Beyond Overwhelmed

Identifying pathways to deliver more effective services for people & their pets affected by hoarding and squalor across NSW
BEYOND OVERWHELMED:
IDENTIFYING PATHWAYS TO DELIVER MORE EFFECTIVE SERVICES FOR PEOPLE & THEIR PETS AFFECTED BY HOARDING AND SQUALOR ACROSS NSW

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The following organisations are members of the NSW Hoarding and Squalor Taskforce:

- Catholic Community Services NSW/ACT
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- South Eastern Sydney Local Health District
- NSW Ministry of Health – Mental Health Drug and Alcohol Office
- NSW Trustee and Guardian
- Housing Policy and Homelessness Directorate, Housing NSW
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- RSPCA NSW
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Catholic Community Services NSW/ACT, a division of Catholic Healthcare Ltd, is a state wide provider of community aged care, homelessness, mental health and disability services. Catholic Community Services provides specialised Hoarding and Squalor services in Sydney, the Hunter, Southern Highlands and the Illawarra. In 2009 and 2012, Catholic Community Services organised the National Hoarding and Squalor Conference in Sydney, with the third National Hoarding and Squalor Conference scheduled for September 2014.

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Executive Summary

In 2008, Catholic Community Services recognised the increasing need for an improved service response to the complexity of hoarding and squalor. An approach to the NSW Minister for Ageing, Disability and Homecare, Kristina Keneally led to the establishment of the Severe Domestic Squalor Project in Sydney. The demand for support and services arising from the geographical funding limitations of this new service was overwhelming. There is a clear need for further specialist support.

In 2009, Catholic Community Services organised the inaugural National Hoarding and Squalor Conference, attended by over 400 people from Australia and New Zealand. At the second National Hoarding and Squalor Conference in 2012, Catholic Community Services responded to a call for action to establish a Hoarding and Squalor Taskforce to address gaps and shortcomings in service responses for people affected by hoarding and squalor. There was strong agreement that these clients were not receiving appropriate access to care and support. A NSW Taskforce was convened to explore existing service provision, identify service strengths and weaknesses and develop recommendations for future action. The principle function of this taskforce includes informing and advising policy review and legislative mechanisms within government. The production of this paper has been funded by Catholic Community Services NSW/ACT on behalf of the NSW Hoarding and Squalor Taskforce.

What is hoarding?
In May 2013, for the first time ‘Hoarding Disorder’ was defined, and included in a new chapter of the DSM-5 on Obsessive-Compulsive and Related Disorders. Hoarding is regarded as abnormal (pathologically) if there has been excessive collection of items such as such as clothing, newspapers, electrical appliances, food packaging (with many such items appearing to have little or no value) and a failure to remove or discard them. This often means that the environment, in which they are being kept, becomes so cluttered that it can no longer be used for the purpose for which it was designed. This consequently impairs basic living activities (such as cooking, cleaning, sleeping, showering, access and moving) for the occupant. Excessive hoarding is a multifaceted, complex problem. Hoarding that comes to the attention of public authorities may be an issue related to mental health, environmental, public health, medical, public safety, legal and housing issues; as well as having financial implications.

Hoarding is a complex disorder believed to be associated with four underlying characteristics: emotional dysregulation; difficulties processing information; intense emotional attachment and fixed beliefs about not wanting to waste objects. Recent studies also indicate there may be strong hereditary factors associated with hoarding behaviour.

What is squalor?
Squalor is the term used to describe an environment where a person’s home is so unclean, disorganized and unhygienic that people of similar culture and background would consider extensive clearing and cleaning essential in contrast to the term hoarding which describes behaviour. Commonly, clients come to the attention of service providers because of the deleterious effect their living conditions have on them-selves or the surrounding community. People who live in a state of severe self neglect and squalor can present enormous challenges, to health professionals, to social services, to the council and environmental health officers, to family, to neighbours, and to themselves. Behaviours that lead to a person living in squalor may be heavily influenced by the mental health of the occupant. Excessive accumulation can result from brain disease or a mental health condition, or sometimes is due to impaired mental or physical capacity to maintain home care.

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1. NSW Hoarding and Squalor Taskforce. Terms of Reference, March 2013.
What is animal hoarding?
Animal hoarding is a poorly understood and distressing community problem. The RSPCA reports that 20,000 animals are believed to be kept in ‘hoarding conditions’ in NSW (population 6 million), and that 200 hoarding cases were uncovered in 2012. Animal hoarding involves keeping a higher-than-usual number of animals as domestic pets without having the ability to properly house or care for them, while at the same time denying this inability. Compulsive hoarding can be characterized as a symptom of a mental disorder rather than deliberate cruelty towards animals. Hoarders are commonly deeply attached to their pets and find it extremely difficult to let pets go. They typically cannot comprehend that they are harming their pets by failing to provide them with proper care. Hoarders tend to believe that they provide the right amount of care for their pets.\(^7\) Research suggests that similar to object hoarding, animal hoarding is likely the response to a diversity of traumatic experiences which result in dysfunctional attachment styles to people and lead to compulsive and addictive behaviour.\(^8\)

The NSW response
Service provision to people and their pets affected by hoarding and squalor is piecemeal across NSW, with pockets of expertise driving the response and coordination of relevant services. To be effective, services need to be well coordinated. They need to work in a collaborative partnership with each other and to value reciprocity and sharing acquired knowledge. Blockages to effective service delivery can emerge where principles are not shared or services lack capacity due to funding restrictions. Clinical, public, community based, and specialist services all have a role in providing a response, and are working together more and more under local derived protocols for service collaboration.

Anecdotal as the evidence may be, it is important to note that the skill and passion of staff working with people affected by hoarding and squalor has a particularly effective and powerful impact. These are the individuals who creatively look at their funding restrictions or core business, and somehow find a way to support individuals living in these circumstances.

Risk management
Many jurisdictions have legislated requirements that employers follow, using procedures to ensure the health, safety and welfare of their employees. Organisations that provide services to people living in squalor must ensure a safe working environment for their employees. Risk management strategies such as having a checklist to identify hazards, including a home safety assessment, help eliminate or control risks to employees engaged in service provision to the community.\(^9\) A combination of controls will often be required to minimize the risks in a squalor situation. Hazards that can be easily addressed will build trust with the client and create success. If the client is not cooperative and the risks associated with the squalor environment cannot be addressed, services may be denied until the situation is rectified.

Legislation
Legal interventions available in squalor and/or hoarding cases may be grouped into three broad categories: those focused on the property, the state of the premises; those focused on the person, the wellbeing of the resident; and those focused on the animal, the health and wellbeing of the animal. Those legal interventions that focus on the property include the action of private nuisance; actions to enforce leasehold conditions (whether in long leaseholds or residential tenancies); and some actions brought by local authorities under public health legislation. The second group of legal interventions focus on the person, the resident and their wellbeing. They may be primarily concerned with issues of legal competency, or more simply, with the conditions in which the resident lives. Their aim is to protect or promote the best interests of the resident.\(^10\)

Interestingly, as a result of the SA ‘Foot in the Door’ project, legislative changes made to the South Australian Public Health Act 2011 now include the Severe Domestic Squalor Policy which provides a definition of severe domestic squalor and declares it a risk to health for the purposes of the Act.\(^11\)

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\(^11\) SA Health (2013) A Foot in the Door - Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia. (Draft) Prepared by Health Protection Programs, Public Health Services, Public Health and Clinical Systems and Department for Health and Ageing on behalf of the Chief Public Health Officer
Tools and resources
A number of tools and resources have been adopted in NSW and have emerged in an attempt to qualify, assess and coordinate service provision and support to people who hoard or live in squalor. These resources involve toolkits, mobile applications, guidelines and protocols, environmental and client outcomes measurement tools. In order to standardise the measurement, rating scales are needed to document degrees of uncleanliness and hoarding, and in the assessment and management of people found to be living in a state of substantial disorganisation and mess. This sort of validated documentation can also serve as an evidence base for court orders, guardianship applications and mental health interventions.

Across Australia
Currently, some coordination and collaborative responses to people and their pets affected by hoarding and squalor exist in NSW, South Australia, Victoria and Queensland; yet it is inadequately identified and piecemeal in most parts of the country. Victoria has been the leader in discussion and guideline development for service providers across the state through the support of the Department of Health in Victoria. South Australia commissioned a Project ‘A foot in the Door’ to influence legislation and develop guidelines for service providers to facilitate cooperation, understanding and collaboration of the hoarding and squalor issues in their state. Queensland support is currently provided through Centacare Brisbane and the local councils are strong and vocal advocates for change and support for services supporting people and their pets affected by hoarding and squalor. There is a distinct lack of information and formal coordination of services to support people who hoard or live in squalor in other Australian States and further investigation into how hoarding and squalor is managed is required.

Key Issues
1. Government leadership
Currently, the complexity of issues surrounding people and their pets affected by hoarding and squalor touch a variety of current political portfolios, yet no one portfolio is poised to assume responsibility for the overarching framework, guidance and dedicated resources to support this issue.

The regularity with which hoarding adversely impacts those who hoard and their families and communities suggests that an encompassing, community response is needed. Nationally and internationally hoarding and squalor taskforces have begun to emerge to support this collaborative approach. There are 85 task-forces in the United States, Canada and Australia at the present time with more developing each month. Interestingly, the success of taskforces across the United States has been linked to the initiative being driven by a Government Human Services agency; for example, the local council, Department of Health, Department of Ageing and Disability etc.

Much of the evidence base regarding the prevalence of hoarding and squalor in NSW is piecemeal and scarce at best. For an effective response to people and their pets affected by squalor and hoarding data need to represent more than just a snapshot of a coordinated area of service. Data create the opportunity to highlight where clinical support services are needed; indicate the true costs associated with hoarding and squalor cases; identify where early intervention supports and identification systems can prevent severe cases of hoarding and squalor; identify where existing systems can be adjusted and reviewed to consider the presentation of clients who hoard or live in squalor; identify where specialist services are required and where education and training can be implemented to minimise the need for specialist services.

The prevalence and incidence of animal hoarding in Australia and the intersection with human welfare have not yet been adequately and systematically recorded, even though the RSPCA receives frequent calls to intervene in cases. It has been stated that the animal welfare problem cannot be solved without assisting owners to improve their own welfare and that a collaborative approach between sectors is needed.12

The development of any response paradigm involves the creation of a common language for all stake holders involved and more often than not utilisation of agreed standardised tools. This ensures that there is consistency of approach and measurable outcome changes with a common tool and familiar language descriptions. Standardised tools will also enable the creation of evaluation data to demonstrate change for the person affected by hoarding and squalor and the

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12 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
effectiveness of associated interventions. In addition, indicators of success will need to encompass a range of domains and have flexibility and objectivity in their descriptions to enable accurate and equitable documentation in order to contribute to a best practice evidence base.

2. Development of state-wide guidelines
Development of state-wide guidelines to support service delivery across human service, emergency and justice service portfolios, tenancy and landlord associations and private organisations will enable consistent and standardised, and thus comparable approaches to effective pathways for people and their pets affected by hoarding and squalor.

In addition, given that many people affected by hoarding and squalor also experience mental health issues, possible cognitive disability and information processing deficits, additional professional development and ongoing training relating to supporting capacity assessment and trauma informed care principles would further equip workers to provide a quality and effective intervention.

3. Research funding
Research that will inform best practice, and impact upon the effectiveness of services for people and their pets affected by hoarding and squalor needs to:

- articulate and define good practice interventions within an Australian context,
- further explore how individuals with hoarding behaviours understand their situations,
- define more clearly the causes of squalor and hoarding,
- articulate methodologies for intervention that are manageable within budget constraints and equip field workers to respond appropriately and skillfully;
- consider leadership for long term research, planning and resourcing, education.

4. Legislative change
The NSW Local Government Conference 2013 proposed as a key strategy to advocate to the NSW Government to develop policy, guidelines and an intergovernmental approach to enable Councils, relevant state agencies, services and community organisations to assist residents who have significant issues of squalor and hoarding. This message was echoed in the Parliamentary Inquiry into the Management and Disposal of Waste on Private Lands in October 2013 at Sydney Parliament House. Similar policy has been developed in Victoria and South Australia.

Local councils are often the first point of call to intervene in cases of hoarding and squalor yet the legislation designed to protect Public Health does not clearly define hoarding or squalor nor declare it a health risk to enable action under the Act.

Similarly, NSW Fire and Rescue are limited by their response and ability to enter a premises under the NSW Fire Brigades Act 1989. The Act allows firefighters to act once a fire has started, however firefighters are limited in their access to private property where there is no fire present, despite their numerous fire prevention strategies and initiatives. Access to a property that is not on fire must be by invitation.

Conclusion
This paper represents an initial overview to identifying pathways to deliver more effective services to people and their pets affected by hoarding and squalor. NSW would benefit from an agreed overarching response framework that encompasses multiple sectors, disciplines and legal jurisdictions. Identifying a central lead coordinating point in each region (one that has capacity to provide a complex care coordination role) will offer the opportunity for effective and efficient case coordination. A number of evidence areas and data gaps have emerged that will require a more thorough investigation and research to ensure that the overarching service response framework is relevant and functional for operational staff and policy makers.
Introduction

At the second National Hoarding and Squalor Conference held in 2012, there was a call for action to progress the service response for people affected by hoarding and squalor. All too often, these clients were seen to fall through service cracks and not receive access to care and support that was needed. A Taskforce was convened to explore current service provision, identify service strengths and weaknesses and refine recommendations for future action.

The principle functions of the NSW Hoarding and Squalor Taskforce include:

- Informing and advising the policy review and legislative mechanisms within government;
- Documenting the existing strengths and weaknesses in the management of hoarding and squalor cases in NSW and recommend strategies for data gathering, identifying ways to collect, share, publish and report data available across a broad range of service portfolios;
- Endeavouring to identify those engaged in directly dealing with people affected by hoarding and squalor, and the resources supporting them;
- Documenting and showcase examples of service partnership and care coordination that provide successful models of service intervention;
- Establishing research agenda and publish data and recommendations from the evidence collated of agencies engaged in hoarding and squalor service provision;
- Identifying possible ways to attract research funding to address critical gaps in the management of hoarding and squalor and identify cost effective models and interventions;
- Investigating the effectiveness of existing professional development resources in supporting workers to engage and respond effectively with people affected by hoarding and squalor;
- Identify best practice models for coordinated care and develop policy, standards and guidelines;
- Exploring opportunities for building the capacity of the non-government sector to respond and/or coordinate activities across service systems;
- Documenting a list of recommendations across a range of government and non-government portfolios to strengthen the service response for people affected by hoarding and squalor;
- Seeking opportunities to liaise with the NSW Government and present the Task Force report and recommendations.

In 2012 / 2013, we have seen several major fires as a result of hoarding that have raised public awareness about the serious risks that abound, highlighting yet again the challenges in developing an integrated service response that unites local government, fire and rescue services and health and community care services together to deliver a service response that supports both those that are affected by hoarding and squalor and their surrounding community.
1. What are we talking about?

Hoardings and squalor are complex issues that can present in a number of different forms. To be able to properly tackle these issues a clear understanding of these different presentations and the possible reasons behind them is essential.

1.1 Defining hoarding

The excessive collection of items such as such as clothing, newspapers, electrical appliances, food packaging (with many such items appearing to have little or no value) and a failure to remove or discard them has been referred to as abnormal or pathological hoarding. The environment in which such articles are being kept commonly becomes so cluttered that it can no longer be used for the purpose for which it was designed. This will consequently impair basic living activities (such as cooking, cleaning, sleeping, bathing and moving) for the occupant.

Excessive Hoarding dominates time, space and personal functioning of the person and others, contributing to unhealthy and unsafe living environments. It has a severe impact on the person’s living environment, their work life, social patterns, health status, family relationships and capacity to build and maintain friendships. It leads to diminishing financial means, enhances likelihood of engagement with justice, legal and civil authorities and cause of high distress with neighbours.

Culminating a 14 year revision process, the American Psychiatric Association published and released the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in May 2013 and for the first time Hoarding Disorder was defined and included in a new chapter on Obsessive-Compulsive and Related Disorders.

‘Hoarding disorder is characterized by the persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions. The behaviour usually has harmful effects – emotional, physical, social, financial, and even legal—for the person suffering from the disorder and family members. For individuals who hoard, the quantity of their collected items sets them apart from people with normal collecting behaviours. They accumulate a large number of possessions that often fill up or clutter active living areas of the home or workplace to the extent that their intended use is no longer possible.

Symptoms of the disorder cause clinically significant distress or impairment in social, occupational or other important areas of functioning including maintaining an environment for self and/or others. While some people who hoard may not be particularly distressed by their behaviour, their behaviour can be distressing to other people, such as family members or landlords.’

Importantly, criterion F in the definition of Hoarding Disorder states that “...the hoarding is not better accounted for by the symptoms of another DSM-5 disorder”, giving examples of obsessive-compulsive disorder, major depression, schizophrenia, dementia and autism. Maier (2004) pointed out that in various psychiatric and neuropsychiatric disorders including dementia, autism and chronic schizophrenia, acquisition of items is neither compulsive nor lacking impulse control in contrast to hoarding behaviour; it is ‘just motor activity without clear intention or aim’. Indifference to the removal of acquired objects also features as part of the behaviour. He termed this behaviour as ‘collectionism’ rather than hoarding. The collection does not necessarily have purpose or meaning.

Hoardings is a multifaceted, complex problem. Hoarding that comes to the attention of public authorities can be an issue with mental, environmental, public health, medical, public safety, legal, housing, and financial implications. Hoarding, particularly when it results in safety and health hazards, is difficult to address and resolve successfully through the efforts of any single agency or organization.

Housing support services will become aware of hoarding situations through a landlord, a housing provider or a health service usually when there is risk of eviction or the real estate agent has come to the conclusion that the property is not being properly maintained in accordance with the Residential Tenancies Act.

There may be an accident, medical or health issue where the property environment might be identified as causing or contributing to a health and safety risk which results in a health service contacting the housing provider to address the hoarding situation.

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15 Snowdon et al (2012)
Hoardings situations that come to the attention of public authorities often require intensive, lengthy, costly and complex responses. Given that a large number of community, agency, familial and individual resources are brought to bear on any single case of hoarding, it is critically important that those who encounter hoarding respond strategically. A coordinated plan of intervention that maximizes resources across agencies is likely to achieve the best possible result for the person who hoards and those affected by the problem.  

1.2 Defining squalor

The concept of domestic squalor is unique to the Australian context but it has considerable overlap with two other concepts that are used internationally; those of self neglect and Diogenes Syndrome.

The problem of gross domestic squalor is not new. In the 1850s a correspondent for the Wolverhampton Chronicle wrote; ‘With difficulty, by the faint rays of light, admitted into the loathsome den, I could trace a human form, clothed only in a horse-rug, leaving his arms, legs, and feet perfectly bare. Already eleven weary winters had he passed in this dreary abode, his only bed being two sheepskins and his sole companions the rats, which may be seen passing to and fro with all the ease of perfect safety. During the whole of his seclusion he has strictly abstained from his ablation. Consequently his countenance is perfectly black. How much it is to be regretted that a man, as gifted as this hermit is known to be, should spend his days in dirt and seclusion’.

In 1890, the psychologist, William James, referred to public health officials encountering “bushels of such miscellany as is to be found only at the city dump” when moving in to clear a “miser’s den” in Boston. There was unprecedented press attention to the home of siblings, known as the ‘Hermit of Harlem’, found to be in an appalling state of filth and clutter after their deaths in 1947.

The individual who lives in domestic squalor may be completely independent and causing no particular concern to anyone. Sometimes, people come to attention, having been referred for another problem, and then are found to be living in squalid living conditions, previously unknown to others. If people are living in squalor but not causing any harm to themselves and/or others, intervention is not necessary. Views of cleanliness vary markedly between cultures. Some people get worried by clutter and filth while others don’t. Some people are clean; some people are dirty. But even in the most tolerant societies, some cases of filth and clutter would be regarded as excessive.

‘The term “severe domestic squalor” is applied when a person’s home is so unclean, messy and unhygienic that people of similar culture and background would consider extensive clearing and cleaning essential. Accumulated dirt, grime and waste material extend throughout living areas of the dwelling, along with the possible presence or evidence of insects and other vermin. Rotting food, excrement and certain odours may cause feelings of revulsion among visitors. As well as accumulation of waste, there may have been purposeful collection, and/or retention of items to such a degree that it interferes with occupant’s ability to adequately clean up the dwelling.”

More often, clients come to the attention of service providers because of the deleterious effect their living conditions have on themselves or the surrounding community. People who live in a state of severe self neglect and squalor can be enormously challenging, to health professionals, to social services, to the council and environmental health officers, to family, to neighbours, and to themselves.

The person who lives in squalor is frequently opposed to assessment and may be unaware there is even a problem. If they do agree to speak, they are unlikely to be prepared to leave the dwelling. Interviews are often brief, conducted while standing and constantly dodging a maze of accumulated property, discarded rubbish or decaying organic matter. Occupational health and safety regulations may prevent professionals from even entering the dwelling. The client may be suspicious or evasive, perceiving the assessment as a potential threat to their independence. Links with social supports and family have often been lost. Even when there are potential informants, clients may withhold permission to contact them for collateral history. Some neighbours are sympathetic and helpful. Others, frustrated and exhausted, can be unhelpfully vociferous with their opinions.

In the most extreme cases, where there is substantial risk to the individual or others, it may be necessary to utilize legislation in order to assist. Apart from the difficulties navigating the legal system, the adversarial nature of the process is likely to profoundly limit any possibility of establishing a relationship with the affected person. In cases where a person may agree to cleaning, it can be difficult to find an appropriate affordable service that is willing to provide it. And when progress is made, and the cleaning completed, it is not at all uncommon for the problem to recur and, six months later, appear as it was at the outset. Furthermore, after cleaning, in safe surroundings, with any other problems that may have been present attended to, it is not unusual for the client to express ambivalence or even regret and deny any improvement in quality of life!

Finally, there are the ethical and philosophical challenges. When intervening in the case of someone who lives in gross domestic squalor, while striving for beneficence, one is frequently confronted with the prospect of violating a host of other bioethical principles, namely autonomy, non-malfeasance, justice and confidentiality.
2. What does the research tell us?

2.1 Hoarding

Hoarding is a complex problem that is believed to be associated with four underlying characteristics. First there are certain core vulnerabilities including emotional dysregulation in the form of depression or anxiety along with family histories of hoarding and generally high levels of perfectionism.

Second, people who hoard appear to have difficulties processing information. In particular, these difficulties appear as problems in attention (including ADHD-like symptoms), memory, categorization, and decision-making. The areas of the brain that control these functions roughly correspond to the brain regions that have been shown to activate differently in people who hoard. Third, people who hoard form intense emotional attachments to a wider variety of objects than do people who don’t hoard. These attachments take the form of attaching human-like qualities to inanimate objects, feeling grief at the prospect of getting rid of objects, and deriving a sense of safety from being surrounded by possessions. Fourth, people who hoard often hold beliefs about the necessity of not wasting objects or losing opportunities that are represented by objects. Additional beliefs about the necessity of saving things to facilitate memory and appreciation of the aesthetic beauty of objects contribute to the problem. 22

The prevalence of clinically significant hoarding in the USA is estimated to be in the region of 2 to 5% of the general population (Samuels et al., 2008; Iervolino et al., 2009 Mueller et al., 2009; Fullana et al., 2010) and 10 to 20% in anxiety disorder or OCD clinics (Tolin et al., 2011; Chakraborty et al., 2012). Thus, hoarding difficulties appear to be frequent.23 A recent study shows that hoarding is highly heritable with genetic factors accounting for 50% of the variance in hoarding behaviour within the population. 24

One potential mechanism for investigation lies in an individual’s sensitivity to, and tolerance of, the emotional and cognitive sequelae of stressful experiences. Emotional intolerance is defined as over amplifying the negative emotional consequences of an experience and using rigid, often non-adaptive strategies for regulating the emotional response (Zvolensky & Otto, 2007).

Emotional intolerance may be one such individual difference variable that could change the perception of a Significant Life Event (SLE). Someone high in emotional intolerance may perceive stress as more aversive and could therefore be more likely to resort to anxiety-driven coping skills, such as avoidance. In the same vein, emotional intolerance may elicit more hoarding symptoms (Timpano et al., 2009). The direct mechanism by which emotional intolerance is associated with hoarding remains an area for further study.

Emotional intolerance appears to operate as a mediator. In one direction, it could make the experience of a stressful event more aversive, leading to the use of coping skills that manifest themselves in subsequent hoarding symptoms. In the other direction, individuals with hoarding may perceive a relatively mundane trigger as more aversive, thereby registering it as a significant life event (SLE).

While several researchers have theorized that hoarders have interpersonal deficits, research has yet to support this theory (Grisham, Steketee, & Frost, 2008). Although hoarders may not be socially impaired, they do report high levels of interpersonal stress. One possible explanation for these findings is that hoarders may have higher interpersonal sensitivity, which would make them more vulnerable to interpersonal interactions and could subsequently increase their symptoms.25

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More data are needed on the course and family history of hoarding; however it appears that onset can occur in childhood or early adolescence and has been seen in children as young as three. Grisham, Frost, Steketee, Kim and Hood used retrospective assessment of the onset of various hoarding symptoms in their 2003 study of 40 hoarding individuals and their families. Findings suggested that mild hoarding symptoms began at age 18, but that hoarding did not reach moderate levels until 8 years later. Results also suggest that individuals who described a traumatic or stressful event at the time they began saving items had a significantly later age of onset than those who reported no traumatic event at the time when their saving behaviour started. This finding suggests that for some individuals compulsive hoarding is a lifelong, characterological phenomenon, whereas for others, hoarding behaviour may develop later as a reaction to stress or loss. These factors have a significant impact and influence on the interventions that will be successful in treating hoarding disorder.

Tolin (2013) proposes that there is a direct connection between these disruptions of brain activity and the problems our hoarding patients encounter during routine decision-making. Specifically, when people with hoarding problems are asked to make a decision about whether to keep or discard possessions, they get swamped. Their attention starts to wander (‘I’ll work on sorting my possessions as soon as I finish watching this TV show’); they begin to doubt the accuracy of their memory (Did I have a need for this? I forget; better keep it in sight); they have difficulty with categorization (Should this go in the keep, discard, or recycle pile?); the process starts to feel punishing rather than rewarding (I have to grieve the loss of these possessions); and they have problems delaying gratification (Ooh, that’s pretty; I must have it!). The end result for many people is that sorting, deciding, and discarding become such an overwhelming and unpleasant experience that they choose to avoid it altogether.

In a study conducted by Frost et al (2011) people with hoarding problems reported more decision-making problems than children or spouses, and considerably more than community controls from other studies. Adult children of people with hoarding reported more indecisiveness than spouses, suggesting that this characteristic runs in families. Among the hoarding group, decision-making problems were correlated with all three core features of hoarding (excessive acquisition, difficulty discarding, clutter/disorganization), and the associations were independent of depression, anxiety, and obsessive-compulsive (OC) symptoms. Higher indecisiveness scores were also associated with earlier age of onset of hoarding independent of hoarding severity. Depression was associated mainly with the negative consequences of hoarding, while OC symptoms were related to the excessive acquisition of free things.

Most people who hoard do not live in squalor. Yet we know from reports about people who hoard that some have great difficulty keeping their dwellings clean because of the amount of hoarded material.

### 2.2 Squalor

In contrast to the term hoarding which describes behaviour, the term ‘squalor’ refers to the environment in which a person may be living. The behaviours that may lead to a person living in squalor are heavily influenced by the mental health of the occupant. Living in squalor is not necessarily attributable to what- ever mental disorder is diagnosed. Accumulation of refuse and useless items as a result of apathy and impaired executive function can often result from brain disease and mental disorder; however, sometimes the accumulation is due to impaired mental or physical capacity to maintain home care. It is likely that those who live in squalor start doing so because of a complex interplay of triggers and vulnerabilities.

In cases described in the squalor and/or hoarding literature, there have been reports that point to organic aetiologies. Various features in cases of severe domestic squalor are also those of frontal lobe dysfunction. Reduction of self care and personal hygiene, lack of empathy and concern for others, disinhibition and impaired social skills, are features of dementia of frontal type (Gregory and Hodges, 1993). Neuroimaging has shown frontal lobe dysfunction in a number of cases of severe domestic squalor.

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30 Snowdon et al (2012)
Among older subjects living in squalor, the commonest diagnostic associations have been recorded as dementia, schizophrenia and alcoholism. Frontal lobe changes may be found in all three and so may be the determinant of living in squalor. Decline in executive function correlates with increased risk and severity of the living conditions of this client group. Younger patients living in squalor were more likely to have schizophrenia or to abuse drugs then have dementia.32

Many cases where brain abnormalities are prominent suggest a strong causative link in severe domestic squalor cases, including intellectual disability, autism, and attention-deficit hyperactivity disorder (ADHD) and depression. Disorganization can feature in all of these occurrences of brain abnormality and impact upon an individual’s motivation and ability to retain or discard items.

Australia currently contributes strongly to the evidence base on squalor with significant studies on neuropsychological characteristics of people living in squalor33, sampling of cases referred to professional services35, recommendations and considerations for the DSM-V definitions36 and analysis of a key measurement tool, the Environmental Cleanliness and Clutter Scale37.

2.3 Animal hoarding

Animal hoarding is a poorly understood and destructive community problem. Animal hoarding is not uncommon. Most of the published material relating to animal hoarding has come from North America, but discussion in other areas of the world makes it clear that the problem exists world-wide. Recent media releases from the RSPCA report that 20,000 animals are believed to be kept in hoarding conditions in New South Wales (population 6 million), and that 200 hoarding cases were uncovered in 2012.38

Research by American authors, derived from dozens of clinical interviews by psychologists and social workers with hoarders, interactions with hoarders through law enforcement and court-ordered assessments, interviews of family members, and analysis of case reports by social scientists, suggests that, similar to object hoarding, animal hoarding is likely a final common pathway from a variety of traumatic experiences which result in dysfunctional attachment styles to people and lead to compulsive and addictive behaviour.39 The diagram overleaf offers a pathway explanation from trauma to animal hoarding.

32 Snowdon et al (2012)
Animal hoarders’ impaired judgment and actions, or failures to act, may arise from a variety of factors. These include difficulties understanding relevant information about animals’ needs, inaccurate appreciation of a situation and its consequences, being unable to reason about treatment options and alternative courses of action, faulty self-governance, psychological defences and behaviours in response to stress, as well as magical thinking, lack of insight, and other cognitive distortions. When these impairments become associated with functional deficits (e.g., failure to provide adequate food, water, proper sanitation, necessary medical care, and failure to recognize and attend to fundamental behavioural and mental needs of animals), incompetent care occurs and animal suffering results.\(^\text{41}\)

 Threats to the hoarder’s way of life, which could include interference from outsiders or deterioration and sickness of the animals, can reinforce the need to dissociate in order to maintain the desired world view, and refusal of support or the intervention becomes absolute. Exaggerated threat appraisal and hypervigilance are quite common among animal hoarders, who tend to be very wary of authorities or anyone offering help, particularly if help is perceived to involve downsizing or intrusion into their sphere of control.\(^\text{42}\) Most alarmingly, studies have shown a 100 per cent recidivism rate for animal hoarders. They go back to their old ways in a new place after being convicted and they still don’t believe they are doing anything wrong.\(^\text{43}\)

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\(^\text{41}\) Hoarding of Animals Research Consortium (HARC) (2010) [http://vet.tufts.edu/hoarding/abthaord.htm](http://vet.tufts.edu/hoarding/abthaord.htm)


\(^\text{43}\) Dr Hugh Wirth (2007) Call for animal ‘hoarding’ to be seen as a mental illness. The Age.
2.4 Fire and Rescue

Fire & Rescue NSW (FRNSW) responds to over 4500 residential fires each year which result in approximately 20 fire deaths. Anecdotal evidence by firefighters suggests that many have responded to hoarding related fires. However, there is currently no standard system for fire services to report a hoarding incident; the post-incident national data collection system has no specific area in which to identify hoarding and/or squalor.

In 2012, FRNSW’s Fire Investigation and Research Unit investigating fire fatalities found three occasions where hoarding or squalor was evident. Since 2007, twelve percent of all fire fatalities were reported as living in hoarding and squalor conditions. Currently, FRNSW reports and refers notifications of premises where significant hoarding and squalor are present; however this has proved difficult as there is currently no state-wide standard protocol for addressing situations of hoarding and/or squalor and referring affected people to services and treatments programs.

Consequently, FRNSW is increasingly working with government and non-government agencies to reduce fire risks related to hoarding and refer occupants living in unsafe conditions to appropriate services where available. At a minimum, to increase firefighter safety and preparedness, FRNSW accepts hoarding and squalor fire risk reports from community agencies and firefighters to ensure that in the event of an emergency, responding firefighters are aware there is hoarding at the property and there are sufficient resources to manage the fire.

A fire spreading to or being ignited from a hoarding household poses severe hazards to firefighters and the surrounding properties and their occupants. Hoarding has been known to increase the risks of fire because:

- The accumulation of possessions results in an abnormally high fuel load which provides a much greater opportunity for ignition.
- Blocked exits and narrow internal pathways impede escape for the occupant and make access difficult for firefighters.
- Utilities such as electricity are often disconnected or misused. Non functional utilities can result in the occupant conducting unsafe practices when cooking and heating.

In 2009, Melbourne’s Metropolitan Fire and Emergency Services Board (MFB) was assisted by a team of students from Worcester Polytechnic Institute (WPI), MA, USA to conduct research examining hoarding from a fire services perspective. This study found that between 1999 and 2009, hoarding related fires were responsible for 24% of all preventable residential fires and posed increased risks and costs to MFB and the community. The source of ignition in hoarding fires was also similar to other residential fires with the most common cause accounting for 39 percent of incidents being cooking. A heater, open flame, or lamp and electrical faults were the other most common causes. Smoking caused 12 percent of the fires and accounted for three fatalities.

2.5 Street Homelessness, Hoarding and Squalor

Whilst there is a significant body of work exploring the phenomena of squalor and hoarding in a traditional domestic context, little is known of its extent, or demographic profile, amongst those who are street homeless. This lack of data is unusual, given that rough sleepers have a higher rate of serious morbidity and co morbidity compared to the general population, perhaps linked to key traumatic life events or experiences that precipitated rough sleepers’ homelessness, such as childhood abuse, relationship breakdown, mental health issues, and bereavement.

One explanation why there appears to be little data on squalor and hoarding in a street homelessness context is the mobility of rough sleepers. Outside of the few who have collected so many items that they are unable to easily transport it around their location, this means the rough sleeper will have moved on before their impact on the environment, themselves and others, can come to the attention of the authorities. At the same time, it is highly unlikely that people who are rough sleepers who are hoarding and/or living in squalor will ask for help to manage their possessions.

Despite the lack of data, some significant work is being done to address the issue of street homelessness, squalor and hoarding. Although they report a low incidence of the issue, the City of Sydney Council’s Homeless Unit has developed a response, which aligns with their Protocol for Homeless People in Public Places. The response is based on building a relationship with the person/ persons involved to foster consent; being aware of the ethical and legal questions that guide what actions to take; what agencies in the NGO and public sector to partner with to implement the response, as well as subsequent regular monitoring.44

44 City of Sydney Council, Homelessness Unit, Protocol for Homeless People in Public Places. (October 2012)
Why is it important that there is a co-ordinated response to squalor and hoarding in a street homelessness context? Apart from obvious reasons, like the potential environmental and medical health and safety risks posed by squalor and hoarding, such interventions could well play a long-term role to increase the rough sleeper’s ability to be housed and to remain housed, in that it the intervention has the potential to be built on by engaging with the rough sleeper to discuss that ambitions they may have for being housed in the future. Similarly, such a constructive intervention by consent is arguably preferable to an approach that is purely driven by enforcement of the law. Even more importantly, a well-thought and sensitively delivered intervention treats the rough sleeper with respect for their dignity as a human being, and creates an opportunity for the person to have a positive experience with the authorities.45

3. Effective Interventions

3.1 Factors affecting intervention

Relatively little has been written concerning how best to intervene in cases where people hoard or live in squalor. Outcomes and difficulties in intervening have been presented in case reports, newsletters and journals, but few scientific studies of what works best in particular situations have been conducted. Commonly, intervention outcomes detail that effective management of these situations is time consuming and complex, frequently requiring liaison and cooperation amongst several agencies.48

3.1.1 Engagement

It is hardly surprising that people affected by hoarding and squalor might not welcome a service provider into their home. In fact, they may not have allowed even close family members or friends into their homes for years. They may engage in behaviours that thwart or stall the intervention process by failing to respond to a request to schedule a home visit or refusing to open the door at the time of the visit. They may also become angry or distressed during the visit and argue or verbally confront the visitor. Service providers can minimise conflict and obstructionist tactics by considering the behaviour to be the person’s best attempt to protect himself or herself against uncomfortable or painful feelings. People who feel attacked naturally defend or protect themselves, often by arguing or refusing to communicate, keeping others at a distance.49

Different approaches are required for different individuals. The reasoning, cognitive impairment, personality and recognition that help may be of benefit is so vastly varied that no ‘one size fits all’ approach will ever work. However one of the key factors that influence the ability to engage with people affected by hoarding and squalor is the quality of the relationship that can be built with the service provider or individual attempting to engage with the person. Rapport is built through alleviating the fears inherent in the person affected by hoarding and squalor, thus often a flexible, respectful and persistent presence is required. Building this relationship takes a considerable amount of time and these impacts upon agency’s resources which can in turn impact on the outcome for the individual.

For example, a client may be too fearful to open the door to a stranger; perhaps a face-to-face introduction to the service provider by a person known to the client or a note in a post-box inviting the client to make contact can reduce the fear associated with accepting help and assistance inside their home.

3.1.2 Type of accommodation

As it increases in severity, hoarding and the associated clutter and squalor can have very serious housing consequences, sometimes putting the building itself at risk, as well as the people living in or near the home and the building owner.

Public Housing administrators and Community Housing providers have the responsibility to address the problem where an individual’s hoarding or squalor situation impact upon the health, safety and wellbeing of other tenants, including the occupant. Often a person’s housing stability is affected by hoarding or squalor. Renters face eviction because of lease violations and public housing landlords are faced with the dilemma of knowingly evicting tenants who will become homeless. Although public housing landlords are entitled to periodic property inspections, these attempts may be thwarted by the occupant; impossible due to the inability to enter the property due to the accumulation of clutter; and agreed action may be improbable due to lack of financial means compounded by the psychological distress to the occupant. The most successful interventions involve the inclusion of health professionals in the solution to provide health and psychiatric assessment and treatment with the addition of support agencies for continued maintenance and support of the individual in their home.

Laws can be used to apply pressure to tenants who do not respond to requests or comply with health and safety orders, however it should be emphasized that the law is a blunt instrument and that experts and agencies are fallible.50

Property owners who are affected by hoarding and squalor are often more difficult to detect and offer assistance as they do not experience periodic property inspections and can refuse right of entry to most service providers due to

50 Snowdon et al (2012)
Privacy laws. Local Councils can obtain orders for clean up of premises based on the Public Health Act, however this involves obtaining evidence for orders applications, commonly obtained through home visits.

Additionally, where private owners have negligible assets, councils are often left with large bills and the need for significant financial outlay. Hence there can be a reluctance or delay in action despite clear evidence of breaches of the Public Health Act. Fire risk would seem to spur action; however firefighters have found that they can only enter a premise if invited or not until a fire has been reported. As a result, council staff and firefighters may refer to appropriate health and community services, often then taking on a liaison and coordination of services role.

3.1.3 Severity of living conditions

Cases of hoarding and squalor vary greatly from situation to situation and thus the range of responses and types of interventions required to assist people who hoard or live in squalor vary also. Considerations of who is best placed to intervene; the risk for workers associated with entering the property to attempt to assess, clean or monitor the situation; the assessment of risk to neighbours and community members; the resources and time require to adequately address the individual situation; are all greatly dependent upon the severity and impact of the presenting living conditions.

Snowdon, Halliday and Banerjee (2012) provide a working classification of types of hoarding and/or squalor in their book ‘Severe Domestic Squalor’:

1. **dry, neglectful squalor**
   
The home is very dirty. Windows, walls and ceilings are grimy. Surfaces and floors in the kitchen, bath- room, living room and elsewhere have obviously not been cleaned for many months. Dust and carelessly dropped items are seen everywhere. Pots, pans and crockery remain unwashed, piled in the sink or else- where, and food may have putrefied. There has been little or no purposeful accumulation of goods or items. Clothes may have been left around in heaps or untidily, covering much of the furniture and floors.

2. **rubbishy, neglectful squalor**
   
The home is very untidy, with an accumulation of garbage, waste, or rubbish, especially in the kitchen but often in other rooms too. When brought into the dwelling, items had a purpose: the rubbish includes dis-carded glass, metal or plastic containers and bottles, packaging, remnants of meals, etc. As in (1) above, the dwelling is usually dusty, with grimy walls and greasy surfaces. Basins, stoves and the toilets have not been cleaned for many months.

3. **wet, neglectful squalor**
   
The home may be as filthy as in (1) above, but rather than there being a large quantity of rubbish, there is excrement (animal or human faeces, urine and maybe vomit) throughout the dwelling, especially around the toilet bowl or in other places where animals or humans excrete. Neglectful overflow or spillage, and roting food may accord with the descriptor of ‘wet squalor’.

4. **dry clutter**
   
The dwelling is cluttered in a disorganised way. A variety of items and material is spread around the home, including clothes, papers, boxes, videos, DVDs, electrical goods, and various items either purchased, freely distributed or found on streets and elsewhere. The clutter covers most surfaces and floors and consequently cleaning has been difficult or impossible. It is messy but not in a ‘wet squalor’ way. The mess is disorganised rather than neglect.

5. **dry extensive clutter or hoarding**
   
Large parts of the dwelling are inaccessible because of items and material collected and brought in for storage. The accumulation of goods is too great to refer to it as merely clutter. At one time the collection may have even been fairly organised, but now the occupant is unable to access most of the items and material because it is in such a disorganised state. The items may be piled as high as the ceiling. It may be impossible to reach basins or the kitchen, and the home has become dirty because of an inability to clean it. The main problem is hoarding, not the secondary squalor.

6. **dry, semi-organised hoarding**
In some dwellings, accumulated articles and materials are kept in a semi-organised way, with ‘pathways’ through the piled up items. Parts may be inaccessible, but others are accessible enough to clean them. Although the squalor may be mild, risks of fire or accident make a clear-out desirable. When articles or material have been collected in a systematic and organised way, the home can be kept clean even though it is perceived as ‘full’ of hoarded items. The occupants hoard; they do not live in squalor, not even mild squalor. Whether there is a fire risk depends on what has been hoarded.

3.1.4 Adequate assessment and appropriate referral
A key feature of responding to people affecting by hoarding and squalor and their animals is ensuring a comprehensive and meaningful assessment is completed with the appropriate professionals engaged to enable useful and collaborative referral for support and promotion of client participation in the intervention.

Dr Graeme Halliday developed a set of algorithms (Figures 1 and 2 below) showing the varied interventions and steps that may be appropriate in cases of severe domestic squalor for the 2003 report for the Department of Ageing, Disability and Home Care in collaboration with Professor John Snowdon.51 The factors considered in these algorithms are also applicable for people who hoard.

FIGURE 1: Assessment and management of people living in squalor

3.1.5 Animal protection and human welfare

A key tension that animal protection agencies manage is the balance between protection of animals and the impact on the individual person when external action or intervention is required to protect their animals. In NSW, the RSPCA inspectors receive Mental Health First Aid training to ensure that their approach to animal owners is with awareness of underlying health, emotional or mental health issues and interactions can be modified to ensure the development of a positive trusting relationship with the owner.

Four key aspects of interaction guide the RSPCA’s approach to people who hoard animals and/or live in squalor with numerous pets:

1. forming a respectful and trusting relationship with the owner. This often involves multiple visits before the owner will engage, invite or talk to the inspector. These relationships are developed through discussion of mutual benefits and an understanding of how the RSPCA can assist the owner to better care or reduce their care responsibilities for their animals.

2. educating the owner on basic animal husbandry. This may involve flea prevention, worm prevention and other animal health related strategies, educating the owner about expected and normal animal behaviour and how to support this development in their own animals, referrals to courses and training to improve knowledge and provision of practical assistance to create animal only areas on the property.
3. reducing the numbers of animals through re-housing and de-sexing programs. Often owners will only surrender extremely unwell animals and are reluctant to relinquish custody of their animals. The importance of the trusting relationship then comes into play to enable compromise on reducing the breeding ability of existing animals or handing over some of the animals for support.

4. follow up and monitoring. RSPCA inspectors continue their support to the owners by regularly following up with owners through visitations, phone calls and unscheduled drop-ins to monitor the conditions the animals are living in and ensure that the owner can maintain the care of the agreed animals in their custody.

Prosecution is used as a last resort and is often a collaborative intervention between the magistrate and the attending RSPCA inspector. Where prosecution occurs, the orders requested are bespoke to the individual’s circumstances and always aim to enable some custody of animals to remain with the owner. For example, Section 31 of the NSW Prevention of cruelty to Animals Act 1979 enables an order to relinquish custody of all or some animals or mandates that an owner cannot purchase or acquire additional animals. Alternatively, a good behaviour bond can order an owner to only reside with a certain number of animals or no animals at all. Again, the response and order requests are balanced against the protection needs of the animals and the owners’ need to own and care for animals.

The greatest challenge for animal protection agencies is responding to their core business utilising their unique skill set with the added responsibility of responding to the welfare of the owner involved with the animals. Inspectors often rely on human service agencies to support their work to enable a safe and sustainable result for animal and human alike.

3.1.6 Ethics of intervening

While hoarding and living in squalor is often a significant problem for many people, it is important to preserve the personal rights amidst differing preferences and standards for how we live. Naturally, landlords, building managers and inspectors will have values and standards for how a home should look and are of- ten responsible for the interpretation of public laws and determining violations. Thus, an awareness that our own judgements are often clouded by our own cultural, familial and person expectations is crucial when assessing a person’s right to self determination and choice in the condition of their living quarters.

Christopher Ryan (2012) offers an algorithm to support ethical decision making for intervention in cases of hoarding and squalor (Figure 3).  

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**FIGURE 3:** Ethical intervention decision making algorithm

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3.1.7 Guardianship

Situations of squalor and hoarding present particular challenges for those working with people whose environment and self-care would be considered by most members of the community to be less than ideal for daily living. The complexity of underlying factors that effect or influence the person and their environment in this situation necessitates clear and effective strategies to better manage the often competing demands of the individual, the community, other organisations and agencies working to resolve difficulties.

The manifestation of problems in situations of squalor and hoarding includes:

- Different perceptions of what the problem is and how or who should resolve it;
- High levels of resources used to try and address the problem which have a significant impact on the capacity of emergency, community support services, health and welfare services at Local, State and Federal levels;
- Difficulty in resolving conflict between the person, services, health professionals, emergency workers, family/friends in response to recommended plans of action and on-going management;
- Capacity for interagency collaboration and negotiation with the person and formal services or agencies to achieve outcomes that recognise the rights and obligations of all involved.

The use of guardianship legislation should be considered as last resort for a person with a diagnosed decision making disability.

Guardianship is the most restrictive outcome for a person with decision making incapacity as there is limited capacity for supported decision making in this process.

The Public Guardian (PG) and NSW Trustee and Guardian (TAG) can be appointed to address the need for substitute decisions affecting a person’s health and well being and the subsequent impact these conditions have on a person’s income and estate.

The process involves making an application to the Guardianship Division (GD) to appoint a substitute decision maker. Evidence is required of the person’s decision making incapacity for complex decisions affecting their health and welfare and a decision is needed. The urgency for appointing a guardian and or a financial manager will depend on the evidence of immediate harm or risk to the person with decision making disability.

Capacity assessment for financial decision making is different to capacity for lifestyle and health decisions. Depending on the complexity of the person’s health and welfare issues, substitute decisions affecting a person’s lifestyle, financial, legal and other needs need to take time to ensure comprehensive consideration of facts and views, especially those views of the person with a decision making disability, to make a well informed decision.

Decisions made against the wishes of the person with decision making incapacity can only be made if this authority is stated in a guardianship order by the GD.

Urgent decisions can be made but this undermines both the rights of the person with the decision making disability and the process for gaining optimal collaboration with the multiple agencies expected to stay involved in the medium to long term. On-going conflict between direct support services such as the RSPCA, welfare agencies and health professionals and the person with a decision making disability can compound the problem.

There is good evidence to the PG that early consultations and strong partnerships across agencies to build collaboration on who will be involved and strategies for how to address the individual complex issues of squalor and hoarding for a person with a decision making disability, are more likely to achieve sustainable outcomes. The expectation a guardian can achieve a ‘quick fix’ to clean or impose a successful management plan by the guardian is common. In practice, such action is usually counter productive and not sustainable.

It is the capacity of services and other authorities to implement any decision made by the guardian which has the greatest ability to create change. This is a delicate process as how decisions are implemented may have a detrimental effect on the very relationships needed to maintain support to the person in the community.
3.2 Response approach

When looking to respond to a referral for support for a person affected by hoarding and squalor, it is important to have the most current research and remember that the clients in question have experienced trauma of some description; including actual traumatic events, for example death of a significant other, loss of a pet, the Global Financial Crisis, removal of children from custody; trauma to the brain affecting executive functioning; emotional trauma through abuse; and neglect of the development of personal and life skills. Thus, the process and approach to engagement is crucial.

Different approaches are needed for different individuals. Clients referred because of their living conditions vary in personality, attitude, willingness to engage with those keen to help them, recognition that they would benefit from help in other ways. Flexibility is important when attempting to establish rapport. Cultural sensitivity and appropriateness are also important.53

The reality of hoarding and squalor and the people who live in these environments and exhibit these behaviours, is that they are often quite difficult to work with, to contact and to gather information from. It often takes many unsuccessful home visits and attempted contacts before the front door will even be opened and even longer before any intervention strategies can be put into place. Working with situations of hoarding and squalor requires patience, persistence and determination.

3.2.1 Trauma Informed care

An emerging approach across responding agencies and in collaboration with local mental health services, to support clients with complex needs is ‘trauma informed care’. Trauma informed care is the re-conceptualisation of traditional approaches to health and human service delivery whereby all aspects of services are organised acknowledging the prevalence of trauma throughout society.

‘Trauma-informed’ services are aware of and sensitive to the dynamics of trauma as distinct from directly treating trauma per se. Trauma-informed services are alert to the possibility of the existence of trauma in the lives of all clients/patients/consumers, irrespective of whether it is known to exist in individual cases. The five principles of trauma-informed care include:

- SAFETY: Ensure physical and emotional safety
- TRUSTWORTHINESS: Maximise trustworthiness through task clarity, consistency, and interpersonal boundaries
- CHOICE: Maximise consumer choice and control
- COLLABORATION: Maximise collaboration and sharing of power
- EMPOWERMENT: Prioritise empowerment and skill-building54

The National Mental Health Recovery Framework 2013 identifies trauma informed care as a key component of recovery-oriented practice. It is understood under the framework as encapsulating mental health care that understands that people who have lived of unresolved trauma struggle to feel safe, considers the possibility of unresolved trauma in all service settings, and incorporates the five principles of trauma informed care into service provision. The framework promotes workforce development and training in trauma informed care for all practitioners and providers.55

3.2.2 Service coordination and collaboration

For the majority of cases, a number of agencies and services will be involved in providing support to persons who hoard or live in domestic squalor. This capacity to respond is and collaborate is certainly limited in some more region, rural and remote areas where the full suite of support does not exist. It is essential to ensure that all service providers and agencies have a consistent approach to the person. This could be arranged through a case meeting where agencies identify their roles and responsibilities and a case manager is appointed.

The principal aims of cooperation between agencies are to:

1. identify a key worker or case manager responsible for ongoing liaison with the person who is hoarding or living in squalor

54 Mental Health Coordinating Council. Integration of a trauma-informed care and practice approach. Draft policy template
55 Australian Health Ministers’ Advisory Council (2013). A national framework for recovery-oriented mental health services: Guide for practitioners and providers
2. report on the initial assessment of the person and the proposed interventions,
3. determine the course of action, agreed interventions, monitoring arrangements and the individuals responsible.

Often the person who makes the initial contact with the client will assume the role of case manager. In some cases, the person who receives the referral will contact another agency and request that this agency assume the coordinating role. The service that conducted the initial assessment might wish to convene a joint agency case conference with representatives from the relevant services.

Identifying the interventions required should be determined through a joint care planning process, in consultation with the relevant agencies. Resource constraints apply to human service agencies, and therefore the resources available will need to be prioritised on a case-by-case basis.\(^{56}\)

To be effective, if two or more agencies are involved, there needs to be good coordination. They need to work in a collaborative partnership with each other and to value reciprocity and sharing acquired knowledge. Blockages to effective service delivery can emerge where these principles are not shared or services have limitations due to funding restrictions. McDermott and Gleeson’s 2009 evaluation of Catholic Community Services NSW/ACT Severe Domestic Squalor (SDS) project states that they ‘...had difficulty collaborating with other organisations over half the time. Qualitative data points to two reasons for this. First, many services in the community are guided by strict eligibility criteria and boundaries around their particular area of responsibility. Health and mental health services were reported to have particularly inflexible service boundaries..... Because of the conflicting views about risk, SDS had difficulties engaging aged care and mental health services to work in partnership in some situations of squalor.... These organisations often declined to be involved unless the person was legally assessed to lack the capacity to make decisions. The cost of cleanups in situations of squalor and hoarding was particularly problematic for Housing NSW and local councils.... It takes time to build trust with people who are living in squalor or hoarding and .... the resource intensive nature of interventions in these situations precludes the ongoing coordination with agencies that do not have the time to sustain such relationships’.\(^{57}\)

### 3.2.3 Skilled and passionate staffing group

Anecdotal as the evidence may be, it is important to note that the skill and passion of staff working with people affected by hoarding and squalor has a particularly effective and powerful impact. These are the individuals who will creatively look at their funding restrictions or core business and find a way to support individuals living in these circumstances. These personalities are also involved in establishing and driving area coordination initiatives and support guidelines for field staff. Care coordination is often only successful due to this group of professionals who have invested their careers in supporting hoarding and squalor support.

Retention and turnover of this group of skilled and passionate group of employees are key issues. Often subject matter experts and their knowledge disappear when the individual does and the initiatives that were driven by these passionate individuals fall by the wayside. It is thus important to consider an educative and training model that sustains the transfer of skill, information and knowledge from these subject matter experts to all field staff who may encounter people affected by hoarding and squalor. These specialised support skills can become a natural extension and professional development opportunity for employees of government, community and non-government agencies alike.

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3.2.4 Trauma Informed Care
Below is a selection of practice examples provided by members of the taskforce describing current practice in NSW.

FIGURE 4: Trauma Informed Approach Case Study

Male 23 years old, referred by Newcastle Mental Health Services Case Worker 19th November 2009. Client has a diagnosis of obsessive compulsive disorder and borderline personality disorder.

Mental Health worker had not viewed the property due to client’s embarrassment but client had provided this information for the referral. Client residing in very small bedsit accommodation with large amounts of rubbish and infestation of cockroaches. Referral also stated client has engagement issues.

Arrangements were made to meet with client and mental health worker at Newcastle Mental Health Services to discuss Living Conditions Pilot project with client. However, client was admitted to the Mater Mental Health unit, so arrangements were made to go ahead with meeting client at the hospital. Client became unwell due to his living conditions and an inability to cope with the situation.

As a result of the initial meeting client agreed to attend his bedsit with caseworker to assess the situation. The psychiatrist arranged PRN 5mg of Valium to help reduce client’s anxiety with re-entering the bedsit. When caseworker picked client up from hospital it was noted that anxiety was still high and that perhaps the Valium had not started to have the required effect or client was unsure of me due to limited contact. So client was taken to McDonalds, provided with lunch and after about 30 minutes of conversation was more settled.

Entering client’s bedsit, approximately 4x4 meters, there was rubbish which filled 19 garbage bags and cockroaches everywhere. Client’s bed was alive with cockroaches; we bagged up the rubbish, set roach bombs and left the property returning to the hospital. Two days later all rubbish and bed were removed and another roach bomb set prior to returning to the hospital.

Then met with the property manager to discuss situation, they were very understanding and have arranged to have carpet removed prior to spraying due to this being a common breeding area for cockroaches, at no cost to client. Pest control was arranged by Living Conditions Pilot project. Throughout this time the Social Worker at the hospital agreed to complete Housing NSW Priority application and gathering medical support documentation with client.

Rubbish removal process commenced on 3rd December 2009 and was totally removed on the 7th December 2009. Final clean was completed on 15th December 2009. Negotiations between Social Worker and Psychiatrist have taken place to ensure client can remain in hospital until bedsit is satisfactory for short term accommodation. Referral has been made to the Personal Helpers and Mentor program to provide ongoing support once the client is discharged from hospital. Social Worker has also made referral to Morisset Hospital for rehabilitation, but there is an eight month wait. Client had begun having Dialectical Behaviour Therapy prior to going to hospital, this will continue when discharged.

HISTORY PROVIDED BY CLIENT
Client has not seen his mother since he was a baby and mum had schizophrenia. Client’s father could not cope with client’s illness and client has been alone from the age of twelve. Client resided in many youth refuges, lived on the street and this rental property is the third, two prior properties ended in eviction due to squalor. Client has had previous contact with many community service providers but has for whatever reason not had the support required, possibly due to engagement issues. Client does attend PRA and Newcastle Youth Services for meals and social interaction. At this stage client remains engaged with Living Conditions Pilot project until all supports are on board.58

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58 Case study provided by Catholic Community Services, Hunter Living Conditions project.
Mr M was referred to the Assistance with Care and Housing for the Aged Care and Assessment Team (ACHA) by the Department of Housing, who had discovered severe domestic squalor whilst undertaking a regular inspection of his property. Department of Housing staff had also received complaints from neighbours about Mr M’s behaviour including his abusive behaviour and threats of violence affected by his considerable use of alcohol. Department of Housing staff attempted to negotiate the organisation and disposal of some of his hundreds of books and other items that he had hoarded over twenty years of residency. They enlisted the aid of the Aged Care Assessment Team’s psychogeriatrician and social worker, staff from ACHA and the Fire Department in an effort to provide support.

Mr M vacillated between being cooperative and agreeing to the idea of getting rid of some of his things, to outright refusal and hostility towards those attempting to make him do the things he didn’t want to do. As he saw it, there had been twenty people tramping all through his place ‘like an ant’s nest’ and then leaving after a brief visit. They had no idea of the value of the things he collected and he thought they were likely to discard prized possessions including war medals, photos and memorabilia. In addition, he thought his place was no more of a fire risk than the bookshop down the road. There were one or two bags that he said he would take to the rubbish, but that would be the extent of it.

Strategies to address his situation included building rapport over a long period of time with the recognition that any change in his home was likely to take upwards of two years. It seemed there would be considerable problems if an eviction notice were granted, since he said he would fight anyone who ordered him to do anything.59

There is a long history of hoarding in this property. The owner, Mr S, is a highly intelligent, reasonably physically fit man in his 50’s. As far as we are aware he does not have any immediate family. His father was also a hoarder before he passed away. He previously owned a number of properties where he accumulated items which were subsequently cleared by Council or the Strata.

2005 - A Local Government Act, Section 22A Order was served on Mr. S requesting the removal of accumulations. The council had to engage contractors to remove accumulations as the Order was not complied with. Mr. S could not be contacted during this process; however, he did attend the court hearing to settle costs. Mr. S continued to re-hoard items over the years; a number of complaints were received by Council however we could not get access to the property to establish a nuisance.

2013 - A complaint was received in from a neighbour in August 2013 who was concerned about odours, rodents & the risk of fire. The front & rear garden were overgrown and there were accumulations of miscellaneous items (including combustibles) both inside the property and in the garden. There were 5 large composting bins that were causing a foul odour and the condition of the property would provide harbourage for pests. Due to these factors it was established that there was a risk to public health and an Order to clear the accumulations was essential.

Investigation – It was established that a debt recovery agency had been appointed executors of Mr. S’s estate. 3 of his properties were sold to pay debts owed. The agency confirmed that efforts were made to locate Mr. S but they were unsuccessful. The debt recovery agency had powers to

execute orders on behalf of Mr. S; they engaged the service of a contracting company to act on the Order.

**Removal** - Once the works began Mr. S presented himself at the office of the agency. He agreed to allow access to the property. The council liaised with Catholic Care, a representative called to the property - she and Mr. S did not deem their involvement necessary. Mr. S was surprisingly willing to discard of a lot of items however he wanted control over the situation – physically moving every item in the house & deciding about it. Environmental Health Officer’s were initially there to supervise the work however he challenged our presence as we were there to enforce the Order. Council agreed to allow him work with the contractors until the majority of the house was empty (this took about 4 weeks). The house went from being completely inaccessible to about 70% free of clutter. He requested for additional time to sort through items himself & agreed to contact the contractors to call back to remove additional items. He also requested that additional vegetation be removed from the garden which indicated progress. Unfortunately Mr. S has not contacted the contractor since this time. I called to the property a number of weeks ago and noted an increase in miscellaneous items stored in the property. The cycle of hoarding and the need for reactive measures will continue unless the hoarding issue and behaviour is actually addressed.60

**FIGURE 7: Decision Making Capacity Case Study**

Terry is a divorced male aged 54. Diagnosed with alcohol-related brain damage, he lives alone in his privately owned unit in the Northern suburbs. He was found by a neighbour, unconscious with severe indicators of physical neglect due to uncontrolled diabetes, malnutrition and doubly incontinent. His condition was described as near to death.

Terry is reported to live in squalor. His home is occupied by piles of wine casks, bottles and newspaper; there is virtually no access to the kitchen and bathroom. There are complaints about uncontrolled vermin and evidence of incontinence which have created a health and safety risk for him and others.

Terry has repeated admissions into hospital. On this admission, Ambulance officers report the living conditions were extremely unsafe when they were called to the unit.

Although considered medically stable, Terry is not able to walk independently and refuses to participate in the rehab program. He also refuses to participate in discharge planning. Terry says he wants to go home & live his life his way, denying any problems with his health and housing conditions.

Terry has a history of refusing services. Meals on Wheels and Home Care decide they cannot continue to try and provide a service because of the unresolved OH&S issues. The hospital recommends Terry is placed into aged residential care and an assessment by the Aged Care Assessment Team (ACAT) determines he is eligible for high level residential aged care, despite his young age - there are no age appropriate accommodation alternatives.

The hospital social worker, doctors and allied health professionals believe he has impaired capacity to make decisions about where he should live and what services he needs.

There is conflict in whether Terry’s right to autonomy should be upheld while others argue he cannot weigh up the consequences of his lifestyle due to impaired cognition. There is a risk his return will lead to his death in a state of severe self neglect.

There is also evidence that Terry is being financially exploited. Terry is targeted by others to give

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60 Case study provided by City of Sydney Council
them money and his council rates are in significant arrears. The condition of the property is a concern to the local council who have issued him with multiple notices for breaching the environmental laws. Terry ignores these.

An application by the hospital social worker is made to the GD for guardianship and financial management. The PG appointed as ‘guardian of last resort’ as there are no other persons willing or able to act as guardian. The functions (or areas of decision making authority) in the order include coercive Accommodation (i.e. the decision can be made against Terry’s wishes) and Services.

The NSW Trustee and Guardian (TAG) is appointed as financial manager as Terry is found to lack capacity to manage his income and assets in his best interests.

**OUTCOMES:**

Mindful to Terry’s views that he wants to return home the PG act to involve him as far as possible in the discussions about where he should live and what the options would be to live independently as far as possible in the community.

Consent is provided for an OT to conduct an assessment of the property and Terry’s living skills to find out what needs to happen for him to go home. Terry agrees to the assessment.

The OT reports Terry’s home requires major renovations before it would be safe for him to return home. A professional clean is required; this is costly and would take days to do if the unit was safe to work in. The assessment also advises Terry’s disabilities impact on his ability to manage his incontinence, insulin, diet, food preparation, shopping and personal care. He requires assistance with all his daily living tasks.

The PG advocates for all support options to be explored. A complex case conference is requested to bring together all those involved to work on a action and management plan.

TAG must make a comprehensive assessment of his estate, income and expenses to determine if he has sufficient funds to pay for necessary services, repairs as well as his legal debts, when considering whether a return home is possible. TAG’s investigations show it is unaffordable for him to pay for major repairs to his home. His property may be sold but is unlikely to leave him with sufficient funds to purchase another unit. As his debts are extensive, a repayment plan is needed.

Working in collaboration with each other, the PG and TAG will refer to the evidence and views from all those involved.

Terry’s need for government funded and self-funded services and support is beyond the resources available to him. In the absence of any less restrictive accommodation he is waitlisted for a nursing home bed.

A decision is made by the PG that Terry will not be returning to his home and will accept a suitable place in residential aged care. This decision is made against his wishes.

Throughout the decision making process the PG will advocate for a collaborative approach with all parties to identify the least restrictive accommodation and support options.

TAG will have a continuing role in managing his income and assets. They will work with the PG in regard to how these funds may be utilised to improve the quality of Terry’s life.61

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61 Case study provided by the Public Guardian and NSW Trustee and Guardian
FIGURE 8: Public Housing Risk Case Study

Mr B is a 33 year old man with chronic schizophrenia who lives alone in a Housing NSW bedsit. Mr B was last hospitalised over a year ago. He has little insight and has avoided contact with mental health services since his Community Treatment Order expired approximately 7 months ago. Mr B is generally suspicious and irritable and Housing NSW has had difficulty organising a routine inspection of his accommodation. When this finally occurs, Mr B is found to be in a severe state of self-neglect. Mr B has minimal furniture but all walls, fixtures and surfaces are severely dirty and damaged by cigarettes burns and moisture. The bathroom and kitchen are in a particularly bad state and the floor has been extensively damaged by water. Mr B says he deliberately left the taps dripping to obscure distressing persecutory auditory hallucinations. Mr B agrees to see the local mental health team but refuses to go to hospital.

DISCUSSION:
In this case, psychotic phenomena were interfering with a man’s ability to care for himself and his home. The neglect led to the damage of the building that was shared by others. He had no insight. Undoubtedly there were fire risks as a result of his smoking. His untreated mental illness was putting the lives of others as well as his own at risk. Compulsory treatment was necessary. Assertive follow-up, to monitor his self-care and to help him to improve his quality of life and wellbeing, will be important to arrange. It would also help identify whether substance abuse exacerbated his psychotic symptoms. 62

FIGURE 9: Cooperative Guardianship Management Case Study

Rosanna is 83; she lives with her husband in public housing in the community.

Rosanna is diagnosed with vascular dementia and has other chronic health issues including cardiovascular disease, hearing and visual impairments, unstable diabetes and chronic osteoarthritis. Her husband is caring for her without formal services as she refuses to agree to any outside help. Her husband does not want to go against her wishes.

Rosanna uses a walker in the home but this is becoming too difficult due to the amount of clutter in the home so she is staying in bed for extensive periods of time.

Access to the kitchen and bathroom is not possible due to the quantities of discarded packages, soiled clothing and food waste. The Housing office has issued them with a notice of a breach of their tenancy agreement. The home is a health and safety risk which may lead to their eviction.

The Aged Care Assessment team makes an application for guardianship. Rosanna is estranged from her family. There is a view she requires placement into aged care if support services are refused.

The PG is appointed with decision making authority in the areas of Accommodation with a coercive authority, Services and Health Care.

Under a Services authority a request is made to have a case manager identified and develop a management plan to prevent their eviction and reduce the risk of harm.

A review by a Psychogeriatrician would help inform the guardian and others about treatment and behaviour support options for those working with Rosanna. Consent by PG is provided under the Health Care function.
There will be a referral under the Services function for assessment by an agency experienced in hoarding and squalor. This service needs to consider how to implement gradual changes in collaboration with Rosanna, her husband and the housing office.

Rosanna’s husband is currently her financial manager. His understanding and cooperation is critical to paying for necessary services. His need for carer support is also explored.

The plan will be to reduce the hazards to make it safe rather than trying to make the place ‘clean’. The Accommodation function is used to advocate for Rosanna’s rights in her tenancy and consider any alternatives to where she should live including permanent and respite care. Respite may be needed to create an opportunity for services to come in. If Rosanna objects to this and her removal could involve seeking the assistance of the NSW Ambulance or Police.

Decisions at this level are often a very traumatic experience for all involved and made only when all other alternatives are exhausted.

A review of the management plan outcomes will consider whether there is a need for an application to the Guardianship Division for appointing an independent financial manager.63

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FIGURE 10: Animal Hoarding Case Study

A 49-year-old man was referred to the RSPCA by neighbours because of the smell coming from his property. An inspector found that his dwelling was filthy and his many cats were poorly cared for. However, he agreed to the instructions she gave him regarding treatments the cats needed for ear, eye and respiratory infections, and to provide appropriate care and conditions for the animals. He was seen by a psychiatrist, who found that he had personality issues, but did not have an Axis 1 DSM-IV psychiatric diagnosis. He had accumulated an excessive number of cats, partly as a ‘rescuer’ of abandoned kittens, partly because he welcomed their child-like dependence on him, and partly because he didn’t want to de-sex the females. He had a source of income, but nevertheless, a few months later, found that he was becoming overwhelmed by the number of cats (over 200) and the expense and emotional impact of trying to look after them. He remained unwilling to part with any. The inspector called every month, and at the most recent visit found his dwelling and the surrounding fenced off grassy areas relatively clean. Of considerable concern, given his feelings of being overwhelmed, were the facts that several cats needed urgent veterinary attention and that ten or more of the females were pregnant following the incursion (he said) of a ‘wild cat’.64

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63. Case study provided by the Public Guardian and NSW Trustee and Guardian
4. Managing Risk

The compulsive hoarder’s home may pose risks for fire, falling, poor sanitation and other health risks. As a democratic society, nobody can impose a standard of living onto other people but there needs to be maintenance of common standards to ensure that no harm is caused, and living conditions are safe and healthy for the person/s concerned and the neighbourhood.61

Many jurisdictions have legislated requirements that employers follow procedures to ensure the health, safety and welfare of their employees. Organisations that provide services to people living in squalor must ensure a safe working environment for their employees. Risk management strategies such as having a checklist to identify hazards, including a home safety assessment, help eliminate or control risks to employees engaged in service provision to the community. In some cases of severe domestic squalor, occupational health and safety (OHS) concerns may in the first instance prevent service providers from entering premises and carrying out comprehensive assessments.62

A combination of controls will often be required to minimize the risks in a squalor situation. Hazards that can be easily addressed will build trust with the client and create success. If the client is not cooperative and the risks associated with the squalor environment cannot be addressed, services may be denied until the situation is rectified.

The risk control hierarchy below can be used to identify possible risk control solutions.

<table>
<thead>
<tr>
<th>TABLE 1: RISK CONTROL HIERARCHY EXAMPLE64</th>
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<tbody>
<tr>
<td>RISK CONTROL ACTION</td>
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<tr>
<td>---------------------</td>
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<tr>
<td>1. Eliminate the Hazard</td>
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<td>2. Substitute for a lesser risk</td>
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<td>3. Isolate the hazard from the person at risk</td>
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<td>4. Use Engineering Controls</td>
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</tbody>
</table>
### 3.2.4 Trauma Informed Care

Below is a selection of practice examples provided by members of the taskforce describing current practice in NSW.

#### 4.1 For the Individual

People who hoard and/or live in squalor and are older, disabled or who have a mental health condition are at greater risk due to a broad range of health conditions and related consequences, including reduced mobility. They may or may not live alone and/or have supportive neighbours, but they certainly face challenges that could be life-threatening, for instance:

- trying to walk inside a cluttered home or outside in a cluttered yard, is a challenge for anyone young or old but manoeuvring around accumulated possessions that threaten safety (for example, hazardous material poorly stacked/stored, excessive dust and disintegrating debris, blocked pathways, risk of falling/tripping) and that don’t permit routine care activities (that is, a functioning kitchen, a place to eat meals, access to a shower or bathtub);
- easily losing keys, money and important papers such as bills, wills, mobile phones;
- misplacing medications and/or keeping old expired medicines that are no longer safe to use, refusing to discard the drug believing it would be wasteful;
- risking illness or even death if old medicines are taken along with currently prescribed and/or over the counter medications - certain drugs should never be combined;
- reduced vision and hearing as well as difficulty moving about, would enhance the possibility of falls and serious injury;
- delayed access by emergency personnel in order to find/reach them; clutter/muck causes further delay if the person has to be carried out on a stretcher;
- the neglect or abuse of children where they are being brought up either by parents or grandparents in a hoarding/squalor environment and exposed to multiple risks.67

Part of the comprehensive assessment process should include completion of a home risk assessment form to identify how the above challenges can be minimised and/or eliminated. An example can be found at Appendix 1.

#### 4.2 For the Neighbours

Although neighbours do not live in hoarding and squalor homes or properties, they are at risk of the environment that hoarding and squalor creates, often initiating complaints to local Councils with regard to

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67 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
that property and its effect on the amenity of the neighbourhood. It may depend on what is visible inside/ outside the house and/or what can be smelt. No matter what the circumstance, the following concerns may apply:

- public health problems (for example, spread of pest infestation to adjacent apartments and homes);
- structural problems due to too many heavy items (for example, boxes, machinery parts) for building load limits;
- flooding when pipes are in need of repair;
- fire from electrical wiring or heating systems in need of repair;
- the house being condemned due to unsafe or unclean conditions, such as:
  - walls deteriorating with age and rotting/collapsing due to piles of belongings shoved against them
  - floors rotted with age under piles of garbage and belongings;
- lost property value and rental income for landlords who must make costly repairs due to hoarding/squalor;
- or who have to pay legal fees (for example, to end a tenant’s lease);
- if a house or property is perceived to be a fire risk or indeed disintegrates to the point of being
  condemnable, the appropriate authorities would need to be involved to minimise harm. 68

Managing risk to neighbours and their properties also involves managing expectations about the possibility and likely trajectory of change. Managing these relationships can often be part of the service provider’s role as the neighbours can form a crucial part of the solution if managed well.

### 4.3 For the Animals

Taken to its inevitable conclusion, animal hoarding results in considerable animal suffering from neglect. In worst-case scenarios the impact on the environment of large numbers of starving and maltreated animals due to hoarding, creates squalor conditions and contributes to:

- illness and disease in the animal;
- malnutrition due to poor diet or contaminated diet;
- developmental disability due to confined spaces and resulting changes in posture to navigate the environment;
- mental suffering caused by maltreatment.

In the course of investigating animal cruelty offences, inspectors are empowered to: enter property; seize animals; seize evidence of animal cruelty offences; issue animal welfare directions/notices; issue on-the-spot fines; and initiate prosecutions under animal welfare legislation. Although inspectors are afforded these powers, in the majority of cases inspectors will seek to resolve animal welfare issues through the provision of education and advice. Enforcement action, such as the seizure of animals and initiation of prosecutions, is reserved for serious cases of animal mistreatment.

Inspectors are often entering premises where the air quality and environment are compromised and personal protective equipment is required to enter the properties to enable an assessment of the welfare of the animals residing there.

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68 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
4.4 For the Worker

In order to enable employees to enter premises that are squalid and pose multiple risks to the safety and welfare of the worker due to clutter and hoarding, service agencies need to provide safe working practice models to ensure risks are identified, managed and mitigated where possible. Some examples of safe working practices include:

1. Safety
   - Where possible develop a ‘buddy system’ for the first visit to a client, i.e. pair an experienced worker with a newer worker to enable modelling of good practice and thorough risk assessment.
   - A safety plan should be developed prior to a home visit.
   - Issues such as parking, lighting and crime need to be considered when developing a safety plan.
   - Field staff should register the address of their home visit and the time they think they will be on-site. If circumstances change then a reviewed time should be sent by text to the office and/or their manager.
   - Staff can keep in touch with manager via text.
   - Local service managers should have a phone contact for the local Police station. This could be useful if a staff member does not call in at the arranged time. This is most important for rural/regional services.

2. Cleaning and managing odours
   - To assist staff in dealing with the odours when in a clients home it may help to place some Vicks under the nose. If you are cleaning home then placing some eucalyptus oil or tea tree oil on a face mask may lessen the impact of odours or use an electric oil burner. It is also appropriate to ask the client to open a door or windows. If the odours are such that they cause you to gag just apologise (honour process).
   - If the house has high levels of squalor then and the odours are severe then spend 10 minutes inside and break for 5 minutes outside in fresh air. It is sometimes necessary to take a break to handle some squalor environments.
   - Some people can develop immunity to shocking odours with regular exposure.

3. Networking
   - It is important to develop links with staff at the key agencies which will be relevant for your clients, particularly the local health services.

4. Make use of a break
   - Working with hoarding and squalor clients can cause mental exhaustion so it can help if after seeing a client you take a break and use the time to debrief with your manager either face-to-face or via phone. This time can also be used to complete your case notes on the visit. Another way to record your notes is to call your phone message bank, or if you have it on your phone use the audio notes function.

5. Staff
   - When employing staff it is essential to consider both their skills and their life experience. Look for staff who have demonstrated experience working with vulnerable people who have complex needs.
   - Vigilant monitoring and ample opportunity to tune awareness are crucial features of enabling safety and wellbeing for workers supporting clients living with hoarding and/or in squalor.

4.5 For the Firefighter

Fire-fighters face tremendous risk when responding to hoarding fires, often not knowing what they are dealing with until trying to enter the burning building. When fire-fighters go into an unknown environment it is always dangerous. Hoarding has been known to increase the risks of fire because:

- The accumulation of possessions results in an abnormally high fuel load which provides a much greater opportunity for ignition.
- Blocked exits and narrow internal pathways impede escape for the occupant and make fire fighting difficult.
- Utilities such as electricity are often disconnected or misused. Non functional utilities can result in the occupant conducting unsafe practices when cooking and heating.

**FIGURE 11: Marrickville Fire – Fire-fighters Experience.** (Excerpt from The Age July 29, 2013)

Fire-fighters struggle to contain blaze at house packed with rubbish – Megan Levy

A candle may have sparked an intense blaze that ripped through a home in Sydney’s inner west that was so packed with rubbish that fire-fighters needed a ladder to climb into the front yard. More than 10 hours after the fire ignited at the home on Edinburgh Road at Marrickville, fire crews were still trying to access the blaze because the elderly couple who lived there had hoarded so much rubbish that it had blocked access to parts of the house. Piles of rubbish reached more than two metres high in places.

Superintendent Tom Cooper, from Fire and Rescue NSW, said fire crews arrived at 9.20pm on Sunday to find a 68-year-old woman standing at the front of her house with her clothes on fire. Her 71-year-old husband was trapped inside the house, with flames coming out of the windows.

But before fire crews could reach the woman, they had to get a ladder to climb over the front gate because the couple’s belongings were piled so high around it.

“They tried to get in the front door, but they were hampered by the amount of stuff that was there,” he said.

“They had to get a ladder up over the front gate. They got up to the front door and there was a woman, her clothing had caught alight. She was an elderly woman; they doused her with water and removed her.”

Fire-fighters then entered the home and rescued the man, who was suffering from smoke inhalation. The couple’s belongings were piled just as high inside, and their roof had also been filled with items.

The woman was taken to hospital, where she was treated for burns to her chest and legs. She is expected to be released from hospital on Monday.

Her husband was being treated for smoke inhalation in hospital.
Seven fire pumpers were fighting the blaze at its height on Sunday night, and three crews remained overnight to monitor the flames because there was so much fuel in the house.

Fire-fighters were standing on piles of rubbish in the home’s front yard on Monday morning. Among the items piled high were children’s toys, pot plants, surf boards, fishing rods, clothes lines, table lamps, washing baskets and suitcases.

“Name any item and it’s here,” said one man watching fire crews from the street on Monday morning.

Two vehicles and a trailer packed with more items were also parked on the street at the front of the home.

Superintendent Cooper said the cause of the blaze was still under investigation.

“We’re not quite sure what started the fire, but it was mentioned that it could have been a candle,” he said.

Surrounding homes were evacuated on Sunday night as a precaution, with residents having to arrange alternative accommodation.

Neighbours are believed to have complained about their neighbours and the state of the semi-detached home previously.

Marrickville Council has been contacted for comment.

Superintendent Cooper said hoarding items in homes posed a potentially lethal problem.

“It poses a danger, not only to the occupants who can’t escape if there’s a fire, but to the fire-fighters as well,” he said. Police have taped off the area and have set up a crime scene as investigations continue into the cause of the fire.
• Installed sprinkler system within unit blocks could be compromised by increased fuel loads with the possibility of being overrun or high levels of storage causing a shielding effect between the sprinkler and the fire.
• Stored items in common areas could reduce required egress width and contribute to fire spread.\textsuperscript{70}

Stacked and accumulated items significantly impact on search and rescue operations and increase the risk of fire-fighters performing these duties. Often the only way fire-fighters can get into a building filled with hoarded material is to smash the walls down from the outside, only to find another wall of tightly packaged hoarded material up to the roofline.

Fire-fighters have to hack their way through and over compacted hoarded material to somehow find the fire source. This is particularly difficult in multi storey homes if trying to find a stairway which is often hidden/lost in the collected clutter.\textsuperscript{71}

The Community Education and Development Division of NSW Fire and Rescue offer support to agencies assisting those affected by hoarding and squalor and recommend at a minimum that:

• smoke alarms are installed and tested;
• exits are unblocked;
• widen internal pathways are widened;
• utilities are reconnected for the resident as soon as possible;
• safe cooking and heating areas are available.

Domestic squalor does not fit neatly into any one hazard type or class as each case or situation is vastly different from another. There is no uniform prescribed assessment and management practice so these vary from state to state, having said that, severe domestic squalor poses a significant risk to the resident, their neighbours, workers, visitors the broader community and the environment and therefore requires assessment, risk management and ongoing review.

\textsuperscript{70} NSW Fire and Rescue. Hoarding and Squalor Fire Safety. \url{http://www.fire.nsw.gov.au/page.php?id=913&homepage}
\textsuperscript{71} Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
5. Legal Framework

Legal interventions available in squalor and/or hoarding cases may be grouped into three broad categories: those focused on the property, the state of the premises; those focused on the person, the wellbeing of the resident; and those focused on the animal, the health and wellbeing of the animal.

Those legal interventions that focus on the property include the action of private nuisance; actions to enforce leasehold conditions (whether in long leaseholds or residential tenancies); and some actions brought by local authorities under public health legislation. None of these actions are designed with a therapeutic agenda and often involve mandatory orders to clean up the premises voluntarily with the threat of forced action from another party at the resident’s expense.\(^{72}\)

It is important to realise that legal interventions alone are no guarantee that change for the better can be achieved in cases of serious squalor and hoarding. The legal framework has significant limitations even when mandatory orders are realised. For example; a successful financial management order appointing the NSW Trustee and Guardian as financial manager of a person living in squalor or with hoarding does not mean that access to the person’s property can be assured or that de cluttering or a clean up can be undertaken. Rather the provisions in legislation are a tool or mechanism to be used as part of a co-ordinated approach to working with the individual or residents involved.

The United Nations Convention for the Rights of People with Disabilities presupposes a shift from substitute decision making models of assisting people with decision making incapacity, to a supported decision making framework. In practise this could mean it is less likely that people living in squalor or with hoarding issues will become subject to guardianship or financial management orders. There will be no other option in those situations than to work with the person in order to reduce the risk their living environment presents, and improve their quality of life.

5.1 NSW Public Health Act 2010

The objectives of the Public Health Act are to:

- Protect and promote public health
- Control the risk to public health
- Promote the control of infectious diseases
- Prevent the spread of infectious diseases
- Recognise the role of local governments in protecting public health.\(^{73}\)

Power to act under the Public Health Act 2010 applies if the Minister considers on reasonable grounds that a situation has arisen that is, or is likely to be, a risk to public health. Definitions under the Act to do not specifically outline either ‘reasonable grounds’ nor ‘risk’; making the Act difficult to interpret, evidence against action criteria and implement in situations of hoarding and squalor.

In contrast, the South Australian Public Health Act 2011 provides a modernised and flexible legislative framework that enables South Australia to better respond to both new and traditional public health challenges. Pursuant to Part 5 of the Act, the Minister for Health and Ageing has published the South Australian Public Health (Severe Domestic Squalor) Policy 2013 (the Policy). The Policy includes a definition of severe domestic squalor and declares it a risk to health for the purposes of the Act. The Policy also links severe domestic squalor to Part 6 (General Duty) of the Act, stating that it constitutes harm for the purposes of the General Duty.\(^{74}\)

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\(^{74}\) SA Health (2013) A Foot in the Door - Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia. (Draft) Prepared by Health Protection Programs, Public Health Services, Public Health and Clinical Systems and Department
This legislative change arose as a result of the SA ‘Foot in the Door’ Project with the aim of assisting local government public health officers to better respond to squalor environments.

Another example: The NZ Ministry of Health (MOH) presents its experience from a population health perspective indicating that legislation such as the Public Health Amendment Act 1918 and the Health Act 1920 provide a basis for removing people from places of squalor into institutions, should the case require it. The NZ Health Act 1956 also provides right of entry and inspection of any dwelling house, building, land, ship, or other premises.75

5.2 NSW Local Government Act 1993

The NSW Local Government Act 1993 outlines the role and responsibilities of local councils and how they should function in their area of responsibility. Part 2 of the Act outlines the Orders that the local council has the responsibility to act upon when a concern is raised from the general community.

Local council can issue orders on the owner of occupier of the premises where it has been assessed as not being in a safe and healthy condition, under Order No 21 in S.124 of the Local Government Act. The Order would typically deal with a situation of accumulated garbage and/or other items on the premises which are likely to be providing a harbourage for vermin. Typically the situation can be assessed without entering the residential part of the premises by observations made from a neighbouring property or the street. Non compliance with the order can result in fines of up to $2,200. However, if the person fails to comply the City may also carry out the work or arrange for the work to be carried out, and recover expenses occurred.

Local council can also issue an Order requiring a resident to remove or dispose of waste on the premises and then refrain from keeping waste on the premises in future under Order 22A in S.124 of the Local Government Act. Before this order can be issued an assessment of the premises by an authorised officer must confirm the threat to public health or health of the individual. Herein lies the challenge as entry to the property is rarely voluntarily offered and more often than not a search warrant needs to be obtained to gain access.76

5.3 NSW Residential Tenancies Act 2010

The NSW Residential Tenancies Act 2010 sets out a standard residential tenancy agreement that gives rights and obligations to landlords and tenants. The Act also gives the Consumer, Trader and Tenancy Tribunal (CTTT) power to hear and settle disputes about residential tenancies. Landlords have the right to regular property inspections quarterly. Additional inspections must be conducted with full tenant consent or in the case of an emergency.

The majority of tenants under a residential tenancy agreement are with social housing providers who have clear mandates and organisational direction to avoid contributing to the homeless population in NSW, thus often the orders are often concerning forced clean up and then maintenance of living conditions. However, landlords are entitled to seek an Order of Possession under Section 73 of the Act to retake the premises where the situation is irretrievable.77

5.4 NSW Strata Schemes Management Act 1996

With hoarding and squalor issues becoming more prevalent within the community, more Australians are being directly impacted – and more body corporate/owners corporation are turning to strata managers for advice. Under Section 117 owners, occupiers and other persons cannot create nuisance including causing a hazard to self or other lots. Where resolution of the hazard nuisance cannot be settled through mediation, an Adjudicator can make order to settle disputes or rectify complaints.

75 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor, Ageing and Aged Care Branch
76 City of Sydney Council (2013). Unhealthy Land and Premises Policy
77 http://www.tenants.org.au
5.5 NSW Prevention of Cruelty to Animals Act 1979

Animal welfare legislation is developed and administered at the state and territory level. It has undergone significant reforms in recent times. Most notably, legislation has evolved to broaden its scope from simply prohibiting acts of cruelty to animals, to actively promoting the welfare of animals. This is reflected through the concept of ‘duty of care’. If you are in charge of an animal, you have a duty of care to that animal - no matter why you are in charge of it, what you are using it for or how long it will be in your care. Duty of care is based on the internationally recognised ‘Five Freedoms’ of animal welfare:

1. **Freedom from hunger and thirst**: by ready access to fresh water and a diet to maintain full health and vigour.
2. **Freedom from discomfort**: by providing an appropriate environment including shelter and a comfortable resting area.
3. **Freedom from pain, injury or disease**: by prevention through rapid diagnosis and treatment.
4. **Freedom to express normal behaviour**: by providing sufficient space, proper facilities and company of the animal’s own kind.
5. **Freedom from fear and distress**: by ensuring conditions and treatment which avoid mental suffering.

Where a person breaches any of these duties of care categories, both local council and animal welfare agencies like the RSPCA can enforce removal of animals and issue orders for living conditions improvement before animals will be returned or permitted to reside in the premises again. Further litigation through the courts for offences of cruelty to animals can also be pursued. In NSW, an individual found guilty of crimes of cruelty towards animals can be jailed for up to 5 years and fined $22,000. However, these cases are not quickly resolved and court action does not necessarily deter future problems.

The second group of legal interventions focus on the person, the resident and their wellbeing. They may be primarily concerned with issues of legal competency, or more simply, with the conditions in which the resident lives. Their aim is to protect or promote the best interests of the resident. They may include coercive options that can be deployed without the resident’s consent and may be actively resisted.

5.6 NSW Mental Health Act 2007

The objects of the 2007 Act are to make provisions with respect to the care, treatment and control of mentally ill persons and mentally disordered persons and other matters relating to mental health.

Under the Act, person can be detained involuntarily for assessment or compulsory treatment. Whilst this may present an opportunity to clean or clear out the patient’s premises whilst they are being treated or assessed, the impact of any such intervention on the patient’s general wellbeing should be carefully evaluated before proceeding.

The Office of Chief Psychiatrist has confirmed that a squalor presentation would not in and of itself be considered reason to hold someone involuntarily under the Mental Health Act unless they also appeared to be suffering from a serious mental illness and were a danger to themselves or others and no other less restrictive treatment option was appropriate. If a squalor presentation also appeared to be mentally ill, they can be referred for an assessment to specialist mental health services where the strict criteria of the Mental Health Act apply, that is, are they a danger to themselves or others; are there less restrictive or more appropriate options for treatment etc.

The above comments would also apply to compulsive hoarding. While it might be recognised as a mental health ‘condition’, the Mental Health Act only applies where there is an immediate danger to the person or others etc. A useful analogy to explain further might be depression. While this is a mental health condition, just because a person has depression does not mean they would be subject to the Mental Health Act.

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79 Slatter, M. (2012)
80 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
5.7 NSW Guardianship Act 1987
Where a person living in severe domestic squalor or a hoarding situation is found to have decision-making impairments, to lack the cognitive capacity to make relevant decisions about their circumstances, such as accommodation, health or financial management, then decisions will need to be made on their behalf. A substitute decision maker can be appointed under the NSW Guardianship Act 1987. The Act outlines the guardian’s responsibility, at what point the guardian can act and how a person’s capacity is assessed. To support the assessment of capacity the Department of Attorney General and Justice has produced a ‘capacity toolkit’. Part of this process involves a medical certificate to confirm the loss of decision making capacity. The process of applying for guardianship and the ability to make decisions on behalf of another person can take a lengthy amount of time and cause great distress where a person does not voluntarily chose this pathway.

5.8 NSW Trustee and Guardianships Act 2009
A person living in squalor or who hoards may be deemed to be incapable of managing their estate. A financial manager can be appointed under the NSW Trustee and Guardianship Act to manage their estate which can include finances and physical assets such as their property. A financial manager can authorise the disposal or storage of assets, payment for treatment and kennelling of pets, payment for the cleaning of a property, and in certain circumstances authorise access to the person’s property. As with appointments of a guardian, applications for a financial management order can cause significant distress to the person who is subject of the application, and take a long time.

5.9 NSW Legislation and the UN Convention of the Rights of People with a Disability (CRPD)
In NSW the Guardianship Act 1987, s4, refers to a set of general principles which guardians have as a duty to observe when making exercising their authority under the Act. These principles are:

a) the welfare and interests of such persons should be given paramount consideration,
b) the freedom of decision and freedom of action of such persons should be restricted as little as possible,
c) such persons should be encouraged, as far as possible, to live a normal life in the community,
d) the views of such persons in relation to the exercise of those functions should be taken into consideration,
e) the importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognised,
f) such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs,
g) such persons should be protected from neglect, abuse and exploitation,
h) the community should be encouraged to apply and promote these principles.

Under the UN Convention of the Rights of People with Disability (CRPD), Article 12, there is the presumption of legal capacity for all people with a disability.

In meeting obligations under the CRPD, supported decision making processes and mechanisms should be fully explored in order to recognize these rights and adopt the least restrictive mechanisms for inclusion and engagement in order to meet the needs of the person with decision making incapacity.
5.10 NSW Children and Young Persons (Care and Protection) Act 1998
The Children and Young Persons (Care and Protection) Act 1998 talks about the child protection system in NSW. It explains how children and young people, who are at risk or being abused, should be cared for in NSW and how vulnerable families should be helped. It outlines the responsibilities of Community Services and other agencies, as well as parents, authorised carers.

The Act covers things such as when to make a report of abuse or risk of harm, what happens when a report is made, and what happens when child or young person can’t safely live with their family.

It outlines ways of working with children, young people and families to help them to remain safely at home, and reduce the need for them to enter care.

The Act also outlines when a child or young person can be removed from an environment under a significant risk of harm risk rating. A hoarding and squalid living environment constitutes abuse or neglect of these children or young people.

5.11 NSW Fire Brigades Act 1989
Under the Fire Brigades Act 1989 (The Act), the F&R NSW Commissioner has the authority to make decisions with respect to fires, hazardous materials and the employment of firefighters. The Commissioner can authorise other members of the F&R NSW to exercise functions of the organisation.

The Act gives the FRNSW the authority (amongst other things) to:

- Proceed with speed to suspected fires or hazardous material incidents (s11)
- Close streets and public places in the vicinity of a fire or hazardous material incident (s14)
- Use water from water mains, pipes, hydrants, well, tank or stream to extinguish or control a fire (s15)
- Remove any person, vehicle or vessel in the vicinity of a fire or hazardous material incident that might impede the work of the fire brigade (s19).

The Act allows firefighters to act once a fire has started, however firefighters are limited in their access to private property where there is no fire present; despite their numerous fire prevention strategies and initiatives. Access to a property that is not on fire must be by invitation.

As our understanding of hoarding and squalor deepens, so does the concern with traditional legal ‘remedies’. Involuntary relocation (temporary or permanent); eviction, comprehensive forensic cleans; forced de-cluttering by strangers; the sudden removal of goods and animals; restrictions on the use of one’s home: such outcomes increasingly seem unsatisfactory. Their effects are often unsustainable. We now appreciate that, without support, the situation is likely to recur because the residents behaviour will continue or resume. Fortunately, this more complex understanding is complemented by some changes in agency practice and legal processes. A growing number of judges and lawyers are becoming aware that the legal system can play a key role in effecting enduring change in hoarding cases with appropriate interventions that reflect understanding of hoarding as a social and personal problem, respect for the rights of individuals and protection of those who are affected.

82 Victorian Department of Health (2012). Discussion Paper Hoarding and Squalor. Ageing and Aged Care Branch
6. Tools and Resources

A number of tools and resources have been adopted in NSW and have emerged in an attempt to qualify, assess and coordinate service provision and support to people who hoard or live in squalor. This is certainly not an exhaustive list.

6.1 Hoarding and Squalor Toolkit & App

Catholic Community Services NSW/ACT has developed a Hoarding and Squalor Toolkit and Toolkit app which aim to provide direction for both service providers and community members to respond to situations of hoarding and squalor. The toolkit can be found on Catholic Community Services NSW/ACT website and through the Apple and Google app stores.

6.2 Guidelines and Protocols

In 1999 NSW Government established “Partnerships against Homelessness” (PAH) to improve services for people experiencing homelessness by bringing together the NSW government agencies responsible for homelessness service provision. As part of this initiative, the Department of Ageing, Disability and Home Care (ADHC) commissioned and released the “Guidelines for the Field Staff to Assist People living in Severe Domestic Squalor”. Acknowledging the challenges domestic squalor and hoarding present for NSW Housing Services Divisions it was proposed that the ADHC funded Domestic Squalor Project, operating in Central Sydney was formalised in an agreement between ADHC, Housing NSW and NSW Health in collaboration with Non Government Organisations, including Catholic Community Services NSW/ACT.

Three Local Implementation Groups (LIG) were established across Housing NSW Central Sydney Region to develop practical implementation strategies incorporating the learnings from the pilot project and the National Squalor Conference. Based on the PAH Guidelines, Eastern Sydney LIG built upon the Good Living Protocol (Illawarra) to develop a local resource for practitioners working with people living in severe domestic squalor.83

Consequently, a number of local councils and non government agencies have adapted and promoted local protocols utilising these guidelines as the backbone of the intervention guidance. These include:

- Good Living Conditions Protocols: For services supporting people living in severe domestic squalor in the Illawarra (2009)
- Domestic Squalor Information Package: A guide for services to assist with identifying and dealing with Domestic squalor in the Blue Mountains (2010)
- South East Sydney Hoarding and Squalor Interagency Protocol (Draft for consultation, 2013)

6.3 Environment Cleanliness Clutter Scale

The Environmental Cleanliness Clutter Scale (ECCS) was designed as a brief, user-friendly way of quantifying severe domestic squalor and, perhaps differentiating those that were related to hoarding from those mainly attributable to failure to dispose of filth. The scale has been developed for use by workers from a variety of services, including those working in health, housing and community agencies. Items were sourced from relevant publications in the medical and psychiatric literature (Macmillan and Shaw, 1966; Snowdon, 1987; Samios, 1996; Steketee et al, 2001; Chiu et al, 2003).84

The ratings on the ECCS are mainly for documentation purposes, to record what has been observed in order to relay this to others, and then to be able to rate changes in living conditions over time. They give an indication of what one observer found on a particular day, and co-ratings so far have revealed that different raters tend to rate similarly. However, scores do not tell raters how to respond to a particular situation.

83 South East Sydney Hoarding and Squalor Interagency Protocol (Draft for consultation, 2013)
The ECCS (Appendix 3) has 10 items, rated between 0 and 3. Where possible, all rooms should be inspected before making a rating. The cleaner and less cluttered the home; the more likely the score is to be 0. The maximum score for these domestic items is 30, and a rating of at least 20 usually means that the person lives in severe domestic squalor. Ratings of less than 12 imply that although the person may need help with cleaning or sorting out possessions, they do not live in a situation of Hoarding and Squalor. It is also relevant to consider whether they live in very cluttered surroundings without being markedly unclean, and this will be indicated by ratings on items A and C of the scale.

How to intervene is determined by a number of other factors, not simply the observed degree of domestic squalor. Supplementary questions allow documentation of observations concerning personal cleanliness, availability of essential services, and the structural safety and upkeep of the premises.85

South Australian agencies utilise an adapted version of the ECCS called the Severe Domestic Squalor Assessment Scale (SDSAS) and use it as an evidence tool to comply with legislative responsibilities under Sections 56 (General Duty) and 92 (Notices) of the South Australian Public Health Act 2011.

6.4 Clutter Image Rating Scale

The Clutter Image Rating (CIR) scale was developed to overcome problems with subjectivity in estimating degrees of hoarding, or more specifically, clutter. The CIR (Appendix 4) consists of photographs of three main rooms found in most dwellings – a kitchen, a living room and bedroom. There are nine images for each room that illustrate an increasing degree of clutter ranging from 1 (no clutter) to 9 (severe clutter). The stimulus picture were created by filling a small furnished apartment with piles of the objects thought to be accumulated by people who hoard, such as newspapers, boxes, clothes, dishes, chairs, bottles, can, books, pillows, appliances, cereal boxes, food containers and junk mail. Items were piled up as high as 60cm from the ceilings so as to resemble the ‘most severe hoarding cases’.

A major strength of the instrument is that the visual comparison may reduce error introduced by language and different perceptions of words such as ‘clutter’, ‘hoarding’ or even ‘accumulation’.86

The NSW Fire and Rescue utilise the ECCS as part of their Hoarding and Squalor Fire Risk report available online for the general public to report fire load concerns directly to the Fire Department.

85 South East Sydney Hoarding and Squalor Interagency Protocol (Draft for consultation, 2013)
86 Snowdon et al (2012)
6.5 (TACC) Environmental Health Scale

RSPCA Inspectors utilise the TACC Environmental Health Scale (Table 1) as part of their assessment process when putting together a case record following an investigation request.

<table>
<thead>
<tr>
<th>TABLE 2: Condition of Animal’s Environment – TACC Environmental Health Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acceptable</td>
</tr>
<tr>
<td>2. Marginal</td>
</tr>
<tr>
<td>3. Unsanitary</td>
</tr>
<tr>
<td>4. Very Unsanitary</td>
</tr>
<tr>
<td>5. Filthy</td>
</tr>
</tbody>
</table>

6.6 Four Degrees of Squalor

The Squalor Survivors website outlines the following four degrees of squalor to enable a person who suspects they may have a problem with squalor and hoarding a tool to help them measure where they are in terms of the severity of the problem they recognise and are trying to address:

- **First degree squalor:** You are getting behind in tasks that you would normally manage, like laundry and dishes. You are not the tidy person you once were. Little piles are starting to emerge and your disorganization is starting to affect your life and inconvenience you. Things are just starting to get out of hand and become unmanageable. A sign of first degree squalor could be that you might be embarrassed for other people to see your mess ... but you would still let them in the house.

- **Second degree squalor:** Now things are really starting to get out of hand. Signs that you have reached second degree would include losing the use of normal household items like your bed, table, television or telephone, because the piles have expanded to cover the items up. You start to develop new methods of moving around your house, as normal movement is impeded by your piles of stuff. You might start making excuses to discourage people from entering your house.

87 Patronek, G. (1997) Tufts Animal Care and Condition (TACC) Environmental Health Scale
• **Third degree squalor**: At this stage, you have all the above, plus you have rotting food and animal faeces and/or urine in the house and this is the rule not the exception. You cannot cope with the growing mess. Essential household repairs may not be done, because you are too afraid to let a tradesperson see your house. Just the thought of someone seeing your mess causes you great stress.

• **Fourth degree squalor**: At fourth degree squalor, you have all of the above, plus you have human faeces and/or urine in your house that is not in the toilet.88

These descriptions include both the physical environment and also the accompanying emotional impact experienced by the person living in poor environmental conditions.

### 6.7 Fire and Rescue assessment tools

NSW Fire and Rescue are in the process of developing risk response rating scale based on the scores of the Image Rating Scale to enable fire-fighters to be adequately and suitable equipped for the fire load they may encounter in a hoarding and squalor fire.

There is considerable variation on the severity and nature of living conditions affect by hoarding and squalor. Rating scales are needed to document degrees of uncleanliness and hoarding, and in the assessment and management of person found to be living in a state of substantial disorganisation and mess. Full, meaningful assessment if why a person is living with hoarding or in domestic squalor requires documentation not just of the uncleanliness but of factors that might have contributed to it development.89 This sort of validated documentation can also serve as an evidence base for court orders, guardianship applications and mental health interventions.

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7. Painting the Australian story

7.1 New South Wales

In 2002 a number of service providers in South East Sydney and Central Sydney, who had been experiencing many difficulties in coordinating efforts to help and provide services for people living in severe domestic squalor and had become increasingly concerned with the impact of the problem posed to neighbours and other in the community, applied to ADHC for funding to develop recommendations concerning how best to intervene in cases of severe domestic squalor.

These service providers; namely South East Sydney Area Health, Central Sydney Area Health Old Age Psychiatry and Catholic Community Services (formerly Mercy Arms, Catholic Healthcare); had been exploring in an effort to improve interventions international practice and found taskforces set up in London, Ontario in 1999 and in the USA by Fire and Rescue Departments 1998/99 proposing recommendations on how best to deal with squalor associated with hoarding. The ADHC project was auspiced by Central Sydney’s Area’s Mental Health Service. A reference group was convened and Professor John Snowdon, a psychiatrist was appointed Chairperson and a Project Officer, Wendy Weir, was recruited to conduct a review of the evidence relevant to squalor, to consult stakeholder groups and to write a report on how best to intervene in cases of severe domestic squalor. The Reference Group recognised that comparable problems were encountered by service providers in rural areas as well as urban settings, had an extensive awareness of experiences and reports of interventions in other countries and their own experiences showed that most jurisdictions and government departments around the world had no documented policies or plans concerning the management of such cases. The final report with a list of recommendations was submitted to ADHC in September 2004.90

The Guidelines developed through the ADHC project were published through the “Partnership against Homelessness”, including the term severe domestic squalor; extreme household uncleanliness, and hoarding (only where the accumulation of material led to the environment being unclean, unsanitary or dangerous for example, fire risk) algorithms for managing collaboration, effective assessment and referral and best practice approach to support; as mentioned in Section 6.2 Guidelines and Protocols.

A number of key agencies in NSW have influenced the knowledge base, progression of coordinated support and development of services. A comprehensive list of agencies responding to people affected by hoarding and squalor can be found in Appendix 1: Mapping the NSW response.

In November 2009, Catholic Community Services hosted the inaugural National squalor conference in Sydney which aimed to raise the profile of severe domestic squalor and aspects of hoarding, generate discussion and develop agreed priorities for future action.

Conference planning was guided by a Steering Committee,91 promoting the conference in Australia and New Zealand, targeting:

- community services, health, aged care, mental health
- housing providers, clinicians, social work, animal welfare
- emergency services, local, state and federal government, Academia, consumers and carers.

The conference program presented a rich tapestry of perspective and experience in relation to squalor and aspects of hoarding from service providers and specialist around Australia. Based on the success of the first conference a second conference was held in September 2012. Following this second conference there was a call for action to establish a Hoarding and Squalor Taskforce to address gaps and shortcomings in the service response for people affected by hoarding and squalor. There was strong agreement that these clients were not receiving appropriate access to care and support. A NSW Taskforce was convened to explore current service provision, identify service strengths and weaknesses and develop recommendations for future action.

91 Steering Committee made up of five representatives from Catholic Community Services, Dr Shannon McDermott, Social Policy Research Centre UNSW and Professor John Snowdon, Psycho-geriatrician
7.2 Victoria
The Victorian Government published a discussion paper on hoarding and squalor in 2012. They identified that a boutique response is not sustainable. The estimated numbers of people living with a hoarding condition and/or in squalid living conditions are relatively small compared to the overall population. However, their need for appropriate support does not diminish due to this fact. The associated impact on families and communities also needs to be considered, combined with relative risk factors. In addition, these numbers may be under-estimated given the difficulty identifying and intervening in hoarding and squalor cases.

Due to the complex nature of the hoarding condition and the need to be tightly client centred in each case (including appropriate care planning practice and assessment), a clear service coordination point in each region needs to be recognised, one capable of dealing with complex cases, available and resourced to meet the needs of all sectors and disciplines.

The solution to cases involving hoarding and/or squalor is not necessarily found in legislation and enforcement, yet these are essential elements especially when risk extends to vulnerable groups such as children, frail older people and animals.

Further discussion is required covering a range of perspectives such as ethical dilemmas and the tension between public expectation versus duty of care of workers. In addition a range of sector concerns need to be worked through to enable service system capacity to respond, for example Occupational Health and Safety.

It is important to emphasise that compulsive hoarding cases in particular, as apart from squalor cases, are very difficult to work with and that interventions achieve limited outcomes.

In June 2013 Victoria released service response guidelines, *Hoarding and Squalor: A practical resource for service providers*, developed with a representative stakeholder group together with international, national and local knowledge of the subject of hoarding behaviour and squalor. This practical resource offers a basis to guide service delivery and practice. Its purpose is to build service system capacity by assisting services to work in a collaborative manner, encouraging the coordination of sector response.

7.3 South Australia
During 2012 Anglicare funded a project to review the practice of providing services to people who live in domestic squalor. The aim of this project was to develop guidelines for the Northern Housing Inclusion Program, that provide case management support to clients in accordance with funding provided by the South Australian Department for Communities and Social Inclusion (DCSI), to support people who are homeless or at risk of homelessness.

These guidelines are designed to assist Anglicare’s Northern Housing Inclusion Program case managers, to constructively intervene and improve the situation of clients who are living in severe domestic squalor. The aim is to improve the efficiency, speed of action and coordination of work between relevant agencies, resulting in improved tenancy conditions, improved health and quality of life for individuals who have been living in domestic squalor.

These guidelines provide case managers with:

- processes to assist people living in domestic squalor;
- clarity of the roles and responsibilities of agencies and service providers, to enable coordination and integration of services;
- practical information regarding referrals and intervention options.

In 2013, the South Australian Department of Health supported the preparation of ‘A Foot in the Door – Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia’; a guideline to support local government environmental health officers understand, assess and manage cases of severe domestic squalor in South Australia. This guideline does not mandate a single approach to the management of severe domestic squalor. It is designed to remove value-based assessments by promoting a consistent, supportive, and risk based identification and management framework, which acknowledges
that different people have different living standards. It recognises the importance of interagency cooperation in achieving successful outcomes. As such, the guideline may be useful for other agencies that support individuals in severe domestic squalor. Agencies are encouraged to adopt and adapt this guideline for use within their local communities. This document is currently still in draft form.

The South Australian Department of Health indicated that while a formal hoarding ‘task force’ would be great; an agreed interagency approach can achieve the same results without the need for significant resources. Their next immediate steps were to:

- complete new legislation, hopefully in late 2011, that would assist local government public health officers to better respond to squalor environments, that is the South Australian Public Health Bill 2009 and the South Australian Mental Health Act 2009,
- complete the guidance documentation including the risk assessment checklist completion (expected late 2011), which might well be useful for other sectors apart from Environmental Health Officers.

Consequently, the Minister for Health and Ageing published the South Australian Public Health (Severe Domestic Squalor) Policy in 2013. This policy guides the relevant authorities to sections of the ‘Foot in the Door’ guidelines which outline how to identify, assess and manage public health risk associated with severe domestic squalor.

7.4 Queensland

Queensland councils are lobbying the state for funding as well as better access to services and the development of a kit to help them tackle extreme hoarding and domestic squalor and the social and mental health issues that often lead to it. Brisbane City Council figures show there are between 30 and 60 cases of hoarding identified in the council area each year. Following a particularly challenging case where a resident is estimated to have hoarded about 20 tonnes of material in her yard and inside her house; Mackay Regional Council has called on the state to help, joining in the motion with Brisbane.

Centacare Brisbane currently operate specialist cleaning and support services and has recently signed a $250,000 contract with Brisbane council to support hoarders and those living in severe domestic squalor in the LGA. Additionally, Centacare Brisbane offers hoarding help by providing a ‘fee for service’ program and specialize in providing not only the cleaning, but a respectful and supportive process.

Great momentum is building in Brisbane through the Homelessness Community Action Plan Working Group exploring responses to hoarding and domestic squalor. As a result the Brisbane Hoarding and Squalor Working group has emerged in Brisbane. The Brisbane Hoarding and Squalor Working Group is a collaborative interagency model that supports holistic and sustainable responses to the issues of severe domestic squalor and/or compulsive hoarding and to reduce the risk of housing insecurity or homelessness. The breadth of the collaboration covers 17 agencies including NGOs from a variety of sectors, local government, a number of Queensland and Australian Government departments and individuals and families living in hoarding and squalor environments. Workers were able to receive support after dealing with the traumatic work of supporting families in this situation thus reducing the stress encountered.

Due to the success of the group, supporting organisations in other regions have already commenced work in Logan City and Moreton Bay to replicate this collaboration.

7.5 Western Australia

The Western Australia Department of Health has identifying that working with individuals in challenging domestic environments such as squalor and hoarding is emerging as an area of finely tuned combined effort. The collaboration between services across sectors mirrors the respectful relationships required to engage individuals for long term change. A ‘community of interested workers’ exists to provide resource information and strategies in this emerging area. Currently there are no formal structures or distinct response coordination in Western Australia except upon a case by case basis.

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92 SA Health (2013) A Foot in the Door - Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia. (Draft) Prepared by Health Protection Programs, Public Health Services, Public Health and Clinical Systems and Department for Health and Ageing on behalf of the Chief Public Health Officer

7.6 Australia Capital Territory

A report from the Joint Office of the Community Advocate and ACT Mental Health Service project on Squalor March 2002 explored the management of cases of squalor in persons with diminished capacity. A squalor workshop initiated between government and non-government community and health agencies was facilitated by Dr. Graeme Halliday, Psychiatrist from Central Sydney Area Health, and a published specialist in the area of squalor. This workshop was used to inform the development of a Squalor Panel to promote a model of co-case management between agencies who encountered severe domestic squalor.

Workshop participants identified:

- That there is a lack of coordination and clients are passed between services.
- Current long-term follow-up and monitoring is inadequate
- Restoration and clean-up costs are significant and agencies/services are not budgeted to pay these costs
- Agencies are lacking in knowledge to address squalor and are unsure of the avenues they can pursue for clients who are refusing services, for example Guardianship and Mental health Assessment Orders
- Conflict between a person’s autonomy and the probability of diminished capacity
- Gaining consent was a major issue
- Clear definition of squalor
- Occupational health and safety issues.

In order to combat the increasing problem of squalor in the ACT and in an attempt to address the above issues, the workshop participants formed a Squalor Panel. The Panel committed to:

- Providing a single point of contact for ACT persons or services needing assistance in cases of squalor
- Providing intensive coordination over the period of time necessary to assist in cases of squalor
- Holding conferences as needed for coordination (estimated at 2-4 meetings per case)
- Possessing the resources and budget to clean and store services
- Resolving the confidentiality problem, i.e. How the services that identify the incidence of squalor can then refer and appropriately disclose client information to another agency who can manage the domestic squalor.
- Maintaining a database for service delivery and research purposes
- Utilising the Environmental Cleanliness and Clutter Scale (LCRS), for assessment and research purposes
- Providing professional and community education on squalor and its management.

Subsequently, Southside Community Services Inc Squalor Project continues to work other agencies in the ACT in recognising the need to develop an early intervention domestic squalor and compulsive hoarding program to provide better outcomes for people living in such conditions. The project includes a survey of services and Government and non-government agencies are encouraged to participate.

7.7 Tasmania and the Territories

There is a distinct lack of information and formal coordination of services to support people who hoard or live in squalor in the Northern Territory and Tasmania and further investigation into how hoarding and squalor is managed is required.

Anecdotally, Aboriginal community health treatment programs in the top end of the Northern Territory include a housing treatment as part of the Treatment Protocol as many of the infestations of scabies, skin sores and tinea, amongst others, begin in the home where there are very young children; visits often revealing quite squalid and cluttered living environments.

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8. What is still missing across Australia?

Call for action

8.1 Build the national evidence base

8.1.1 Prevalence Data

Although there have been no prevalence studies of hoarding in Australia to date, similar research in the US, UK and OECD countries indicate that between 400,000 and 1.1 million Australians may hoard excessively. Much of the evidence base regarding the prevalence of hoarding and squalor in NSW is piecemeal and scarce at best. Some states across Australia do not have any coordinated response to managing people affected by hoarding and squalor thus if this data is collected, it is not necessarily recorded in a central place, however there has been some data collected in NSW and Victoria. In NSW, the management of hoarding and squalor is regional and coordinated in some regions and reactive in others. In addition, agencies like the RSPCA and NSW Fire and Rescue collect data where the incidences affect their core business; however this is not necessarily translated to a central database for analysis and allocation of resources for future incidents.

Prevalence studies in the USA estimate between 2 and 5% of the general population are affected to a clinical level by hoarding. A study conducted in South East London Community Health area in 2013 by Nordsletten et al found a lower-bound prevalence of approximately 1.5% of hoarding disorder of 1698 adult individuals recruited to the study. Results found 19 individuals met DSM-5 criteria at the time of interview. Those with hoarding disorder were older and more often unmarried (67%). Members of this group were also more likely to be impaired by a current physical health condition (52.6%) or co morbid mental disorder (58%), and to claim benefits as a result of these issues. Individuals with hoarding disorder were also more likely to report use of mental health services.96

A 10 year study in Australia conducted by Snowdon and Halliday (2011) in a defined area of large metropolis; comprising suburbs of various socio-economic and ethnic composition; estimates from the referral rate to the old age psychiatry team, a minimum prevalence of cases of moderate to severe domestic squalor of 1 per 1,000 (0.1%) of people aged 65 years or more. A number of cases of squalor in the area may have been referred to other services (including psychologists for intervention in cases of hoarding) but not to old age psychiatry and others may not have been referred to anyone. Thus the true prevalence rates could be even higher then the study suggests.

During the ten years, 53 people were referred to the old age psychiatry team for mild squalor and 120 in moderate to severe squalor. The median age for this sample was 76 years. The principle diagnosis made in the 120 cases of moderate to severe squalor were dementia (35%), substance abuse and/or alcohol related brain damage (24%), schizophrenia or paranoid state (15%), personality disorder (9%), physical illness or disability (8%) and depression (3%). In 5% of cases, criteria for DSM-IV or significant physical illness/disability were not fulfilled.

Of the 173 people referred to the old age psychiatry team for squalor, 41% had never been married, 27% were widowed, 23% were separated or divorced, and 9% were still married. About 44% of the sample lived in homes that the occupants or their relatives owned, while a similar proportion lived in public housing and 6% lived in privately rented accommodation or boarding houses. This accommodation profile differs from that reported in Halliday et al (2000) study of a cross-age population, but also from the country as a whole, where only 5% of Australians live in public housing.97

An evaluation of Catholic Community Services Severe Domestic Squalor project in 2009, by which time 218 clients aged between 21 and 94 years had been referred to the project; 58% aged under 65 years and 56%

were male. Approximately 54% lived in public housing, 39% lived in properties they owned and 7% rented privately. The project’s figures suggest that the rate at which older people are referred to helping agencies to consider intervention in cases of severe domestic squalor is about five times higher than the rate applying to younger adults.98

Catholic Community Services NSW/ACT provided the following report for the National Hoarding and Squalor Conference in 2012:

**OUR STATISTICS SHOW**

- These statistics are based on a sample of 118 CCS clients (female and male) at the point of entry into the CCS Hoarding and Squalor service program, in the Sydney and Newcastle-Hunter regions between 9 March 2009 and 24 December 2011.
- Of our client group 59% lived in public housing, 34% owned their own home and 7% lived in private rental accommodation.
- One in three clients were living with other people, thus exposing children and relatives to health and safety risks, which impact on their wellbeing.
- Clients were at high risk of eviction with 80% of public housing tenants and 60% of private renters experiencing the threat of eviction at the time they sought help from our program.
- Male public housing clients in Sydney were at highest risk of not being able to remain in their home on program entry (81%), compared with female clients (63%).
- More than one third of clients had been in squalor for 5–9 years. The majority of clients seen by CCS had lived in squalor for between 2–9 years (79%).
- Clients have high levels of physical health and safety risks (88%).
- Clients also experience high levels of mental health issues (82%) with signs of depression and anxiety in many clients and schizophrenia in some cases.
- Most clients are at high risk of fire (95% in Sydney and 59% in the Newcastle-Hunter region) as a result of the accumulation of items.

For an effective response to people and their pets affecting by squalor and hoarding data need to represent more than just a snapshot of a coordinated area of service. The data can highlight where clinical support services are needed; the true costs associated with hoarding and squalor cases; where early intervention supports and identification systems can prevent severe cases of hoarding and squalor; where existing systems can be adjusted and reviewed to consider the presentation of clients who hoard or live in squalor; where specialist services are required and where education and training can be implemented to minimise the need for specialist services.

Challenges faced in developing prevalence data across the country, let alone the state includes:

- different databases used by different agencies, including a variety of client management systems used by non-government agencies;
- databases do not speak to each other to share data;
- not all cases of hoarding and squalor are linked into assessment processes with the database;
- historically merged data can be contaminated;
- ‘hidden’ population of people affected by hoarding and squalor that are only identified often at crisis point.

The San Francisco Taskforce on Compulsive Hoarding led by the San Francisco Human Services Agency, Department of Ageing and Adult Services, utilised a mixed methodology to obtain prevalence data on the incidence of hoarding with broad representation from a range of public and private organisations.

including drug treatment programs, legal services, healthcare providers, religious organisations, shelters, housing related services, social services, and mental health service groups. These data enabled the task-force to recommend and accurate cost early intervention pathways to prevent or minimise the impact on the person, their family and neighbours of their hoarding behaviours. The methodology included the use of focus groups, surveys of people with hoarding behaviours, key stakeholder interviews, an environmental scan, and a landlord survey.99

Despite the challenges and associated costs, if services are to be effective in supporting people and their pets affected by hoarding and squalor, national leadership is required to enable the systematic coordination of data collection. The costs that will accumulate both financially and socially for these individuals will outweigh any initial resource injection to create pathways of effective and preventative support.

8.1.2 Animal Hoarding and Human Welfare

The RSPCA national statistics 2001-2012 report 51,961 investigations of animal cruelty involving 266 prosecutions and resulting in 298 convictions.100 The number of prosecutions over the last eight years total 39 with each costing approximately $35,000; a total of $1,365,000 with an average of $170,625 per annum. An additional 21 in the last year did not proceed to prosecution stage.

As argued in the Victorian Hoarding and Squalor Discussion paper, RSPCA NSW experiences the following impacts as a result of responding to cases of animal hoarding:

- large amount of resources required (inspectors, animal ambulances, veterinary and shelter staff);
- enormous cost of veterinary care and ongoing treatment and care costs;
- overcrowding in animal shelters and increased workload;
- health concerns for the staff involved;
- high ammonia levels – respiratory protection often needed;
- injuries such as bites and scratches from animals who are frightened, aggressive or feral injuries from capturing animals in unsafe environments (for example, accumulated rubbish);
- resistance from owners - sometimes violence;
- zoonotic diseases (for example, salmonellosis, giardia, ringworm, psittacosis, sarcoptic mange); and
- emotional impact on staff and volunteers.

NSW RSPCA identifies the human welfare problem as well:

- Owners are usually living in the same conditions as the animals.
- Owners often have very strong bonds with their animals, even though they neglectful and cruel.
- Children or the elderly may also be living in the home.
- There may be drug and alcohol related problems.

RSPCA NSW suggests the animal welfare problem cannot be solved without assisting owners improve their own welfare and that a collaborative approach between sectors is needed. Consistent with their goal of preventing animal cruelty is continuation of program development and partnerships that have both an animal and a human welfare focus. By supporting pet owners they support the welfare of their pets and assist with reducing incidence of abuse and neglect.101

There is good reason for mounting a study of the prevalence of mental disorder and personality problems among people deemed to be ‘animal hoarders’ as to date there have been no such studies. This lack of information is at least partly attributable to lack of involvement of mental health professionals when attending to cases of animal accumulation. However, given it is better recognised that effective intervention is dependent upon interdisciplinary action to resolve the complexity associated with animal hoarding and sometimes resulting squalor, it is desirable that research initiatives are set up.102

99 San Francisco Taskforce on compulsive Hoarding (2009) Beyond Overwhelmed: The Impact of compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services.

100 www.rspca.org.au//content/facts

101 Victorian Department of Health (2012), Discussion Paper Hoarding and Squalor; Ageing and Aged Care Branch

A crucial part of collaboration between animal welfare and human welfare is timing of the response. Often if animal welfare inspectors need to act due to the critical health of the animal/s and human welfare service are not in a position to support the pet owner, then the likelihood of recidivism is high and the emotional and health toll on the pet owner may not be adequately supported.

Nation-wide, where animals are affected by hoarding and squalor the partnership between animal welfare and human welfare is fundamental. Currently, in individual regions where coordination of service occurs around cases of hoarding and squalor, animal welfare agencies such as the RSPCA form part of the assessment process and intervention strategies through localised protocols. Animal hoarding cannot be overlooked in the scheme of the response and needs to form part of the solution matrix in all regions across the state and country to ensure effective pathways to appropriate and supported service intervention.

8.1.3 Standardised Tool utilisation
As a result of the Partnerships Against Homelessness project that first introduced Guidelines for Field Staff working with People living in Severe Domestic Squalor in 2007, a number of common tools were introduced to services attempting to coordinate support for people affected by hoarding and squalor. These tools included assessment pathways and accompanying tools to support service provision decision making and assessment tools specifically to assess an individual’s mental health or decision making capacity. The final suite of tools introduced concern themselves with assessment of the environment.

Currently, the Environmental Cleanliness and Clutter Scale (ECCS); developed by Snowdon and Prof Halliday, 2009 and outlined in the Guidelines for Field Staff working with People living in Severe Domestic Squalor is being utilised by agencies who have adopted the guidelines into their local protocol. This tool has been used as an evidence document for local court proceedings and guardianship applications with varying success; completely dependant upon the magistrate or tribunals knowledge of the instrument. However, tools such as the ECCS have the capacity and ability to strengthen work practice through objective assessment focusing on the environment; improve client outcomes with a measureable change tool; which in turn will contribute to the national evidence base for effective pathways of support.

In addition, the Image Clutter Scale; developed by Frost et all, 2008; is currently being used by NSW Fire and Rescue and the RSPCA in NSW to rating the amount of clutter and hoarding in a property which is then linked to response categories dependant upon the rating assigned.

The development of any response paradigm involves the creation of a common language for all stakeholders involved and more often than not utilisation of agreed standardised tools. This ensures that there is consistency of approach and measureable outcome changes with a common tool and familiar language descriptions. Standardised tools will also enable the creation of evaluation data to demonstrate change for the person affected by hoarding and squalor and the effectiveness of associated interventions.

8.1.4 Australian Best Practice Resources
In addition to the tools introduced to services to enable individual and environmental assessment, additional resources have been developed by responding agencies across NSW to support continuous improvement and enable a localised framework of support to flourish. Again, these resources are piecemeal and largely dependent upon a group of dedicated and passionate people to support their development and promotion of good practice.

Although internationally many resources have been developed to support as many of the complex facets of supporting people who hoard or live in squalor, many need to be adjusted to suit the Australian environment, taking into account legislation, human services frameworks and funding support. The tools outlined in the sections above are demonstrative of the capacity the Australian service system has to develop and promote good practice resources.
National practical resources to support a common framework would include:

- discussing the difference between hoarding behaviour and a squalid environment, where they intersect and why
- placing the person, human dependants and animals first in a planned response, ensuring they are safe and risk is minimised
- presenting direction on how all services might work collaboratively
- confirming a common language, systems and tools that can be utilised by services
- presenting information about service types, what they do and how to contact them
- presenting questions and answers, case studies and a resources and contacts listing.

A consideration to the medium through which the resource is provided is required as applications through Apple and Android functions have been successful and resource websites with further links to material produced by working groups and taskforces across the country can equip new and emerging groups with tried and tested resources; for example terms of reference documents, assessment forms and measurement tools.

8.1.5 Realistic Indicators of Success

When considering indicators of what success looks like in cases of hoarding and squalor; it is important to remember that ‘cleaning up’ may not be the high priority for the individual living in this environment and if de-cluttering or cleaning is not completed in consultation or collaboration with the individual where possible; the success will be short-lived.

One of the worst experiences for someone with a hoarding problem occurs when another person or crew arrives to clear out the home, usually at the order of the public health department or a frustrated family member ... These scenarios almost always leave the hoarder feeling as if his or her most valued possessions have been taken away, which in fact may be the case. Beyond this, most hoarders have a sense of where things are amid the clutter. When someone else moves or discards even a portion of it, this sense of “order” is destroyed. We know of several cases in which hoarders have committed suicide following a forced cleanout.

The time, expense, and trauma of a forced cleanout are not worth the effort if any other alternatives are possible. Although conditions in the home may improve temporarily, the behaviour leading to those conditions will not have changed. Moreover, the likelihood of obtaining any future cooperation after such trauma is slim. One Massachusetts town in our survey of health departments conducted a forced cleanout costing $16,000 (most of the town’s health department budget). Just over a year later, the cluttered home was worse than ever.103

In addition, indicators of success will need to encompass a range of domains and have flexibility and objectivity in their descriptions to enable accurate and equitable documentation in order to contribute to a best practice evidence base.

Approaches that deal with compulsive hoarding through a chronic illness management model – which addresses client self-care, coordination within systems of care, and consistent follow-up – or a harm reduction model – which focuses on managing and mitigating the negative impact rather than eradicating the hoarding behaviour entirely – show promise as both respectful and effective ways of helping individuals with hoarding behaviours to improve their lives. Treatment using these approaches is not a “cure” or one-time fix, but must be continued over time.104

104 San Francisco Taskforce on compulsive Hoarding (2009) Beyond Overwhelmed: The Impact of compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services
Thus, it would follow that indicators of success need to include bio-psycho-social measurement that demonstrate change or progress in a range of health, social, mental health and environmental domains; rather than immediate elimination of the clutter or mess.

8.2 Research funding

There is a world of research on hoarding and squalor waiting out there to be designed, funded and completed. However, in order for the research to inform best practice and impact upon the effectiveness of services for people and their pets affected by hoarding and squalor in Australia it needs to:

- articulate and define good practice interventions within an Australian context,
- further explore how individuals with hoarding behaviours understand their situations,
- define more clearly the causes of squalor and hoarding,
- articulate methodologies for intervention that are manageable within budget constraints and equip field workers to respond appropriately and skilfully;
- consider leadership for long term research, planning and resourcing, education.

There are a number of existing research agendas that are relevant pathways for research opportunities into hoarding and squalor. These include:

1. National Homelessness Research Agenda 2009-2013

Existing research has been largely qualitative, small scale and sub-group specific. A number of research gaps have been identified through a literature review, a researcher roundtable, responses to the Green Paper Which Way Home and the White Paper, and select consultation on the draft Research Agenda. The research priorities and questions under the Agenda reflect these research gaps.

Firstly, given the high risk of eviction without alternative suitable, affordable and sustainable accommodation for many people referred to current services; the risk of homelessness is imminent. In a similar way to the lack of prevalence data, the National Homelessness Research agenda priorities research on socio-demographic factors, risk and protective factors, causal mechanisms, pathways and outcomes would also improve the evidence base.

Secondly, as a pathway into homelessness the National Homelessness Research agenda is looking for service system research to focus on system capacity and responsiveness and needs assessment service planning at local, state and national levels. Best practice research and models of integrated service delivery should be used to inform service delivery including evaluation of program delivery, cost and outcomes is required, in order to assess the effectiveness of interventions. There is insufficient evidence on effective responses to clients with complex needs.

And finally, the impacts of early intervention and maintaining social connections and social reintegration programs are areas for further research.105

2. National Disability Research and Development Agenda

The National Disability Research and Development Agenda sets out national priorities, focus and direction for disability related research to improve the lives and outcomes for people with disability. The Agenda aims to facilitate the creation of a comprehensive evidence base and the foundations of robust research that will inform the policies and practices of the disability sector, governments and the mainstream community.

It is not intended that all of the research directions and areas of inquiry set out in this Agenda will be resourced through this disability research and development commitment. Rather, the Agenda has a broad scope and seeks to influence the inclusion and direction of research relating to disability across a range of national research initiatives and sectors.

105 Department of Families, Housing, Community Services and Indigenous Affairs. National Homelessness Research Agenda 2009-2013
Given current research into the aetiology of hoarding and squalor has linked cognitive impairment and disability to these environments, research opportunities relating to causality and possible treatment options appear like a natural application to develop the research base in Australia.

In addition, the National Disability Research and Development Agenda’s directions of:

- Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support options.
- Analysis of the factors that support sector sustainability, sector development and improved organisational capability.
- Research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability.

It may be possible for research into the disabilities that affect people who hoard or live in squalor to be included under this research agenda.

3. NSW Mental Health Research Framework

Recent national plans and reviews, such as the Fourth National Mental Health Plan (NMHP4) and the National Health and Hospital Reform Commission (NHHRC), emphasise the need to focus on translational and multidisciplinary research practice. The NMHP4 adopts a population health framework, recognising that mental health and illness result from the complex interplay of biological, social, psychological, environmental and economic factors at all levels. Under this Plan, research and evaluation will cover relevant areas such as:

- effectiveness of treatment
- community support services
- service coordination models
- prognosis and course of illness.

With the intention of delivering high quality research that is relevant to policy and practice, the Mental Health Research Framework will consider proposals that address specific mental health issues. In light of the fact that hoarding is now included in the DSM V as a disorder, there may be an opportunity to seek funding into hoarding disorder in Australia.

In addition, the frameworks priority of improving the translation of research into practice may also create another opportunity to explore treatments and effective intervention. As knowledge builds and a cohesive evidence base develops, information should be disseminated in a manner that is most likely to influence individual outcomes for people with mental health problems and mental illness. Research should focus on enhancing the capacity of the mental health sector to address gaps and improve service delivery through synthesis, dissemination and utilisation of new knowledge. Existing evidence should be assembled, and gaps in the evidence should receive particular research and evaluation attention.

The onus to ensure clear linkages and alignment with research agenda priorities lies with relevant interested parties, however government support for investigation into the causes, treatments and intervention framework would go a long way to securing an evidence based national framework for people and their pets affected by Hoarding and Squalor.

8.3 Safety and wellbeing issues of children living within an environment of hoarding and squalor

In Australia, there have been no formal studies around the prevalence, impact or safety issues facing children living within an environment of hoarding and squalor. Neglect is the second highest substantiated

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107 NSW Ministry of Health & Mental health and Drug and Alcohol Office. NSW Mental Health Research Framework. Updated February 2012.
harm type in NSW; where neglect refers to the failure (usually by the parent) to provide for the child’s basic needs, including failure to provide adequate food, shelter, clothing, supervision, hygiene or medical attention. Neglectful behaviours can be physical, emotional, educational or environmental (Child Family Community Australia, 2012). It is reasonable to expect that children who have come to the attention of formal services would be represented in these figures. It is important to remember however, that these figures represent only those children who have come into contact with child protection services.

Anecdotally, a Family Referral Service in the Illawarra region state that 1 in 10 families referred to their service has some issue with hoarding and squalor. This equates to about 800 families per year. The hoarding and squalor is more often than not linked to a mental health condition and usually comes to the attention of formal services following extended non-attendance periods of the children at school. The safety concerns that have been seen include: weapons in the backyard, broken glass and metal sheets, vermin and associated excreta, no personal space within the house, utilities turned off due to non-payment of bills and social isolation enforced by parents who do not want anyone in their home environment.

According to the World Health Organisation, due to their size, physiology, and behaviour, children are more vulnerable than adults to environmental hazards. Children are more heavily exposed to toxins in proportion to their body weight, and have more years of life ahead of them in which they may suffer long-term effects from early exposure.

Children under age 5 breathe more air, drink more water, and eat more food per unit of body weight than adults do, so they may experience higher rates of exposure to pathogens and pollutants. Typical childhood behaviours, such as crawling and putting objects in the mouth, can also lead to increased risks.

It is reasonable to assert that household environments that involve hoarding and squalid environments in children’s living areas present the following risk to health and wellbeing:

- Air pollution (indoor and outdoor) – resulting in increased cases of asthma, allergies, headaches and acute respiratory infections;
- Unsafe drinking water and poor sanitation – resulting in a range of diarrheal diseases and gastroenteritis, poor nutrition and personal hygiene;
- Infectious diseases as a result of insect and vermin infestations;
- Potential exposure to hazardous chemicals dependant upon the type of clutter in the environment, resulting in poisonings and burns;
- Physical safety threats including hoarding of fire-arms and weapons, rusty metals, needles, and other sharp objects;
- Unpredictable and potentially volatile emotional behaviours from caregivers due to their own anxieties about changes in their environment and interventions to remove their clutter.

It is confusing growing up with an authority figure who has distorted beliefs about objects or animals. It is hard to understand getting in trouble for putting things in the garbage, being reprimanded after the item is retrieved. The reality at home often seems different from the reality at school/outside. Children struggle to process a lifestyle where they compete for a parent’s attention in a house overrun with animals.

Where hoarding is a symptom, often there are undiagnosed personality disorders as well. Many of us held our breath at the sound of the doorbell because we learned “you aren’t supposed to let people IN.” As adults, many of us still carry that shame with us, even though we’ve moved away. (Phrase coined in our support group in ’06 for this: “Doorbell Dread.”)

Even if it’s not true, to a child’s mind, it can appear that the parent suffering from this disorder values objects or animals more than the child.

Because this disorder is often fuelled by anxiety, a Hoarder can express an extreme range of (usually negative) emotions when anyone tries to clean up, when things are touched or moved. This is difficult for a young mind to understand. In addition, unhealthy perfectionism is a large part of the hoarding disorder, and those standards are often hard to live up to.

‘Keep Them Safe’ is the NSW Government’s response to the Wood Special Commission of Inquiry into Child Protection Services in NSW, which was established on 14 November 2007. Part of the reform included the development of Mandatory Reporter Guidelines; a structured decision making system; to assist mandatory reporters who have become concerned about possible abuse or neglect of a child/young person and must make a decision whether or not to report their concerns to the Child Protection Helpline.

The decision tree most relevant to children affected by hoarding and squalid environments is physical shelter/environment represented in Figure 12.

The decision tree refers to illness and injury as a result of environmental conditions, allowing for a report to be made on this basis for children living in hoarding and squalor environments.

The limitations of the current data available including some data embedded in some contexts does not allow for an accurate picture of the safety and wellbeing issues faced by children living within hoarding and squalor environments in the Australian context. Anecdotally and internationally there are basis for investigation in Australia, however there are also a number of unanswered questions about impact on parenting, learned behaviours, effective interventions and child protection issues. Opportunities for agencies that are already supporting children living in these environments by default to improve their skill set, receive support through a systematic and coordinated approach to intervention promoted by relevant government child protection authorities; can enable a thorough investigation of the situation for children in New South Wales and indeed, Australia. These areas of investigation will further lead to a more robust National Framework response to enable delivery of more effective services to people and their pets affected by hoarding and squalor.

*For reports concerning a young person (aged 16 or 17) who is homeless, his/her consent is necessary prior to making a report.

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110 Children of Hoarders: Awareness, Understanding and Support for COH. www.childrenofhoarders.com
8.4 Effective responses for families and carers

Data from a snapshot of service referrals to Catholic Community Services NSW/ACT Living conditions program in Hunter, NSW showed that 59% were living alone. The remaining 31% identified as co-habitating with children, partner, spouse and/or other non-related person. Again, there has been no significant data collection or research to enable an accurate picture of the impact upon families and carers in Australia.

For those family members who live with a hoarder, such as a wife, husband, child, or older dependent parent, it is impossible to live amongst clutter while avoiding the harmful physical and emotional trauma. Not only the clutter, but the hoarder's need to control all items and areas of the home causes extreme friction and tension.

A primary area of contention is that clutter often results in a loss of once functional living space, even in communal areas (e.g. kitchen, living room, etc.). Financial strain also results from compulsive acquisition associated with hoarding, and the need to acquire additional storage facilities (chests, lockers, garages, sheds, etc.). Compulsive acquisition, or compulsive shopping, is also a major source or friction. It can lead to debt; purchases are often not discussed; credit cards may be “maxed out”, and money therefore cannot be allocated to purchases that other family members may desire or require.

Not only do hoarders often claim areas within regions of the home that are reserved for other family members, but the control of how that space is used or what items should be discarded is frequently at the hoarders discretion. Family members lack control in decision making, which leads to feelings that family members are living in someone else’s home, causing discomfort and disrespect. Commonly, family members will get so frustrated with clutter that they will attempt to clean or organize without the consent of the hoarder, which invariably results in additional arguments and fights.111

Relationship breakdown is thus assumed as one of the most common factors for families and carers of people who hoard or live in squalor. Family members experience resentment, embarrassment and potential be blamed for any deterioration of the relationship. This causes significant psychological distress and often impacts their future relationship behaviors. Adult children of hoarders or those who live in squalor often distance themselves significant once they are old enough to leave the family home and thus often have a strained and estranged relationship with their parents due to the way they were forced to live as children.

The family member who is a caregiver for an independent aging parent (or other elderly family member) has additional worries when Mom or Dad is a compulsive hoarder. Aging adults tend to have mobility problems and poor eyesight. When an aging senior has to climb over piles and piles of “stuff” to get from one room to another, the situation becomes dangerous. There are other unhealthy situations that result from hoarding.112

As with children living with a hoarder or in squalor, adult family members can also be significantly affect ed by the conditions in the home. For instance, compulsive hoarders and their families often experience headaches, respiratory problems (asthma, etc.), and allergies, due to living conditions associated with a hoarder’s lifestyle. As clutter develops and is maintained, it becomes impossible to remove accumulated dust from spaces that are most affected primarily because people are not able to vacuum or dust their homes, sometimes for years. Additionally, spilled liquids such as, soda, juice, and water are often not cleaned up causing mildew, fungus or infestations. Health-related effects of hoarding reach all members of the household, not merely the hoarder, him/herself.

Excess clutter may cause other issues related to safety. It is common to have such excessive clutter that pathways need to be constructed through the clutter in order to navigate through the home. These pathways may become obstructed by fallen or new clutter, which can result in people tripping, slipping and falling. Not only is this an impact on those that are physically able, but may impose an even greater threat for an older dependent parent that is living in the home and that may lack mobility. Furthermore, if clutter blocks entryways or access to fire extinguishers, members of the household will not be able to take action,

112 How can an Adult Child Help a Hoarding Elderly Parent? http://www.suite101.com/content/elderly-compulsive-hoarding-means-extra-worries-for-caregivers-a255671#ixzz1CahPVPsL
should a fire start. Additionally, during a fire, burning materials may fall, creating a trapping hazard, interfering with firefighters being able to save the people from the home and increasing their chances of danger. Furthermore, toxic fumes emitted from the flammable materials may create further health problems for all those who are exposed.113

Family members and carers of a person who hoards or lives in squalor are under further pressure to understand the emotional and psychological factors involved in their family member’s living environment. Family members and carers are often overwhelmed and often don’t know where to seek help. An understanding of realistic change and expectations is often an area of support for the family or carer as they have reached their breaking point and need to see action now.

Some carer support groups have formed in Victoria under small grants from local regional council to provide support and practical strategies for those affected by hoarding. Topics such as managing anxiety, motivation and how to maintain it are part of the session plans. New South Wales does not currently operate carer support groups for carers and family members affected by hoarding and squalor.

With informal carers providing the bulk of the care support to people with a disability, mental health issue and the elderly, this group of people desperately need support to manage the more complex needs of their caring roles and require consistent, adequate resources to manage their responsibilities and maintain positive relationships with the people they care for. Across NSW there are 849,700 carers, that is 12 per cent of the NSW population. There are 2.6 million carers Australia-wide.114 So, even if one third of the estimated people affected by hoarding and squalor (0.02% of the population) across the country have a carer, we are looking at over 156,000 carers who will be experiencing the complex relational, safety and wellbeing issues associated with supporting someone affected by hoarding and squalor.

8.5 Government Leadership

8.5.1 Establishing a dedicated political portfolio

The complexity of the issues surrounding people and their pets affected by hoarding and squalor touch a variety of current political portfolios; both at a State and Federal level; including:

- Homelessness;
- Health and Ageing;
- Housing;
- Attorney Generals;
- Disability;
- Social Inclusion; and
- Child protection.

However, no one portfolio is poised to assume responsibility for the overarching framework, guidance and dedicated resources to support this issue. Responses to coordination and collaboration of services (government, non-government, community and private) have been driven largely by localised need, limited community resources and organisational capacity. Thus, responses are ad hoc; dependant upon motivated and passionate individuals; often unfunded and a financial burden to the responding agency; and potentially unsustainable over any extended period of time.

Hoarding and squalor have the ability to touch many reform agendas and action plans currently in existence across State and Federal governments, for example:

- **COAG National Partnership Agreement on Supporting Mental Health Reform** – the investment in accommodation support and a better response to the needs of people with severe and debilitating mental illness echo the needs of many people affected by hoarding and squalor.

- **NSW State Homeless Action Plan** – the strategic priorities of preventing homelessness, responding effectively to prevent system entrenchment and breaking the cycle are all relevant priorities and often the experience of people affected by hoarding and squalor.

• National Disability Strategy – all six priority areas for action to improve the lives of people with disability, their families and carers have a strong synergy with the disabling condition hoarders and people who live in squalor face. Strategies that promote inclusion and access; protection and legislative support; economic security; personal and community support; learning and skill development; and health and wellbeing are also central to an effective response for people affected by hoarding and squalor.

• National Framework for Protecting Australia’s children – under this framework child protection is everyone’s business and the highest level of collaboration between Commonwealth, State and Territory governments and non-government organisations to ensure Australia’s young people and children are safe and well.

Establishing a political portfolio dedicated to developing and supporting effective pathways of intervention for people and their pets affected by hoarding and squalor will create the opportunity for the development of an overarching framework for support including:

  • A platform for legislative change;
  • Community education;
  • Policy development for responding agencies;
  • Agreed and documented agency roles and responsibilities in the solution;
  • Standardised guidelines for local area response expectations;
  • Adequate and suitable allocation of funding;
  • Allocation of suitable resources for framework implementation and ongoing monitoring;
  • An opportunity for centralised data collection and client outcome measurement;
  • Performance indicators that can contribute to mental health, disability, homelessness and social inclusion portfolio outcomes.

8.5.2 Taskforces and local protocols
There are 85 hoarding and/or squalor taskforces in the United States, Canada and Australia at the present time with more developing each month. The regularity with which hoarding adversely impacts those who hoard and their families and communities suggests that an encompassing, community response is needed. Collaborative partnerships often referred to as coordinating councils, task forces or coalitions (Allen 2005), are useful approaches for resolving community problems through a multidisciplinary approach (Roussos & Fawcett 2000). These groups provide an avenue for community stakeholders to work collectively to advance community-level change (Allen 2005). Such partnerships have been used to address social problems such as domestic violence, criminal activity, child abuse and educational achievement (White 1997, Allen 2005, Brewer et al. 2007). Bratiotis116 has identified three models of hoarding taskforce structure:

  • Education – primary purpose to provide education about the problem of hoarding and appropriate interventions. Can be internal education for an agency or taskforce members and is often the mechanism for dissemination of latest research and best practice.
  • Case Consultation – primary purpose is for taskforce members to discuss cases and receive feedback and input. This structure allows for professional support and promotion of best practice.
  • Direct Intervention – primary purpose is for taskforce to serve as the intervention/response mechanism for hoarding cases in a given community. This structure allows for a coordinated response and promotes a central point of contact for the community.

Given that any coordinated response to people and their pets affected by hoarding and squalor is in its infancy in Australia, the primary purposes of all three models of taskforce structure are required to ensure a quality, consistent, evidence-based framework for national implementation.

Interestingly, the success of taskforces across the United States has been linked to the initiative being driven by a government Human Services agency; for example, the local council, department of health, depart-

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ment of ageing and disability etc. The decision of individuals or organisations to join a hoarding task force was driven by one of the following goals: to meet the demands of hoarding cases, share professional expertise, and reduce frustration and to influence systems and policies in their communities.\textsuperscript{117}

The taskforces are often well positioned to improve services by supporting changes in agency and community policies; creating a single point of entry and system of care for hoarding cases; supporting early identification and intervention; reducing stigma, shame, and isolation; and better using professional expertise in the community.

Taskforces across the country have identified a range of community best practices for addressing compulsive hoarding. For example, having clear housing department laws and regulations can be valuable because they can provide a baseline for working with people with hoarding behaviours. If there are clear written standards about what constitutes a hazard and what kinds of conditions can result in public intervention, people attempting to ameliorate their clutter have clear benchmarks for reducing hazards.

Cross-agency coordination and/or multi-disciplinary teams are widely recognized as valuable. Many taskforces addressing compulsive hoarding were developed as a vehicle for different stakeholder agencies to improve communication, better understand one another’s perspectives and roles in working with people with hoarding behaviours, and coordinate responses and resources in difficult cases. Confidentiality requirements can sometimes be a barrier to such coordination, but models for working together effectively while protecting confidentiality do exist.

Clear systems for channelling cases, ensuring that diverse stakeholders have a clear understanding of which agencies to call for assistance, and having simple forms to enable fire and police department personnel to report cases to relevant social service providers have all also been identified as best practices. Determining which first responders are most appropriate to enter a home in which hoarding may be causing a serious hazard or violation is also important. For example, in one city, the fire department is called because fire personnel are perceived more positively than police.\textsuperscript{118}

In NSW, there are a number of existing supported housing partnerships such as the Housing and Accommodation Support Initiative which is a partnership between FACS Housing NSW and NSW Health. Another partnership is the coordination of services for homeless people under the National Partnership Agreement on Homelessness (NPAH). These partnerships have demonstrated the success of local protocols emerging from a direct intervention structure, commitment to responsible action and coordination of expertise to optimise resources and ensure a quality response.

Local protocols, supported by an overarching framework, enable a local district area to ensure that the implementation of these collaboration agreements are reasonable within the individual community context, the regions resources and relevant to the services and agencies expected to participate.

**8.5.3 Cost effectiveness of specialist and multi-agency approach**

Whilst it is difficult to describe and quantify the absolute impact of hoarding and squalor some calculation extrapolations can be estimated and case studies can demonstrate the cost effectiveness of providing a coordinated multi-agency approach.

The below case study will present the costs associated with a Living Conditions Intervention based on costs comparable with the Hunter Living Conditions Pilot Project compared with the consequential costs of not providing the intervention based on limited reportable data from other agencies.

\textsuperscript{117} Bratiotis, C (2013) Community Hoarding task forces: a comparative case study of five task forces in the United States. Health and Social Care in the Community. Vol 21(3), 245-253

\textsuperscript{118} Bratiotis, C. (2008) cited in San Francisco Taskforce on compulsive Hoarding (2009) Beyond Overwhelmed: The Impact of compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services.
CASE STUDY: MR P

Mr P is a 79 year old male living alone in public housing managed by Housing NSW. Mr P was referred to the Living Conditions project by Community Mental Health and Community Drug and Alcohol support. Mr P has deteriorating health, poor mobility and is at tenancy risk due to his living conditions. Mr P has a fall in the local park and is transported to hospital. Mr P’s treating doctor does not want to discharge him home as his living arrangements will not support his health and deteriorating mental health needs. Mr P’s decision making skills have diminished and he is placed under the OPC for all financial, health and accommodation decisions. Mr P was supported by the Hunter Living Conditions for a period of 79 days to achieve safe, secure and appropriate housing. Housing NSW terminated Mr P’s tenancy once he received a residential placement and had to renovate and repair the unit before further occupancy with another tenant was possible.

TABLE 3: Costs associated with Mr P’s Service Intervention

<table>
<thead>
<tr>
<th>TYPES OF COSTS</th>
<th>INTERVENTION</th>
<th>NO INTERVENTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Coordination Costs</td>
<td>30 hours</td>
<td>$915</td>
</tr>
<tr>
<td>Administration</td>
<td>20 hours</td>
<td>$610</td>
</tr>
<tr>
<td>Assertive Outreach hours</td>
<td>10 hours</td>
<td>$305</td>
</tr>
<tr>
<td>Linen replacement, some furniture</td>
<td>–</td>
<td>$1200</td>
</tr>
<tr>
<td>replacement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ambulance transfer</td>
<td>1</td>
<td>$300</td>
</tr>
<tr>
<td>Clinical Outreach Assessment costs</td>
<td>4 hours</td>
<td>$300</td>
</tr>
<tr>
<td>Hospital Inpatient stay</td>
<td>6 weeks</td>
<td>$32,884.61</td>
</tr>
<tr>
<td>ACAT Assessment</td>
<td>2 hours</td>
<td>$150</td>
</tr>
<tr>
<td>Housing NSW costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forensic Clean</td>
<td></td>
<td>$2227.81</td>
</tr>
<tr>
<td>Carpet replacement, fumigation,</td>
<td></td>
<td>(based on av cost experienced by HLC Forensic Cleans)</td>
</tr>
<tr>
<td>repainting, fixture repairs,</td>
<td></td>
<td>$2569.66 (online quote based on 90sqm)</td>
</tr>
<tr>
<td>complaints management (CSO hours – 10)</td>
<td></td>
<td>$800 (online Quote)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$4000 (online quote based on 2 bedroom home)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$1000 (approx cost)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$270</td>
</tr>
<tr>
<td>Centrelink costs</td>
<td>12 social worker hours</td>
<td>$540</td>
</tr>
<tr>
<td>Emergency payment (1)</td>
<td></td>
<td>$500</td>
</tr>
<tr>
<td>Consumer, Traders Tenancy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribunal costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal Representation</td>
<td></td>
<td>$250</td>
</tr>
<tr>
<td>Tribunal application costs</td>
<td></td>
<td>$33</td>
</tr>
<tr>
<td>Crisis accommodation costs</td>
<td>3 months</td>
<td>$12,420</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$57,945.08</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>$3,300</td>
<td>$57,945.08</td>
</tr>
</tbody>
</table>

119 Includes Guardianship applications, collection of evidence to support clinical assessments and applications for residential care
120 This is the time taken to engage the client in the project intervention
121 An average acute bed costs $285 000 per annum as per NSW position on relieving pressure on NSW public hospitals.
122 (2009) NSW Health Reform
Mr P’s case study clearly indicates the costly consequences of irretrievable living conditions. Once an individual’s living conditions require a forensic clean, it is common that other repairs and replacements will be necessary and this can become a costly experience for Housing NSW if more than one clean is required where no service support has been engaged. The cost to the health system is also considerable when inpatient costs, clinical outreach costs and emergency services costs are factored in. The homelessness services sector also bears a costly responsibility should the client then become homeless.\textsuperscript{123}

There are psychological and financial impacts for individuals, families, carers, service providers and the community. The table below summarises some of these impacts but it is important to note that this is by no means an exhaustive list.

<table>
<thead>
<tr>
<th>POTENTIAL IMPACT</th>
<th>PSYCHOLOGICAL IMPLICATIONS</th>
<th>FINANCIAL IMPLICATIONS</th>
<th>REFERENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children can have elevated rates of distress, find it more difficult to make friends, experience an increased strain on family life and feel embarrassed about the condition of their home.</td>
<td>✓</td>
<td></td>
<td>Tolin et al 2008</td>
</tr>
<tr>
<td>Individuals can feel as though they have lost normality in their life.</td>
<td>✓</td>
<td></td>
<td>Wilbram et al 2008</td>
</tr>
<tr>
<td>Individuals can experience anger and frustration. This can subsequently result in family breakdown.</td>
<td>✓</td>
<td></td>
<td>Wilbram et al 2008 &amp; Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>Individuals can feel marginalised, resulting in social withdrawal and isolation (especially with neighbours).</td>
<td>✓</td>
<td></td>
<td>Wilbram et al 2008 &amp; Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>Increased risk of eviction.</td>
<td>✓</td>
<td>✓</td>
<td>Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>Carers can feel alienated from service providers because they feel unheard and misunderstood.</td>
<td>✓</td>
<td>✓</td>
<td>Wilbram et al 2008</td>
</tr>
<tr>
<td>Increased risk of injury and illness (e.g. from falls).</td>
<td>✓</td>
<td>✓</td>
<td>Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>Increased risk of fire.</td>
<td>✓</td>
<td>✓</td>
<td>Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>Rubbish removal / clean-ups</td>
<td>✓</td>
<td>✓</td>
<td>Mental Health Association of San Francisco 2009</td>
</tr>
<tr>
<td>The use of service provision from government and nongovernment agencies.</td>
<td>✓</td>
<td></td>
<td>Mental Health Association of San Francisco 2009</td>
</tr>
</tbody>
</table>

\textsuperscript{123} Case Study provided by Catholic Community Services – NIB Hunter Living Conditions Pilot Evaluation (September, 2010)  
\textsuperscript{124} SA Health (2013) A Foot in the Door - Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia. (Draft) Prepared by Health Protection Programs, Public Health Services, Public Health and Clinical Systems and Department for Health and Ageing on behalf of the Chief Public Health Officer
Bratiotis (2012) comparative case study of five hoarding taskforces in the United States found taskforce involvement appeared to help with cost containment:

‘We’re no longer spending funds to do cleanouts because we know now that isn’t a solution, just money wasted.’

Many agencies also reported a cost saving because of collaborations; one member noted:

‘Instead of assigning each one of us our own case on the same place, not everybody is running out to the same house for the same thing at the same time...It is time and cost effective also.’

Although there has been no formal cost benefit analysis conducted in Australia with delivering specialist and multi-agency approach services, if we use the case study of Mr P, the cost comparison is abundantly clear – the cost to provide a specialist service who coordinates all other agency responses was less than 6% of the expected costs than if there is no coordination and agencies respond individually.

Further, if we take the indicative data from prevalence studies in the US, UK and OECD countries then between 400,000 and 1.1 million Australians may be affected by hoarding and squalor and in need of help. Then if all affected by hoarding and squalor receive one intervention; on average $3000 per intervention; then the national cost of responding is between $1,200,000,000 - $3,300,000,000 to support the entire population. However, service experience and research has shown us that people affected by hoarding and squalor will only come to the attention of formal services when there is a point of crisis and then not all are willing to participate in support options, these intervention costs will depend upon the level of consent offered by the client.

### 8.5.4 Benefits of early intervention

The development of an overarching response framework for effective response needs to include guidance and opportunities for first responders to develop the confidence to make an assessment upon entering a person’s home whether or not service referral at this stage could be a preventative strategy in reducing the future risk of intensive and essential service intervention. For example; NSW Fire and Rescue utilise the Image Clutter Rating Scale when assessing a home for additional fire load; if the scale scores a 4 or under the department do not need to act; however anything above a 4 is flagged as an alert on their notification system. However, initiating a referral to support services; with the consent of the person; when the environment is scoring a 4 could prevent the score ever progressing beyond that rating and immediately reducing the risk to the occupant.

Similarly, animal welfare agencies involved in in-home support to elderly pet owners and pets of people at risk of homelessness can also provide a monitoring role to ensure that any deterioration in the environment for the pets warrants a referral to support services for the pet owner.

The San Francisco Taskforce on Hoarding completed a comprehensive costing and mapping exercise of service interventions in San Francisco in 2009. The results include a cost comparison of providing services at an early intervention stage; both financial and social; and how the costs can increase significantly should the scenario change. This model of cost benefit analysis would be useful to replicate in the Australian context; however the San Francisco example has many similarities in cost type likely to be experienced in Australia. The San Francisco Hoarding Taskforce paper includes many of the research tools it utilised to gather the cost data for it’s comparisons that will be relevant or easily adaptable for Australia.

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125 Bratiotis, C (2013) Community Hoarding task forces; a comparative case study of five task forces in the United States. *Health and Social Care in the Community.* Vol 21(3), 245-253
FIGURE 13: San Francisco taskforce on hoarding social and financial costs example

EXAMPLES OF FINANCIAL AND SOCIAL COSTS OF HOARDING AND CLUTTERING*

Stuff piles up for “Chris.” The fire exit is blocked and items are piled on the stovetop, causing a fire hazard. Chris becomes isolated. He feels panic, shame, and denial about his situation and doesn’t know what to do.

The apartment heater stops working due to heavy boxes stacked on it. To get it fixed, Chris calls the building manager. Before the manager comes, Chris cleans, but not enough to hide the clutter. The building manager enters and repairs the heater, but recognizes that there’s a larger problem with fire and safety hazards and is concerned about pest infestation.

The building manager reenters the unit to deal with the pest infestation.

The manager knows about compulsive hoarding and uses the roadmap to contact the single point of entry. She gets advice on service options available.

The manager is able to give Chris clear written standards about how to come into compliance and encourages him to call the single point of entry.

Chris is stressed and afraid, and refuses help.

The landlord launches eviction proceedings.

Social services contact Chris and attempt to intervene. Chris receives legal assistance to secure reasonable accommodation.

Chris accepts some heavy cleaning over protest. He stays in his housing but is still at high risk to repeat the process.

The stress has impacted Chris’s health and he is now more afraid and isolated.

The landlord pays for pest control.

The landlord pays for cleaning and pest control and loses rent.

Chris contacts the single point of entry for services.

The assessment team responds and connects Chris with support and treatment group services.

After joining a support group, Chris slows his rate of acquiring and manages to clear a path to the emergency exit.

Chris joins a treatment group and eventually clears the top of his heater and stovetop.

Chris is stressed and afraid, and refuses help.

The landlord launches eviction proceedings.

Chris accepts some heavy cleaning over protest. He stays in his housing but is still at high risk to repeat the process.

The stress has impacted Chris’s health and he is now more afraid and isolated.

The landlord pays for pest control.

The landlord pays for cleaning and pest control and loses rent.

Chris sees the public education and outreach on compulsive hoarding.

The building manager reenters the unit to deal with the pest infestation.

The manager knows about compulsive hoarding and uses the roadmap to contact the single point of entry. She gets advice on service options available.

The manager is able to give Chris clear written standards about how to come into compliance and encourages him to call the single point of entry.

Chris is stressed and afraid, and refuses help.

The landlord launches eviction proceedings.

Social services contact Chris and attempt to intervene. Chris receives legal assistance to secure reasonable accommodation.

Chris accepts some heavy cleaning over protest. He stays in his housing but is still at high risk to repeat the process.

The stress has impacted Chris’s health and he is now more afraid and isolated.

The landlord pays for pest control.

The landlord pays for cleaning and pest control and loses rent.

COST TOTAL: $2,607 for one year of services

COST TOTAL: $4,316 for one year of services ($484 to landlord, $3,832 to social services)

COST TOTAL: $5,662 per occurrence ($1,484 to landlord, $4,178 to social services), high risk of repeat occurrence

COST TOTAL: $36,880 per occurrence ($26,480 to landlord, $10,400 to social services), high risk of repeat occurrence

* This example does not include animal hoarding, which requires assistance from additional agencies, such as Animal Care and Control.

© 2009 San Francisco Task Force on Compulsive Hoarding

126 San Francisco Taskforce on compulsive Hoarding [2009] Beyond Overwhelmed: The Impact of compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services
8.5.5 Flexible funding arrangements
One of the barriers often faced by people supported by services is the restraints placed upon agencies due to geographical boundaries, rigid service specifications and funding arrangements. Whilst all of these boundaries are often required to monitor, evaluate and administer service contracts, they can often exclude people from receiving services, limit the amount of services a person receives, not provide the right level of service or have such long waiting lists that service provision is an intangible dream.

The complex needs of hoarding cases call for the coordination of care. Agencies that share responsibility for various tasks can maximise efficient division of labour to manage limited budgets. In addition, how the person who hoards perceives the role of service providers can aid greatly in attaining positive outcomes. By their nature and function, some disciplines (e.g. social work and nursing) can take roles as friendly helpers, whereas others can serve as regulators (e.g. housing code enforcement, fire safety). When coordinated, these positive and negative official roles can be effective in resolving hoarding (Bratiotis et al. 2011). Thoughtful coordination of hoarding services allows a cross-pollination of information and ideas, collegial support and a comprehensive conceptualisation of the client’s hoarding problem from multiple perspectives. Evaluating the person with hoarding through different professional lenses is most likely to produce a successful response that addresses important needs in each case.127

An overarching response framework needs to include the provision for extension and expansion of services where collaboration with local agencies still sees a service gap that could be provided if funds, resources, limitations of geography were all mitigated.

8.5.6 Triage and the Road Map
One of the recurring messages from service providers in NSW is that they don’t know where to go when it comes to supporting someone who hoards or lives in squalor. In order to assist first responders and other agencies unfamiliar with available guidelines, the San Francisco Hoarding Taskforce proposed the development of a road map and a single point of entry (triage).

A proposed services roadmap has been created, and the Department of Aging & Adult Services Intake Screening Unit is proposed as the single point of entry to streamline services and enable people with hoarding behaviours, their families, service providers, and landlords to follow the services road-map and access needed information and services. The unit would provide referrals and information for people with hoarding behaviours to help support their current level of independence and functioning. The intake unit would be knowledgeable in all community and institutional services for seniors and adults with disabilities, regardless of their economic status. Informing the general public and key audiences such as landlords and service providers about the roadmap and single point of entry would also be essential.128

128 San Francisco Taskforce on compulsive Hoarding (2009) Beyond Overwhelmed: The Impact of compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services
8.6 Development of guidelines to support service delivery

A key aspect of effective service delivery is an understanding of the presenting issue, recommended intervention strategies derived from an evidence base, standardised documentation, communication protocols, documented referral pathways, risk management, practice guidance enhanced by current research and recommended education and training to support field workers. Development of state-wide guidelines to support service delivery across human service, emergency and justice service portfolios, tenancy and landlord associations and private organisations should enable consistent and standardised, and thus comparable approaches to effective pathways for people and their pets affected by hoarding and squalor.

The NSW Local Government Conference 2013 proposed to advocate to the NSW Government to develop policy, guidelines and intergovernmental approach to enable councils, relevant state agencies services and community organisations to assist residents who have significant issues of squalor and hoarding as a key theme strategy. This message was echoed in the Parliamentary inquiry into the Management and Disposal of Waste on Private Lands in October 2013 at Sydney Parliament House. Catholic Community Services, Professor John Snowdon (Sydney Local Health District) and Mr Steve Coleman (CEO – RSPCA) were invited to comment to the parliamentary committee based on their experience and expertise in the support and management of cases of hoarding and squalor.

As well as initiatives undertaken in 2002-3 in NSW, leading eventually to the publication of guidelines for intervention in the cases of squalor in 2006; Victoria has dedicated time and resources to invest in a coordinated approach to supporting people affected by hoarding and squalor. The Victorian Department of Health produced a Discussion Paper in 2012 mapping the current service responses, the gaps in delivery and recommendations for best practice based on an existing evidence base from national and international models. Numerous private and public services and Victorian government Departments contributed their expertise in developing a practical resource available to any “first responders” and provides advice, guidance and structure for effective intervention when supporting those who hoard or live in squalor. The table of contents from the Hoarding and Squalor: A practical resource for service providers, June 2013, demonstrates the breadth of relevant areas covered and is certainly replicable in NSW. (See Appendix 5) In addition, the South Australian ‘A Foot in the Door’ draft guidelines are an opportunity to develop a NSW edition also removing value-based assessments by promoting a consistent, supportive, and risk based identification and management framework, acknowledging that different people have different living standards.

Existing tools and resources in NSW can be updated and expanded to meet the need for standardised guidelines across the state. As discussed in the Tools and Resources section, a number of local councils and non-government agencies in NSW have adapted and promoted local protocols utilising the “Guidelines for the Field Staff to Assist People living in Severe Domestic Squalor”; promoted by Department of Ageing, Disability and Home Care (ADHC), as the backbone of the intervention guidance. There is an opportunity in light of the work completed in Victoria for the further development of these guidelines to enable state-wide applicability.

Work Health and Safety (WHS) concerns and risk management often present difficulties for services to manage and can create barriers to service access due to the hazardous environment. Recommendations from “Hoarding and Squalor: A practical resource for service providers” state: that all relevant organisational policies and procedures apply, including occupational health and safety considerations. However, should there be occupational health and safety concerns; these should not be used as a reason for not responding to hoarding and squalor situations. Additional planning and resourcing involving consultation with other services – both public and private – could be beneficial to find a means to move forward in a different way than might usually have been considered.

These cases often challenge the way service response is considered and planned for, particularly when such environments are difficult to navigate and work in. It is important to provide staff with the necessary tools and equipment to undertake this work to ensure their cleanliness, health and safety.129

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129 Victorian Department of Health (2013) Hoarding and Squalor – A practical resource for service providers
Thus, it is evident that practical steps to identifying safe work practices and risk minimisation utilising relevant state and federal legislation are identified and documented in any NSW Guidelines.

First responders to situations of hoarding and squalor may not be trained in therapeutic approaches and assessment in order to manage a first meeting with a client who hoards or lives in squalor. One of the key features of the guidelines developed in NSW under the Partnerships Against Homelessness initiative and also the Victorian Guidelines is the some educative material around how a person living in these circumstances may present and possible underlying issues in the effort to provide some insight into the situation and enable a appropriate and respectful response. However, many employees of government and non-government agencies are calling for resources for continued professional development in this area to support worker engage and respond more effectively with people affected by hoarding and squalor. Investment in further professional development to a larger workforce will enable the specialist service to focus upon the most severe cases and transfer their knowledge to other services to manage the less severe cases of hoarding and squalor.

In addition, given that many people affected by hoarding and squalor also experience mental health issues, possible cognitive disability and information processing deficits; additional professional development and ongoing training relating to supporting capacity assessment and trauma informed care principles would further equip workers to provide a quality and effective intervention.

Further development of NSW Guidelines to support people and their pets affected by hoarding and squalor will prevent the re-invention of the wheel and improve cost effectiveness and expedite resolution of problems.
9. Conclusion

Despite the paucity of empirical data, it is clear from the presentation to a range of human and community services, that people and their pets affected by hoarding and squalor is prevalent in NSW. Given the complexity of the underlying issues that accompany hoarding and living in squalor behaviours, no one agency has taken the lead in coordinating a state-wide approach. It is clear that a range of professionals from various disciplines are likely to respond in cases of hoarding and squalor; and that these professionals need the support and training of a agreed common service response framework to ensure a full understanding and appropriate approach to protecting the safety and health of the individual concerned, their pets, family members and neighbours.

NSW would benefit from an agreed overarching response framework that encompasses multiple sectors, disciplines and legal jurisdictions. The overarching response framework needs to be supported and resourced at a government level to ensure consistent quality implementation across NSW and should include a strong professional development component for professionals across all sectors. Specialist services need to focus on the most severe cases and other human services professionals require the confidence, skills and understanding to competently respond to people and their pets affected by hoarding and squalor.

A number of agencies have attempted to develop their own local protocols and coordinated service response based on work completed under the auspice of Department of Ageing, Disability and Home Care in 2007. A number of agencies have emerged as specialist in the area, but are limited in their reach due to funding and geographical boundaries. Identifying a central lead coordinating point in each region; one that has capacity to provide a complex care coordination role offers the opportunity for effective and efficient case coordination. Further development to the guideline work completed for field staff is required to ensure quality, adequate and consistent guidance, tools and data collection methods to contribute to a more robust evidence base. Hoarding and Squalor: A practical resource for service providers, June 2013, developed by the Health Department in Victoria is a relevant starting point to amend for the NSW context.

A number of evidence areas and data gaps have emerged that will require a more thorough investigation and research to ensure that the overarching service response framework is relevant and functional for operational staff and policy makers. These include:

- Prevalence data;
- Research to support clinical and community intervention practices;
- Actual costs associated with providing intervention services compared with community, system and individual costs of not intervening;
- Further comprehensive service mapping;
- Impact research on children, family members and carers of people who hoard or live in squalor.

This paper represents only the tip of the iceberg when it comes to identifying pathways to deliver more effective services to people and their pets affected by hoarding and squalor. Similarly, taskforces and working parties across the nation and internationally are grappling with solutions to this complex issues, however it is clear that the most successful results emerge when government departments, non-government agencies and community service providers work collaboratively, take responsibility for their part in the solution and cooperate with other involved agencies.
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San Francisco Taskforce on compulsive Hoarding (2009) *Beyond Overwhelmed: The Impact of Compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care*. Prepared by the Mental Health Association of San Francisco and sponsored in part by a grant from the City and County of San Francisco Human Services Agency, Department of Ageing and Adult Services.


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Appendices

Appendix 1: Mapping the NSW Response

The following details the response to hoarding and squalor delivered by a range of services across NSW. This list is certainly not exhaustive and further detailed mapping across the state is required to gauge the true resources dedicated to effective service delivery for people and their pets affected by hoarding and squalor.

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<tr>
<th>COMMUNITY SERVICE</th>
<th>SERVICE RESPONSE</th>
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<tr>
<td>Homelessness NSW</td>
<td>Information provided to member Specialist Homeless Services (SHS) regarding hoarding and squalor resources</td>
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<tr>
<td>Catholic Community Services NSW/ACT</td>
<td>Catholic Community Services NSW/ACT (CCS) has hoarding and squalor teams operating in Sydney, the Hunter, the Illawarra and Southern NSW. CCS has extensive expertise in working with clients who live in complex living environments and are able to provide both skilled specialist case management services as well as community care workers with expertise working with clients in these living/housing situations. CCS has convened two Pathways through the Maze National Hoarding and Squalor Conferences, held in Sydney (2009, 2012) and continues to provide strong leadership in the provision of comprehensive services and information for those affected by situations of Hoarding and Squalor. These conferences have attracted international speakers and experts in the field. CCS has developed an educational package that delivers a one day workshop that explores hoarding and squalor, the case management response to hoarding and squalor and other key issues for support providers and case managers. CCS, in collaboration with a Newcastle Psychologist deliver a 10 week evidence based group therapy program “Buried in Treasures” designed by Randy Frost and Gail Steketee. Participants are bulk billed when they have a referral from their GP and have a current mental health plan in place, or participants can choose to pay a $300 fee for the 10 week program. CCS has also developed a Hoarding and Squalor Toolkit that aims to provide direction for both service providers and community members to respond to situations of hoarding and squalor. This is available on the web. A Pathways Through The Maze App has also been developed to translate the Toolkit into an Apple and android mechanism that can assist people around the world to find relevant information to assist in managing the impact of hoarding and squalor. CCS also provides a nation-wide fee for service advice and education support program.</td>
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<td>COMMUNITY SERVICE</td>
<td>SERVICE RESPONSE</td>
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| Lifeline Harbour to Hawkesbury (LLH2H)   | Lifeline Harbour to Hawkesbury (LLH2H) is developing a defined response to clients displaying signs of hoarding. Due to a need in the local community LLH2H plans to run a therapy programme as follows:-  
  • Individual and group therapy (15 weeks)  
  • Run by a team of psychologists at Lifeline Harbour to Hawkesbury, 4 Park Avenue, Gordon  
  • commenced: July 2013  
  • Cost: Funding and Medicare rebates.                                                   |
| The “Brown Nurses” (Our Lady’s Nurses for the Poor) | Our Lady’s Nurses for the Poor (affectionately called the ‘Brown Nurse’s) have quietly provided in-home healthcare, advocacy and friendship for the poor and marginalised throughout Sydney, Brisbane, Newcastle and Wollongong.  
  The Brown Nurses Ministry is committed to the service of people who are unable to access health care and welfare support.  
  These are people who are disadvantaged, marginalised and often live in impoverished circumstances, suffering mental illness, the long-term consequences of drug and alcohol addiction, homelessness and dysfunctional families.  
  The Brown Nurses have been providing support and clinical nursing care to many people who hoard or live in squalor for decades. The Brown Nurse are one of the first non-government agencies to work through WHS issues to provide care and support within a person’s home. |
| The Benevolent Society                   | The Benevolent Society in the Eastern Suburbs runs a Community Options Program through The Eastern Suburbs Community Care office. This program aims to provide ongoing case management and support for people who are or have experienced situations of hoarding and squalor within the Botany, Randwick, and Waverley and Woollahra local government areas. |
| Barnados Australia – Illawarra           | Barnados Illawarra runs a Family Referral Service for self-referring families without a risk of significant harm. Amidst a myriad of complex presenting issues, more often than not a component of the support involves brokerage funds for hoarding and squalor clean ups to mitigate family environmental safety concerns. |
| UnitingCare Ageing South Eastern Region  | Good Living Conditions project is based on a community development approach to sustainable service improvement. It has developed an agreed local area protocol to implement the DADHC Guidelines. The purpose of this project was not to undertake the cleanup work, but to establish an interagency protocol, including pathways for referral, to ensure people living in severe domestic squalor are assisted in a consistent and systematic way. |
### COMMUNITY SERVICE

**RSPCA**

*Royal Society for Prevention of Cruelty to Animals* provide a range of services including shelters and veterinary services and also take reports on animal cruelty. Under the *Prevention of Cruelty to Animals Act, 1979*, RSPCA Inspectors have the power to remove animals from owners who are cruel, neglectful or indifferent to their animals’ suffering.

**RSPCA NSW**

- **Community Programs**
  - RSPCA NSW offers a range of community focused programs which assist in supporting the human/animal bond.
  - ‘POOPS’ Pets of older persons, focusing on providing in-home support to elderly pet owners. The program also assists with short stay foster care during medical and other events. The program can provide transport services to veterinary appointments. Links from POOPS to re-homing services should this be necessary.
  - ‘Safe Beds for Pets’ supports victims of domestic violence and their pets by providing safe emergency housing for pets. This may be in shelter or foster care where necessary.
  - ‘Living Ruff’ supports the wellbeing of pets of homeless and temporarily disadvantaged people. Principally driven by temporary pet accommodation, ‘living ruff’ helps support transitions between accommodation.
  - RSPCA NSW is currently working to build service capacity in all of these areas and it must be recognised that capacity is limited.

**Inspectorate Services**

The RSPCA NSW Inspectorate comprises of 14 Inspectors based in the Sydney Metropolitan Region and 16 Inspectors spread across the State. Core duties involve responding to animal cruelty complaints and animal rescue situations. In some cases, the cruelty complaint involves situations of animal hoarding.

When managing animal hoarding cases, capacity to respond is limited to the *Prevention of Cruelty to Animals Act 1979*.

If the animal hoarder meets specific criteria the RSPCA can refer the case to one of their community programs for ongoing management. This is at the discretion of the animal hoarder and requires their permission for this to occur. Other human services are called from time to time depending on the situation and willingness of the animal hoarder.

**Housing NSW**

*Housing NSW has a wide-ranging set of policies and products aimed at assisting tenants who live in or are at risk of living in squalor or hoarding.*

<table>
<thead>
<tr>
<th>1. Identification</th>
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<tr>
<td>• Currently, clients who hoard/or are at risk of hoarding are identified through Client Service Officer visits, either routine or in response to complaints from neighbours.</td>
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<tr>
<td>• Some clients are reported to HNSW via external agencies or maintenance contractors.</td>
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<td>COMMUNITY SERVICE</td>
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| **1. Identification (cont.)** | PAS – Property Assessment Survey  
  - The Property Assessment Survey (PAS) assists Land and Housing Corporation (LAHC) staff to identify properties in need of priority maintenance. It is a visual assessment of the condition of social housing assets and common areas owned by the LAHC.  
  - PAS question 8 collects information on “ability to safely walk through and egress dwelling”. The possible responses are;  
    - No Issues  
    - Entrances Only  
    - Minor Obstructions  
    - Major Obstructions  
  - Properties which are flagged by this question are scheduled for an inspection by a CSO within four to five weeks.  
  - The PAS commenced in May 2012, with approximately 1,000 properties already completed. The PAS is expected to be finished in four years. |
| **2. Assistance to tenants** | Where extreme hoarding or unclean behaviours create a public health or safety risk (such as fire risks), Housing NSW will attempt to negotiate with the tenant, emphasising the safety, aesthetic and access implications of their actions. Local staff have indicated they attempt to engage a community mental health worker with the client.  
  - Currently, clients who hoard/or are at risk of hoarding are identified through Client Service Officer visits, either routine or in response to complaints from neighbours.  
  - Some clients are reported to HNSW via external agencies or maintenance contractors.  
  **Partnership approaches**  
  - Housing NSW may try to resolve the problem in partnership with housing support partners, through initiatives such as HASI, DHASI and other support partnership agreements.  
  **Regional approaches to squalor and hoarding**  
  - FACS Housing NSW’s response to squalor and hoarding is largely based on local/regional partnerships and taskforces. There is therefore some variance in the models used in FACS Districts |
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<tr>
<th>COMMUNITY SERVICE</th>
<th>SERVICE RESPONSE</th>
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| 3. Enforcement    | • Tenants have a responsibility under the tenancy agreement to keep the premises in a reasonable state of cleanliness.  
• Squalor and hoarding present a threat to the health and safety of the tenants (also to neighbouring tenants in many cases), to the quiet enjoyment of neighbouring tenants, and to the condition of the premises. FACS Housing NSW is therefore required to enforce the terms of the tenancy agreement concerning property care..  
• Where tenants refuse support/assistance and their behaviours continue to be in breach of their Residential Tenancy Agreement, action may be taken through the NSW Civil and Administrative Tribunal (NCAT). Firstly;  
  - A Specific Performance Order (SPO) can be issued by the NCAT. SPOs may be sought under Section 16 of the RTA 2010 without issuing a notice of termination first. Particularly in instances where the tenant has not previously breached their agreement or agreed to stop/rectify the breach.  
  - Secondly, the NCAT can issue a Notice of Termination (NOT), it is issued under section 87 of the RTA and requires the tenant to vacate the premises on a specific date because they have breached their tenancy agreement.  
• However, FACS Housing NSW will only seek termination of the tenancy as a last resort, after all attempts to resolve the problem through counselling or support provision have been rejected by the tenant or failed to resolve the problem. |

**NSW Trustee and Guardian**
Both trustee and financial management service areas of the NSW Trustee and Guardian can be involved in managing the affairs of people for whom squalor and hoarding is an issue. Financial management orders can and are sought where a person’s capacity to manage their finances and assets is identified as a factor in their living in squalor or their hoarding behaviour. Those people for whom orders are made may have mental illness, brain injury, intellectual disability, dementia or other disabilities. Appointments can be made by the Mental Health Review Tribunal, the Guardianship Division, NSW Civil and Administrative Tribunal and Supreme Court.

**NSW Ministry of Health**
The specialist, public mental health system consists of clinical services and psychiatric disability rehabilitation and support services. Clinical mental health services are managed by public hospitals and provide assessment, diagnosis, treatment and clinical case management to people with a serious mental illness. Psychiatric disability, rehabilitation and support services are provided by non-government community organisations. The below list is a snapshot of South East Sydney Local Health District in NSW.
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<tr>
<th>COMMUNITY SERVICE</th>
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<tbody>
<tr>
<td>Adahps Services for people with HIV and Complex Needs</td>
<td>• Staff Training&lt;br&gt;• Referral to services&lt;br&gt;• Partnerships with other services&lt;br&gt;• Joint case management</td>
</tr>
<tr>
<td>South East Sydney Local Health District (SESLHD) HIV and Related Programs – outreach</td>
<td>• Assessments are undertaken by experienced clinicians (e.g. refer to hoarding and/or squalor assessment tools)&lt;br&gt;• Review other indications for cause (e.g. mental or physical health)&lt;br&gt;• Liaise with Squalor Team if assessed as appropriate&lt;br&gt;• Organise additional service supports to help maintain tenancy/living situation (e.g. Adahps, CSN, etc.)&lt;br&gt;• Team can provide ongoing targeted or comprehensive case management&lt;br&gt;• Staff have attended or encouraged to attend further education on hoarding and squalor&lt;br&gt;• Six monthly audits are undertaken on the number of clients hoarding and/or living in squalor</td>
</tr>
<tr>
<td>SESLHD Mental Health Services – Intake</td>
<td>• Dependant on level of risk and there must be a mental health issue present for continued involvement.&lt;br&gt;• MHS work collaboratively with other identified service providers.</td>
</tr>
<tr>
<td>SESLHD Prince of Wales Community Health – ACAT and Nurses&lt;br&gt;– Social Workers and Dementia Nurses</td>
<td>• Identification and referral&lt;br&gt;• Client engagement and/or coordination and/or referral and/or guardianship if required&lt;br&gt;• Receive referrals from local hospitals (e.g. Social Work Dept) and other agencies (e.g. council) and neighbours.&lt;br&gt;• Identification and referral to our service and/or other agencies Refer to (and work with depending on need) other agencies for case management and/or support (e.g. ARV [Coordinator ACHA Program], Benevolent Society [COPS], and Catholic Community Services NSW/ACT [Squalor Team]).</td>
</tr>
<tr>
<td>Calvary Community Health – Community Social Work team</td>
<td>• Specialised committee on Hoarding and Squalor established in November 2009, in response to National Squalor and Hoarding Conference, 2009.&lt;br&gt;• Committee comprises health workers from inpatient and community areas, as well as key service providers. Purpose to heighten awareness, implement education and improve our interventions to clients/carers living in these circumstances. Committee meets of bimonthly.&lt;br&gt;• Committee members include- From Health: St George Hospital SW and OT reps, QRP OT rep, Calvary Community Health SW reps, Southcare Nursing and SW rep, and Sutherland Hospital OT and SW reps. Housing rep, Benevolent Society rep, Council rep.&lt;br&gt;• Database established since 2012.</td>
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<tr>
<td>Calvary Community Health</td>
<td>• Cases of suspected hoarding and squalor are referred to the community social workers via family, significant others, community agencies, GPs.</td>
</tr>
<tr>
<td>– Community Social Work team (cont.)</td>
<td>• Internal (cross) referrals to Social Work are also made by community Occupational Therapists, nurses, and medical team members.</td>
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<tr>
<td></td>
<td>• Social Work assessment includes home visit (either sole or joint home visit), for assessment of client, their situation and what they want to do/next steps.</td>
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<tr>
<td></td>
<td>• Assessment involves a health assessment looking at cognition, health problems, physical function, level of risk and whether there is a willingness to accept services.</td>
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<td>• Intervention involves referrals to community services, Advocacy and liaison and input with interested parties, and occasionally applications to the Guardianship Tribunal.</td>
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<td></td>
<td>• Often, involvement in such cases can be over time and with other team members. Medical and neuropsychological assessments are useful in determining levels of impairment.</td>
</tr>
<tr>
<td>Healthy at Home/Quick Response Team</td>
<td>• QRP multidisciplinary assessments conducted either in ED and/or by home visits.</td>
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<tr>
<td></td>
<td>• Home visit includes assessment of the client, their home environment, their situation, and what they want to do.</td>
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<td>• Assessment includes level of risk and willingness to accept assistance/services.</td>
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<td>• Intervention involves discussion at multidisciplinary case conference with Geriatrician and other Community Health services. It may also involve referral to Calvary Community Health Social Work, Neuropsychology, psycho-geriatrics.</td>
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<tr>
<td></td>
<td>• Referrals to appropriate services (e.g. Benevolent Society for case management) completed if agreed to by client.</td>
</tr>
<tr>
<td>St George Hospital – Social Work Department</td>
<td>• Social Work Assessment conducted in conjunction with assessments by other multi-disciplinary team members as indicated (E.g. occupational therapy, physio, neuropsychology, mental health).</td>
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<td></td>
<td>• Responses and discharge options may include placement in residential care, return home with services, application to The Guardianship Tribunal for appointment of a guardian and/or financial manager, liaison with Housing NSW.</td>
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<tr>
<td></td>
<td>• If returning home, then referral may be made to services for ongoing assessment and intervention. Referrals may be made to ACAT, ComPacks, The Benevolent Society Community Options Program (for case management).</td>
</tr>
<tr>
<td>The Sutherland Hospital – Social Work Department</td>
<td>• Social Work Assessment conducted in conjunction with assessments by other multi-disciplinary team members as indicated (E.g. occupational therapy, physio, neuropsychology, mental health).</td>
</tr>
<tr>
<td></td>
<td>• Responses and discharge options may include placement in residential care, return home with services, application to The Guardianship Tribunal for appointment of a guardian and/or financial manager, liaison with Housing NSW.</td>
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</table>
The Sutherland Hospital
– Social Work Department (cont.)

- If returning home, then referral may be made to services for ongoing assessment and intervention. Referrals may be made to ACAT, ComPacks, and The Benevolent Society Community Options Program (for case management).

Local Health District
– Old Age Psychiatry and Specialist Psychiatry

As shown in research studies, a majority of persons found to be living in severe domestic squalor fulfil criteria for psychiatric diagnoses. Cases are commonly referred to Mental Health Services by General Practitioners, Community Services and various agencies, for assessment and advice concerning interventions. In the catchment areas of each local health district, old age psychiatrists and community adult mental health psychiatrists, working with community mental health teams, are able to visit occupants of premises deemed to be unhygienic or unacceptably filthy (a majority cluttered with rubbish), and to provide recommendations concerning treatment (e.g. for schizophrenia, dementia or substance abuse). In some cases, admission to general or psychiatric hospitals or units for investigation or to initiate treatment, will be appropriate, but for others admission to residential care facilities may be appropriate. In a majority, community mental health staff will seek involvement of other agencies in order to deal with the various problems without institutional care including cases where the occupants have no insight into their need for help. Community psychiatric nurses and social workers, together with psychiatrists and others, can provide ongoing support and facilitate cleaning and linkage to other services. For a minority who fulfil criteria for hoarding disorder, referral to psychologists may lead to successful de-cluttering.

Private Psychiatrists and Psychologists
Members of the NSW Hoarding and Squalor taskforce have contacted and put together a list of psychiatrists and psychologists with a passion, expertise and willingness to work with people who hoard or live in squalor.

Fire and Rescue NSW
Fire & Rescue NSW (FRNSW) works closely with local communities to reduce the prevalence and impact of fire and other emergencies. FRNSW achieves this by forging new partnerships with government and non-government agencies to access hard to reach at-risk community groups to promote good prevention and preparedness activities.

Fire services have limited powers to enter residential premises unless there is a fire emergency. However, based on increased dangers and costs to affected individuals, responding firefighters and the community, FRNSW is exploring the most effective way to address the risk of hoarding fires and ensure people affected by hoarding are supported to address their risk.

Currently, FRNSW reports and refers notifications of premises where significant hoarding and squalor is present. Notifications of these premises are forwarded to local Councils including Environmental Health Officers for action as a health and amenity concern and to Council’s Community Ageing and Disability Officers to link the person with local service providers.

To improve the safety and preparedness of responding firefighters, hoarding notifications have also been placed on the station turn out information which is automatically generated for an emergency. This ensures adequate resources are responded in the event of a fire and increases firefighters preparedness in the expectation there will be access and egress issues and other hazards.

While FRNSW cannot inspect residential premises without permission, even if suspected of being a fire hazard, fire stations can work with social workers and service providers to install and maintain working smoke alarms in their homes under FRNSW’s Smoke Alarm and Battery Replacement (SABRE) program.
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| Education, risk assessment and mitigation | The Community Safety Division is responsible for creating capacity within the NSWFB to prevent emergencies. This is delivered through a group of closely aligned units which work to support frontline staff in delivering prevention services within their communities by:  
- Creating the safest built environment in which to live, work and otherwise enjoy.  
- Assisting in the development of information and programs that enable communities to keep themselves safe.  
- Continuously learning about the causes and effects of emergencies and feeding this intelligence back to improve all NSWFB services.  
A project that evolved out of the Division is the Hoarding and Squalor Risk report available to the public on the NSWFB website. Collection of this data enables the brigade to flag where additional fire loads risks may be and allocate a risk rating to ensure the responding fire-fighters have an adequate level of equipment and personnel to manage a potential fire. As the NSWFB cannot engage directly with the occupant, the concern is forwarded to the relevant Council as a health and amenity concern for action. In addition, the NSWFB website provides guidance and recommendations for hoarding and squalor fire safety. |
<p>| Environmental Health Officers | These positions within local council undertake regulatory inspections and respond to complaints under relevant environmental and public health legislation. Orders under the Local Government Act 1993 can be issued when the premises and/or land is assessed as not being in a safe or healthy condition. Environmental Health Officers can also order removal and disposal of waste and to refrain from future or further keeping of waste on the premises. Environmental Health Officers are often the first point of contact for many people who hoard or live in squalor and often negotiate suitable referrals to support agencies in an attempt to reduce recidivism. |
| Ageing and Disability Development Officers | The Councils Aged and Disability Services Development Officer is responsible for providing advice, input and advocacy on issues relating to improving the quality of life of the frail aged, people with a disability and people living with or recovering from a mental illness. This support may include: a referral to a community care service to assist with the clean up of the property. Or the coordination of other services so that the health and well being of the person is supported, and the identification of the possible issues that contributed to the property becoming of a squalid nature are identified so that the property does not revert back to its squalid nature. |</p>
<table>
<thead>
<tr>
<th>COMMUNITY SERVICE</th>
<th>SERVICE RESPONSE</th>
</tr>
</thead>
</table>
| Personal Helpers and Mentors | The Personal Helpers and Mentors (PHaMs) service funded by the Federal Department of Social Services:  
• aims to provide increased opportunities for recovery for people whose lives are severely affected by mental illness  
• takes a strengths-based, recovery approach, and  
• assists people aged 16 years and over whose ability to manage their daily activities and to live independently in the community is impacted because of a severe mental illness.  
PHaMs workers provide practical assistance to people with severe mental illness to help them achieve their personal goals, develop better relationships with family and friends, and manage their everyday tasks. One-to-one and ongoing support ensures the individual needs of the PHaMs participants can be addressed. They are assisted to access services and participate economically and socially in the community, increasing their opportunities for recovery. |
| Housing and Support Initiative | HASI is an innovative partnership program between NSW Health, the Department of Housing and the non-government (NGO) sector that provides housing linked to clinical and psychosocial rehabilitation services for people with a range of levels of psychiatric disability.  
HASI builds upon the successes of the Joint Guarantee of Service for People with Mental Health Problems and Disorders Living in Aboriginal, Community and Public Housing (JGOS) and provides a funding base to strengthen partnerships and protocols already established between the agencies. The HASI model is based on the 2002 NSW Health, Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders.  
HASI operates as a three-way partnership in service delivery:  
• Accommodation support and rehabilitation associated with disability is provided by NGOs (funded by NSW Health).  
• Clinical care and rehabilitation is provided by specialist mental health services.  
• Long-term, secure, and affordable housing and property and tenancy management services are provided by public and community housing (funded by the Department of Housing).  
HASI is designed to assist people with mental health problems and disorders requiring accommodation (disability1) support to participate in the community, maintain successful tenancies, and improve quality of life and most importantly to assist in the recovery from mental illness. |
<table>
<thead>
<tr>
<th>COMMUNITY SERVICE</th>
<th>SERVICE RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home and Community Care program (ADHC)</td>
<td>Home and Community Care (HACC) services help older people and people with disability to remain at home and prevent their inappropriate or premature admission to residential care. HACC services provide support to: • frail older people • younger people with disability • their carers To be eligible for a service you must have a moderate, severe or profound disability or be caring for someone with the disability. People with disability who already receive an equivalent service through another program are not eligible to receive a HACC service. A range of HACC services are available to help maintain the independence of eligible people, including case management, help with household chores, health and personal care, activities and transport, short breaks and home maintenance and modification. A service available under HACC is Community Options. This support provides assistance to people with high level, complex support requirements including people with mental illness and functional disabilities. COPS packages assist people to identify their needs and the options available to meet these needs. COPS have funding to broker out a full range of in home support and community access. The program provides service coordination, service monitoring and case management, where identified as necessary.</td>
</tr>
<tr>
<td>Commonwealth Home Care Packages</td>
<td>“Home care” is a type of aged care under the Aged Care Act 1997. Home care is funded by the Australian Government through the Home Care Packages Program (see below). Previously, home care was known as “community care”, or sometimes “community packaged care”. The objectives of the Home Care Packages Program are: • to assist people to remain living at home for as long as possible; and • to enable consumers to have choice and flexibility in the way that care and support is provided at home. A Home Care Package is a coordinated package of services tailored to meet the consumer’s specific care needs. The package is coordinated by a home care provider, with funding provided by the Australian Government. A range of services can be provided under a Home Care Package, including care services, support services, clinical services and other services to support a person to live at home. There are four levels of Home Care Packages: • Home Care Level 1 – to support people with basic care needs. • Home Care Level 2 – to support people with low level care needs. • Home Care Level 3 – to support people with intermediate care needs. • Home Care Level 4 – to support people with high care needs. Home Care Level 2 is equivalent to the former Community Aged Care Packages (CACPs), while Home Care Level 4 is equivalent to the former Extended Aged Care at Home (EACH) packages.</td>
</tr>
</tbody>
</table>
Appendix 2

Catholic Community Services NSW/ACT Client Risk Home Environment Assessment Checklist

Adapted from the Health and Safety for Home and Community Workers: Guidelines for Managing OHS – Forms WorkCover Grants Scheme, SAFER Industries, November 2000.

This Checklist is to be completed at the commencement prior to the first service and/or as deemed necessary thereafter.

All hazards or risks identified are to be transferred to the Risk Management Plan for action.

CLIENT NAME: __________________________________________  DOB:____/____/______   URN:_______________
ADDRESS: ___________________________________________________
_______________________________________________________________________________________

(Observe before you tick the appropriate box)

<table>
<thead>
<tr>
<th>OUTSIDE RESIDENCE</th>
<th>YES</th>
<th>NO</th>
<th>N/A</th>
<th>COMMENT</th>
</tr>
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<tbody>
<tr>
<td>Adequate parking</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Gates (easy to open)</td>
<td></td>
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<tr>
<td>Pathway/Garden</td>
<td></td>
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<tr>
<td>• Level</td>
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<tr>
<td>• Non slip</td>
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<td></td>
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<tr>
<td>• Uncluttered</td>
<td></td>
<td></td>
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<tr>
<td>Steps/Stairs</td>
<td></td>
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<tr>
<td>• Level</td>
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<tr>
<td>• Non slip</td>
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<tr>
<td>• Uncluttered</td>
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<tr>
<td>Veranda/Porch Surface</td>
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<tr>
<td>• Level</td>
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<tr>
<td>• Non slip</td>
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<tr>
<td>• Uncluttered</td>
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</tr>
<tr>
<td>Pets</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>• Present, restrained</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>• Separated</td>
<td></td>
<td></td>
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<tr>
<td>Lighting at Night is adequate</td>
<td></td>
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<tr>
<td>Door Clear of Obstruction/ Easy to Open</td>
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<tr>
<td>INSIDE RESIDENCE</td>
<td>YES</td>
<td>NO</td>
<td>N/A</td>
<td>COMMENT</td>
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<td>-----------------------------------------------</td>
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<tr>
<td>Floor Surfaces</td>
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<tr>
<td>• Non Slip</td>
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<td></td>
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<tr>
<td>• Uncluttered</td>
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<tr>
<td>Lighting</td>
<td></td>
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<tr>
<td>• Adequate for walking</td>
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<tr>
<td>• Adequate for doing work</td>
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<tr>
<td>Pets</td>
<td></td>
<td></td>
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<tr>
<td>• Present, restrained</td>
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<tr>
<td>• Separated</td>
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<tr>
<td>Tasks involving working at heights</td>
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<tr>
<td>Weapons (e.g. guns) – visible or reported to be in the house</td>
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<tr>
<td>Emergency Exit – visible with easy access</td>
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<tr>
<td>Smoke Detector – present and working</td>
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<tr>
<td>ELECTRICAL/GAS</td>
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</tr>
<tr>
<td>Electrical Leads/Extension Cords/Power Boards are not exposed or damaged</td>
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<tr>
<td>Switches/Plugs in good working order</td>
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<tr>
<td>Power Points not located near Water</td>
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<tr>
<td>Gas Cylinders used on site (hot water/oxygen)</td>
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<tr>
<td>EQUIPMENT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vacuum cleaner in working order</td>
<td></td>
<td></td>
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<tr>
<td>Carpet Sweeper in working order</td>
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<tr>
<td>Broom has adequate handle length</td>
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<tr>
<td>Bucket &amp; Mop adequate for use</td>
<td></td>
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<tr>
<td>Iron in working order, board is adjustable height</td>
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</table>
## EQUIPMENT (Cont.)

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<thead>
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<th>Equipment Description</th>
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<th>NO</th>
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<th>COMMENT</th>
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<tbody>
<tr>
<td>Washing Machine no moving parts exposed, wiring / connection to wall is safe</td>
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<tr>
<td>Dryer in good working order</td>
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<tr>
<td>Hot Water system – set to temperature</td>
<td></td>
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<tr>
<td>Pipes are not exposed</td>
<td></td>
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<td></td>
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<tr>
<td>Step ladder in use • Level</td>
<td></td>
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</tr>
<tr>
<td>• Non Slip</td>
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<tr>
<td>Food preparation equipment clean</td>
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<tr>
<td>Clothes Lines – • adjustable height</td>
<td></td>
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<td></td>
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<tr>
<td>• safe access</td>
<td></td>
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<tr>
<td>Does the equipment generate harmful noise</td>
<td></td>
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<tr>
<td>Does the equipment generate vibration</td>
<td></td>
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<tr>
<td>Does the equipment generate dust, fumes or vapours</td>
<td></td>
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</table>

## BATHROOM/TOILET

<table>
<thead>
<tr>
<th>Bathroom/Toilet Feature</th>
<th>YES</th>
<th>NO</th>
<th>N/A</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Bath adequate height and space</td>
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<td></td>
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</tr>
<tr>
<td>Shower has a non slip surface</td>
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<tr>
<td>Toilet appropriate height and room</td>
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<tr>
<td>Drainage adequate to ensure non slip</td>
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<tr>
<td>Ventilation adequate to ensure fresh air</td>
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<tr>
<td>Water Temperature appropriately controlled</td>
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<tr>
<td>Electrical equipment not used in bathroom</td>
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</tr>
<tr>
<td>KITCHEN / DINING</td>
<td>YES</td>
<td>NO</td>
<td>N/A</td>
<td>COMMENT</td>
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<tr>
<td>------------------</td>
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</tr>
<tr>
<td>Stove in safe working order</td>
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</tr>
<tr>
<td>Electrical equipment</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>• cords not frayed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• not used near water</td>
<td></td>
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<tr>
<td>Microwave in safe working order</td>
<td></td>
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<tr>
<td>Work Space Organisation</td>
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<td></td>
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<tr>
<td>• uncluttered</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• non-slip floor surface</td>
<td></td>
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<tr>
<td>Table/Benches appropriate height</td>
<td></td>
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<tr>
<td>Chairs stable and appropriate height</td>
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<tr>
<td>Other (please list)</td>
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<td>LAUNDRY</td>
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<tr>
<td>Workspace Organisation</td>
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<tr>
<td>• uncluttered</td>
<td></td>
<td></td>
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<tr>
<td>• bench top good height</td>
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</tr>
<tr>
<td>Drainage</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>• non-slip floor surface</td>
<td></td>
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<td></td>
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<tr>
<td>• no build-up of water</td>
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<tr>
<td>Electrical equipment</td>
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<tr>
<td>• cords not frayed</td>
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<td></td>
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<tr>
<td>• not used near water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water temperature appropriately controlled</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ventilation – adequate</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>BEDROOMS</td>
<td>YES</td>
<td>NO</td>
<td>N/A</td>
<td>COMMENT</td>
</tr>
<tr>
<td>Sufficient Space Around Bed – uncluttered floor space</td>
<td></td>
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<tr>
<td>Bed Suitable Height for working with client</td>
<td></td>
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</tr>
<tr>
<td>Heaters present and safe – no bedding, cloths or water near heater</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Electrical Cords/Power Points/ Power Boards – no exposed wiring, power points secure</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>LOUNGE</td>
<td>YES</td>
<td>NO</td>
<td>N/A</td>
<td>COMMENT</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>Work Space Organisation – uncluttered work area</td>
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<tr>
<td>Furniture Position</td>
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<tr>
<td>• heighted adequate to work from</td>
<td></td>
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<tr>
<td>• stable</td>
<td></td>
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</tr>
<tr>
<td>Electrical Cords/Power Points/Power Boards – no exposed wiring, power points secure</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>HAZARDOUS SUBSTANCES</th>
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<tr>
<td>Substance on the Approved CCS List</td>
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<tr>
<td>Substances Labelled appropriately</td>
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<tr>
<td>Substances in Original Container</td>
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<tr>
<td>Suitable for the Purpose</td>
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<tr>
<td>Stored in Safe Position</td>
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<tr>
<td>PPE available as required</td>
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<tr>
<td>Material Safety Data Sheets available</td>
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<tr>
<td>Ventilation adequate for the use of hazardous substances</td>
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<tr>
<td>Health effects – emergency procedures known for hazardous substances</td>
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</table>
### OTHER ITEMS IDENTIFIED AS A RISK

<table>
<thead>
<tr>
<th>E.g. through file notes/risk assessments/incidents etc.</th>
<th>YES</th>
<th>NO</th>
<th>N/A</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of aggression or violence / threat to staff</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Resistance to care noted</td>
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</tr>
<tr>
<td>Unable to accept instructions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk of infection</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manual handling assessment completed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### CCS EQUIPMENT ON LOAN

<table>
<thead>
<tr>
<th>Instructions for use of equipment available</th>
<th>YES</th>
<th>NO</th>
<th>N/A</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons are training in safe use of equipment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the equipment serviced per manufacturers instructions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has electrical equipment been tested and tagged</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the equipment clean</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aged Care Equipment Assessment Checklist Form completed as required</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete preventative maintenance as per schedule</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### OBSERVATION / CHECKLIST

Completed by:_________________________________ Date: __/__/____

Postion:___________________________________

All items identified as a risk are transferred to Risk Management Plan. See attached □ Date: __/__/____

Signed:___________________________________

Supervisor Review □ Date: __/__/____

Risks are recorded on risk register.

Supervisor Name:____________________________
Appendix 3

Environmental Cleanliness and Clutter Scale

This form has been designed for service providers to respond to situations involving squalor. The form assists with rating the cleanliness of a person’s accommodation.

This first page may be removed if it is desirable to de-identify the person when communicating with other agencies.

<table>
<thead>
<tr>
<th>DEMOGRAPHIC DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of person</td>
</tr>
<tr>
<td>Surname</td>
</tr>
<tr>
<td>Other names</td>
</tr>
<tr>
<td>Date of birth and/or approximate age of person</td>
</tr>
<tr>
<td>Gender (please circle)</td>
</tr>
<tr>
<td>Marital status (please circle)</td>
</tr>
<tr>
<td>Address</td>
</tr>
<tr>
<td>Does he/she live alone? (please circle)</td>
</tr>
<tr>
<td>If not, who with?</td>
</tr>
<tr>
<td>Number and type of pets</td>
</tr>
<tr>
<td>Home ownership (please circle)</td>
</tr>
<tr>
<td>Accommodation type</td>
</tr>
<tr>
<td>How long has he/she been living like this? (please circle)</td>
</tr>
<tr>
<td>Known medical illnesses and/or disabilities</td>
</tr>
<tr>
<td>Mental disorders now or in the past</td>
</tr>
</tbody>
</table>
Raters should circle the box or number that best fits their observations in relation to the different items. These descriptions are meant to be indicative, but raters may decide between one category and another based on aspects not mentioned in the boxes.

Name of Rater: ____________________________________________________________
Rater’s phone no.: __________________________ Date: __/__/____

### A ACCESSIBILITY (Clutter)

| Easy To enter and move about dwelling. | Somewhat Impaired access, but can get into all rooms. | Moderately Impaired access. Difficult or impossible to get into one or two rooms or areas. | Severely impaired access, for example, obstructed front door. Unable to reach most or all areas in the dwelling. |
| 0–29% | 30–59% | 60–89% | 90–100% |

(percentage of floor space inaccessible for use or walking across.)

### B ACCUMULATION OF REFUSE OR GARBAGE

In general, is there evidence of excessive accumulation of garbage or refuse, eg, food waste, packaging, plastic wrapping, discarded containers (tins, bottles, cartons, bags) or other unwanted material?

| None | Little Bins overflowing and/or up to 10 emptied containers scattered around. | Moderate Garbage and refuse littered throughout dwelling. Accumulated bags, boxes and/or piles of garbage that should have been disposed of. | Lots Garbage and food waste piled knee-high in kitchen and elsewhere. Clearly no recent attempt to remove refuse and garbage |
| 0 | 1 | 2 | 3 |

### C ACCUMULATION OF ITEMS OF LITTLE OBVIOUS VALUE

In general, is there evidence of accumulation of items that most people would consider are of little use or should be thrown away?

| None | Some accumulation, but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances. | Moderate excessive accumulation: items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean. | Markedly excessive accumulation: items piled at least waist-high in all or most areas. Cleaning would be virtually impossible: most furniture and appliances are inaccessible. |
| 0 | 1 | 2 | 3 |

Please indicate types of items that have been accumulated:

- Newspapers, pamphlets, and so on
- Clothing
- Other items
- Electrical appliances
- Plastic bags full of items

(If known, what items?)
# APPENDICES

## CLEANLINESS OF FLOORS AND CARPETS (EXCLUDING TOILET AND BATHROOM)

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Acceptably clean in all rooms.</td>
<td>Mildly dirty</td>
<td>Very dirty</td>
<td>Exceedingly filthy</td>
</tr>
<tr>
<td></td>
<td>Floors and carpets look as if not cleaned or swept for days. Scattered rubbish.</td>
<td>Floors and carpets very dirty look as if not cleaned for months. Rate 1 if only one room or small area affected.</td>
<td>With rubbish or dirt throughout dwelling. Excrement usually merits a 3 score.</td>
<td></td>
</tr>
</tbody>
</table>

## CLEANLINESS OF WALLS AND VISIBLE FURNITURE SURFACES AND WINDOW SILLS

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Acceptably clean in all rooms.</td>
<td>Mildly dirty</td>
<td>Very dirty</td>
<td>Exceedingly filthy</td>
</tr>
<tr>
<td></td>
<td>Dusty or dirty surfaces. Dirt comes off walls on damp rag or finger.</td>
<td>Grime or dirt on walls. Cobwebs and other signs of neglect. Greasy, messy, wet and/or grubby furniture.</td>
<td>Walls, furniture, surfaces are so dirty (for example, with faeces or urine) that rater wouldn't want to touch them.</td>
<td></td>
</tr>
</tbody>
</table>

## BATHROOM AND TOILET

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reasonably clean.</td>
<td>Mildly dirty</td>
<td>Moderately dirty</td>
<td>Very dirty</td>
</tr>
<tr>
<td></td>
<td>Untidy, uncleaned, grubby floor, basin, toilet, walls and so on. Toilet may be unflushed.</td>
<td>Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, and so on. Faeces and/or urine on outside of toilet bowl.</td>
<td>Rubbish and/or excrement on floor and in bath or shower and/or basin. Uncleaned for months or years. Toilet may be blocked and bowl full of excreta.</td>
<td></td>
</tr>
</tbody>
</table>

## KITCHEN AND FOOD

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Clean. Hygienic</td>
<td>Somewhat dirty and unhygienic</td>
<td>Moderately dirty and unhygienic</td>
<td>Very dirty and unhygienic</td>
</tr>
<tr>
<td></td>
<td>Sink, cooktop, insides of all cupboards filthy. Large amount of refuse and garbage over surfaces and floor. Much of the food is putrid, covered with mould and/or rotten, and unsafe to eat. Rate 3 if maggots seen.</td>
<td>Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils and so on. Bins overflowing. Some rotten or mouldy food. Fridge unclean.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>H</td>
<td>ODOUR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Nil. Pleasant.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Unpleasant, eg. urine smell, unaired.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Moderately malodorous: bad, but rater can stay in room.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Unbearably malodorous: rater has to leave room very soon because of smell.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I</th>
<th>VERMIN (PLEASE CIRCLE: RATS, MICE, COCKROACHES, FLIES, FLEAS, OTHER)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None.</td>
</tr>
<tr>
<td>1</td>
<td>Few (for example, cockroaches).</td>
</tr>
<tr>
<td>2</td>
<td>Moderate: visible evidence of vermin in moderate numbers for example, drop-pings and chewed newspapers.</td>
</tr>
<tr>
<td>3</td>
<td>Infestation: alive and/or dead in large numbers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>J</th>
<th>SLEEPING AREA</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Reasonably clean and tidy.</td>
</tr>
<tr>
<td>2</td>
<td>Moderately dirty: Bed sheets unclean, stained, for example with faeces or urine. Clothes and/or rubbish over surrounding floor areas.</td>
</tr>
<tr>
<td>3</td>
<td>Very dirty: Mattress or sleeping surface unclean or damaged. Either no sheets or (if present) extremely dirty bedding/linen.</td>
</tr>
</tbody>
</table>

Add up circled numbers to provide total score:

<table>
<thead>
<tr>
<th>Do you think this person is living in squalor? (circle one)</th>
<th>No</th>
<th>Yes, mild – not clutter</th>
<th>Yes, moderate – not clutter</th>
<th>Yes, severe – not clutter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clutter – (lots), not squalor</td>
<td>Yes, mild + clutter (lots)</td>
<td>Yes, moderate + clutter (lots)</td>
<td>Yes, severe + clutter (lots)</td>
<td></td>
</tr>
</tbody>
</table>
## SUPPLEMENTARY QUESTIONS – TO ADD TO DESCRIPTION, BUT NOT TO SCORE
Comments or description to clarify, amplify, justify or expand on above ratings:

<table>
<thead>
<tr>
<th>Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## PERSONAL CLEANLINESS
Describe the clothing worn by the occupant and their general appearance:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Clean and neat. Well cared for.</td>
</tr>
<tr>
<td>1</td>
<td>Untidy, crumpled: one or two dirty marks and in need of wash</td>
</tr>
<tr>
<td>2</td>
<td>Moderately dirty: with unpleasant odour. Stained clothing.</td>
</tr>
<tr>
<td>3</td>
<td>Very dirty: stained, torn clothes, malodorous.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there running water in the dwelling?</td>
<td>YES or NO</td>
</tr>
<tr>
<td>Is electricity connected and working?</td>
<td>YES or NO</td>
</tr>
<tr>
<td>Can the dwelling be locked up and made secure?</td>
<td>YES or NO</td>
</tr>
</tbody>
</table>

## MAINTENANCE, UPKEEP, STRUCTURE
This rates the state of repair and upkeep by owner/landlord. If the accommodation was cleaned up as much as possible, to what extent would the dwelling require painting, refurbishment, structural repairs and so on before it would be reasonably habitable?

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Little – minor repairs and some painting.</td>
</tr>
<tr>
<td>2</td>
<td>Fair amount – some structural repairs plus painting.</td>
</tr>
<tr>
<td>3</td>
<td>Lots – major structural repairs required, and then painting.</td>
</tr>
</tbody>
</table>

## TO WHAT EXTENT DO THE LIVING CONDITIONS MAKE THE DWELLING UNSAFE OR UNHEALTHY FOR VISITORS OR OCCUPANT(S)?

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Possible risk – of injury for example, by falling.</td>
</tr>
<tr>
<td>2</td>
<td>Considerable risk – of fire, injury or health problem.</td>
</tr>
<tr>
<td>3</td>
<td>Very unsafe – the dwelling is so cluttered and unhealthy that people should not enter it (except specialists with appropriate clothing and equipment) and/or there is high fire-risk.</td>
</tr>
</tbody>
</table>
Appendix 4

Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.
Clutter Image Rating: Bedroom
Please select the photo that most accurately reflects the amount of clutter in your room.

Clutter Image Rating: Living Room
Please select the photo below that most accurately reflects the amount of clutter in your room.
Appendix 5

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    7.1.2 Local municipal council environmental health – a happy outcome
    7.1.3 Rural and metropolitan Melbourne property ownership
    7.1.4 VCAT
    7.1.5 Private rental

7.2 People (clinical, capacity, health and dependents)
    7.2.1 Health – the complexity of labelling Diogenes syndrome
    7.2.2 Metropolitan local municipal council aged and disability service
    7.2.3 Aged Care Assessment Service (ACAS)
    7.2.4 Metropolitan Fire and Emergency Services Board (MFB) operations emergency response
    7.2.5 Victoria police request for welfare check

7.3 Animals (pets, livestock, wildlife and pests)
    7.3.1 Department of Health (DH) Hospital Admission Risk Program (HARP)
    7.3.2 Public housing (mental health and animal hoarding)
    7.3.3 Local municipal council environmental health acting on the nuisance provisions of legislation (hoarded material and animal collection)
    7.3.4 RSPCA Victoria
    7.3.5 RSPCA Victoria Inspectorate

8 Tools to assist

8.1 Environmental Cleanliness and Clutter Scale (ECCS)
8.2 Clutter Image Rating Scale (CIRS)
8.3 Hoarding rating scale interview (HRS-I)
8.4 Squalor and hoarding profile: creating a pathway
8.5 Fire risk reduction flyer
8.6 Contact other local services after receiving an initial referral
8.7 Shared action plan checklist
8.8 Local hoarding and squalor service directory
8.9 Templates to assist with service coordination tasks
8.10 Sample sector and local area flow chart response to hoarding
8.11 Planning for the provision of cleaning (flow charts and cleaning agreement)

9 Resources and contacts

Legislation (Acts) mentioned in this resource

Appendix 1 Hoarding and squalor project stakeholder group
Appendix 2 DSM-5 changed the diagnostic criteria of hoarding
Appendix 3 Information Privacy Principles
Appendix 4 Sample ‘cycle of change’ model

Acronyms and abbreviations
References