relying solely on those who are subject to violence and rights denial in human services to voice their allegations through formal complaints is to simultaneously overlook the nature of dependency in services and other evidence that violence may be present. Respondents in the Hague study (2011) also reported that although there were many social care staff, including social workers, entering their homes, only one picked up on the difficulties faced by the woman dealing with oppressive paid workers or the violence of intimate partners. One common feature, depression (which was addressed in a clinical response) was linked to living with disability, not to stress dealt with residing in a non-peaceful home.

An analysis carried out by researchers from Loughborough University of 100 cases selected from the files of the Independent Safeguarding Commission in the UK, entitled *Safeguarding in the Workplace* (McKenna, K; Day, L and Munro, E, 2012), identified 2 significant categories of abuse, namely one-off incidents related to opportunism or poor response to stress and multiple, more systematic incidents of abuse. This research was undertaken to specifically explore warning signs grouped in these three categories:

- the behaviours demonstrated by the referred individuals that lead to their referral;
- the circumstances in terms of relationships, culture and policy within which the harm occurred and was reported; and
- actions taken by the employer leading up to and in response to those behaviours. (p.1)

They noted:

Some possible warning signs for employers include where there is over familiarity with the person being cared for, alongside signs of stress or discomfort experienced by the vulnerable adult. In financial abuse cases, the signs potentially include employees being preoccupied with their money problems, combined with secretive or — unsupervised handling of financial documents. (p.1)

Looking at more contextual issues they identified a number of salient factors including, poor recruitment practices, poor fit of employee for care related tasks and:

Organisational culture and policy issues in the workplace were strongly implicated across the types of abuse. Low levels of training and supervision and poor financial accounting procedures were commonly found, along with allegations of "bullying" and stressful working conditions (p.2).

The Social Care Institute of Excellence has developed a typology of abuse (including physical and sexual violence) and indicators which can be found at: http://www.scie.org.uk/publications/guides/guide03/abuse/types.asp.

These indicators relate to changes in the physical or psychological condition of the dependent adult and can be read alongside indicators of perpetrator behaviour and organizational context consistent with the Loughborough University analysis (2012).

Linked to this, some researchers suggest that paying attention to self-harm rates among people with intellectual disability may provide a more accurate pointer to the presence of abuse than expressed complaints (see Jones, et al 2004). One Norwegian study, looking at psychiatric illness among people with severe intellectual disability living in a residential setting went so far as to conjecture that their distress was primarily related to the stress of living in deprived and violent settings (Mybrakk, E and von Tetzchner, S, 2007). They reported:

There were no direct associations between individual behaviour problems and psychiatric disorders, but the group with mild/moderate intellectual disability showed a somewhat different pattern of associations than the group with severe/profound intellectual disability. Depression was associated with screaming and aggression in the participants with severe and profound intellectual disability, and with self-injury in the participants with mild and moderate intellectual disability. The finding that the majority of the participants with behaviour problems showed symptoms of psychiatric disorders suggests that many behaviour problems may be (unconventional) symptoms of psychiatric disorders or reflect a difficult life situation caused by psychiatric disorders, or that a difficult life situation may contribute to both psychiatric disorders and behaviour problems in individuals with intellectual disability (p,316, emphasis added).

Others employ evaluation tools to identify evidence of non-peaceful environments – evidence of physical upheaval, overturned and broken furniture, smashed walls and windows, barred rooms etc. Employment policies might also be relevant here. There is some evidence from the US that agencies employing workers with very low levels of training are also more highly

represented in abuse reports generated within aged care facilities (known as Assisted Living Facilities) (Phillips and Guo, 2011). Their study goes on to suggest there may be a link between — physical violence, low staff levels and staff burnout in larger services with psychological abuse being linked to low levels of staff training.

1.4 What gets in the way of people complaining?

- Impaired communication capacity
- Fear
- Trauma which can contribute to silencing
- Voicelessness produced by being overwhelmed by their circumstances
- Stifled expectations leading to a normalization of abuse
- No expectation of change and not being heard
- Fear of cost and retribution
- Worker uncertainty
- Social indifference

The HCSCC has identified reluctance among service recipients to activate both internal and external complaints systems in order to conciliate through seeking reparation and compensation. We can indeed identify a number of barriers to a person (and/or their family and close associates) activating both internal and external complaints processes.

First, as we have noted above those with compromised capacity to communicate are demonstrably at more risk, presumably because perpetrators know that they will not be able to voice a complaint.

Secondly, those who might complain are often rendered voiceless both by the way the organisation works and by the overwhelming nature of their circumstances. This is dramatically indicated in the *Shut Out* Report (2009) in which many individuals and families pointed out that there were no avenues through which to seek reparation and change. The person may also be unheard because the service assumes that because of their impairment or condition they have nothing of sense to say. They may have no expectation that change will come. This may be based on observations of other complaints processes; a sense that the service is change resistant; failed early attempts to seek an informal settlement – amounting to a sense of powerlessness and impaired self efficacy (Vie et al 2010 examine this through an investigation of workplace bullying and self-labelling as 'victim').

Thirdly, the person who has experienced or witnessed rights denial and violence will often be afraid about what more will happen. We know from our understandings of domestic or family violence that fear can paralyse someone, inhibiting their capacity to take protective steps (for simple useful information see http://www.hurt.net.au/dfv.htm).

Fourthly, the person may experience such trauma from the violence and rights denial that they are unable to pursue processes which require a revisiting of painful experiences. This is particularly the case when the person experiences a high level of avoidance of the situation or person who is linked to the violence. This reaction, known as 'numbing', could have the person experiencing levels of withdrawal, or even something akin to amnesia and severe depression (see Herman 1997). An extensive literature about trauma and PTSD (e.g. Herman, 1997; Jones and Wessley, 2007; Bloom & Farragher, 2011) demonstrates that some people will become hyper-vigilant, often resulting in behaviour that is considered uncooperative in a human service setting, exposing the person to further excessive regulation and restriction. Often hyper-arousal will be associated with a re-experiencing of the events with the associated high levels of fear and terror, often misconstrued as anger and aggression. Added to this, heightened arousal may contribute to a more aggressive response to attempts to contain or control.

This cycle of traumatized reactions being met with by further abuse and neglect is contributed to by not being believed as Joyce (2003), points out in her audit of allegations identifies a number of barriers to disclosure:

This creates additional difficulties for the victim in terms of disclosure, pursuing the allegation and then living with the consequences of it (Brown et al. 1996). However, even for people with severe ID, disclosure or discovery of abuse was not dependent on staff observation alone. However, disclosure was a difficult process: some individuals did not have the communication skills to describe clearly what had happened to them, while those that did also found the process difficult. These difficulties can be compounded when staff do not believe the disclosure (Corbett et al.1996) or when allegations are disbelieved because carers do not believe that colleagues could be capable of abuse (Hames1996) (Joyce 2003, 612).

The disbelief can be added to by a process of 'diagnostic capture' i.e. that these signs of distress are attributed to another diagnosis e.g. autism spectrum disorder in which a person who has not experienced violence may nonetheless exhibit hyper-vigilance. Therefore it is important to enquire further about the roots of and precursors to certain behaviours (see Bloom and Farragher, 2011).

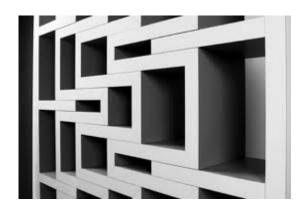
Fifthly, there is strong anecdotal evidence that fear of retribution for complaining constrains individual's pursuit of justice and change, especially in services upon which they are highly reliant for basic life support services (such as personal care, accommodation support and support with the activities of daily living). This is likely to be the case when the service culture displays the characteristics Bloom et al (2007) identify as consistent with a violent culture, see: http://www.sanctuaryweb.com/violent-nonviolent-communities.php, noting especially the gap between the espoused and the expressed values, breakdown in communication and cooperation inside the organization; high levels of blame; denial of violence...

A recent small scale study carried out by the Office of the Public Advocate in South Australia and reported at the *World Elder Abuse Prevention Day Conference, Adelaide Convention - Centre, June 2011* (Brayley, 2011) enquired into gaps in reporting of violence and rights denial in services, communities and within families, with a particular focus on older people. The study found that often workers in the sector were uncertain about where and how to report concerns and raise complaints along with 'services waiting for a crisis to occur before acting, conflict between services, lack of suitable risk assessment tools, limited access to generic domestic violence assistance.' While this can be attributed in part to poor training at organisational levels, the Public Advocate reflected that a reliance on a welfare model of support as opposed to a rights framework is a major underlying cause in failing to see those dependent on services as people with rights.

This finding, particularly relating to worker and professional uncertainty, is backed up by the findings of a larger factorial study carried out by Killick and Campbell (2011) in which they found that: 'Recognition and reporting (of various forms of abuse) were influenced by case factors specific to the abuse event while contextual factors did not significantly influence recognition or referring of abuse.' They also showed that:

The client's wish for, consent to or request for an investigation had a direct impact on recognition and referring behaviour. The client's wish for no action to be taken had an impact on referring behaviour but this was shown to be dependent on the capacity of the individual (p825).

Finally, case studies analyses, such as the work of Calderbank (2000), point to social indifference contributing to resignation, acceptance of intolerable behaviour and reluctance to complain among disabled people, including those with physical impairments. These studies link with a long history of social psychology studies, especially labelling studies about devaluation, stigmatization and dehumanization (see Phillips, 1990; Zola 1993; Zimbardo, 2009; Kendrick, 2004; Scior, 2011) and become relevant for exploration of the representation of the problem.



2.0 Expanding our insights

This section problematises (in the sense of "to question and consider whether it is either a cause or symptom of larger problems," Weekes, 2000) a number of key concepts at play within this policy arena. We have seen that there is sound evidence for the corruption of care and that those who suffer rights denial and violence are constrained from complaining. This section looks at some of the theories developed to explain these phenomena and to open up pathways for change.

2.1 Problematising intrinsic vulnerability

- Risk society
- History/succession (Kelly)
- Children and women now those considered vulnerable through age and impairment
- Comparison of adult harm with child harm rather than domestic and community violence

All researchers record difficulties in arriving at a comprehensive understanding of violence and the threat of violence across the full population of those people who use disability services. They caution against assuming that it is the impairment profile and level alone that exposes the person to rights denial and violence. Questioning notions of intrinsic vulnerability (in which the person is seen as automatically more vulnerable to violence because of their impairment attributes), they identify other sources of threat, primarily within residential and day-care service settings, families and within the wider community (Cambridge et al 2011; Kelly, 2010, Brown, 2009). This also links to questioning notions of intrinsic propensity to harm. While most authors accept that there are 'bad apples' who link themselves into disability services with predatory intent, the majority of authors also point to environmental factors that might fuel assaults and neglect and organisational policies that permit excessive use of seclusion and restraints.

This does not mean that we cannot identify some aspects of individual characteristics in order to establish increased vulnerability. Those with severe or profound impairments are more likely to spend significant periods of their lives in 'clienthood' (Wolfensberger and Thomas, 1994), contributing to increased exposure to environments that are violent. The connections with trauma reactions have been made (Bloom, 2000) and will be explored further below. Relatedly, not all services can be characterised as violent or prone to rights denial. Indeed there is a strong history of disability services resisting such practices (matters of service environment are addressed further in the following sections).

Beck (1992) describes our current state as a risk society, in which specific risks (say of early death for the poor) have been in part replaced by more generalized risks (such as the possibility of climate change influencing whole societies). Increased vulnerability, even under these more generalized conditions, is understood to more likely affect those with fewer resources to determine a different outcome (e.g. heating and cooling for those on low and fixed incomes). This risk society also brings with it a wider catchment of those populations considered at risk of violence, neglect or exploitation. In particular we can observe the changing focus from women and children (throughout the 19th and 20th centuries) to include those with heightened vulnerability related to impairment (including mental illness) and advanced age (Daniel and Bowes, 2011). This growing appreciation can be seen reflected in the development of international instruments of rights protection; and national and local rights protection bodies, including HCSCC.

One disadvantage of this shift has been to conceptually link adult abuse with child abuse and relatedly, adult protection models have tended to ignore the discourses about domestic and community violence. This document proposes that a focus on violence and non-violence and violence prevention can open doors to strategies that may have been overlooked in adult protection approaches in Australia (Hague et al, 2011).

Services and professionals have attempted to address these issues through the development of risk assessment tools and processes. While these tools can pick up intrinsic risk factors we shall see that they have been less effective in identifying risk factors within service environments. This is important for highlighting the fact that 'experiences of abuse are not merely unfortunate encounters with bad people, but are more likely given certain environmental factors. These may include structures and processes promoting disadvantage and social exclusion, constraining individuals' resources and life chances.' (Daniel and Bowes, 2010)

2.2 Problematising Risk Assessment

Gillingham (2006) classifies two approaches to risk assessment as forensic and actuarial. Forensic risk analysis is an inductive process through which an observer will build up a picture of actual violence by close examination of the person (in Gillingham's work, a child). Here we would expect to see evidence of physical assault, neglect, age-inappropriate sexualized behaviours, disturbed sleep, and hyper-vigilance at school and so on. We have seen that such

an approach is also useful when identifying the possibility of violence in the life of an older person with disability. While this links directly with assumptions about intrinsic vulnerability it — relies on careful evidence gathering of actual rights denial and violence.

The importance of lifespan (see Daniel and Bowes, 2010) and context fits more with a deductive, actuarial approach to risk assessment. Here the assessor will identify known intrinsic risk factors, such as (in the case of use of restraints and seclusion) multiple and complex needs and poor communication capacities, a history of being subjected to rights denial and violence. They might also look at reliance on services, involuntary detention, relationship deficits (especially missing out on being known for a long time by someone who has your interests at heart), a long history of intergenerational disadvantage, poor community connections, a service with high churn, low training, a long history of running oppressive services and a defensive service culture...

Both these approaches can be used in risk assessment but Gillingham offers a further challenge. He focuses on micro-practice to advance the view that such approaches distort professional-client relationships by elevating focus on risk management rather than other, more life-expanding, empowering goals; by distorting to the checklist the ways that decisions in complex and intense situations are made by oversimplification of the factors at play; and a narrowing of perspective on the particular person's life and situation because looking out for risk factors tends to focus more on the present and vivid rather than more 'historical' aspects of the person's life which may be affecting their reactions.

Gillingham looks closely at the work of Dingwall and others (1993) to identify trends in decision-making shaped by 'the rule of optimism' namely that professionals tend to view situations (in this case the family) in a favourable light. The same could be said of services i.e. that they exist to provide care and support. Dingwall's analysis, which builds on well-established work related to decision-making shaped by organisational heuristics (or rules of thumb), focused on uncritical cultural relativism (all cultures care for people in equal although different ways) and the assumption of natural love (the parallel in services would be the assumption that only those with the best interests of those reliant on them would put themselves forward for such roles.) Gillingham also refers to Dingwall's further analysis of 'defensible decision-making'. He explains:

This refers to a rationale for making a particular decision that can be promoted as the best decision, sometimes because it is presented as the only decision that could have been made. 'Defensible decision making' adds a new influence to the process of decision making in the form of accountability. Accountability and its influence on decision making is not straightforward because there may be a tension between who or what the decision maker feels more accountable to (the client or the organisation).(p.92)

We can see how such a process might begin to influence decisions made about the use of restraints and seclusions, particularly in crowded or stressed shared accommodation. While

we can see that Gillingham's critique is both singular to his practice and self-critique in conversation with a growing literature in the area, his conclusion that current approaches to risk assessment and assumptions about risk management are implicated in the problems of the service system, and are not a ready antidote, provides a timely warning as such tools are subjected to ongoing refinement. In short, he argues that we cannot look at issues around protection of vulnerable people without considering that our attempts at remedy through risk identification and management might also be contributing to the difficulties faced by those we strive to protect.

2.3 Problematising complaints handling

We have already seen that there are barriers to individuals or the families (or indeed human services workers) to exposing rights denial and violence through the mechanisms of complaints handling. The practice of complaints handling started within retail organisations, in which the consumer was encouraged to let management know if things weren't good. This has expanded into all areas of services, entering the Australian human services sector in the late 1980s. While the value and efficacy of such mechanisms has been widely canvassed in service evaluations and some academic literature, this section looks at 2 main concerns:

The myth of the empowered consumer/complainant.

We have already seen that those who are most vulnerable to rights denial and violence in services and community settings are those who experience the most sustained and comprehensive service dependency and/or certain intrinsic characteristics such as reduced capacity to communicate. We cannot assume then that this person is the empowered consumer captured here in a statement by IBM (on the subject of winning over the empowered consumer!):

Today's consumers seek and accept shopping advice from peers, family, friends and even strangers. They bring attitudes and expectations, shaped by experiences across a broad spectrum of industries, to every interaction with retailers. And through this lens of connectivity and collaboration — which enables them to know almost everything about every product and brand — these "smarter," empowered consumers ultimately decide which retailers have earned their trust.

[http://www-935.ibm.com/services/us/gbs/thoughtleadership/ibv-empowered-consumer.html]

The danger of individualizing the problem.

Beardwood et al (1999) analysing the growth of complaints approaches within the Ontario public hospital system raise concerns about individualising approaches which cannot focus on systemic issues that may influence professional behaviour. They point out that: 'When a consumer rights discourse is juxtaposed against high expectations of medical science and level of service at a time of cutbacks and restricted services, complaints seem inevitable (p.368).'

We have already seen that complaints arising within disability services are less inevitable but Beardwood's point about rights discourses meeting issues with funding levels and unmet — need is well made and will be further expanded below.

Neither of these concerns is sufficient to arrive at a conclusion that complaints processes do not hold an important part in any systematic safeguarding approach. What they do point to however, is the necessity to activate other processes within and around complaints processes if they are to fulfil their promise of assisting harmed individuals and groups to pursue recognition and redress.

2.4 Problematising clienthood and services

When we don't see systems, we see individual characteristics. Our explanations are personal, and our solutions are personal. Fix the individual. When we see systems, quite another world opens up to us. What we have here is not a personal problem but a social disease – a disorder of the 'we' (Oshry, 1995,167)

(Acknowledgement: this section includes and builds on notes produced by Dr Sally Robinson, Southern Cross University, unpublished, 2012)

Penhale (1999) distinguishes three levels of institutional abuse (note the terminology here): 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. In her work in the elder abuse field (Bennett, Kingston & Penhale, 1997), Penhale also talks of abuse as existing at three different structural levels – the macro (political) level, the mezzo (institutional) strata, and the micro (individual) level.

A second 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).

A more complex view is presented by Sobsey, who develops an integrated ecological model of abuse (1994). 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.

This social ecological view, which can be seen to integrate aspects of both Penhale's and Brown's work provides a means to look at services within wider social, political and community contexts and to see that service level operations cannot be understood without attention to those forces, structures and transactions that produce services and their clients.

Sobsey's work is largely informed by the widely known work of Urie Brofenbrenner who theorised about child abuse during the 1970s. His work which focuses on the levels identified — by Penhale, in turn can be enriched by the earlier work of community psychologist James Kelly who in 1966 identified these principles of systems interactions:

- Adaptation: i.e. what individuals do is adaptive given the demands of the surrounding context, (e.g. such that a person becomes passive in the presence of violence)
- **Succession**: every setting has a history that created current structures, norms, attitudes, and policies, and any intervention in the setting must appreciate this history and understand why the current system exists in the form that it does (this is important for understanding trauma-organised services)
- Cycling of resources: each setting has resources that need to be identified and
 possibilities for new resources to be developed; a resource perspective emphasizes a
 focus on strengths of individuals, groups, and institutions within the setting and
 interventions are more likely to succeed if they build on such existing strengths,
 rather than introduce new external mechanisms for change (this is important for
 mobilising the strengths of those who hold positive values and vision, and are well
 trained and supported in their roles)
- Interdependence: any change to one aspect of the setting will have consequences for other aspects of the setting, so any intervention needs to anticipate its impact across the entire setting, and be prepared for unintended consequences (this is important for understanding the need for sustained effort to build safety and quality in services).

As we look further into the iatrogenic aspects of services and services systems such that care is corrupted, we can see how consideration of these elements is important for both analysis and the planning and evaluation of change initiatives. This phenomenon becomes known as *malignant positioning* (Sabat et al 2004) in which we can observe the collusion of a social view, family view, service providers and then the person themselves (this is also known as adaptive preference) that the person is either highly risky requiring monitoring, control and restraint or that they are unable to give a truthful account of things happening in their lives, that they are burdensome etc. When malignant positioning occurs even those who care for the person can 'innocently treat people in depersonalizing ways' (Sabat et al, 2004, 178).

The construction of service recipiency as a master status is a clear example of this depersonalizing which in turn, as famously demonstrated by McKnight in *Do No Harm: A Policymaker's Guide to Evaluating Human Services and Their Alternatives*, exposes the person to more intense and destructive rights denial and harm and violence leading to dehumanization. Essentially he argues that if we establish a view, through advocacy and social policy as well as through direct service provision, that the person needs to be surrounded by professional services in order to survive, even to the point that they must be placed at some remove from community life, they may themselves adopt what is called 'inappropriate

behaviour', which exposes them to more interventions to manage, modify and restrain behaviour. Add to this our understandings that traumatised people tend to hyper-vigilance, hyper-arousal and increased defensiveness (often expressed through aggression) and we can see how 'inappropriate' behaviour morphs into 'risky, threatening, violent' behaviour.

2.5 Focusing on the organisational context:

Human service actors face the world with imagined identities built on good intentions and high ideals, while simultaneously casting a deep and sinister challenge. (Kennedy, 2009)

At the macro level an existing powerful critique of current approaches to risk and protection argues that instead of focusing on individual vulnerability (or indeed resilience) state intervention should instead focus upon the structural factors that elevate the risks for particular groups and communities (Baldwin and Spencer, 2005). Here we examine the literature about organizations that behave unethically, that act out the shadow of human services and become increasingly tolerant of abusive behaviour. In other words, we look at organisations that host violence toward those who rely on them for service.

Wardhaugh and Wilding, writing in 1993 ask this question (which is consistent with our WPR approach):

How do institutions, organisations and staff, supposedly committed to an ethic of care and respect for others, become 'corrupted' in their power and with their clients? (1993,4)

They start with Martin's groundbreaking work *Hospitals in Trouble*, written in 1984, in which he advances a set of pre-conditions that are likely to result in the breach of values and of trust, the escalation of violence and the denial and abuse of rights of those people dependent on services. They also build on Kelman's 1973 work on *Violence without Moral Restraint* to challenge any remnant claims that these transgression occur because of the 'bad apple'. While this work is not contemporary it represents a landmark in moving the analysis from individuals to systems and context and provides beginning insights into the organisational elements that might point to the possibility of the corruption of care.

They propose these steps lead into organisational violence:

- Placing the service recipient outside the bounds of the normal moral concern –a
 process of extreme depersonalization. They also describe this as neutralization and
 exclusion
- 2. Reinforcing powerlessness and prolonged vulnerability among those reliant on services
- 3. Reinforcing social devaluation and expounding the proposition that looking after these people is difficult and dangerous work

- 4. Allowing staff to become isolated from management through a failure to set values and aims; 'a remarkable resistance to internal complaints'; and a willingness to accept that difficult conditions require strong measures
- 5. Allowing the organization to become closed and inward-looking leading to the stifling of internal criticism, the strengthening of staff solidarity, the restriction of new ideas, and the preservation of routines and their rationales
- 6. Ignoring any mechanisms or processes of accountability
- 7. Developing certain models of practice which are more susceptible to a corruption of care including, narrowing clinical models, establishing strict hierarchies, promoting too much growth of bureaucracy, and concentrating 'the most difficult cases' into service units
- 8. Alienating families from care
- 9. Identifying some groups as more in need of harsh treatment e.g. young offenders, angry people, needy people and intimidating others

This work has been furthered developed within the mental health sector, especially by Bloom and Farrager and become known as The Sanctuary Model. They start with an analysis of the impact of organisational stress which contributes to the development of *trauma-organised* systems:

Just as the encroachment of trauma into the life of an individual client is an insidious process that turns the past into a nightmare, the present into a repetitive cycle of reenactment, and the future into a terminal illness, so too is the impact of chronic strain on an organization insidious. As seemingly logical reactions to difficult situations pile upon each other, no one is able to truly perceive the fundamentally skewed and post-traumatic basic assumptions upon which that logic is built. Just as an earthquake can cause the foundations of a building to become unstable, even while the building still stands, apparently intact, so too does chronic repetitive stress or sudden traumatic stress destabilize the cognitive and affective foundations of shared meaning that is necessary for a group to function and stay whole... organizations under repetitive stress can become crisis-oriented, unsafe, fragmented and amnestic, impoverished, authoritarian, abusive, disempowered, aggressive, chronically bereaved, and demoralized. In doing so they are likely to replicate, rather than remedy, the problems of the clients who come into their care. (Bloom, S 2007 Organisational stress as a barrier to trauma-sensitive change and system transformation)

As part of a growing international movement they advocate that the system needs to become trauma-informed, saying: We believe that is what a "trauma-informed" culture has to be – it requires a shift in the very foundations of the way we think, what we feel, how we communicate, and how we practice (2010). An organisation must become aware of the impact of trauma in the responses to stress of both clients and workers, and to deal with these through mobilising strengths, building resilience, embracing commitment to collaboration and

empowerment and building a service culture that does not use violence to control people who are afraid, lonely and agitated.

2.5.2 Bringing back the individual: Any ecological model cannot deny that an individual worker is also making decisions about how to act.

Gillingham (2006) addresses some of the ways in which individual workers can distort their thinking. He nominates the 'rule of optimism' and defensible decision-making as particular traps for those who either formally or informally assess risk. Milner and O'Byrne (2002) remind us that 'social psychology tells us that it is not easy to make objective assessments in any social situation. And the human tendency to make attributions, develop stereotypes and increase risk-taking in groups (through group think) is such robust behaviour that exhortations to keep an open mind are worthless.' (p185). They argue that individuals make decisions, even with strong cultural and group pressure inside an organisation and that in the end we must accept responsibility for our own decisions. This perspective links with Post World War 2 personalist understandings of moral leadership in difficult settings which privilege the dignity of the human person, subjectivity and autonomy, community and solidarity (Whetstone, 2002).

It is important that we understand the motivations and actions of those who, within trauma organised systems and human services that habitually displace personal need with systems power, are able to preserve a string focus on vulnerable people, to resist the transfer of power away from them and to respond openly to challenge. To abstract all actions to 'the system' is to lose touch with the vital force for transformation.

3.0 Analysing systems that aim to make a difference

The particular structures, orientations and approaches in the work of a professional group may create divides between their own everyday and commonplace professional assumptions and practices and those of other professional groups, and render them less able to see practice from a different professional perspective.(Hester, 2011, 839)

3.1 Multiple planets

Hester, writing in the British Journal of Social Work, reflects on 2 decades of multi-agency working in the areas of domestic violence and child protection, and records a an ongoing (and shared) frustration that: despite the prolific and positive work of practitioners to tackle domestic violence, frustrations are often voiced by social care and other professionals—and echoed in women's and children's experiences—that it can be difficult to ensure and sustain safe outcomes for women and children in circumstances of domestic violence (p838). We have already noted a related frustration about being able to significantly alter the experiences of rights denial and violence faced by many people with disability reliant on services. Hester's analysis is therefore apposite in this arena. The parallel '3 planets' might be identified here as the disability services system; the Australian human rights protection regimen, including the HSCCC and the SA OPA; and the community based violence prevention processes. We could

add a 4th which is the criminal justice system with its understandings of criminal behaviour, evidence and 'justice' for victims.

Hester argues that each of the planets is characterised by its own history, culture, laws, populations (of professionals) which she identifies as leading to tensions and contradictions in professional discourses and practices. Perhaps the clearest examples we have of this in South Australia is the analysis carried out by the Office of the Public Advocate into 'deprivation of liberty' and the allegations of sexual assault by disability support workers (Annual report, 2010-2011). A close reading demonstrates an expressed willingness of various agencies (including HCSCC) to work together to ensure changes in policy and practice. The report also points to the lack of resolution in these areas, the tensions in understanding what constitutes improper use of restraints, the nature of sexual assault, and the rights of accused workers and so on.

This is further highlighted by the work of Milner and O'Byrne (2002) who examine interagency distortions through the lens of behavioural economists Kahnemann and Tversky (winners of the Nobel Prize for Economics in 2008 for their work on the irrationality of decision-making). They take a slightly different view here, arguing that 'two heads are not necessarily better than one' identifying group think, group polarisation and prospect theory as drivers for interagency ineffectiveness and tendency to accept high levels of risk (P176-181).

With these tensions, influenced by the decisions different 'planets' make about boundaries, resource exchanges, and information flows as advanced by the critical systems analysts (Ulrich 2002, Kagan, 2004) the possibilities for collaboration that aims at quality and safety remain constrained, but not impossible. It might be that singular leadership is an important component of building a better future for those reliant on disability services.

3.2 What is the current policy context for the HCSCC?

Since the 1990s significant work has been undertaken in adult protection in Anglo-phone countries such as Australia, UK, Canada, New Zealand and USA, yet the goal of prevention and the necessity to intervene to protect and to redress, require ongoing vigilance and creative intervention to ensure that the dynamics of risk in the lives of people with heightened vulnerability are addressed by sufficiently potent measures.

Disability policy in Australia is undergoing a major upheaval as all levels of government come to grips with the expectations of the UNCRPD, expressed in part through the National Disability Strategy; the foundations for the development of a National Disability Insurance Scheme are built; and the project of personalization advances across all jurisdictions. In this context state and federal governments have revisited safeguarding approaches. A nascent conversation about the possibility for a national approach to safeguarding is focusing on both specialist provisions and mainstream violence prevention and rights protection.

These shifts toward more personalised models of support and increasingly market model approaches to service delivery are contributing to rapid change in community services. Sector

leaders express concern about increased fragmentation, declining regimes of accountability and the entry of for-profit services with little community oversight.

Finally, these evidence and policy concerns are associated with a fertile debate about ways to conceptualize the situation of those with disability who become reliant on services which in turn become prone to increasing patterns of rights denial and oppressive practice.

3.3 Where are further opportunities?

Key provisions within the Health And Community Services Complaints Act [SA 2004], especially Objects (a) (d) and (e), namely an obligation to improve the quality and safety of health and community services through complaints handling; building complaints handling capacity in services; and to pursue systemic issues. Further, the Commissioner's 12 functions under Section 9 give effect to these objects specifically to identify and review issues arising out of complaints and to make recommendations for improving health and community services and preserving and increasing the rights of people who use those services (Sec 9 1(b)). Relatedly, Sec9 1(c) and (d) address the causes of complaints and trends; the provision of information relating to the Charter; rights and responsibilities; and other matters as determined by the Commissioner. Most importantly the Commissioner is directed to be mindful of the needs of and barriers faced by special groups. For the purposes of this project, and based on solid evidence, people with disability, their families and carers constitute just such a special group.

3.4 Additional strategic opportunities

Strategic opportunities include those offered by the June 2012 release of the UNCRPD Shadow Report; SA *State Strategic Plan* (2012); the findings and recommendations of the Social Inclusion Board's *Strong Voices* report (2011); 2010 and 2011 annual reports from the HCSCC and the SA Public Advocate; increased budget spend on disability services and investment in an expanded Community Visitor's Scheme(2012-13); the development and dissemination of the HCSCC Charter; the promised development of a SA Disability Act; revised policy on consent and restrictive practices in Disability SA; and public and parliamentary debate about the merits of a mandatory reporting regime in disability services and the wider community.

Part #2 Towards quality and safety in services and communities

1.0 Building quality and safety in services and communities

An implementation strategy that positions the HCSCC as a leading agency in rights protections and complaints resolution, including a comprehensive approach to prevention as well as complaints elicitation, resolution and redress, with a strong focus on eliminating actual and threatened retribution

1.1 Change model

We have identified a social ecological model e.g. a model that strives for a systems understanding of those factors and transactions that contribute and/or could undermine rights denial and violence in disability services in particular and communities more generally, while recognising the significance of individuals, their decisions and actions and their capacity for moral leadership. It is not necessary to fully explore all the change implications of social-ecological perspectives here – they will flow from ongoing analysis in the field. (After all, social-ecological perspectives are very useful for investigating complex fields of practice and community life, not simply carrying out experimental research.) We shall see how this approach opens up various 'effects' that can become a focus for change efforts, namely spheres of influence and cross-level effects (including top-down, bottom up and interactive effects).

It is also useful to revisit the early work of Watzlawick and others on orders of change. Following the classic work of Watzlawick, Weakland, Fisch and Erikson (1974) we can identify 1st order efforts which are located within existing systems, often employing common sense solutions e.g. more resources, more training, reducing overcrowding, increasing reporting, complaints elicitation and resolution. These change theorists are at pains to point out that 1st order changes are not inferior change efforts, (they may be all that is possible), however, for systems altering change or 2nd order change a more detailed approach to reframing is required. This report has strived for that reframing by opening us up to other discourses related to rights denial and violence and to theories such as those related to trauma organised systems.

The strategies proposed here and expanded further in this part include:

- 1. The development of a public health model with a strong focus on promotion and asset building
- 2. Rights protection
- 3. Anti-oppressive practice
- 4. Empowerment

These strategies can in turn be evaluated seeking to gain a better understanding of how thay can become increasingly:

- 1 Outcomes focussed
- 2 Strengths based
- 3 Non-discriminatory
- 4 Engaged with the community
- 5 Socially just and decent

1.1 Health promotion approach to building nonviolent services in nonviolent communities

Building on models developed in palliative care where there is a close link made between a need for a finely tuned personalised approach + a wider service + community based approach, Kellehear, in designing an adequate public-health approach to end-of-life care proposes a conceptual framework called 'Compassionate Cities' to capture these elements; traditional public health practices of prevention, policy development, government leadership and intersectoral cooperation (2005, 35). He expands this into the Healthy Cities model proposed by the WHO, to refocus effort on building Compassionate Cities in which a person can expect a profoundly personalised response to their needs at end-of-life. The community assets have been built up to ensure that they are not abandoned to stressed, under-resourced, paid care.

Kelleher starts with the Ottawa Charter for Health Promotion, World Health Organization (1986) to list five key action areas for health promotion:

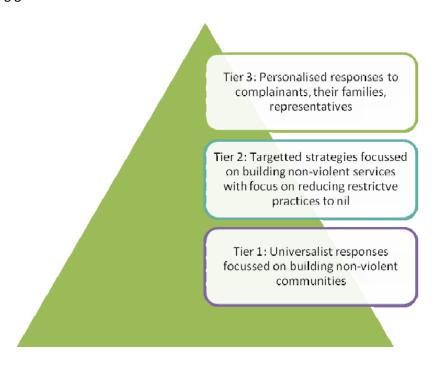
- 1. Build public policy
- 2. Create supportive environments
- 3. Strengthen community action
- 4. Develop personal skills (empowerment)
- 5. Reorient health or human services

This model can also be adapted to build a coherent strategy around quality and safety in services and communities. Consistent with Kellehear's work on compassion (see Box 4, page 44) we could argue that:

- 1. Quality, safety and rights protection are moral and ethical imperatives for developing services and communities
- 2. Quality, safety and rights protection implies a concern with full personhood
- 3. Quality, safety and rights protection are positive concepts, especially for those at current and historical risk of violence and rights denial

4. Quality, safety and rights protection address the social- ecological aspects of services and communities, especially transactions, multiple systems, complexity and intensity

Kellehear goes on to say: If we fear institutionalisation at the end of life, if we deplore the ongoing morbidity and mortality of refugees and indigenous peoples, and if we aspire to our own health until the end of our life, we require a seamless public health approach to life that is inclusive of death and loss.(2005,115). Kellehear has overlooked issues related to disability and to long term human service dependency that places such people in danger of rights denial and violence. Perhaps we could add that to this seamless public health approach to life that we must be inclusive of disability and interdependence. In order to make this real, any model must incorporate community development. In this way we can see the classic public health model being generated.



This model also allows for the emergence of a shared policy and practice discourse across the 'planets'.

Consistent with the HCSCC mandate the areas that offer the most fertile opportunities, especially in Tier 2 are in:

- 1 Contributing to creating supportive environments
- 2 Contributing to strengthening community action
- 3 Contributing to developing personal skills (empowerment)

The following sections address these strategies. Each section identifies resources to assist in the development of these strategies and identifies some first steps that could be taken by the HCSCC. Within this approach the HCSCC is enabled to preserve a strong focus on those who are most vulnerable to rights denial and violence (those who are voiceless, reliant on services, distanced from family and community, traumatised by previous violence and afraid).

1.2 Creating supportive environments through rights protection and fulfilment It is clear that human rights impose some obligation on the state to ensure that those rights are respected, protected and realized (Ife, 2001, 89)

Rights protection initially builds from top down. The UN Conventions provide an international framework to which Australia is a signatory. These have a declaratory power and set the grounds for expectations that those who live with violence can reasonable expect that their rights will be promoted and respected. Most recently Australia has signed up to the Convention of the Rights of Disabled Persons, signalling a commitment on behalf of all Australian Governments to processes that ensure that citizens living with disability live from torture, from inhumane treatment, have their bodily integrity protected....

Jim Ife, a highly regarded human rights based social worker argues however that these rights will not be fulfilled without a bottom up effort (2010). Ife, a community worker, identifies community building as crucial to these processes, alongside but not reliant on complaints based processes which have the potential to disclose deeper and more extensive 'patterns' of rights denial.

Within current HCSCC activities The Charter and associated projects constitute a major contribution to this bottom up approach and could be expanded into a more comprehensive community education and mobilisation strategy aimed particularly at assisting community members, professionals and service workers and managers to 'see' the extent of violence and rights denial in services and to recognise the barriers to self directed faced by those who must live in these environments.

Within this strategy the HCSCC could also align with existing advocacy activities, especially those advanced within the Independent Shadow Report presented to the International Treaty Body, along the following lines...

Example: Recommendations re Article 15 Australia's Independent Shadow Report 2012

- That Australia ratifies the Optional Protocol to the Convention against Torture.
- That Australia enacts legislation in all jurisdictions in Australia to comprehensively criminalise cruel, inhuman or degrading treatment or punishment and provides for legal action to be taken to remedy a breach.
- That Australia establishes a nationally, consistent legislative and administrative framework for the protection of people with disability from behaviour modification

and restrictive practices that cause harm and punishment, including the prohibition of and criminal sanctions for particular behaviour modification practices.

- That Australia develops an evidence-based national plan that outlines actions for the
 development of positive behaviour support strategies that acknowledge and respect
 the physical and mental integrity of the person; and for the elimination of
 environments and treatment approaches that have been shown to exacerbate
 behaviour that leads to application of inappropriate levels of restriction and restraint.
- That Australia conducts a national inquiry into the use of restrictive practices on children and young people with disability in mainstream and segregated schools and identifies and implements recommendations for the elimination of these practices.
- That Australia acts on the recommendations of the UN Committee against Torture to ensure immigration detainees are provided with adequate physical and mental health care including routine health checks.¹

This approach would ensure that the focus on restraints and other oppressive practice fulfils an HCSCC obligation to be mindful of the most vulnerable and to focus attention on building supportive environments consistent with the proposal contained within the *Strong Voices* Report (2011).

1.2 Strengthening community action through asset and alliance building to reduce violence in communities and in services

The above section on the difficulties of attempting to 'align the planets' highlights the barriers faced by those who recognise that this field requires concerted action through the building of alliances and assets. The considerable literature and practice in community development, rather than bureaucratic alignment, offers more opportunity to identify joint goals, shared work, and points at which different groups can contribute assets. The naming of abuse and harm in disability services as violence and right denial opens up the possibility for shared work to emerge with non-disability focused players, especially those involved in building peaceful communities, anti-violence work and social inclusion.

The HCSCC could invest in identifying and enlisting those who are working in these fields, especially adopting community education (as asset building) and community development (especially in areas where services tend to be clustered) and sector development (especially work with women's organisations and Aboriginal organisations involved in anti-violence work).

¹ Committee against Torture, Concluding Observations of the Committee against Torture: Australia, 40th sess, UN Doc CAT/C/AUS/CO/3 (22 May 2008) para 25.

1.3 Developing personal skills of workers through anti-oppressive practice

Dominelli's model of social work/social care (2002) known as anti-oppressive practice seeks to – address the dual nature of services that is acknowledged here – the ambivalent combination of caring and oppressing. She proposes that those who work in these services environment in direct care, professional and management roles can 'see through' the rationalisations that can sustain violence and rights denial. Anti-oppressive practice starts at but goes beyond non-oppressive practice (which empowers the worker to refuse to contribute to the violence, to choose not to apply restrictions or intimidations etc). Anti-oppressive practice also addresses those forces which lead to the entrenchment of rights denial and violence as ways of managing in intense and complex settings.

This approach is also enriched by Bloom's 'trauma-informed model' which provides the organisation with ways to recognise how much the service has become organised through trauma and needs to be released from the mindset that perpetuates violence.

Many workers in services report anecdotally that they are concerned about the impact of the environments in which they work both on service recipients and themselves as workers. There is some acknowledgment that high levels of churn within some services may point to this unease and powerlessness. As Kennedy says:

The gauntlet has been thrown down, not to the minority who engage in self-serving and injurious behaviour, but to the majority who are mostly well intentioned, but internally and externally unanchored, unreferenced and undecided in the small and large actions in human services activity (2009,274).

The HCSCC could focus resources on giving those workers opposed to rights denial and violence in services to speak out without fear of retribution by their managers and employers. This could be linked to International Disability Day, 3 December with the Commissioner issuing a call for workers to speak out.

As a more enduring strategy the HCSCC could investigate possibilities for training, including by peers and disabled persons. (c.f. The Better Practice Project in the Aged Care sector)

1.4 Developing personal skills of service users and families through empowerment approaches

If people are to protect themselves from abuse, they need to be aware of what abuse is, be informed about their rights and have the skills and resources to be able to deal with it. SCIE http://www.scie.org.uk/publications/reports/report41/empowerment.asp

Empowerment is being increasingly understood as central to long term positive health outcome for people who have experienced exclusion and violence. There is a vast literature on the meanings of empowerment, the processes towards it, the evidence for it at both individual and community levels and links with quality services, safety and rights protection. It

is not possible to canvas here all these elements in this growing conversation, however, it is important to acknowledge some important features of empowerment work.

According to Judith Lee (2001):

The empowerment of minority groups and individuals living on the margins of society is an incremental process, not an absolute outcome. Moreover, the empowerment of minority groups can frequently be reduced to token representation of individuals who are acceptable to the dominant group...the territory defined by the empowerment approach is personal/political – intensely personal and unavoidably political. (P6,7)

The intensely personal aspects of empowerment point to the work of recovery that many people who have been subjected to violence and rights denial will need in order to regain health, hope and self-efficacy. This is part of the reparation that services will need to make when a complaint has been established. However, it also requires that, as services move from being trauma-organised to trauma-informed, they will become more aware of the enduring clinical needs of their clients. Part of the transformation of practice is the effective, clinical response to trauma, even when the person has articulated neither a complaint nor a request for support. That clinical support may need to be provided outside the service in order to establish trust and a therapeutic alliance.

Furthermore, the person will require skills development and opportunities to take risks, to grow, to dream and to act on dreams. All of this requires a commitment inside services to move towards quality, safety and rights fulfilment, to move away from narrow instrumental goals in the life of the person and to adopt personalised approaches at every point. It is not sufficient to say that this work cannot happen because of systems constraints. Current thinking among indigenous communities points to the capacity of individuals to grow and develop even when faced with significant systems barriers (Whiteside, 2009). Indeed, it might be central to the empowerment of the person beyond the personal to offer healing, hope and growth before they are able to work in more politically focussed work.

It is however a folly to think that empowerment work belongs only to services and professionals in relationship with 'clients'. Empowerment is a goal for anti-oppressive practice but it must always remain the person's goal, independent of services and families.

Perhaps the most significant contribution made by those who seek empowerment is the wide repertoire of resources they mobilise. Empowerment may be influenced by but is not contingent on services – the scope for involvement with multiple community and political resources, including the media, the arts and recreation. This adds breadth to the health promotion approach and opens up possibilities for action for the HCSCC.

2.0 Planning + Programming

Which practical strategies will enable the HCSCCC to contribute to the prevention and redress of rights denial, abuse & neglect of people living with a disability?

Consistent with the health promotion approach which builds specifically on assets building, the advance of anti-oppressive practice and empowerment, the HCSCC has access to a unique arrange of resources and opportunities including,

- 1. Continuing to elicit and deal with complaints respectfully and in a timely fashion, as well as collecting data about complaints
- 2. Taking leadership, along with other key players, in addressing restrictive practices, consistent with the *Strong Voices* report (2011)
- 3. Further developing the HCSCC Charter work and the champions network
- 4. Building up resources through the website
- 5. Employing the arts as a means to provide voice and intensity to the demands to be treated with respect and to live from violence and rights denial. A process that discloses present oppression, focussed, for example, on restraint and seclusion, in order to build community compassion and action.
- Carrying out a Public People's Commission which invites those affected to tell their stories in an entirely safe and supportive environment but no longer condemns service users, families and concerned workers to silence.
- 7. Examining strategies used in other sectors such as child protection e.g. 'Signs of Safety' as ways of assisting those who come into contact with people reliant on services to recognise both the signs of abuse and the signs of safety.
- 8. Working with National Disability Services at state and national levels on building quality and safety focussed on recognising violence and rights denial and taking action to transform services into trauma-informed organisations in which restrictive practices are no longer used
- 9. Undertaking similar work with Disability SA
- 10. Building connections and shared work with women's organisations, including Women with Disability Australia on their anti-violence work

3.0 Conclusion

We have acknowledged the profound tension in disability services between a shining history of working well alongside those reliant on services to open up their lives, and a shadow in which people are exposed to rights denial and violence. Following Martin and others we have named this shadow the 'corruption of care.' Part #1 of this report has focussed on the corruption of care, while advocating the mobilisation of those individuals and organisations who can contribute to building quality and safety in services.

Asking how the problem is represented we have focussed on developing a knowledge base about the nature and extent of violence and rights denial in services, concluding that, while gold standard data are not readily available, we have solid grounds for concern. We have explored the evidence for violence and rights denial when individuals do not complain and the barriers to complaining.

The report has looked at theories in the field in an effort to build a deeper understanding of the dynamics that drive violence and rights denial in services. Taking a social-ecological approach we have been able to see how organisations, through time and without mal-intent can become devaluing and depersonalising, replacing system concerns for client concerns. This understanding is further enriched by understandings of trauma-organised systems.

Part 2 takes us into the possibilities for action, identifying a health promotion approach based on the Ottawa Convention. The report then explores avenues for action for the HCSCC to fulfill the mandate to work at a systems level to reduce those factors and dynamics that lead to people needing to seek recognition and reparation through complaints.

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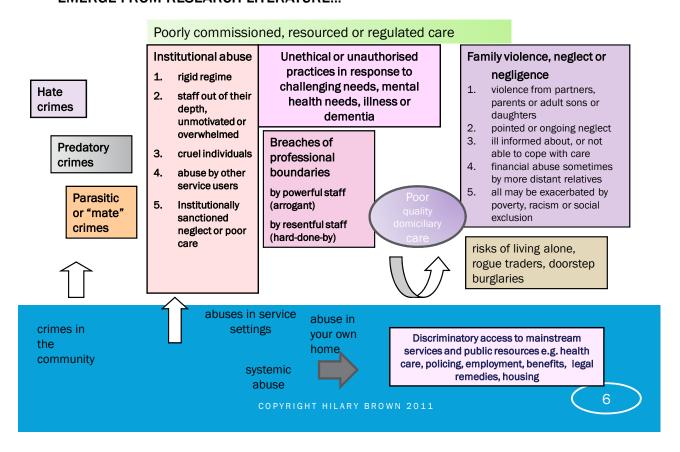
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Appendix 1: About the author

Dr Lorna Hallahan, who has 30 years experience working in not-for-profit human services and disability advocacy organisations, is a senior lecturer in the School of Social and Policy Studies at Flinders University where she teaches a range of social theory and practice topics including social work ethics. Lorna is affiliated with the Flinders institute of Public policy and Management and her research focuses on the multiple aspects of realising the vision of community inclusion for people with disability. Lorna's policy advice roles include being a member of the National Disability Insurance Scheme Advisory Group; Deputy Chair of the National People with Disability and Carers Council; and member of the South Australian Health Ethics Advisory Council. Lorna was Chair of the SA Minister's Disability Advisory Council from 2007- July 2012 and, as member of the SA Social Inclusion Board (2009-2011) chaired the subcommittee that developed the *Strong Voices* report. Lorna, who lives with mobility impairment, speaks and writes regularly on contemporary issues in the disability sector and ethical issues faced by workers in complex human services.

Appendix 2: Hilary Brown model on contexts of abuse

FUNCTIONAL DEFINITIONS SHOWING CONTEXTS (NOT TYPES) OF ABUSE THAT EMERGE FROM RESEARCH LITERATURE...



Acknowledgment: Dr Sally Robinson, Southern Cross University provided this graphic.