Discussion paper
hoarding and squalor
2012
Ageing and Aged Care Branch
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2012
Acknowledgements

We would like to thank the various organisations and Victorian government departments who generously contributed their knowledge and expertise to the development of this paper.

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Executive summary

Not all those who self-neglect or who hoard, live in severe domestic squalor and vice versa. Conditions described as ‘compulsive hoarding’ and ‘severe domestic squalor’ are quite different from each other and should be treated as such, they depend on individual circumstances, though at times may well coexist.

Compulsive hoarding

People who compulsively hoard are unable to resist the urge to acquire possessions and are unable to organise or discard, even at the point of excess, which leads to cluttered living spaces.

Compulsive hoarding is not as yet a clearly diagnosed health condition in its own right. Currently it is coded in the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders - DSM-4-TRTM 2000 - as one of the eight symptoms of obsessive compulsive personality disorder (OCPD).

The compulsive hoarding condition is pervasive, dominates time, space and personal functioning of the person and others, contributing to unhealthy and unsafe living environments. It is evidenced by symptoms such as severe impact on the person’s living environment, their work life, social patterns, health status, family relationships, capacity to build and maintain friendships, diminishing financial means, enhanced likelihood of engagement with justice, legal and civil authorities and cause of high distress with neighbours.

Research is still developing and findings are inconclusive. Recent evidence points to compulsive hoarding being a genetically and neurobiological discrete entity.1

Characteristics of a person with a compulsive hoarding condition:

- They can be any age, socio economic group, geographic location, family group, employment status or profession, level of education or standing in the community.
- Hoarding behaviour is thought to begin in childhood or adolescence possibly as a result of some kind of trauma or grief, but may not become problematic until later in life. The condition would always have been present but not recognised or understood to the point of providing appropriate support.
- As an adult they tend to be single and should they marry, tend to divorce and live alone. They often live isolated lives, even if living with family. Accumulated items are a symptom of the condition, not a cause.
- The social and health problems of a person who hoards remain largely untreated. Dementia brings a sudden deterioration to any hoarding situation.
- They may live in a government funded residential facility such as aged care, disability, family group home, mental health service or supported and public housing. The person could be a ‘rough sleeper’, not living in any one particular dwelling or place for any period, but could equally be living in their own home in the community.

How common is hoarding?2

- In the general population compulsive hoarding is rare, though exactly how rare is unclear as an epidemiologic study has not been undertaken.
- Estimates range from 1 in 350 or 400 people in the UK as well as Australia. The number of problem hoarders is possibly in the range of 60,000 to 90,000, but there is no research data available. It is estimated there are as many as 1.2 million problem hoarders in the USA.3

Domestic squalor

This term and definition seems particular to some Australian jurisdictions (particularly NSW). Severe domestic squalor is not a diagnosis but a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group of people are living in such conditions.

How common is severe domestic squalor?

Few studies have systematically examined squalor in the Australian context. Cases differ greatly between each other relating to so many other complexities including a person’s health status. Determining how common squalor is rests on isolated research with discrete groups in specific geographic areas.

---

3 Mogan C. The Psychology of Compulsive Hoarding, NATIONAL SQUALOR CONFERENCE. Sydney, November 5-6, 2009
Current service response

International and national approaches to compulsive hoarding and/or squalor consistently present what works and what doesn’t work from a clinical and practical perspective. These two perspectives must work hand in hand to be best placed to comprehensively support people living in these environments.

Clinical intervention

Clinical treatment methods and approaches currently used are not that successful. Co morbidity is common in OCD hoarding cases with 92 per cent having one additional psychiatric diagnosis.

People who hoard or live in squalor tend to be resistant to intervention so defining success is difficult. Treatments for compulsive hoarding may contribute to improvement in cases where squalor is attributable to restricted access, due to clutter.

Squalid living conditions relate to a complex range of causes, at times related to hoarding behaviours, but other times to mental health and other conditions involving substance abuse.

Practical intervention

Practical intervention aims to support people with compulsive hoarding behaviours to successfully ‘reduce, recycle and reuse’ (the three R’s).4

There is common generic agreement internationally, nationally and in Victoria that quick fix clean-ups do not work. Imposing controls and cleaning up without respecting the needs and health status of the person who hoards, lead to rapid relapse and highly reinforce the resumption of hoarding.

It is better to understand the personal context, build rapport and motivation and target small improvements. Achieving small goals and active collaboration between agencies (including treatment specialists when appropriate), is the best and most effective type of service response.5

Both hoarding and squalor interventions require the consent of the individual, a comprehensive assessment including consultation/liaison with relevant services, advocacy and referral when appropriate.

The overall aim of intervention in a case concerning hoarding and/or squalor is to support the person to achieve their planned outcomes, not to impose a standard of living. Often negotiated outcomes need to be agreed to and met to address concerns of neighbours, fire risk, animal safety, environmental health, personal safety and health issues of the person and others living on the same property, or in the vicinity.

One particular challenge for service providers is which other services to engage with and how, as sector configurations are not always familiar nor used to working together. Sector connections need to be established, knowledge shared, roles understood and good working relationships formed – with a willingness to work together, knowing how best to respond.

Generally insufficient attention, resources and research have been committed to improve professional service response to hoarding and squalor conditions as well as what defines an effective intervention.6

Fire response

Fires involving hoarding properties present significant enhanced risk and cost for fire fighting departments. Seventy per cent of residential hoarding fires responded to by the Melbourne Metropolitan Fire and Emergency Services Board (MFB) are privately owned homes, as distinct from properties supported or funded by government.

Intermittent local service response

Even though there has been a mushrooming of quite a broad range of service response in some parts of Victoria from multiple sectors and disciplines, capacity to respond and resources are inconsistent particularly in rural and regional Victoria.

Current local service response initiatives evidence duplication of effort and repetition with regard to education for managers and workers, determining appropriate response methods and tools, understanding and engaging with other appropriate sectors and providers and managing costs.

4 Gaston, R.L et al, 2009
In some regions/local areas, where particular organisations have developed competence and leadership responding to hoarding cases, other providers in those areas tend to refer rather than contribute a role themselves.

This pattern may contribute to a culture of organisational behaviour that creates dependency rather than capacity building. Staff in these leading organisations have stated they do not see this model sustainable as it places too much of a burden on one organisation, does not build capacity in the region, nor understanding for other organisations about how to provide the best support for the person or family concerned.

**Future**

A boutique response is not sustainable. The estimated numbers of people living with a hoarding condition and/or 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.

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 (OHS) issues and the responsibility of employers to ensure staff 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.

**Victorian government response**

Some stakeholders suggest a taskforce is required to adequately address the need to develop a uniform, consistent clinical and practical service framework. Whether a taskforce is required needs to be considered. If not a taskforce, then what strategy could be employed to further this work to achieve a similar outcome?

**More research is needed** with regard to both compulsive hoarding and severe domestic squalor to:

- define good practice interventions
- further explore how individuals with hoarding behaviours understand their situations
- define more clearly the causes of squalor and hoarding
- consider leadership for long term research, planning and resourcing, education.

**Clinical indications appear promising** and extremely hopeful that DSM-5, which is currently being planned and prepared and due for publication in May 2013, will include hoarding diagnosed as a discrete condition (refer Appendix 2). This new clinical status could mean that treatment might be able to be claimed on Medicare; that greater capacity for researchers to obtain funds might be possible and the condition may well be included in professional curriculum for medical students, social workers, psychologists, psychiatrists and related fields.

**Conclusion**

Consideration needs to be given to a means of providing consistent best practice standards, clear guidance to and basic education for the multiple sectors, professions and programs that respond to cases of compulsive hoarding and/or squalor.

---

1 Introduction

The fact that people with hoarding behaviour and/or are living in squalid environments is not a new social phenomenon, however public recognition of the problem and its related social and community impacts are becoming better known, creating an increasing interest and expectation of a means to understand and manage such circumstances.

Compulsive hoarding and acquiring is a debilitating problem and is more widespread than commonly believed, either because sufferers are ashamed of their compulsions or because they don’t believe it is a problem that merits professional attention.\(^8\)

A squalid situation usually presents itself with an accumulation of rubbish and an individual’s inability or desire to not dispose of household waste.\(^9\)

The purpose of this discussion paper is to document what is known about hoarding and squalor behaviours, circumstances, multiple sector frameworks as well as clinical and practical service response.

The objectives are to explore whether there is a role for the Victorian Government in this area; whether there is a need to develop a service response and if so, identify what that response might be.

This paper scopes the following points, it:

- discusses national and international research and evidence based perspectives on the subject of ‘hoarding’ and/or ‘squalor’
- briefly defines ‘hoarding’ as distinct from ‘squalor’ and any interrelatedness
- identifies current thinking and evidence with regard to effective service response and interventions
- explores service needs taking into account:
  - service gaps
  - sector alternatives, and
  - consistency/alignment with higher level policy statements such as the Victorian Health Plan 2012 – 2022; Public Health and Wellbeing Plan 2011–2015, Mental Health, Disability, Protective Services, Housing, Justice and Primary Industry
- defines service response issues (including need) and associated considerations
- identifies current service responses in Victoria (strengths and weaknesses)
- considers future policy and service response options.

Clear themes and concerns emerge around the characteristics of people with hoarding behaviours, the interrelationship between hoarding (as a mental health condition), squalor (as a living environment) and their correlation points, at times co existing with multiple other challenging health and complex living conditions.

The fact that international clinical definition and effective treatment for people with a hoarding condition is still unclear and challenging, is also mentioned.

The paper presents a sample of the types of service response to hoarding/squalor in Victoria, providing information on the broad range of organisations and program types involved, all repeatedly educating and defining how best to support the needs of people who find themselves living with these conditions. The issue of capacity for services to respond is raised.

How many people live with a hoarding condition is not clear, how many live in squalor is also not clear, though the estimates per head of population are small. There is no doubt the impact on the lives of these people (whether they work or not) and those around them is extensive, the cost to their health, safety and wellbeing is significant.

---


\(^9\) Catholic Family Welfare, Sydney, NSW, Australia.
2 Compulsive hoarding

Most people enjoy acquiring and using their possessions and nearly everyone keeps some things they don’t need or use. Hoarding is a fairly common behaviour in terms of keeping bits and pieces in case they become useful in the future.

People who compulsively hoard keep things for the same reasons as anyone else:

- for sentimental value, for example, emotional attachment or to remember an important life event
- for utility value, that is the item is, or could be, useful
- for aesthetic value, meaning the item is considered to be attractive or beautiful.

However, people with compulsive hoarding behaviour carry this to an extreme applying these values to a far larger number of items. For them, ridding themselves of extra possessions is emotionally exhausting and extremely difficult. Organising is difficult, and resisting the impulse to acquire (gather) new things is almost impossible.10

Acquisition occurs through purchasing, pursuing ‘freebies’, stealing, or a combination of strategies. Commercial and non-commercial sites are utilised for purchasing including: garage sales, newspapers, rubbish dumps and the internet.

The advantage of online purchasing for compulsive hoarders is that it reduces possible embarrassment when purchasing multiple items. Persistent acquisition for some, leads to debt, theft of monies and depletion of personal and family savings.11

Compulsive hoarders acquire more items than non hoarders. The items may be similar; however acquisitions are often multiples of identical items. Initially the hoard is organised, disorganisation transpires as volume increases.

2.1 Research

Compulsive hoarding has received relatively little empirical study compared with obsessive-compulsive disorder (OCD) and many of its subtypes. National and international research communities agree that the precise nosology of compulsive hoarding has yet to be determined.

Recent data highlights a range of perspectives, including that compulsive hoarding can also be a standalone problem:

- Compulsive hoarding and saving behaviours are often associated with a number of psychiatric disorders, including age-related dementia and cognitive impairment, but they are most commonly associated with OCD and obsessive-compulsive personality disorder.12
- Some researchers suggested that OCD is the most common reason for people to excessively hoard possessions and then to live in unclean conditions.13
- A recent Hong Kong (HK) study14 found that, ‘Over half the subjects had >90 per cent of the dwelling covered by hoarded items, but only one subject was diagnosed as having OCD’.
- Other research into the brain patterns of compulsive hoarders15 shows the disorder may have been misclassified, suggesting that hoarding may be a distinct type of OCD.
- ‘When you are looking at obsession patients, hoarders seem to stand apart, and they don’t respond well - if at all - to standard anti-obsession treatments, which makes you think they might be a bit different’. These researchers say: ‘Standard therapies for OCD often seem to have little effect at reducing these particular symptoms’.
- A UK study suggests, ‘Hoarding seems to be a non-specific symptom, as it has been associated with a wide range of psychiatric disorders. Validating hoarding as pathological is controversial and its status remains unresolved.

12 Frost and Gross 1993; Chu
13 Saxena et al, 2002; Steketee & Frost, 2003
• Individuals with compulsive hoarding behaviour typically report levels of depression and functional impairment that exceed those of patients with obsessive-compulsive disorder (OCD) and other anxiety disorders.\(^{16}\)

The fact that compulsive hoarding occurs in psychiatric disorders other than OCD and in nonclinical populations, has prompted the suggestion that the condition be viewed in generic terms as a ‘multifaceted behavioural phenomenon’.

Growing evidence from epidemiological, phenomenological, neurobiological, and treatment studies suggests that compulsive hoarding may be best classified as a discrete disorder with its own diagnostic criteria.\(^{17}\)

2.2 International classification scales

2.2.1 Diagnostic and statistical manual of mental disorders (DSM)

The American Psychiatric Association first published the DSM in 1952 with several revisions at irregular intervals since then. The DSM is used to a greater or lesser degree around the world by health professionals, insurance companies and pharmaceutical companies. Policy makers often refer to DSM when making funding decisions.

Currently, compulsive hoarding is coded in DSM-4-TRTM 2000, as one of the eight symptoms of obsessive compulsive personality disorder (OCPD).

In most individuals, compulsive hoarding appears to be a syndrome separate from OCD, which is associated with substantial levels of disability and social isolation. However, in other individuals, compulsive hoarding may be considered a symptom of OCD and has unique clinical features (refer Appendix 1: Case studies).

DSM-5 edition is currently being planned and prepared and is due for publication in May 2013.\(^{18}\) There is strong anticipation from clinical stakeholders that hoarding will be included as a discrete disorder,\(^{19}\) severing it from OCD. Hoarding is being considered for inclusion as a formal diagnosis in its own right, to be called ‘hoarding disorder’ with its own diagnostic criteria (refer Appendix 2). How compulsive hoarding is to be represented in DSM-5 is as yet unknown.

2.2.2 International Classification of Diseases (ICD-10)

ICD was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in WHO Member States as from 1994 (first edition 1893). ICD- 10 presents an international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use.

Hoarding is not explicitly covered in ICD–10 and literature suggests that diagnosis of mental illness may consequently be missed in this population.\(^{20}\)

2.3 Defining compulsive hoarding

There is no explicit definition of compulsive hoarding. Therefore the working model, treatment strategies and even basic definitions of this syndrome are still under development.

Compulsive hoarding has frequently been considered a symptom (or symptom dimension) of OCD, its diagnostic boundaries are still a matter of debate\(^{21}\) and can occur in the context of a variety of neurological and psychiatric conditions.

2.3.1 Widely accepted international definition

Despite this, there is a widely accepted definition of the compulsive hoarding syndrome as suggested by Frost,\(^{22}\) made up of three primary symptoms:

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\(^{16}\) Frost, Steketee, Williams, & Wamn, 2000.
\(^{21}\) Van Grootheest et al.
\(^{22}\) Frost & Gross, 1993.
1. The acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value.
2. Living spaces are cluttered to the point that they can not be used for the activities for which they were designed.\(^{23}\)
3. Significant distress or impairment in functioning, caused by the hoarding.

Frost suspects there are three categories of hoarders:
- ordinary hoarders
- animal hoarders and
- trash hoarders.

The latter two seem much more severe, he says, but the dividing lines are murky and overlapping.

Hoarders compared with other clinical groups and community controls show significant difference in socio-economic status (income).\(^{24}\)

### 2.3.2 The most frequently hoarded items

#### Table 1: List of the most frequently hoarded items\(^{25}\)

<table>
<thead>
<tr>
<th>Description</th>
<th>Rank</th>
<th>% Endorsing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clothes</td>
<td>1</td>
<td>89%</td>
</tr>
<tr>
<td>Greeting cards/ letters</td>
<td>2</td>
<td>79%</td>
</tr>
<tr>
<td>Bills, statements</td>
<td>2</td>
<td>79%</td>
</tr>
<tr>
<td>Books</td>
<td>3</td>
<td>77%</td>
</tr>
<tr>
<td>Magazines</td>
<td>4</td>
<td>68%</td>
</tr>
<tr>
<td>Knick-knacks</td>
<td>5</td>
<td>66%</td>
</tr>
<tr>
<td>Mementoes/souvenirs</td>
<td>5</td>
<td>66%</td>
</tr>
<tr>
<td>Records/tapes</td>
<td>6</td>
<td>64%</td>
</tr>
<tr>
<td>Pictures</td>
<td>7</td>
<td>62%</td>
</tr>
<tr>
<td>Sentimental objects</td>
<td>8</td>
<td>60%</td>
</tr>
<tr>
<td>Recipes</td>
<td>8</td>
<td>60%</td>
</tr>
<tr>
<td>Wrapping paper, materials</td>
<td>9</td>
<td>58%</td>
</tr>
<tr>
<td>Papers, pens, gifts</td>
<td>9</td>
<td>58%</td>
</tr>
<tr>
<td>Stationary, old things</td>
<td>10</td>
<td>56%</td>
</tr>
</tbody>
</table>

Other items include:
- **hobby/craft material**: art materials, bells, bones, bottles of wine, craft projects, playing cards, post stamps, rocks, sheet music, shells, timber, and loose wool.
- **information**: advertisements, assignments, business cards, classic novels, old diaries, email, exercise routines, footy records, holiday pamphlets, information, maps, medications (out of date), notices, sayings/musings from self/others, school books, university notes.
- **personal**: coats, dental floss, hair conditioner, jumpers, moisturisers and bubble baths from hotels, perfume bottles, phone messages, photographs, shampoo bottles, shoes, shower caps, skin scabs, tooth brushes, tooth paste.
- **sentimental**: baby clothes, blankets from grandma, child art, children’s books, children’s school work, collars from deceased dogs, dead plants, knitting from grandma, letters, little gifts, love letters, own notes on rock or folk music events, pay slips, theatre or opera programs, toys, broken items I love which I forget to mend.
- **useful things**: broken things, building materials, dried food stuffs (out of date) envelopes, fittings, glad wrap washed and recycled, industrial waste, kerbside cast-offs with mechanical or Steptoe potential, metal/tin, nuts and bolts, paper, bits and pieces of paper of all sorts, plastic, plastic bags, plastic containers, product samples, recyclables, tin, wire, wood.

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\(^{23}\) Frost and Hartl, 1996.
\(^{24}\) Mogan C., The Psychology of Compulsive Hoarding. Presentation Department of Human Services, Office of Housing. January 2010
2.3.3 Causes of compulsive hoarding

Possible causes of compulsive hoarding include:
- reacting to developmental and attachment deficits
- maladaptiveness, abandonment issues
- perceived lack of family warmth
- uncertainty regarding self and others
- distorted behaviours are used to bolster the self against loss, ambivalence, relationship issues
- self-in-my things - Compulsive Hoarder
- self/kinship-in-animals - Animal Hoarder

A study of hoarders\textsuperscript{26} found that the most likely justification for keeping an item was:
- future need (‘I might need this some day’), followed by
- lack of wear or damage (‘this is too good to throw away’)
- sentimental saving (‘this means too much to me to throw away) and
- potential value (‘this may be worth something someday’).

Various studies explore correlations between life experiences and OCD, such as whether traumatic events influence the clinical expression of compulsive hoarding. Initial associations were found to be robust, but further examination revealed the clutter factor of compulsive hoarding (not difficulty discarding or acquiring) was most strongly associated with having experienced a traumatic event.\textsuperscript{27}

Figure 1: Examples of hoarding

2.4 Characteristics

A hoarder will commence by collecting items that are important to them, such as newspapers, cosmetics, magazines, mechanical items or clothing, things that potentially might have some potential future use but to an objective outsider the need to collect such items is clearly overblown.

Some known characteristics of a compulsive hoarder are:\textsuperscript{28}
- **Compulsive acquisition** - hoarders acquire extra things just in case, more than they’ll ever use.
  Compulsive acquisition can include buying and collecting free things, as well as discarded items (for example, from rubbish bins or skips). Acquisition is often associated with euphoria or positive mood states or can be used as a compensatory behaviour to soothe negative moods.
- **Disorganisation** - hoarders find organisation difficult, so things end up in haphazard piles. The final defining feature is extreme clutter in the home (or surrounding areas), office or car. Clutter typically prevents the normal use of space and such daily activities as cooking, cleaning, and bathing.

\textsuperscript{26} Frost and Gross’s, 1993.
• **Difficulty discarding** – a compulsive hoarder can not throw anything away without experiencing severe anxiety. The failure to discard worthless or worn-out objects results from the view that possessions have value in excess of their true worth.

A compulsive hoarder will be very concerned about maintaining control over their possessions and often perceive the items as extensions of themselves, not wanting to waste things or lose a connection with something that reminds them of an important part or person in their life. They may also have difficulty making decisions.

Psychosocial morbidity is higher in compulsive hoarders than in OCD non-hoarders. Many compulsive hoarders never marry, family discord is common and 50 per cent are unemployed.\(^{29}\)

Hoarders are secretive, embarrassed and often ashamed by their predicament, avoid visitors, and live a relatively solitary existence. This shame can at times be tempered with a sense of relief when somebody comes to them with an offer of help.

Compulsive hoarders are not willing seekers of help, the situation is normally brought to the attention of welfare, local government or public health authorities when something like fire or eviction occurs or there is a problem. For example if the person lives in a flat, in a cluster of flats, and is behaving in a way that is dangerous with regard to perceived fire risk, or the person themselves is just not keeping the terms of their lease.

Many compulsive hoarders live and maintain external lives in jobs and social relationships outside of the home. Colleagues, close family or friends are often totally unaware of the extent of the problem until an incident of some type occurs.

The items hoarders acquire usually have some meaning to them but they can become less discriminative as the disorder worsens.

In some cases the meaning of the hoarding behaviour can be more apparent when understanding the person’s background. For example an elderly holocaust survivor who develops dementia can revert to the types of behaviour that served them well in times of privation, such as when food was at a premium and hoarding food was a survival mechanism. In later life, with a lack of recognition with where they are now, they might revert to this type of food behaviour perceiving that it might be useful for them in the future.

All these characteristics lead a person to lose control of their environment and their capacity to manage it.

### 2.5 Animal hoarding

Animal hoarding is a specific type of hoarding, generally accompanied by other forms of hoarding like possessions and objects. It is a poorly understood, maladaptive, destructive behaviour whose aetiology and pathology are only beginning to emerge.\(^{30}\)

The Hoarding of Animals Research Consortium (HARC) was formed in the US in 1997 as an informal group of researchers concerned about human and animal welfare. The group was interested in exploring the problem of animal hoarding to find more effective and humane solutions, and brought together different professional perspectives - animal welfare and humane law enforcement, sociology, forensic psychiatry, social work and rehabilitation services, veterinary medicine, and hoarding psychology and intervention.

Until HARC was founded there had been almost no systematic research into this problem. Dealing with these cases was left almost entirely to animal shelters and animal welfare workers. There was little recognition of the human health implications of animal hoarding or the similarities to other kinds of compulsive hoarding.

#### 2.5.1 Definition

Animal hoarding is recognised as a public health issue, formally mentioned in public health literature in 1999. The published definition of an animal hoarder\(^{31}\) is someone who:

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30 Patronek GJ. & Nathanson J. N. 2. A Theoretical Perspective to Inform Assessment and Treatment Strategies for Animal Hoarders 1Animal Rescue League of Boston,10 Chandler St, Boston, MA 02131, USA; 2 Boston, MA, 02131, USA.

accumulates a large number of animals
• fails to provide minimal standards of nutrition, sanitation, and veterinary care
• fails to act on the deteriorating condition of the animals (including disease, starvation and death) or the environment (severe overcrowding and extremely unsanitary conditions), and
• fails to act on the negative effect of the collection on their own health and well-being and that of other household members.

The Humane Society of the United States (1994) characterises animal hoarders as ‘people who accumulate a large number of animals for whom they are unable to provide adequate care’.

2.5.2 Behaviour

Animal hoarding is a complex behaviour that results from a variety of psychological and behavioural deficits that may limit a person’s ability to care for themselves or others.

Although hoarding animals may start out as a seemingly benevolent mission to save them, eventually the needs of the animals become lost to the person’s need for control. The resulting compulsive care giving is pursued to fulfil unmet human needs, while the real needs of the animals are ignored or disregarded.

Sometimes hoarders act as individuals and other times they masquerade as animal rescuers developing an overwhelming sense of responsibility for the animals, believing they have an innate ability to communicate and empathise with them.32

People with animal hoarding behaviour should never be confused with these legitimate and worthwhile efforts. However, a legitimate shelter, rescue or sanctuary puts the needs of the animals first, recognises when capacity to provide care is exceeded, and takes the required steps (stopping intake, increasing adoption, increasing staff or resources) in order to provide proper care.

Animal hoarders have lost touch with reality and as a result keep their animals in over-crowded conditions where they can suffer from starvation, disease, behavioural problems and eventual death.33

The owner fails to act on the deteriorating condition of the animals, denies neglect of the animals, considers that appropriate care is provided despite evidence to the contrary, and is reluctant to surrender the animals for fear of euthanasia.

Animal hoarders tend to think the animals they look after are well cared for although objective reality suggests the opposite is usually the case. The failure to discard of animal droppings and the consequent smells that arise from living situations will often bring an animal hoarder to attention.34

Seventy-six percent of animal hoarders are women aged 60 plus years, residing alone, who also tend to hoard inanimate objects.35 However, animal hoarders can be found across all demographics – both genders, all ages, all family situations and across the socio-economic spectrum.

Animal hoarders live in every community and are not always unemployed nor live alone. It is estimated that there are three to five thousand cases each year in the US, involving up to 250,000 animals.36

2.5.3 Victorian animal hoarding study

A recent Victorian animal hoarding study37 sent a questionnaire to the coordinator of animal management in each of the 79 local municipal Councils in Victoria, with a 75 per cent (59) response rate.

Analysis of the 59 questionnaires returned suggests that:
• Two-thirds of respondents had experience with animal hoarding (41 out of 59 responses).
• Eighty-one cases were reported between October 2009 and October 2010 in Victoria, equating to an average of 1.4 cases inspected per council or one case for every 50,711 people over the 12 month period.

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32 Snyder 2009.
33 Vaca-Guzman and Arluke 2005.
36 International OCD Foundation http://www.ocfoundation.org/hoarding/types.aspx
• The main species hoarded was cats (48 per cent), dogs (28 per cent), livestock (14 per cent), other (8 per cent) and wildlife (1 per cent).
• Fourteen councils seized animals due to welfare concerns in 75-100 per cent of cases.
• The majority of councils believe the animal hoarding problem is remaining stable.

An outcome of the study suggests that further research is needed to better understand this condition, the number of animals involved and the degree to which their welfare is compromised.

2.5.4 Is animal hoarding an offence?
There are currently no specific offences or penalties associated with the term ‘animal hoarding’ in Victorian legislation, however:
• The Prevention of Cruelty to Animals Act 1986 contains various sections relating to how animals are to kept and cared for, for example, Section 9 ‘Cruelty’ and Section 10 ‘Aggravated Cruelty’ specify offences relating to the care and treatment of animals. Penalties apply for breaches of these sections - such breaches would occur in many animal hoarding situations.
• In addition, there are Codes of Practice38, created under Section 7 of the Prevention of Cruelty to Animals Act, specifying how animals should be kept and cared for.
• Under Section 42, Part 3, Division 4 of the Domestic Animals Act 1994, each municipal council can make local laws relating to the number of animals which may be kept, these differ from council to council. This is where (that is, in the local laws, rather than directly in the Domestic Animals Act) penalties could be applied regarding the number of animals. Refer extract:

Division 4—Powers and duties of Councils with respect to the control of dogs and cats
42: Power of Councils to make local laws.
A Council may make a local law for or with respect to all or any of the following -
(a) regulating the number of dogs or cats which may be kept on premises situated in the municipal district of the Council.

2.6 Prevalence
While recognised in ancient Greek times and having a clinical history dating back decades, compulsive hoarding has only recently become the subject of empirical inquiry.39

It is unclear how widespread compulsive hoarding is, as the problem often only surfaces after a neighbour’s complaint or a medical emergency. There have been no major epidemiological studies on the prevalence of compulsive hoarding in its own right.

Compulsive hoarding is today recognised as a public health issue with sufferers experiencing significant co morbidity and morbidity as well as impaired neuropsychological functioning.

Researchers say that because many people who have a hoarding problem live alone, and don't entertain, it's difficult to estimate how many are affected.40 Estimates indicate that about 2 million Americans have a hoarding problem.

In surveying USA public health departments in 2003 it was found that over a five year period 26 complaints of hoarding per 100,000 people were received. Researchers suggest that this figure seriously underestimates hoarding’s prevalence.41

Other studies indicate that:
• Among US college students the prevalence of compulsive hoarding was estimated at roughly two to four per cent and that less than one in 200 or 0.5 per cent of those with OCD, presented with compulsive hoarding.

38 There are a range of codes (for example Cat, Dog etc), all of which can be found at: http://www.new.dpi.vic.gov.au/agriculture/about-agriculture/legislation-regulation/codes-of-practice-animal-welfare.
40 Frost, R.O. PhD, Saxena, S. MD, 1Professor of psychology at Smith College, Northampton, Mass., USA., 2Associate Professor of psychiatry, University of California San Diego, School of Medicine, La Jolla.
OCD has a lifetime prevalence of one to two per cent of the population and around 25 – 30 per cent of people with OCD are clinical compulsive hoarders and in twice as many males as females. This estimate is thought to be conservative and is much higher, possibly nearer five per cent.

Two to three per cent of the USA population (seven to eight million) has OCD and up to a third of those exhibit hoarding behaviour.

A recent German population-based study explored the prevalence rate of compulsive hoarding and its association with compulsive buying in a nationally representative sample of (N = 2307).

In this study compulsive hoarding was assessed using the German version of the Saving Inventory-Revised. Individuals with compulsive hoarding did not differ significantly from those without compulsive hoarding with regard to age, gender and other socio demographic characteristics.

Significant correlations were found between compulsive hoarding and compulsive buying measures. Participants with compulsive hoarding reported a higher propensity to compulsive buying than respondents without hoarding. About two thirds of participants classified as having compulsive hoarding were also defined as suffering from compulsive buying.

An Australian Study (Victoria) indicated that 10 to 20 per cent of all OCD patients have compulsive hoarding as their primary diagnosis and 42 per cent as a secondary symptom.

Symptoms of clutter and difficulty with discarding occur earlier than active acquisition of items.

Compulsive hoarders often have a first degree relative who hoards. Further evidence for genetic factors has emerged from the OCD Collaborative Genetic Study, which showed a significant linkage to compulsive hoarding on chromosome 14 in families with OCD where there were two or more hoarding relatives. In families with fewer than two hoarding relatives there was a suggestive link on chromosome 3.

Co morbidity

Co morbidity is common, with 92 per cent having one additional psychiatric diagnosis (Table 2). Those who compulsively hoard have significantly more co morbidity than those with non hoarding OCD, with females having greater co morbidity than males.

### Table 2: Most common co morbidity in OCD hoarding

<table>
<thead>
<tr>
<th>Major depression</th>
<th>Panic disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bipolar disorder</td>
<td>Generalised anxiety disorder</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>Social phobia</td>
</tr>
</tbody>
</table>

Compulsive buying, pathological gambling also commonly co-occur with compulsive hoarding. Personality disorders are also common, particularly OCD (dependent and avoidant).

Non-OCD hoarding

Compulsive hoarding occurs in illnesses unrelated to OCD, may be a feature of an impulse control disorder or the result of a stereotypical ritualistic behaviour.

### Table 3: Compulsive hoarding in illness unrelated to OCD

<table>
<thead>
<tr>
<th>Prader-Willi syndrome</th>
<th>Attention deficit disorder</th>
<th>Anorexia nervosa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>Mental retardation</td>
<td>Brain damage</td>
</tr>
<tr>
<td>Tourette syndrome</td>
<td>Schizophrenia</td>
<td>Autism</td>
</tr>
<tr>
<td>Dementia (studies suggest up to 23% of those with dementia compulsively hoard)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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42 Saxena S, University of California.
43 Frost RO, Professor of psychology Smith College in Northampton, Mass., USA.
49 Jefferys D., Moore K.A., School of Psychology, Deakin University, Victoria. Pathological hoarding clinical practice Reprinted from Australian Family Physician Vol. 37, No. 4, April 2008
2.7 Age of onset

Hoarding is more prevalent in older than younger age groups. Initial onset of hoarding symptoms is believed to occur in childhood or adolescence with a chronic and progressive course throughout the lifespan.

There is little evidence for late onset hoarding. Hoarding severity increases with each decade of life, thus older adults experience very serious levels of hoarding. This increase in hoarding symptoms is particularly interesting given findings of decreasing prevalence of other psychiatric disorders in late life. Other than dementia, hoarding may be the only psychiatric disorder that actually increases in severity and prevalence throughout the life course.

The onset of compulsive hoarding behaviour has only started to be defined over the past 15 years, so there is very little known and suggested ages therefore varies. While childhood and adolescence is the norm for onset of symptoms, most people only recognise they are compulsive hoarders in adulthood. Studies indicate hoarding behaviours can start as young as 10 years of age, becoming disruptive around 17 and unmanageable by the mid thirties. The accumulation of objects doesn’t impact to a fuller extent until the person is in their 40’s or 50’s and frequently much later.

Information to date suggests that people are more likely to seek help when they are over 50 years of age.

2.7.1 Older people who hoard

Historically, compulsive hoarding behaviours of older people were discussed in terms of Diogenes syndrome and domestic squalor with syllogomania (that is, unnecessary or out-of-control collecting and hoarding of possessions) a common symptom.

Today, the validity of Diogenes syndrome is disputed due to overlapping symptoms of OCD, other psychiatric illnesses and dementia.

Most elderly hoarders are women who have never married, with 92% having clutter without apparent organisation. Pertinently, most hoarders who are elderly consider their hoarding a physical health threat but do not consider themselves cognitively impaired.

An older person who recently sought treatment for their hoarding behaviour was able to recall identifying with hoarding when they were 6 years old.

Hoarding behaviours have been associated with the severity of dementia. Hoarding and hiding behaviours are commonly reported in nursing home patients with dementia; however it is not clear whether this behaviour is a manifestation of dementia or a prior history of hoarding.

There is limited research on hoarding in older adults with the majority of published articles on isolated case reports or in dementia samples. Nevertheless, it is well known that late life hoarding is a serious psychiatric and community problem that warrants considerable attention.

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56 Catherine R. Ayers, Ph.D., ABPP. International OCD Foundation
3 Domestic squalor

Cleanliness varies between homes and between individuals and can be presumed to be influenced by multiple factors including upbringing, peer and family expectations, living arrangements, social and financial circumstances, cultural background and surroundings.

However some people live in conditions so filthy and unhygienic that almost all observers, in whatever culture, would consider them unacceptable.

3.1 Research

No studies have looked at the benefits of providing targeted support to people living in squalor.\(^{57}\)

A recent literature review\(^{58}\) involving over 1100 identified cases of severe squalor indicated that half of those described as living in severe squalor were elderly, with often poor intervention outcomes. The study indicated that people living in severe squalor were most commonly diagnosed as having dementia, alcoholism or schizophrenia, though personality problems were evident in a high proportion.

The review revealed a second body of literature indicating that accumulation of rubbish was described in over half of the case reports on severe domestic squalor, but suggested this should only be called hoarding if it results from the purposeful collection of items.

This study concluded there was need for further studies with the aim of using standardised ratings of living conditions, investigating and trying to understand the complex interplay of triggers and vulnerabilities, exploring how best to intervene and examining the outcomes of interventions.

3.2 Defining domestic squalor

Australian context

The term *domestic squalor* is specific to the Australian experience\(^{59}\) and is used to describe living conditions, not people. A squalid dwelling or living place (as opposed to clothing or appearance) refers to somewhere that is filthy, unclean or foul indicating extreme self neglect through a lack of care, cleanliness or general neglect.

The confrontation is in relation to domestic environments rather than to the people living there, though often the associated but unspoken thought is, ‘How could people live like that? How have they allowed their living conditions to deteriorate in that way?’

There is some research discussion around defining wet squalor from dry squalor\(^{60}\) though it seems there is not a clear-cut division between the two. When people hoard animals as well as other stuff, the resultant squalor can be described as a mixture of wet and dry.

There is a range of squalor situations. Some people live in filthy homes without a lot of clutter. Some live in very cluttered dwellings that can not be cleaned because of the clutter.

Whether someone lives in ‘squalor’ is subjective and often influenced by the attitude, exposure to the unclean environment and personal living conditions of the person making the assessment. There have been attempts to define:

**Poor living conditions:** an appropriate and sensitive term for most unpleasant domestic situation covering a range of health conditions and domestic circumstances, and

**Severe domestic squalor:** which suggests more extreme conditions.

Importantly neither living condition is defined by financial means, employment status nor a person’s standing in the community.\(^{61}\)
Both conditions overlap in different ways with other concepts such as senile squalor, OCD and Diogenes syndrome and social withdrawal.

In the USA and the UK situations of squalor are often called self neglect and can be classified as a type of elder abuse. In Australia, self neglect or squalor are not included as a form of elder abuse, when elder abuse is defined as occurring within a relationship of trust.

In no cases in Australia can an older person be removed from their home against their wishes without first gaining a legal ruling that they are not capable of making decisions about their personal affairs.

It is argued that some squalor situations can be addressed through the use of legislation (e.g. a state or territory mental health or public health act), however these acts are not directly applicable to all squalor circumstances.

The National Squalor Conference (Sydney) emphasised the need to come to terms with severe domestic squalor, proposing that such cases were not living in states of ‘moral degradation’ - there should be no judgements about morals nor degradation. The conference proposed that poverty should not appear in a definition, even if the latter is sometimes a factor to consider.

The conference impressed the need for governments and others in general to take action and responsibility for such cases where living conditions are unacceptably unclean, unsafe and/or unhygienic and that have unacceptably deleterious effects on the people living there or nearby.

### 3.3 Factors contributing to severe domestic squalor

Severe domestic squalor can occur in a number of circumstances and situations affecting a range of household types and age groups, both younger and older people, as well as couples.

Some environments such as those that are cluttered and inaccessible, may be more likely to be labelled as ‘squalid’ even though they may be no dirtier than other places where there is less property and possessions.

It is likely that those who live in severe domestic squalor start doing so because of a complex interplay of triggers, vulnerabilities and circumstances such as:

- Obsessive compulsions and indecisiveness
- An accumulation of refuse and useless items is attributable to apathy and impaired executive function resulting from brain disease or mental disorder
- Lack of impulse control could contribute
- Limited but growing evidence that frontal lobe dysfunction may be a major factor.
- Associated factors including domestic violence, economic and cultural poverty, diverse cultural values and beliefs, war or other trauma.
- Evidence suggesting that half to two-thirds of all persons living in severe domestic squalor may also have dementia or alcohol-related brain damage or mental health issues such as schizophrenia and depression.

The person’s behaviour is more often due to other problems like drug addiction or the loss of cognitive function so they may not be able to make judgements and therefore might eat rotting food. This type of squalor is usually associated with foul smells, a sense of decay and rotting floor boards.
Table 4: Findings from a cross-age study of severe squalor in South London

<table>
<thead>
<tr>
<th>Findings from a cross-age study of severe squalor (needing heavy-duty cleaning) in South London</th>
</tr>
</thead>
<tbody>
<tr>
<td>57 (70%) of 81 subjects had an ICD-10 mental disorder</td>
</tr>
<tr>
<td>17 (21%) schizophrenia etc. (9% + drug &amp;/or alcohol abuse)</td>
</tr>
<tr>
<td>13 (6%) dementia (6% + alcohol abuse)</td>
</tr>
<tr>
<td>5 (6%) other organic mental disorder, (all 6% + alcohol abuse)</td>
</tr>
<tr>
<td>8 (10%) drug or alcohol abuse but no other mental disorder</td>
</tr>
<tr>
<td>5 (6%) anxiety-related disorder</td>
</tr>
<tr>
<td>4 (5%) mood disorder</td>
</tr>
<tr>
<td>9 (11%) developmental disability (1% + drug abuse, 5% + other mental disorder)</td>
</tr>
<tr>
<td>Other 14 anxious-avoidant personality, 5 paranoid/schizoid, 10 conscientious, perfectionist, houseproud and 1 dissocial.</td>
</tr>
</tbody>
</table>

Studies have shown moderate to high rates of medical problems for people who live in severe domestic squalor conditions particularly in relation to mobility, continence, sensory impairment (especially visual) and nutritional deficiencies such as diabetes and obesity.

Some other indicators include:

- persistent self neglect (for example,. exceptionally poor hygiene: soiled clothing; bleeding skin infection; inadequate toileting practices)
- failure to attend to life functions (for example, defecation in sleep area)
- poor property maintenance (for example, no clean washing facility; no refrigeration)
- inadequate living conditions
- low awareness of consequences to self and others (for example, unbearable stench emanating to all but the occupant, who is blissfully unconcerned by the situation)
- hostile attitudes (for example, towards family, friends, authorities)
- stubborn refusal of help (for example, rubbish removal; intense clean ups).
- a rationale incongruent with their situation (for example, living with large numbers of uncared for animals [cats, dogs, birds, rats, mice] who feed and defecate wherever they want)
- a lack of concern about their living conditions (for example,. excrement and decomposing food are strewn around the floors; rotting mess).

Environmental and geographical factors such as rubbish disposal methods, housing and urban design, building structures and the availability of local services may also be included.

3.4 Prevalence

Although psychiatric and other community service providers commonly encounter cases where intervention is needed due to a person’s unclean or cluttered living condition, evidence concerning the referral rate and prevalence of severe domestic squalor is sparse.

By 2007 the literature on squalor reflected 74 case-reports and 15 reports of case-series in health sciences journals. The following data provides some indication of prevalence, though are confined to the limitations of the projects undertaken:

3.4.1 Severe domestic squalor study - Sydney

Research in Australia

The first empirical study conducted in 1987, surveyed 83 people who lacked personal and environmental cleanliness. It was estimated that three to four people out of 1000 live in squalor and suggested that figure may be higher.

A severe domestic squalor study was undertaken in New South Wales, Central Sydney (Eastern sector). Cases were referred to an old age psychiatry service in Sydney, where ratings of cleanliness and clutter were made. Where possible a one-year follow-up was arranged and indicated that:

- 173 persons aged 65+ were assessed as living in squalor of which 120 were moderate or severe.
- Of the 157 followed up after one year, 47 per cent were still living at home, 32 per cent were in long-term care homes, 12 per cent had moved elsewhere and 9 per cent had died.
- The annual new referral rate in the catchment area was close to one per 1000 elderly people and for moderate or severe squalor was 0.66 per 1000.
- Limited follow-up was provided to those in moderate or severe squalor, 41 per cent were still at home.

Table 5: Health status of presenting cases Central Sydney study

<table>
<thead>
<tr>
<th>Diagnoses given to people aged 65+ years in Central Sydney, living in severe or moderate squalor (2000-2008)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia (including FTD*)</td>
<td>43 (40%)</td>
</tr>
<tr>
<td>ARBD** and/or alcohol abuse</td>
<td>22 (20%)</td>
</tr>
<tr>
<td>Other drug abuse</td>
<td>2</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>14 (13%)</td>
</tr>
<tr>
<td>OCD</td>
<td>6</td>
</tr>
<tr>
<td>Other personality disorder</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
</tr>
<tr>
<td>Frailty, medical illness (for example, CVA)</td>
<td>10</td>
</tr>
<tr>
<td>Unrecorded or no diagnosis</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>113</strong></td>
</tr>
</tbody>
</table>

* Front temporal dementia
**Alcohol-Related Birth Defects

Additional considerations from this study were:

- These cases agreed to be referred as part of this study however the number of non-referred cases can only be guessed. Some cases were referred but refused to be involved.
- Because half of those living in moderate or severe squalor were found to be still at home after one year and others had moved in with relatives, the prevalence of moderate or severe squalor among people aged 65+ is estimated at 1.5 per 1000.
- This study did not scope people younger than 65 years of age who might also live in squalor, which discounts a large population cohort when endeavouring to determine prevalence.

Figure 2: Examples of squalid living conditions

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77 Snowdon J., University of Sydney. 1987
78 Snowdon J, Discipline of Psychological Medicine, University of Sydney, Concord Hospital, Sydney, Australia and Halliday G., Sydney South West Area Health Service, Concord Hospital, Sydney, Australia. 2000 – 2009.
4 Interrelationship between hoarding, squalor and collectionism

Severe domestic squalor can be accompanied by hoarding and the accumulation of consumer items and packaging, however, care needs to be taken not to label every case of hoarding or excessive collecting as severe domestic squalor. This would not be helpful and could be regarded as insulting to the ‘collector’ concerned.

Some people neglect (seem not to care about) cleanliness of themselves, their dependants or their homes and don’t get rid of rubbish but this may be due to a broad range of possible other health conditions such as dementia, schizophrenia, drug addiction or alcoholism, to name a few.

Others are physically or cognitively unable to take action to manage their living environment or the circumstance may encompass a mix of both the above.

4.1 Compulsive hoarding

The literature on hoarding presents various reports, some mentioning squalor, but no research on the prevalence of severe uncleanness in cases of hoarding.

It has been suggested that compulsive hoarding is really an impulse-control deficit rather than a compulsion and that some hoarders collect ritualistically rather than compulsively or on impulse. Others who hoard don’t collect, they just don’t throw away.

4.1.1 Models of Hoarding

Abnormal psychology model is a focused Delusional Disorder (that is, odd and bizarre reasons for keeping things):
- claiming affinity with animals or special relationship with or need for things
- deny obvious neglect, harm and chaos; hostile, rejecting of help
- function well outside delusional system.

Squalor model
- dementia and other deteriorating models emphasise loss of self-care and organisation
- secretive, isolated, uncooperative; decayed food, animal waste, pest infestation
- hoarder profiles emphasise 65+, single, female
- dementia brings a sudden deterioration to any hoarding situation
- require structure, psychiatric assessment, protective interventions and medication.

Addictive model
- totally pre-occupied with hoarding focus
- denial, excuses, claims of persecution, ignoring overall outcome of hoarding
- impulse control issues in compulsive acquiring of things or animals
- significant co morbidities.

Attachment model
- emphasises disorganised early attachment with compromised chaotic parenting; animal or object as stable fixtures
- compensatory unconditional love for and from animals has explanatory power
- consistent with compulsive hoarding where sense of self and grief-like loss connected with things
- compulsive need to keep animals or objects to protect them, maintain connectedness.

Obsessive compulsive disorder (OCD) model
- OCD associated with hoarders’ key felt responsibility to care for possessions including things, animals, memories
- harm prevention, special relationships or other symbolic meanings
- sense of ‘mission’ whether for animals or responsibility for things
- avoidance behaviours can reach delusional levels.

80 Stepney, 1994.
4.2 Squalor

The term *squalor* is used to describe living conditions, not people. Squalor is the accumulation of objects that have no meaning, resulting in a mess.

A person living in squalor can at times also display hoarding behaviour with an accumulation of animals, broken appliances, leaking taps, dysfunctional toilet/laundry and general rubbish throughout the home. Dr. Kiran Rabheru\textsuperscript{84} states:

> ‘The difference is that people with OCD realise their actions are illogical, people who live in squalor don’t…. Squalor is frequently associated with the elderly, but such cases involve adults of all ages and in all socio economic categories.’

Management of such cases is difficult as many people in these circumstances have severed ties with family and friends and mistrust doctors, so don't seek medical care or support generally (refer Appendix 3: Snapshot and commentary, progressive kitchen cleanup in squalid condition).

4.3 Collectionism

Some people collect ritualistically rather than compulsively or on impulse. Ritualistic collection and unmotivated accumulation of rubbish should not be referred to as hoarding.\textsuperscript{85}

Compulsive hoarding can also be differentiated from collecting behaviour, where collectors are proud of their collection, enjoying and displaying them. The collector's items are maintained, displayed, organised and functional, with further items added when budget permits; the home is not cluttered.

In contrast to compulsive hoarding, collecting is purposeful with specific items often acquired and retained in a way that reflects pride in what they have collected. A compulsive hoarder tends to be more ashamed of their behaviour and their items are not organised, particularly at terminal stages.

Lack of impulse control may contribute to collecting behaviour, resulting in reduced living space, if there is also a failure to discard. Some people neglect (seem not to care about) cleanliness of themselves, their dependants or their homes and don’t get rid of rubbish (for example, some with dementia, schizophrenia, alcoholism). Some are physically or cognitively unable to take action.

Excessive or inappropriate collecting (and especially failure to discard) may lead to difficulty in cleaning.

**Table 6: Aspects of collectionism, self-neglect and severe domestic squalor**\textsuperscript{86}

<table>
<thead>
<tr>
<th>Collectionism</th>
<th>Self neglect and severe domestic squalor</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Organised and systematic collecting</td>
<td>* Neglect personal care and home cleanliness</td>
</tr>
<tr>
<td>* Compulsive acquisition with little attempt to resist (items may be of value, collected systematically but to excess)</td>
<td>* Neglect basic health needs (including medication)</td>
</tr>
<tr>
<td>* Hoarding (acquisition of, and failure to discard possessions of limited use or value)</td>
<td>* Poor care of finances</td>
</tr>
<tr>
<td>* Accumulation of rubbish</td>
<td>* Fail to eat/drink enough</td>
</tr>
<tr>
<td></td>
<td>* Neglect social needs</td>
</tr>
<tr>
<td></td>
<td>* Fail to protect self from financial or sexual abuse</td>
</tr>
</tbody>
</table>

\textsuperscript{84} Rabheru, K., Extreme squalor presents a therapeutic challenge- American Association for Geriatric Psychiatry. Clinical Psychiatry News, May, 2003 by Norma MacReady, May 2003

\textsuperscript{85} Maier, 2004.

5 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.

Well-meaning family members and/or professionals who try to help by sorting and purging the clutter on the hoarder's behalf are likely to find their good deed has an unanticipated result, that is, an increased effort on the part of the hoarder to protect their stuff from ‘unauthorised touching’.

5.1 Safety and security for people who hoard and/or live in squalor

Hoarding or living in squalor can lead to a wide range of serious problems, particularly as the condition worsens, keeping in mind hoarding characteristics refer Section 2.4.

5.1.1 Susceptibility to poor health and illness

People living in hoarding and/or squalid conditions are more susceptible to poor health and illness, for example:

5.1.2 Vulnerable people

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.

5.1.3 Impact of animal neglect on the environment

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:

- the home being damaged from accumulated faeces and urine, fur, infestation and sleeping habits of large numbers of animals – may result in the home being condemned as unfit for human habitation
- frail adults with health challenges who hoard animals, usually can not keep up with cleaning demands
- a person’s health is affected when animal droppings dry and turn to dust, the particles can be inhaled causing lung and respiratory health concerns, bacteria spreads and there is limited infection control.

88 Read more at Suite101: Elderly Compulsive Hoarding Means Extra Worries for Caregivers http://www.suite101.com/content/elderly-compulsive-hoarding-means-extra-worries-for-caregivers-a255671#ixzz1CahPVPsL
5.1.4 Neighbours, building and property

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 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.

5.2 Fire

The Melbourne Metropolitan Fire and Emergency Services Board (MFB) and the Country Fire Authority (CFA) both say that hoarding/squalor houses or properties increase risk and danger for the occupant, their neighbours, firefighters and service providers.

MFB suggest that every fire associated with hoarding and/or squalor that they attend is completely different to each other due to diversity of the persons age, socio economic and geographic spread, diverse family group structures, single person households and housing types.

Both MFB and CFA respond to hoarding fires in Victoria which they say involve people of all ages, but suggest the fire risk for people who hoard is acute and generally increases for people aged 65 years and over.  

Hoarding increases the risk of fire due to:

- accumulated possessions resulting in an abnormally high fuel load with greater ignition opportunity
- blocked exits and narrow internal pathways impeding escape for the occupant and firefighter access
- non functional gas or electricity may result in unsafe practices for cooking and heating
- poorly connected, disconnected and/or improvised utilities (e.g. running clean water, heat, refrigeration and sewerage).

Research involving MFB has identified that people aged 50 years+ who hoard, are at particular risk and accounted for 24 per cent of all preventable fire deaths between 1999 and 2009. The study suggests that older people and people with disabilities were found to have been at a greater risk of fire fatality (refer Appendix16: MFB and CFA research studies).

5.2.1 Risks for firefighters

Firefighters face tremendous risk when responding to hoarding fires, often not knowing what they are dealing with until trying to enter the burning building. When firefighters go into an unknown environment it is always dangerous. Hoarding fires make it even more so due to accumulated items often stacked:

- from floor to ceiling, metres deep, unstable and at risk of caving in and falling over
- in rooms and along walls, hallways and around entrances restricting movement of operational firefighters in full turn out gear and breathing apparatus.

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89 Harris J. Community Ageing Specialist, Metropolitan Fire and Emergency Services Board, Melbourne, Victoria. Working with people with hoarding behaviours DVD. Copyright Vision Australia 2010.

90  Aufiero, M., Carlone, T., Hawkins, W., Murdy, S. Analysis of Preventable Fire Fatalities of Older People and People with Disabilities: Risk Reduction Advice for the Community Care Sector. An Interactive Qualifying Project Report submitted to the Faculty of Worcester Polytechnic Institute in partial fulfilment of the requirements for the Degree of Bachelor of Science (May 2011).


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Stacked and accumulated items significantly impact on search and rescue operations and increase the risk of firefighters performing these duties. Often the only way firefighters 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.

Firefighters 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.

Excessive use of extension leads (often poor quality) supplementing power access from one side of the house to the other contributes to fire risk particularly when live wires are left lying carelessly around.

MFB say that many people who hoard are aware of this danger so will not use heating or warming amenities due to fear of starting a fire. They may however make do with makeshift and exposed and unsafe wiring, leaving half/or the whole house without any power, as well as using candles. Old kerosene heaters often in poor condition are also used for heating and/or cooking.

At times extraordinary methods are used to heat and cook (for example, a makeshift pizza oven built out of bricks or old oven pieces, in the middle of a lounge room on the carpet – surrounded by clutter and hoarded items).

**Figure 3: Examples of electrical fire risk**

A fire crew member from the Phoenix Fire Department, USA who battled a recent hoarding blaze which destroyed a home, described his experience:

> ‘Going in he had a feeling it wasn’t going to stay ‘first-alarm” for very long. As he prepared to break through the front of the house, he saw stacks of boxes both inside and outside the main entryway. He was putting his mask on when an explosion rocked the home, forcing him to dodge smoking debris and rocks.
> 'I've never been shot with a shotgun, but it felt like getting pelted with a bunch of rocks…on the side of your head,’ he said. The explosion blew apart the east and west walls of the home, making it a total loss.
> Firefighters attributed the explosion to the amount of combustible material found in the backyard as well as inside the home. The crew member suffered second-degree burns on his face, ear and hand.
> The residents of this home had a furniture-building business and were selling items from their house. The backyard and inside rooms had been packed with furniture after the residents could no longer afford to store it.’

The deputy chief of public affairs for the Phoenix Fire Department said he remembers a hoarding incident where a four-bedroom home and garage was packed floor to ceiling with newspapers, textiles and other materials. Inside, one part of the ceiling had been ripped off and exposed to add more room, enough to chain a fibreglass boat to the rafters.

In such cases, firefighters could easily come across flammable liquids, plastics and other dangerous materials without realising it. Firefighters often find extreme hoarding conditions during medical calls.

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92 Refer: http://www.azcentral.com/community/tempe/articles/2011/03/24/20110324hoarding-safety-hazard-firefighters.html#ixzz1MfR6efDK
5.3 The legal system

Some people who hoard are motivated to seek treatment on their own; others are pressured to seek treatment by court order after inspections from agencies such as fire and public health departments or a housing authority.

Due to the nature of hoarding behaviour, people who hoard may fail to recognise the dangers of hoarding. It is not surprising then, that those who hoard may not feel motivated to change the conditions in the home. However, as the severity of hoarding increases, sometimes others must act to prevent harm; they can turn to the legal system for support.

The following are some situations in which the legal system becomes involved in cases of hoarding.

- A landlord may petition the court to evict a tenant when excessive possessions or unsanitary conditions violate a lease.
- Protective service workers may seek guardianship of children, disabled or older adults when they determine that hoarding constitutes abuse or neglect of these individuals.
- Members of the public health or fire departments may appear before a judge for a court order to bring a property in compliance with health and safety codes or, in extreme cases, to condemn the property.
- Animal welfare workers may petition the court to remove abused or neglected animals from their owner.

Standard legal interventions in cases of hoarding often involve sanctions, such as evicting the individual, mandating a clean out, or removing vulnerable individuals from the home. When this happens without other interventions, the underlying disorder is not addressed and recidivism is typically high.

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.

Officers of the court often work together with social service providers and others to implement a more sophisticated approach that coordinates both pressure on the individual to change and support in making necessary changes. A key part of this process is creating an explicit plan that clarifies necessary changes in the home and establishes a time-line to reach mandated benchmarks. For those who decline treatments but fail to make progress, judges can mandate treatment or other human service intervention.

5.4 Eviction and homelessness

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 kept in line 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 the risk, which means a health service contacts public housing who aims to address the hoarding situation.

5.5 Economic and social burden

It is relatively easy to spot the home of a hoarder. What is less visible is the financial wreckage committed by the estimated 600,000 to 1.2 million hoarders (USA). Their compulsive, incessant acquiring behaviour can leave bank accounts as empty as their homes are full.

How hoarding leads to money problems

The financial impact of hoarding is often most distressing. About 75 per cent of people with hoarding problems buy excessively, with over half qualifying for a diagnosis of compulsive buying. They tend to have lots of credit cards creating huge credit card debt. Power and gas may be disconnected, homes fall into disrepair, primary assets slowly unravel and deplete.
To worsen matters, hoarders typically have great difficulty organising their possessions, especially paperwork. The volume of clutter and disorganisation means they can not find bills, receipts or cheque books when they need them. Consequently, bills don't get paid on time, pay cheques get lost, receipts necessary for reimbursements never get found. Hoarders also tend to rent storage space to house excess items, depleting income even further.

A compulsive hoarder may also find it difficult to get or keep a home insurance policy due to heightened fire and injury risk, consequently seen as too high a risk to insure by some home insurance companies.

Friends and family members affected

Hoarder's may reach a point where basic household bills have run into debt and are unable to be paid with the burden falling onto friends and family, particularly when it becomes apparent that amenities such as gas, water and electricity are cut off.

These circumstance place both morale and fiscal pressure on family and friends, presenting a circumstance requiring a response to either finding a way to pay the outstanding (often recurring) debts themselves or dealing with the fact that their relative/friend might be evicted and then live where? Should/can they take some kind of responsibility for their relative? The lifestyle of the person who hoards may become the emotional and ethical concern or responsibility of family member/s and/or friends.

In addition, should tragedy occur for the hoarder such as ongoing depression or suicide, the family are left dealing with not just the emotional fallout but their relative's liabilities and a house bursting with things.97

5.6 Media interest

Hoarding cases and/or squalid environments (including animal hoarding) often and seemingly increasingly, attracts the attention of the print (dailies and local) and electronic media, particularly television.

Media exposure of such cases may raise awareness and possibly encourage action by individuals and/or their families, but equally the situation could be sensationalised and presented as an intrusion into the private and emotional lives of people and their families.

Governments are frequently involved in responding to media claims, particularly when cases involve clients involved with Housing, Child Protection, Disability and Mental Health services, where senior Victorians are involved as well as if there is a public or environmental health concern.

6 Effective intervention

A home can contain a great deal of clutter and still not pose any problem for the person living there. Clutter per se, is not the problem - only clutter that causes distress, impairment or is unsafe to the occupant/s or immediate neighbourhood requires intervention. Where does service response begin?

This section primarily discusses intervention with regard to compulsive hoarding cases, including when squalor is involved.

There may well be similarities between compulsive hoarding and squalor interventions, however cases involving squalor are quite different (refer sections 3 and 4) so interventions achieve different outcomes for these people. In instances where someone has, for example, self neglect resulting from a dementing illness the kind of interventions would be very different to treatments offered to a person with OCD or with a compulsive hoarding condition. Further work on squalor interventions would be undertaken, should a broad service response framework to such cases be developed.

6.1 What doesn’t work well?

6.1.1 No, to ‘a quick fix’

The key message from all stakeholders (international/national and Victoria) no matter which sector, with regard to effective intervention be it for a case involving compulsive hoarding or a squalid environment is that trying to treat the situation through a quick fix, that is an enforced one off physical cleanup, has proven to be ineffective and is discouraged for the following reasons: 98

- it will severely impact on the person living there, in most cases causing extreme anxiety and trauma as the cleanup was not willingly done or enforced by the person with the hoarding behaviour
- the home will return to its original state very quickly, filled to the brim with newly collected items
- it does not deal with the psychological disorder which is of course, the cause of the resulting behaviour to hoard.

Trying to remove evidence of the psychological disorder does not bring about change, health (including mental health) and community services need to work with the person concerned to ensure sustained gradual change.

Many people who have experienced a quick fix have had terrible reactions such as severe depression and in some cases suicide. In some USA states or counties, quick fixes as a compulsive hoarding intervention have been banned for those reasons.

6.1.2 Psychological or medical treatments

Hoarding, either alone or in the presence of OCD, usually does not respond well to medical or psychological treatments. Most studies have found that only a third of people who hoard show an adequate response to treatments involving medications. 99

The treating of hoarding is complex due to the following factors:

- Hoarders have highly-personalised reasons for hoarding.
- Hoarders have ambivalent and avoidant personality styles.
- Their uncertainty about self and others leads to object-driven compensatory behaviour.
- Treatment needs to accommodate interfering variables (for example, rigidity, control, reluctance for treatment).
- Fear of making decisions, control and memory and deep-seated beliefs held by hoarders. 100

Treatment of hoarding requires:

- assessment of hoarders in their context to determine broad and specific treatment goals
- liaison with health and welfare agencies – hoarding complexities require collaboration

98 Mogan C., Working with people with hoarding behaviours, DVD. A learning resource containing practical strategies designed to assist Victorian Home and Community Care (HACC) staff working in this area. Copyright Vision Australia, 2010.


100 Mogan C., The Psychology of Compulsive Hoarding. Presentation Department of Human Services, Office of Housing. January 2010
therapy is not a quick-fix, the outcomes are based on specifying goals, and the focus is on harm minimisation (similar to treatments for drug addiction).

The myths of saving need challenging

A hoarder maintains a range of beliefs and thoughts, a mythology which an effective treatment program challenges, for example:

- Someone will find this useful.
- I never throw anything away.
- I must keep all things that recall this person.
- I know exactly where everything is.
- How helpful to me is this clutter and mess?
- These things are my life… I don’t know why!
- Throwing things away is rejecting them.
- Keeping a thing is to accept it into my life.

Dr Mogan suggests that a hoarder’s obsessive focus on things needs to shift to skills about relating with others. The person over-values hoarding which is underpinned by experiential avoidance, that is - possessions are seen as basic to their sense of identity and safety. He suggests better management of emotions is also needed as this is the key to relationships and problem-solving. The fusion of self and objects brings resistance and lack of insight in the hoarder.

From an OCD perspective hoarding has been notoriously difficult to treat. Both clinical trials and case reports show that hoarding does not respond well to selective drug uptake or to psychotherapies that alleviate other OCD symptoms. On average from the time OCD begins, it may take 14 -17 years for a person to get the right treatment.

Efforts to treat hoarding behaviours with traditional cognitive-behaviour therapy (CBT) are also often ineffective, however a CBT hoarding protocol has been developed that shows considerable promise.

- Treatment is delivered in a group format, focusing on compulsive acquisition, difficulty in discarding clutter and disorganisation.
- In the group, compulsive hoarders have their thoughts and emotions that sustain these behaviours identified and there validity challenged. Exposure and response prevention techniques are applied. (e.g. group participants go on shopping excursions without buying anything, or they discard objects both in the group setting and as homework). They also learn methods for organising their belongings.
- Preliminary results are promising. Participants treated in this manner begin to tolerate the anxiety associated with discarding objects and gradually reduce the clutter in their homes. Research into combining this treatment protocol with different combinations of medication is ongoing.

Although the CBT program was developed for people who hoard as a symptom of OCD, some of its tactics can be applied to the treatment of hoarding in brain-injured patients and patients with Alzheimer disease, front temporal dementia and other neurodegenerative diseases. In short, effective treatment for hoarding behaviours is still being developed.

6.1.3 Inhibitors to clinical and practical intervention

Even with the best coordinated service coordination plans and available resources, there can still be a myriad of blockages to progress, many stemming from the behaviour of the person concerned or their family members. Some inhibitors include:

- **Hiding symptoms:** Some people choose to hide their symptoms, often in fear of embarrassment or stigma. This causes many people to not seek the assistance of a mental health professional until many years after the onset of symptoms.

- **Less public awareness of OCD:** Until recently, many people did not know there was even a name for their illness and with no name; they assumed there was no treatment.

- **Lack of proper training in health professionals:** People with hoarding behaviours often experience incorrect diagnosis from health professionals, maybe seeing several doctors and taking several years before getting the right diagnosis.
• **Difficulty finding local professionals** who may be able to assist.
• **Cost** - not being able to afford psychological or other treatment.
• **Insight** into the severity of symptoms and necessity for change is essential to the success of any form of treatment. When people do not have insight into their illness, they are much more likely to either not seek support in the first instance, stop taking medication or to drop out of treatment.

Research has shown that people who hoard often have worse insight into their symptoms than people with OCD who do not hoard.

Often, people who hoard only agree to commence treatment after being threatened with eviction or some other negative consequence that is secondary to those caused by their hoarding.

This lack of insight can also be frustrating for family members and may drive them away, feeling their loved one has become delusional and consequently they do not know what to do.103

### 6.2 What does work well?

Compulsive hoarding cases are very difficult to work with, even utilising the most appropriate strategies, interventions may only achieve limited outcomes.

Generically agreed intervention aims to support people with compulsive hoarding behaviours to successfully ‘reduce, recycle and reuse’ (the three R’s).104

Stakeholders (that is, the person, neighbours and service providers) often have different views about what should happen, and agreement must be reached prior to intervention commencing.

Understanding the individual when considering whether and how to arrange intervention is essential. Some may be pleased to receive service support, they may be friendly and may show insight, others not so. The various factors that may have led a person to live with hoarding behaviours and/or in squalor need to be identified before intervention starts.105

It is essential to take into account who or which organisation/s have a good relationship with the person concerned, as that relationship may need to be fostered and maintained over a long period of time.

Intervention Plans for cases involving hoarding and/or squalor require collaborative planning (refer Section 8.2).

The following points are not that different from already established intervention models, however additional considerations need to be taken into account due to the nature and health status of people living in hoarding and squalor conditions.

#### 6.2.1 Intervention principles

Models of intervention that aim to achieve sustained change need to establish collaborative engagement with the person concerned to be able to move forward, rather than for example, have a doctor step in to provide a decision about what course of action is best.106 The following guiding principles are suggested:

• treat the person with respect
• treat each case and each person, individually
• commence engagement to minimise surrounding harm
• develop a means to minimise identified suspected or actual harm
• work with the person/s concerned to bring about sustainable change
• move the person to different levels of improvement, but do this at their own pace
• work in a collaborative way, with an agreed action plan, to clean the property in the passage of time
• do not to touch or move the person’s belongings without permission, based on the understanding that the client sees these items as an extension of themselves107

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103 International OCD Foundation: [http://ocd.about.com/od/treatment/a/Hoarding-Treatment.htm](http://ocd.about.com/od/treatment/a/Hoarding-Treatment.htm)
105 Snowdon, J., National Squalor Conference 2009 Sydney
106 Macfarlane, Steve., Director, Caulfield Aged Psychiatry, Service, Caulfield Hospital, Working with people with hoarding behaviours, DVD. A learning resource containing practical strategies designed to assist Victorian Home and Community Care (HACC) staff working in this area. Copyright Vision Australia, 2010.
• recognise the relationship of the property to the person and be non judgmental, leave the control for that decision with them
• let the person do things for themselves, service providers motivate and provide guidance to keep going
• develop agreed systems (for example, working together to clean up – the worker would always ask permission of the person with regard to each item before throwing it out)\textsuperscript{108}
• act respectfully towards the person ensure they know their space is respected and seen as theirs, that workers are not going to come and takeover.

6.2.2 Consent to intervention or care planning

Obtaining consent from the person to intervene moves through a number of stages, preparedness to receive initial support is one thing - preparedness to engage in a more planned approach, to clean up or to agree to a clinical treatment program is another. Once consent has been gained and the aim and type of intervention agreed, strategies should be discussed with the person seeking their consent to develop an intervention or care plan

Additional considerations

**Hoarding** usually requires:
• sensitivity to the fact that many people who hoard have not allowed anyone into their home in years; a useful care plan goal can be to encourage the person to allow family and friends into their home on a regular basis
• utilising an OHS checklist (refer Appendix 5 – Attachment 4)
• meetings with the person and appropriate services to review progress
• planning to achieve short term goals (refer Appendix for sample checklists/inventories)
• discussing impediments to the process and fostering continued cooperation is paramount
• a longer-term care plan includes more frequent, regular visits to assist the person to reduce and/or store excessive items.

There is little evidence to indicate that the nature of items hoarded makes a difference to the type of care plan, with two exceptions:
• when animals are collected and kept in great numbers, the condition of the home is typically compromised, and
• when hoarded items include rotten food, body products or similar items, a squalid living condition can be severe.

**Squalor** often requires:
• a short term, intensive plan with the need for ongoing services commencing soon after the initial intervention is complete
• the initial intervention to include a clean up with permission of the person concerned\textsuperscript{109}
• effective interventions in cases of severe domestic squalor are commonly expensive and require good inter-agency collaboration
• budgetary support must be available to enable appropriate services to take on cases and provide case management.

In a practical sense local councils are frequently involved in responding to severe domestic squalor notifications to regulatory organisations underpinned by a number of local government laws (for example, the Domestic Animals Act 1994 and public health authorities),

Referrals to clinical services of people living in severe domestic squalor are not uncommon though little has been published concerning how best to intervene.

Different studies by groups in London (Ontario) and Sydney (NSW) have recommended the development of coordinated services to intervene in cases of squalor. A recent review referred to interventions to over 1100 identified severe domestic squalor cases, of which half were elderly people.\textsuperscript{110}

\textsuperscript{107} Nancarrow J., Housing Support for the Aged, Loddon Mallee Housing Service. Working with people with hoarding behaviours, DVD. A learning resource containing practical strategies designed to assist Victorian Home and Community Care (HACC) staff working in this area. Copyright Vision Australia, 2010.

\textsuperscript{108} Glenda Hair, Case Manager, Inner South Community Health Service. Working with people with hoarding behaviours, DVD. A learning resource containing practical strategies designed to assist Victorian Home and Community Care (HACC) staff working in this area. Copyright Vision Australia, 2010.

\textsuperscript{109} Graham, S., Senior Coordinator, Severe Domestic Squalor Program. McDermott, S., Service Manager, Homeless and Housing Support Services

\textsuperscript{110} Graham, S., Senior Coordinator, Severe Domestic Squalor Program. McDermott, S., Service Manager, Homeless and Housing Support Services
This review concluded that generally intervention outcomes are often poor. Further studies were needed using standardised ratings of living conditions to investigate and understand the complex interplay of triggers and vulnerabilities exploring how best to intervene and examine outcomes of interventions.

### 6.2.3 Animal hoarding

Intervention in animal hoarding cases is almost always complex. There is no one universal solution. Each person comes with a different history, a different set of circumstances and resources, unique medical and psychological diagnoses that may all affect what kind of intervention might work best.

Animal hoarding is taken much more seriously than, for example the hoarding of machinery, however there is very little known about animal hoarding and very few people trained to assist.

Animal hoarding has almost a 100 per cent recidivist rate\(^{111}\), meaning the person keeps offending. Some would say treatment of a person who hoards animals requires a lot of therapy, commitment and preparedness of the person to want to make a change to that behaviour.\(^{112}\)

The same principles mentioned in Section 6.2.1 apply when animals are involved. Similarly any approach by local government or others (for example, police) to seize animals or remove hoarders from their home and forcibly clean up the property does not work (refer Section 6.1.1).\(^{113}\) Taking away hoarded animals from the location can cause tremendous fear, apprehension, loneliness and grief for the person concerned.\(^{114}\)

A USA study suggests that to intervene most effectively, it becomes critical to clarify some of the developmental factors of animal hoarding behaviour and its correlation with self-neglecting behaviours in general. With enhanced knowledge and understanding of animal hoarding, human service professionals would be better prepared to respond, evoke greater rapport and cooperation and engage in the interdisciplinary efforts that are essential for optimal resolution.\(^{115}\)

Cases can present with a different range of intervention considerations due to the poor health status of the animals and the consequent compounding impact on the living environment.

In 2006, an expert working group developed a preliminary typology of animal hoarders, refer Table 7.

**Table 7: Preliminary typology of animal hoarders**\(^{116}\)

<table>
<thead>
<tr>
<th>Overwhelmed caregiver</th>
<th>Rescuer hoarder</th>
<th>Exploiter hoarder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some awareness, more reality based</td>
<td>Mission leading to unavoidable compulsion</td>
<td>Tends to have sociopathic characteristics</td>
</tr>
<tr>
<td>More passive acquisition</td>
<td>Fear of death</td>
<td>Lacks empathy for people or animals</td>
</tr>
<tr>
<td>Problems often triggered by change in circumstance</td>
<td>Active versus passive acquisition</td>
<td>Indifferent to harm caused</td>
</tr>
<tr>
<td>Unable to problem-solve effectively</td>
<td>S/he is the only one who can provide care</td>
<td>Rejects outsiders’ concerns</td>
</tr>
<tr>
<td>Animals are family members</td>
<td>Rescue followed by adoption becomes rescue only care</td>
<td>Superficial charm and charisma</td>
</tr>
<tr>
<td>Likely to be socially isolated</td>
<td>May have extensive network of enablers or be a group activity</td>
<td>Lacks guilt or remorse</td>
</tr>
<tr>
<td>Self esteem linked to role as caregiver</td>
<td></td>
<td>Manipulative and cunning</td>
</tr>
<tr>
<td>Fewer issues with authorities</td>
<td></td>
<td>Adopts role of expert with need to control</td>
</tr>
</tbody>
</table>

Each of these types will respond to or require different types of intervention approaches. The overwhelmed caregiver is more likely to be responsive to a more therapeutically oriented approach, whereas the exploiter hoarder will most likely require aggressive prosecution for animal cruelty in order to achieve change. The rescuer hoarder may require a bit of both.

110 Snowdon J., a1 and Halliday G. a2: a1 Discipline of Psychological Medicine, University of Sydney, Concord Hospital, Sydney, Australia. a2 Sydney South West Area Health Service, Concord Hospital, Sydney, Australia. How and when to intervene in cases of severe domestic squalor. International Psychogeriatrics, 21, pp 996-1002, 2009.
111 Worth and Beck 1982, IOCDF 2010
113 Kyrios et al, Swinburne University. Melbourne. 2010
116 Patronek, Loar, and Nathanson, 2006
A therapeutically-oriented approach involves:

- helping the person arrange for desexing of the animals
- providing necessary veterinary care
- reviewing the environmental condition and how well it meets the animals' needs for exercise, socialisation, and mental stimulation as well as basic care, and
- finding avenues for adoption for whatever number of animals exceeds the person’s capacity for care.

Some kind of on-going informal monitoring and support is also essential.

A law enforcement approach is by nature much more adversarial via enforcement of the anti-cruelty laws. In some cases, the physical environment is so toxic and the person so resistant to improving conditions, no other option but forcible removal of the animals is available. As the rules of criminal justice and evidence collection apply, this approach is more burdensome and complex. Police will obtain a search warrant, and the animals will be taken into protective custody as the legal process unfolds. This could take months to years, and if convicted of animal cruelty, could even result in jail time for the offender. Often the media become involved, and the case is a matter of public record if charges are filed.

Refer Section 8.2 for relevant Victorian organisations which respond to animal hoarding.

Figure 4: Examples of animal hoarding

6.3 Empowering and supporting workers

Empowering and supporting managers, supervisors, specialist staff and direct care workers is always important. This is even more important when staff are involved in hoarding and squalor cases which are complex, difficult and can at times be unsavoury work.

There are increasing numbers of staff in health services and community based agencies (refer Appendix 12: Victorian local service response) who work extremely well with people who hoard and/or live in squalid conditions.

Staff can be supported in a variety of ways, such as:

- specific hoarding and squalor education and training opportunities to assist
- opportunities are delivered via broad learning models (including interactive online or DVD), small or large groups as well as individual learning options
- regular acknowledgement of outcomes achieved.

Organisations/services need to acknowledge that this kind of work does not suit everyone. It takes specific staff and management skills, expertise and character traits to undertake the approach and work required to manage cases involving hoarding and squalor.
6.4 Working within appropriate legislative environments

All interventions need to be approached within the appropriate legislative environment (e.g. safety of the environment, public health, council by-laws, building standards and/or fire safety and at times child protection).

If a house has deteriorated to the point where it is condemnable, then the authorities have the right to act which is based more on an administrative decision than a clinical one. Legislation can provide useful leverage to engage with a person. Often without that lever there maybe little formal reason or opportunity to approach and engage them, particularly in their living environment.

Engaging the appropriate authorities at an early response stage to discuss the most effective roles and actions should ensure a sustained outcome.

Some agencies might utilise a legislation response to cause engagement with a person, which might look like a stronger inflexible intervention, but it can actually enable a more flexible and supportive approach to evolve.

6.5 Post intervention

Nearly all people who hoard or live in squalor will require ongoing service support to ensure the intervention is sustainable. What service/s is available and the person’s willingness to participate, should all be considered PRIOR to intervention. Components of post intervention support might include:

- **client support** - personal support needs based on current need and history
- **service provision** - service suitability, eligibility and availability
- **prevention** - is there a need for any continuing regular service support or monitoring?

6.6 Educating the community

Very few cases involving poor living conditions are resolved quickly. Many people living in poor living conditions do not admit or recognise there is a problem. Often the issue is discovered and reported by neighbours, relatives or friends who are concerned and want to see some kind of improvement.

Concerned members of the community might initially contact local government, public health and by-laws officers who can then include other sectors as needed. However, official responses and orders from local government and body corporate groups are often ignored, denied or refused by the person concerned.

A house can be filled with pieces of machinery and not impose a health risk nor condemn the property. Finding the balance between individual living conditions and community safety is difficult, the spectrum is broad. It is impossible to establish a global rule indicating at what stage an individual has a right to carry on hoarding behaviours, balanced against community and individual safety.

The way in which the person is informed of the issue or concern can determine how effectively and successful an outcome can be achieved. Planning and reviewing intervention needs to maintain a balance of responsibility between the person concerned and those around them.
7 Assessment and testing tools

7.1 Assessment

Assessment drives appropriate service response. As hoarding and squalor constitute significant health hazards, clutter is the first matter to address. It is important to distinguish whether the clutter is an effect of compulsive hoarding or a result of physical or mental impairment, such that the person is unable to attend to his or her living quarters. In the latter instance, suitable cleaning assistance should suffice.

If active or passive hoarding (or both) is the problem, an assessment would be required including the possibility of referring the person (if they agree) to an appropriate psychologist for treatment or coach a caregiver in management techniques. Not all people who hoard or live in squalor would agree to a referral for treatment as part of their care plan, particularly not initially.

Caregivers can assist in reducing hazardous clutter in a number of ways as well as utilising resources available. For example, the New York City Hoarding Task Force\(^1\) has prepared a series of reports on hoarding including tips for managing it, both in general and in the context of dementia (refer Appendix 4).

Collegiate effort between a broad range of community and health service providers (refer Appendix 5: Attachment 3.1 Impact of Squalor Checklist), can assist in managing cases in a variety of ways, depending on the expertise required and available. No one service response has been found to be effective for all compulsive hoarding cases.

Considerations

Assessment strategies will involve a multi-disciplinary team or network, long term involvement and on-going support, taking into consideration the individual, the environment, the property, the community and any specialist, one off or ongoing services required.

A major factor in resolving cases of compulsive hoarding or severe domestic squalor will be the length of time that the person has been living in such conditions. The situation is best addressed as soon as it has been identified, as the longer it is allowed to exist the harder it is to resolve.

A home assessment is highly recommended as it provides significant decision making information as to where to begin declutter efforts. Visits by someone the person trusts, begin to desensitise the person to visitors. Background information is also useful.\(^1\)

A person with hoarding behaviours may well be hospitalised often for a general medical problem, and it may be discovered she/he is living in a hoarding or squalid state when discharge or post operative care is being arranged. Medical personnel might assess for a mild cognitive disorder or a psychiatric disorder underlying the hoarding behaviour, taking into account the person’s capacity to make reasoned decisions prior to returning to their home environment.

7.2 Tools - hoarding

Various questionnaires and interview checklists have been created over the years to assess compulsive hoarding and squalor.\(^1\) They have been developed by academics for research, clinical application and for the many sectors involved in working with people living in hoarding or squalid circumstances.

Most of these tools or measures can be used by assessment officers or therapists in a home environment and can be divided into:

- those that are subscales of general measures of obsessive-compulsive disorder (for example, Obsessive-Compulsive Inventory and Yale-Brown Obsessive-Compulsive Scale) and
- those that were developed specifically for hoarding and related phenomena.\(^1\)

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\(^{1}\) New York City Hoarding Task force. Practical tips refer: http://www.cornellaging.org/gem/hoa_bes_pra.html?name1=Best+Practices+Decluttering+Tips&type1=2Active. 2003

\(^{1}\) Refer: NSW Catholic community Services squalor and hoarding toolkit: http://www.catholiccommunityservices.com.au/squalorandhoarding


The former were largely developed without the benefit of research identifying the nature of hoarding, while the latter capture the specific dimensions of hoarding and are recommended for clinical and general use.\textsuperscript{121}

The tools below are those most commonly referred to in the literature, as well as by international, national and local stakeholders to test for hoarding behaviour.\textsuperscript{122}

### 7.2.1 Savings Inventory Revised (SI-R) 123

Probably the most widely used self-report measure of hoarding is the SI-R, a 23-item questionnaire designed to measure the three main features of hoarding: excessive acquisition, difficulty discarding, and clutter (refer Appendix 6).

The items are scored zero to four, so SI-R total scores range from zero to 92. Scoring instructions are located at the end of the questionnaire together with a table of average scores of people who do not suffer from hoarding, as well as cut offs for what is thought to indicate a probable hoarding problem. There are extensive data supporting the reliability and validity of the SI-R.

Several recent studies have indicated that the SI-R is reliable and can discriminate identified hoarding cases from non-hoarding controls and non-hoarding OCD cases. No gender differences are apparent for the SI-R total, Clutter, or Difficulty Discarding, although women score higher on Acquisition, which reflects the gender differences seen in studies of compulsive buying.

One limitation of the SI-R inventory tool is the use of self-reporting to determine hoarding status and severity. Poor recognition of a person’s own hoarding problem can lead to underestimation of hoarding, therefore there is a need for a different kind of tool or adjustments to this one.

**Use:** Appropriate instrument for assessing symptoms of compulsive hoarding in clinical and non-clinical environments between a worker and the person concerned.

### 7.2.2 Hoarding Rating Scale – Interview (HRS-I)\textsuperscript{124}

The HRS-I is a five-item semi-structured interview that assesses hoarding and its critical features and can also be used as a questionnaire.

The five questions include three about clutter, difficulty discarding, and excessive acquisition while the remaining two focus on distress and interference caused by the hoarding behaviour. Initial studies suggest that a score of 14 or higher indicates a probable hoarding problem (refer Appendix 7).

**Use:** Appropriate for assessing symptoms of compulsive hoarding in clinical and non-clinical environments between a worker and the person concerned.

### 7.2.3 Hoarding Assessment Tool (HAT) 125

HAT is a comprehensive four page document made up of three components: a telephone screening, condition of the dwelling and client assessment (refer Appendix 8).

**Use:** Appropriate for an initial assessment including the environment when on site and face to face with the person concerned.

### 7.2.4 Clutter Image Rating Tool (CIR) 126

One problem with both the self-report and the observer-report of clutter is that they can be heavily influenced by individual interpretations of what constitutes clutter. For some people a room with a few piles of papers and books seems ‘heavily cluttered’, while for others the room would be seen as free of clutter.

The CIR is a novel assessment device designed to provide a measure of clutter that is more objective and not dependent on beliefs about what constitutes clutter. Unlike other tests for rating clutter, CIR requires no written language.

\textsuperscript{121} A case illustration and additional clinical considerations in the assessment of hoarding is provided.© Wiley Periodicals, Inc. J Clin Psychol: In Session 67:1–11, 2011.

\textsuperscript{122} Refer: The International OCD Foundation website http://www.ocffoundation.org/hoarding/tests.aspx


\textsuperscript{125} Frost, R., Developed this tool.

The scale contains nine equidistant photographs of clutter severity representing each of three main rooms of most people’s homes: living room, kitchen, and bedroom (refer Appendix 9).

In general, clutter that reaches the level of picture number 4 or higher impinges enough on people’s lives that they should be encouraged to get help for their hoarding problem. The scale has been demonstrated as being effective above level four.\textsuperscript{127}

The CIR helps eliminate different definitions of hoarding between data collectors and the under- or over-estimation of clutter. Different evaluators are able to use this tool to evaluate the level of hoarding in a household with very similar results, given CIR’s high test-retest reliability.

The CIR has been used in a variety of recent studies and has been found to correlate highly with the HRS-I, in particular, the clutter item and has also been found to be sensitive to treatment effects.\textsuperscript{128}

Use: The CIR measures only one component of hoarding, clutter and must be supplemented with measures of the other aspects of hoarding. The worker, person/s living in the environment, therapist or researcher, simply matches the level of clutter in the room being examined to one of the pictures in the CIR.

\textbf{Figure 5: Examples of difficult to access hoarding house and clean out of a squalid living environment}

\begin{figure}[h]
  \centering
  \includegraphics[width=\textwidth]{example_images.png}
  \caption{Examples of difficult to access hoarding house and clean out of a squalid living environment}
\end{figure}

7.3 Tools - squalor

Taking into account the subjective nature of the issue there have been several attempts to measure poor living conditions by measuring domestic squalor on a rating scale.\textsuperscript{129}

There are not many tools available for testing squalid environments, keeping in mind that squalor is reflecting a living environment, rather than the person/s living there. In many cases it would appear that the hoarding assessment tools are also used for squalor, particularly where the two conditions overlap.

7.3.1 Environmental Cleanliness and Clutter Scale (ECCS)\textsuperscript{130}

The tool most used for testing squalor environments is the ECCS (published July 2009), which provides a 10-item rating scale to rate the degree; severity and various aspects of clutter and uncleanliness in relation to squalid environments (refer Appendix 10). The ECCS was adapted from an earlier scale which had limited reliability and validity.

\textsuperscript{128} Tolin et al., 2010.
\textsuperscript{129} Central Sydney Area Health Service, 2003.
Using the ECCS, descriptions of cases can be grouped according to severity or into:
1. those where accumulation of useless items and articles have obstructed proper care of a person’s living conditions - ‘dry squalor’.
2. those where filth and refuse have accumulated because of failure to get rid of them; there may be filth without a lot of clutter or can be ‘wet squalor’
3. both (1) and (2).

The ECCS has good inter-rater reliability and validity when compared with other ratings of squalor. The overlap with hoarding is unknown, although one of the items on the ECCS is the accumulation of objects.

Use: The tool is seen as an excellent scale for use by workers, therapists, researchers and the person living in environment, as it is accessible and provides an immediate rating of where hoarding might exist.

The ECCS proved reliable and useful in rating cases where elderly people were living in severe domestic squalor. It is recommended that the tool be completed by more than one party to increase the likelihood of subjectivity.

7.3.2 The Living Conditions Rating Scale (LCRS)\textsuperscript{131}

Taking into account the subjective nature of the issue there have been several attempts to measure poor living conditions by measuring domestic squalor on a rating scale.\textsuperscript{132}

Use: The LCRS (refer Appendix 11) enables government and community organisations to gauge the nature and urgency of the issue. It promotes better planning and intervention strategies, especially when seeking the support and assistance of other agencies or family members.

For example:


\textsuperscript{132} Central Sydney Area Health Service. 2003.
8 Service response

In the context of theoretical uncertainties, people who show hoarding behaviours or live in squalor still need to be accurately assessed, supported and treated.

Worldwide reports suggest that agencies are generally uncoordinated and consequently inefficient when trying to intervene and offer assistance. Countries such as the UK, different states in the USA, Japan, Canada and New Zealand all contribute consistently to current thinking and positioning regarding the best way respond to compulsive hoarding or squalor across a variety of professions and sectors.

8.1 International and National

A broad body of international research and models of service response to compulsive hoarding is referred to throughout this paper including research, tools, checklists and efforts to show prevalence.

Identifying international domestic squalor intervention models has proven to be difficult due to the fact that the domestic squalor model is seemingly unique to Australia. Squalid environments exist worldwide, but are diagnosed in a range of different contexts depending on which country. For example, in the USA and UK domestic squalor is aligned with Diogenes Syndrome, self-neglect or elder abuse. The terms severe squalor and compulsive hoarding are often referred to interchangeably, without clarity or regard for definition, context or health status.

Australian service response to hoarding or squalor differs between states and territories. Distinct initiatives by discrete organisations are at times supported by a one-off commitment from a respective state or territory government. Some of these initiatives are presented in Appendix 5: Examples of national service response. Some Australian states and territories refer to the term severe domestic squalor to describe certain types of living conditions (refer Section 3.2).

Some community organisations and academics from a broad range of sectors have been working together endeavouring to instigate a national focus to coordinate and define appropriate and sustainable responses to squalor (refer Appendix 5: Examples of national service response).

8.2 Victoria

A broad range of sectors and disciplines in Victoria are involved in developing means and approaches to address the needs of people living in hoarding and/or squalid conditions (refer Appendix 12: Victorian local service response)

What initiatives are developed and how they are acted upon is often driven by the interest, determination and ability of particular staff and management in organisations in a local area or region. The capacity of a service or organisation to respond may depend on competing organisation/sector priorities or demands, resource availability or occupational, health and safety concerns, as well as not understanding the condition and consequent appropriate response.

Scope of service response

These programs and services are part of a local service mix that responds to compulsive hoarding cases. Service response varies from region to region and within regions, involving a diverse mix of Commonwealth, State and Local government resources as well as private businesses.

Table 8: Scope of Victorian service response

<table>
<thead>
<tr>
<th>State Government</th>
<th>Ageing and Aged Care</th>
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<tbody>
<tr>
<td>Department of Health</td>
<td>- Home and Community Care – (jointly funded by the Commonwealth and Victorian governments)</td>
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<tr>
<td></td>
<td>- Aged Care Assessment Services, Victoria (jointly funded by the Commonwealth and Victorian governments)</td>
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<td></td>
<td>- Low Cost Accommodation Support programs (Community Connections Program; Housing Support for the Aged; and the Older Persons High Rise Support program, funded by Aged Care, Mental Health, the Home and Community Care program (jointly funded by the Commonwealth and</td>
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133 Halliday et al.,2000.
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<thead>
<tr>
<th>State Government</th>
<th>Victorian governments</th>
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<tbody>
<tr>
<td><strong>Community Health Services</strong></td>
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<td><strong>Mental Health</strong></td>
<td>- Aged Psychiatric services</td>
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State Government

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<td>Geriatricians</td>
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<td>Psychologists</td>
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Other

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<td>estate management (rental properties)</td>
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<td>VCAT</td>
<td>evictions, rental arrears</td>
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<td>OPA</td>
<td>guardianship issues</td>
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<tr>
<td>Utility services</td>
<td>water, gas, electricity</td>
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<tr>
<td>RSPCA</td>
<td>RSPCA inspectors – role in relation to hoarding of animals (other than livestock species)</td>
</tr>
<tr>
<td>Environment Protection AuthorityVictoria</td>
<td>advice regarding transport and disposal of contaminated items (asbestos or chemicals)</td>
</tr>
<tr>
<td>ChildFIRST/Family Services</td>
<td>funded by Department of Human Services to support vulnerable children and families</td>
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Private business

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<th>Role</th>
<th>Services/Issues</th>
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<tbody>
<tr>
<td>Specialist Clinical Practitioners</td>
<td>Dr Christopher Mogan a Clinical Psychologist, Director of The Anxiety Clinic, Richmond, with compulsive hoarding expertise having completed the first major study of Compulsive Hoarding in Australia (refer 8.3.2).</td>
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<tr>
<td></td>
<td>Professor Michael Kyrios holds the Chair in Psychology in the Faculty of Life and Social Sciences, Swinburne University of Technology where he is Director of the Brain and Psychological Sciences Research Centre (BPsyC), and chairs the Executive Committee of the National e-Therapy Centre (refer 8.3.3). He is a researcher, teacher, trainer, supervisor and practitioner with world leading expertise in compulsive hoarding. He supervised Dr. Mogan’s study, collaborates with Professors Frost and Steketee from the USA, and leads a team of clinicians and researchers focusing on hoarding.</td>
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<tr>
<td>Industrial cleaning companies</td>
<td>sensitive to the needs and approaches required to clean/organise the home of people with compulsive hoarding problems and/or living in a squalid environment (refer Useful resources).</td>
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<td>rental properties (issues regarding eviction)</td>
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<td>Amenities companies</td>
<td>water, gas, electricity</td>
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<td>Legal practitioners</td>
<td>estate management, financial management</td>
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Department of Health

8.2.1 Ageing and Aged Care Branch

- Home and Community Care (HACC)

The HACC Program offers a range of services to support frail older people, younger people with disabilities and their carers. These services provide basic support and maintenance to people living at home and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long-term residential care. Services available include domestic assistance, property maintenance, delivered meals, social support and day programs, assistance with showering and other personal care requirements.

This program is funded jointly by the Commonwealth and Victorian governments. Local government in Victoria is a major provider of HACC services and also contribute significant funding to the services they provide. Other HACC providers include community health services, district nursing services and a wide range of non-government organisations including Aboriginal and ethno-specific organisations.

As a generic service program, HACC services understand that service response to compulsive hoarding cases relies on clinical and practical expertise. Home and Community Care service providers are aware that it is part of a broad range of service types and disciplines that might assist in such cases. Occupational Health and Safety considerations need to be taken into account (refer 9.3.1).

Currently some HACC funded providers respond to compulsive hoarding on a case by case basis along with other services, such as municipal local laws, RSPCA or CFA. HACC funded providers might also participate in local education sessions to better understand the nature of compulsive hoarding.
• **Aged Care Assessment Service (ACAS)**

The Aged Care Assessment Service (ACAS) consists of independent teams who assist frail older people and their carers to identify what kind of care will best meet their needs. The teams are multi-disciplinary and include health professionals such as medical officers, social workers, nurses, occupational therapists and physiotherapists.

They conduct comprehensive assessments for people needing community services or residential aged care services and assess for all restorative and potential care options. ACAS approval is mandatory for access to Commonwealth funded residential care, residential respite, Community Aged Care Packages (CACPs), Extended Aged Care in Home (EACH) packages or Extended Aged Care in Home Dementia (EACHD) packages and flexible care. ACAS teams do not deliver in-home support or residential care services, but may provide short term care coordination in complex cases.

ACAS teams may support other service providers to engage eligible clients in cases involving compulsive hoarding. Some ACAS teams are more engaged in local sector response to compulsive hoarding than others. The extent of ACAS involvement varies across teams depending on capacity, the mix of other service providers in local areas, and the particular professional interest in that health service or locality.

ACAS currently has no standardised tools or best practice standards developed to address compulsive hoarding cases.

• **Low Cost Accommodation Support Programs**

All three programs below provide support by funding community based organisations (refer Appendix 13) which provide services to people with complex needs, including people with compulsive hoarding behaviours.

**Community Connections Program (CCP)**

The CCP recognises that people with multiple or complex needs who are homeless or living in insecure or low-cost accommodation are often very isolated and not well connected into health, housing or community services. These people tend to have difficulty negotiating their way around services and often slip through the gaps in service systems.

The CCP uses an assertive outreach model to proactively find, engage, assess, and link people into the services they need. Each CCP service has a pool of flexible care funds to assist clients to overcome a pressing need or crisis. There are currently 16 CCP services located across Victoria, most commencing in the year 2000. CCP services are HACC and Aged Care funded. This program currently has no age limit, nor any defined period of engagement with the client.

CCP works with local services assisting them to become more accessible and responsive to the needs of this client group.

**Housing Support for the Aged Program (HSAP)**

HSAP supports people 50 years and over with complex needs and a history of homelessness to maintain long-term public housing and improve their health and wellbeing. Ongoing case management and support is provided as they enter public housing through the priority segments of the Segmented Waiting List or into community managed housing, or those already in public housing where their tenancy is at risk.

This client population typically have:

- complex support needs associated with combinations of conditions (for example, psychiatric disability, alcohol or drug dependence, acquired brain injury, sensory disability, age-related frailty or chronic health issues)
- a history of homelessness and social marginalisation
- minimal support from friends and family and not well linked into services.

HSAP provides low-level monitoring, case management to coordinate client access to services, and practical assistance such as helping clients to get to appointments or linking them into social and recreational activities. Workers have access to a flexible pool of funds to overcome crises (including evictions) or respond to a pressing need that cannot be readily met by existing services.

HSAP clients are usually identified and referred by CCP. There are currently 13 HSAP services in Victoria, most commencing in 2000-2001 and funded by Aged Care. Most employ one worker and have a capacity to support 20 to 25 clients at any point in time.
The Older Persons (OP) High Rise Support program

The OP High Rise Support program commenced in 2001–02 and is funded by the Aged Care Branch to provide monitoring and support to tenants of eleven older persons’ high-rise public housing estates in the inner suburbs of Melbourne.

On-site workers use a case management or outreach approach to ensure isolated and vulnerable tenants are linked to support and services. These tenants often lack support from friends and family and may have a history of not being well linked into health and community services. People with mental illness, drug or alcohol dependence and acquired brain injury are highly represented.

OP High Rise Support workers have a flexible pool of funds which are used to assist vulnerable tenants who have unmet, complex needs and to access services. The workers provide an accessible point of contact, information and referral for all tenants, which contribute to their sense of safety, independence and security, contributing to their involvement in social activities and community life.

Additional comments:

The CCP was designed as a throughput model with Care Coordination. Over time, it has become a case management service although this was not the original intention.

All three of these programs tend to work with highly complex clients. Consequently it is often difficult to refer to the generic service provider. All three programs respond to hoarding cases and are involved in the life of the client. The specifics around how to respond to hoarding are left up to staff at the local level.

8.2.2 Integrated Care

The Hospital Admission Risk program (HARP) provides specialised client-centred medical care and care coordination in the community or ambulatory setting through an integrated response of hospital and community services. HARP aims to:

- improve patient outcomes
- provide integrated seamless care within and across hospital and community sectors
- reduce avoidable hospital admissions and emergency department presentations
- ensure equitable access to healthcare.

Some HARP programs, depending on their purpose, respond well to cases of hoarding and squalor (refer Appendix 12: Point 8).

8.2.3 Public Health, Environmental Health Unit

The Environmental Health Unit (EHU) responds to a range of issues including complaints, enquires or concerns in relation to hoarding and squalor.

The Public Health and Wellbeing Act (PHWA) 2008 (effective January 2010) replaces the previous Health Act 1958. The PHWA updates and modernises Victoria’s public health framework and is a key piece of legislation designed to protect the health of the population.

The EHU sees that a multi-disciplined, multi-sector response is required to better address and sustain improved outcomes for people with hoarding behaviour, their families and when appropriate, the nearby community.

Tools that may be useful for an environmental health officer in determining a ‘nuisance’, in addition to setting goals for a clean-up, are the ‘Clutter-Hoarding Scale’, with parameters on health and safety issues and, the ‘Clutter Image Rating’. This shows a series of hoarding images to assist in rating the extent of hoarding and for communication of this information to other agencies, for example, ‘bedroom is class 7 on the Clutter Image Rating’.

An authorised officer has the following powers in seeking to enter a residential premise:
• **With the consent of the occupier**, as per section 168(1)(b), for the purpose of investigating whether there is a public health risk or to manage or control a risk to public health, an officer may enter any premises including any residential premises. Consent is not required to enter a public place.

• **Without a warrant at any time if**, as per section 169(2)(a), the officer believes there may be an immediate risk to public health; and, (b) the entry is necessary to enable the authorised officer to investigate, eliminate or reduce the risk.

• **At any time**, as per section 169(3), for (a) the purposes of investigating a possible contravention of this Act or the regulations, with the consent of the occupier; or (b) with a warrant issued under this Act.

b) **Part 6 PHWA (Prescribed Accommodation)** applies mainly to rooming houses and associated health standards and conditions.

- Consumer Affairs Victoria has certain responsibilities under the *Residential Tenancy Act (1997)* – regulating tenancy relationships between a landlord and tenant as well as regulating rooming house agreements between rooming house residents and rooming house operators.
- Local government health promotion officers are linked and supported by the Department of Health, Prevention and population health unit.

Responding to hoarding and/or squalor cases can draw a response from any or all of these contact points.

### 8.2.4 Mental 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.

Specialist clinical mental health services in Victoria are provided on an area basis, and are often referred to as area mental health services. They include adult mental health services, child and adolescent mental health services and aged persons mental health services providing services primarily to people aged 65 years and over. Each of these service categories provides inpatient psychiatric services, in addition to a range of residential and other community-based services.

The presence of a mental illness does not in itself necessitate a referral to a specialist mental health service. Most people with a mental illness are effectively managed by services in the community such as GPs or non-specialist community based services. People enter the Area Mental Health Service (AMHS) system not because of a particular diagnosis but because the level of risk or behavioural disturbance that cannot be managed safely by their GP or general community based service providers.

AMHS components are made up of multidisciplinary teams that provide community-based assessment, treatment, rehabilitation and case management, acute inpatient services, and specialist bed-based services in residential care.

Access to specialist mental health clinical services is via triage which is centralised for each catchment area. Telephone contact numbers can be accessed at [http://www.health.vic.gov.au/mentalhealth/services/index.htm](http://www.health.vic.gov.au/mentalhealth/services/index.htm)

Responses to people with hoarding behaviours are assessed on a case by case basis.

### Department of Human Services

#### 8.2.5 Multiple and complex Care Initiative (MACNI)

The Multiple and Complex Needs Initiative (MACNI) was implemented in August 2004, as a result of a history of concerns that the government was delivering poor service outcomes for a small but significant group of individuals with complex needs that challenged existing policy and legislative frameworks.

MACNI targets individuals 16 years and older with multiple and complex needs, centreing on a time-limited specialist intervention that aims to:

- stabilise housing, health, social connection and safety
- pursue planned and consistent therapeutic goals for each individual, and
- provide a platform for long term engagement in the service system.
On 1 June 2009, new legislation via the Human Services, *Complex Needs Act 2009* devolved some of the decision making powers to Department of Human Services regions and some change to the MACNI model including:

- Legislation which remains in place to determine eligibility criteria, a framework for assessment and care plan coordination, information sharing provisions and right of refusal. The statutory body MACNI Panel ceased.
- The maximum service period increased from two to three years, to include assessment, planning and transition.
- The continuation of specifically funded Community Service Organisations (CSOs), 10 staff, a state-wide remit, to conduct assessments, develop and coordinate care plans, with a strengthened role in secondary consultation and mentoring with local agencies and with regional panels.
- Access to brokerage funding regionally and centrally. Regions can approve locally held brokerage funds; extra funds, available centrally, can be approved on application.
- A Central Eligibility and Review Group (CERG) consisting of senior program managers and senior practitioners from the Department of Human Services, Department of Health and Department of Justice, as well as community experts (including former MACN Panel members) - determine eligibility.
- Regions approve and review care plans as needed, but are subject to periodic review by CERG, including when central brokerage funds are requested.

MACNI is a tightly focused program, predominately addressing the needs of people living with substance abuse and related concerns. Service Delivery and Performance (SDP) coordinates MACNI funding. MACNI care plan coordinators may respond to hoarding issue on a needs basis, case by case.

**8.2.6 Housing and Community Building (H&CB)**

H&CB provides public and social housing and support for those most in need, including homelessness and crisis support, affordable rental housing and training and employment opportunities for people in public housing. H&CB aims to drive a more connected service that offers not only stable housing, but the opportunity and support for people to grow and thrive in their community.

A) **Support for High Risk Tenancy Program (SFHRT)**

SFHRT evolved from a Department of Human Services Strategic project (2005–06), into receiving additional funds (2008-12) to achieve the objectives from the original pilot which were to strengthen the human service system response to complex clients through the integration and co-ordination of services to:

- facilitate access to service responses to address client need
- create sustainable tenancies for individuals or households with high and complex needs
- develop greater understanding of client needs and service response options and promote learning
- identify service development opportunities (gaps) and action these with the aim of increasing regional capacity.

The program underpins Department of Human Services principles of prevention or early intervention, joint working, planned and coordinated service delivery and flexibility in the type and duration of service response and resourcing.

The project focused specifically on high-risk tenancies in public housing. In certain circumstances, however, clients with complex needs who were not currently residing in public housing could also be eligible for consideration by the regional coordinator.

The project recommendations highlighted that people in high-risk tenancies were identified as having many problems and complex life situations, with characteristics similar to other Department of Human Services high risk client groups who often require a service response crossing program boundaries, as well as requiring coordination and flexibility. A priority Action Plan identified four main priorities:

1. make links with and build on established initiatives
2. resource development and staff training
3. consolidate evidence about the client group and what works
4. establish regional coordination processes.

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Much of the implementation of the Action Plan is undertaken at a local level between Department of Human Services regional programs, other sectors and a broad range of service providers. SFHRT regional coordinators are able to lead the case coordination or planning phase.

The SFHRT Regional Coordination program has brokerage money which provides in hoarding cases, the resource flexibility required for things like clean ups and purchasing case management services.

**Eligibility** - referral to the SFHRT program requires that:
- the person is not responding to multiple intervention attempts
- the person is experiencing extraordinary difficulty accessing required intervention
- the person has exhausted many of the common interventions for their presenting behaviours or circumstances
- the service system has experienced ongoing difficulty with engagement including assertive outreach
- there is evidence of enduring and repeatedly poor outcomes
- the person is experiencing multiple and repetitive crises
- there is a multiplicity of views among program or service providers regarding the most appropriate service response(s) and no clear agreement on a way to proceed.

**Regional Coordinator’s role involves:**
- acting as the single point of entry to the service coordination process, including providing secondary consultation to programs that are considering making a referral
- enhancing regional service coordination across Department of Human Services programs and the community service sector
- coordinating services around individuals or families to sustain their tenancy
- regional coordinators receiving direction and support from a regional panel, who have expertise in working with complex clients and make recommendations in response to individuals or families referred.

**Compulsive hoarding response**
People with hoarding behaviours became a visible high risk client group, through the SFHRT eligibility criteria, so the Office of Housing took steps to address it by determining that hoarding:
- affected the person’s capacity to maintain their tenancy agreement (public or private) thereby placing themselves at risk of eviction
- potentially provides a key pathway to homelessness (for example, rental arrears and unpaid bonds), and
- draws media attention.

**The SFHRT program** has collected two sets of data since the commencement of the program:
- A collation of biannual reporting (July 2009–June 2010) compiled into a state-wide report, provided a snapshot of the SFHRT client demographic and major themes being experienced with at-risk tenancies. Originally the system design did not include hoarding data, but this requirement has now been built into the SFHRT annual data collection system.
- As hoarding became more evident, a snapshot report was undertaken of an identified high-risk cohort. The data reports on targets, activities and brokerage relating to hoarding/environmental neglect/squalor for the period July 2010 to May 2011.

**Figure 6: SFHRT Data report hoarding/environmental neglect/squalor July 2010 - May 2011**

<table>
<thead>
<tr>
<th>SFHRT Hoarding data July 2010 - May 2011</th>
<th>Program targets</th>
<th>Actual referrals</th>
<th>Number identified as Hoarding</th>
<th>Brokerage spent on hoarding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statewide</td>
<td>300</td>
<td>488</td>
<td>181</td>
<td>64%</td>
</tr>
</tbody>
</table>

- The Department of Human Services, Office of Housing developed a draft hoarding information kit and flow charts (refer Appendices 14 and 15) and adapted some practice tools for SFHRT regional coordinators to implement locally.
- SFHRT regional coordinators developed various local strategies based on this information (refer Figure 7 and Appendix 12:point 1, Housing - SFHRT), working with a mix of local service providers from a range of sectors, to support people with compulsive hoarding behaviours.
Figure 7: Summary of SFHRT hoarding tasks July 2010 - May 2011

<table>
<thead>
<tr>
<th>Summary of SFHRT Central and regional tasks achieved - July 2010 to May 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provided service coordination (case conferencing) and brokerage to assist in sustaining tenancy.</td>
</tr>
<tr>
<td>• Developed an information toolkit (includes terms of reference, clutter rating chart and service mapping flowcharts).</td>
</tr>
<tr>
<td>• Contributed funds to support a symposium and two workshops on compulsive hoarding held by the Australian Psychological Society at the International Congress of Applied Psychology (ICAP).</td>
</tr>
<tr>
<td>• Provided funds to implement training on compulsive hoarding to housing staff and SHASP providers, state-wide.</td>
</tr>
<tr>
<td>• Created a regional sub working group, to focus on the research data collected that will feed into the regional project.</td>
</tr>
<tr>
<td>• Provided regional training sessions for housing staff and SHASP providers.</td>
</tr>
<tr>
<td>• Established a regional hoarding working group with a range of interested stakeholders. This group has evolved and split into an interest group and an action group.</td>
</tr>
<tr>
<td>• Facilitation of a forum on hoarding.</td>
</tr>
<tr>
<td>• Developed regional guidelines on the use of brokerage for hoarding and environmental neglect.</td>
</tr>
<tr>
<td>• Funded two professional consultation sessions with specialist psychiatrist to discuss cases and reflect on practice.</td>
</tr>
<tr>
<td>• Contributed funds towards a launch event.</td>
</tr>
<tr>
<td>• Held regional information sessions for all interested stakeholders including mental health, housing, aged care, disability and other local services.</td>
</tr>
<tr>
<td>• Funded regional, quarterly professional consultation sessions with a specialised psychologist to provide debriefing and advice on practice in relation to supporting those with hoarding issues.</td>
</tr>
<tr>
<td>• Actively participating in a local government working group developing strategies around hoarding response.</td>
</tr>
</tbody>
</table>

B) The Social Housing Advocacy and Support Program (SHASP)

SHASP is a Victorian Government initiative planned to achieve improved housing outcomes for social housing tenants and public housing applicants, forming part of the government’s ongoing commitment to sustainable tenancies. Community service organisations (CSOs) are funded to support public and social housing tenancies via the following approaches:

- Establishing Successful Tenancies (EST)
- Intervention At Risk Tenancies (IART)
- Early Housing Applications (EHA)
- Advocacy (A)

The program provides assistance to tenants to overcome literacy and language difficulties that prevent them from understanding and responding to contact from the Office of Housing (OoH), as well as involving tenants in the service planning and management of SHASP services.

C) Homelessness Accommodation and Support

Victoria has an integrated homelessness and housing system which is designed as a progressive pathway out of homelessness. The Homelessness Accommodation and Support Unit is responsible for homelessness program development including crisis, transitional and supportive housing responses.

The Victorian Homelessness Action Plan 2011-2015 is committed to providing greater assistance to vulnerable Victorians to tackle underlying causes of homelessness. The range of people experiencing homelessness includes a small but significant cohort of clients with high and complex needs who have experienced chronic homelessness, multiple tenancy breakdowns or abandonment and sleeping rough for prolonged periods. These individuals typically often interact with or come to the notice of high cost emergency or crisis services in the community, with no discernable effect on their wellbeing or long term housing stability.

Practice and research with this client group indicates a high level of trauma preceding or coinciding with the onset of homelessness and a close association with a persistent vulnerability to homelessness among this client group. A range of responses to this client group are being explored by specialist homelessness support services including:
Melbourne Street to Home (MS2H): a partnership between HomeGround Services, Salvation Army Adult and Crisis Services and the Royal District Nursing Service. MS2H identifies and prioritises people in long term primary homelessness (rough sleepers) according to the fragility of their health, provides assertive outreach, accommodation and housing focused support with the aim of tenancy retention and positive health outcomes.

Journey to Social Inclusion (J2SI): Sacred Heart Mission. J2SI is a pilot project (over three years from November 2009); assisting up to 40 chronically homeless people to break the homelessness cycle by developing skills to successfully transition into mainstream life. J2SI draws on research that shows people who are chronically homeless can benefit from individually tailored, on-going, intensive support.

Supportive Housing: Housing and Community Building (H&CB) is developing a range of supportive housing responses that provide safe, long-term affordable housing combined with support services for tenants according to their identified needs. These responses particularly support chronically homeless people with high needs, including those on low incomes experiencing mental health, drug, alcohol and other issues that can restrict capacity to access secure housing and the support treatments they need.

The people involved in the above programs live with extremely complex issues requiring an integrated approach from specialist services. One vulnerable cohort within the homelessness service system are people with hoarding behaviour who require an intensive, coordinated and longer-term response to stabilise and manage their circumstances.

8.2.7 Disability
The Victorian disability service system provides supports for people with a disability whose impairment meets the definition of disability as defined in the Disability Act 2006 and the priority for access indicators as outlined in Disability Services Access Policy.

Disability support services are based on individualised approaches that support people with a disability to live in their community and complement other funded support available through the broader service system such as health, housing and community services.

While the disability services system does not have any specific initiatives that target people with compulsive hoarding behaviours or who live in squalor, consideration of the potential impairment of a person with a disability in these circumstances is a key indicator in individualised planning processes and whether a disability service system response is the most appropriate.

For a person with a disability to access specific disability services, a support plan is established that outlines their needs and goals as well as the strategies required to meet them. This would include a response to hoarding behaviour and/or squalor if appropriate, and where relevant, referral to other appropriate services such as mental health.

8.2.8 Protective Services
The Department of Human Services Child Protection program receives reports of children at risk as a result of child abuse or neglect. Sometimes a report may be about the impact on a child of a parent’s hoarding behaviour or squalid living conditions, or these issues may be identified during the course of child protection involvement.

Where living conditions pose a significant risk of harm to children, the department will make substantial efforts to assist the family to address the situation. This may include engaging other services such as family services, local government, mental health and practical support such as arranging and funding industrial cleaners or rubbish removal. Children may be placed out of home if necessary to ensure their safety and development. This can occur either by agreement with their parents or by court order, depending on the circumstances.

8.2.9 Youth Justice
The Department of Human Services is responsible for the statutory supervision of young people in the criminal justice system. The department’s Youth Justice Service provides programs and resources to assist these young people to develop the knowledge, skills and attitudes to manage their lives effectively without further offending.

Through supervision, offending related programs and linkages to appropriate support services, Youth Justice promotes opportunities for rehabilitation and development of life skills and works with other services to strengthen community-based options for young people.
Should hoarding and squalor behaviours be identified as impacting on a young person’s ability to remain in the community and sustain an offence free lifestyle, Youth Justice will link the young person with appropriate support services and arrange practical support such as funding industrial cleaners or rubbish removal and in some circumstances assist with minor repairs and maintenance.

Department of Primary Industry (DPI)

8.2.10 Bureau of Animal Welfare (BAW)

The DPI, BAW is the State Government’s animal welfare policy and legislation unit formed to be the focal point for liaison, co-ordination and co-operation in animal welfare matters between the states, Commonwealth Government, local governments and animal welfare agencies in Victoria. The Bureau administers the *Prevention of Cruelty to Animals Act 1986* and the *Domestic Animals Act 1994*. For general information on animal hoarding refer to Section 2.5.

Animal hoarding investigations and enforcement are the responsibility of DPI’s Animal Health Field Services group, the RSPCA and Local Government. DPI and the RSPCA have a Memorandum of Understanding that DPI will take the lead in investigating animal hoarding in primary production enterprises, and RSPCA will take the lead in investigating the cruelty aspects of animal hoarding in all other cases. Local Government officers such as Animal Management Officers have a role in investigating excess numbers of animals (specified under Local Laws), and those Local Government officers authorised under the *Prevention of Cruelty to Animals Act 1986*, may also investigate cruelty cases.

Following an RSPCA seminar on animal hoarding in 2009, a Victorian Animal Hoarding Advisory Group (AHAG) was formed, with representatives from the RSPCA, Local Government, Australian Veterinary Association and DPI. AHAG is managed and chaired by BAW in DPI. Its objectives are to:

- Consider the relevant legislation in regards to how effectively it addresses animal hoarding cases, and ascertain whether amendments are needed.
- Provide the chair of AHAG with animal hoarding specific advice, to share at broader government forums/meetings on hoarding to ensure animal welfare, as well as human welfare is considered.
- Direct the work of AHAG’s two working groups (Data Collection and Operational Resources).
- Implement action plans arising from meetings, utilising contact networks within industry to circulate information.

AHAG’s Data Collection working group is collecting data such as, the average cost of animal hoarding cases, and the frequency and details of cases, which can be utilised to provide information about animal hoarding to broader government forums/meetings.

A Masters in Animal Science student has completed two projects – one looking at the extent of animal hoarding in Victoria (refer Section 2.5.3), the other using focus groups of RSPCA Inspectors and Local Government officers to investigate their experiences with animal hoarders in Victoria.

An Honours student has also completed a project examining case studies of animal hoarding in Victoria.

AHAG’s Operational Resources working group is developing resources for enforcement officers dealing with animal hoarding cases, including guidance on how to interact with hoarders. AHAG has sought the advice of a clinical psychologist who specialises in hoarding disorders to assist in developing these resources. The aim is to assist officers in dealing with animal hoarders at an ‘early intervention’ stage, aiming to prevent cases progressing to poor animal welfare and cruelty and also at the cruelty stage, when animals have to be seized.

AHAG has assessed whether the Mental Health First Aid course would be of assistance to officers, and has concluded that a more targeted training program would be of greater assistance.

Commonwealth Government programs

8.2.11 Personal Helpers and Mentors (PHaMs) service

The Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs, commenced funding the Personal Helpers and Mentors (PHaMs) service in May 2007. It aims to provide increased opportunities for recovery of people whose lives are severely affected by mental illness.

The service takes a strengths-based, recovery approach assisting people whose ability to manage their daily activities and to live independently in the community is impacted because of a severe mental illness. A recovery approach recognises that a person can live a satisfying and contributing life within the limitations caused by the illness. Recovery does not mean cure.
The program consists of a Program Manager, Volunteer Co-ordinator, Outreach Support workers and a Recovery Guide, working with people to assist with:

- increased access to appropriate support services at the right time
- improved coordination of care
- increased personal capacity of self reliance
- increased community participation.

Training is provided for volunteers, who are linked with individual clients of the service for the provision of friendship and social support.

To be eligible for PHaMs a person must:

- Be 16 years of age or over.
- Score three or more on the Eligibility Screening Tool (EST) assessing the impact of mental illness alone.
- Be willing to participate in the service voluntarily and able to make an informed decision to participate.
- Complete the FaHCSIA provided data transfer consent form.
- Be willing to address dual diagnosed/co morbid drug and alcohol issues during program participation.
- Not be restricted in their ability to fully and actively participate in the community due to their residential setting.
- Not be receiving or entitled to receive non-clinical community support similar to PHaMs through the state or territory government as a result of their detention or incarceration.

*Note: People who are homeless are automatically eligible for PHaMs.

The PHaMs eligibility criteria, program structure and flexible timeframe respond well to meet the engagement needs of a person with hoarding behaviour.

8.2.12 Community Aged Care Packages

The Commonwealth Department of Health and Ageing funds packages legislated under the Aged Care Act 1997 (the Act) that target older people with complex care needs who wish to remain living in their own homes (including residents of retirement villages), and are able to do so with the assistance of a care package. They must first be assessed by an Aged Care Assessment Service (ACAS) to determine the type and level of package required.

People can self-refer or be referred through a hospital, community clinic, community nurse, General Practitioner or other community services. There are three types of packages:

- **Community Aged Care Packages (CACPs)** – target older people with low level care needs, principally providing services to meet their daily living needs which may include bathing, showering, or personal hygiene, toileting, dressing or undressing, mobility, transfer, preparing and eating meals, sensory communication, fitting sensory communication aids, laundry, home help, gardening, or short-term illness.

- **Extended Aged Care at Home (EACH)** – target older people including personal assistance with high level care needs which may include: registered nursing care, allied health care (that is, physiotherapist, podiatrist or other), personal care, transport to appointments, social support, home help, and assistance with oxygen and/or enteral feeding.

- **Extended Aged Care at Home Dementia (EACHD)** packages are tailored to help older people who experience difficulties in their daily life because of behavioural and psychological symptoms associated with dementia. Package services are very flexible providing the same full range of services that EACH packages provide (refer above). They also offer service approaches and strategies to meet the specific needs of care recipients with dementia who experience behaviours which may impact on their daily quality of life.

The flexible application of community aged care packages adheres well to be able to assist an older person with a hoarding condition and/or who may be living in squalor.

8.2.13 Assistance with Care and Housing for the Aged (ACHA)

The ACHA program aims to support older people to secure or maintain housing and care in order to effectively live in the community of their choice. Services under the Program can include:

- identifying frail older clients with support needs
- linking clients to suitable care options
- linking clients to housing services
• advocacy and
• linking clients to other relevant services (for example, Aged Care Assessment Services, Aboriginal and Torres Strait Islander communities).

ACHA is a linkage program largely provided by charitable or religious not-for-profit organisations, rather than a program that provides ongoing care. ACHA providers work with state government housing authorities to assist eligible clients to obtain better, more stable accommodation. The type of assistance provided for ACHA clients varies suiting the needs of the individual who is then linked to appropriate community services.

<table>
<thead>
<tr>
<th>Service Area</th>
<th>Victorian ACHA service providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Port Phillip LGA</td>
<td>Sacred Heart Mission, St Kilda</td>
</tr>
<tr>
<td>Maribyrnong and Brimbank LGAs</td>
<td>Western Region Health Centre, Footscray</td>
</tr>
<tr>
<td>Mansfield, Wangaratta, Benalla, Alpine, Wodonga, Indigo, and Towong LGAs</td>
<td>The Salvation Army Pathways, Shepparton</td>
</tr>
<tr>
<td>Yarra, Darebin, Banyule and Nillumbik LGAs</td>
<td>Spectrum Migrant Resource Centre, Preston</td>
</tr>
<tr>
<td>Knox, Maroondah and Yarra Ranges LGAs</td>
<td>Villa Maria Eastern Community Services, Brandon Park</td>
</tr>
<tr>
<td>Bayside, Kingston and Dandenong LGAs</td>
<td>Southern Health Community Aged Care Services, Dandenong</td>
</tr>
<tr>
<td>Stonnington LGA</td>
<td>New Hope Incorporated, Prahran</td>
</tr>
<tr>
<td>Mildura LGA</td>
<td>Mallee Accommodation and Support Program, Mildura</td>
</tr>
<tr>
<td>Yarra, Darebin LGAs</td>
<td>Homeground Outreach, Collingwood</td>
</tr>
<tr>
<td>Maribyrnong LGA</td>
<td>City of Maribyrnong, Footscray</td>
</tr>
<tr>
<td>Boroondara LGA</td>
<td>Salvation Army EastCare, Hawthorn</td>
</tr>
<tr>
<td>Melbourne LGA</td>
<td>Wintringham Northern Office, Ascot Vale</td>
</tr>
</tbody>
</table>

ACHA is a relatively small but essential service funded by the Commonwealth Government with a national budget in 2011-2012 of $4.637 million.

8.2.14 Respite and Carelink Centres

The national network of Commonwealth Respite and Carelink Centres are information centres for older people, people with disabilities and those who provide care and services, which provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia.

The Centres also arrange respite when carers need to take a break from caring by acting as a single contact point for information need by carers, and by organising, purchasing or managing respite care assistance packages for carers. Hoarding is addressed on a case by case basis, working with other providers to address the breadth of need.

8.3 Other key stakeholders

8.3.1 Municipal Association Victoria (MAV)

The MAV is well aware that cases involving hoarding and squalor have and do exist in municipalities, but at this stage does not hold a specific position. The MAV knows that local council practitioners in environmental health, local laws, town planning enforcement, the HACC program and animal management services have a broad range of accumulated knowledge and skills to address such cases.

Councils are generally contacted by mental health services or police due to a safety or nuisance concern, of the person, their family or neighbours with regard to impact on the environment or public health, on their local amenity or their own property.

The Victorian State and Local Government Environmental Health Officer’s (EHO) are authorised under the Public Health and Wellbeing Act 2008 (PHWA) which imposes a statutory obligation on the Minister for Health and each local council, to promote proper standards of public and environmental health within the state and each jurisdiction respectively.

Section 58 of the PHWA (nuisance provision) as well as the Municipal Association of Victoria PHWA Guidance Manual for Local Government Authorised Officers (2010) provides more detailed information regarding the use of the PHWA 2008 enabling response to hoarding situations.

Local Laws officers act in accordance with the discreet local laws of each Council. Not all councils have a local law enabling response to concerns about hoarding or squalor.
Animal Management officers act in accordance with:

1. The *Prevention of Cruelty to Animals Act 1986* contains various sections relating to how animals are to kept and cared for – for example. Section 9 ‘Cruelty’ and Section 10 ‘Aggravated Cruelty’ specify offences relating to the care and treatment of animals.

2. In addition, the *Codes of Practice*, created under Section 7 of the *Prevention of Cruelty to Animals Act*, specifies how animals should be kept and cared for.

3. Under Section 42, Part 3, Division 4 of the *Domestic Animals Act 1996*, each municipal council can make local laws relating to the number of animals which may be kept and these can differ from council to council.

The HACC program acts in accordance with established government policy, procedures and practice.

The MAV has undertaken no specific consultation with local governments to determine a response to hoarding. In October 2011, the State Council of the MAV resolved that the MAV ask the Victorian Government to investigate the extent and impact of hoarding across Victorian local governments with a view to developing a collaborative framework to address this burgeoning issue.

### 8.3.2 Dr Christopher Mogan, Clinical Psychologist (The Anxiety Clinic, Australia)

Dr Mogan collaborates with the SwinPsyCHE Research Centre at Swinburne University in research and training in Compulsive Hoarding. He runs training workshops for health professionals in compulsive hoarding and related areas and is actively involved with professionals from MFB, Department of Human Services, Office of Housing, local government and the RSPCA. He seeks to raise awareness and provide education about hoarding issues including animal hoarding.

Currently Dr Mogan runs two hoarding treatment support groups called Compulsive Hoarding and Acquiring: Group (CHAG) for individuals, couples and families in the community - one at the Inner South Community Health service, the other at Swinburne University. CHAG is a 12 session group program addressing problems with compulsive hoarding and acquiring.\(^{135}\)

This group treatment program for hoarding is based on a program developed by Randy Frost and Gail Steketee (USA) based on principles of ‘cognitive behavior therapy’ which aims to help people develop the skills to deal with their hoarding (for example, decision making, tolerance for emotions associated with sorting). The program was adapted for Australia by the Swinburne Psychology Clinic (Prof. Michael Kyrios’ research group). As the treatment group is not government-funded, participants require a Mental Health plan to be developed by a GP in order to enable payment through Medicare. Dr Mogan also treats individuals.

With regard to community-based practice, Dr Mogan suggests that in some cases, particularly for previously homeless or complex clients, it is difficult to engage clients in treatment because of the need to have a referral from a GP; difficulties with travelling to the clinic and the willingness or capacity to engage in social activities.

Dr Mogan indicates that an ongoing relationship with a key worker is the main determinant of success with hoarding cases. He supports enhancing existing service system responses at a home care or case management level, coupled with access to therapeutic resources. Workers need to be skilled to be able to engage the client in addition to offering cleaning services. Progressive change is visible - photographs are a useful tool to show improvements to clients marking progress, offering positive reinforcement.

Dr Mogan suggests there is an absence of research around the needs of children in hoarding households, and that an evidence base needs to be developed in relation to this issue.

### 8.3.3 Professor Michael Kyrios – Swinburne University

Professor Kyrios collaborates internationally on compulsive hoarding research and publications, including DSM-V developments. He specialises in the study of depression, anxiety and obsessive-compulsive spectrum disorders (OCD, compulsive buying and hoarding, problem gambling, Body Dysmorphic Disorder [BDD]) and chronic medical illnesses.

Prof Kyrios presents regularly and frequently at Victorian, National and International conferences on compulsive hoarding, including squalor. He works with Professors Randy Frost and Gail Steketee (USA) on the study of compulsive hoarding and was an invite to be a consultant on a hoarding-related project funded by the National Institute of Mental Health in the USA. Having undertaken studies of compulsive hoarding in Australia, he subsequently supervised Dr. Chris Mogan's PhD study and has continued to develop manual interventions, internet-based resources and intervention, training modules, and models of care for people.

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experiencing hoarding problems. He continues to lead a team at Swinburne University that studies compulsive hoarding, which includes Dr. Richard Moulding, Dr. Sunil Bhar and Dr. Maja Nedeljkovic. He has a range of research and clinical resources at Swinburne University focused on compulsive hoarding.

Prof Kyrios advocates strongly for government (state or federal) to help establish a standardised service response framework (including tools to assist a practical response); specialist and generalist services, both practical and clinical; opportunities for intersectorial and interdepartmental collaboration, communication, and training; broad, consistent educational opportunities for workers and managers as well as enhanced research opportunities. He has also made various offers to make available resources that could facilitate the establishment of publicly available information, services, appropriate training materials, and the evaluation of responses.

8.3.4 Royal Society for the Prevention of Cruelty to Animals (Victoria) [RSPCA]

The RSPCA (Vic) was established in Melbourne in 1871 and since that time has become Australia's leading animal welfare charity being seen as experts in animal care and protection. The RSPCA investigates incidents of hoarding on a case-by-case basis, though common factors emerge such as:

- Half of animal hoarders tend to live alone and may be socially isolated.
- Up to 75 per cent of animal hoarders may be older women.
- The average number of animals kept by hoarders is 39.
- Cats, dogs, horses, farm animals and birds are the most commonly hoarded animals.

When investigating animal hoarders, RSPCA inspectors often find:

- Animals have overrun the property.
- Filthy living conditions with animal matter accumulating in living areas.
- Dead and/or sick animals in the households.
- Non-functional household utilities.
- Living areas crowded by inanimate objects, furniture, etc.

During RSPCA investigations and following prosecutions the RSPCA Inspectorate and shelters work with local councils (environmental health; local laws as appropriate), emergency services, social welfare and mental health practitioners, offering practical advice - working to prevent people with hoarding behaviour from re-offending. Encouraging people with hoarding behaviour to seek mental health support is critical as the risk of re-offending is very high.

Prosecutions

In addition to investigating cruelty, RSPCA Inspectors prepare animal cruelty cases and attend court. In the last year a total of 50 defendants were taken to court, relating to 50 offences (not all related to hoarding).

Whilst the RSPCA's record in prosecution is good, the financial penalty of losing a case can be extremely high. Court cases and potential appeals can be extremely costly and difficult to plan for. Fines imposed by the court are allocated to the State Government and while costs can be awarded to the RSPCA, these are often difficult to recover from the offending person/s.

The following hoarding example involving the Geelong Magistrates Court illustrates penalties deemed appropriate by the Magistrate's Court. The maximum penalty for any charge under the Prevention of Cruelty to Animals Act is a $24,000 fine and/or 24 months imprisonment term.

Case study: Animal hoarding and penalties

XX was a known animal hoarder having received arrest warrants in other Australian states. In 2008 RSPCA Inspectors were called to a property in rural Victoria following information received by Victoria Police that X and her husband Y were located at a property in the vicinity. Upon arrival at the property a large number of dogs could be seen, both confined and roaming free, many had obvious leg injuries as they were unable to bare weight on their legs and displaying signs of aggression such as fighting.

Upon closer inspection of the property and its various buildings, inspectors calculated there were approximately 130 dogs, including puppies and three pigs on the property. Many of the animals were in very poor condition and unsociable. Inspectors identified a number of welfare issues including injuries, sickness, parasite burdens, deformity, inadequate shelter and inadequate confinement.

127 dogs/puppies were seized from the property by RSPCA Inspectors including 45 dogs and puppies, and three pigs were removed from the site and placed in the care of RSPCA shelters in Victoria. The remaining 82 dogs and three pigs were unfortunately euthanized under veterinary guidance on humane grounds.

XX pleaded guilty to 20 charges of animal cruelty in August 2009 at the Geelong Magistrates Court and was convicted of all 20 charges and ordered to pay $20,000 in costs.
8.3.5 Fire response - MFB

Victorian Fire Services have the dual responsibility of emergency response and community safety with a high emphasis on prevention of fires and fire related fatalities. The Metropolitan Fire Brigade (MFB) works collaboratively with the Country Fire Authority (CFA) in relation to hoarding, but leads this work on the basis that the primary focus of the MFB in relation to fire is residential fire rather than residential fire and bushfire.

Risk factors for fire fighters with regard to hoarding properties, have been highlighted in Section 5.2.1.

MFB identified hoarding in residential fires as a significant issue in 2008, following three preventable residential fire fatalities within a four month period. Since then MFB has:

2009: - convened two hoarding forums involving key community stakeholders in relation to hoarding from housing, aged care, assessment services, mental health, disability
  - developed and released risk reduction advice based on the WPI study (refer Appendix 16)
  - developed a report for the Minister for Police and Emergency Services promoting a state-wide approach.

2011: - convened two meetings with the Department of Health (Aged Care Branch, Mental Health), Department of Human Services (Office of Housing, Children Youth and Family Services, Disability Services Division), Department of Primary Industry (Bureau of Animal Welfare), the Coroners Court of Victoria and CFA to share information relating to hoarding and squalor.
  - MFB developed an internal policy/process to refer people (with their consent) affected by hoarding and squalor identified via MFB emergency response, to access assessment and possible services.
  - provided information on hoarding and squalor and delivered over 70 information sessions to community and health service providers.
  - participated in news media, forums and conferences in relation to hoarding and squalor.

MFB Operations identify hoarding and squalor properties through:
- emergency response to fire incidents and Emergency medical response
- assistance to Victoria Police to gain entry for welfare checks
- requests from Ambulance Victoria to assist in the removal of an individual to hospital
- post incident Fire Investigation Analysis.

MFB Community Resilience identifies hoarding and squalor properties via inquiries or referrals through:
- MFB Operations (Emergency Response)
- local government: (Environmental Health, Bylaws and Aged/Disability Departments)
- RSPCA
- ACAS, Community aged care package providers, Community nursing services, Occupational Therapy, Acute Health (Social Work)
- APATT, Adult Mental Health Services Providers
- Office of Housing
- real estate agents
- VCAT Residential Tenancies List
- community housing providers including rooming house operators
- child protection and family support services
- family members and friends of the affected person
- individuals and neighbours of people affected by hoarding.

If not an emergency or following an emergency response

If the incident is not a severe emergency or following the provision of an emergency response, MFB will attempt to engage the person and gain consent to refer them for assessment and possible services. People affected by hoarding and squalor more commonly experience a range of health, safety and wellbeing issues which may be able to be addressed by relevant funded services.\(^\text{136}\)

MFB use the Environmental Cleanliness and Clutter Scale (ECCS) (refer Appendix 10) to determine what levels of hoarding fires occur and quantify at what levels fatalities start to occur.

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\(^{136}\) Rod East, Fire Investigation Officer, Metropolitan Fire and Emergency Service Board, Melbourne. Working with people with hoarding behaviours, DVD. A learning resource containing practical strategies designed to assist Victorian Home and Community Care (HACC) staff working in this area. Copyright Vision Australia, 2010.
MFB attracts WPI undergraduate students to undertake studies on a range of subjects

Two studies of particular interest to this paper are:
1. An Analysis of Fire Incidents Involving Hoarding Households - May 22, 2009

For further information refer Appendix 16: MFB and CFA research studies.

MFB hoarding property notification system

The MFB continues to pursue the development of a Hoarding Notification System which involves placing an electronic alert on a property address, which in the event of a fire or other emergency, would increase firefighter preparedness and deliver an improved outcome for the occupant. The ‘high fuel load’ alert ensures responding firefighters are aware that:

- their access will be compromised by hoarding inside and/or outside the residence
- exiting the property will be compromised resulting in an increased need to search for and rescue the occupant
- containment of the fire to the room(s) of origin is less likely
- additional fire fighting appliances are more likely to be required
- there may be an increased risk to neighbouring properties.

MFB collects data from their firefighters and community based service providers (where consent was obtained from the occupant) on the notification system. The data:

- is collected via submission of an electronic form which has no capacity to include the name of individuals living at the address
- is renewed every two years through automatic generation of a renewal notice to the referring service
- is automatically removed after four weeks of the request for no renewal, is received
- the alert can be removed at anytime.

With regard to the above data MFB advises that:

- the information will not be shared with any other agency
- while MFB is developing this capacity no agency will be obliged to participate
- over the last five years MFB have received an increase in requests from agencies to place an alert on hoarding properties in order to improve outcomes for the occupant in the event of fire.

There are a range of issues to be worked through for this to occur, some pertinent to MFB, others from service providers with regard to client privacy and duty of care. Consideration needs to be given to how this data would be collected, updated and submitted to MFB.

Client consent would need to be obtained for private or rented properties prior to referral for registration on the MFB system. Consideration needs to given as to whether inclusion on the register could affect property insurance premiums and what the process for information sharing might be.

MFB has sought legal advice confirming that when a hoarding property is identified in the first instance, MFB can use the information for the purposes of noting hoarding by placing an electronic tag against the relevant address in the MFB database.

MFB also obtained legal advice in relation to obligations of external (to MFB) agencies which may elect to participate in the hoarding notification system. MFB has developed draft documents in recognition of these obligations which are predicated on the consent of individuals being obtained prior to the referral process to MFB. While MFB has canvassed informal feedback from potential participating agencies, the engagement of key state government stakeholders for a formal consultation process is MFB’s focus.

MFB recognises that the use and disclosure of any personal information must comply with the requirements of applicable privacy legislation. MFB recognises that external agencies may wish to obtain their own independent legal advice to ensure that any information collected meets appropriate privacy legislation.
Figure 8: Examples of hoarding households: combustible material

MFB Case example: fire crews had responded to a fire in an elaborate period home, during which the owner was moving around the environment not saying very much.

The Fire Investigative Officer was called in afterwards to determine the cause of fire. Part of this process was to chat to the owner of the house whom he noticed was more focused on the discarded water bottles the firefighters had left on the front veranda whilst fighting the fire. The first chance the owner had he collected all the plastic bottles, taking them inside the burnt out front part of the house, putting them to the side possibly for later on.

The Fire Investigative Officer perceived the owner to be coherent though noticed his fixation on the need to collect and keep the discarded plastic bottles and recognised these as characteristics portrayed by hoarders. The owner explained that the hoarding process for him started when he was a young boy and that he was just looking after all of the stuff that was previously stored. When the Officer spoke to the neighbours after the event, they had no idea that this was occurring inside the owner’s house.

8.3.6 Country Fire Authority (CFA) Research Project on Hoarding in Communities

The CFA is funding a project to research fire incident information that includes the effects of hoarding on fires and CFA response personnel (refer Appendix 16: MFB and CFA research studies). CFA is looking to gather sufficient data to better support emergency fire responders.

CFA suggests that responding to hoarding is not the domain of any one agency or department and that their role is a small part of a complex environment. CFA sees hoarding as a specialist field, requiring mixed models of treatment and service response.

8.3.7 Fire Safety information in National Community Services Training Packages

In December 2009, the Australian Fire and Emergency Services Australia Council (AFAC) released a national initiative to embed basic home fire safety information into the national Community Services Training Package. Basic home fire safety information is now included in the qualifications for a range of community services workers. The lesson materials for this have been centrally developed to ensure their application and use in all states and territories.

In addition to use in formal training the material is also recommended for use by community agencies in staff induction for new workers and skills maintenance for existing workers. The information includes identification of high risk groups, high risk behaviours and smoke alarms.

The training aims to support community service agencies that provide services to people in community settings as well as reduce the risk of fire for community service recipients, workers and provider agencies. The information also has a high workplace to home transferability for the workforce.

Basic home fire safety information is now part of nine separate units of competency which are part of a range of qualifications including those related to Aged Care, HACC and Disability workers. The material can be downloaded at http://knowledgeweb.afac.com.au/hfstm.
9 Victorian response – strengths and weaknesses

The previous section provides a snapshot of government departments, programs and private enterprises currently involved in responding to hoarding and squalor cases in Victoria. The examples in Appendix 12: Victorian Local Service response, reflect a variety of experience from discreet sectors, each unique in their own right, yet yielding many common themes. These representations are by no means exclusive, as many other Victorian initiatives are missing which would bring further depth and understanding to this discussion.

9.1 General themes

9.1.1 Multi sector – multi service response

In the majority of cases multiple sectors and disciplines are connecting in different ways, working together to figure out how best to address and support people of all ages, living with these health concerns.

- Service response includes not only funded organisations but charitable supports such as local church congregations and in some cases sporting clubs.
- Information sharing, networking and relationship building were all seen as valuable in terms of referrals and best practice.
- Privacy and consent issues often make it difficult to share information and link clients to appropriate services.
- The most useful service response was to have direct, hands on workers as well as secondary consultation and advocacy, that works across sectors.
- The idea of imbedding a hoarding program into an existing organisation rather than creating satellite teams was considered preferable.
- Hoarding related fires affected people across all ages and social demographics.
- Ongoing training, both private or public, was seen as essential for direct care workers, supervisors and managers – something that could be tailored for specific central, regional and local multiple sector needs.

9.1.2 Resourcing

- Some saw the aged care sector, as a whole, as having well developed responses to hoarding, and saw a gap in terms of support and funding available for people under 55 years of age.
- Some local government EHOs, saw the cost of successive one-off cleanups as inhibiting, seeking means to reclaim costs (for example, some local governments can claim as a debt against the value of the persons property, where that property is privately owned, recouping when the property is sold).
- Some programs stated allocating human resources for the long haul to hoarding cases was difficult, either due to program policy constraints or that it significantly impacted on the capacity to support other clients.

9.1.3 Client support

- Linking clients into clinical therapy or treatment was often seen as difficult due to service system restraints and prioritisation criteria, in addition to clients being reluctant to engage, particularly if they were homeless or had multiple and complex needs.
- People from all age groups, in a range of living conditions, social and demographic areas, economic status, working or not, can have these health conditions, in a continuum anywhere from low to high.
- The impact of hoarding on children must be factored in; many initiatives reported that children living in hoarding households was quite common.
- At times hoarding issues become apparent when people, often of an older age, are hospitalised with consequent rehabilitative assessment for their return home reveals hoarding. ‘Holding’ individuals in hospitals until cleaning can be arranged may clog a hospital bed and resources, as often the issue is discovered at an advanced stage where there are decades of accumulated goods.
- Hoarding behaviours are often identified among people with a disability when they move from supported group homes to independent living, revealing that living skills development is a key area of need.
- Intellectual disability and autism spectrum disorders have some correlation with hoarding or living skills development.
- Drug and alcohol, mental health, agoraphobia and long standing issues around living skills development all seemed to play a part when hoarding behaviours were present with the Indigenous client group.
- A heightened sense of secretiveness and fear of involvement with services are experienced by the Indigenous client group. A history of impingement on rights and value judgement have to be considered in tailoring interventions or support for this group.
- Family members who are carers living in the same house, or in their own house need support.
- Clinical treatment and counselling are only suitable for a certain type of client.

9.2 **Strengths**

Currently in Victoria, practice and clinical response to hoarding and squalor is ‘home grown’ rather than led by an agreed shared strategy or framework. However that being the case, many multiple services are responding in a consistent way with regard to basic principles; understanding complexity and seeing the behaviour as a health condition. This may well be due to the engagement, support and advocacy of Dr Mogan, Prof Kyrios, Dr MacFarlane and MFB as well as the effort of a broad range of other professionals (refer Appendix 12).

This section identifies some common themes from existing practice emerging across Victoria.

9.2.1 **Capacity to respond**

- Staff support - many providers stated the importance of building positive reinforcement, appropriate external supervision and peer support structures to adequately build and maintain capacity for staff involved in responding to these cases.
- OoH services have taken steps (refer Section 8.2.6) to address hoarding and collect data.
- The Victorian guidelines for psychiatric disability rehabilitation and support service (PDRSS) clearly state that target eligibility is for people who have a psychiatric disability as a result of a serious mental illness. Serious mental illness needs to be diagnosed; the overall program directions are to work ever more closely with clinical services and to have joint clients.
- PHaMS programs are also well positioned to respond, though as a national program, not all have hoarding on their priority listing.
- HACC contributes at a local level in a variety of ways, working with other sectors including other council services such as EHO, Local Laws and Animal Investigation officers, particularly in rural and regional Victoria. In metropolitan Melbourne the Royal District Nursing Service is often engaged with the family in the home, where other services have cited OHS as an obstacle.
- A flexible relationship with local ACAS providers was seen as helpful, characterised by being adaptive to the client’s needs, including pro-active engagement and lateral thinking around gaining consent. This is commonly difficult with this client group due to secretiveness associated with the condition.
- Agencies which are funded to provide or have access to community aged care packages are seen as extremely useful due to their flexible nature, to respond to hoarding interventions (when the person is assessed as program eligible), although the package amount was often insufficient.
- Some agencies have access to home maintenance teams within their own organisations and this assists in building an appropriate approach capable of doing slow or regular cleaning sensitive to the trauma of disposal.
- HARP (depending on purpose of the discreet HARP program), will take referrals without consent.
- Community agencies could use the ECCS tool as part of their internal referral processes, for example, when a room reaches level 6, one agency could decide they need to partner with one or two other agencies (depending on the assessed need), to enable continued work with that client.
- Some Public Housing programs use the ECCS which provides a system that is unbiased and can be drawn upon reliably, providing case consistency, identifying if someone is at risk and what level of risk that might be. Public Housing considers level 7 – 9 as fairly high risk which informs the approach the organisation would take with the client.
- A hoarding training needs analysis survey was developed in Melbourne’s North West metropolitan region to ascertain the training needs of staff working with people with hoarding behaviours. It was undertaken by the Team Leaders from PHaM (Merri Community Health), TRAAC (St Vincent’s Health) and Community Housing and Support: Northern/City (Wintringham), refer Appendix 17).
9.3 Weaknesses

Due to the fact that such a broad range of sectors respond, either in isolation or together, to hoarding and squalor situations, many involved are able to identify weaknesses, gaps and issues.

9.3.1 The need for best practice

- Service response capacity and coordination are inconsistent between and within regions and in metropolitan, rural and regional geographic areas.
- Due to preparedness of some organisations to lead and respond to hoarding cases in a number of regions, a regional service system culture can develop to refer cases to those organisations rather than broaden regional capacity to respond or contribute. Staff from these ‘lead’ agencies have stated they see their evolved role as unsustainable. They suggest a response must be multi sector and multi disciplined, to enable the provision of an appropriate service response.
- At times difficulties are experienced with general practitioners appropriately identifying hoarding, (although this may be difficult if the person is only seen in a clinical environment),
- Engaging clinical support is at times difficult. AMHS may not accept referrals as there is no clinical diagnosis for hoarding and a hoarding condition is often seen as a behavioral problem.
- HACC providers and others, often cite OHS restrictions as a reason for not being able to engage with clients in the home.
- The capacity of HACC and other services to respond is influenced by OHS issues and the responsibility of employers to ensure staff safety (refer 10.2.1).
- Insufficient available resources may compound capacity to be able to work at the depth and for the timeframe required to make a long term impact on outcomes for this client group
- Some (for example, police, by laws and others) would often like to see a quick fix, which is not possible
- Office of Housing workers can feel pressure to take action, such as full scale industrial cleaning in response to neighbourhood and council complaints and to reduce fire risk.
- Individual consent (refer 6.2.1, 6.2.2) is a key issue before HACC and ACAS services can become involved. This requires more discussion and it can be hard to get an ACAS assessment due to the difficulty gaining consent from clients.
- Local Council EHOs may experience limitations in terms of only being able to respond to hoarding when a complaint is made; action prior to this might make for a more cooperative response and outcome.

9.3.2 Some pressure points

- Opportunity shops and council hard rubbish collections play an unknowing role in resourcing hoarding, exploring options for minimising could be beneficial.
- Long term service provision and access to specialist practitioners is an issue, many services are unable to provide such service provision for great lengths of time.
- If agencies do not have access to home maintenance, success is dependant on localised relationships with public and appropriate private cleaning companies.
- Full scale industrial cleans can have a role to play, but only if follow up support by funded service providers is implemented.
- Ongoing case management for any age is seen as integral to success, but hoarding is often hard to ‘fit’ within existing service delivery models.
- For the homeless person with a hoarding condition, options for storing their items are extremely limited, often having to condense their whole lives into one room or space.
- Linking Transitional Housing Management (THM), Rooming House and Crisis Accommodation providers into the hoarding discussion is important as they experience hoarding in their properties. Improved communication or handover between these services and OoH may minimise the behaviour snowballing upon entry into long term housing.
- Building an evidence base around hoarding needs to be defined and undertaken.
- Older adults who hoard may have multiple, chronic health conditions, but home care services may be denied to the person until the hoarding is resolved.
- Prescription and non-prescription medicines can be buried under mounds of paper or clutter, making them hard to find, which could mean health conditions being treated with prescribed medications, resulting in undesirable outcomes.
- A health condition such as asthma for example, could become exacerbated by dust and mould; equally bacteria found in environments carrying mould and vermin could contribute in a variety of ways to ill health, particularly over time.
- Working with a person of any age living in a private property is more difficult than working in a rental or public property, as there is far less regulation and impetus for change.

9.3.3 Education required
- The capacity of all service providers needs to be strengthened (no matter which sector or discipline), do that they are aware of respective roles and responsibilities when responding to cases of hoarding and squalor.
- Consider the development of a Victorian hoarding and squalor education and resource website providing appropriate material, links and best practice examples. Maintenance and resourcing of the website would need to be addressed.
- Responding to hoarding and squalor has a stigma of being difficult dirty and work. It is important to recognise that success is possible to experience with clients, occurring fairly quickly once trust and rapport has been established.
- There is a lack of awareness and/or understanding of the determinants of hoarding and squalor, the aetiology of hoarding behaviour is multi-factorial and rarely with clear causation, often present are long-standing mental health issues, which may be undiagnosed or unsuccessfully managed
- Clients are often socially isolated, with poor family and social support and rarely have advocates to assist them, which effects the style of engagement required.

9.3.4 Hoarding or squalor issues when identified during the course of or following hospital admission
- Clinicians in a hospital setting are often not equipped to adequately manage short to medium term discharge planning for this client group. The primary reason for this may be limited community resources to work at the intensity required to resolve long-standing patterns of hoarding behaviour
- Clients who consent to participate need advocacy and intensive case management, as well as coordinated care to address possible medical and mental health issues on a long term basis. Existing commonwealth funded aged care packages (CACP, EACH, EACHD) or HACC services (that is, Linkages) are not sufficient to sustain the functional assistance or the case management that this client group requires.
- ACAS frequently receives referrals for these clients often earmarked as urgent by referrers, for what are very long standing issues. Local councils are similarly limited in their capacity to adequately meet this group’s need on both a short and long term basis.
- In extreme cases there may be need to temporarily relocate the client from their residence to enable a major clean-up or essential structural works to make their home habitable. In such cases, access to temporary accommodation can be significantly limited and requires consideration in a comprehensive service response.
- Identification of hoarding behaviour or squalid living conditions may also trigger referrals within the health service for a competency assessment and possible appointment of a guardian, resulting in protracted inpatient stays.
10 Future policy and service response considerations

Tackling social issues that are not confined to a discrete area, but are socially and geographically widespread, requires planning and supportive systems to underpin and strengthen any particular local service model or approach. Such systems are comprised of authorising common frameworks and locally based community organisational structures and processes.

10.1 Service response

10.1.1 Current

Victoria has no overall strategy or framework to address or support people with hoarding behaviours or who are living in squalid environments. As a result, service response across sectors to such cases is piecemeal and inconsistent with limited capacity to identify and appropriately assess cases, including risk.

Understanding hoarding behaviour, its diagnosis and what constitutes an appropriate service response is at an early stage of development, for example:

- A response clearly involves multiple sectors and disciplines, some of which have similar cultures and working practices; others in their day to day practice have very little to do with each other.
- Different programs and sectors are responding in the following ways:
  - Department of Human Services: Housing and Community Building (SfHRT) program has strengthened their response to complex needs clients who hoard, by establishing service coordination positions in regions, providing templates, tools and training opportunities for their staff and other sectors (refer Section 8.2.6)
  - Department of Health: The Environmental Health Unit is currently developing guidance material for local government environmental health officers on how to deal with hoarding as a mental health condition rather than one that usually responds well to a regulatory action in the first instance.
  - Department of Health: Aged Care Branch has committed resources to develop this paper.
  - Municipal Association of Victoria (MAV): In October 2011, the state council of the MAV resolved that the MAV ask the Victorian Government to investigate the extent and impact of hoarding across Victorian local governments with a view to developing a collaborative framework to address this burgeoning issue.
  - Metropolitan Fire Brigade continues to advocate and present at hoarding forums, sponsor studies on at-risk groups and educate on how to enhance fire safety.
  - Country Fire Authority is undertaking a hoarding prevalence study in rural Victoria.
  - Department of Primary Industries: Bureau of Animal Welfare has developed a Victorian Animal Hoarding Advisory Group, now with two working groups (Data collection and Operational), and has undertaken two research projects.
  - A number of cross sector sub regional hoarding working groups meet (refer Appendix 12).
- There are some common links between the above initiatives, apart from the fact that they are occurring in discreet sectors or program areas. None of these initiatives will be as effective as they could be if they exist in isolation from each other. Many initiatives may repeat similar information but with a different orientation and application, however, there will be no comprehensive outcomes to impact on all the sectors involved.
- Local service providers from a range of sectors will embrace information or solutions that are promoted and look to find a fit for themselves. Currently access to information regarding hoarding and squalor is ad hoc and not systemised.
- Some Commonwealth government programs and private businesses are also part of local current service response (refer Sections 8.2 and 8.3).
10.1.2 Challenges
Given the fact that multiple sectors and disciplines from Commonwealth, state and local government programs respond to cases of hoarding or squalor, service response frameworks vary, for example:

- DH/DHS – operate from a similar client intention model, that is client centred care, such as the One DHS service model. For this complex condition which requires a multiple agency response, questions arise such as – how do different government department service frameworks work together in a multi government department response?

- Service providers work together to produce a result within, and at times despite policy or service model differences – programs have different purposes (for example, regulatory, clinical, in the home or out of the home) and consequently different cultures and approaches to working with people.

- Previous common working arrangements between programs change in response to government direction. Sometimes this leads to the creation of different tools and approaches being developed separately, and these could benefit other sectors (for example, the Service Coordination Tool Templates, which are not used by Housing, but have much appeal for them). Should a multi government department response framework be developed to address hoarding and squalor?

- Some providers experience reluctance from mental health services to see the hoarding issue as part of their inherent territory. This may relate to concern about an expectation that 'the problem' might be directed their way, and require staff to undertake assessments, and a tendency for squalor where it occurs in the setting of, for example schizophrenia, to be viewed by AMHSs as an unrelated problem rather than a related phenomenon.

- Difficulty accessing an appropriately skilled assessor even when AMHSs agree to conduct an assessment. Ideally, these presentations require a neuropsychological assessment and difficulties can arise from squalor lying at an uncomfortable boundary between psychiatry, neurology or behavioural sciences.

- The fact that management often comes down to social or environmental changes rather than a 'treatment' to be prescribed, as such. This results in social services or non government organisations and council services being the defacto case managers for what are really very complex care issues.

- The reluctance of some services to become involved, refusing to assist on health and safety grounds – ‘too dirty to allow us to go in and clean it up’. Further work is needed to explore when a hoarding or squalor property is seen as a health and safety risk, leading to a refusal to enter or engage. If so, how can this position be worked into a service response to hoarding (refer 10.2.1).

- The language of 'rights' and competence to refuse assessment being invoked may well avoid a responsibility to provide such people with desperately needed assistance.

- An assumption of competence in people whose living circumstances are objectively squalid is flawed, circular, unproductive and self-defeating in terms of conducting necessary interventions.

10.2 Public policy

10.2.1 Strategies
Given that a large number of community, agency, family and individual resources are brought to bear on cases of hoarding, it is critically important that those who encounter hoarding respond thoughtfully and strategically.

A boutique approach is not what is required in this instance. Instead a coordinated response that maximises resources across clinical and practical community based agencies is likely to achieve the best possible result for the person who hoards or lives in squalor, as well as those affected by the problem.

A best practice response should be explored and made up of:

- A strategic approach that builds service system capacity by broadening sector understanding and awareness, as well as an expectation to contribute, thereby removing reliance on a small number of regional agencies.

- A collaborative government response including key stakeholders (refer Section 8.2) that would:
  - develop a common response framework for multiple agency and sector use
  - develop government guidelines for cross sector use (including: client centred principles or practice, definitions, common language, discreet roles, risk assessment, monitoring progress, resource links and contact points for treatment if required).

- Determine and adapt appropriate assessment tools based on those already available (refer Section 7).
• Provide cross sector training to encourage appropriate service response that emphasises a coordinated service response, but builds in flexibility on a case by case basis.

• Support groups and behavioural change programs for hoarders to assist them to change their behaviours, as well as carers or family members (including children), to support them to understand the condition and to be able to better sustain their own lives.

• Create respective services roadmaps for people with hoarding behaviours and their families, service providers and landlords so that people know which agencies to contact in different situations and have a way to identify and seek assistance.

**The establishment of agreed service system supports** such as:

• a local, regional interagency service coordinating point (not referral) that would plan referral, assessment and coordinated service responses

• a guide to networking locally with other service systems, formally and informally, including information sharing

• consent is a key issue before HACC and ACAS services can become involved and this requires greater discussion

• the capacity of HACC and other services to respond is influenced by OHS issues and the responsibility of employers to ensure staff safety. There needs to be a fuller discussion with the MAV about OHS issues in relation to the capacity to respond to squalor and hoarding and to psychological and health issues.

• organised and agreed assessment, referral and intervention protocols and processes – including a stronger focus on treatment and intervention services for joint work

• flexible service delivery model options, for example, outreach, secondary consultation, on-site

• development by AMHSs of agreed local protocols with the relevant LGAs, NGOs and community based services around the assessment or management of cases

• specific funding to allow neuropsychological assessments to be accessed for these cases

• a clear statement from the Department of Health about whether a presentation of squalor would, in and of itself, be considered sufficient evidence of ‘risk’ and of ‘appearing to suffer from a mental disorder’ to at least permit a period of evaluation under the MHA.

(\textit{Note January 2011: 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).

**10.2.2 Effective intervention**

Generally people with a hoarding condition or living in a squalid environment have ‘fallen through the gaps’ of mainstream health, mental health and community-based services. Establishing guidelines that are too rigid would be counter-productive, such guidelines would need to encourage flexibility due to the nature of the hoarding condition and the consequent need for an individualised approach.

**Practical**

More often than not, several areas of a hoarder’s life are affected. Effective intervention requires professionals working together in the same direction and at the same pace, meeting legal and ethical requirements while also ensuring the current and future health and safety of the person who hoards and affected others.

Hoarding can pose a number of associated problems in a person's life which may involve laws, policies and requirements in areas as diverse as sanitation, safety, mental health, physical health, animal protection and others.
In addition to public and government involvement, often specialist private services such as visiting nurses, psychiatrists, counsellors, occupational therapists, professional organisers and cleaning companies may be employed to assist.

A planned, coordinated response between agencies not only enables access or provides a means of getting into a person’s home, but also establishes an approach to build progressive support for those with a serious hoarding condition.\(^{138}\)

In many instances of hoarding or severe domestic squalor, a clean up of the property exposes structural damage and the cost of repairs can be considerable. Ongoing support and building maintenance can be costly and many people living in severe domestic squalor cannot afford to undertake property repairs.

Many incidents of squalor involving poor living conditions have been resolved successfully. Discussions with people involved in dealing with poor living conditions indicate that a key to success is organisations committed to working together.

With people increasingly living on their own, incidents of squalor will continue to occur and money alone will not resolve such occurrences. The need to identify and build good relationships with other service providers is essential, as is the person reporting the incident and most importantly the person living in squalor.

Dealing with poor living conditions does not begin or end with the ‘clean up’ and satisfied neighbours. Good relationships with people who are at risk or actually living in poor conditions need to be built and maintained after the intervention and be based on compassion, respect and understanding.

Good linkages and relationships must be built with a range of community and media organisations so that people in the general community know how to respond appropriately to people living in hoarding or squalor.

**Clinical**

When the outcome of DSM-5 is known (April 2013), a flow on effect should assist with building capacity in professional fields such as mental health in general, psychiatry, social work and the medical profession.

However, in the mean time there appears to be a deficit in capacity or lack of preparedness in some clinical professions to respond actively and appropriately to hoarding cases. This is more than likely due to the current level of clinical understanding and more than anything else, the definition of the condition. Effectively diagnosing and treating a hoarding condition is at such an early stage of development, even though as stated earlier hoarding and its symptoms have existed for generations all around the world.

Services involved in providing a practical service response are seeking clinical support options for not only the people they work with, but for themselves, in order to understand how best to respond. Access to support from either public or private practitioners is limited, particularly in regional and rural Victoria.

**Costs (property, clean ups and human resources)**

The cost of cleaning up a property can be excessive, especially if the property or problem has not been addressed early. Intensive cleaning can cost up to $2000 dollars a day and sometimes requires having at least six workers from different community and government organisations involved in the case.\(^{139}\)

The cost of case management or service coordination and community support needs to be factored in as this is often underestimated.

In other states, funding provided by government has also assisted community agencies to fund some of the initial clean up work. There are many examples of different levels of government and community organisations combining resources.

### 10.2.3 Hoarding task forces

In the USA there were some 50 taskforces\(^ {140}\) established to address compulsive hoarding, although more than one third no longer function. The purpose and function of each taskforce varied, some building community level understanding and response to compulsive hoarding and/or squalor, others involving diverse agencies to address interdisciplinary and inter-agency coordination. For example in 2003, an interdisciplinary New York City Hoarding Task Force convened to address the hoarding disorder in older adults and to

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\(^{139}\) Taylor (2007)

\(^{140}\) Extract Beyond Overwhelmed... Appendix F. U.S. Task Forces on Compulsive Hoarding – Building Community-Level Responses
develop practical tools and resources for community service providers (refer Appendix 4: New York City - Checklist).

How task forces in general are formed, organised, and maintained varies greatly. Some task forces form for a specific purpose, such as hosting a hoarding conference or providing support groups for discreet groups and their families. Others develop to achieve set goals and commit to a specific timeline for meeting those goals.

Some smaller communities choose a within-agency task force model, which would be appropriate for larger organisations for a shorter time, for example a local government prioritising something like hoarding, as a problem that required a coordinated response from police, fire, public health, social work and inspection departments.

The SA Department of Health indicated that while a formal hoarding task force might benefit South Australia, an agreed interagency approach can achieve the same results.

NSW (DADHC) produced some guidance material (refer Appendix 5: Examples of national service response: Section 3.1) to assist agencies with regard to severe domestic squalor, not hoarding (except for where the two conditions overlap).

In Victoria some stakeholders suggest a state-wide taskforce is required to address a range of concerns including: building service system capacity, consolidating knowledge and providing policy direction for a multiple sector response. This would reduce the current repetitive, cyclic effort within sectors, which duplicates resources and effort, and at times inappropriate service response.

141 Hoarding Task Forces - International OCD Foundation (IOCDF) - Hoarding Centre, Christiana Bratola, PhD. Boston University
11 Conclusion

Self-neglect generally is a classic example of a human problem which falls into that grey area between health, social work, housing services and environmental spheres of influence. Hoarding is a problem that requires intensive, lengthy, costly and complex responses.

Most local communities have agencies staffed by professions from various disciplines that are likely to respond to cases of hoarding or squalor. Respective professions may become involved for somewhat different reasons, but the underlying intention is the same — to protect the health and safety of the individual concerned.

Addressing the issue rather than the impact, through interagency effort and cooperation (such as networking and protocol development) is what works best. Strategic decisions that enable shared consistent guidance, responsibility, interventions, sustained results, empowered engagement and the education of multiple sectors, would strengthen appropriate service response.

Victoria would benefit from an agreed common service response framework – one that encompasses multiple sectors, disciplines and legal jurisdictions, one that addresses components such as:

- connecting existing sectors at a local level
- identifying a central lead coordinating point in each region; one that has capacity to provide a complex care coordination role
- development of guidance material applicable to all sectors and disciplines encompassing how clinical and practical service response should interact locally and regionally
- costs for practical and clinical service response and sustainability
- data collection that would add value (by whom, which program/s and for what purpose)
- the provision of common and consistent education for managers and direct service workers (both clinical and practical) across all sectors.

What next?
This discussion paper will be distributed to appropriate government departments and key stakeholders for comment and contribution, which will aid in determining what actions might be required, particularly regarding the need to develop a common framework.
Appendix 1: Client Case studies

a) A case of compulsive hoarding syndrome without OCD

‘Ms S’ was a single, 51-year-old secretary. She reported that she had experienced difficulty discarding items for as long as she could remember, although she never considered this behaviour to be problematic. In recent years, she noticed that her three-bedroom flat started to become increasingly cluttered. Despite her efforts to clear the clutter, she felt unable to discard most common items (especially paperwork) because she believed that they might be useful in the future. She also started to become more sentimentally attached to her possessions that served as a reminder of happier times when she was married. She reported feeling ‘safer’ with these possessions. She managed to keep her kitchen and bathroom relatively uncluttered, but her living room was cluttered to the degree that she could no longer sit on the sofa and only had one chair on which to sit. She had not been able to invite anyone to her home for two years because she was embarrassed.

Her hoarding behaviour had a major impact on her social life, and she became gradually depressed as a consequence (with a Beck Depression Inventory score of 18). During the past year, Ms. S consulted several mental health professionals who could not agree whether she had OCD. In fact, she did not report any other obsession or compulsion other than hoarding. Additionally, she did not report any obsessional thoughts or checking/repetitive behaviours associated with the hoarding. When she was asked how she felt about her behaviour, she described her symptoms as being mainly egosyntonic, but she decided to seek help once the clutter started to interfere with her life.

b) A case of compulsive hoarding as a symptom dimension of OCD

‘Ms P’ was a 48-year-old woman who was diagnosed with prototypical OCD at the age of 16. Her symptoms included contamination fears and checking but not hoarding.

Four years ago, after experiencing a divorce, she began to feel very anxious when she had to discard any item. This developed into a severe avoidance of discarding virtually every item that belonged to her, which even extended to her body products such as nails, hair, and faeces.

She experienced overwhelming anxiety and feelings of incompleteness whenever she was asked to discard these items. If she was forced to discard a specific item, she would examine the item for a long period of time in an attempt to memorise the way it looked. Before going to sleep, she would then feel compelled to recall every discarded item with as much detail as possible, as a way of ‘not losing it forever’. Ms. P’s obsessional fears and hoarding behaviour controlled almost every aspect of her life and were experienced as egodystonic.
Appendix 2: DSM5 Proposed diagnostic criteria

Hoarding is being considered for inclusion as a formal diagnosis by the American Psychiatric Association as they prepare for publication of the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*. This table shows the proposed diagnostic criteria for Hoarding Disorder, which is the name that has been proposed.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Proposed DSM-5 criteria for Hoarding Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>Persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions.*</td>
</tr>
<tr>
<td>B.</td>
<td>This difficulty is due to strong urges to save items and/or distress associated with discarding.</td>
</tr>
<tr>
<td>C.</td>
<td>The symptoms result in the accumulation of a large number of possessions that fill up and clutter active living areas of the home or workplace to the extent that their intended use is no longer possible. If all living areas are uncluttered, it is only because of the interventions of third parties (for example, family members, cleaners, authorities).</td>
</tr>
<tr>
<td>D.</td>
<td>The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).</td>
</tr>
<tr>
<td>E.</td>
<td>The hoarding symptoms are not due to a general medical condition (for example, brain injury, cerebrovascular disease).</td>
</tr>
<tr>
<td>F.</td>
<td>The hoarding symptoms are not restricted to the symptoms of another mental disorder (for example, hoarding due to obsessions in Obsessive-Compulsive Disorder, decreased energy in Major Depressive Disorder, delusions in Schizophrenia or another Psychotic Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder, food storing in Prader-Willi Syndrome). Specify if: With excessive acquisition: If symptoms are accompanied by excessive collecting or buying or stealing of items that are not needed or for which there is no available space. Specify whether hoarding beliefs and behaviours are currently characterised by: Good or fair insight: Recognises that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic. Poor insight: Mostly convinced that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary. Absent insight: Completely convinced that hoarding-related beliefs and behaviours (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.</td>
</tr>
</tbody>
</table>

* The Work Group is considering alternative wording: ‘Persistent difficulty discarding or parting with possessions, regardless of their actual value’.
Appendix 3: Snapshot and commentary progressive cleanup of kitchen in squalid condition

Photos and comments have been provided by a person managing their squalid living environment, in this case, the kitchen.

Kitchen: As usual, I started by picking at bits and pieces, little by little... I think this keeps me from getting overwhelmed at a big job, sort of desensitizes me a bit, and the job gradually gets its claws in me, and then I jump in and finish it off. So, during the week, I picked up things here and there, and filled a bag of trash. Then, that weekend, I got out the gloves and got it done.

I spent literally an entire DAY washing dishes. The two sinks had been filled and abandoned about four years ago. Dirty dishes that wouldn't fit there were left wherever in the house I had last used them, or stacked in piles behind things, or in a big plastic tub. Tin pie plates and cheap utensils corroded into dust in the sink, and left stains on the plates.

So, here is some of what I started with. This is NOT all of it. Underneath that box is a tub about 2.5 feet in diameter and about 3 feet deep, which was also filled with dishes. See all the rusted silverware?

Since I currently have no gas for heat water, I heated two large pots of water on the electric stove, filled the tub in the sink, and let the dishes soak while I heated another pot in order to be able to rinse the dishes with hot water too. That process alone took about 30 minutes, and I had to repeat it for each new load of dishes that fit in the little tub. Initially I had planned to wash the dishes in a big tub outside, but as I started to fill that with hot water, I realized it had a major leak!!! So, I resorted to plan B.
This was the sink after I cleared the dishes out, after 4 years of sitting there. I was amazed that I did NOT find any sink pudding! (Meaning a consolidated solid mass of decaying material).

And here is about half of the ‘after’ dishes. They are clean, but have some rust stains on the edges. I can live with that until I get around to replacing them.

After having worked really, really hard on the kitchen, I treated myself to a nice, homemade dinner served on real plates with real utensils, with a glass of Chardonnay in a real wine glass.

I have not used ONE paper plate or plastic fork since!!!

Extract Squalor Survivors website (www.squalorsurvivors.com)
Appendix 4: New York City Hoarding Task Force

New York City Hoarding Task Force checklists:

(A) General top 20 decluttering tips

1. **Let go of ideal notions of cleanliness.** Your client may value items that appear to you as worthless or be rubbish. Parting with their belongings (even used paper cups) can cause severe emotional distress.

2. **Listen to your client’s ideas and plans for their belongings.** Explore their hopes, both realistic and unrealistic, and accommodate them if possible. Clients have been helped to donate or sell their belongings. One woman even sent her ‘stuff’ to relatives in her home country.

3. **Work at the client’s pace if you can.** Start with short periods of time. Some clients cannot tolerate even a half hour in the beginning. Keep in mind, though, that a client’s decluttering pace is usually slower than the eviction process.

4. **Partner with a legal group, home care or nursing agency** to find out what level of cleanliness your client needs to achieve in order to attain their goal, whether it is eviction prevention or home care services. You have to meet certain standards, but you don’t have to exceed them.

5. **Focus on fall prevention.** Create pathways free of debris, loose cords or slippery rugs. Some frail clients hold onto furniture or other items while moving through the home; ask how your client gets around and preserve their ‘props’ until other assistive devices (canes, walkers) can be introduced.

6. **Focus on fire prevention.** Make sure your client has a smoke alarm and test it monthly. Red flags include newspapers stored on top of or inside a gas stove or near working radiators. Help relocate their belongings from a hazardous area to a safe place.

7. **Be creative and negotiate.** Perhaps the client can keep the previous year’s copy of a particular magazine, but throw away the prior twenty years’ collection. Consider photographing belongings, as this may help the client part with them and preserve memories.

8. **Begin by reorganising,** if time allows. Start with a small corner of a room, a single table, or just a section of the table.

9. **Ask your client what they would like to do that currently they cannot do because of the clutter.** For example, ‘Would you like us to help you to figure out how you can cook again?’ or ‘How could you do this differently so you can use the stove?’

10. **Motivate your client by helping them be realistic.** Some clients will declutter only if told they face eviction or cannot be discharged home after a hospitalization. Gentle but firm pressure is appropriate if a client’s home or health is at stake.

11. **Create a limited number of categories for belongings.** Large plastic crates or wicker baskets can help separate items into these categories.

12. **Be resourceful in finding workers.** Volunteers and other informal supports have been used with success, such as hired high school students who pack up agreed upon donations.

13. **Have a social worker present during a major cleanout,** preferably one who already has a supportive relationship with the client. Clean-outs can be overwhelming to people with severe hoarding behaviour. Have a back-up plan in case emergency psychiatric services are needed.

14. **Discuss how to safeguard valuables in the cleaning process.** Have a written contract. Agree on what to do with valuables that turn up, such as money, jewellery, checks, bonds, stock certificates, and collectibles.

15. **Call the ASPCA** (Note: Victorian reference - RSPCA) if you need help finding a temporary or permanent home for pets while the cleanout is being conducted.

16. **Consider relocating** an individual to a new apartment if the clutter is the result of physical or mental frailty. A new environment can provide a fresh start and enable the client to receive needed services sooner.

17. **Encourage the client to participate** even during a major cleanout. Get them involved so they can be part of the process and have some level of control. Ask them if you can help find something they might be looking for, or give them a box to help sort through.

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143 City of New York Hoarding Task Force. Refer: http://www.cornellaging.org/gem/hoa_bes_pra.html?name1=Best+Practices+Decluttering+Tips&type1=2Active
18. **Plan for a carefully orchestrated clean-up** which can result in decreased client anxiety. Make sure you make arrangements:
- with the building for entrance and egress when removing possessions and trash
- for use of the elevators
- for cost, rental and removal of dumpsters (*Do not leave a dumpster or trash bags on the property after a cleanout, even overnight*)
- for storage if needed, including cost of transportation to storage facility.

19. **Communication is Vital.** It is important for the client to communicate with the cleaning crew - making their concerns known. If the crew doesn’t speak the same language as the client, there should be a supervisor/translator/advocate present so that the client can make his/her needs known and can feel as if he/she has some control over the situation.

20. **Plan for on-going maintenance and supervision to maintain a decluttered environment.**

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(B) **Working with individuals with dementia who rummage and hoard**

People with dementia experience memory loss, mental confusion, disorientation, impaired judgment and behavioural changes, which may include rummaging and hoarding. The following information may be helpful to you when working with individuals who are experiencing these symptoms.

**Rummaging**
People with dementia may spend excessive amounts of time rummaging through their possessions. This may happen because they are searching for items they have misplaced or hidden. Oftentimes, people with dementia hide their possessions, forget where they have hidden them, and then blame others for stealing them.

Rummaging behaviour may also result from boredom as people with dementia find it difficult to initiate activities and rely on others to keep them active. Quite often, redirecting individuals to activities that they enjoy, such as music, gardening, and/or meal preparation, can help distract them from engaging in distressing behaviours. For individuals in the later stages of dementia, certain repetitious activities, such as folding napkins or sorting coloured socks, can satisfy the need to be active and engaged.

**Hoarding**
Some people will hoard or save numerous items, including dirty clothes, food, and papers. Keep in mind that individuals with dementia are continuously losing parts of their lives. Losing a meaningful role in life, an income, friends, family, and a good memory can have an impact on a person’s need to hoard and or to ‘keep things safe’. Hoarding in this population is oftentimes triggered by the fear of being robbed.

When working with persons who have dementia, it is essential to keep their safety in mind as they become increasingly unable to protect themselves. Order, routine and simplicity are most helpful and a house or apartment that is relatively uncluttered is the ideal environment.

**Tips to consider**
1. **Building trust** – Any changes you make in the home of a person with dementia could cause the person to become very anxious and agitated. It is essential, therefore, that you build a sense of trust between yourself and your client before you attempt to make any changes at all.
2. **Focus on fire prevention** – Check for papers stored on top of or inside a stove or microwave, and near working radiators. Make certain your client has a working smoke alarm and arrange for someone to test it monthly.
3. **Focus on preventing poisonous ingestion** – Be aware that people with dementia may not recognise that some things are not good to eat. Keep potentially dangerous materials such as cleaning fluids, plant soil, lotions, and medicines out of reach. Check the refrigerator on a regular basis to make sure that rotten food is thrown away.
4. **Focus on fall prevention** – Make certain that pathways are clear and that there are no slippery rugs that could cause falls. Keep in mind that some frail adults hold onto furniture while moving through the home. Observe how your client gets around and make sure that these supports are stable.

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144 Authors: Rosemary Bakker, MS, ASID. Weill Medical College of Cornell University and Paulette Michaud, LMSW. Manager, Education & Training, Alzheimer’s Association, NYC Chapter
5. **Minimise the number of hiding places** by locking unused closets or doors. Put signs that say ‘NO’ or ‘STOP’ on places that you want the person to stay out of. Note: This may not work for people who are advanced in the illness.

6. **Limit the amount of valuables** or cash that are within reach of the person with dementia.

7. **Keep the amount of junk mail to a minimum** so the person has less to manage. If possible, arrange for bills to be sent to some one else for payment.

8. **Remove non-essentials** such as out of season clothing to lessen the amount of clutter. Remember, however, that a person with dementia will experience increased anxiety if she/he believes that these possessions have been stolen.

9. **Understand coping mechanisms** – For example, some people with dementia keep their belongings, including clothing, out in the open otherwise they forget where they have placed them. This coping mechanism, with oversight by a caregiver, may help a person continue to function in the beginning or middle stages of the disease. Other individuals may be willing to put their belongings away if large signs or labels, such as "Socks" or "Blouses" help them identify the location of their possessions.

10. **Fill a drawer full of ‘odds and ends’** for the person to enjoy rummaging through.

11. **Check wastebaskets for ‘lost’ items** before they are emptied.

12. **Provide support** such as home care for on-going maintenance.

13. **Learn their hiding places** – If a person hides things, learning where their favourite hiding places are will help you locate their important items. Items are often put in the same places, such as under carpets or mattresses and in shoes, handbags, coat pockets, or drawers.

14. **Keep duplicates of important items** such as glasses, hearing aids, keys, etc. as back-up. Have the client's doctor's name on hand if duplicate prescriptions need to be filled.

15. **Remove discarded items immediately** – If you are removing items from your client's home, it is best to remove them immediately from the premises or your client may rummage through the garbage and bring them back into the house.
Appendix 5: Examples of national service response

1. New Zealand

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.

MOH Population Health provided referral data to them for severe domestic squalor cases in Canterbury and Otago:

<table>
<thead>
<tr>
<th>Referrals</th>
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<th>Annual Cases</th>
<th>Rate per 100,000</th>
<th>Rate over 100,000 aged 65 +</th>
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<tr>
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<td>1.1</td>
<td>7.5</td>
</tr>
<tr>
<td>Otago</td>
<td>18</td>
<td>1.8</td>
<td>1.0</td>
<td>6.9</td>
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</table>

Referral sources

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<td>Community</td>
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<tr>
<td>Other agencies</td>
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Reason for referral

<table>
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<th>Reason</th>
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</thead>
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<tr>
<td>State of the house</td>
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<tr>
<td>Others</td>
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</tbody>
</table>

Once a referral is received, the MOH applies to the District Court for an Order to remove the person from the environment of concern; the Judge may make an Order then the MOH may revoke the order if no longer required. The person concerned may appeal to the Court.

The legal test is applied against each case which includes these considerations - is the person aged, infirm, incurable or destitute and their current living environment for example, are they living in insanitary conditions or without proper care and attention.

The following Legal Principles are applied when considering the above:

- Onus of proof on applicant
- Individual’s welfare is only concern
- Situation at the time of the application
- Adequacy of care and attention
- Individual’s views not decisive
- This individual in these circumstances.

MOH removes people from squalid environments for the following reasons:

- Risk of personal harm
- Risk from inadequate support at home
- Risk to others
- To manage anti social or at risk behaviour.

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145 Holmes, John, Medical Officer of Health, Clinical Senior Lecturer, Dunedin. University of Otago. Medical Officer of Health and also a Clinical Senior Lecturer in the Department of Preventive and Social Medicine in the Dunedin School of Medicine, University of Otago. He is currently on secondment to the Ministry but retains his teaching role. Section 126, Health Act 1956. New Zealand. 2009.
2. South Australia (SA)

2.1 SA Local Government Interventions using the Public and Environmental Health Act 1987-
A foot in the door project

The SA Department of Health (DH), Public Health (Environmental Services) ran an Insanitary Conditions workshop (2006) for state and local government environmental health officers (EHO) who are authorised under the Public and Environmental Health Act 1987, to promote proper standards of public and environmental health within the state and each jurisdiction.

Local municipal councils are called to intervene in situations of severe domestic squalor (and squalor related compulsive hoarding), primarily as a result of complaints about the condition of a property. Cases may be deemed to constitute an insanitary condition which is defined as premises which:

- gives rise to a risk to health
- is so filthy or neglected that there is a risk of infestation by rodents or other pests
- causes justified offence to the owner of any land in the vicinity
- emits offensive materials or odours
- for some other justified reason.

Should a premises be deemed unfit for human habitation by reason of an insanitary condition, the local council can issue a Notice which orders the owner or person responsible for the insanitary condition, to take necessary action to improve the condition of the premises. Notices are appealable to the District Court or the Public and Environmental Health Council.

Interventions under the Act are often resource intensive and frequently produce sub-optimal outcomes or unsustainable improvements in living conditions, meaning one-off industrial cleanouts of a premise do not change the behaviour of the person residing there, so the situation repeats.

The Act establishes the Public and Environmental Health Council (the Council). Appeals to the Council result in a full review of the case. The Council can dismiss the appeal, revoke or alter the Notice. The Council’s decision can be appealed to the District Court.

In addition to serving as an appellate body, the Council has mandated responsibilities including:

- Overseeing the administration of the Act
- Reporting to the Minister on matters relating to public and environmental health
- Initiating, carrying out or overseeing programmes and activities designed to improve or promote public and environmental health.

A foot in the door project (2008)

Under the auspice of the Public and Environmental Health Council, the SA government commenced developing locally based guidance material for EHO. Key stakeholders were from government and non-government agencies. This project aimed to:

- promote appropriate administration of the Public and Environmental Health Act 1987 at the local government level as it relates to severe domestic squalor and compulsive hoarding as it relates to a squalor situation
- achieve better outcomes for people living in severe domestic squalor and with compulsive hoarding where there is a tangible public health dimension.

Research methodologies informing the guidance document were based on focus group interviews and discussion sessions (qualitative), as well as surveying local councils and key stakeholder groups. Investigations did not constitute a full study and results are indicative only.


- On average approximately 4-7 home visits and 16-25 hours of staff time are required in order to reach an end point (usually a clean up).
• Approximately 52.6 per cent of cases are resolved without the need for legal action, that is, they are solved via negotiation and mediation. Where legal action was used approximately 55 per cent of cases did not comply.

• Clients were aged between 61-80 years in approximately 47 per cent of cases.

Figure 1: SA Local Government Environmental Health hoarding/squalor statistics 2004 -2008

This project and survey, was designed to address severe domestic squalor in particular and only included compulsive hoarding where the two conditions overlapped, so the figures reflect that outcome, neither domestic squalor nor discretely compulsive hoarding, they intertwine mixed with other conditions.

Qualitative feedback indicated a lack of knowledge about other sectors, but a strong willingness to do the best they could when managing squalid living environments:

• ‘We resolve complaints without other agencies. We do not address mental health problems, but do take them into account.’

• ‘In the absence of support and assistance by any other agencies, a Guardianship application was made in relation to the ongoing case that has been dealt with since 2006. Many … community service agencies have never been approached because we didn't know of them nor been informed of them.’

• ‘I will never forget that clean up day. I had mental health nurses present as you can not deny the client from being there and the emotion was overwhelming. The woman was climbing into the skip bin and removing matter that would appear to be rubbish to most but not her. I did not involve the police because I understand what police presence has on many mentally ill people who are not a danger. This can have a devastating effect. They are not criminals.’

• ‘… if the person has breached council laws …then it’s a legal issue regardless of intent or mental wellness. All the health field can do is….present to a GP for assessment and diagnosis and referral on to specialists for further treatment and care. But really if the council reckon that counselling and therapy is going to solve their squalor problems then they’re going to be sadly mistaken...’ SA GP

The Project aims to produce a Risk assessment tool (based on ECCS\textsuperscript{147}) divided into 4 sections:

1. Is there evidence of compulsive hoarding or domestic squalor?
2. Does the condition of the dwelling impact on the health of those who live inside?
3. Does the condition of the dwelling impact on the public’s health?
4. Other issues for consideration as well as Pathways for managing interventions for EHO.

The SA DH 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:

\textsuperscript{147} Halliday, G., Snowdon, J.,
• 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 EHO.

2.2 SA Royal District Nursing Service (RDNS) project

The SA RDNS conducted a small research project\(^\text{148}\) (2007) to:

• develop an understanding of the strategies and decision-making processes that nurses use when providing care to clients living in domestic squalor

• describe the ways nurses assess this client group

• identify the decision-making processes nurses use to inform their nursing care so that it is effective

• understand the assumptions used to distinguish between self-neglect, hoarding and squalor

• explore the organisational structures that assist and impede care giving

• understand the impacts of caring for this challenging client population, on the nurse.

The research methodology utilised qualitative biographical design, 20 community nurses who had experience in working with people living in domestic squalor and a comprehensive literature review. The findings of the project were:

• defined and described squalor, hoarding and self neglect

• indicators of squalor

• assessment of people living in squalor

• interventions and how to discuss squalor with people

• the impact of squalor on care giving

• organisational processes.

The project carried limitations such as small sample size; one organisation/one location; no client perspective and rural and remote conditions were not considered. Implications for practice included:

• person centred practice

• client types are quiet different for compulsive hoarding and squalor living conditions

• non judgemental approach

• relationship development

• assessment skills

• develop expertise in complex behaviours

• communication between health services

• multi-service and inter-agency protocols.

Next steps included Inter-agency inter-disciplinary collaboration and seeking research funding to undertake a larger study involving clients.

2.3 SA Flinders University: ‘Stuff’, ‘Mess’ and ‘Hoarding’: a maze of language and law\(^\text{149}\)

Flinders Institute for Housing, Urban and Regional Research explored squalor as a legal concept, discussing the realities around individual rights and legalities and the extreme messiness where cohabitation and varying living standards exist side by side presenting conflicting pressures (for example, liability; ombudsman, treasury and the media).

The point made is that social policy undertaken within a human rights framework ensures that:

• The primary principle of intervening in an individual's life is respect for that individual's autonomy and self determination, ensuring the right of individual choice is paramount, placing the responsibility on the individual to understand and accept the consequences of the choices they make.

• A secondary principle of equal importance is the right of individuals to live in the community free from exploitation and harm, which places the responsibility on the community to ensure that policies are developed ensuring that options to live free from harm are available.


\(^{149}\) Michele Slatter, Associate Professor of Law. Flinders Institute for Housing, Urban and Regional Environments. Flinders University. S.A.
The right of respect of individual choice is only available to individuals who are able to make choices between a range of options available and often marginalised and disenfranchised individuals are not able to exercise this right if they lack options. Public housing and tenancy perspectives were discussed where examples of resolution were presented, which were not based on threats of eviction.

Flinders University suggested managing compulsive hoarding will be an issue for the 21st Century. The question is how and when to intervene. When developing a social development model of intervention, legal remedies have their place and are often found in existing Acts such as the Mental Health Act, the Health Services Act and local government regulations.

2.4 Ethics and decision making - a domiciliary care SA training initiative for staff working in complex home environments

Domiciliary Care South Australia (DCSA), a large SA organisation provides a range of community based assessment and direct care services for older people across metropolitan Adelaide. They recognise DCSA staff work in complex home environments including squalor/hoarding/neglect/clutter situations.

Some experienced DCSA Social Workers drew on their experience and practice wisdom to decide how to extend and develop their knowledge in responding to such cases, as well as remaining dynamic locally. A project was initiated (2009) looking at how best to train and support staff working in this area. The project involved their Personal Support staff as well as listening to and promoting the voices of clients. A video 'Everyone Deserves a Chance', was developed to convey key themes and is a core component of the training workshops which point out how effective work in this area can lead to a range of benefits.

The training package recognises and promotes the value, knowledge and skills already used by staff in preference to deferring to expert knowledge or ‘solutions’, which reflects DCSA’s endeavour to remain client centred and to look beyond labels to the stories and life struggles of the people they work with.

2.5 New counselling service – before the end of 2011

Chronic hoarding of disused possessions and animals is a big problem for councils. A SA Health survey showed "squalor-related" complaints to councils rose from 124 in 2004 to 642 in 2008.

Hoarders in SA who litter their homes with junk will receive free counselling to avoid council clean-ups. The approach aims to assist the estimated seven in ten suburban hoarders thought to be suffering from obsessive-compulsive disorder or other mental health problems. The SA Public and Environmental Health Council is co-ordinating the service based on a NSW idea which seeks to break the cycle of council clean-up orders and mass dumping of people's possessions.

The SA Health Director of Health Protection said (January 2011) that this new approach would tackle the causes and the symptoms and should be in place before the end of the year, and would include mental health and welfare agencies such as UnitingCare Wesley, Anglicare and the RSPCA.

3. New South Wales (NSW)

The service response and intervention effort in NSW seems to focus on squalor and aspect of squalor that includes hoarding conditions.

3.1 NSW Department of Ageing, Disability and Home Care (DADHC)

In 2002-2003 concerns were raised by representatives from NSW DADHC, the NSW Department of Housing, local councils, community health nurses and other organisations which provide support to older people in their homes, about an increasing number of people living in squalor in the eastern suburbs of Sydney.

During 2004 DADHC funded a review of services provided to this target group, aiming to develop guidelines particularly for staff providing Home and Community Care (HACC) services that were intervening in such cases, more than likely on an ad hoc basis.

Some service providers’ became frustrated with the lack of a coordinated response, resulting in a meeting of staff from various community organisations in Sydney (2005) that aimed to develop guidelines to better work with people living in severe domestic squalor. An initiative of the (then) Partnerships Against Homelessness (PAH) Committee, the project was auspiced by Central Sydney Area Health Service (now the Sydney South West Area Health Service) and was coordinated initially by a Reference Group150 with experience in assisting people who live in squalor.

150 Reference group representation: Psycho-geriatricians: Health Services; Community Services Worker/Chiriczein: Alcohol and Drug service; Risk Management, Fire Brigade; RSPCA; Community Worker for Older People: Municipal Council; Shared Accommodation Officer, Sydney Municipal Council; Aboriginal Liaison & Senior Client Service Officer, NSW Department of Housing; Disability Advisory Service, Protective
Professor John Snowdon, a psychiatrist was appointed Chairperson and a consultant was recruited to conduct a review of the evidence relevant to squalor, to consult stakeholder groups and to write a report on which the Guidelines “Partnership against Homelessness” was developed, 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).

These guidelines assist staff of various government and non-government agencies to constructively intervene and improve the lives of people living in severe domestic squalor, as well as to improve the efficiency, speed of action and coordination of work between relevant agencies across multiple health and community bases sectors, providing them with:

- a step-by-step framework (that is, the initial visit, interagency cooperation, referral to other service providers, strategies to assist people unwilling to accept assistance and/or with impaired decision making capacity)
- simplified procedures to assist people living in domestic squalor (refer Attachment 1: Flowchart 1)
- practical information regarding referrals and intervention options (refer Attachment 2: Flowchart 2)
- clear roles and responsibilities of agencies and service providers to improve coordination and integration of services (refer Attachment 3: Impact of Squalor checklist)
- occupational Health and Safety checklist (refer Attachment 4)
- a series of case studies explaining the issues and current events arising in typical cases of severe domestic squalor (refer Attachment 5).

3.2 Catholic Community Services [Sydney] (CCS) – Toolkit development

CCS have developed a strong interest in developing means to address squalor and hoarding issues consequently play a strong leadership role on the subject in NSW, and at times nationally.

In 2008, Catholic Healthcare Ltd received one-off funding from NSW DADHC to develop a project that would provide assistance for people living in domestic squalor in a large region of Sydney (including Ashfield, Botany Bay, Hornsby, Hunter’s Hill, Ku-ring-gai, Lane Cove, Leichhardt, Manly, Marrickville, Mosman, North Sydney, Pittwater, Randwick, Ryde, Sydney, Warringah, Waverly, Willoughby, and Woollahra).

CCS acknowledge that hoarding or squalor situations contain highly complicated and often compounding issues which need to be investigated to ensure a successful and sustainable intervention.

CCS developed a toolkit for both service providers and members of the community within the City of Sydney, to respond to situations of squalor and hoarding, made possible by the City of Sydney's Community Services Grants program. The Toolkit builds on the recommendations as set out in the 'Partnerships against homelessness' Squalor Guidelines, providing:

- definition and descriptions of the complexities involved (Getting Started)
- an intervention flowchart ('Pathway through the maze', 2010)
- resources and contact details for relevant local NSW organisations (Services and Resources), and
- links to useful information pertinent to the geographic scope of service delivery.

CCS recommends that the Toolkit is read in its entirety before a course of action is determined. The intervention flowchart is interactive making it necessary to complete all of the questions and carefully consider the potential for the situation to be retrieved. Each question assists in guiding the user towards suitable contact points and services for assistance in addressing issues.

The CCS material applies to the catchment area of the project (that is a large area of Sydney). Other organisations could adapt the resource listing to their own geographic area and circumstances. The CCS material is useful re squalor concepts and aspects of intervention, but stops short in terms of how to work with a person beyond an industrial clean up, though other projects have addressed this (refer 3.3). The material is designed to feedback to CCS.

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154 Note: This guidance material was not intended to cover cases of self-neglect where squalor was not an issue, nor in cases of hoarding without squalor conditions.
3.3 CCS Homeless and housing support services - solution focused interventions for squalor and hoarding: Beyond the clean-up approach

This project focuses on the issue of squalor rather than the impact, challenging the need to think differently about community and social structures rather than the person. Potential aetiology could include health, personality, functionality, life experiences and societal factors. The project addresses the complexity of assessing severe squalor cases, highlighting irretrievability and sustainability as fundamental to assessment, suggesting the development of solutions to:

Individual assessment: a balance between duty of care, societal values and personal choice; the person’s daily decision making capacity; understanding the facts; the main choices; consequences and affect

The building: tenure; fire or safety or security risks; OHS; who assists with accommodation options if needed

The environment: internal; external; access; intervention; pets; vehicles; legal /tribunal or council orders

The community: impacts; rights; expectations, fire or safety or health risks

Post intervention plans: client support, service provision and prevention.

The project emphasises shared solutions, responsibility, interventions and results between sectors.

3.4 National squalor conference, Pathway through the maze: 5-6 November 2009 (Sydney)

CCS hosted the inaugural National squalor conference 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, 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. Over 400 delegates attended from around Australia, New Zealand and Ireland (refer table 8).

Table 1: National Squalor Conference - Sydney 2009: Delegate geographic breakdown

<table>
<thead>
<tr>
<th>State</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>69.2%</td>
</tr>
<tr>
<td>VIC</td>
<td>12.5%</td>
</tr>
<tr>
<td>SA</td>
<td>6%</td>
</tr>
<tr>
<td>QLD</td>
<td>5.5%</td>
</tr>
<tr>
<td>ACT</td>
<td>4.5%</td>
</tr>
<tr>
<td>NT</td>
<td>0.8%</td>
</tr>
<tr>
<td>Overseas</td>
<td>0.8%</td>
</tr>
<tr>
<td>WA</td>
<td>0.5%</td>
</tr>
<tr>
<td>TAS</td>
<td>0.2%</td>
</tr>
</tbody>
</table>

Keynote speakers included Professor John Snowdon, Psycho-geriatrician; Susan Graham, CCS Severe Domestic Squalor Project; Assoc Professor Jill Gordon, University of Sydney; Dr Shannon McDermott, Social Policy Research Centre UNSW and Father Bob Maguire (Victoria).

Follow up National workshop Sydney - March 2010

This workshop was attended by a representative group from the diverse sectors involved in responding to squalor or hoarding in general; they discussed the following topics:

- What is the role of a National Consortium? (that is, possible functions and how the consortium could assist in progressing an improved response to this issue).
- How could case or field workers be better supported?
- How well do the sectors involved collaborate and coordinate our responses?
- How do we encourage a greater understanding of squalor and hoarding issues?

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155 Graham, S., Senior Project Coordinator, Solution Focused Interventions for Squalor and Hoarding (Catholic Community Services, Homeless and Housing Support Services) 2009.
157 Lauder, et al. 2005
159 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.
• What do we need from the next National Conference (proposed 2011)?

Note: Another National Hoarding and Squalor conference is planned for 21 – 22 February 2012.  

3.5 The ethics of intervention in squalor - The University of Sydney

Ethical dilemmas are often about impossible social tasks and in the case of squalor, there is the valid proposition that living in squalor is undesirable for a range of reasons. However, there is the equally valid proposition that humans should have the right of self determination and if they choose to live in squalor that right should be respected. This is a particularly difficult pill to swallow for the helping professions.

While it may seem clear, especially in cases of danger that intervention is justified, it is equally clear that resources can be wasted if the focus is on squalor, rather than the person living in squalor. Thus the result of a well-intentioned cleanup can be a return to the same squalid conditions.

One thing that these ideas can do is to challenge and crystallise the questions:

• Why are self neglect, environmental neglect and hoarding problems?
• Who has the problem?
• How do we evaluate risk?
• What is our duty of care? Who shares in that duty?
• How can we balance autonomy and beneficence?
• How can we balance client’s rights and the rights of others?

It is important to recognise that in fields as complex as health and social care ethics inevitably involve balancing competing principles and values. In the case of squalor we may never expect to feel wholly at ease with decisions that need to be made, as here will always be room for regret, if only the regret that comes from seeing an elderly person forced to relinquish their autonomy, no matter how necessary this may be for their overall wellbeing.

Dilemmas may be irresoluble, but decisions are unavoidable. Working through the ethics of intervention may assist to see a number of different sides of a problem.

3.6 Animal hoarding - Human or animal welfare? RSPCA NSW

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)
• 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.


3.7 UnitingCare Ageing South Eastern Region NSW

UnitingCare Ageing South Eastern Region NSW have undertaken a project based on the DADHC Guidelines (Partnership Against Homelessness 2007) to assist people living in severe domestic squalor. The project called, Good living conditions, aimed to improve the living conditions of people living in severe domestic squalor in the Illawarra Region (Wollongong, Shellharbour and Kiama).

In March 2009 an interagency working party was established with the purpose of:

- focusing on service co-ordination and cooperation to pool resources
- building on the existing evidence base, knowledge and expertise in the sector
- establishing an agreed local area interagency protocol
- including pathways for referral
- ensuring a consistent, sustainable and efficient service response.

Preliminary work indicated not many organisations were aware of the DADHC guidelines and of those that were, only a small number were using the ECCS as recommended. Project progress:

- The guidelines and the Northern Sydney Squalor Information Pack were distributed.
- A squalor survey was completed and a list of useful resources developed.
- A case study questionnaire was developed and mental health awareness training provided.
- A list of referral sources and client support services, outside of the traditional approach was developed.
- Service gaps and organisational limitations or eligibility were identified.
- An agreed course of action was developed including guidelines and flowcharts.
- A draft protocol was developed.
- A squalor monitoring table was developed and distributed for data collection.

The protocol was finalised in October 2009 with the aim of taking it further to include engagement with and endorsement of organisations. An educational DVD for community services staff is to be developed, educational forums on squalor are planned and associated service support responses are to follow.

3.8 Public places - private issues: Helping rough sleepers in squalor: Mission Australia

People who are rough sleepers in squalor need to be understood in the following context:

- rough sleeping (not every rough sleeper lives in squalor)
- how do squalor and hoarding apply when sleeping rough
- self-neglect when sleeping rough
- squalor and hoarding in a refuge.

Principles need to be balanced between the right for people to be in public places and the right not be harassed or moved on from public places unless there is a threat to security or personal safety or if people are causing a breach of the peace.

Relationship with the person is the key, built on the following considerations:

- purpose of the intervention (that is, how to approach the person; build a relationship; health and safety first, amenity is secondary; time to become familiar with rules).
- action is informed by the current situation (that is, respond flexibly – particularly regarding health status)
- regular, predictable visits (that is, plan visits and clean ups, for example every Friday morning)
- consistency in attitude, behaviour and rules (that is, go regularly with the same attitude and rules)
- set limits (that is,. have agreed standards - health, hygiene, size of hoard
- replace necessities (bedding, clothing) if removed for health or safety reasons
- short lead times for agreed clean ups - one week
- reward positive behaviour (for example, compliments, shopping, transport as appropriate)
- flexibility and persistence (that is, look for new solutions to entrenched problems)
- consent (that is, the rough sleeper needs to acknowledge the need for a reduction or clean up).

Ethical and legal questions need to be considered, for example the removal of objects and personal items from a public place is theft. Partnerships with a range of sectors and services such as NGOs, cleaning; lighting; fencing (City of Sydney), police, mental health, physical health, local (housed) residents. Refer Attachment 3 for a sample of successful cases.
Attachment 1: NSW PAH: Flowchart 1: For people living in squalor

165 Source: Partnership Against Homelessness- Guidelines for field staff to assist people living in severe domestic Squalor. August 2007
Source: Partnership Against Homelessness - Guidelines for field staff to assist people living in severe domestic squalor. August 2007
## Attachment 3: Impact of squalor checklist

Extracted and adapted (January 2011) from *NSW Partnership against homelessness. Guidelines for field staff to assist people living in severe domestic squalor* (August 2007)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Relevant Agency/Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excessive hoarding causing health and safety issues for neighbours</td>
<td>DoH, local council</td>
</tr>
<tr>
<td>Complaints from adjoining neighbours regarding the mess, invasion of space, excessive smells (from rubbish and/or sewerage), fire hazards, or vermin infestation</td>
<td>DoH, local council, some cleaning services, local water authority</td>
</tr>
<tr>
<td>Presence of dependent others, for example, children, elderly relatives</td>
<td>DHS (Protective Services), DH, ACAS, HACC services</td>
</tr>
<tr>
<td>Pets kept in poor health</td>
<td>RSPCA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Condition</th>
<th>Relevant Agency/Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-neglect with poor nutrition, dehydration, probable untreated medical problems</td>
<td>Medical, psychiatric services</td>
</tr>
<tr>
<td>Confusion, disorientation, memory impairment, wandering and getting lost, delirium, acute psychiatric symptoms such as hallucinations, threatening self-harm, suicidal behaviours or symptoms suggestive of severe depression</td>
<td>Medical, psychiatric services</td>
</tr>
<tr>
<td>Aggressive behaviour or threatened harm to others</td>
<td>Medical, psychiatric, drug and alcohol services, police</td>
</tr>
<tr>
<td>Exposure to possible financial exploitation or abuse</td>
<td>Seniors Rights Victoria, Office of the Public Advocate, ACAS, NGOs, police</td>
</tr>
<tr>
<td>Threatened eviction and at risk of becoming homeless</td>
<td>Housing authority (DoH, landlord/real estate agent), NGOs, local government housing support service</td>
</tr>
<tr>
<td>Lives alone and/or unable to access help or supervision, marked decline in activities of daily living and functional status</td>
<td>Medical services, DHS, ACAS, local HACC assessment, GP</td>
</tr>
<tr>
<td>Limited mobility and risk of falls, incontinence</td>
<td>Medical services, intake and referral section of DHS, ACAS, Community NGO’s</td>
</tr>
<tr>
<td>Utilities not present or not functioning, i.e. water, power, sewerage, heating, telephone</td>
<td>Local council, local water authority, NGOs, DoH, landlord/real estate agent</td>
</tr>
</tbody>
</table>
### Attachment 4: Occupational Health and Safety Checklist

Extract: *NSW Partnership against homelessness. Guidelines for field staff to assist people living in severe domestic squalor* (August 2007)

<table>
<thead>
<tr>
<th>Question</th>
<th>Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the structure of and fabric of the building safe and secure?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are the premises safe to enter (floorboards, ceilings)?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are the electricity, gas and water connected?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there insulated or damaged power lines that could cause electric shock?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there animals on the premises?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Is there a fire hazard?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are protective clothing, gloves, safety helmet, mask, safety spectacles or goggles required?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Is special equipment required?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Is there a health risk?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there weapons or explosive materials on the premises?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there booby traps on private property?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there slip hazards because of faeces?</td>
<td>Y/N</td>
</tr>
<tr>
<td>Are there fall hazards from climbing over barricades</td>
<td>Y/N</td>
</tr>
<tr>
<td>Will there be the likelihood or probability of physical attack from the occupant?</td>
<td>Y/N</td>
</tr>
</tbody>
</table>

**Note:** It would be helpful if as many as possible of the above questions can be answered prior to the first home visit, that is, at the point when referral is taken.
### Attachment 5: Successful case studies – squalor

Some successful cases for people who are rough sleepers in squalor living in Sydney, New South Wales

#### A: Couple rough sleeping in squalor

**Before**
- Always an argument about reduction and cleansing
- Was more than 6 cubic metres included: rotting food and clothing, foul stench

**Intervention**
(a about 8 weeks (4-5 visits per week) from argument to cooperation)
- Agreed on permissible amount (2 cubic metres stacked neatly; in bags)  
- Any health risk (rotting food, soiled clothing) or loose material removed. (no roof)  
- Bedding to be rolled neatly and moved twice per week for cleaning  
- They decide what is to go to bring it to allowable level. (empowers them).

**After**
- Now tidy, no foul odour (local community and police accept the standard of tidiness)  
- Now ask for unscheduled reduction.

#### B: Self-neglect and squalor

**Before**
- Rotten mess; defecate in sleep area; fed rats and pigeons where he slept, foul stench  
- Exceptionally poor personal hygiene (soiled clothing; bleeding skin infection, foul odour)

**Intervention**
(from foul mess to acceptable standards in 3 weeks, 4 visits per week)
- Reductions and cleansing decided by council and he was given choice on what bedding to keep. Permitted two bags of clothing and he decided what to keep.  
- Any household items removed (for example, VCR but no power)  
- Health risk (dead animals; rotten food) must be removed  
- Local residents gave food and he was asked to refuse what he couldn’t use that day.

**After**
- Now housed. Went to hospital (poor health) then housed.  
- Not living in squalor. Excellent personal hygiene.

#### C: Pizza boxes

**Before**
- Collected food scraps; waste litter (pizza boxes; plastic bags; food wrapper)  
- Poor toilet habits but toilet separated from sleeping area, very dirty bedding and clothing

**Intervention**
(from foul mess to acceptable standards in 1 week, 4 visits per week)
- Gave option for self management of squalor and he collected more  
- So then agreed on limit (excepting health risk) and tidiness (for example, in bags)  
- All material (other than agreed) was removed. Empowered and cooperative when given choice of what to keep.  
- Reductions twice weekly and each time it was a difficult negotiation

**After**
- Was keeping to agreed tidiness standards.  
- Now left location after being assaulted.

#### D: Still friends after Guardianship

**Before**
(was evicted for extreme squalor ‘worst ever’ including collection of dead animals)  
- Hoarding (indiscriminate collection but neat) on the street was about 8m3 (filled a truck)  
- Hoarding on the street became a safe haven for vermin (including rats)

**Intervention**
(6 weeks from uncontrolled hoard to following limits [size & content])
- Extremely vulnerable woman over 60 year old; first priority to develop relationship  
- After about 6 weeks agreed to reduction; minor conflict during weekly reductions to 3m3  
- Rewards for cooperation: shopping and compliments. She chooses what’s kept in limit


**E: Self-neglect and squalor; eviction; getting back on track**

**Before**
(Self-neglect and squalor led to eviction; then squalor on street)
- Regular admission to Accident & Emergency (A&E) Centres across Sydney; routinely engaged when impatient then disengaged and returned to squalor
- Continual intoxication and extreme self-neglect and squalor; extremely vulnerable

**Intervention**
(8 weeks from self-neglect and squalor to sobriety)
- Establish single central support, I-CHOSS (used every A&E and still homeless)
- All connections across Sydney A&E Centres advised of plan to contact I-CHOSS.
- Assessed and new plan for housing created

**After**
- Sober for several months; Actively planning for housing
- Agreed to limits while in shelter.

**NSW Contacts for working with rough sleepers and initiatives above:**

Phone: (02) 92647219  
Complex Needs Project Coordinator, Homelessness Unit, City of Sydney  

Phone: (02) 92659472  
Public Space Liaison Officer, Homelessness Unit, City of Sydney  

Phone: (02) 83943900  
Community Services Worker, Outreach Team I-CHOSS, Mission Australia
### Appendix 6: Saving Inventory Tool

Revised (SI-R) (Modified Format)

For each question below, circle the number that corresponds most closely to your experience **DURING THE PAST WEEK**.

**Table 1**: Clutter in the Home

<table>
<thead>
<tr>
<th>Question</th>
<th>None</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Most/ Much</th>
<th>Almost All/ Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2  How much control do you have over your urges to acquire possessions?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3  How much of your home does clutter prevent you from using?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4  How much control do you have over your urges to save possessions?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5  How much of your home is difficult to walk through because of clutter?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 2**: Difficulty with Throwing Things Away

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Mild</th>
<th>Moderate</th>
<th>Considerable/ Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>6  To what extent do you have difficulty throwing things away?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7  How distressing do you find the task of throwing things away?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8  To what extent do you have so many things that your room(s) are cluttered?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9  How distressed or uncomfortable would you feel if you could not acquire something you wanted?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10 How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don’t do because of clutter.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11 How strong is your urge to buy or acquire free things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 3**: Distress and Compulsive Acquiring

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Mild</th>
<th>Moderate</th>
<th>Considerable/ Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 How strong is your urge to buy or acquire free things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13 How upset or distressed do you feel about your acquiring habits?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14 To what extent do you feel unable to control the clutter in your home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15 To what extent has your saving or compulsive buying resulted in financial difficulties for you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 4**: Avoidance of Discarding Possessions

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes/Occasionally</th>
<th>Frequently/ Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>17 How often do you avoid trying to discard possessions because it is too stressful or time consuming?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18 How often do you feel compelled to acquire something you see? For example, when shopping or offered free things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19 How often do you decide to keep things you do not need and have little space?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>How frequently does clutter in your home prevent you from inviting people to visit?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>How often do you actually buy (or acquire for free) things for which you have no immediate use or need?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>How often are you unable to discard a possession you would like to get rid of?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SI-R (Modified) Scoring Subscales:**

1. **Clutter** Subscale (9 items):  
   Sum items: 1, 3, 5, 8, 10, 12, 15, 20, 22

2. **Difficulty Discarding/Saving** Subscale (7 items):  
   Sum items: 4 (reverse score), 6, 7, 13, 17, 19, 23

3. **Acquisition** Subscale (7 items):  
   Sum items: 2 (reverse score), 9, 11, 14, 16, 18, 21

   Total Score = sum of all items.

**Interpretation of Scores**

Means for Nonclinical samples:

- **Acquisition** Mean = 8.1; standard deviation = 4.1
- **Difficulty Discarding** Mean = 7.8; standard deviation = 4.5
- **Clutter** Mean = 8.1; standard deviation = 7.1
- **Total Score** Mean = 24; standard deviation = 12.0

Typical scores for people with hoarding problems:

- **Acquisition** Score greater than 13
- **Difficulty Discarding** Score greater than 13
- **Clutter** Score greater than 15
- **Total Score** Greater than 40
Appendix 7: Hoarding Rating Scale – Interview (HRS-1)\(^\text{167}\)

Hoarding Rating Scale
Please use the following scale when answering items below:

0 = no problem
2 = mild problem, occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items
4 = moderate, regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items
6 = severe, frequently (several times per week) acquires items not needed, or acquires many unneeded items
8 = extreme, very often (daily) acquires items not needed, or acquires large numbers of unneeded items

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all difficult</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extremely Difficult</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all difficult</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extremely Difficult</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extreme</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>None/ Not at all</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extreme</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. To what extent do you experience impairment in your life (daily routine, job / school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>None/ Not at all</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Extreme</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Interpretation of HRS Total Scores** (Tolin et al., 2010)
Mean for Nonclinical samples: HRS Total = 3.34; standard deviation = 4.97.
Mean for people with hoarding problems: HRS Total = 24.22; standard deviation = 5.67.
Analysis of sensitivity and specificity suggest an HRS Total clinical cut off score of 14.

**Criteria for Clinically Significant Hoarding:** (Tolin et al., 2008)
A score of 4 or greater on questions 1 and 2, and a score of 4 or greater on either question 4 or question 5.

Appendix 8: Hoarding Assessment Tool

A. Telephone Screening:

Date referral received: ______________________

Worker receiving call: ______________________ Department: ______________________

Client name: ______________________________ Age: ________________________

Address: ___________________________________________________________________

Type of dwelling: _____________________________ Phone: _______________________

Referral Source (may be omitted to preserve confidentiality): _______________________

Phone: _ (_____)______-______

Household members: _________________________________________________________

Pets/animals? _________________ Own/Rent: ______________________

Family or other supports: (include names and phone numbers)_______________________

__________________________________________________________________________

Other Programs or private agencies involved: _____________________________________

__________________________________________________________________________

Physical or Mental Health Problems of client: _________________________________

Are basic needs being met (that is, food/shelter)? ________________________________

Clients’ attitude towards hoarding _____________ Will client allow access:_____________

Description of Hoarding Problem: (presence of human or animal waste, rodents or insects, rotting food, are utilities operational, are there problems with blocked exits, are there combustibles etc.)

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Other Problems/ Needs: ______________________________________________________

Initial Hoarding Severity Rating: None ___ Mild ___ Moderate ___ Severe ___

Others to Involve in Initial Assessment:

_____________________________________________________________________________

_____________________________________________________________________________

*Modified after Arlington County, VA Hoarding Task Force’s Assessment Tool

168 Developed by Dr Randy Frost
**B. Condition of the dwelling:** (to be completed at the property)

Date: ________________

Response Team Members and Phone numbers:

________________________________________________________________________

Please indicate whether the following appliances/utilities are in working order.

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stove/Oven</td>
<td>1</td>
<td>2</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fridge/Freezer</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Kitchen sink</td>
<td>1</td>
<td>2</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathroom sink</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Washer/Dryer</td>
<td>1</td>
<td>2</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toilet</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Electricity</td>
<td>1</td>
<td>2</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water heater</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Furnace/Heat</td>
<td>1</td>
<td>2</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shower/Tub</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
</tbody>
</table>

**Other:**

Please indicate the extent of each of the following problematic living conditions.

<table>
<thead>
<tr>
<th></th>
<th>none</th>
<th>somewhat</th>
<th>severe</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structural damage to house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Rotten food in house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Insect or rodent infestation in house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Large number of animals in house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Animal waste in house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Clutter outside of the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Cleanliness of the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Other (e.g. human faeces)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate the extent to which each of the following safety problems exist.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Very Much</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does any part of the house pose a fire hazard? (e.g. unsafe electrical cords, flammable object next to heat sources like furnace, radiator, stove)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>How difficult would it be for emergency personnel to move equipment through the home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Are the exits from the home blocked?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Are any of your stairwells unsafe?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Is there a danger of falling due to the clutter?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate the extent to which clutter interferes with the ability of the client to do each of the following activities.

<table>
<thead>
<tr>
<th>Activities of Daily Living</th>
<th>N/A</th>
<th>Can do</th>
<th>Can do with difficulty</th>
<th>Unable to do</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prepare food (cut up food, cook it)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use refrigerator</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use stove</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use kitchen sink</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Eat at table</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Move around inside the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Exit home quickly</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use toilet (getting to the toilet)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use bath/shower</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Use bathroom sink</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Answer door quickly</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Sit in your sofas and chairs</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Sleep in your bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Clean the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Do laundry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Find important things (e.g. bills)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Care for animals</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
C. **Client Assessment:** (to be completed during an interview with the client)

**Mental Health Issues:** for example, Dementia; see guidelines

Frail/ elderly or disabled: _______________________________________________________

Family and other social supports: ______________________________________________

Financial status/ ability or willingness to pay for services: _________________________

**Hoarding Interview (questions to ask the client):**

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
   - Not at all difficult
   - Mildly
   - Moderately
   - Extremely Difficult

2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?
   - No difficulty
   - Mildly
   - Moderately
   - Extremely Difficult

3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?
   - No problem
   - Mild problem
   - Moderate problem
   - Severe problem

4. To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?
   - No distress
   - Mild distress
   - Moderate distress
   - Severe distress

5. To what extent does the clutter, problems discarding, or problems with buying or acquiring things impair or interfere with your life (daily routine, job/school, social activities, family activities, financial difficulties)?
   - Not at all
   - Mildly
   - Moderately
   - Severely

D. **Summary:**

**Level of risk:** (Based on assessment of condition of the dwelling.)

<table>
<thead>
<tr>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
</table>

**Level of insight:**

<table>
<thead>
<tr>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Fully aware &amp; cooperative</th>
</tr>
</thead>
</table>

(Level of insight should be determined by comparing responses to the Hoarding Interview to the observed conditions of the dwelling.)

Complicating factors: (for example, dementia, disabled)

---

E. **Recommendations:**

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________
Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.

1 2 3
4 5 6
7 8 9

Appendix 9:

169 Frost et al., 2008
Clutter Image Rating: Bedroom
Please select the photo that most accurately reflects the amount of clutter in your room.
Appendix 9:
Part 3 of 3

Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room:
Appendix 10: Squalor - to rate cleanliness of a person’s accommodation

Demographic details
(This sheet may be removed if it is desirable to de-identify the client when communicating with other agencies)

<table>
<thead>
<tr>
<th>NAME OF CLIENT</th>
<th>SURNAME</th>
<th>OTHER NAMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth and/or approx age of client</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex (please circle)</td>
<td>MALE</td>
<td>FEMALE</td>
</tr>
<tr>
<td>Marital Status (please circle)</td>
<td>SINGLE</td>
<td>MARRIED/ DEFACTO</td>
</tr>
<tr>
<td>Address</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he/she live alone? (please circle)</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>If not, who with?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number and type of pets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home ownership</td>
<td>OWNER</td>
<td>TENANT-private</td>
</tr>
<tr>
<td>Accommodation type</td>
<td>HOUSE</td>
<td>UNIT</td>
</tr>
<tr>
<td>How long has he/she been living like this? (please circle)</td>
<td>LESS THAN 1 YEAR</td>
<td>1-3 YEARS</td>
</tr>
<tr>
<td>Known medical illnesses and/or disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental disorders now or in the past</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(ECCS) 170

170 Developed by G. Halliday and J. Snowdon (2006). This scale is based on the version devised by Snowdon (1986) which mostly used items listed by Macmillan & Shaw (1966). Some descriptions used by Samios (1996) in her adaptation of the scale have been included.
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.

**ACCESSIBILITY (clutter):**

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0</strong></td>
<td><strong>1</strong></td>
<td><strong>2</strong></td>
<td><strong>3</strong></td>
</tr>
<tr>
<td>EASY TO ENTER and move about dwelling</td>
<td>SOMEWHAT IMPAIRED access but can get into all rooms</td>
<td>MODERATELY IMPAIRED access. Difficult or impossible to get into one or two rooms or areas.</td>
<td>SEVERELY IMPAIRED access, e.g. obstructed front door. Unable to reach most or all areas in the dwelling.</td>
</tr>
</tbody>
</table>

0-29% 30 to 59% 60 to 89% 90 to 100% of floor-space inaccessible for use or walking across

**ACCUMULATION OF REFUSE or GARBAGE**

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

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0</strong></td>
<td><strong>1</strong></td>
<td><strong>2</strong></td>
<td><strong>3</strong></td>
</tr>
<tr>
<td>NONE</td>
<td>A LITTLE</td>
<td>MODERATE</td>
<td>A LOT</td>
</tr>
<tr>
<td>Bins overflowing and/or up to 10 emptied containers scattered around.</td>
<td>Garbage and refuse littered throughout dwelling. Accumulated bags, boxes and/or piles of garbage that should have been disposed of.</td>
<td>Garbage and food waste piled knee-high in kitchen and elsewhere. Clearly no recent attempt to remove refuse and garbage</td>
<td></td>
</tr>
</tbody>
</table>

**ACCUMULATION OF ITEMS OF LITTLE OBVIOUS VALUE:**

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

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>0</strong></td>
<td><strong>1</strong></td>
<td><strong>2</strong></td>
<td><strong>3</strong></td>
</tr>
<tr>
<td>NONE</td>
<td>SOME ACCUMULATION</td>
<td>MODERATE EXCESSIVE ACCUMULATION</td>
<td>MARKEDLY EXCESSIVE ACCUMULATION</td>
</tr>
<tr>
<td>but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances.</td>
<td>Items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean.</td>
<td>Items piled at least waist-high in all or most areas. Cleaning would be virtually impossible: most furniture and appliances are inaccessible.</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate types of items that have been accumulated:

- Newspapers, pamphlets, etc.
- Clothing
- Other items (what?)
- Electrical appliances
- Plastic bags full of items (If known, what items?)
### D. CLEANLINESS of floors and carpets (excluding toilet and bathroom):

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

### E. CLEANLINESS of walls and visible furniture surfaces and window-sills:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Acceptably clean in all rooms.</td>
</tr>
<tr>
<td>1</td>
<td>MILDLY DIRTY: Dusty or dirty surfaces. Dirt comes off walls on damp rag or finger.</td>
</tr>
<tr>
<td>2</td>
<td>VERY DIRTY: Grime or dirt on walls. Cobwebs and other signs of neglect. Greasy, messy, wet and/or grubby furniture.</td>
</tr>
<tr>
<td>3</td>
<td>EXCEEDINGLY FILTHY: Walls, furniture, surfaces are so dirty (e.g. with faeces or urine) that rater wouldn’t want to touch them.</td>
</tr>
</tbody>
</table>

### F. BATHROOM and TOILET:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Reasonably clean</td>
</tr>
<tr>
<td>1</td>
<td>MILDLY DIRTY: Untidy, uncleaned, grubby floor, basin, toilet, walls, etc. Toilet may be unflushed</td>
</tr>
<tr>
<td>2</td>
<td>MODERATELY DIRTY: Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, etc. Faeces and/or urine on outside of toilet bowl</td>
</tr>
<tr>
<td>3</td>
<td>VERY DIRTY: 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>
</tr>
</tbody>
</table>

### G. KITCHEN and FOOD:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Clean / Hygienic</td>
</tr>
<tr>
<td>1</td>
<td>SOMEWHAT DIRTY AND UNHYGIENIC: Cook-top, sink untidy and surfaces dirty, maybe with some spilt food. Refuse mainly in garbage bin. Food that could go off (for example, meat, remains of meal) left uncovered and out of fridge. Rate 1 if no food but fridge dirty</td>
</tr>
<tr>
<td>2</td>
<td>MODERATELY DIRTY AND UNHYGIENIC: Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils etc. Bins overflowing. Some rotten or mouldy food. Fridge unclean.</td>
</tr>
<tr>
<td>3</td>
<td>VERY DIRTY AND UNHYGIENIC: Sink, cook-top, 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>
</tr>
</tbody>
</table>

### H. ODOR:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Nil / pleasant</td>
</tr>
<tr>
<td>1</td>
<td>UNPLEASANT for example, urine smell, unaired.</td>
</tr>
<tr>
<td>2</td>
<td>MODERATELY MALODOROUS: Bad but rater can stay in room.</td>
</tr>
<tr>
<td>3</td>
<td>UNBEARABLY MALODOROUS: Rater has to leave room very soon because of smell.</td>
</tr>
</tbody>
</table>

### I. VERMIN (Please circle: rats, mice, cockroaches, flies, fleas, other):

<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>A FEW (e.g. cockroaches)</td>
</tr>
<tr>
<td>2</td>
<td>MODERATE: Visible evidence of vermin in moderate numbers e.g. droppings and chewed newspapers.</td>
</tr>
<tr>
<td>3</td>
<td>INFESTATION: Alive and/or dead in large numbers.</td>
</tr>
</tbody>
</table>
### J. SLEEPING AREA:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasonably clean &amp; tidy.</td>
<td>MILDLY UNCLEAN. Untidy. Bed unmade. Sheets unwashed for weeks.</td>
<td>MODERATELY DIRTY. Bed sheets unclean &amp; stained, for example, with faeces or urine. Clothes and/or rubbish over surrounding floor areas.</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 a TOTAL SCORE:

<table>
<thead>
<tr>
<th>DO YOU THINK THIS PERSON IS LIVING IN SQUALOR?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(circle one)</td>
</tr>
<tr>
<td>NO</td>
</tr>
<tr>
<td>Clutter (lots), not squalor</td>
</tr>
</tbody>
</table>

### SUPPLEMENTARY QUESTIONS (to add to description but not to score)

Comments or description to clarify / amplify / justify or expand upon above ratings:

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

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLEAN AND NEAT. Well cared for.</td>
<td>UNTIDY, CRUMPLED One or two dirty marks and in need of a wash</td>
<td>MODERATELY DIRTY With unpleasant odour. Stained clothing.</td>
<td>VERY DIRTY Stained, torn clothes, malodorous.</td>
</tr>
</tbody>
</table>

Is there running water in the dwelling?  
YES or NO?

Is electricity connected and working?  
YES or NO?

Can the dwelling be locked up and made secure?  
YES or NO?
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, etc before it would be reasonably habitable?

<table>
<thead>
<tr>
<th></th>
<th>NONE</th>
<th>A LITTLE</th>
<th>A FAIR AMOUNT</th>
<th>LOTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
<td>Minor repairs &amp; some painting.</td>
<td>Some structural repairs plus painting.</td>
<td>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></th>
<th>NOT AT ALL</th>
<th>POSSIBLE RISK</th>
<th>CONSIDERABLE RISK</th>
<th>VERY UNSAFE</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
<td>of injury e.g. by falling</td>
<td>of fire, injury or health problem</td>
<td>The dwelling is so cluttered and unhealthy that people should not enter it, (except if specialists with appropriate clothing and equipment) and/or there is a high fire-risk.</td>
</tr>
</tbody>
</table>
Appendix 11: Living Conditions Rating Scale

Living conditions rating scale (LCRS)\(^{171}\)

The aim of this rating scale enables Governments and community organisations to gauge the nature and urgency of the issue.

It promotes better planning and intervention strategies especially when seeking the support and assistance of other agencies or family members.

The scale has 13 domains, totalling 39 - each scoring 0 to 3.

1 = acceptability
2 = moderate
3 = extensive

Information for Scoring:

<table>
<thead>
<tr>
<th>Interior of house</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>Score according to ability to access for example, 3 for completely unable to enter due to holes in floor/belongings piled up.</td>
</tr>
<tr>
<td>Odour</td>
<td>Score 3 only if it is physically impossible to stay in the residence.</td>
</tr>
<tr>
<td>Lighting</td>
<td>To score 3, no lighting/natural lighting that is, very dark and unable to see without torch.</td>
</tr>
<tr>
<td>Floor/carpet</td>
<td>Score 3 if unable to see the majority of carpet due to covering of newspapers etc.</td>
</tr>
<tr>
<td>Walls</td>
<td>To score 3, the majority of the wall is covered with filth etc.</td>
</tr>
<tr>
<td>Furniture</td>
<td>To score 3, there is only a mattress and no other furniture.</td>
</tr>
<tr>
<td>Kitchen</td>
<td>To score 3, there must be no evidence of organisation, cleaning or rubbish removal over a long period of time; or no kitchen.</td>
</tr>
<tr>
<td>Food</td>
<td>To score 3, there must be only minimal food/poorly stored food.</td>
</tr>
<tr>
<td>Bathroom/toilet</td>
<td>To score 3, there must be a blocked or not functioning sewerage system; or no bathroom; and/or no toilet.</td>
</tr>
<tr>
<td>Disposal of excreta</td>
<td>To score 3, human or large pet excreta (exclude occasional cockroach dropping).</td>
</tr>
<tr>
<td>Hoarding</td>
<td>To score 3, there must be a massive number of items stored in the home.</td>
</tr>
<tr>
<td>Clutter</td>
<td>To score 3, there must be more clutter than accessible routes through the home.</td>
</tr>
<tr>
<td>Vermin</td>
<td>To score 3, vermin must be visible on inspection.</td>
</tr>
</tbody>
</table>

Living Conditions Rating Scale

Organisation of Person who completed rating scale: ..............................................

Age of Client: ............ Sex of Client: ............ Post Code..............

Dwelling [circle those appropriate]:

single/ shared/ unit/ house/ group home/ rented/ privately owned/other..............................

Age of Dwelling: .........................

<table>
<thead>
<tr>
<th>Interior of house</th>
<th>Tick / comment</th>
</tr>
</thead>
</table>
| Accessibility     | • within acceptable standards  
|                   | • some difficulty entering the house or rooms  
|                   | • moderately difficult to enter the house or rooms  
|                   | • rooms or house inaccessible or impossible to enter safely |
| Odour             | • within acceptable standards  
|                   | • slight unpleasant smell  
|                   | • moderate unpleasant smell  
|                   | • unable to spend any length of time in house due to the smell |

| Lighting | • within acceptable standards  
• poor lighting  
• most lights not working  
• no lighting available |
| --- | --- |
| Floor/carpet | • within acceptable standards  
• some rubbish, food stains, filth covering floor  
• moderate amount of rubbish, food stains, filth covering floor  
• thick covering of newspaper, cardboard, discarded packaging and stains on floor covering |
| Walls | • within acceptable standards  
• some filth, nicotine stains and grime covering some walls  
• moderate filth, nicotine stains and grime covering most walls  
• all walls covered with filth, nicotine stains and grime |
| Furniture | • acceptable amount of furniture (bed, table, chairs, white goods)  
• short of some necessary items (that is, no couch or bed)  
• missing essential items (for example, no fridge or stove but has a bed)  
• no essential furniture (that is, mattress only) |
| Kitchen | • within acceptable standards  
• some unwashed crockery and benches left for a couple of days  
• most crockery unwashed and benches unwiped for some time  
• full of unwashed crockery, mouldy scraps evident, benches not wiped for months or more |
| Food | • acceptable amount of storage space and healthy variety of food  
• some storage problem (that is, food not in cupboards)  
• reasonable variety of food  
• balanced diet only on pay days and/or shopping left in bags on the floor  
• little food in the house egg staple diet of tea, bread, biscuits, cakes and tinned food and/or inappropriate storage of food (that is,, frozen food not in freezer) |
| Bathroom/toilet | • workable sewerage system  
• blocked or non-workable sewerage system |
| Disposal of excreta (include pet excreta) | • no excreta noted throughout the house  
• excreta noted in the house i.e. on floor or walls |
| Hoarding | • within acceptable standards  
• some collection of singular items i.e. cartons, bottles, newspapers  
• moderate collection of singular items  
• mass collection of singular items |
| Clutter (include clothing) | • within acceptable standards  
• some cluttering of living space  
• moderate amount of clutter starting to affect living space  
• bags and boxes markedly reduce living space |
| Vermin | • within acceptable standards  
• some evidence of vermin present  
• moderate amount of evidence of vermin present  
• rats/cockroaches are evident most of the time |

Please note that this is a guide only, if a person you are assessing does not rate highly on this scale; it does not mean that they should not be referred to relevant services for assistance.

Appendix 12: Victorian local service response

The following examples of practical service response are loosely defined by program type, but more so by informal local networks, made up of a broad range of service providers and program types that respond to cases of hoarding and/or squalor. These samples are by no means exclusive.

1. Housing – Support for High Risk Tenancy (SfHRT)
1.1 North and West Region Hoarding Working Group

This working group is run in conjunction with Aged Care, North and West Region with representation from Department of Human Services: SfHRT, Complex Clients; Disability; Department of Health: Aged Care, Mental Health; Aborigines Advancement League; Wintringham; Moonee Valley Council, Aged and Disability Services; North East Housing Service Melbourne Clinic; HomeGround SHASP and Outreach; Salvation Army, Aged Care; Merri Community Health Services, PHaMs; Geriatrician, Western Health; ACAS; HACC; RDNS.

The group focuses on localised responses to public housing tenants experiencing hoarding as well as information sharing and collaboration across program areas, such as deciding on some key best practice principles for working with the hoarding client group:

- harm minimisation, utilising existing frameworks
- strong data collection to build an evidence based framework
- grass roots/practical responses
- multi disciplinary approach
- capacity to access formal secondary consults - including complex case discussion, group de-briefing and clinical supervision
- flexible, holistic and long term worker involvement
- specialised therapy and links to mental health supports.

In January 2010, a draft Information pack (including two flowcharts) was produced to support a regional response to clients with compulsive hoarding behaviour and in October 2011 an education forum was organised (refer Attachment 1). This working group discussed the benefit of developing a resource guide and is considering the usefulness of a state wide website.

1.2 Loddon Mallee Region Hoarding Working Group

In 2009, Loddon Mallee Housing Group (LMHG) Community Connections Program, initiated a focus on hoarding after acknowledging increasing demand and lack of alternative resources or case management response. In January 2010, a multi disciplinary working group was developed within LMHG which later expanded to include service providers external to LMHG (which commenced trading as Haven in 2011).

This working group meets bi-monthly. Member organisations include Haven, DHS SfHRT, Advocacy and Rights Centre, Bendigo Health - Case Management Services/HART/ACAS; Villa Maria; La Trobe University, RSPCA; Police, CFA, DHS OoH; Community Housing Ltd, Community Equity Housing, St Lukes Mental Health, Council HACC, DH – Aged Care.

The purpose of the working group has been to assist in identifying and supporting individuals in the Loddon Mallee Region who are experiencing difficulties due to their hoarding and/or squalor behaviour by aiming to:

- create a best practice framework for local agencies
- develop and review an information pack
- provide the community with education formally and informally.

La Trobe University, Bendigo is running a research project called ‘Living beyond the Pale: Understanding compulsive hoarding and domestic squalor, and associated environmental health concerns’. A full report on the preliminary study ‘Scoping Hoarding in Central Victoria’, will be publically available in the near future.

Haven has received strong organisational support from upper level management, including their Board. Haven are recognised as an authority on hoarding and squalor in the state and by the Department of Health regional office, however the agency is not funded to provide this service and due to increasing demand needs to prioritise clients. Haven is providing data to the Department of Health regional office to evidence their hoarding/squalor work.
1.3 Barwon South West

City of Greater Geelong (CoGG): Cross Divisional Hoarding Project (CDHP)

The CoGG developed the CDHP in response to hoarding being identified as an emerging community health and safety issue. In 2011 the CDHP won the joint MFB/CFA Fire Services Award which recognises Aged and Disability providers who have improved fire safety for their clients, workers or in their local community.

The CDHP project considers all aspects of hoarding and seeks to support the community through the provision of supportive services, networking within Council and with agencies external to Council using education and awareness raising strategies.

The process within this framework has resulted in a number of outcomes such as:

- CoGG ran a community Hoarding Forum (April 2011), to provide an opportunity to hear from experts in the field (Dr. Mogan, Professor Michael Kyrios, MFB, CFA, Dr Sook Meng Lee), to raise awareness of hoarding issues and to broaden the membership and scope of the existing Council Hoarding Taskforce which aimed to develop strategies, positive processes and procedures in response to hoarding. Organisations were invited to become active members.

- The Geelong Hoarding Network was developed aiming to: maximise opportunities, share information, develop activities that are innovative and strategic, identify gaps, take up funding opportunities and share resources from agencies to develop and deliver initiatives to fill those gaps.

  The Geelong Hoarding Network is open to all community, housing, health care services, education and Local and State Government departments that have hoarding as a component of their work, or have incidences of people experiencing hoarding when they otherwise would not have this on their agenda.

- Membership of the Hoarding Network is made up of Bethany Community Support; CFA; City of Greater Geelong; Borough of Queenscliffe, Barwon Health; GP Association, Geelong; The Salvation Army Kardinia Network; St Laurence; Victoria Police; DHS - Office of Housing, Wintringham, SalvoConnect and Southern Cross Care).

The network meets monthly and is coordinated by the CoGG and chaired by a CoGG local Councillor. The Councillor is also a member of the CDHP. The CDHP aims to continue to develop and deliver key health and safety outcomes.

CoGG motion to MAV State Council

The CoGG submitted a motion for consideration by the MAV State Council on 28 October 2011 asking: ‘That the MAV investigate the extent and impact of hoarding across Victorian Local Governments with a view to developing a collaborative framework to address this burgeoning issue.”

1.4 Eastern Metropolitan Region (EMR)

The DHS EMR combined the regional functions of the Multiple and Complex Needs Initiative (MACNI); the At Risk Tenancies Initiative (ARTI) and the High and Complex Needs programs (HACN programs) within Housing, Primary and Complex Care, calling it the DHS EMR Complex Care Program (EMR CCP) which includes:

- regional coordination and consultation
- access to HACN programs
- complex care regional panel (including access to MACNI central programs).

Support models that enhance case and service coordination and provide opportunities for secondary consultation and systems review have been shown to improve outcomes. People in this target group often require multiple and coordinated service responses or specialised responses that exceed the capacity of core services.

The EMR CCP offers regional coordination and consultation to any people with high and/or complex needs who are over 16, are struggling to obtain supports because they fall through service gaps, present significant safety risks and/or are exhausting the existing provider’s ability to provide support. The EMR CCP receives calls from the public, private providers/practitioners and funded programs seeking advice and consultation.
The main role of the program is to pull together a multi sector response (practical and clinical), maintain a Coordination role, as well as carry a small case load. The EMR CCP establishes and reviews care plans, separate to a response to an urgent situation.

In the above context the EMR CCP responds to cases of hoarding and/squalor, coordinating appropriate regional program involvement, depending on what is required on a case by case basis. Working in multi disciplinary teams is the most effective model to respond to people with hoarding behaviour and/or living in squalor conditions.

EMR CCP connects with the area mental health team for clinical services, other programs like Salvation Army Eastcare, non-government psychiatric disability rehabilitation and support services (PDRS) and a range of local council services. Some agencies will do clean ups, it depends on the level of outreach support, capacity to respond and OHS concern.

The Personal Helpers and Mentors program (Cwlth) is particularly responsive due to unrestricted timeframes and clients do not need a diagnosis to receive support. The Community Connections program also plays an important role in relation to hoarding response.

DH Mental Health fund Eastern Access Community Health (EACH) to cover the outer east of EMR, MIND (mental health) to cover the Central East and JobCo for the Boroondara area. Community Health programs are not generally accessed as their services are predominately centre based with minimal outreach. This client group are less likely to attend a centre for assistance.

There is goodwill to move forward. Clinical expertise is growing with mental health (PDRS) and private practitioner Dr Mogan, providing support and education.

DHS EMR is looking at some time in the future, to develop a broader regional focus for this program, with a reference group. There is capacity to expand this regional model with heightened resources and capacity.

1.5 Southern Metropolitan Region

In 2011, a training session on hoarding was provided by SfHRT for OoH and SfHRT staff, a one day session by a private consultant as well as by Dr Mogan. DHS Housing is hoping to run another training session in 2012 for the same group, but expand to include staff from homelessness agencies.

The DHS Housing program also attends the SMR Hoarding Special Interest Group (refer point 7).

1.6 Gippsland

As in other regions, the profile of hoarding and squalor is increasing. Gippsland responds on a ‘case by case’ basis. There has been development (particularly in housing), with education of staff, referral processes to supports, procedures to capture more information and to help provide a more detailed profile of hoarders within the region.

Hoarding is an issue that SfHRT has highlighted and an area where service gaps exist, there is no ‘one fix for all approach’ - rather the opposite. Due to the complex nature of hoarding behaviour, response requires a collaborative approach of services and supports.

There are opportunities available to identify issues for action/ service gaps such as hoarding: develop regional responses within the SfHRT position, seek support from OoH and the newly developed DHS - Client Outcome Teams, of which SfHRT is part of. In addition the One DHS model will provide the mechanism for SfHRT to further develop and promote collaborative approaches to respond more effectively to complex clients.

2. Salvation Army, EastCare: Living Well Program

The HACC Living Well Program (formed 2009) is an amalgamation of the HACC Home Care program and HACC Outreach Worker (HOW) pilot project (2005), working closely with the Community Connections brokerage program funded by the Victorian DH, Aged Care.

The aim of the HOW pilot project was to work with clients with complex needs to improve their daily living skills and address the OHS issues enabling them to access mainstream HACC services and continue to live independently in the community. Funding for this pilot project was allocated to Salvation Army EastCare as they had existing programs (The Community Connections Program and Home Care position), that would provide peer support for the HOW position.
Following an evaluation of the HOW pilot (January 2007) the project was recurrently funded and amalgamated with the Home Care position as both programs were similar, forming the Living Well Program enabling region-wide coverage.

**Current status**

The Living Well program works with HACC eligible clients with complex care needs whose environment, living circumstance and/or behaviours create a barrier to the provision of mainstream HACC services.

A focus of the program is hoarding due to the high prevalence of complex care referrals from regional HACC and other program providers, who cite occupational health and safety restrictions/risks in working in the homes of people with hoarding behaviours. EMR HACC providers also indicated their funding limitations due to the type and length of intervention required regarding hoarding cases.

The Living Well service provides generally 3 – 5 hours of contact per client once a week; a focus on getting to know the clients very well, placing a strong emphasis on positive reinforcement for changes to the property, as well as general well-being.

Motivators for change are encouraged; linking the person into the community as well as paying attention to their immediate space, using rubbish skips if needed. It is difficult to define a “typical” hoarder due to the wide range of underlying motivations and co-morbid issues associated with these behaviours.

The Living Well program works closely with SfHRT, mental health, HACC and generalist case management services as well as with Dr Chris Mogan, to ensure practice is grounded in a research and evidence base.

**Table 1: EastCare Living Well Program referral characteristics 2007-2009**

<table>
<thead>
<tr>
<th>2007-09</th>
<th>Referral characteristics</th>
<th>- 2% had indigenous status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>- majority born in Australia</td>
</tr>
<tr>
<td>82 cases</td>
<td>Spread evenly across the Eastern Metropolitan region (more in the Outer East)</td>
<td></td>
</tr>
<tr>
<td>12.5%</td>
<td>31-40 years old</td>
<td>- 66% females</td>
</tr>
<tr>
<td>21.3%</td>
<td>41-50 years old</td>
<td>- 34% males</td>
</tr>
<tr>
<td>15%</td>
<td>51-55 years old</td>
<td></td>
</tr>
<tr>
<td>12.5%</td>
<td>61-70 years old</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Majority of referrals came via community based services and ACAS</td>
<td>at the time of referral, other health issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 26% was common</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 9% diagnosed with definite mental health issues.</td>
</tr>
</tbody>
</table>

The Living Well program has a long waiting list. The DH EMR office have commenced planning for an evaluation of the Living Well program.

**3. Salvation Army (SA) CACPS – Western region**

The SA Community Aged Care program provides CACPs in the north western metropolitan region. Approximately 30 per cent of their clients have issues with hoarding and excessive clutter and a much smaller amount of clients have issues with squalor.

Clients are prioritised from social and financially disadvantaged backgrounds with limited familial or community connections, with histories of homelessness residing in public housing, boarding/rooming houses, supported residential services, caravan parks or in their own homes - which may be in varying degrees of disrepair.

The SA CACP client’s are aged with varying degrees of alcohol use/abuse, mental health, dementia, challenging behaviours, intellectual disability, acquired brain injury, gross self-neglect and usually poor insight into their living conditions. The SA has found that hoarding/squalor is chronic and progressive requiring intensive case management; it doesn’t discriminate and can affect anyone, presenting an increased risk to elderly clients.

The SA CACP program view hoarding and sometimes squalor as a learned behaviour initially, used by the client as a way of coping and managing certain stressors (e.g. anxiety, loss, grief) in their daily lives. Over time this behaviour grows in frequency and scale to a point where it is destructive and far less helpful to the

172 Extract Office of Housing North and Western Hoarding Local area service provider support network. Minutes 29 September 2010.

173 Stylli Tom, Manager Community Connections and AOD Programs, Adult Programs, The Salvation Army. Eastcare. Feb 2010
client’s health and welfare. People affected by hoarding seem to have poor insight, they change when they are ready to and progressing to that point service wise requires time and intensive engagement. Sometimes external forces rather than a client’s choice seem to trigger the need to change.

SA CACP provide long-term support to older people with hoarding behaviour within program guidelines, valuing the relationship, being patient, supportive, helpful and empathic - encouraging clients to make choices for themselves exercising their preferred levels of dignity of risk.

4. Inner South Community Health

DVD production
A DVD called Working with People with Hoarding Behaviours was produced in 2010 as a learning resource containing practical strategies designed to assist HACC staff to work in the area of Hoarding.

The project was an initiative of Southern Metropolitan Region (SMR) HACC Training (Vision Australia) and SMR HACC Training Advisory Committee in partnership with the Inner South Community Health Service. The SMR HACC Training Program receives funding from the Victorian and Australian Governments through the Victorian HACC program.

The DVD explores hoarding with a range of experts and care providers who have worked with people who hoard. Some people with hoarding behaviours also share their personal insights. Education material was also provided as part of the package made up of discussion and reflection questions and resources.

Hoarding support group - Dr Chris Mogan currently runs a hoarding support group at Inner South Community Health. Planning for 2012 is currently underway.

5. Wintringham

Wintringham provide a broad range of affordable housing and support services to frail, elderly homeless men and women in Melbourne. Their Community Housing and Support Team (Northern/City) utilise a mix of their CACP, EACH, ACHA and HSAP services to respond to cases of hoarding and/or squalor. They learn as they go with regard to what works and what doesn’t, suggesting success is very much dependant on localised relationships and having regular contact with a consistent and limited group of workers. Supporting case managers is a challenge as hoarding behaviours can be such a difficult issue to work with.

Wintringham utilise Dr Chris Mogan as a secondary consult, but suggest that the counselling model is only suited to a certain type of client. They also appreciate working with MFB when appropriate.

Wintringham emphasise their intervention is limited to older aged clients, but are eager to continue raising awareness and working collaboratively, to share their experience and expertise with other sectors such as community mental health and APAT. Wintringham hope that hoarding will be included in DSM 5 as it could assist referral pathways and treatment options.

Wintringham value capacity building opportunities such as networking, building referral links and expanding case management knowledge, in this context they organised a North and West Metropolitan Region forum (September 2011) with the support of other service providers, to raise awareness and work towards improved outcomes for people with hoarding behaviours and living with environmental neglect (refer Attachment 1: North and West Region Hoarding Forum Flyer).

Hoarding data snapshot - 1 January, 2011

Wintringham collected data from their residential aged care, community aged care and housing services in their Northern/City division. The snapshot data was counted and provided by Managers and Case Managers in those funded services, providing an example of the number of hoarding related cases an aged care organisation such as Wintringham, is supporting in residential care facilities and supported community housing properties.

174 Provided by Kate Rice, Manager, Wintringham Community Housing and Support programs, Northern Metro and Melbourne city.
Table 2: Wintringham hoarding data snapshot 1 January 2011

<table>
<thead>
<tr>
<th></th>
<th>Total number of residents at time of count</th>
<th>Compulsive Hoarding Behaviours</th>
<th>Squalor/Environmental Neglect Behaviours</th>
<th>Clutter Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Residential Care Facilities</td>
<td>220</td>
<td>17</td>
<td>33</td>
<td>10</td>
</tr>
<tr>
<td>2 Wintringham Housing Properties</td>
<td>200</td>
<td>6</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>3 Community Care (including CACPS, EACH, EACH D)</td>
<td>23</td>
<td>28</td>
<td>22</td>
<td></td>
</tr>
</tbody>
</table>

6. Western Health: Western Aged Care Assessment Service (WACAS)

Hoarding associated with Squalor – a working model for field staff

Clients with hoarding behaviours and/or who live in squalor are increasingly referred to WACAS with varying types of response depending on the individual assessors’ experience and knowledge of the condition.

The WACAS model is based on a combination of available evidence, experience and resources reflecting agreement at a local level between a range of organisations. WACAS has established working relationships with The St Vincent de Paul Society and the Salvation Army CACPs, a private cleaning service, RDNS, Lort Smith Hospital, RSPCA, MFB and VCAT when required.

WACAS draws upon its multidisciplinary team to assess hoarding clients. When cognitive, physical or psychiatric illness is present the person is referred for appropriate treatment. WACAS coordinates the intervention after obtaining consent. Pre-intervention planning is necessarily detailed with frontline staff briefed prior to the intervention. Available response time is often limited due to competing pressures.

WACAS obtains funding for initial de-cluttering from The St Vincent de Paul Society. The client is subsequently referred to the Salvation Army CACP for case management, ongoing monitoring and maintenance of the client's health care needs and domestic environment. The success of this model is dependant on client consent and where the client is deemed safe to remain at home with increased community supports. The long-term feasibility of such partnerships is uncertain.

WACAS advocates and lead with regard to supporting clients with hoarding behaviours in the community, by supporting their own staff and providing education opportunities such as forums (e.g. video-conferencing to country Victoria), to better understand and manage clients with hoarding behaviour.

7. Caulfield Aged Persons Mental Health

The Caulfield Mobile Aged Psychiatry Service (MAPS) is seen as pro-active in responding to hoarding cases. They have worked with the MFB on hoarding since before 2008 and have been instrumental in developing the DVD Working with People with Hoarding Behaviours 2010, with Inner South Community Health Service and Vision Australia.

SMR Hoarding Special Interest Group

The SMR Hoarding Special Interest Group commenced as a collaboration between Caulfield Aged Psychiatry Service and Bayside CACP program, both of whom had an interest in hoarding, and noticed that other services were struggling with the same issue, so a group was formed to pull together ideas about what approaches services were taking, what resources they had and to identify gaps.

The group meets bi monthly and is open to anyone with an interest in hoarding - currently service providers from the Cities of Port Phillip, Stonnington, Glen Eira, Kingston, Bayside and Greater Dandenong attend. The meetings provide education, the development of a services data bank sensitive to issues related to hoarding (e.g. cleaning, rubbish removalists and gardener's), opportunity to share ideas and interventions strategies around difficult engagement, accommodation (rental or MOH), age, capacity and legal issues.

At times there is perceived pressure from other providers to ‘fix’ the problem. Trying to balance different and at time competing interests can be very difficult. Service response varies as there are no clear

175 Dr Sook Meng Lee (Geriatrician) Western Health Service
guidelines indicating who takes overall responsibility. This fragmentation is reflected in the experiences of people who have a hoarding issue and often why they are reluctant to seek assistance.

**Caulfield MAPS response model**

The Service Director of Caulfield MAPS\(^{176}\) sees assessment of patients with hoarding issues as part of core business for AMHSs, based on a premise that everybody who hoards or lives in squalor more than likely has impairment, even though the literature suggests that up to 50 per cent have no psychiatric diagnosis.

Dr Macfarlane suggests this is because a ‘standard’ psychiatric assessment (undertaken by a CAT team or generic AMHS clinician) is geared towards detecting dementia (MMSE) depression, schizophrenia and bipolar disorder. CAT teams often lack knowledge of frontal lobe assessments that might otherwise allow detection. He suggests adapting appropriate hoarding and squalor assessment tools, based on those already available would he useful as well as considering guidance for AMHSs on the assessment of hoarding/squalor as a mental health condition and on frontal lobe functions.

All this assumes that the team agrees to assess a person in the first place. Often intake criteria for assessment emphasise risk to self or others (usually narrowly defined as risk of self-harm, suicide, or physical threat by violence to others), in the presence of psychiatric symptoms. Hoarding/squalor, perhaps by virtue of non-inclusion in DSM, are not seen by CAT teams as symptoms.

The Caulfield Aged Psychiatry Service triage worker alerts the Service Director to any hoarding/squalor referrals with a view to him assessing them as he knows what to look for, has a research interest and ensures the outpatient team is supported in the best way possible.

The Service Director sees people with hoarding behaviours at the Caulfield campus if they can arrange their own transport, he also makes home visits which are often far more instructive and useful but impact more on limited time. After an assessment, diagnostic and management advice is provided to the referrer and/or any identified GP, with the patient's consent.

### 8. St Vincent's Health Melbourne (SVHM): Treatment Response and Assessment for Aged Care (TRAAC)

The Hospital Admission Risk Program (HARP) aims to reduce the avoidable use of hospitals through interventions provided in the community, focusing on people with chronic and complex health care needs and those who are frequent presenters to the public hospital system.

Multiple SVHM programs are managed under HARP including the Assessment Liaison and Early Referral Team (ALERT), The Cottage and Treatment Response and Assessment for Aged Care (TRAAC). Each program has formal partnerships with community agencies including Local government, Community Health and RDNS. Cases involving hoarding and squalor present a considerable challenge to SVMH HARP clinicians who attempt to support safe discharges from and prevent future readmission to hospital.

People who experience compulsive hoarding and/or squalor can be difficult to manage when they present within the hospital system as the condition is often undetected, the presenting condition may be typical of an ageing person such as a fall or complications re medication mismanagement. People who hoard have difficulty with organisation and are unable to follow medical regimes, however most of the time their general practitioners are unaware they have a hoarding condition.

The HARP program responds to referrals from the community or a recent presentation to the hospital only to discover at a home based assessment, that the symptoms are the direct result of hoarding behaviors.

The SVHM TRAAC team have staff based with Local Government services (SVHM catchment Darebin, Moreland, Yarra and Boroondara), usually co-located with HACC/other aged care services. This alignment places TRAAC staff in a uniquely flexible position to co-ordinate an appropriate service response involving contributions from a number of services in local government as well as health services such as geriatricians, Aged Psychiatric Assessment Team (APAT), Cognitive, Dementia and Memory Service (CDAMS).

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\(^{176}\) Steve Macfarlane, Clinical Director and Associate Professor of Aged Psychiatry, Caulfield Aged Psychiatry Service, Caulfield Hospital, Victorian Department of Health.
TRAAC suggested hoarding behaviours eventually catch up with people, they can no longer hide or cover their behaviours or symptoms, the effort becomes too onerous in addition to other health conditions (e.g. heart, diabetes, falls), thus the unplanned admission to hospital. TRAAC indicated the hoarding condition is well developed by this stage and even more challenging to address and difficult to engage the person.

TRAAC has brokerage which is used flexibly and broadly for example, purchasing respite in residential age care facilities whilst the person’s home is cleaned up to some extent, prior to them returning, or respite time in SVHM The Cottage (6 beds), usually provides strengthening time (pre/post hospital care) for homeless people. TRAAC also links with St Vincent’s at Home.

Planned research study
TRAAC plan to undertake a research study that will explore the problem of hoarding and squalor amongst HARP clients who present to the program through various entry points including Emergency Department, ACAS, RDNS and St Vincent’s at Home, ALERT, The Cottage and Local Government. Comparative data will be gathered to identify current responses to hoarding and/or squalor amongst the various HARP programs including barriers to service delivery and service coordination.

TRAAC have never documented their response to hoarding and squalor nor have they collected any data, seeing fewer than 10 cases per year varying greatly in complexity and severity.

The research intention is to develop a multi-disciplinary, service coordination HARP approach to respond to people who are neglecting their home environment to the extent that it creates a health risk and confounding hospital discharge planning. With community partners, HARP is well positioned to include the involvement of community stakeholders in the development of a response ensuring a client focus with outcomes that minimise risks and improve the health and wellbeing of people with hoarding behaviors who neglect themselves and their environments.

9. Merri Community Health Services (PHaMs)
Not all PHaMs work with people who hoard and/or live in squalor, though the Commonwealth PHaMs guidelines provide flexibility for this to occur. PHaMs clients can have a 6 month break from the program to see how they manage themselves, and can return should they need to without having to re-enter via the waiting list.

Two years ago the Merri Community Health Service PHaMs decided to address the needs of people with hoarding behaviours and/or who were living in squalor, including them in their client priority list that determines eligibility and waiting list access (refer Attachment 2: Case studies).

a) Services provided for the person with a hoarding/squalor condition are:
   - risk assessment; living skills development- including assistance with cleaning and community linkages; council services (regular weekly rubbish collections, health promotion, insertion of smoke alarms)
   - reconnecting the person with family, friends and other community support services - whatever is appropriate and/or important
   - connecting with GP/clinical services if appropriate.

b) Services are provided to the carer/family members (refer Attachment 3: Information session).

c) Hoarding and/or squalor data has been collected for this program from March 2010 – October 2011 (refer Attachment 4: Merri CHS/PHaMS - March 2010-October 2011).

10. ChildFIRST/Family Services
DHS funds Child FIRST (the community intake) and family services to receive referrals for vulnerable children and families where there are concerns for the wellbeing of the child or young person. A referral may include concerns regarding the impact of the parent's hoarding behaviour or squalid living conditions on a child, or such conditions may be identified during the course of family services support. Where the living conditions are identified as impacting on the child's wellbeing, family services will support the family to make changes to address the situation.

Family services play a critical role in promoting outcomes for vulnerable children and families, and provide a range of service interventions with a whole-or family focus. The focus includes strengthening the capability of parents to provide basic care, ensure safety and promote their child's wellbeing.
11. Local Government Environmental Health/By Laws – the need for flexibility within regulatory frameworks

Neighbours will more than likely complain to their local municipal council about dogs barking all the time or some other type of concern about animals, or the person who is their neighbour or neighbours property - which results in a visit by a council officer (i.e. EHO; Local Laws, Animal Management Officers (AMO) or a Planning Enforcement/Investigative Officer) to investigate the concern.

In some cases a squalid living environment and/or hoarding household might be identified. Reliable signs that council officers might notice on approaching the property are a stench when approaching the door and/or windows blacked out, particularly in the front.

Apart from a regulatory approach as defined by State Laws (refer 9.1.3 Environmental Health; 9.1.10 Animal Health Field Services; 9.1.15 MAV) some, but not all council’s have a Local Law enabling a broader investigative approach to a hoarding and/or squalor complaint or concern. How council officers respond is integral to a successful outcome.

In cases where there is no such Local Law, a council department might develop their own policy and procedures which provides capacity to respond often more flexibly, one not limited by time constraints as required by some regulations, therefore one that enables longer term management.

Council officers, due to the regulatory environment they work in, more often than not respond to the symptoms of hoarding and/or squalor not the cause. So for example, slipping a Notice under the door for action will not engage the person nor help them understand what the concern is. The issuing of a Notice will however commence an administrative process for action, one that builds on itself and will lead to the Magistrates Court if appropriate action does not materialise. This process often incurs repetitive costs, potentially wasted employee hours and no sustainable outcome for the person/s concerned.

Some officers would say that a more flexible approach than a strict regulatory one would enable a planned and inclusive response involving other sectors, family members and neighbours working together to achieve a sustainable outcome. Commencing from an understanding that the person who hoards has a mental health condition presents a different premise to plan a response from.

Cost retrieval for continual one off clean ups can be an issue for some councils. In some cases, where the person owns their own home, the Council can ratify that the debt for the clean ups is placed against the value of that person’s property, to be recouped when the property is sold.

Three possible areas for improved service response to hoarding and/or squalor cases as they present to any part of council business could be:

- Be aware, plan and draw on all council programs able to respond to a complaint or case
- Develop a traceable Council Case Coordination quality system, one that registers a concern/case; indicates which part of Council is responding to it; decides who else needs to know about it as well as monitor and review concern/case progress.
- Identify costs retrieval mechanisms – billing the person in these circumstances will rarely satisfy the debt owed.

177 Ken Waixel, City of Port Philip, Coordinator Parking Enforcement. Previous experience City of Bayside Local Laws, RSPCA, CFA.
Attachment 1: North and West Metropolitan Region Hoarding Forum

Creating space for change:

Sorting through the responses to hoarding and environmental neglect

A free Forum for programs and services in the North and West Metropolitan Region to come together and work towards improved outcomes for clients experiencing behaviours associated with hoarding and environmental neglect.

The focus of the day will be on capturing existing expertise from specialists such as Dr Chris Mogan as well as creating space for change across a range of program areas and community service organisations including:

- Housing and homelessness
- Aged Services
- Mental Health
- Disability Services
- Children, Youth and Family
- Metropolitan Fire Brigade
- Local Government
- Public and Community Health
- Office of the Public Advocate
- Legal Services

When: Wednesday 14th September
Time: 9.30 am—4.00 pm
Where: William Angliss Institute
1st Floor Conference Centre
555 La Trobe Street, Melbourne.
Cost: Free, a USB stick full of information will be provided on the day.

RSVP by Monday 15th August 2011

Please register your interest with Kate Rice.
kate@wintringham.org.au.

For any inquiries call Kate on 9375 3774.

This forum is presented by Wintringham with funding from the Department of Human Services and the Department of Health and the valued support of a range of community service organisations across the region.

Wintringham
Case study 1.

**Background** - CS is a 76 year old man who lives alone in *. He suffers from Anxiety, Depression, Obsessive Compulsive Disorder and Hoarding Behaviours. He worked for many years in the Aviation industry, until he was retrenched 10 years ago. He has severe scoliosis of the spine and needs a walking aid. He has also had prostate cancer which has rendered him incontinent. He receives Meals on Wheels and occasional assistance from Council for modifications to his home in order to maintain his independent living.

CS is a cautious, isolated and proud man who struggles to cope with change and support from outside his home. For example, he cannot cope with two or more appointments in a week and does not let neighbours or friends inside his home. CS speaks that the role of information has had in his life which allowed him to work as an engineer. CS still collects information in the form of newspapers, catalogues and receipts; he also does not discard items, partly in fear of the rubbish being blown away, rather than dropping into the rubbish truck. As he has OCD, all food containers are thoroughly cleaned and then kept in various piles and rooms around his home. He is unable to access much of the 3 bedrooms, his kitchen benches are covered in items, and half of the floor space is filled with items.

**Intervention** - CS was referred to PHaMs (Mental Health Outreach) by MCHS Allied Health Occupational Therapist in conjunction with a MCHS (Merri Community Health Service) Community Nurse. This referral process was seamless as service units regularly collaborate in order to provide targeted role defined care and joint care planning on the shared database. Collaborative relationships and structures also assist in the sharing of information and support with the care team.

PHaMs was requested due to the complex nature of CS’s physical and mental health needs. The O.T. focuses on CS’s physical or structural needs, such as moving the toilet inside and having an appropriate chair. The Community Nurse works with CS on his physical health needs particularly his prostate and incontinence issues, and the need for a personal alarm.

CS has identified to me that he would like to reduce the fire risk in his home, widen the pathways to allow him to use a walking frame and to consider selling his home to move into a smaller property. I work with CS to develop strategies that support him to reduce the flow of papers/catalogues into the home, to develop sorting and storage strategies and to develop new patterns of thinking and behaviour that facilitate the removal of items from the home.

Together we can now sort items and on a good day, fill a recycling bin!

**Outcome** - CS remains engaged with all three professionals who are difficult for him to tolerate, however we all engage in regular communication and pace our contact with him. CS’s environmental safety has been enhanced, in terms of additional structural supports and a reduction in fire or fall risks. CS’s physical health has improved as he is supported to access appropriate medical care and to reduce his compulsive intake of particular vitamins. From a mental health perspective, he continues to remain engaged in change conversations and he has begun to increase the frequency of cognitive behavioural exposures to the anxiety associated with his sorting and discarding of possessions.
I have two sons. It's my eldest son who collects things, shoes, newspapers, pots for plants, pieces of wood, and boxes of nails. It started with pieces of material.

When he was a little boy, he liked to study snails and insects and would keep them in a bug catcher. He always liked animals. It was good he liked snails, he would catch them and I would use them in my spaghetti. He used to work with my husband at a material factory. Then my husband had a stroke and for one year was in a hospital on a drip. He couldn't speak anymore. After the hospital, he went to a nursing home for seven years and then he died. My husband has been now dead for 10 years.

After my husband's stroke, my son for two years kept working at the factory. But he started to bring home pieces of the fabric. My son would say 'it's too good to throw away' when I asked him why he would bring it home. He doesn't listen to me.

He loves books, books are good, there is nothing wrong with reading, but he brings too many. He loves Collingwood, it's good to have football, football scarves, football umbrella but just collect one thing, not lots of things.

Now my son doesn't work and everyday he brings home more stuff. The basement is full, I can't sit on the veranda and have a coffee, and there is stuff on the table. I can't hang my washing on the line under the veranda, there is too much stuff. I can't walk down the hallway; there is only a small path. I tell him 'if you don't stop with this collecting, I will hurt my leg on all this stuff'. He bought home all these boxes of nails, I said 'Why, you don't fix anything, you are not a handyman'. 'Why do you have all these boots, you don't go to the snow'.

I went to the doctor, he said my son is an adult he can do want he wants. The doctor has given me two tablets to take in the mornings, so I can relax. My son has is 48 and he has his own house with renters so he gets his money from them. I want to get a smaller house, but he says this is a good house.

I also have another son, I look after him, and he has a disability.

I think my son misses his father; they used to go to soccer and do lots of things together. My husband came to Australia when he was young so he knew all the places to go to. I don't know all the places to go.

I still have my own room; he can't put stuff in there. A friend came and cleaned out the basement, now it's full again. If I put stuff in the bin, sometimes it's ok, but if he sees it in the bin, he will get it out again.

My daughter is sick of it too, for six months she didn't come around with my grandchildren because it wasn't safe for the kids and they don't want to see the rubbish. I am sorry for this.

I want to relax for one hour in the afternoon, I go out to relax. It's good to get away; I go to a walking group.
Attachment 3: Merri Community Health Service/PHaMs

**Free Information Session for Carers/Friends/Family/Concerned about the Hoarding Behaviours of Others**

It is a common and rarely spoken about illness that can result in people living in cluttered and unhealthy living situations. People who care can often

- experience a loss of normal family life,
- anger, frustration, conflict,
- struggle to cope with the symptoms of these behaviors; and
- feel isolated from others.

Merri Community Health Services invites you to attend an information session and discussion about hoarding behaviors and what help is available. The session will be held in Coburg and is for residents of Moreland.

R.S.V.P. by Monday 7th March for catering purposes only.

You do not need to give any personal information to attend.

Tania Reid
PHaMs Team Leader
Merri Community Health Services
21 Victoria St, Coburg 3058
Ph: 9355 9975
Or email taniar@mchhs.org.au

Where: Uniting Church,
19 Victoria St Coburg

When: Tuesday 15th March 1-2pm
Wednesday 16th March 6-7pm

Please contact Tania for inquiries and to R.S.V.P.
## Attachment 4: Merri Community Health Service – PHaMS program
### Data collection March 2010-October 2011

<table>
<thead>
<tr>
<th>Gender</th>
<th>Hoarding / Squalor</th>
<th>Age</th>
<th>Housing</th>
<th>Income source</th>
<th>Co morbidity</th>
<th>Living situation</th>
<th>Referral source</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>H and S</td>
<td>41</td>
<td>Privately owned</td>
<td>DSP</td>
<td>ID/low I.Q.</td>
<td>Mother removed due to extremely poor health</td>
<td>MCHS community nurse</td>
<td>Deceased – cause unknown.</td>
</tr>
<tr>
<td>M</td>
<td>H</td>
<td>60</td>
<td>Privately owned</td>
<td>DSP</td>
<td>schizophrenia</td>
<td>Alone</td>
<td>Exchange</td>
<td>Current PHaMS client</td>
</tr>
<tr>
<td>M</td>
<td>H</td>
<td>65</td>
<td>Privately owned</td>
<td>DSP</td>
<td>OCD and anxiety</td>
<td>Alone</td>
<td>Gambler’s help</td>
<td>Current PHaMS client</td>
</tr>
<tr>
<td>F</td>
<td>H</td>
<td>50</td>
<td>Privately owned</td>
<td>Husband is employed</td>
<td>Anxiety, possibly autism spectrum</td>
<td>With husband and 3 children</td>
<td>Self – from PHaMs community sessions</td>
<td>PHaMs closed-not engaging</td>
</tr>
<tr>
<td>F</td>
<td>H and S</td>
<td>55</td>
<td>Privately owned</td>
<td>DSP</td>
<td>PTSD</td>
<td>Many cats</td>
<td>MCHS community nurse</td>
<td>Client closed</td>
</tr>
<tr>
<td>M</td>
<td>H and S</td>
<td>55</td>
<td>Privately owned</td>
<td>Workers compensation</td>
<td>ABI and depression</td>
<td>Alone</td>
<td>Financial administrator</td>
<td>PHaMs closed-not engaging</td>
</tr>
<tr>
<td>F</td>
<td>S</td>
<td>60</td>
<td>Privately owned</td>
<td>DSP</td>
<td>ID</td>
<td>Alone</td>
<td>Council</td>
<td>PHaMs closed-not engaging</td>
</tr>
<tr>
<td>M</td>
<td>H</td>
<td>76</td>
<td>Privately owned</td>
<td>Aged pension</td>
<td>OCD, anxiety, agoraphobia</td>
<td>Alone</td>
<td>MCHS community nurse and OT</td>
<td>Current</td>
</tr>
<tr>
<td>F</td>
<td>H and S</td>
<td>56</td>
<td>Privately owned</td>
<td>Employed full time - librarian</td>
<td>Depression</td>
<td>With autistic adult son</td>
<td>Building Family Skills Together, Mind</td>
<td>Current</td>
</tr>
<tr>
<td>F</td>
<td>H and S</td>
<td>42</td>
<td>Private rental</td>
<td>DSP</td>
<td>Depression, PTSD, RSI</td>
<td>With 3 children, one who has autism-child protection involvement</td>
<td>MCHS Integrated Family Services</td>
<td>Closed by client due to worker notifying child protection of concerns.</td>
</tr>
<tr>
<td>M</td>
<td>H</td>
<td>52</td>
<td>Lives in Private rental, has own home which is rented</td>
<td>Employed full time - librarian</td>
<td>Depression, OCD</td>
<td>With Partner</td>
<td>Self – from PHaMs community sessions</td>
<td>Current</td>
</tr>
<tr>
<td>M</td>
<td>H and S</td>
<td>48</td>
<td>Lives with mother in her own home, has two private rental properties</td>
<td>DSP</td>
<td>n/a</td>
<td>With Mother and younger brother who has a disability</td>
<td>Mother via Carer Links North</td>
<td>Current</td>
</tr>
<tr>
<td>F and F</td>
<td>H and S</td>
<td>45 and 47</td>
<td>Privately owned</td>
<td>DSP</td>
<td>Multiple physical health</td>
<td>With 4 others who have ID and mental health issues, 5 cats, 8 dogs</td>
<td>Moreland City Council</td>
<td>Current</td>
</tr>
<tr>
<td>M</td>
<td>H</td>
<td>53</td>
<td>Privately owned</td>
<td>Self employed – antique dealer and handy man</td>
<td>Depression</td>
<td>With partner</td>
<td>Self – from PHaMs community sessions</td>
<td>Closed by client as achieved goals</td>
</tr>
<tr>
<td>F</td>
<td>H</td>
<td>31</td>
<td>Public housing</td>
<td>DSP</td>
<td>PTSD</td>
<td>With 2 children</td>
<td>Other MCHS PDRSS group</td>
<td>Current</td>
</tr>
<tr>
<td>M</td>
<td>S</td>
<td>57</td>
<td>Lives in house owned by father</td>
<td>DSP</td>
<td>ID</td>
<td>Alone</td>
<td>Self</td>
<td>Current</td>
</tr>
<tr>
<td>M</td>
<td>H and S</td>
<td>67</td>
<td>Public housing</td>
<td>DSP</td>
<td>Depression</td>
<td>Alone</td>
<td>Other MCHS program</td>
<td>Current</td>
</tr>
</tbody>
</table>
## Appendix 13: DH Aged Care Community Service Organisations delivering Low Cost Accommodation Support – as at September 2011

<table>
<thead>
<tr>
<th>Region</th>
<th>Organisation</th>
<th>CCP</th>
<th>HSAP</th>
<th>OPHR</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSW</td>
<td>Brophy Family and Youth Services Inc</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSW</td>
<td>St Laurence Community Services (Barwon) Inc</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Gramps</td>
<td>Centacare Catholic Diocese of Ballarat Inc</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>LM</td>
<td>Haven (Loddon Mallee Housing Service)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Hume</td>
<td>The Salvation Army Pathways</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Gipps</td>
<td>Quantum Support Service Inc</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>N&amp;W</td>
<td>Doutta Galla Community Health Service Inc</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>N&amp;W</td>
<td>Merri Outreach Support Service Inc</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>N&amp;W</td>
<td>North Yarra Community Health Inc</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>N&amp;W</td>
<td>The Salvation Army (Vic) Property Trust – Western</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>N&amp;W</td>
<td>Society of St Vincent de Paul (Vic)</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N&amp;W</td>
<td>Western Region Health Centre Ltd</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>N&amp;W</td>
<td>Wintringham</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>EMR</td>
<td>The Salvation Army (Vic) Property Trust – Eastern</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EMR</td>
<td>UnitingCare Community Options</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>SMR</td>
<td>City of Kingston</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SMR</td>
<td>ERMHA – Eastern Regions Mental Health Assoc Inc</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>SMR</td>
<td>Inner South Community Health Service</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>SMR</td>
<td>Peninsula Community Health Service</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>19 TOTAL</strong></td>
<td><strong>16</strong></td>
<td><strong>13</strong></td>
<td><strong>5</strong></td>
</tr>
</tbody>
</table>

*Community Connections Program (CCP)*  
*Housing Support for the Aged Program (HSAP)*  
*Older Persons High Rise Support Program (OPHR)*
Appendix 14: Department of Human Services – Housing and Community Building (SfHRT)

DIAGRAM 1: ASSESSMENT & MANAGEMENT OF PEOPLE DEALING WITH HOARDING

A. TENANCY RESPONSE
   - Housing Services Office (HSO), Customer Service Delivery (CSD) or Family Service (FSF)
   - Obtain background information including potential OH&S issues

B. Register:
   - Tenant/Customer High Risk/Intensive Care/Security
   - Supportive living in other areas (e.g., aged care, youth care)
   - Contact affiliated service providers

C. ASSESSMENT OF SITUATION
   - Tenancy Property Team
   - Inspect property for cleanliness
   - Identify safety risks
   - Prepare risk management plan

D. RECOMMENDATION
   - Refer to Tenancy Property Team
   - Provide support for tenancy intervention

E. FOSTER CARE RESPONSE
   - Interim support for the tenant
   - Implement tenancy intervention

F. HOUSING VACANT
   - Tenancy property Code
   - Rent
   - Tenancy
   - Dependency
   - Capacity

G. HOUSING VACANT
   - Tenancy property Code
   - Rent
   - Tenancy
   - Dependency
   - Capacity

H. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

I. CONTINUING FOLLOW UP:
   - Supervision to prevent recurrence
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

J. MENTAL HEALTH PLAN
   - Tenancy property Code
   - Service provider
   - Tenancy property Code
   - Service provider

K. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

L. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

M. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

N. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

O. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

P. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

Q. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

R. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

S. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

T. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

U. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

V. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

W. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

X. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

Y. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

Z. POSSIBLE INTERVENTIONS
   - Tenancy support in rent management
   - Tenancy property Code
   - Housing and community services
   - Tenancy property Code
   - Housing and community services

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Appendix 16: MFB and CFA research studies

A) MFB - Worcester Polytechnic Institute [WPI] Massachusetts, (USA) studies

MFB attracts WPI undergraduate students to undertake studies on a range of subjects such as the two mentioned below. The studies are submitted to WPI as evidence of completion of a degree requirement. WPI routinely publishes these reports on its website without editorial or peer review.

Study 1: An Analysis of Fire Incidents Involving Hoarding Households - May 22, 2009

This project was sponsored by MFB and undertaken by three WPI students (supervised by WPI and MFB), who examined hoarding households from a fire safety perspective looking at hoarding related fire incidents. The result presents a comprehensive fire fatality and incident study of all preventable community residential fires involving hoarding that occurred within the MFB district of Melbourne between 1999 and 2009 (March).

The goals of this project were to obtain information about the victims of fire incidents in hoarding households, to quantify the characteristics common in these incidents and to identify if risk reduction advice could be developed from the evidence provided by the study. This information could be used by MFB and other organisations to raise awareness, identify key triggers and contribute to intervention programs for people affected by this disorder. The following objectives were pursued:

- develop a greater understanding of the nature of hoarding fires
- find the prevalence of unorthodox use of utilities among hoarding fires
- create a profile of victims involved in hoarding fires
- draft an informational brochure to educate internal and external stakeholders about hoarding.

Forty-eight hoarding fires were identified and were found on average to be more severe than ordinary fire incidents, 10 resulted in a fatality representing 24 per cent of all preventable residential fire fatalities that occurred over the same time period. Comparisons within the study revealed that while an average household fire required about seven firefighters to fight the fire, a hoarding household fire requires on average 17 firefighters to do the job and the average cost of structural damage to the property increases from $12,500 to $100,000.

Only 26 per cent of hoarding households had a working smoke alarm, compared to the household average of 66 per cent. It is worth noting that with 23 per cent of these fires occurring in OoH properties which are provided with hard wired smoke alarms which reduce the hoarding households with smoke alarms in those living outside of public housing as three per cent. In 38 per cent of hoarding incidents, impeded egress or access was specifically mentioned in incident reports, but no correlation could be made between blocked egress and hoarding level.

Seventy-three percent of hoarding fires occurred in households where the occupant was over 50 years old, 77 per cent male and reportedly uncooperative in 10 per cent of incidents. About 30 per cent of these fires occurred in apartments while 70 per cent were in homes. Twenty-three percent of incidents occurred in public housing facilities.

The most common cause of hoarding fires was cooking (accounting for 39 per cent of incidents and yet it caused none of the fatalities), a heater, open flame, or lamp and electrical faults were the other most common causes. Smoking caused 12 per cent of the fires but accounted for three fatalities. The source of ignition in hoarding fires is not much different than the average residential fire however 13 per cent of these fires started from an unorthodox use of utilities.

As a result of the study MFB developed risk reduction advice for hoarding households which is to:

- install smoke alarms and test them
- unblock exits and widen internal pathways
- check utilities are connected
- prioritise removing clutter from around cooking area and stove tops as 39 per cent of fires in hoarding homes result from cooking
- ensure clutter is removed from around heaters and electrical items and discourage the use of open flame as combined, these factors account for 44 per cent of fires in hoarding homes.

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178 Refer WPI http://www.chemistry.ac.chula.ac.th/bsac/MFB%2Hoarding_Project_Proposal.pdf
On the basis of the information resulting from the study, MFB risk reduction advice would potentially reduce the risk for the occupants of these homes by a significant degree. MFB promotes risk reduction in the first instance as opposed to large scale removal of all hoarded items from the residence. MFB has developed a further study proposal to quantify incidence rates since March 2009.

MFB aims to reduce the high fire risk of people affected by hoarding by addressing their other needs through an integrated multi agency approach, applying risk minimisation techniques.

**Improved MFB recording system**

Since the completion of the 2009 analysis, MFB has identified a significant increase in the number of households in which hoarding is identified through the provision of an MFB emergency response system. Current estimates are one incident every 14 days.

MFB understands this increase is attributed to higher organisational awareness as well as an increased capacity for operational firefighters to formally identify hoarding and/or squalor households.

**Study 2: Analysis of Preventable Fire Fatalities of Older People and People with Disabilities: Risk Reduction Advice for the Community Care Sector – May 2, 2011**

MFB sponsored four students from WPI to undertake a comprehensive fire fatality study of all preventable residential fire fatalities that occurred within the MFB district of Melbourne between 2000 and 2010. Older people and people with disabilities were found to have been at a greater risk of fire fatality due to frailty, minimised mobility and lack of appropriate or working warning systems such as smoke alarms. This report does not directly reference hoarding but highlights recent MFB work effectively targeting people most at risk.

Many people in this cohort also receive community services, thereby placing the community sector in a unique position to assist vulnerable groups. The researchers aimed to provide simple fire safety solutions for sectors to utilise and potentially incorporate into policies, such as:

- identify clients who are smokers, have reduced mobility and live alone
- encourage installing photoelectric smoke alarms in these homes (with 10 year long life battery, thereby eliminating annual battery changes).

**B) CFA**

The CFA is funding a project to research fire incident information to include the effects of hoarding on fires and CFA response personnel.

The aim of the project is to collect and report any existing information available across regional Victoria in relation to hoarding cases, and the possible implications to CFA. This is a preliminary project to increase CFA knowledge with a view to developing a more comprehensive procedure and managing future incident reporting and personnel safety.

The research at the time of this request (Oct 2011) has shown:

- that within the CFA community area there are noticeable anecdotal numbers of ‘hoarding’ cases
- evidence from other fire fighting agencies shows there is high risk of a fatality if a fire results within these households
- some agencies are on the way to developing a process to deal with and manage their clients with this disorder, very few are reporting these cases specifically as hoarding
- the numbers specified are largely anecdotal or part of a larger category titled ‘high risk’. This data is supported through LGA’s Local Laws, Environmental Health, Community Development, Aged and Disability Services and external Case Managers working through smaller funded agencies.

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179 Aufiero, M., Cartone, T., Hawkins, W., Murdy, S. Analysis of Preventable Fire Fatalities of Older People and People with Disabilities: Risk Reduction Advice for the Community Care Sector. An Interactive Qualifying Project Report submitted to the Faculty of Worcester Polytechnic Institute in partial fulfilment of the requirements for the Degree of Bachelor of Science (May 2011).
Appendix 17: North and West Metropolitan Region Hoarding Training Needs Analysis report - January 2011

A hoarding training needs analysis survey was developed to ascertain the training needs of staff working with those who display hoarding behaviours, in Melbourne’s North West metropolitan region. It was undertaken by Managers from PHaM (Merri Community Health), TRAAC (St Vincent’s Health) and Community Housing and Support: Northern/City (Wintringham).

The survey was distributed to staff participating in the North and West Regional Hoarding Working Group as well as other known service providers working with those who display hoarding behaviours in Melbourne’s North West. The survey ran from December 14, 2010 to December 23rd, 2010. It was completed “on line” using the Survey Monkey tool.

OUTCOMES

- 100 respondents completed the survey from approximately 40 different services. Agencies were as diverse as Aged Care Assessment Services, council, home nursing, case management programs, hospital, community health, HARP, residential care and housing.

- Discipline backgrounds were:
  - 35% allied health
  - 18% housing
  - 11% case management
  - 5% mental health
  - 34% aged care

Table 12: Results Melbourne NW Metropolitan Region Hoarding TNA report January 2011

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>OH&amp;S legislation and organisation policies and procedures</td>
<td>59</td>
</tr>
<tr>
<td>Chronic nature of hoarding/ability to manage property</td>
<td>65</td>
</tr>
<tr>
<td>Supports available</td>
<td>51</td>
</tr>
<tr>
<td>Determining short term objectives</td>
<td>36</td>
</tr>
<tr>
<td>Determining long term objectives</td>
<td>33</td>
</tr>
<tr>
<td>Resources available to clients</td>
<td>54</td>
</tr>
<tr>
<td>Hard to engage</td>
<td>44</td>
</tr>
<tr>
<td>Time and resources required</td>
<td>51</td>
</tr>
<tr>
<td>Knowing treatment options</td>
<td>42</td>
</tr>
<tr>
<td>Knowing how to refer to</td>
<td>44</td>
</tr>
<tr>
<td>Client denial of issues</td>
<td>65</td>
</tr>
</tbody>
</table>

Most challenging aspects:

- OH&S legislation and organisation policies and procedures
- Chronic nature of hoarding/ability to manage property
- Supports available
- Determining short term objectives
- Determining long term objectives
- Resources available to clients
- Hard to engage
- Time and resources required
- Knowing treatment options
- Knowing how to refer to
- Client denial of issues
Training topics of interest

<table>
<thead>
<tr>
<th>Topic of interest</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical strategies</td>
<td>88</td>
</tr>
<tr>
<td>Aged care clients</td>
<td>66</td>
</tr>
<tr>
<td>Impact of capacity</td>
<td>61</td>
</tr>
<tr>
<td>Squalor</td>
<td>51</td>
</tr>
<tr>
<td>Animal hoarding</td>
<td>31</td>
</tr>
<tr>
<td>Peer support</td>
<td>20</td>
</tr>
<tr>
<td>People in public housing</td>
<td>52</td>
</tr>
<tr>
<td>People in private rental</td>
<td>37</td>
</tr>
<tr>
<td>People in their own homes</td>
<td>53</td>
</tr>
</tbody>
</table>

Preferred learning formats:

The top three challenging aspects of this work were client denial of issues, chronic nature of hoarding and OH&S concerns.
## Useful resources

<table>
<thead>
<tr>
<th>Topic</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Animal Hoarding</td>
<td>Refer: <a href="http://www.tufts.edu/vet/hoarding/resource.htm">http://www.tufts.edu/vet/hoarding/resource.htm</a> Website of the Hoarding of Animals Research Consortium in the US, for your paper. It contains links to a number of scientific papers.</td>
</tr>
<tr>
<td>Obsessive Compulsive Foundation – Hoarding Centre</td>
<td>Randy O. Frost, Gail Steketee, USA Refer: <a href="http://www.ocfoundation.org/hoarding/welcome.aspx">http://www.ocfoundation.org/hoarding/welcome.aspx</a></td>
</tr>
<tr>
<td>Stuff: Compulsive Hoarding and the Meaning of Things</td>
<td>Bratiotis C., Schmalisch, C. S., Steketee, G. (2011) The first of its kind, organised around the common ways hoarding captures the attention of social service providers (social workers/human service providers in a broad range of fields), this user-friendly guide provides tools to assess the problem, to coordinate and delegate tasks and to work directly with reluctant hoarders and those affected by the hoarding. Chapters give hands-on guidance and decision trees for who should be involved and what strategies are needed for each case. Refer: <a href="http://www.ocfoundation.org/hoarding/community_services.aspx">http://www.ocfoundation.org/hoarding/community_services.aspx</a></td>
</tr>
<tr>
<td>Understanding Compulsive Hoarding</td>
<td>Thobaben, M. Source: Home Health Care Management &amp; Practice 18(2): 152-154,(2006). Abstract: Compulsive hoarding is the excessive acquisition of material goods and difficulty discarding worthless items until they interfere with day-to-day functions such as home, health, family, work, and social life. There are a higher percentage of older adults who hoard compared to younger people. Home health nurses will need to assess the functional level, competency, insight and understanding of clients who compulsively hoard. Home health workers may be able to teach techniques that assist with accumulating less clutter. No one treatment has been found to be effective for all compulsive hoarders.</td>
</tr>
<tr>
<td>Acronym</td>
<td>Definition</td>
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<tr>
<td>---------</td>
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</tr>
<tr>
<td>ACAS</td>
<td>Aged Care Assessment Services</td>
</tr>
<tr>
<td>BAW</td>
<td>Bureau of Animal Welfare</td>
</tr>
<tr>
<td>CACP</td>
<td>Community Aged Care Packages</td>
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<tr>
<td>CAV</td>
<td>Consumer Affairs Victoria</td>
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<td>CFA</td>
<td>Country Fire Authority</td>
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<tr>
<td>CTO</td>
<td>Community Treatment Order</td>
</tr>
<tr>
<td>DoHA</td>
<td>Commonwealth Department of Health and Ageing</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EACH</td>
<td>Extended Aged Care at Home package</td>
</tr>
<tr>
<td>EACHD</td>
<td>Extended Aged Care at Home Dementia package</td>
</tr>
<tr>
<td>DH</td>
<td>Victorian Department of Health</td>
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<tr>
<td>DHS</td>
<td>Victorian Department of Human Services</td>
</tr>
<tr>
<td>DoJ</td>
<td>Victorian Department of Justice</td>
</tr>
<tr>
<td>DPI</td>
<td>Victorian Department of Primary Industries</td>
</tr>
<tr>
<td>EHO</td>
<td>Environmental Health Officer</td>
</tr>
<tr>
<td>FaHCSIA</td>
<td>Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs</td>
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<tr>
<td>FMO</td>
<td>Financial Management Order</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
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<tr>
<td>MAV</td>
<td>Municipal Association Victoria</td>
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<tr>
<td>MFB</td>
<td>Melbourne Metropolitan Fire and Emergency Services Board</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-government organisation</td>
</tr>
<tr>
<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
</tr>
<tr>
<td>OCPD</td>
<td>Obsessive Compulsive Personality Disorder</td>
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<tr>
<td>OPA</td>
<td>Office of the Public Advocate (Victoria)</td>
</tr>
<tr>
<td>RSPCA</td>
<td>Royal Society for the Prevention of Cruelty to Animals (Victoria)</td>
</tr>
<tr>
<td>SHIRT</td>
<td>Support for High Risk Tenancy Program</td>
</tr>
<tr>
<td>VCAT</td>
<td>Victorian Civil and Administrative Tribunal</td>
</tr>
</tbody>
</table>
References


Central Sydney Area Health Service (2003), Living Conditions Rating Scale (LCRS).


Dyer, C.B., Goodwin, J.S. Pickens-Pace, S., Burnett, J. and Kelly, P.A. (2007), Self-neglect among the elderly: A model based on more than 500 patients seen by a geriatric medicine team, Research and Practice, 97 (9), 1671-1676.


Hailstones, A.(1992) Discussion paper; abuse of older people in their homes, Charles Sturt University, Riverina. N.S.W., Australia.


Partnership Against Homelessness (2007), Guidelines for field staff to assist people living in severe domestic squalor. NSW, Australia.
Pathway through the maze: National Squalor Conference. Sydney (2009). Refer:


Tolin D. F., a, b Frost R. O., c Steketee Gd, Gray K., Fitch K. E., cThe Institute of Living/Hartford Hospital, Hartford, CT, USA; bYale University School of Medicine, New Haven, CT, USA; cDepartment of Psychology, Smith College, Northampton, MA, USA; dBoston University School of Social Work, Boston, MA, USA. eDepartment of Psychology, University of Hartford, Hartford, CT, USA; The economic and social burden of compulsive hoarding. Accepted August 2007. Available online July 2008.

