Canterbury
District Health Board
Te Poari Hauora ō Waitaha

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8 September 2021

9(2)(a) [redacted]

RE Official Information Act request CDHB 10688

I refer to your email dated 16 August 2021 requesting the following information under the Official Information Act from Canterbury DHB. Specifically:

1. **I would like to get some statistics on how many cases of hoarding the DHB has come across in the last few years, Or any stats that are available on hoarding.**

This information is not held in an easily retrievable electronic data system and would only be available in an individual's clinical records. We are therefore declining your request pursuant to section 18(f) of the Official Information Act i.e. *….to provide the information requested would entail a manual search of clinical records which would take a substantial amount of time and resource".*

We note that the publication (the only epidemiology study in NZ) by Dr Janet Spittehouse, Research Fellow Otago University "NZ study of Hoarding: CHALICE Study (2010-13)" confirms prevalence appears to be the same in NZ as in International studies.

2. **I would also like to know what sort of services (funded) are currently offered to help people with hoarding.**

Canterbury District Health Board currently funds an Anxiety Disorders Service (ADS), as part of Specialist Mental Health Services. This provides services to adults 18-64 years referred by General Practitioners or other Services within Specialist Mental Health Service (SMHS). This service provides assessment and treatment for people with hoarding difficulties.

There is ample information online for evidence-based treatment (Cognitive Behavioural Therapy) and the ADS team has developed expertise/experience over years. Treatment is usually slow and time/resource intensive. The team works with small numbers (ie 1-3) at any one time. Treatment is primarily based on the work of an International expert, Gail Steketee. Treatment relies on a very collaborative approach involving family and a range of agencies determined through assessment and is acceptable to the consumer.

Other Services within SMHS also accept referrals, usually where Compulsive Hoarding is not the primary presenting problem. eg the Adult Community Services may work with someone who has a primary mood disorder but who may also have hoarding issues.

Local NGO providers also provide support for people who hoard. Comcare, for example, offer support with managing home environments of people believed to be hoarders. They advise that:

- The majority of people referred to Comcare for housing rescue/support that are believed to be hoarders are actually not – they just need help to sort out their belongings
- The approximately one in ten people who are hoarders have complex emotional issues underpinning the behaviour
- Comcare experience approximately one person a month that fit this profile and it's often a slow and sensitive approach that is needed
- People come to attention because of other peoples' concerns rather than the person that hoards
- Unless housing security is at risk, there can be little motivation to address the hoarding; e.g. if the person owns their own home.

Older Persons Mental Health provide assessment and recommendations only. They do not have the capacity to provide individual therapy for Compulsive Hoarding. However, they do have a group that are developing guidelines in response to the scoping report completed in 2020 "Enabling Spaces, Supporting Older People who Hoard in Canterbury (attached).

3. **Also what agencies are involved in helping people with hoarding?**

Please refer to "Enabling Spaces, Supporting Older People Who Hoard in Canterbury - 2020", appendix F2 for a list of interested local agencies (attached as **Appendix 1**).

Taranaki and Southern DHB are using the work of Professor John Snowdon, a psychiatrist of the Sydney South West Area Health Service "Guidelines developed by the Partnerships against Homelessness (PAH) Committee". The Southern District DHB has developed a document that is called "Good Living Conditions Southern" (attached as **Appendix 2**).

I trust that this satisfies your interest in this matter.

Please note that this response, or an edited version of this response, may be published on the Canterbury DHB website after your receipt of this response.

Yours sincerely

Tracey Maisey
Executive Director
Planning, Funding & Decision Support

APPENDIX 1

Enabling Spaces

Supporting older people who hoard in Canterbury

About the photos:

The images that start each chapter are photographs of an exhibition called *Waste Not* by Song Dong, of all the items his mother had accumulated in her house over decades.

His mother, Zhao Xiangyuan, came from a wealthy family that lost everything in the Cultural Revolution. Waste not was a survival tactic that she continued to the extreme. Another contributing factor to her hoarding was the immense loss and void created by the unexpected death of her husband. She refused to throw anything away, or move out and part with her possessions, until Song Dong proposed an art project to meaningfully recycle and preserve them.

Other images: Cover image Otis Williams. Page 10, Darkday (Creative Commons 2.0) . All other photographs are stock photos from Envato or Shutterstock.

Recommended citation:

Williams, O., Gee, S., Hawkes, T., Williams, A., & Croucher, M. (2020). *Enabling spaces. Supporting older people who hoard in Canterbury: A scoping report*. Christchurch, NZ: Canterbury District Health Board.

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Canterbury District Health Board
Te Poari Hauora ō Waitaha

University of Otago
Te Whare Wānanga o Otāgo
New Zealand
Christchurch

Enabling Spaces

Supporting older people who hoard in Canterbury

Contents

Enabling Spaces

Supporting older people who hoard in Canterbury

THE CONTEXT OF HOARDING

More than 2 out of every 100 people aged 50+ may hoard.

Older people are more likely to hoard and are more vulnerable to negative impacts.

People who hoard seldom seek treatment themselves.

Moving forward:
~ Collate service information
~ Explore hoarding in Māori elders

UNDERSTANDING HOARDING FOR THE INDIVIDUAL

It helps to understand the ways clutter can arise: including from obsessive compulsive hoarding. hoarding disorder, or non-purposeful accumulation.

It helps to understand why it is hard to give up objects: emotional attachments can link to identity, security, or avoiding waste.

It helps to understand the impact for the individual and others: with social, physical, fire, and housing related risks.

Moving forward:
~ Provide guidance resources
~ Support public and family awareness

RESOURCING AND POLICY

It helps to have resources: that enable long term support and are flexible, and include therapy and stepped care.

It helps to have integration: a coordinated multi-disciplinary approach with clear guidance about sharing information between agencies.

Moving forward:
~ Facilitate coordination
~ Fund hoarding support as a longer term commitment

A PERSON-CENTRED APPROACH

It helps to establish trust: by being non judgemental, making a connection, and going at their pace.

It helps to create mutual goals: by respecting autonomy, building motivation, setting small meaningful goals, and focusing on safety.

Moving forward:
~ Provide guidance resources
~ Support public and family awareness

About the project

This project brings together information from a range of perspectives to help understand what great support for people who hoard might look like.

The enabling spaces project

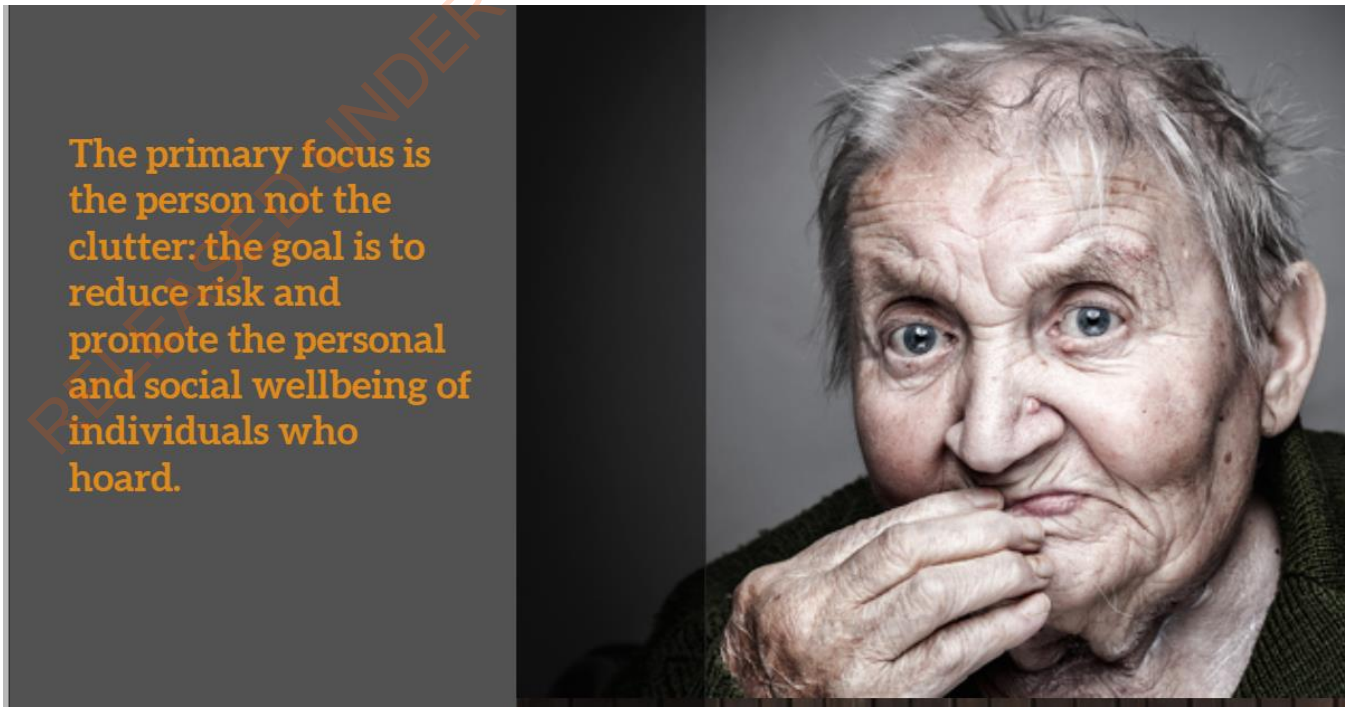
People who hoard live with excessive amounts of 'stuff' which they have difficulty discarding. This clutter can render living spaces unusable, create health and safety risks, cause distress for the individual and those that support them, and lead to functional and social impairment.

The purpose of this scoping study was to synthesise information from stakeholders and relevant literature in order to inform effective person-centred practice, planning, and policy to support people who hoard in Canterbury.

This report reviews the key insights from the study, identifies available resources, and outlines potential initiatives that might improve Canterbury's capacity to provide appropriate support for people who hoard.

The report outlines key insights that emerged about

- The context of support for people who live with hoarding in Canterbury
- Understanding the meaning of hoarding for the individual
- Establishing trust and mutual goals
- Supportive policy and resource environment



This scoping study engaged with stakeholders and the literature to ask:

- What features are important in service provision for people who hoard?
- What is working well currently to support people who hoard?
- What could ideal services for people who hoard look like?

Professional perspectives

Lived experience

Research literature

Focus groups with representatives of stakeholder agencies

A series of three focus groups were held to build up a picture of the current context and what stakeholders see as important in support for people who hoard.

If a professional was unable to attend one of the focus groups, an individual interview was offered (4 participants). A total of 16 professionals took part in the discussions.

See Appendix A for a summary of the range of professionals and agencies involved.

Interviews with people with personal or family experience with hoarding

Face to face interviews were utilised to hear from three people who have hoarding behaviours in their own home, and with one family supporter.

These discussions focussed on their experiences with hoarding and with support services, and what they value in these services.

See Appendix B for an overview of the lived experience interviews.

A rapid review of the NZ and international literature

A rapid review of the research and grey literature was conducted to further understand the best practice approaches and tools that are currently available.

Priority was given to New Zealand work to the extent that it was available.

Understanding the context

To place hoarding in context generally and in Canterbury it is useful to understand what hoarding is, who hoards, and the effectiveness of forced clean-ups and therapy.

The context of support for hoarding

"Sometimes I get referrals…saying 'they're a hoarder and it's really cluttered' and I'll go in and see there's heaps of space...Look it's not that bad"

What is hoarding?

The use of the term "hoarding" has varied across time and context. Throughout this report, hoarding is considered to be when ***a person has difficulties with:***

1. Accumulation of and difficulty discarding objects, regardless of their actual value
2. which results in excessive clutter in living spaces, restricting their use
3. creating significant risk, distress, or impairment of function

Hoarding may or may not involve active acquisition. For most people who hoard, belongings accumulate because the individual finds it difficult to discard posessions *and* excessively acquires new objects with a limited amount of storage space. If an individual is actively acquiring, limiting the objects coming into the home can be a good starting point for support (for example, stopping junk mail for someone who collected paper items). In some instances, however, accumulation is driven purely by avoidance of discarding commonly acquired objects.

Hoarding applies to belongings *regardless of their actual value*. While hoarded items are often things that others would see as worthless, any type of object can be accumulated.

> *"[There is a woman] in a wealthy part of Christchurch who hoards china and crystal. Now, she's got boxes and boxes of it in her house with little alleyways. There's the bed, you know, but it's got boxes all around it, she climbs over the end of the bed to get into it…It's still a problem. It's still a safety issue."*

Hoarding may or may not involve squalor. Not all cases of hoarding involve squalor. Likewise, not all cases of squalor involve hoarding. Squalor refers to a living environment that is unsanitary due to extreme and/or prolonged neglect, and that poses substantial health and safety risks to the individual, the other people or animals living in the property, and/or neighbours[1].

How common is hoarding?

The most specific New Zealand study of the prevalence of hoarding estimated that 2.5% of a group of 50 year olds were experiencing pathological hoarding[2]. Another New Zealand study, using a collection of questions from existing InterRAI assessments rather than a specific hoarding measure, estimated that 3.5% of this more frail group may have hoarding issues[3] These figures are consistent with international research[4]. However identification is difficult and studies may underestimate hoarding prevalence as people who hoard may be reclusive, unwilling to self-report their behaviour, or lack insight.

Who hoards? Cultural differences in hoarding remain largely undocumented, with the majority of studies carried out in Europe or the USA with mainly Caucasian individuals. While hoarding is assumed to be a universal phenomenon, there is evidence that how people experience hoarding difficulties can vary across cultural contexts[5], and that Caucasians may be over-represented. In Canterbury, there is little evidence of Māori with hoarding difficulties coming to the attention of support services, and the professionals who attended focus groups had not been involved with cases involving Māori individuals. It remains to be seen whether this represents meaningful differences or another example of the disparities in Māori access to healthcare services[6].

The prevalence of hoarding is probably approximately equal for males and females overall[4]. However, females are more likely to receive clinical services[7]. This could stem from differences in the willingness to ask for help or support.

"Sometimes I've gone in and actively gagged. I just say: this is not safe for me and it's not safe for you to live like this"

Hoarding behaviours occur across a wide socioeconomic spectrum, although they have been observed to become more common with lower household incomes[8], meaning those who hoard are often unable to provide personal funding for support services.

Why a focus on later life? The data gathering in the present report was weighted towards services for older people, although this was not an exclusive focus. Behaviours that underly hoarding often begin as early as adolescence[9], although it is often difficult to distinguish problematic behaviour from behaviourally appropriate saving and collecting at young ages[10]. Hoarding difficulties are chronic and progressive[7], with the severity generally increasing over time and traumatic events later in life often exacerbating the behaviour[11].

Often the presence of a partner or parent (with hoarding in children) can act as a mediator and prevent clutter building up[12]. Loss of this support system (often in older age, with the loss of a partner) or other events such as a decline in mental or physical capabilities, or even inheriting a large number of possessions from a deceased relative can exacerbate behaviours and result in the development of risk, distress, or disability[13]. Along with having more time to accumulate, older people may be particularly vulnerable to the negative impacts of hoarding due to increased risk of frailty, comorbid medical conditions, and cognitive impairment. A sobering indicator of the vulnerability of this group is the finding that elderly people who hoard have a 5 year mortality rate of approximately 50%[11] compared with 26.7% in the wider population[14]. Given its ageing population, Canterbury will include an increasingly large group of older people who will potentially suffer the most from hoarding difficulties.

What clinical treatments are effective?

The focus of this scoping study was on general support for older people who hoard and only a small segment of our participants were involved in a clinical treatment role. Furthermore, studies of clinical treatments have consistently high dropout rates[14], emphasising the importance of considering the totality of support services and the relationship between individuals and support workers. Intervention studies also have relatively poor methodological quality[15].

The literature is clear on what interventions are unsuccessful. One-time forced clean-ups produce poor outcomes[16], and are cautioned against almost unanimously in the research and grey literature[17-23]. Although these types of interventions remove the clutter, this is often only a physical manifestation of the underlying problem. This means recurrence of hoarding behaviours is likely, which often makes the distress and costs unjustifiable.

"Her daughter ordered in a skip. Throwing away her things was like throwing away her memories. She was upset."

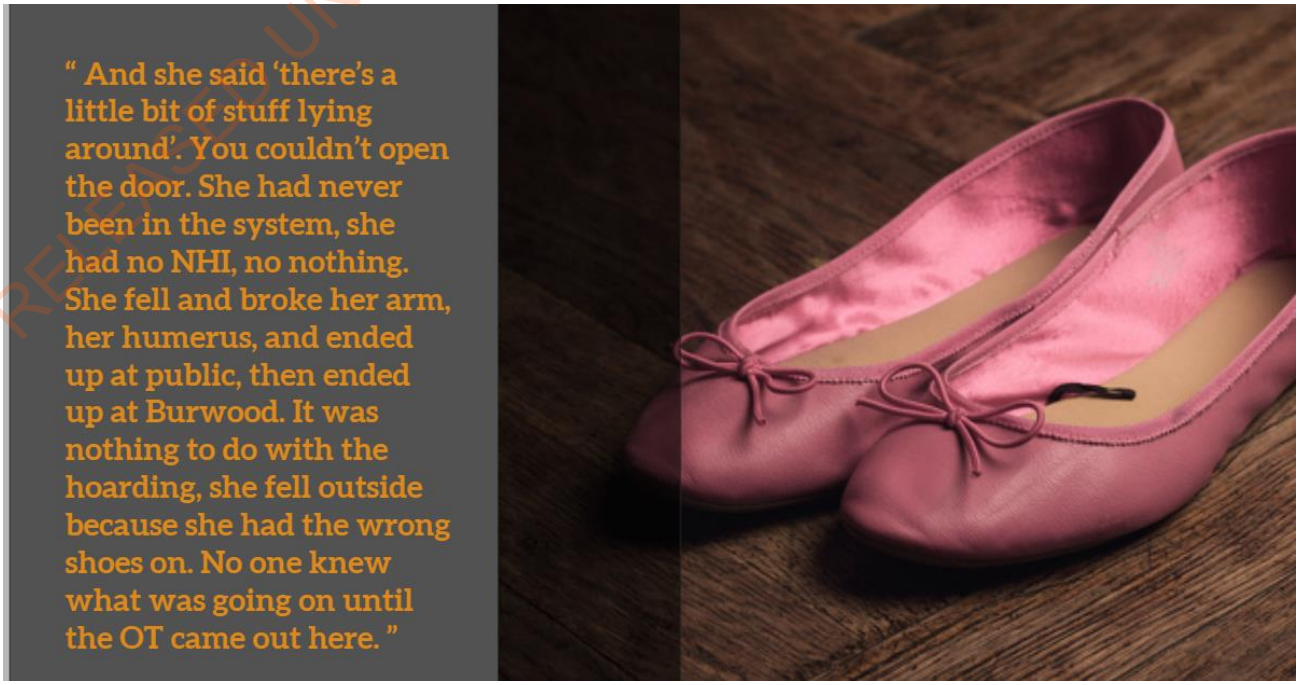
Much of the earlier clinical intervention work was formulated specifically for Obsessive Compulsive Disorder (OCD). This research also used OCD-based outcome measures which had very little analysis of hoarding-related behaviour.

There is some evidence for the efficacy of medications, with one meta-analysis (overview of research) finding that over half of participants with difficulties responded positively to medications used to treat depression[24]. However, again the interpretation of this research is limited as five out of seven studies did not use hoarding-specific measures.

Currently, the most effective treatment seems to be a multi component treatment protocol based on the cognitive behavioral therapy (CBT) model of hoarding developed by Steketee and Frost[25, 26]. This protocol has been shown to be effective at reducing hoarding severity[19, 26,27], particularly helping to overcome difficulty in discarding objects[28]. Though initially designed as an individual treatment, this CBT model has been adapted for group therapy[29], bibliotherapy (in the form of a self-help book)[30] and has had early success as a webcam-based therapy. The individual therapy seems to be the most effective[27], but other forms are less expensive to offer. There is potential for a stepped-care model where individuals begin with the more accessible options and only progress to more resource-intensive therapy if needed.

How do people who hoard enter services?

The unique attributes and needs of people who hoard largely preclude the use of the traditional healthcare identification model, where a concerned individual will request help from their general practitioner and be treated or referred elsewhere. The social isolation, shame and/or lack of insight into the problematic nature of their hoarding often mean that people who hoard will not seek treatment themselves. Hoarding is often not brought to the attention of any support services until the person is referred by others who are concerned about the hoarding, or housing agencies run into problems with the person's hoarding[31]. In the focus groups the accumulation was often identified because the person came into contact with services for another reason, such as other mental health issues, a hospital admission, or following a domestic fire. In Canterbury a number of people who hoard were identified due to housing disruptions in the 2011 and subsequent earthquakes[19,32].



Steps to consider

to help understand the context of hoarding in Canterbury

Collating information on service use.

Within the focus groups there were instances when a professional from one sector was surprised by the numbers encountered or mentioned by someone working in a different context. There is very limited data available on the actual numbers of people who hoard to inform service planning. This lack may be particularly salient when attempts are made to justify funding for initiatives.

As noted, there are considerable difficulties involved in attempting to research the prevalence of hoarding. One potential step to consider is to explore the feasibility of a systematic collation of the numbers of individuals who hoard that are known across agencies. While this would only provide a lower limit for estimating the size of the issues, it would provide initial hard data that is currently lacking. Another potential step to consider is to more formally document and analyse the anecdotal stories of cases of hoarding uncovered subsequent to the Canterbury earthquakes, to identify any lessons around the types of cases that were previously unidentified and if there were particular aspects of response in that situation that were effective.

Exploring hoarding in the Māori community and service responsiveness.

Anecdotally, none of the professionals who attended focus groups had been involved in support for hoarding for an individual who identified as Māori. It was speculated that the differences in cultural values could mean that there is less emotional attachment to personal possessions, possibly reducing the prevalence of hoarding amongst Māori elders compared to the non-Māori population. Alternately there is the concern that there are underlying issues of accessibility and appropriateness that are limiting service use among older Māori who hoard. A potential step to consider is to consult with service providers who work with older Maori to gather information about whether there are any known cases, whether their needs are being met outside mainstream services, and how accessible culturally responsive support could be provided.

Understanding the individual

A cluttered living environment may come about in a range of ways, and have a range of meanings. Good support for people in challenging living environments needs to be based on an understanding of hoarding for that individual.

It helps to understand the ways clutter can arise

"First of all, I want to get to know the person. It's not all related to obsessive acquiring, it can be related to trauma, it can be about keeping safe, it can be because they just don't have organisational skills. I think it's really important that you're building that trust, you're getting to know the person. And try, through your conversations, to define what's driving the hoarding. Then you can look at how you're going to approach it".

A diagnosis of hoarding

Hoarding has come to be recognized as a distinct mental health issue, albeit one that is very often accompanied by other mental health issues. In some cases, there may be a specific diagnosis of hoarding. In other cases, a formal diagnosis is not available as the individual may not have had access or co-operated with a health professional. Arguably, hoarding is best viewed as a "disorder" in terms of being a maladaptive 'way of being', although an illness may underlie it.

A formal diagnosis of hoarding was seen as positive in some situations by the professionals. A diagnosis may provide a key to unlocking services. The diagnosis may help those around the individual to better understand the hoarding, rather than seeing it as a 'lifestyle choice'[19] or 'laziness'[33].

It was also recognised however that a diagnosis or label of hoarding may be seen as stigmatising and people may reject services associated with it.

"I know it's a mental health issue and I'm pleased that people can be diagnosed now. But hoarding or hoarder… it just sounds so horrible I guess"

Compulsive hoarding

For some people the need to acquire or to avoid discarding certain things is caused by obsessions or compulsions. In the past, all hoarding was thought to be a symptom of obsessive compulsive disorder (OCD)[15]. It is now that thought that OCD plays a role in around 20% of cases[34].

"I had to buy a wee pair of slip on slippers just for her place (her insistence). As I said, the place was absolutely filthy, it was dirty, it was smelly and she didn't like you touching things because you would 'contaminate things'. It didn't make any sense but you've got to be respectful"

Hoarding disorder

Since 2013, hoarding has been considered a distinct mental disorder within the current edition of the DSM-5, the diagnostic handbook for mental disorders most commonly used in NZ. The DSM-5 classifies hoarding as persistent difficulty and distress associated with discarding items due to perceived need, resulting in the accumulation of possessions leading to significant impairment that is not attributable to a medical condition or better explained by the symptoms of another mental disorder[35].

Insight. It has been estimated that around half of people who hoard do not view the issues associated with their hoarding as problematic[20]. Without this insight the person doesn't "*want to change*" and this motivation to change was repeatedly seen as key by many of the professionals. For family members this lack of insight can be distressing and may increase the likelihood of family conflict[27]. For those seeking to provide support, a lack of insight can be one of the biggest challenges and necessitates a different starting point for beginning to work together.

Non purposeful accumulation

Sometimes, excessive clutter can occur in the absence of intentional accumulation or resistance to discarding. This may be due to a lack of motivation or an inability to clean up effectively, for example because of depression or physical illness. Sometimes the clutter may develop due to the loss of organisational capabilities or awareness of what to keep due to cognitive impairment[36]. For these people it may be most effective to manage the underlying issue, provide support for a clean-up, and then provide appropriate on-going home-based support.

"There was a couple who the gentleman was very compromised. He was on dialysis... just exhaustion on everyone's part."

Controlled hoarding

In some cases, the psychology and behaviours underlying hoarding are present and the individual experiences distress and difficulty associated with discarding, but, for any of a multitude reasons, the clutter has not yet accumulated to a level that causes significant impairment or risk. An example may be a person whose spouse limits the accumulation of clutter within the house.

Understanding common presentations of clutter can be one of the factors that help professionals decide the best approach to support each individual. The figure on the page 15 provides a model for some underlying conditions that can manifest as a cluttered home. It also gives examples of how interventions may differ based on the circumstances.

It helps to understand why it is hard to give up objects

"She took stuff to the Riccarton market to sell and her husband and daughter said what was left over is going to the op-shop. And she said, 'I'm standing in front of the van', [she was] crying and screaming that they were taking the stuff away".

When supporting people who hoard it can be tempting to see the clutter as innately problematic and to structure interventions around the goal of 'cleaning up'. This is complicated by the fact that people have different standards of living and one person can live happily in an environment that would distress another. Accumulated possessions often provide a source of positive emotions[15] even in the face of overwhelmingly negative consequences.

Attachment

We all value some objects in our life for different reasons. We may see them as having an essential functional role, conferring status, holding sentimental value, or possessing desirable aesthetic qualities. It can be useful to conceptualise hoarding as an extension of this as there is evidence that emotional attachment to objects plays an important role in hoarding behaviours[37]. People who hoard may form attachments to a wider range of objects than what is typical. Whatever the reasons, people who hoard value their possessions just as anyone else does and understanding this can help support people to better empathise with the distress involved in discarding them.

The level of attachment that an individual has to their belongings may influence whether an assisted cleanup is appropriate. For example ,an individual who non-purposefully accumulates may benefit from a large-scale clean up and development of skills to maintain the change, whereas this is unlikely to be acceptable or helpful for a person with DSM-5 Hoarding Disorder.

"For most of them, the bits they have are really precious. A lot of my clients are or were war children or babies, so you don't throw anything away because you might need it"

Vulnerabilities

There is often a family history of hoarding, for example with one study found that 85% of people who hoarded could identify another family member who also hoarded[1]. Hoarding behaviours are also associated with elevated risk of certain mental health disorders. Just under a quarter of people who hoard are estimated to have social phobia and approximately half to have major depressive disorder[34].

"One appointment we said 'Okay, we are going to work this afternoon on how we are going to sort it and you can carry on that process'. But interestingly, the Aunty turned up as well because she hoards, mum hoards, grandma hoarded so they're all wanting to learn""

Attention

Attention deficit problems[38] and information processing deficits[27] have also been associated with hoarding difficulties, and it has been theorised that categorisation and organisational deficits can play a role in the development of hoarding behavior and hinder progress with decluttering. This can have implications for those providing support, for example one professional talked about how she employed explicit strategies to help her clients focus.

"They're very distractible…they flit"

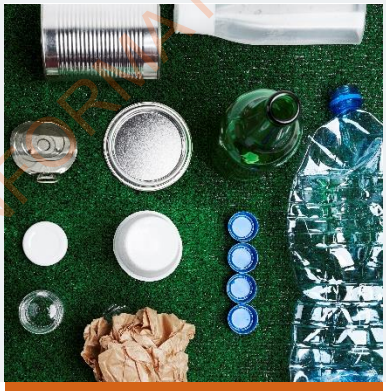
Everyone places value on objects for different reasons. This can help cultivate empathy for the distress people experience in discarding hoarded objects. As one person said: *"You want to know my why?"*

Identity

Objects can hold value for the person through an association with positive memories, as a way to express how they see themselves, or through the potential to allow engagement in meaningful activities. Examples were given of an engineer who hoarded machinery, a woodworker who hoarded wood, a crafter who hoarded crafting materials, and a 'giver' who hoarded cookbooks. While for an outside observer the person may not 'actually' be engaged in these roles, it may be hard to give up the potential of leading the life they want to live.

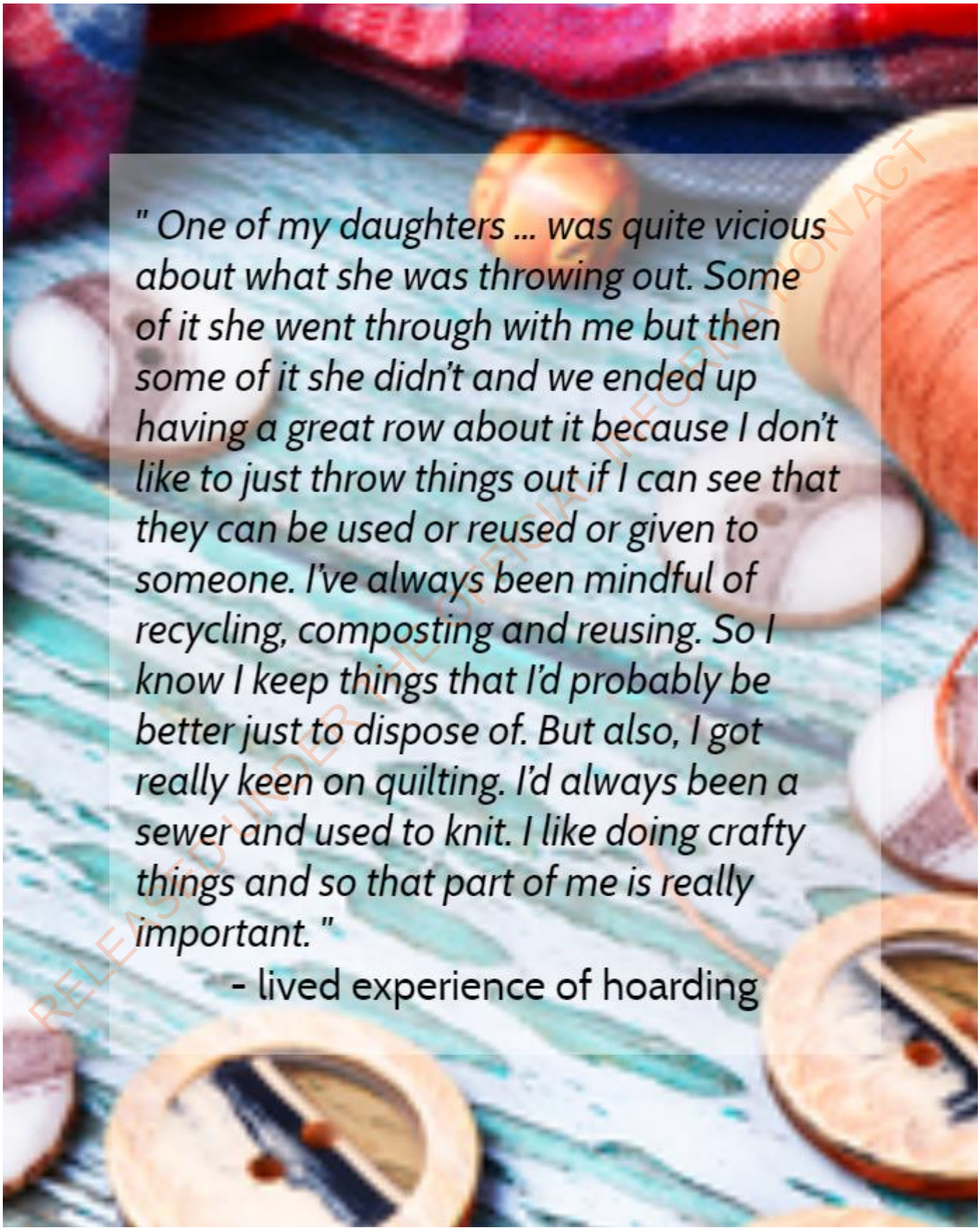
Security

Social phobia, depression, and anxiety disorder are very common amongst people who hoard[34]. People who have more severe hoarding are more likely to have experienced traumatic life events. For example, one individual who was interviewed saw a link between her own accumulation and a period of intense emotional and financial insecurity as a young mother due to her partner's alcoholism. People who hoard may find particular comfort from having their possessions[38].



Avoiding waste

For some people it is hard to throw things away because this is seen as a waste. Some may believe that they are being ecologically friendly and helping the environment by not discarding the objects. Many anecdotes were shared about people who were entirely unwilling to relinquish belongings unless they were sure that they would be put to good use and not thrown out.



It helps to understand the impact for the individual and others

"One of my clients, she's just so complex, she was referred for PTSD, depression, anxiety, all sorts of other stuff and hoarding just wasn't seen as the main problem, but it was impacting on her a lot".

Significant impact

Hoarding becomes a focus for intervention when there is risk, distress, and/or disability as a result of hoarding behaviours.

- **Risk** refers to the likelihood and imminence of future health and safety issues or diminished quality of life for the individual or for others as a result of the hoarding.
- **Disability,** also referred to as **functional impairment**, refers in this context to an inability to perform important activities. It is important that impairment is considered relative to societal norms *and* relative to the individual's own values (i.e. whether the individual is able to perform the activities that matter to them).
- **Distress** refers to substantial negative emotions for the individual or for others associated with the hoarding, both distress acknowledged by the people themselves and that observed by others.

Focus A clear focus on whether or not the impact of hoarding has become truly significant can help to keep the person and their well-being central and to separate the personal values of support workers from the goals of successful support. This can help shift the focus from 'cleaning up' and aiming for social conformity to ensuring the safety and boosting the quality of life for someone experiencing hoarding difficulties.

"It's the safety goal. So, what is going to make it safe? Because, I personally believe that my house is my castle, I live the way I want to live in my house and what right do people have to tell me to do what I want to do in my own home. As long as it's safe"

Measurement. One of the most commonly used tools for assessing hoarding severity is the Clutter Image Rating Scale[39], a set of visual examples which allows key functional rooms to be rated on a scale of one to nine. This score can be averaged to give an indication of the level of clutter in the home, along with an idea of the corresponding functional impairment. This tool can be used without any expertise and gives an easily understood rating, making it ideal for interagency communication based on the level of clutter. However, it does not gauge how the hoarding influences the individual's wellbeing and is not sufficient in isolation as an assessment or outcome measure. There are a number of other measurement tools that assess the degree of distress and the impact of hoarding, probably the most used and well-validated being the Savings Inventory Revised (SI-R)[26, 40].

Risks of hoarding

Hoarding is associated with significant impairment across various aspects of functioning, as well lower quality of life[41]. The myriad of impacts that hoarding can have on an individual can be devastating, not only from their direct effects but also in how they accrue and influence an individual's wellbeing.

Social

Social isolation and loneliness were identified as common for older adults who hoard both within the focus groups and the literature [11,42]. This may be a two-way interplay with hoarding placing a strain on relationships and loneliness exacerbating hoarding. Regardless of which comes first, hoarding or social isolation, hoarding often has a negative impact on social well-being. The presence of clutter or squalor may make an individual less likely to invite others to visit due to the fear of judgement and it may make others less likely to engage due to disgust. It can lead to frustration, confusion, and rejection amongst family members[43]. Well-intended attempts to help by colluding or by organising forced cleanups can further damage relationships[13].

"she said 'no one has ever had a coffee with me in my house before. People don't do it, If I offer they say no'."

Physical

Clutter can increase the risk of falling, and of 'clutter avalanches' when a large pile of clutter falls on top of the occupant. Obstruction of spaces can make self-care difficult by limiting access to the bathroom or kitchen facilities[45] and significantly limit activities[44]. Major health concerns can arise if the hoarding behavior creates squalid or unhygienic conditions. This can include infestations, mould, rotting food, and even accumulation of excrement. These conditions can also endanger service providers and make it difficult to provide support

"we've got disposable overalls, hand sanitizer, face masks and gloves. Big deal... I had one chap who said, 'don't put your hand anywhere but where I put mine'. He had live wires".

Fire

Hoarded items such as clothes, papers, and books can create large fire loads and flammable surface areas. This represents a danger not only for the person who hoards but also for pets, dependents, emergency responders and occupants of surrounding properties. Severe clutter makes it extremely difficult for emergency services to enter and locate occupants. A study in Melbourne found that although hoarding fires made up only 0.25% of all residential fires, they accounted for a tragic 24% of all preventable domestic fatalities[46].

"When she turned around she saw the flames coming up the back of the couch…. She did manage to get out but the worst thing for her was that her cat didn't. She couldn't get in to the cat because of the clutter"

Housing

Hoarding in rental properties can pose serious challenges to housing agencies or other landlords, potentially damaging the home and causing complaints of neighbouring properties. This can eventually culminate in threats of eviction[AD].

Anecdotally, two of the people with lived experience of accumulating mentioned the daunting nature of the accumulation as a reason for considering entering aged residential care.

Statutory powers

When there is a reasonably imminent risk of serious harm to a person who is hoarding or to others, and the context prevents less restrictive approaches from being undertaken, there are legal avenues that can provide for compulsory interventions in certain limited circumstances. There are three main legal processes that may be relevant.

The Protection of Personal and Property Rights Act 1998 allows for citizens to appoint their own 'proxy agents' to act in their stead in respect of their property and their health and welfare: "Enduring Powers of Attorney". If a person is declared to have lost their capacity to manage their own affairs by a suitably qualified health practitioner, usually a doctor, their proxy decision-makers can make any decision required in the person's best interests, with the caveat that they should act in accordance with the person's prior competent wishes. The Family Court is also able to appoint proxy guardians for people who lack capacity to do so but did not set up EPOAs previously, or to make specific orders for the benefit of the subject person. This law is widely misunderstood and should not be viewed as a carte blanche for well-meaning proxy decision-makers to move a person out of their house or clear their hoard, however in some situations this may be warranted. Clinical and/or legal advice is recommended.

The City Council can, under the Health Act 1956 and section 131 of the Building Act 2004, issue a warning notice for an unsafe or unsanitary building, and if the issue is not addressed, it can prevent access to the building. The council can also apply for a court order to have the necessary work done. The Christchurch City Council released an updated Dangerous and Insanitary Buildings Policy in 2018.

Under section 126 of The Health Act 1956 (infirm and neglected persons), a Medical Officer of Health may apply to a court to have an "aged, infirm, incurable or destitute person" found to be living in insanitary conditions, committed to an appropriate hospital or institution. The person can be detained there under the order of committal. The Mental Health (Compulsory Assessment and Treatment) Act 1992 allows for compulsory assessment in a psychiatric hospital but only when there is reasonable suspicion (or definite diagnosis) of a psychiatric illness causing the hoarding-related risks and it is considered possible that psychiatric treatment might be helpful. These avenues cannot be used to enable state agencies to clear a house of material or to remove a person from their home for this purpose.

Across the focus groups and interviews, professionals from a range of roles consistently emphasised that these avenues are rarely employed. This reflected practical considerations of the high threshold for compulsory treatment applications, care models that supported a person's autonomy as much as possible, and a recognition that forced clean-ups are traumatic and seldom deal with the underlying issues. A key impetus for compulsion was when there was a risk to others.

"In my mind, people have the right to make their own decisions about anything in life…Provided they recognise the risks and understand the risks that they are taking. So, it's like a 21-year-old going out and hand gliding or doing other risky things. There's a risk involved, they're aware of the risk involved and are prepared to take it. Where it becomes difficult and where you do have to intervene, is when there is a risk to others."

Steps to consider

to help understand hoarding for each individual

Provide guidance

A shared set of assessment tools could help keep the goals of minimising risk, disability, and distress at the forefront of support service planning and aid interagency integration. While a full suite of suggestions is beyond the scope of this report, the following hoarding specific measures may be of particular interest:

- Christchurch City Council uses a Hoarding Assessment tool which assesses living conditions and safety issues (see Appendix C). A version of this could potentially be used by other agencies with guidance about when and how a referral for council support would be recommended.

- Clutter Image Rating Scale (CIRS) (see Appendix D) provides photo cues to rate clutter which, as discussed earlier, can be a useful, but not a standalone, assessment and outcome measure. An innovative person-centred approach is to use the CIRS to celebrate and reinforce progress by providing the individual with an album of the photos across time. Some regions also use a CIS threshold to trigger a recommendation to refer the individual to fire service support, for example a CIS rating over 5.

- The Savings Inventory Revised (SI-R) is an example of a tool designed to measure hoarding-related distress and impact (see Appendix E). There is again the potential to include guidance of thresholds for recommending referring / funding to stepped care CBT treatment options for people with insight into significant impact.

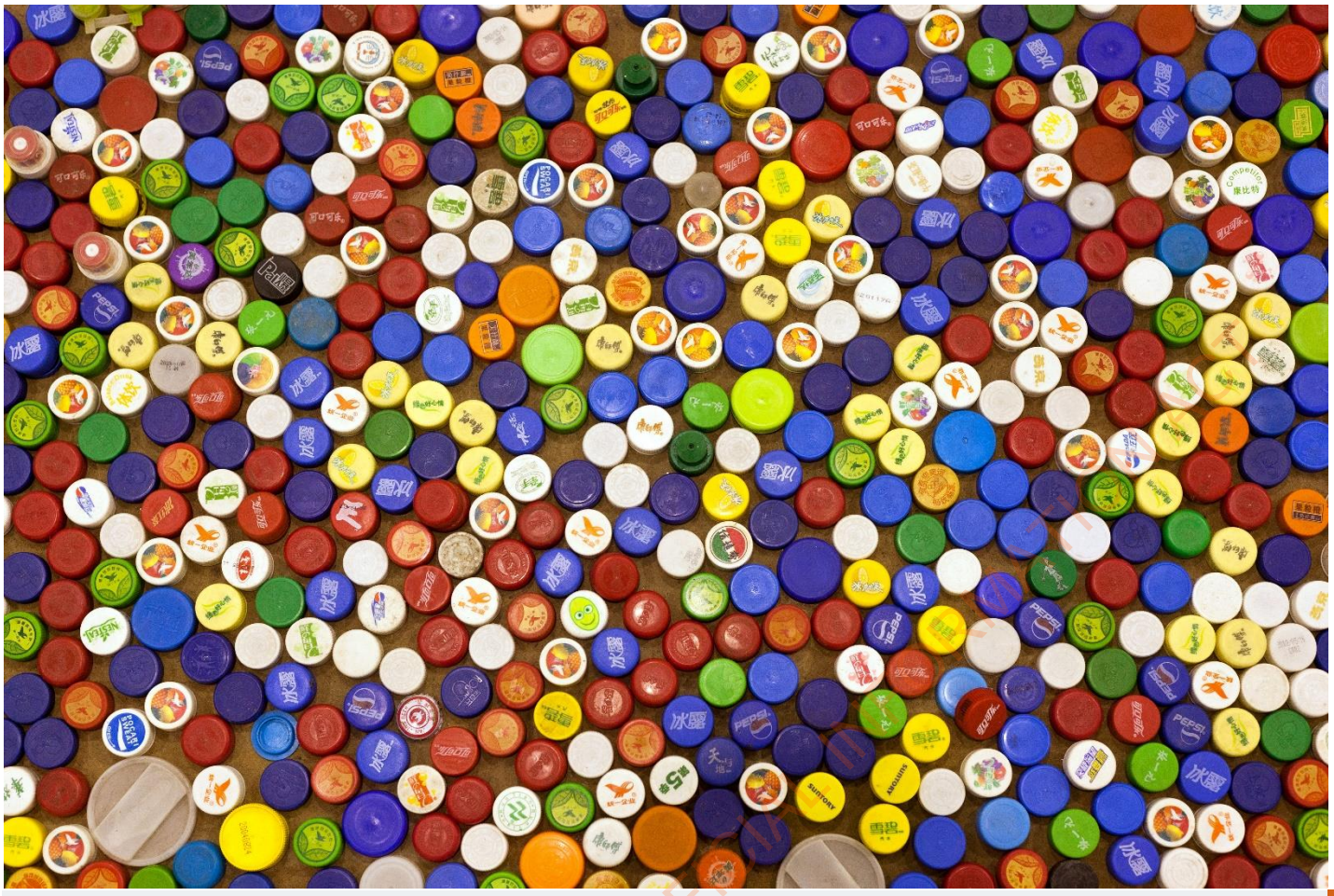
Ideally, this would form part of a person-centred best practice guide that integrates insights from national and international best practice and the current project with local information and pathways. Appendix F provides a list of some of the relevant agencies that may be involved, Appendix G provides a list of some examples of international person-centred educational resources, and Appendix H provides a list of New Zealand information on hoarding.

Support public and family awareness.

The difficulties experienced by those who hoard have recently become more visible in the main stream media with reality television shows from overseas which depict forced clean-ups of severely hoarded houses. These shows do little to improve community understanding of pathological hoarding as a complex disorder with multiple possible causes. Without this perspective, hoarding and its impacts can be perceived disparagingly as the result of the individual's own choices that simply require a forced clean-up "for their own good". Increasing both awareness and understanding in the public may be beneficial for identification and support of people who hoard.

It can be difficult for family members and other non-professional supporters to understand and positively support a person who hoards. In our focus group discussions, this led to the suggestion of information resources aimed at family. An example of a resource aimed at families is the International OCD Foundation's "How to help a loved one with Hoarding Disorder". A possible step to consider is developing a local resource for families that can be available online and in hard copy to be given out by helping services. Hoarding is already included on the CDHB's HealthInfo Canterbury website so this provides a point of access for local information for families. Including hoarding as a topic on the Health Navigator website could be another point of dissemination.

To ensure that people who hoard are being identified and offered support, there must be a community network capable of referring people to services. Having clear and accessible referral pathways could have a positive impact, as members of the public who are concerned about themselves or others would be able to find and contact the relevant support services. In some places, programmes have trained non-healthcare workers who are engaged with the community to recognise signs of hoarding and refer individuals of concern[Q]. Increased clarity about when and where to refer, for example having a single point of entry that coordinated across agencies would enable clear messages about where to seek help to be included in any information materials.



Understanding the relationship

Great support for people in challenging living environments requires supporters to establish trust, support autonomy, and build motivation.

It helps to establish trust

"It's taking that threat away that 'here's another stranger, coming into my home and is gonna chuck everything out, and tell me what to do, and judge me' "

The challenge of trust

From both the literature and focus group discussions it is clear that working with people who hoard is complex and establishing trust is challenging. However, a pervasive theme throughout the focus groups was the need to establish trust with the individual and that the importance of this cannot be overstated. People who hoard are often very vulnerable, and the interviews of people with lived experience revealed the salience of being exploited or betrayed in the past. Letting someone into your home and accepting help can be incredibly exposing and requires a deep level of trust, yet trust is paramount for successfully supporting someone with hoarding difficulties.

"I have had some really awful experiences and I've become very defensive"

Being non-judgemental

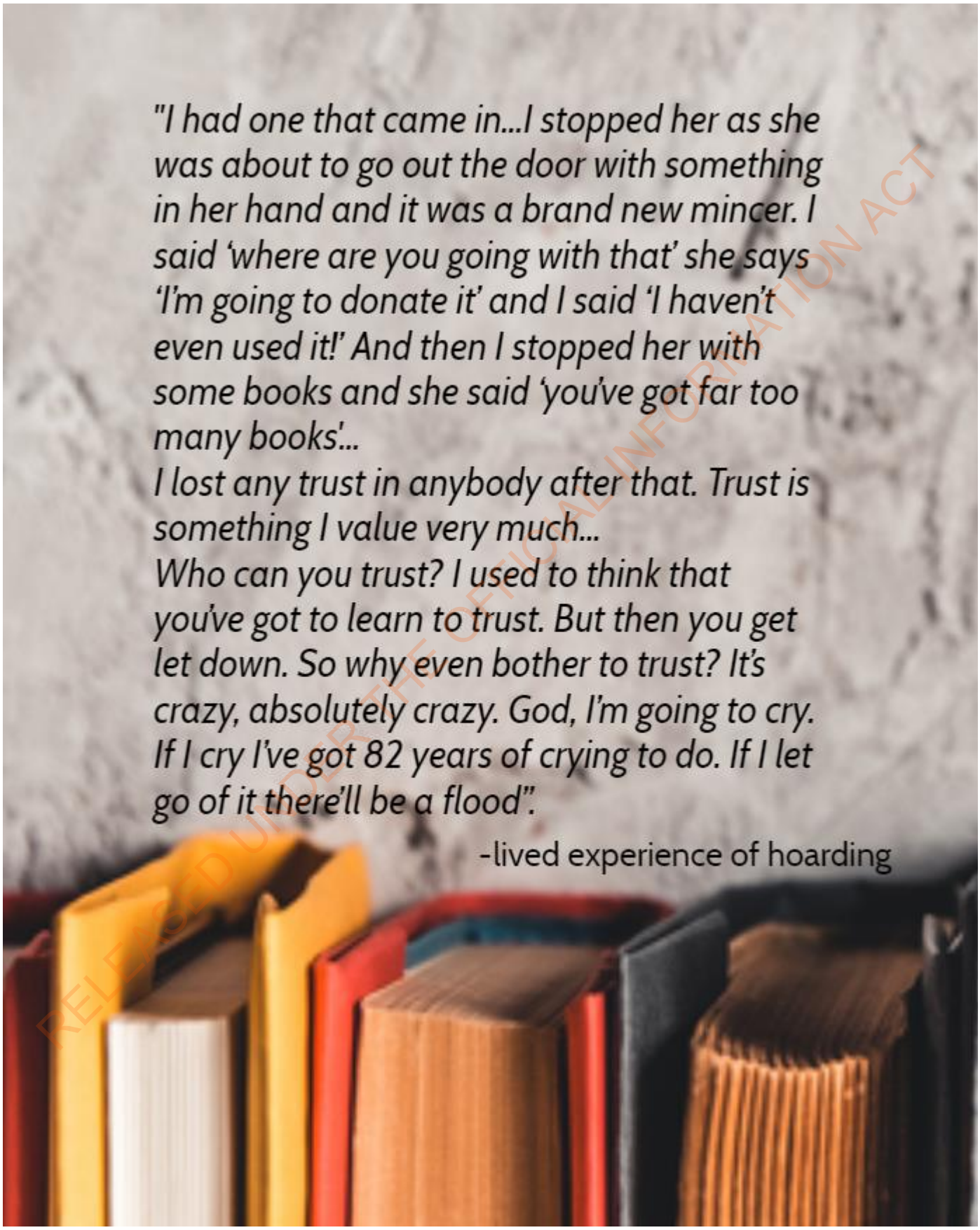
One of the largest barriers to building a trusting relationship that emerged was that people who hoard can feel judged or patronised. Judgement can be perceived in many forms and is often unintentional, making it vital for support workers to be aware of how they are communicating. Professionals in the focus groups stressed the importance of language. For example, people are often uncomfortable with the term 'hoarding' and many professionals avoided this term entirely, instead mirroring the terms that the person them self uses (such as 'collecting' or 'keeping things'). Understanding other people's experiences and acknowledging how interactions can affect them goes a long way.

Non-verbal communication was also discussed, such as the importance of keeping neutral body language and maintaining a 'poker face' rather than showing disgust, which can be challenging in squalid conditions. There was discussion that not every person is able to work in extreme conditions, or to build rapport with the individual, and it is important that there is permission for either party to be able to say when it would be more appropriate to use a different worker:

"please do phone us and we can try somebody else. And that's okay"

Having protective gear on hand can be a valuable tool to enable support workers to safely enter squalid houses. The professionals were aware of the potential for the protective gear to be seen as judgmental or offensive , particularly when the person lacks insight into their living conditions. Generally, an honest but tactful approach was taken.

" I said 'look, I know you like keeping things, and I'm not judging you for that because I keep things too'. She said 'Do you?!'. I said 'of course, everybody keeps things, but we just don't want it to get to a stage where it's going to be unhealthy for you "



Making a connection

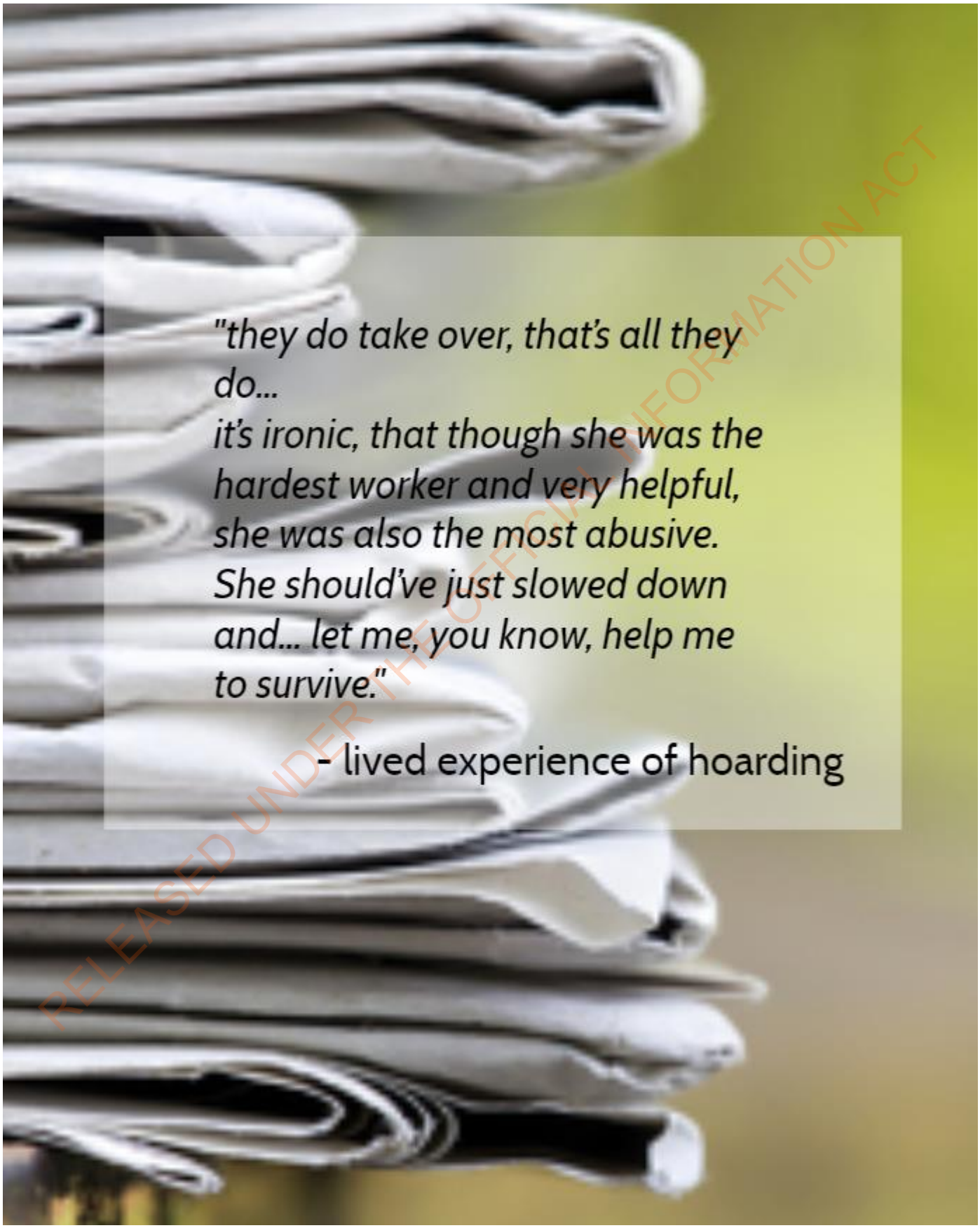
The relationship between the supporter and the individual who hoards was discussed extensively as being a key to success. Finding common ground can be a powerful way to build a relationship. It can also help grow an understanding of the person and cultivate empathy for their situation. The focus group professionals were well versed in relating to a broad range of people and a common piece of advice was to observe cues in the home environment or from the individual's language and use these to navigate the conversation. There were also examples where humour was used to help bond and relax.

> *"you can have a glance around. This guy, he threatened us with a spanner and it was obvious that there was a lot of car parts in the room...Then you can get it and say 'Oh are you interested in repairing car parts? …You try to use the cues that are in the room"*

Pacing

A strong sub theme that emerged from the discussions was that establishing trust takes time and patience. It was described as a process of first establishing the trust and building a relationship *then* moving towards change. Professionals talked of patience and maintaining efforts to build the relationship, even through periods where no progress was being made. Sometimes patience was required with multiple visits before the professional was invited into the home. Where the role allows, actively maintaining a positive relationship by "popping in" even when the person was not receiving intensive support was seen as helping to provide a safety net and making the service more accessible if required in the future. This approach was noted to have funding implications, with funding options and service models sometimes not being flexible enough to reflect the ongoing support required to build a relationship with the individuals concerned.

Several instances were discussed in which support workers or family members had disposed of belongings without permission; even with the best of intentions these betrayals of trust caused major setbacks in support.



"they do take over, that's all they do...
it's ironic, that though she was the hardest worker and very helpful, she was also the most abusive. She should've just slowed down and... let me, you know, help me to survive."

– lived experience of hoarding

It helps to create mutual goals

"For me, it was setting the goal. You know, cause there's always this focus on we have to have goals for everything. I always make a joke of it 'Look, my boss says I've got to have a goal, for us to work together we've got to have a goal. What do you think we could do, if there's one thing that you could do, what is one thing' she said 'I want to spin, I want to be able to spin, my spinning wheel is over there' "

Supporting autonomy and building motivation were central to working towards joint goals between the support worker and person with hoarding difficulties.

Autonomy

Collaborating with the individual to set joint goals was commonly raised as keeping the person's wellbeing central to support work and acting to empower the individual. It was reiterated by many of the professionals that not only is autonomy important in maintaining a person's rights and dignity, but it is also necessary for effective change to occur with any lasting benefit. As one professional summed up in respect of unilateral cleanups "It's not a fix really, it's just a temporary clearance".

The ineffectiveness and trauma of forced cleanups was one of the most consistently emphasised themes in both the literature and focus groups. Even premature death was mentioned as a result of shock from forced cleanup and relocation. While this is only anecdotal, it serves as a reminder of the damage that can result from such approaches.

" A low-key approach has worked more frequently for me than a pushy one. In the past, I would use my health act authority to enter on the land and push it as far as it would go. But it didn't always pan out very well. We've had times where we've served notices and the place has been cleared. But I have to admit that within 6 months, most of those people have died. Just the shock of that complete change."

Support workers can be viewed with suspicion, so many professionals spoke of the importance of clarifying their role to remove any threat of forced cleanup or relocation.

"That's paramount, that's the first thing I say and that's why I didn't go into that lady's house on the first visit. I said, 'my role is to keep you safe and well in your own home' and I will repeat and repeat and repeat that …I think that's made a huge thing because family, neighbours, friends, they've all wanted them out into a rest home"

Building motivation

Many people who hoard do not have insight that their accumulation is problematic. Building help-seeking behaviours and helping the individual to see how their hoarding is not serving them can be one of the largest roles of a support worker.

A strong theme that emerged in the way professionals communicated with people who hoard was avoiding instructing. People spoke of planting ideas and making careful suggestions as opposed to pushing their opinions.

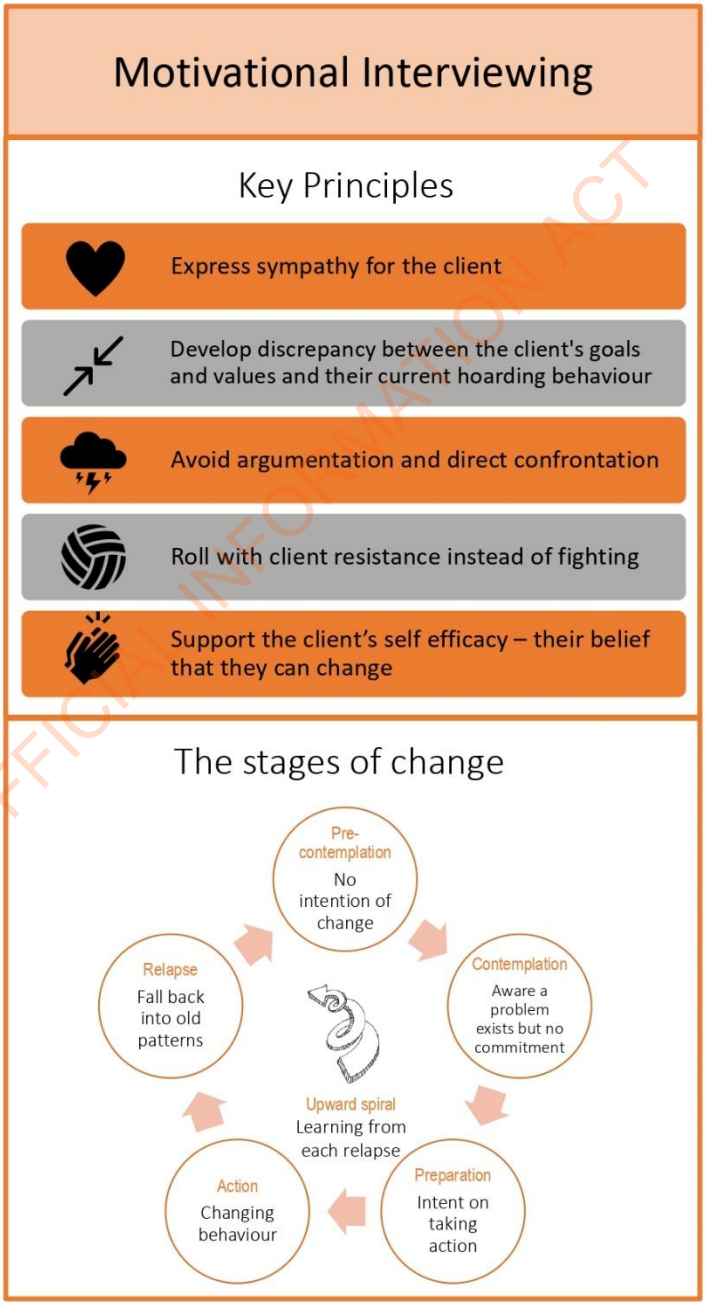
Shifting the focus from physical belongings to activities and the life the person wants to live can form the basis for forming joint goals. Promoting the value of enabling clear spaces for recreation, essential activities of daily living or for safety helps the individual to see the impacts of hoarding and moves away from the mindset of losing possessions.

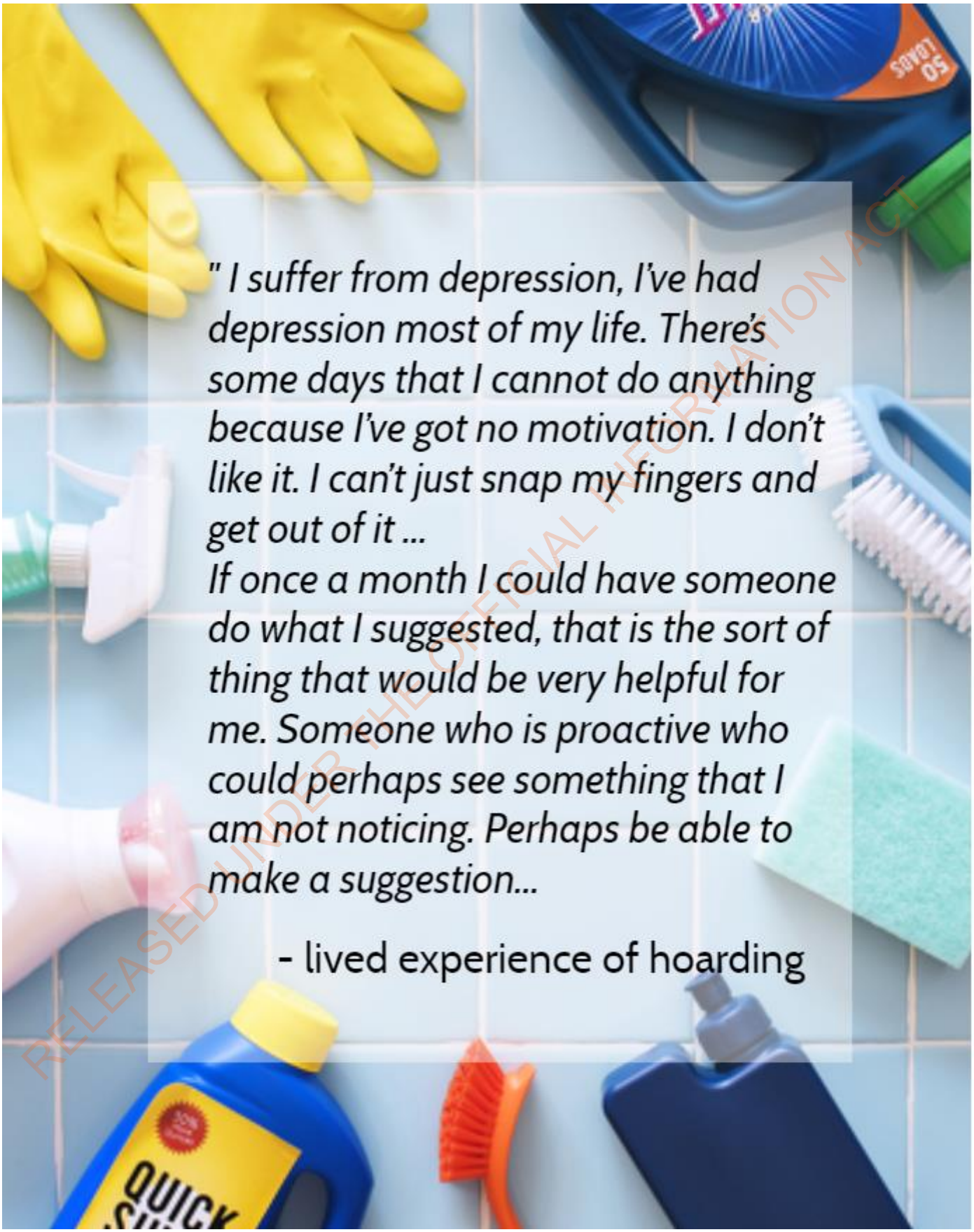
Some individuals were seen as being more responsive to considering the impact of hoarding on others, so encouraging reflection on the effects for dependents, friends, family or the community can be helpful: for example, an individual whose key was concern for the well-being of her cat.

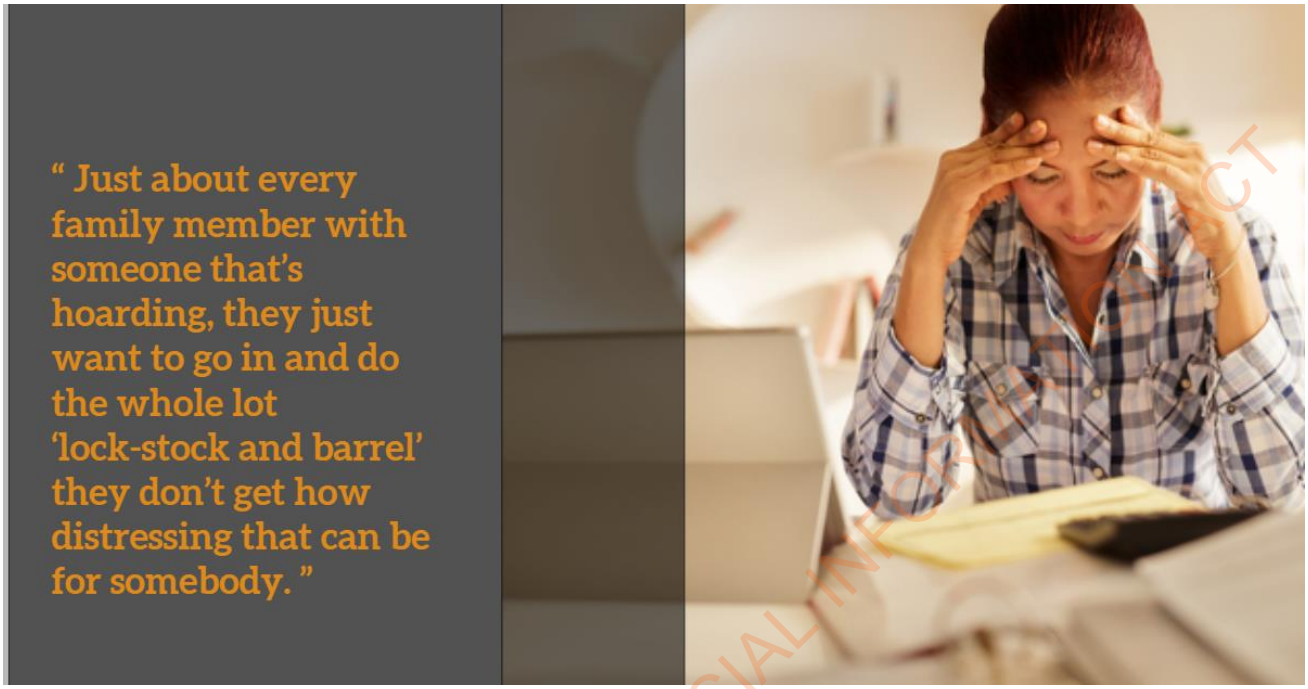
Small meaningful steps: Setting realistic, achievable goals and focusing on small wins was also emphasised. This makes tasks more manageable and avoids overwhelming or pressuring the individual. Seeing progress can create momentum and give the individual a sense of control. Having the accountability of a support worker to check in with and receive praise from can reinforce this process. Examples of simple goals ranged from having space to reach a spinning wheel, to rehoming one or two bags of items at a time, to having space for emergency services to access the house.

> *"She'd be so excited to show me the progress she had made and what she'd go rid of … she actually took the stuff to the charity shop herself. But it worked for her because she wanted that change"*

Motivational interviewing: Motivational interviewing can be a helpful tool for building motivation. This approach guides the client through a "cycle of change" by empathically encouraging reflection on the pros and cons of making versus not making changes. The goal is to help the person reach a stage where they see the benefits of change compared to the status quo and believe that the change is possible[47]. This is summarized in the following infographic[48,49].







Safety: One recurring focus for mutual goal setting was taking small steps to ensure safety, particularly fire safety. The fire service community liaison team is available to make home visits to discuss specific goals to reduce risk and will fit smoke detectors. fire safety.

Some of the professionals were generally successful in gaining consent to involve other agencies, particularly the fire service. Practical tips about possible effective approaches to gaining consent to share information included

- Ensuring rapport is built
- Recognising that trust may often be difficult, and clarifying the confidentiality requirements of other services
- Talking through the risks of concern, particularly safety
- Discussing the positive role that involving the relevant agency can have
- Emphasising that the agencies all have the goal of working together to help the person stay at home safely and
- Taking a very simple personal approach rather than formal scripted approach

"The ones I've dealt with have often responded to the safety aspect of it. 'If you had a heart attack how would the ambulance people get in?' and gone from that angle"

Family: Professionals spoke of the importance of integrating the individual's wider network into the support being provided. They spoke of how family members are often distressed and emotionally invested in trying to help. Some family members are '*burnt and gone*' after years of frustration. Professionals often spoke of having to 'mediate' between the demands of family members and the reluctance of the person who hoards, and of giving family members invaluable knowledge about the best ways to support their loved ones.

Steps to consider

to support best practice

While some of the professionals involved in the scoping study had extensive experience supporting people who hoard, others reported occasional encounters and 'learning on the job'. Some spoke of feeling unsupported and uncertain. Some stakeholders such as home-based support services or housing providers may be involved in supportive non-clinical roles. Some possible steps forward include:

- **Facilitate awareness of online resources**: Increasing the awareness of existing resources for professional supporters would be worthwhile. Appendix G provides a selection of some of the online education and guidance resources about working with people who hoard. Health Navigator is a potential central point for disseminating health information, including separate sections for professionals.

- **Develop local person-centred practice resources**: Two suggestions of local resources for professionals arose from this research. One is a policy document, to be discussed later in the report. The other is a shorter 'engaging tips' booklet for service personnel about the practicalities of engaging with people who hoard in a person-centred way. The information from this scoping study could contribute to the development of such a resource.

- **Record video resources**: Recent educational opportunities in Christchurch include a panel discussion on hoarding at the CDHB's Older Person's Mental health day in 2019, and a seminar by an Australian expert in January 2020. The impact of such events could be expanded in the future by creating video resources of the content and hosting them on an appropriate web platform.

- **Train homebased support workers**: Canterbury District Health Board's person-centred dementia care training programme ("Walking in Another's Shoes") is available for home-based support service providers. This has resulted in a pool of support workers who already have a knowledge of person-centred care and who are sometimes called on for more complex presentations such as people who are reluctant to accept services. There is a mechanism for post-graduation 'booster' training sessions, called "masterclasses". A masterclass on hoarding and non-purposive accumulation could be considered.

- **Establish a hoarding specialist role**. A further step to consider would be the establishment of a focal regional clinical position for hoarding (possible models include a clinical nurse specialist or designated social worker role). Such a person could act as a contact point for the provision of professional support and education, including opportunities for health, social service and other related workers to discuss their experiences. This role could also encompass taking a lead in organising cross-agency case meetings for crisis interventions for people who hoard, and for streamlining referrals.

Understanding policies

Great support for people in challenging living environments requires a supportive resourcing and policy environment.

It helps to have resources

"There's nothing to come in to support you to support this person"

Long-term resources

Because of the need for multiple services and often large time commitments, there are often major resource constraints on hoarding services. One of the prominent themes amongst professionals was that of not having enough resources for the ongoing support that is required.

> *"I've had to fight to keep my ladies on my books. Our [senior doctors] have said no…it's not recoverable, not going to work…every three months"*

Flexible resources

Where people are motivated to declutter, few are able or willing to self-fund cleanup services. One of the individuals with lived experience of hoarding described how services can seem inflexible

> *"they will not move anything, they will not do the rooms that you are in. They'll only do the very minimum."*

Funding was sometimes seen as being too rigidly constrained to adapt to the needs of the person – for example allowing simple cleaning but not de-cluttering support because this was "considered a "spring clean". Some of the professionals were aware that there were possible community source of support or funding for decluttering but there was no clear awareness of how this could be accessed. Some of the NGOs contacted during the research process reported that they had been active in the area in the past but did not currently have the capacity. An ideal scenario raised by some of the professionals is that there would be discretionary funding available for selected clients.

Therapy resources

As discussed earlier, there is an evidence base to support a multi-component Cognitive Behavioural Therapy (CBT) protocol developed by Steketee and Frost[25, 26]. The programme is available as a book which can be used as self-help or a guided therapy. This CBT model has also been adapted for group therapy[29]. There was interest amongst some of the professional participants to build on an initial pilot group in Canterbury and broaden access to this support. A group format has the benefits of delivering therapy in a cost-effective way along with offering peer support and enhanced social connections for those involved.

> *"The book is in the library, Steketee's latest book "Buried in Treasures". It's all there, just pick it up and do it"*

Stepped care

Introduction of a stepped care model was suggested in one group, as well as by some researchers[27]. Many jurisdictions have social workers as the lead workers [27, 50], which can allow more time and resource intensive services to be brought in only when necessary.

> *"We've got some models, lets pilot it. Stepped care would be great. I think something needs to be done at primary or secondary care and then...because we are gatekept at tertiary care"*

It helps to have integration

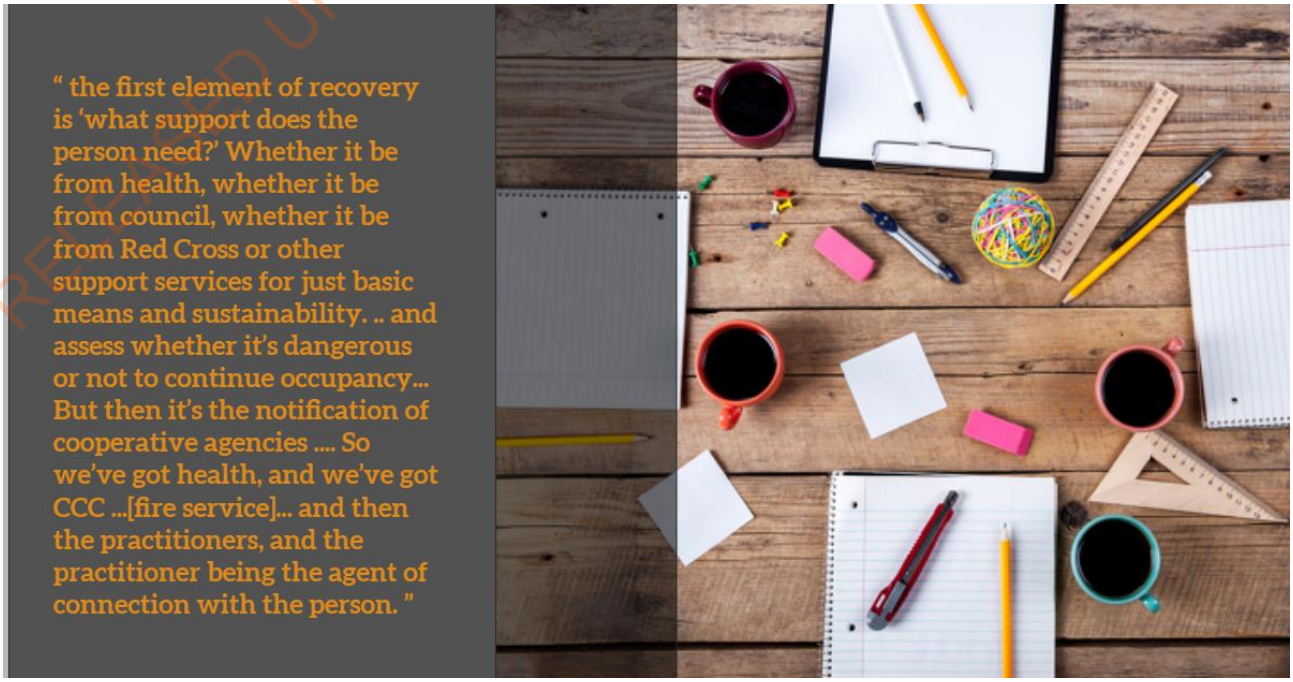
"You can't do it on your own, it's too big. You need an interagency commitment and it would ideally be not individually based but role based. So that if someone retires or moves it doesn't collapse and I really like that idea of some sort of single point of entry where cases come to note and there's some discussion around the table of who could respond to this? What are the needs?"

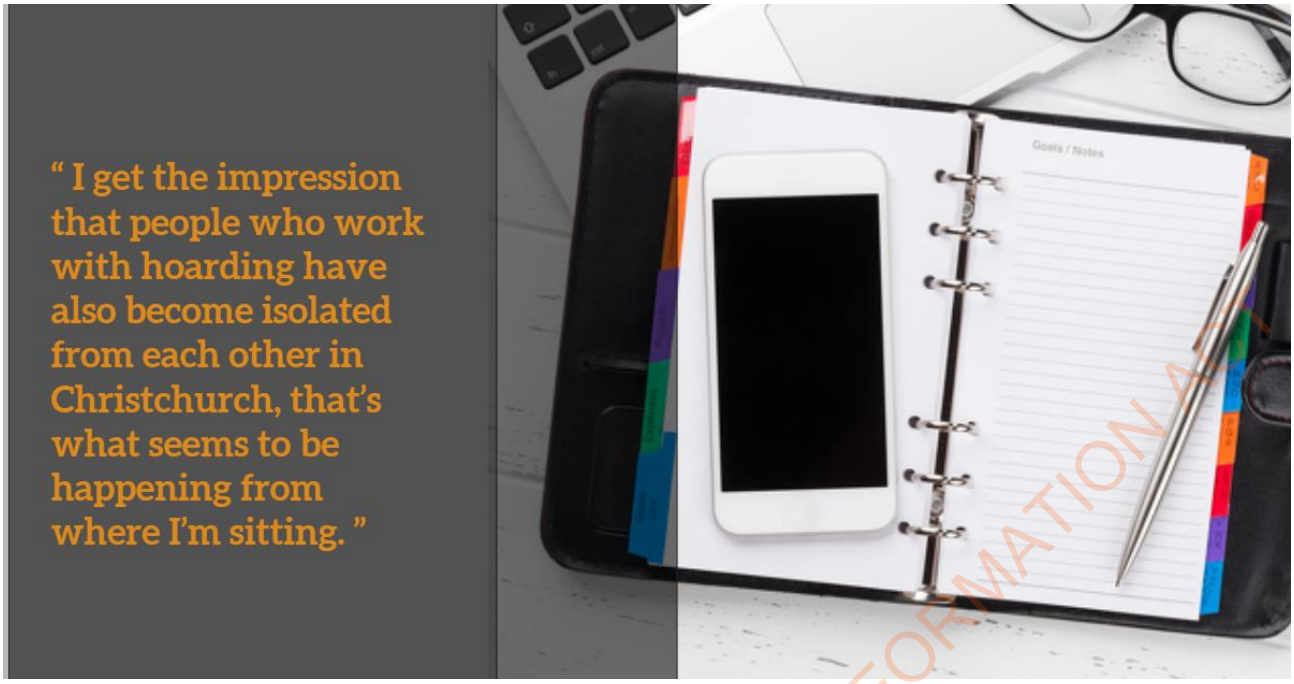
A multidisciplinary approach

Because of the multifaceted nature of hoarding, it is recognised internationally that hoarding is best managed by a multidisciplinary team [7,11,17,18, 20,22,42, 50,51]. As hoarding impacts so many areas of life, an individual whose hoarding has reached a problematic level is often engaged with multiple services. A multidisciplinary team integrates the responses of these services and allows the multifaceted needs of a person who hoards to be met more efficiently and effectively, providing practical, medical, psychological, emotional, legal and safety-oriented support. Some jurisdictions have specialist teams or 'task forces' to address hoarding [50, 52] but this is not the case in Canterbury.

Ultimately, the services that are included in the support approach will depend on the needs of the individual. Key players are likely to involve Fire and Emergency services, Mental Health services, Social workers, Home-based support services, Public Health agencies, City Council and Non-Governmental Organisations involved in housing, mental health, or with vulnerable populations (see Appendix F). A coordinated approach benefits both the individual and the agencies involved by providing integrated biopsychosocial support[4] and allowing greater efficiency and sharing of expertise from agencies[42]. In the Southern DHB a "Joint Agency Panel" model has been adopted.

Even in lieu of a specialised team there are a number of key organisational features of services which can greatly assist in providing an effective multidisciplinary support system. The following features are emphasised in the research and the grey literature from other jurisdictions, and/ or were discussed by professionals in the focus groups.





Coordination. For effective collaboration between multiple agencies there must be strong inter-agency communication. While there were instances of inter-agency meetings for individuals with council / emergency services / public health involvement, these were far from the norm.

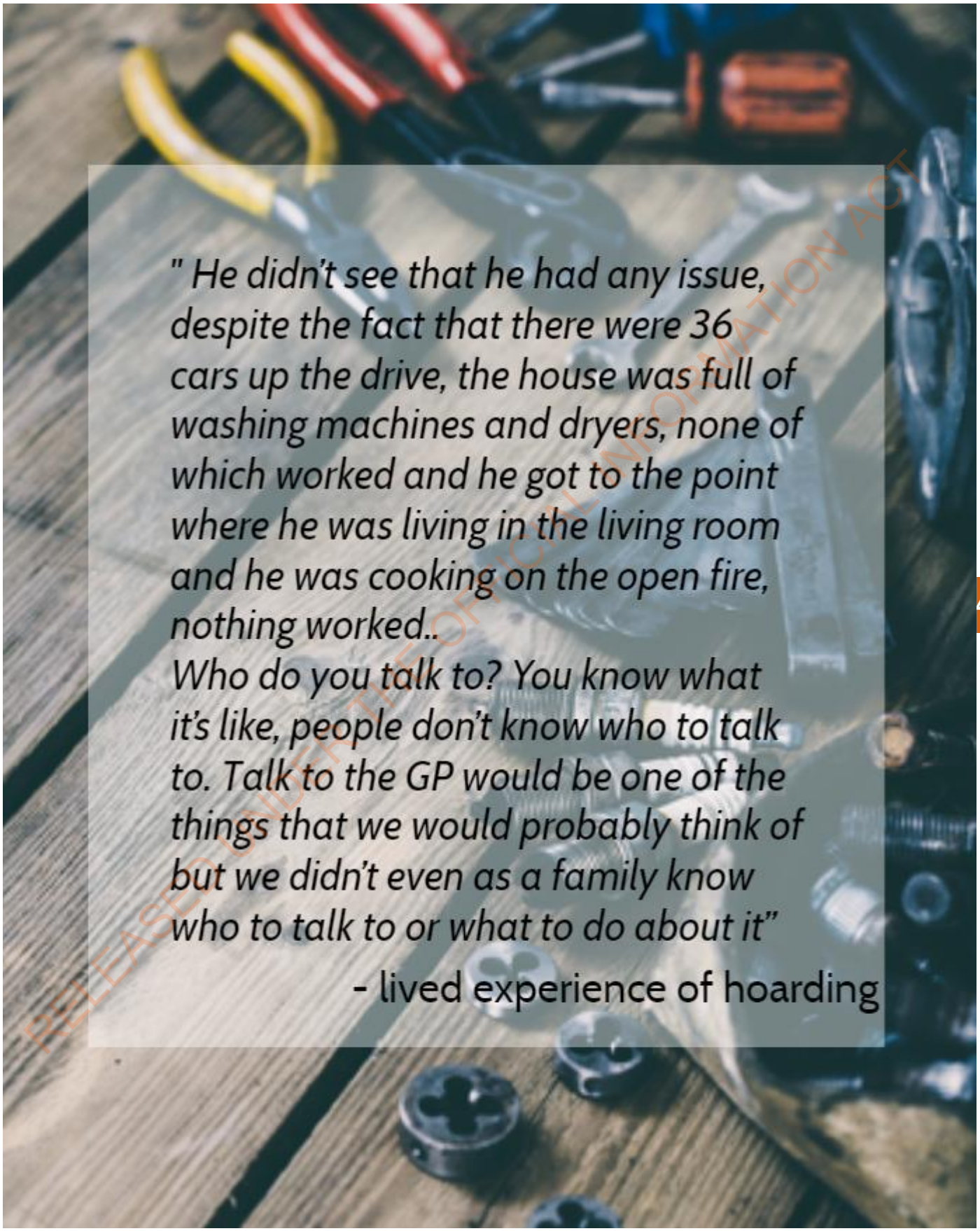
Having a central coordinating agency which is able to act as a single point of entry for referrals and delegate cases can be extremely valuable[20,50]. The usefulness of such a focal point was commented on by the professionals in focus groups and interviews, and a lack of clarity about referral pathways was also emphasised by many professionals. It was also noted that there has been awareness of the need for these features in Canterbury for some time.

Communication. Inter-agency communication can be hindered by privacy restrictions on sharing the information of individuals with other agencies. This was a recurrent point of discussion in focus groups, with multiple agencies holding information on individuals who hoard but little sharing between agencies. The lack of clarity about what can be appropriately shared and when safety concerns might override confidentiality was reiterated.

The potential benefits of enhanced information sharing are particularly evident in respect of risk reduction for emergency situations. The fire service has mechanisms to flag addresses where the accumulation of clutter is of concern and send the appropriate number of appliances, and likewise the St John ambulance service is able to flag addresses with known special response needs. Ambulance and fire services have to make decisions about whether it is safe for officers to assist an individual inside a challenging domestic environment, so information about safe routes within a severely cluttered home could make the difference in some situations. There are no established mechanisms for sharing this kind of emergency response information. Shared information is also obviously necessary for any and all coordinated action plans between agencies or individual case workers of various kinds.

> *"You've had people who won't let you talk to the emergency services. I've always said to them, well, being in the fire or ambulance service, they're bound to the same confidentiality as I am"*

Support. Given the wide range of agencies that can be involved, many of the people who support individuals who hoard learned through experience, rather than receiving formal training about hoarding. The discussion recognized the value of local educational resources, training events. and opportunities to network.



Steps to consider

A supportive policy environment

Possible steps to consider include

Facilitate coordination

Establish protocols and pathways

The development of a regional policy guide by a multidisciplinary group is a step to consider. Southern[51] and Taranaki[53] DHBs already have guidelines that could serve as a model, based on work from Sydney[54]. These guides provide

- A step-by-step guide and simplified procedures
- Clear roles and responsibilities of agencies and service providers
- Practical information regarding referrals and intervention options

It is important to note however that these guides sometimes focus on domestic squalor, not on hoarding or accumulation per se, necessitating a slightly different focus. Two of the professionals involved in the scoping group have offered to coordinate a task group with the development of a guideline document as a primary focus.

Gain traction on a central point of contact

There was a recognition that having an identified central point of contact is an important step to consider to facilitate inter-agency referrals and co-ordinate input so that the right help is provided by the right agency to the right person in a timely way. Some of the stakeholders emphasised that this idea has been mooted for some time without any concrete progress. Establishing such a point of contact would seem to be a priority. If it is not possible for Canterbury's multiple lead agencies to mutually agree on the resourcing of such a role, one agency will presumably need to take the initiative.

Simplify information sharing and referrals

There were different approaches and perspectives on sharing information amongst agencies, and a desire for clarity. One simple step forward may be to develop an interagency consent form for information sharing. An example is a form used in Victoria, Australia[1]. This would need to be backed up by guidance on policies around information sharing in the regional guidance document.

The focus group discussion also suggested that it would be useful to provide guidance on pathways for gaining expert advice and for referrals for capacity assessments.

Fund hoarding support as a longer-term commitment

A recurring emphasis in the literature and discussions was that forced quick 'spring cleans' are ineffective and traumatic. Instead, there is a need for long-term support and maintenance. It seems that several services are already directing significant resources over long periods of time for certain individuals, however this is unevenly and inequitably spread depending on where a person with serious difficulties first comes to light. Therefore, a step to consider for the future is to create options for access to discretionary funding and funding routes for longer-term support to support people who hoard, from a whole-of-system perspective.

A final word

There are a surprising number of people living in Canterbury whose hoarding is leading or has already led them into domestic clutter to the extent that it is causing significant risks to themselves or others, significant distress, or significant disability. Most of us will be aware of a house somewhere in our neighbourhood that is likely to be the home of such a person and a quick look at Google Maps satellite view can confirm how serious the problem is: you can see hoarding from space!

Many of these people are elderly and therefore the numbers of people affected by serious hoarding difficulties are going to steadily increase with the rapid ageing of Canterbury's population.

Effective support for people who hoard requires different skills and different management strategies depending upon the individual person, the social and environmental contexts in which they live, and the underlying reasons hoarding-related problems have developed. One size most certainly does not fit all.

It is not surprising, therefore, that a wide range of Canterbury services are already providing services to try and help these people, from statutory bodies to emergency services, from private businesses to NGOs, and from health services to social services. However, the resources already being utilised would seem to be uncoordinated and piecemeal, and therefore being distributed in an unfair and inequitable manner, if not also inefficiently or even spent in futile ways.

The people engaged in these helping services are often learning 'on the job' and have developed wonderful skills, but they are also reporting being under-prepared for their roles in terms of knowledge, understanding effective interventions, and knowing what other services are available to help their clients and to support their work. They describe a dis-integrated sector.

It is time to invest in an integrated, person-centred, effective approach to hoarding in Canterbury. More resources will inevitably be spent on this issue because of the growing population in which hoarding is most common - that is not a choice. What is within our grasp is to choose whether we will keep using these resources in a disjointed, inefficient, and perhaps ineffective way like we have been doing; or whether we will invest as a society in a coordinated, evidence-based, and person-centred approach to this most human of problems.

We hope that this report has honoured the wonderful participants of our focus groups and individual interviews, especially the people with lived experience of hoarding; and that it has brought together the best of New Zealand and international literature on this topic. Holding in mind that person we all hardly know who lives with some degree of vulnerability in the cluttered property just around the corner, we entrust this summary of our findings to you. We trust that our community service leaders and workforce champions will use it to take the steps forward that our participants have so clearly pointed us all towards.

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Appendices

Appendix A: Summary of professional participants

Appendix B: Interview impressions

Interview 1:

My uncle

'My uncle' was quirky and she loved him for that. After he died, they found he had probably been eating jelly meat and they feel guilty. They knew it was bad but not that bad. What could have been done? They looked in to it, talked with psychiatrists, maybe he should have been sectioned. He may have met the criteria for harm to himself. But he would have resented them for it. It may have even been the right thing to do, for them, for him, for both? 'My uncle' had been an engineer- he now collected all sorts. Probably to one day do something with. He was once quite organised but later lived amongst chaos. It started when his mother died. He was lost and grieving. Perhaps having things meant he didn't need to let anything go or lose anything. Perhaps she had protected him and mitigated his general functional and coping deficits. No one is really sure. But there wasn't a lot of service around who could help. There probably still isn't anything much either. The lines between the law, public health, rights, mental health and frontline services are unclear. Who does what when no one can do anything?

Interview 2:

My husband's things

This house is hoarded by "my husband's things". He was a photographer who developed dementia. She cared for him. I wonder if getting rid of his things means she gets rid of his memory. The house is hoarded by her things. She is a crafter with a social consciousness. She will give her things away when she has no use for them, she plans to make quilts, knit and sew once it is all sorted out. If she does not use it, she will give them away. Perhaps in exchange for some gardening or to people in need. Time is a useful currency- if the world worked in sharing of time, things would be better in life. People would not be ill or lonely. She is both.
During her earthquake repairs, she rearranged things. Her daughter ordered in a skip. Throwing away her things was like throwing away her memories. She was upset. Eventually she will sort the things, maybe she will move in to residential care. The garden is also hoarded out. There are thousands of terracotta pots. The empty pots may one day be filled. The empty pots almost represent an empty life.

Interview 3:

The inheritance

This house was untidy, cluttered in parts with belongings in piles. It could have bordered on poor house-keeping if not for the themes and amount of her things. This lady loved to cook, but is seems she doesn't, there were hundreds of cook books and recipes stacked between the lounge, kitchen and back bedroom. Brand new, unopened. She plans to cook from them one day. She told me this as she ate a meal delivered by meals on wheels. She was due to have KFC for Christmas lunch the next day. She worries about money…her son needs some because he lost his job. She tells me this as she sits amongst thousands of dollars of unopened books, make up and kitchen utensils. She tells me got a huge inheritance from her parents though it has gone. She is vulnerable. Her decisions over her time have been questioned by others. She doesn't see her family much- they are busy and stressed. Home help comes, but they will not clean amongst the belongings. They call that a spring clean. What is cleaned instead I am unsure of. She is alone. And lonely. Who she defines herself as and who I see her as being in that moment could not be further apart.

Interview 4:

Let me tell you my why

This was not only hoarding but squalor. To walk through the house, I had to shuffle on my side, stepping over and between items before eventually perching on a stool, two feet from the participant in order to hear her "why". This lady was charming-funny, generous and strong in spirit. It was with pride she told me about the visiting hedgehog and cats she feeds in the home, she was not bothered rats had eaten through the electrics in her roof rendering the back of the house powerless. She maneuvers through the house bent in on herself, clutching door frames and tenuously stacked objects, often falling, at times becoming stuck amongst her things. Her things are precious to her, but really have no monetary value per se. Empty margarine containers, clothes that will never be worn, old fans, books and papers. The fridge has little food but there is plenty of biscuits for the cats. She defines herself as a weaver and proudly showed me wool that she washes, then washes again before spinning. This is amongst the unwashed floors, dishes and windows. The stark contrasts between who she is and who she wants to be (or was) is overwhelming. She is generous in helping others, but she is alone. People come to offer health services or cold call only. If she upsets her daughter, she may stop coming. Her 'why' stems from having nothing, now she has lots, but I still was left wondering what gap these things really filled. She says she will get to a clean-up, a dust and a sort out…eventually.

Appendix C: Christchurch City Council Hoarding Assessment Tool

CHRISTCHURCH CITY COUNCIL
HOARDING ASSESSMENT TOOL

SOURCE INFORMATION

Date Referral Received: _____ Time: _____

Referrer's name: _____ Agency: _____

Referrer's Phone: _____ Email: _____

Relationship to Client: _____

Client's Name: _____ Age: _____ DOB: _____

Address: _____

Phone/other contact: _____

Will client allow access? ☐ Yes ☐ No _____

HOUSEHOLD INFORMATION

Type of dwelling: _____ Own/Rent: $_____ per week

Household members:

_____

_____

Family or other support - include names and phone number:

_____

_____

Pets/Animals: _____

Other agencies involved: _____

Has the person been helped in the past? By whom? When?

_____

_____

_____

ASSESSMENT OF CLIENT

Physical or mental health problems of client:

- ☐ Does not seem to understand seriousness of problem
- ☐ Does not seem to accept likely health consequences of problem
- ☐ Defensive or angry
- ☐ Anxious or apprehensive
- ☐ Unaware, not alert, or confused

Client's attitude towards hoarding/living conditions:

_____

_____

Are basic needs being met? (*ie. food/shelter*) ☐ **Yes** ☐ **No** _____

Is client's safety compromised? ☐ **Yes** ☐ **No** _____

Is client's wellbeing compromised? ☐ **Yes** ☐ **No** _____

Other Issues/Problems/Needs *(Medication, mobility etc)*

_____

_____

_____

_____

Other agencies etc involved in initial assessment:

_____

Sketch of dwelling: North

ACTIVITIES AFFECTED BY CLUTTER OR HOARDING

	Can do it easily	Can do it with a little difficulty	Can to it with moderate difficulty	Can do it with great difficulty	Unable to do it
1. Food preparation	1	2	3	4	5
2. Use refrigerator	1	2	3	4	5
3. Use stove	1	2	3	4	5
4. Use kitchen sink	1	2	3	4	5
5. Eat at table	1	2	3	4	5
6. Move about house	1	2	3	4	5
7. Use toilet	1	2	3	4	5
8. Use bath/shower	1	2	3	4	5

LIVING CONDITIONS – PROBLEMS IN THE HOME

	None	Few	Moderate	Substantial	Severe
9. Structural damage	1	2	3	4	5
10. Water not working	1	2	3	4	5
11. Heat not working	1	2	3	4	5
12. Power not working	1	2	3	4	5
13. Presence of waste/rotten food	1	2	3	4	5
14. Presence of human faeces	Absent	Present	Degree:		
15. Animal welfare issues	1	2	3	4	5
16. Animal urine/faeces	1	2	3	4	5
17. Vermin infestation	1	2	3	4	5
18. Insect/fly infestation	1	2	3	4	5

SAFETY ISSUES

	None	Few	Moderate	Substantial	Severe
19. Fire hazards *(e.g. paper on stove/flammable objects near the heater etc)*	1	2	3	4	5
20. Unsanitary areas *(bathrooms, WC/strong odours)*	1	2	3	4	5
21. Presence of mould/mildew	1	2	3	4	5
22. Visitors/services moving around the home	1	2	3	4	5
23. Clutter outside the house *(porch, yard, common areas etc)*	1	2	3	4	5

Additional information or comments, eg Asthma/*Alcohol)*

_____

_____

Clutter image rating scale - link:

Living room	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
Kitchen	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9
Bedroom	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9

Photos taken? **Y/N** By _____ _____

What does this home score? _____

RECOMMENDATION FOLLOW-UP ACTION/S:

_____

_____

_____

_____

_____

_____

Officer: _____

Position: _____

Inspection Date & Time: _____

Appendix D: Clutter Image Rating Scale

Clutter Image Rating (CIR)

Date:_____

Using the three series of pictures (CIR: Living Room, CIR: Kitchen, and CIR: Bedroom), please select the picture that best represents the amount of clutter for each of the rooms of your home. Put the number on the line below.

Please pick the picture that is closest to being accurate, even if it is not exactly right.
If your home does not have one of the rooms listed, just put NA for "not applicable" on that line.
Also, please rate other rooms in your house that are affected by clutter on the lines below.

Room	Number of closest corresponding picture (1–9)
Living Room	1
Kitchen	1
Bedroom #1	1
Bedroom #2	1

Use the *CIR: Living Room* pictures to make these ratings.
Scores in the 3 to 4 range in any room are cause for concern.

Dining room	1
Hallway	1
Garage	1
Basement	1
Attic	1
Car	1
Other	1

Please specify: _____

Clutter Image Rating: Living Room

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

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Clutter Image Rating

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

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Clutter Image Rating: Bedroom

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 E: Savings Inventory - Revised

Saving Inventory – Revised

Date: _____

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

	0 None	1 A little	2 A moderate amount	3 Most/Much	4 Almost All/ Complete
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).	0	1	2	3	4
2. How much control do you have over your urges to acquire possessions?	0	1	2	3	4
3. How much of your home does clutter prevent you from using?	0	1	2	3	4
4. How much control do you have over your urges to save possessions?	0	1	2	3	4
5. How much of your home is difficult to walk through because of clutter?	0	1	2	3	4

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

	0 Not at all	1 Mild	2 Moderate	3 Considerable/ Severe	4 Extreme
6. To what extent do you have difficulty throwing things away?	0	1	2	3	4
7. How distressing do you find the task of throwing things away?	0	1	2	3	4
8. To what extent do you have so many things that your room(s) are cluttered?	0	1	2	3	4
9. How distressed or uncomfortable would you feel if you could not acquire something you wanted?	0	1	2	3	4
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.	0	1	2	3	4
11. How strong is your urge to buy or acquire free things for which you have no immediate use?	0	1	2	3	4

Saving Inventory – Revised

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK:

	0 Not at all	1 Mild	2 Moderate	3 Considerable/ Severe	4 Extreme
12. To what extent does clutter in your home cause you distress?	0	1	2	3	4
13. How strong is your urge to save something you know you may never use?	0	1	2	3	4
14. How upset or distressed do you feel about your acquiring habits?	0	1	2	3	4
15. To what extent do you feel unable to control the clutter in your home?	0	1	2	3	4
16. To what extent has your saving or compulsive buying resulted in financial difficulties for you?	0	1	2	3	4

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

	0 Never	1 Rarely	2 Sometimes/ Occasionally	3 Frequently/ Often	4 Very Often
17. How often do you avoid trying to discard possessions because it is too stressful or time consuming?	0	1	2	3	4
18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things?	0	1	2	3	4
19. How often do you decide to keep things you do not need and have little space for?	0	1	2	3	4
20. How frequently does clutter in your home prevent you from inviting people to visit?	0	1	2	3	4
21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need?	0	1	2	3	4
22. 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.	0	1	2	3	4
23. How often are you unable to discard a possession you would like to get rid of?	0	1	2	3	4

Appendix F1: Agencies that may be involved in supporting older Cantabraians who hoard

COMMUNITY	**CDHB Community services for older people**
	Needs assessment: Needs assessment assists older people with long-term disabilities/health problems (i.e. longer than 6 months) to remain living at home, safely and independently, for as long as possible. Needs Assessors complete an assessment of needs with the older person, and Service Coordinators use this assessment to develop care packages of support services to assist at home Phone Adult Community Referral Centre (ACRC): 03 337 7997
	Older Persons Mental Health, Community Mental Health Nurses: OPMH provides clinical home-based support for older people with mental health issues, including dementia. Community Nurses who visit homes and assist older people with mental health difficulties
	Community social work: Helps patients and those that support them solve and cope with problems in everyday life. Some clients have hoarding issues and work with them to overcome problems associated with this.
SPECIALIST	**CDHB outpatient support**
	Clinical Psychology: Clinical psychologists with the CDHB are involved in supporting people who hoard, although the individuals are usually referred for other issues.
	Anxiety Disorders Service : The Anxiety Disorders Service is an outpatient service that provides treatment for people with anxiety disorders. They offer treatment options that directly address hoarding with patients, using hoarding-specific CBT.
	Geriatricians: Geriatricians provide assessment and advice as part of the multidisciplinary team older persons mental health team, including for peple living with hoarding.
HOME-BASED	**Home-based support**
	CDHB contract holders: The CDHB holds contracts with agencies who provide home based support with daily living activities and nursing services, including occasionally for people who hoard. Access Community Health: https://www.access.org.nz/Our-Services Healthcare NZ: https://www.healthcarenz.co.nz Nurse Maude: https://nursemaude.org.nz
	Comcare: Comcare is a Charitable Trust whose purpose is to assist people who experience mental illness and addictions through the provsion of community services, including assistance with the activities that form part of an individual's daily life and a Continuing Support Service for people with long term support needs. They support numerous clients who hoard. https://www.comcare.org.nz/what-we-do/community-support-services/community-support-work/

PUBLIC	**Public Health**
	Christchurch City Council: Environmental health officers investigate, monitor, assess and advise on public health and environmental hazards. The City Council is responsible for investigating insanitary living conditions that may be causing a "nuisance". Phone: 03 941 8999 (or 0800 800 169 for Banks Peninsula)
	Community and Public Health: Community and Public Health has a responsibility to address health risks caused by insanitary living conditions. Staff can work with Environmental Health Officers from the council to make an initial visit to determine if there is a health risk, and who needs to be involved in any resulting intervention. https://www.cph.co.nz/your-health/insanitary-housing/
EMERGENCY	**Emergency Services**
	Fire and Emergency NZ: The fire service are able to offer home visits to talk through risk reduction strategies and install a fire alarm. They may also be involved in multi-agency recovery planning following a response to a domestic hoarding fire. Having a database of properties with hoarding risks helps the fire service to plan appropriate responses to fires (for example number of appliances, safe access routes etc). Email: chchfirerisk@fireandemergency.nz
	Ambulance: St Johns can face difficulties safely accessing a person requiring help in challenging living environments, and in extracting the indiviudal while maintaining dignity. Having a database of homes that have risks associated with hoarding helps the ambulance to plan appropriately (for example safe access routes, the parts of the house that the person uses and is likely to be in etc). https://www.stjohn.org.nz/contact-us/other/
OTHER	**Other**
	Housing. Housing Kāinga Ora (formerly Housing New Zealand): Kāinga Ora are responsible for the efficient and effective management of state houses and the tenancies of those living in them, and work with other agencies to ensure tenants have access to support services including in the context of hoarding. Phone: Kāinga Ora 0800 801 601 Where accumulation is creating a threat of eviction in a rental property, the private property owner, Community Law, and the Tenancy Tribunal may be involved.
	NGOs: Age Concern: Age Concern provides home support, visiting services and community health support services. They see numerous clients who hoard. While they have previously been a go-to agency for support for people who hoard, their capacity has reduced to personnel changes. https://ageconcerncan.org.nz/ Other NGOs such as the Salvation Army may be involved but on an individual case basis.
	Risks to others: If a situation involves animal hoarding the SPCA may relevant, and if there is a risk to young people Oranga Tamariki may become involved.
	Primary Care: The individual's GP can have an important role as a trusted figure and access point for referral to services.

Appendix F2: Local agencies that may be able to assist improving living situations

COSTS	**Possible sources of financial assistance**
	Mayor's welfare fund: A welfare fund for Christchurch city residents who are in extreme financial distress, as a last resort measure for when people have exhausted other appropriate sources. Applicants can only be assisted once in a twelve month period. https://ccc.govt.nz/culture-and-community/community-funding/mayors-welfare-fund.
	Hyman Mark's trust: Provides assistance to individuals or families experiencing financial hardship who have limited access to the basic necessities, in particular in relation to health and warmth. Funding is also available for community support groups/projects. Applications must be made by an accredited community worker. http://www.hymanmarkstrust.co.nz/pages/apply.html.
	Ngāi Tahu Pūtea Manaaki: Provides assistance for members of the Ngāi Tahu tribe towards essential living costs in situations of serious hardship. https://ngaitahu.iwi.nz/whanau/opportunities/putea-manaaki/
CLEANING	**Cleaning companies who work with challenging domestic situations**
	A Woman's touch: Private cleaning business that can provide specialty services to people who hoard. Can work with the individual or independently. https://awomanstouch.co.nz/services/hoarding-clean-up/
	Sunshine cleaners: 'Extreme' private cleaning service who will go beyond the scope of regular cleaning services. Possibly appropriate for severely squalid conditions. https://www.sunshinecleaners.co.nz/forensic-cleaning-services-christchurch
	Jani-King: Commercial cleaning company that offers hoarding remediation services to property owners. https://jke.co.nz/services/trauma-scene-and-hoarding-remediation/
HELP	**Community groups who may be able to assist with labour**
	Comcare home rescue: Community service which provides urgent intervention where there is a risk of housing loss due to a deterioration of mental health, or ongoing barriers to maintaining the tenancy. Provide environmental cleans and rubbish removal, liaison with landlords and assistance with neighbour disputes. https://www.comcare.org.nz/what-we-do/housing-support-services/home-rescue/
	Papanui baptist freedom trust: Charitable trust which provides practical, social and emotional support for individuals. https://www.papbap.org.nz/freedom-trust/

Appendix G: Selected international educational resources

Children of hoarders: Awareness, understanding and support for family of people who hoard.
http://childrenofhoarders.com/wordpress/

OCD foundation hoarding information: International OCD foundation page on hoarding disorder and related information.
https://hoarding.iocdf.org/about-hoarding/is-it-hoarding-clutter-collecting-or-squalor/

Buried in treasures: Informative and self-help book written by David F. Tolin, Randy O. Frost and Gail Steketee based on the CBT model of hoarding developed by Frost and Steketee.
Can also be used to run group CBT. Recommended for people who hoard, family or support workers.
https://books.google.co.nz/books/about/Buried_in_Treasures.html?id=cUwGAQAAQBAJ&printsec=frontcover&source=kp_read_button&redir_esc=y#v=onepage&q&f=false

The British Psychological Society good practice guidelines: Extensive document with information on the nature of hoarding, guidelines for successful support and clinical recommendations for psychologists.
Accessible for anyone working with people who hoard.
https://hoardingdisordersuk.org/wp/wp-content/uploads/2019/03/A-Psychological-Perspective-on-Hoarding-%E2%80%93-DCP-Good-Practice-Guidelines.pdf

Hoarding Best practice Committee guide: Practical guide with recommendations for support services on successful interventions.
Developed in the US but much of the information is relative in an NZ context.
https://umassmed.typepad.com/files/best-practice-hoarding-guide-final-.pdf

Victoria hoarding and squalor practical resource for service providers: A lengthy resource providing direction, context and practical tools to help strengthen the capacity of funded or regulated services to work together when responding to hoarding or squalor.
https://www2.health.vic.gov.au/Api/downloadmedia/%7B852C57C9-89CC-4492-9DF3-D985B8291FD5%7D

Appendix H: New Zealand literature and resources related to hoarding

Taranaki hoarding and squalor guidelines: Guidelines for personnel who are asked to intervene in cases of hoarding leading to severe domestic squalor. Based on PAH committee guidelines from Sydney South West Area Health Service.
https://www.tdhb.org.nz/misc/documents/tdhb_hoarding_squalor_guidelines.pdf

Southern District Health Board Good Living Conditions Southern: Guidelines for front-line workers of various organisations to constructively intervene and improve the situation of people who are living in severe domestic squalor. Based on Taranaki guidelines.
https://www.southerndhb.govt.nz/files/23420_20181017113906-1539729546.pdf

Coping with hoarding: Three health professionals talk about the challenges of dealing with elderly people whose hoarding has been revealed following the Christchurch Earthquakes.
https://www.thefreelibrary.com/Coping+with+hoarding%3A+three+health+professionals+talk+about+the...-a0391460670

Hoarding, A disorder that can be distressing for everyone: Auckland geriatrician discusses experience dealing with hoarding.
http://carers.net.nz/information/hoarding-a-disorder-that-can-be-distressing-for-everyone/

Personality, mental health and demographic correlates of hoarding behaviours in a midlife sample: Research on the prevalence of hoarding in Canterbury and the associated personality traits, demographic features, and physical and mental health variables.
https://www.ncbi.nlm.nih.gov/pubmed/28028484

Identifying hoarding disorder in elderly using the interRAI: Research on the prevalence of hoarding disorder in older people using the InterRAI elderly assessment carried out by the Southern District Health Board.
https://www.ncbi.nlm.nih.gov/pubmed/30391686

Health info NZ hoarding: Canterbury health resource with links to other informative websites.
https://www.healthinfo.org.nz/index.htm?hoarding_1.htm

APPENDIX 2

Good Living Conditions Southern

TABLE OF CONTENTS

Contents

We wish to acknowledge the work of the Taranaki District Health Board in providing the framework which forms the basis of the Southland guidelines.

Taranaki guide lines were based on the Guidelines previously developed by the Partnerships against Homelessness (PAH) Committee under the auspices of the Sydney South West Area Health Service. Representatives with experience in assisting people living in squalor, stakeholder groups and Professor John Snowdon, a psychiatrist with a special interest in this area, were consulted and international evidence collated in the development of the original PAH document.

These Guidelines have been developed principally for personnel who are asked to intervene in cases of hoarding leading to severe domestic squalor in the Southern District.

SECTION 1: Introduction

1.1 Background

Following requests from the community for information and support to assist those living in untidy and unhygienic conditions.

Challenges identified thus far.

- A lack of common understanding what constitutes severe domestic squalor and self-neglect and who does what once it has been identified
- Friends and family, workplaces, neighbours and staff feeling powerless and frustrated, unable to support long term constructive change
- A lack of assessment tools leading to judgement call referrals rather than appropriate assessment of underlying, unmet, undiagnosed mental health or addictions need
- Confusion and uncertainty with limitations and ethical dilemmas for staff
- Uncertainty around rights, privacy and roles including knowledge about the law – monitoring and compliance

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. Managing our own stress and service response will be as important as achieving positive outcomes for individuals and families involved.

The purpose of this working group is to develop terms of reference, establish an agreed local area interagency protocol, including pathways for referral, guidelines and information to ensure that the people living in severe domestic squalor are assisted in a consistent, sustainable and efficient way.

It has also been identified that there could be other work streams such as workforce development, community education and information resource development that may be recommended from this working group.

It is anticipated that there is scope within existing contracts and workloads for any action to be delegated to existing, appropriate networks if they do emerge as priorities beyond the scope of this working group.

1.2 Purpose of the Guidelines

These Guidelines are designed to assist front line workers of various government and non-government organisations (NGOs) primary care and family members to constructively intervene and improve the situation of people who are living in severe domestic squalor. Improving the efficiency, speed of action and coordination of work between relevant agencies, has the potential to improve the health and quality of life for individuals who have been living in severe domestic squalor.

These Guidelines provide front line workers with:

- A step-by-step guide
- Simplified procedures to assist people living in severe domestic squalor
- Clear roles and responsibilities of agencies and service providers, to enable improved coordination and integration of services
- Practical information regarding referrals and intervention options

These Guidelines include flow charts to summarise the processes involved. Included in Appendix 7 are a series of case studies which explain the issues and current events arising in typical cases of severe domestic squalor.

Confidentiality

It is recognised that Panel members may want to discuss issues and/or decisions with peers, nominating organisations and representative groups in order to gain feedback and measure consensus. It is not the purpose of this confidentiality clause to prevent this from occurring, but to protect individual members from being quoted out of context and undermining the integrity of the working groups' initiatives.

Although members are naturally free to express their own views within the context of working group meetings, or the general business of the working group, members should publicly support a course of action decided by the working group. If a member is unable to support a majority course of action, it is that member's responsibility not to publicly comment on decisions.

Also, given the sensitive and complex nature of shared information, case studies and common knowledge of some individual situations it would be anticipated that agency policy and procedure be followed at all times

SECTION 2: Explaining Severe Domestic Squalor

http://biooneaz.com/what-causes-hoarding-risk-factors-triggers-for-hoarding/

https://www.elementsbehavioralhealth.com/dual-diagnosis/hoarding-a-compulsive-mental-disorder/

2.1 Definition of Severe Domestic Squalor

Dictionary definitions of squalor refer to conditions that are filthy, unclean or foul through neglect. Commonly, this results from a person's failure to remove household waste and other rubbish including papers, wrapping, food products, cooking waste, containers and broken or discarded household items.

Cleanliness varies between homes and between individuals and tends to be influenced by multiple factors including upbringing, peer and family expectations, living arrangements, social and financial circumstances, cultural background and surroundings. Some people live in conditions so filthy and unhygienic that almost all observers, in whatever culture, would consider them unacceptable.

The term 'severe domestic squalor' was chosen in order to emphasize, firstly that the focus is not on cases where people live in somewhat unclean surroundings, even if they have severe physical or mental disorders. The concern is for people who live in disgusting conditions. This word is used advisedly in order to make clear that in all relevant cases the insanitary conditions are extreme. Secondly, the aim is not to provide guidance in cases of self-neglect where squalor is not an issue, nor in cases of hoarding without squalor, i.e. those cases where there has been an accumulation of possessions but in an ordered, clean and manageable way. What is included are cases of hoarding where the accumulation has led to the living environment being unclean, unsanitary or dangerous (e.g., because of fire risk).

There is a range of types of squalor, including:

- *Neglect* involving failure to remove household waste and other rubbish including papers, wrapping, food, cooking waste, containers and discarded household items.
- *Multifaceted self-neglect* where the person fails to maintain aspects of their care, health and lifestyle such as personal care, eating adequately or failing to take medications as prescribed.
- *Deliberate hoarding* and the excessive accumulation of items such as clothing, newspapers, electrical appliances, etc. This may involve hoarding of animals.

For the purpose of these Guidelines, the term *severe domestic squalor* includes*:*

- Extreme household unhygienic conditions
- Hoarding, where the accumulation of material has led to the living environment being unclean, insanitary or dangerous e.g. conditions pose a fire risk to persons or emergency services.

The decision regarding whether or not a person lives in severe domestic squalor may be influenced by the attitude, culture, exposure to unclean environments and personal living conditions of the person making the assessment.

International Data

In Sydney, NSW, between 2000 and 2005, 120 cases of people living in severe domestic squalor were referred to old age psychiatry suggesting an annual incidence of 10 people aged over 65 years per 10,000 (Halliday & Snowdon, unpublished data 2005). However, since numerous cases of severe squalor are never referred to medical services, the actual incidence is likely to be considerably higher.

These are characteristics of those living in squalor

In 2000, a study in London of 81 clients visited by a local authority special cleaning service found that:

- 51 % were younger than 65 years
- 72% were men
- 84% lived alone
- 70% had one or more mental disorders
- 32% were diagnosed with substance abuse and around 50% of those who abused substances also suffered from an organic brain disorder (mostly dementia), schizophrenia or a related disorder
- 10% met criteria for a developmental disorder
- 85% had at least one chronic physical health problem
- 26% of the people had a physical health problem, such as immobility or sensory impairment, contributing to the unclean state of their living environment
- 28% regarded their home as 'clean' or 'very clean' when asked about their living conditions (Halliday et al., 2000).

2.2 Features of Persons Living in Severe Domestic Squalor

The evidence suggests that half to two-thirds of all persons living in severe domestic squalor suffer from dementia or alcohol-related brain damage, or mental disorders such as schizophrenia and depression. Most studies refer to individuals who are isolated, suspicious and unfriendly, and have features suggestive of pre-existing personality disorders.

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

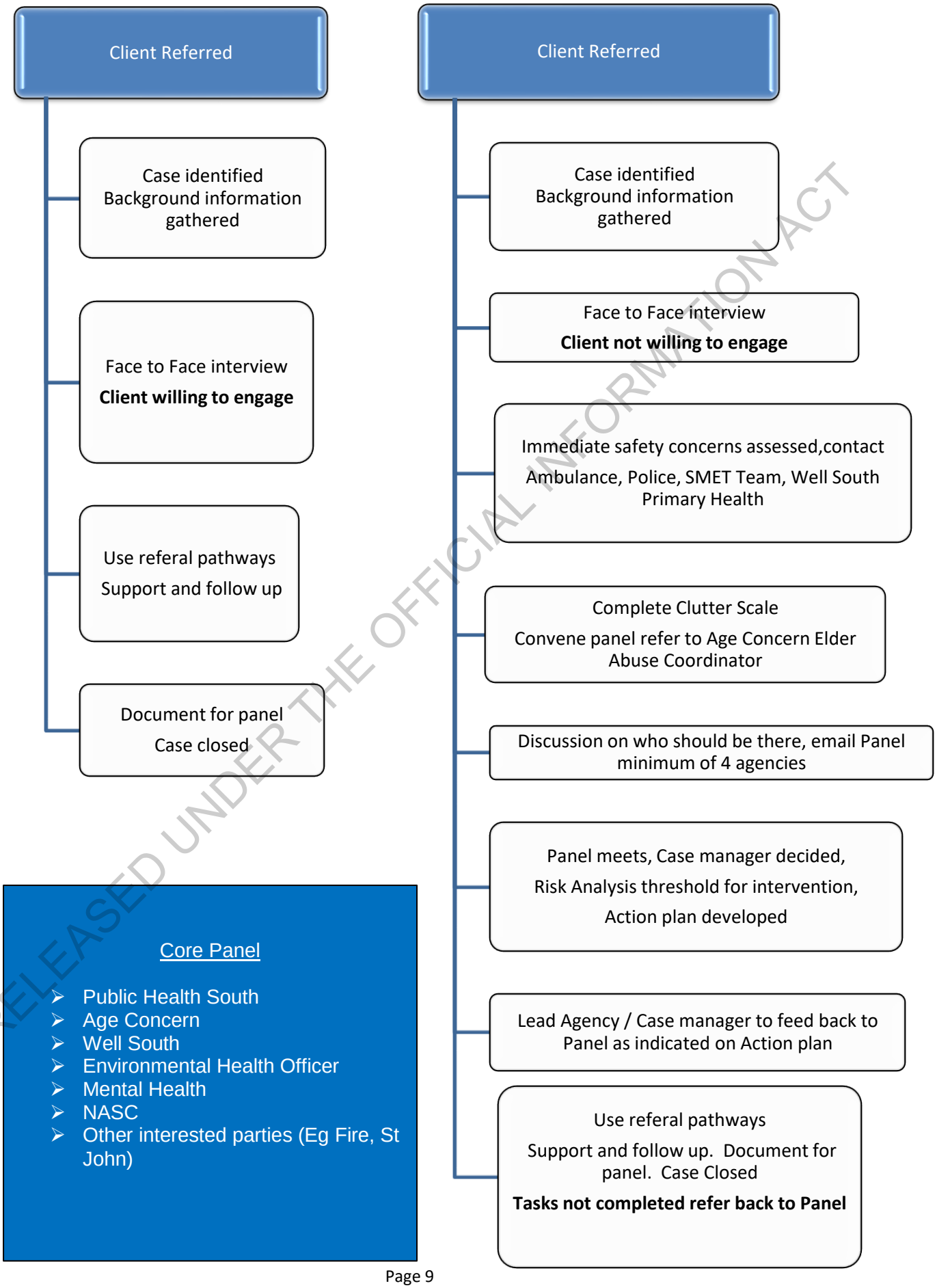
An individual who lives in domestic squalor may be completely independent. If people are living in squalor and not causing any harm to themselves or others, then no intervention is required.

A person who lives in squalor is frequently opposed to assessment and assistance and may be unaware that there is a problem. The person may be suspicious or evasive, perceiving any intervention to be a potential threat to their independence. Reasons for this vary. In some cases, it results from apathy associated with an underlying mental disorder. In others, longstanding habits and the individual's personality traits, including rigidity, unfriendliness, suspiciousness, anxiety or avoidance could be the cause. There may be a history of unsatisfactory dealings with service providers. Links with social supports and family have often been lost. Cultural and language barriers may also contribute to opposition to assessment and assistance.

If the person does agree to engage, they are unlikely to be prepared to leave the dwelling.

In the most extreme cases, where there is a substantial risk to the individual or others, it may be necessary to refer to agencies and service providers that can intervene to provide assistance. See Appendix 7.

SECETION 3: Referral Pathway



3.1. Sources of Referral

People living in states of severe domestic squalor may be referred for assistance by anyone in the community including relatives, neighbours, concerned local residents, service providers, the fire service, police and shopkeepers. People often come to the attention of various service providers because of the deleterious effect that their living conditions have on themselves and the surrounding community.

3.2 Information Gathering Prior to Initial Contact

Prior to visiting someone who is reported to be living in squalor, attempts should be made to find out as much information as possible about the person. This will assist in determining who the best person is to undertake an initial assessment, and how this assessment should be conducted.

Try to access the following background information from the referrer and any other sources:

- Best time of day to visit
- Name
- Address
- Phone
- Family
- Length of time the person has been living in unclean conditions
- History of other efforts to assist
- Type of accommodation e.g., homeowner, private rental, Housing New Zealand
- If the person has a next of kin, carer, supportive neighbor's or involvement of any home services
- Any known medical history and/or whether or not the person has a General Practitioner
- Any potential occupational health and safety issues for which special clothing or precautions may be required
- History of the person's character, habits, and past medical and mental health history
- Cultural background
- If there are language or communication barriers
- Preferred language spoken and whether an interpreter may be required
- History of substance abuse, aggression or criminal behavior
- Whether the person lives alone or with dependents and any details of dependents
- Whether premises are covered by an existing Council Cleansing Order
- Risk to self-e.g. dogs on premises

If a person is known to have a health problem or to receive financial benefits or support from service providers, help may be sought from the relevant health service or from agency staff. The person's type of accommodation may determine whether the person is referred for assistance to the likes of Housing New Zealand or to the District Council. Landlords or property managers may need to be approached if utilities (such as water) have been disconnected or the building is in a state of disrepair.

3.3 Gathering Resources for Use at the Visit

Resources which could be used at the initial visit include the following:

- Health and Safety Checklist (Appendix 1) for the person who is visiting
- Environmental Cleanliness and Clutter Scale (ECCS) (Appendix 4) for the assessor
- Squalor Action Plan (Appendix 2)

SECTION 4: The Initial Visit

4.1 Purpose

The purpose of conducting a home visit to the person who has been referred is to:

1. Assess whether the person lives in squalor and to rate the extent of the squalor
2. Assess whether the person hoards excessively and/or self-neglects, i.e. does not adequately look after his/her bodily requirements and hygiene
3. Assess the nature and severity of any associated health and lifestyle issues
4. Make a preliminary identification of strategies required to address the issues identified

Obtaining entry to the home, preferably with the consent and involvement of the occupant, is a priority but, if a home assessment is not immediately possible, information available to the initial agency involved may permit identification of the issues to be addressed.

The issue of consent in relation to decision-making capacity is complex and is dealt with in more detail in Appendix. Field staff should also refer to their own agency's consent procedures.

4.2 Approaches to Engaging the Person

People living in severe domestic squalor vary markedly in their nature, personality style, acceptance, cooperation, insight and perception of their circumstances. As a consequence, there is a need for flexibility in the approach taken. Some people may respond to a series of initial brief, casual meetings. Others may be more likely to respond to a visit by someone perceived to be in authority, such as a fire officer or the police. However, cultural sensitivity and appropriateness is important here, as some people may feel uncomfortable with authority figures, which may intensify feelings of fear and suspicion.

Generally, the person is more likely to be successfully engaged if an interest is shown in them and their particular reason for needing help. If the person agrees to accept help, the likelihood of achieving significant change and improving conditions for the individual and others is considerably greater.

Options which could be considered include:

- If the person is too fearful to open the door, try leaving a note in the mailbox or under the door, asking them to make contact. Keeping privacy concerns in mind, discrete enquiries with neighbors might be of assistance.
- Repeat visits**.** Sometimes calling after hours, varying the hours or visiting on several occasions may be helpful.
- Arranging to visit with a worker from a particular cultural background or with an accredited interpreter may be appropriate. Check with the client as to their preference and consent prior to making any arrangements.
- If the person requests an interpreter or has inadequate language skills, a professional interpreter should be used. Refer to the procedures of your organisation regarding the engagement and use of interpreters. Cultural and linguistic factors can impact on the success of engagement with the person.
- Ask the person how he/she considers they could benefit from help and identify the perceived needs.
- Be persistent yet sensitive to the person's needs and careful not to overwhelm them
- Even if the person's initial reaction is negative and they reject any intervention, it is still important to continue to try to establish a relationship.

- Consider meeting at the local coffee shop.
- Avoid imposing your own values. Many people living in squalor often do not even perceive that their home is dirty.
- Take time**.** An immediate focus on a need for cleaning can cause distress and sabotage chances of achieving a successful alliance.
- Reframe the need for cleaning in terms of the person's perceived needs and preferences. The person might agree to tidy up as a staged process. Where possible, establish an inventory of possessions, identify valuables and arrange for them to be placed securely.
- Ensure that the person has the capacity to make decisions about giving away property and that service staff do not accept gifts or directly benefit from the clean-up.

It is important to note that in situations of extreme squalor, the assessment of 'risk' is likely to vary between the relevant authorities.

When sharing information with other agencies, be sure that disclosure of information is directly related to the purpose for which it was given and collected.

4.3 Occupational Health and Safety Requirements

The Occupational Health and Safety (OH&S) of persons entering premises where squalor is evident and the safety of the person/s living in these conditions are significant issues. Workers providing services to people living in squalor must comply with the OH&S policy and procedures of their organisation.

The checklist at Appendix 1 provides a concise summary of the OH&S issues to be assessed and considered when gathering information and at the initial visit.

In some cases of severe domestic squalor, OH&S concerns may prevent service providers from entering the premises and carrying out a comprehensive assessment. Field staff should contact their employer's OH&S adviser for advice.

4.4 Assessing the Level of Squalor

Having gained access to the premises, it is advisable to assess whether or not the person is living in squalor. The Environmental Cleanliness and Clutter Scale (ECCS) in Appendix 4 provides a method for objectively assessing and recording observations of various aspects of personal and environmental cleanliness.

Validation and reliability data have been collected and are available from the authors of the original PAH document (Halliday and Snowdon). They have provided definitions that allow raters to consider to what degree various aspects of the premises differ from those that would be considered by people from all cultural and social groups as clean and uncluttered. This does not mean to imply 'normality'. It is accepted that people vary in their subjective views concerning cleanliness, and these differ according to circumstance and upbringing.

The definitions aim to achieve consistency in ratings, though undoubtedly subjectivity will affect decisions. For example, some aspects relating to a kitchen might suggest a rating of 1 (somewhat dirty; garbage mainly in the refuse bin) while others (e.g. mouldy food on the table) might suggest a rating of 3 (very dirty and unhygienic). The rater has to decide what is more important, and whether to give a compromise rating. Some features will always require a rating of 3, even if observations of other aspects do not match the definitions provided in the 'very dirty' column.

The ECCS has 10 items, rated between 0 and 3. Where possible, all rooms should be inspected before making a rating. The cleaner and less cluttered the home, the more likely the score is to be 0. The maximum score for these domestic items is 30, and a rating of at least 20 usually means that the person lives in severe domestic squalor. Ratings of less than 10 imply that although the person may need help with cleaning or sorting out possessions, they do not live in severe domestic squalor. It is also relevant to consider whether they live in very cluttered surroundings without being markedly unclean, and this will be indicated by ratings on items A and C of the scale. The issue of 'capacity' is complex and is discussed further in the guidelines.

It must be emphasised that the ratings on the ECCS are mainly for documentation purposes, to record what has been observed in order to relay this to others, and then to be able to rate changes in living conditions over time. They give an indication of what one observer found on a particular day. Co-ratings have revealed that different rates tend to rate similarly. However, scores do not tell raters how to respond to a particular situation. How to intervene is determined by a whole lot of other factors, not just the observed degree of domestic squalor. Supplementary questions allow documentation of observations concerning personal cleanliness, availability of essential services and the structural safety and upkeep of the premises.

4.5 Assessing the Impact of Squalor on the Person, Family and/or Local Community

The impact of squalor on all relevant persons should be assessed. The checklists for this purpose are set out in sections 4.5.1 and 4.5.2 below.

4.5.1 Impact of Squalor on the Person's Health and Lifestyle

The findings of the ECCS should be summarised to identify the issues which are directly relevant to the person and need to be addressed. Considering the high incidence of both mental and physical disorders associated with cases of severe domestic squalor, it may be necessary to organise an immediate review of the person's health and lifestyle needs by experienced staff. The important issues to be considered at the initial visit relate to:

- The need for medical and/or psychiatric intervention
- The need for assistance with activities of daily living
- Whether the person is at risk of homelessness
- The person's decision-making capacity
- Whether the statutory powers of other agencies i.e. council might over- ride the wishes of the person

As a first step towards determining whether further urgent intervention by experienced staff from other agencies is required, the following checklist provides a list of the factors which might be reviewed and services/agencies where additional advice may be sought.

Factor/s	Sources for Further Information/Advice
Self-neglect with poor nutrition, dehydration, probable untreated medical problems	NASC, Mental Health Services, Age Concern
Confusion, disorientation, memory impairment, wandering and getting lost, delirium, acute psychiatric symptoms such as hallucinations, threatening self-harm, suicidal behaviours and symptoms suggestive of severe depression.	Southern District Health Board ED, Mental Health Well South, GP , Practice Nurse Mental Health Services
Aggressive behaviour or threatened harm to others.	Southern District Health Board Mental Health including Drug and Alcohol Services, Police
Exposure to possible financial exploitation or abuse	Office of the Ombudsman, Age Concern Elder Abuse Response Service, Community Law Otago or Southland
Threatened eviction and at risk of becoming homeless	Housing NZ, District Council, landlord/ property manager, NGOs Community Law (e.g.; Salvation Army, Tenancy Tribunal)
Lives alone and/or unable to access help or supervision, marked decline in activities of daily living and functional status	Medical services, intake and referral section of Access Ability (NASC), Older People Health Doctor
Limited mobility and risk of falls, incontinence	Southern District Health Board Access Ability, Older People's Health
Utilities not present or not functional, i.e. water, power, sewerage, heating, telephones	District Councils – environmental health officers/ building control officers, NGOs, Housing NZ landlord/ property manager, WINZ ,

Other issues which might be considered include:

- The frequency of contact with family, friends or social supports (if any) as a measure of the person's safety and ability to access help or supervision should it be required.
- Feedback provided by the family and/or the general practitioner, providing the person has given informed consent for this.
- Who owns the premises and the person's attitude towards a clear up? This will influence how the clear up process is carried out and who will undertake this

4.5.2 Impact of Squalor on the Family and/or Local Community

In assessing the impact of squalor on partners and/or family members and the local community, field staff may encounter issues identified below and may need to seek further information/advice from relevant agencies listed in the following table.

Issues Information	Agencies/Services for Further
Excessive hoarding causing health and safety issues for neighbor's	District and City Councils throughout Otago and Southland - Environmental Health Team Public Health, Medical Officer of Health Southern District Health Board Police Fire and Emergency New Zealand
Complaints from adjoining neighbor's regarding the mess, invasion of space, excessive smells (from rubbish and/or sewerage), fire hazards or vermin infestation	District and City Councils - Environmental Health Team Public Health, Medical Officer of Health Southern District Health Board Council Contracted Cleaning Services, Fire and Emergency New Zealand .
Presence of partners or dependents, e.g. children, elderly relatives.	Ministry for Vulnerable Children, Oranga Tamariki Southern District Health Board Age Concern - Elder Abuse Responce Service
Pets kept in poor health	SPCA

4.6 Immediate Interventions

The apparent urgency of the situation and the wishes of the individual will determine the next step. The person may be clearly very unwell at the time of assessment and require urgent medical attention, or the person may present a relatively significant public health risk to the local community. *The Health Act 1956 enables councils to respond quickly and effectively to situations that occur on land used for residential purposes that pose a threat to public or individual health. (Ref: Section 29 The Health Act 1956 – 'Nuisances')*

4.6.1 Medical and/or Mental Health Review

If it is believed urgent medical attention is required or a domiciliary medical review cannot be arranged within a reasonable timeframe, arrange for the person to be transferred to hospital. Other medical services which should be considered include referral to:

- The local general practitioner
- Community services, including Adult Mental Health Services and Older People's Health specialist medical services.
- Crisis mental health services e.g. Emergency Psychiatric Service (EPS) and Southland Mental Health Emergency Team (SMHET)

Under the powers of the *Mental Health (Compulsory Assessment and Treatment) Act 1992,* people may be taken to and detained in a hospital/place of assessment if they are mentally ill or mentally disordered, permitting a brief period of community or hospital based assessment and treatment, and decisions regarding ongoing management.

This *Act* is relevant when a person, living in squalor:

- Has symptoms of a mental disorder, such as disturbance of mood, thought disorder, cognitive disorder, sensory misperceptions or behavior suggesting any of these
- Is unable to adequately care for themselves or at risk of harm to themselves or others.

For further information about the provisions of the *Mental Health (Compulsory Assessment and Treatment) Act 1992*, see Section 7.

The Protection of Personal & Property Rights Act (PPPR Act) may be relevant when the person appears to be experiencing cognitive decline. See Appendix 8.

4.6.2 Assistance with Activities of Daily Living (ADL)

If the person is identified as requiring assistance with personal care, or disability related needs, consider referring the person to the relevant NASC service. Details regarding these agencies are located at Appendix 6.

4.6.3 Assessing the Risk on Dependents

Assessing the risk to dependent children and young people is a particularly complex task. Where there are dependent children or young people living in the same dwelling who may be at risk of abuse or neglect, a report of risk of harm may need to be made to Ministry for Vulnerable Children, Oranga Tamariki or the Police.

If the dependent has a disability or there are no other suitable accommodation options, refer the matter to Ministry for Vulnerable Children, Oranga Tamariki or an NGO such as Open Home Foundation as soon as possible.

4.6.4 Relocation of Pets

In cases of suspected or observed failure to provide adequate care of pets and animals, report the matter to the Society for the Protection and Care of Animals (SPCA), other animal welfare agencies or District Council.

4.6.5 Organise a Clear-Up if an Urgent Health or Safety Risk Presents and the Person Supports this Intervention …

This could include contact with the landlord/property manager(if the person is renting privately), housing provider and other relevant agencies to ensure housing is restored to a habitable standard by making necessary repairs or reconnecting amenities (eg running water, electricity etc.)

The options for a cleanup are described in Section 6.1. These options should be discussed (**No 6.1**) with the person, bearing in mind that in cases where the council deems the risk to be serious or the situation to be an emergency, the council may invoke powers under amendments to the Building Act 2004 that override the resident's choice.

In cases where the extent of squalor may not be extreme and there is little apparent risk to the person, neighbours or the fabric of the building, intervention does not need to be immediate but should aim to prevent future problems arising.

SECTION 5: Interagency Co-operation and the Joint Agency Panel

For the majority of cases, a number of agencies and services will need to be involved in providing ongoing support to persons living in domestic squalor. It is essential to ensure that all service providers and agencies have a consistent and collaborative approach with the person. This is where the panel comes into effect, a team of professional people enlisted from Agencies to assess the situation and offer advice and actions on how to proceed. They will identify the lead caseworker and help work out a plan moving forward

5.1 Coordination of services and development of Action Plans

When an instance of extreme squalor has been identified and it is beyond the capacity of the service to manage it, they will contact Age Concern with the initial assessment and collated information. Age Concern will then convene a meeting of the Joint Agency Panel. Please note the contact made to Age Concern is not a referral to Age Concern. Management of the case remains with the service unless a consensus decision is made to transfer it to another service at the Joint Agency Panel meeting.

The **Joint Agency Panel** is made up of representatives from the relevant services depending on the circumstances of the case. These can include:

- **District/City Council** (dependent upon district that client lives in)
- **NASC** (Needs Assessment Service Coordination) service (depending on age and/or needs of client – e.g. Over 65; Under 65 with a Disability; Mental Health client)
- **Clinical Representative** (e.g. Psych geriatrician, Mental Health professional)
- **Other representatives if appropriate at this stage** (e.g. cultural representative, support worker, partner/family members)
- **Age Concern Elder Abuse worker**
- **Well South**

The principal aims of the **Joint Agency Panel** are to:

- Consider the initial assessment of the person and any immediate interventions that may be required
- Identify any other services/agencies which need to be involved, including cultural representation for Maori clients and whanau
- Determine the course of action, agreed interventions, monitoring arrangements and the individuals responsible
- Identify a key worker or case manager responsible for ongoing liaison with the person living in squalor. In many cases it will be appropriate for the person who makes the initial contact with the client to assume this role.

ALL REFERRALS IN SOUTHLAND TO THE JOINT AGENCY PANEL SHOULD BE INITIALLY DIRECTED THROUGH Age Concern Southland 032186351

Age Concern will convene a meeting within 5 working day having to have a quorum of 4 people from the panel List. The Joint Agency Panel will convene a multi-agency meeting and identify a designated case manager. The designated case manager should complete a Squalor Action Plan (see Appendix 3), which identifies the actions to be undertaken, the person(s)/agencies responsible and review dates. The case manager should then distribute the Squalor Action Plan to all involved agencies. This will enable coordination of the necessary services.

ALL REFERRALS IN DUNEDIN TO THE JOINT AGENCY PANEL SHOULD BE INITIALLY DIRECTED AS FOLLOWS

- Kainga Ora Clients Kainga Ora 0800 801 601
- Cases who are Over 65 Years (not Housing New Zealand Clients) Age Concern Dunedin 03 4793053
- Cases who are under 65 Years (not Housing New Zealand Clients) Public Health South 03 476 9800

The relevant agency will convene a meeting within 5 working day having to have a quorum of 4 people from the panel list. The Joint Agency Panel will convene a multi-agency meeting and identify a designated case manager. The designated case manager should complete a Squalor Action Plan (see Appendix 3), which identifies the actions to be undertaken, the person(s)/agencies responsible and review dates. The case manager should then distribute the Squalor Action Plan to all involved agencies. This will enable coordination of the necessary services.

Progress should be closely monitored by the case manager with feedback reported regularly to all involved agencies.

The steering group will meet three times a year to assess the effectiveness of the service.

5.2 Ongoing Monitoring

When an action plan is successfully implemented and there is a substantial improvement in the person's living conditions, ongoing monitoring or follow-up is highly desirable as there is a high risk of recurrence.

In determining which service or agency should provide on-going monitoring, a further meeting of the Joint Agency Panel should be convened at which the following will be considered:

- The need for a continuing role for the case worker
- The nature of the intervention required
- The need for other services, such as residential support services.

Ongoing monitoring and follow up of the person could be provided by a number of individuals, including the General Practitioner, District Health Board staff, NGOs, City**/**District Council and/or the case manager.

Terms of Reference
SOUTHERN Good Living Conditions STEERING GROUP

Background

There is growing understanding of the complexity around cases of severe domestic squalor including the challenges of achieving successful and sustainable outcomes for individuals, their families and communities.

The international evidence shows that a multi-agency co-ordinated approach is the best way of addressing the underlying cause of severe domestic squalor in a non-judgemental way.

Purpose of the reference group is to:

- Provide leadership and co-ordination of relevant agencies and organisations who work in this area across Otago and Southland
- Co-ordinate development of relevant skills to enable organisations to respond appropriately, through training programmes, public information

- Provide oversight to the joint agency panels and receive summary information about their work
- Undertake communications to relevant organisations, service providers and the public
- Identify opportunities for early intervention where possible to prevent severe domestic squalor

Membership - Chair to be agreed by the participants

- Public Health South
- WellSouth Primary Health Network
- Age Concern Managers and Social Workers
- SDHB Mental Health
- NASC
- Local authority environmental health officer
- Fire and Emergency New Zealand
- Police
- St John
- Respect network co-ordinatorHousing New Zealand
- Oranga Tamariki

The steering group members agree to work together in good faith to address the issues of severe domestic squalor. They will provide their expertise and support and participate regularly in the work of the reference group.

Meeting logistics

- Meet three times a year for the purpose of oversight
- Quorum is 50% of members + 1
- Secretariat – agenda, minutes,

Review of ToR two years after signing by member agencies

Terms of Reference
Southern Good Living Conditions JOINT AGENCY CASE MANAGEMENT PANEL

Background

The prevalence of hoarding and clutter behaviors is estimated at 2 – 5% of the general population. It can occur in any age group, develop rapidly or over time, may be associated with people who are socially isolated or who have poor social skills and lack of insight. In a large number of cases there are underlying health issues including substance abuse, mental disorder, organic brain disorder. In many of these situations records relating to cases may be held by a number of agencies.

There is growing understanding of the complexity involved in addressing cases of compulsive hoarding and severe domestic squalor. The international evidence shows that a multi-agency coordinated approach is the best way of addressing the underlying cause of severe domestic squalor in a non-judgmental way. The aim is to achieve successful and sustainable outcomes for individuals, their families and communities.

Cases may come to attention through a variety of avenues and in all cases the safety of the person(s) concerned is of paramount importance. The relationship between a helping agency and the person is critical to successful outcomes. Helping agencies are encouraged to do as much as they can to address the situation before seeking the help of the case management panel, and to

remain engaged subsequently. Early intervention and prevention strategies should be employed.

Purpose
The overall purpose of the Joint Agency case management Panel is to ensure the safety and well-being of the person(s) concerned and to develop an appropriate response to the situation. The agencies will work collaboratively to:

- Consider any referrals
- Upon notification of a case, do a search of agency records so that all details relating to a case are available to panel members to make an informed decision.
- Identify and agree which agencies should be involved in the response
- Develop an action plan including a key case worker
- Maintain oversight of the case to ensure stability of the situation
- Ensure the individual receives entitlements that may assist resolving the issue
- Work with families and concerned 'others' as appropriate

Ethics

- Aim to identify and address the underlying reasons for the person living in severe domestic squalor as far as possible
- Work with individuals in a respectful and supportive way
- Take a proportionate and graduated response to the issues identified
- Respect privacy and maintain confidentiality as per relevant Codes (Human Rights, Health Privacy etc.)
- Any information held by panel will be treated confidentially.

Potential case management panel members

Membership: Invercargill

- Public Health South - Medical Officer of Health – 03 476 9800
- Well South Primary Health Network - Clinical Service Manager - 03 2146436
- Age Concern Coordinator for Elder Abuse – 03 2186351
- SDHB Mental Health – Clinical Team Manager – 03 2145786
- NASC - Manager – 03 2145725
- ICC Environmental Officer- 03 2111777
- Respect Network Coordinator – 03 2184156
- Chair to be agreed by the participants
- Kainga Ora 0800 801 601

Membership: Dunedin

- Public Health South – Medical Officer of Health – 03 476 9800
- WellSouth Primary Health Network – Clinical Service Manager
- Age Concern Otago Elder Abuse Response Social Worker 03 4793053
- SDHB Mental Health – Clinical Team Manager
- NASC Manager
- DCC Environmental Officer
- Access Ability Southern Region
- Chair to be agreed by participants
- Kainga Ora 0800 801 60

Membership: Queenstown-Lakes/Central Otago
Membership: Waitaki

SECTION 6: Organising Referrals to Relevant Agencies and Service Providers

6.1 Cleaning Up

The need to clean up the premises/property must be discussed with the person so as to determine whether the person supports the need for this to be undertaken (bearing in mind that in cases of extreme domestic squalor, the person's choice may be limited or overridden). Examples of the benefits of a clean-up include the following:

- *Makes it possible to invite family, friends or partners back to their home.* While some people who live in squalor are isolated because of personal preference, others may be lonely and desire more contact.
- *Reduces the risk of falling and retains independence***.** Some people will accept that reducing clutter, removing excessive possessions and cleaning are necessary to maintain independence and reduce risk. Others may accept cleaning to allow them to remain independent in their own home.
- *Stops a bad habit and saves money***.** Some people will know that their tendency to collect things is out of their control and is negatively affecting their quality of life. The offer of help can be presented as an opportunity to break a bad habit, save money and enjoy a more positive lifestyle.
- *Helps find a good home for some of the things they have collected*. People who collect things often do so because they consider these things have great value. It may be argued that the item cannot be valued on an individual basis when part of a vast collection and may be lost or damaged.
- *Contributes to a worthy cause***.** It may be possible to convince the person to give away excess property (furniture, appliances, collectibles, for example) if it is being donated to a worthy charity or cause. Emphasis the benefits of recycling.
- *Avoids further complaints***.** Sometimes people will agree to make changes just to avoid being hassled again and/or avoid prosecution, fines or legal action. There is a particularly high likelihood of the problem recurring again in this situation, even though this type of client is the least likely to agree to ongoing monitoring or assistance.
- *Avoids the risk of cessation of services.* Some services e.g., community nurses, meals on wheels, personal care and domestic assistance may be at risk, as the continuation of these services is related to OH&S issues.

Cleaning, rubbish removal and pest extermination service providers contracted to undertake work must comply with OH&S requirements and have adequate Public Liability Insurance.

The City**/**District Council may arrange for the removal of excess property and clearance of the garden. Councils have powers to recover expenses incurred in carrying out work where there has been a failure to comply with a Cleansing Order. Options that councils may consider for recovery of the costs of cleaning include:

- Charging the owner or occupier of the premises the for the removal and disposal of waste services

- Placing a lien on the property, i.e., keep the property until the debt owed is paid
- If a person has a Financial Attorney or Guardian, they should be contacted to seek approval for a cleanup and any necessary repairs which may depend on the funds being available from the person's estate
- Work and Income (Ministry of Social Development) may provide an Advance on Benefit which will have to be repaid.

The City**/**District Council may be able to provide information on sub-contractors and private cleaners who provide heavy-duty cleaning services. For further information about the role of local council see Appendix 6.

Some cleaning services may also be able to remove rubbish and excess property and arrange for tradesmen to carry out repairs and fumigate for pests. Field staff, when planning a cleanup, need to be conscious of the costs involved and who will pay these costs, including the person's ability to pay.

Some NGOs, service organisation and community groups may be able to assist with the cleanup activities if the person cannot afford these.

Specialist forensic cleaning is required when there is a concern about exposure to human waste, body fluids or excretions, needle stick injuries, or there is an infection risk. These forensic cleaners have training in relation to health and hygiene and use specialised cleaning detergents to ensure sterilisation. They can also provide pest control fumigation when required. The cost of heavy-duty and forensic cleaning is frequently prohibitive.

Most people want to remain in their home while it is being cleaned even though this can be very stressful. They are likely to protest at attempts to dispose of excess or damaged property and disused possessions. In their absence, however, subsequent allegations of loss or theft of valuables may be made.

Before cleaning, where possible, together with the person and any family members:

- Establish an inventory of possessions
- Identify valuables and arrange for them to be placed securely during cleaning
- Estimate the cost of cleaning

For a case study example, see Case Study in Appendix 9.

6.2 Building Compliance Issues

Building compliance issues can include the following:

- Structural integrity of the house.
- Ingress of water
- Provision of functional sanitary fixtures (toilets wash-hand basins, and showers/baths)

Building inspectors are employed by all District and City Councils and are available to assist in the event there is evidence of these issues.

6.3 Fire Risk

Hoarding gives rise to serious Health and Safety risks for Fire and Emergency personnel and volunteers in the event of a fire. All cases of hoarding need to have the address notified to Fire and Emergency Fire Risk Management Officers in the relevant community. Refer Appendix 7 for Contact Details.

6.4 Service Providers and Agencies

Services and agencies who can support persons living in domestic squalor include the following:

- Mental Health Services
- Southern District Health Board
- Maori Health providers
- NGOs
- Access Ability
- District Councils
- Kainga Ora
- Age Concern Southland and Otago

Details of these services are provided in Appendix 6.

SECTION 7: Strategies to Help People Who Are Unwilling to Accept Assistance

7.1 When the Person Has Decision-Making Capacity

When a person has decision-making capacity but has initially resisted help, the designated case manager and others involved should continue to try to persuade the person to agree to accept assistance. Although this can be time consuming, voluntary intervention is likely to be more efficient and result in a better outcome. Sometimes, people who were opposed to intervention at the beginning will be more accepting when they have had time to consider the potential consequences of this decision.

When there is a concern about a person's living conditions and they cannot be convinced to address the matter voluntarily, it may be necessary to refer the matter to agencies which have the appropriate legal authority to take further action. These organisations include the following

- Invercargill City Council 03 211 1777
- Dunedin City Council 03 477 4000
- Queenstown-Lakes District Council 03 441 0499
- Waitaki District Council 03 443 0300
- Housing NZ 0800 801 601
- Police: Invercargill 03 211 0400
- Police: Dunedin 03 471 4800
- Public Health: Invercargill 03 211 8500
- Public Health: Dunedin 03 476 9800
- Public Health Queenstown 03 450 9154
- Age Concern Southland 03 218 6351
- Age Concern Otago 03 477 1040

The role of these organisations in gaining access to properties is described in Appendix 6 and 7

7.2 When the Person's Decision-Making Capacity Cannot Be Assessed

There may be cases where capacity cannot be assessed because the person refuses to open the door or speak to anyone. Consideration should be given to the relevance of the following:

The Mental Health (Compulsory Assessment and Treatment) Act, 1992

The Mental Health (Compulsory Assessment and Treatment) Act, 1992, the definition of 'mental disorder' is based on phenomena rather than diagnosis. The Act avoids reference to any particular mental or psychiatric illness. Instead, it provides a number of symptom clusters that might indicate an 'abnormal state of mind'. These are 'delusions, or disorders of mood or perception or volition or cognition'. *The Act* is relevant when a person living in squalor shows signs of a mental disorder and is at risk of harm to themselves or others or is unable to care for themselves adequately. The Act makes provision for an assessment examination to be undertaken. In some cases if the person is showing signs of aggression or is threatening harm then it may be necessary to involve the police. In many cases it may be easier to secure an assessment through a General Practitioner. Anyone considering use of the Act should discuss their concerns with a Duly Authorised Officer (DAO),

registered health professionals that are tasked with providing advice and assistance in relation to the Act, and facilitating the process of the Act. DAO's are predominantly based in urban crisis and rural community, mental health teams.

If, following examination, the person is considered likely to be mentally disordered the Act allows for involuntary admission for further assessment and treatment, initially for a period of 5 days, or further assessment in the community.

If the person is admitted to a hospital as a mentally disordered person and not subsequently found to be mentally disordered, the detention will end.

Under section 126 of The Health Act 1956 (infirm and neglected persons), a Medical Officer of Health may apply to a court to have an "aged, infirm, incurable or destitute person" found to be living in insanitary conditions, committed to an appropriate hospital or institution. The person can be detained there under the order of committal.

SECTION 8: Strategies to Assist People Who Have Impaired Decision-Making Capacity

8.1 Decision-Making Capacity

Determining a person's decision-making capacity can involve complex issues. In some cases, a person living in squalor who refuses assessment will be aware of the potential consequences of their decision and the risks associated with this. Although their decision to refuse assessment may be considered unwise, as long as they can demonstrate adequate understanding of the choices they could make, and the consequences of these choices, then they would generally be considered to have decision-making capacity.

If there is uncertainty about the decision-making capacity of the person, the advice of the GP can be sought in the first instance.

8.2 Guardianship

Once it has been determined that a person living in severe domestic squalor lacks the cognitive capacity to make decisions about their circumstances such as accommodation, health, lifestyle choices and financial management, decisions may need to be made on their behalf. However, this approach requires careful consideration of the ethical principles involved. It is important to respect the person's autonomy and values, while at the same time protecting the person from further harm and minimising the risk of harm to others.

Some people with impaired decision-making abilities may have family or friends who will provide assistance without the need for a legal order. In other cases, when circumstances are such that there are no family members or friends willing or able to assist in achieving the best interests of the person or there is conflict among family members, the appointment of a substitute decision-maker who holds legal authority is required.

Under the Protection of Personal and Property Rights Act 1988 (PPP&R Act), the appointment of a substitute decision maker can be achieved by the activation of any Welfare and/or Financial Powers of Attorney (EPOA) which may have been put in place before the person lost the capacity to make their own decisions.

In the absence of an Enduring Power of Attorney, the appointment of a substitute decision maker can be achieved by an application to the Family Court and the subsequent appointment of a Welfare and/or Property Guardian who will then have the legal authority to make decisions for the person concerned.

SECTION 9: Conclusions

The key points contained in these Guidelines can be summarised as follows:

- Severe domestic squalor may develop in the homes of young, middle-aged and older people.
- The perception of squalor may be affected by the cultural perspectives of both the person and the field staff.
- Language/communication and/or cultural barriers may be impediments to gaining the trust and cooperation of a person living in squalor.
- The evidence suggests that half to two-thirds of all persons living in squalor suffer from one or more mental disorders.
- When assisting people living in severe domestic squalor, it is important to understand the factors which have led to the squalor situation as well as how to assess what needs to be done. Field workers need to be flexible in their approach but conscious of the statutory role of authorities such as the Police and City**/**District Councils and SDHB.
- The impact of squalor on the person, his/her family and the community should be assessed.
- Following initial assessment of the person living in severe domestic squalor, urgent intervention may be required. In such cases, authorities (such as district councils, SDHB, Police) may invoke powers that are contrary to a resident's choice.
- In cases where the squalor is not assessed to be extreme or of risk to the resident or neighbor's, referral to other agencies may not need to be immediate but should aim to prevent future problems arising.
- Where more than one agency is involved, information needs to be shared to enable a coordinated approach. In these cases all agencies need to be mindful of privacy considerations.
- There is a high risk of recurrence of severe domestic squalor, even when cleaning has been successfully completed and there is a substantial improvement to the person's living conditions. Therefore, ongoing follow up of involved persons is highly recommended.

Appendix 1

Sample

Occupational Health and Safety Checklist

Do you have permission to access the property? **Y/N**

Is there safe access to the property? **Y/N**

Is the structure and fabric of the building safe and secure? **Y/N**

Are the premises safe to enter (floorboards, ceilings)? **Y/N**

Are there animals on the premises? **Y/N**

Are there falls or slip hazards? **Y/N**

Electricity, gas and water supplies connected and available? **Y/N**

Are there insulated or damaged power lines which could cause electric shock? **Y/N**

Are there electrical appliances which are unsafe? **Y/N**

Is there a fire hazard? **Y/N**

Is special equipment required? **Y/N**

Protective clothing, gloves, safety helmet, mask, safety spectacles required? **Y/N**

Is there a health risk such as human or animal contaminants? **Y/N**

Is there evidence of infestations? **Y/N**

Are there weapons or explosive materials on the premises? **Y/N**

Are there booby traps on private property? **Y/N**

Are there concerns regarding probability of physical attack from the occupant? **Y/N**

Note: **It would be helpful if as many as possible of the above questions can be answered prior to the first home visit, i.e., at the point when referral is taken (see Section 3).**

Appendix 2

Sample

Declaration of Confidentiality

I_____declare that either during my term as a member of the Good Living Condition Group or after I cease my term as a Member of the Good Living Conditions Group, except by the collective direction of the Good Living Group, I will not divulge or disclose to any other person any of the following as acquired by me in the course of my duties for the Good Living Conditions Group:

- The name or identify of any person
- Information about an individual
- Any information in regards to case work

_____

Date
Printed Name
Signature
Witness Coordinator for Elder Abuse &Neglect Prevention
Printed Name
Signature

Appendix 3

Sample Squalor Action Plan

Client Name:	
Client Address:	
Case Manager:	Employer:
Referral:	
Source:	
Date:	
Initial Visit Date:	
Issues Identified (including language/communication barriers)	
1.	
2.	
3.	
4.	

Actions Required	**Agency**	**Review Date**

This Plan will be reviewed on:

Appendix 4

Sample

Environmental Cleanliness And Clutter Scale (ECCS)

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

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

Demographic details				
Name of person	Surname		Other names	
Date of birth *and/or* approximate age of person				
Gender *(please circle)*	Male		Female	
Marital status *(please circle)*	Single	Married/ de facto	Widowed	Divorced	Separated Not sure?
Address				
Does he/she live alone? *(please circle)*	Yes		No	
If not, who with?				
Number and type of pets				
Home ownership	Owner	Tenant – private	Tenant – DOH	Other – non-owner (e.g. lodger)
Accommodation type	House	Unit	Bedsit	Other (specify)
How long has he/she been living like this? *(please circle)*	Less than 1 year	1–3 years	4–10 years	Over 10 years
Known medical illnesses and/or disabilities				

Mental disorders now or in the past	

* Source: Halliday G, Snowdon J, 2006 Environmental Cleanliness and Clutter Scale (ECCS) 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.

Name of rater:	
Rater's phone no:	Date:

A	**Accessibility** (clutter) of floor space inaccessible for use or walking across			
	0	1	2	3
	Easy To enter and move about dwelling.	**Somewhat Impaired** access, but can get into all rooms.	**Moderately Impaired** access. Difficult or impossible to get into one or two rooms or areas.	**Severely impaired** access, for example, obstructed front door. Unable to reach most or all areas in the dwelling.
	0–29%	30–59%	60–89%	90–100%
Comment				

B	**Accumulation of refuse or garbage** In general, is there evidence of excessive accumulation of garbage or refuse, eg, food waste, packaging, plastic wrapping, discarded containers (tins, bottles, cartons, bags) or other unwanted material?			
	0	1	2	3
	None	**Little** Bins overflowing and/or up to 10 emptied containers scattered around.	**Moderate** Garbage and refuse littered throughout dwelling. Accumulated bags, boxes and/or piles of garbage that should have been disposed of.	**Lots** Garbage and food waste piled kneehigh in kitchen and elsewhere. Clearly no recent attempt to remove refuse and garbage

Comment

C	**Accumulation of items of little obvious value** In general, is there evidence of accumulation of items that most people would consider are of little use or should be thrown away?			
	0	1	2	3
	None	**Some accumulation**, but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances.	**Moderate excessive accumulation:** items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean.	**Markedly excessive accumulation:** items piled at least waist-high in all or most areas. Cleaning would be virtually impossible: most furniture and appliances are inaccessible.

Please indicate types of items that have been accumulated:

❑ Newspapers, pamphlets, and so on ❑ 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)			
	0	1	2	3
	Acceptably clean in all rooms.	**Mildly dirty** Floors and carpets look as if not cleaned or swept for days. Scattered rubbish.	**Very dirty** Floors and carpets very dirty look as if not cleaned for months. Rate 1 if only one room or small area affected.	**Exceedingly filthy** With rubbish or dirt throughout dwelling. Excrement usually merits a 3 score.

Comment

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

Comment

F	**Bathroom and toilet**			
	0	1	2	3
	Reasonably clean.	**Mildly dirty** Untidy, uncleaned, grubby floor, basin, toilet, walls and so on. Toilet may be unflushed.	**Moderately dirty** Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, and so on. Faeces and/or urine on outside of toilet bowl.	**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.

G	**Kitchen and food**			
	0	1	2	3
	Clean. Hygienic.	**Somewhat dirty and unhygienic** Cooktop, sink untidy and surfaces dirty, maybe with some spilt food. Refuse mainly in garbage bin. Food that could go off (eg, meat, remains of meal) left uncovered and out of fridge. Rate 1 if no food, but fridge dirty.	**Moderately dirty and unhygienic** Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils and so on. Bins overflowing. Some rotten or mouldy food. Fridge unclean.	**Very dirty and unhygienic** Sink, cooktop, insides of all cupboards filthy. Large amount of refuse and garbage over surfaces and floor. Much of the food is putrid, covered with mould and/or rotten, and unsafe to eat. Rate 3 if maggots seen.

H	**Odour**			
	0	1	2	3
	Nil. Pleasant.	**Unpleasant**, eg, urine smell, unaired.	**Moderately malodorous:** bad, but rater can stay in room.	**Unbearably malodorous:** rater has to leave room very soon because of smell.

Comment

I	**Vermin** (Please circle: rats, mice, cockroaches, flies, fleas, other)			
	0	1	2	3
	None	**Few** (for example, cockroaches).	**Moderate:** visible evidence of vermin in moderate numbers for example, droppings and chewed newspapers.	**Infestation:** alive and/or dead in large numbers.

J	SLEEPING AREA			
	0	1	2	3
	Reasonably clean and tidy.	**Mildly unclean** Untidy. Bed unmade. Sheets unwashed for weeks.	**Moderately dirty** Bed sheets unclean stained, for example, with faeces or urine. Clothes and/or rubbish over surrounding floor areas.	**Very dirty** Mattress or sleeping surface unclean or damaged. Either no sheets or (if present) extremely dirty bedding/linen.

Comment

Add up circled numbers to provide **total score**:

Do you think this person is living in Dry squalor? (circle one)	**No**	**Yes**, mild	**Yes**, moderate	**Yes**, severe

Do you think this person is living in Wet Squalor? (circle one)	**No**	**Yes**, mild	**Yes**, moderate	**Yes**, severe

Severe domestic squalor

Descriptions of cases can be grouped according to 'severity' (e.g. rated on the ECCS), 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. May be filthy without a lot of clutter. May be '**wet squalor'.**

Supplementary questions – to add to description, but not to score

Comments or description to clarify, amplify, justify or expand on above ratings:

Personal cleanliness Describe the clothing worn by the occupant and their general appearance:			
0	1	2	3
Clean and neat. Well cared for.	**Untidy, crumpled:** one or two dirty marks and in need of wash	**Moderately dirty:** with unpleasant odour. stained clothing.	**Very dirty:** stained, torn clothes, malodorous.

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 and so on before it would be reasonably habitable?			
0	1	2	3
None	**Little** – minor repairs and some painting.	**Fair amount** – some structural repairs plus painting.	**Lots** – major structural repairs required, and then painting.

Comments

To what extent do the living conditions make the dwelling unsafe or unhealthy for visitors or occupant(s)?			
0	1	2	3
Not at all	**Possible risk** – of injury for example, by falling.	**Considerable risk** – of fire, injury or health problem.	**Very unsafe** – the dwelling is so cluttered and unhealthy that people should not enter it, (except specialists with appropriate clothing and equipment) and/or there is high fire-risk.

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room

1

2

3

4

5

6

7

8

9

Clutter Image Rating: Living Room

Please select the photo that most accurately reflects the amount of clutter in your room


1


2


3


4


5


6


7


8

9

Clutter Image Rating

Using the 3 series of pictures (CIR: Living Room, CIR: Kitchen, and CIR: Bedroom), please select the picture that best represents the amount of clutter for each of the rooms of your home. Put the number on the line below.

Please pick the picture that is closest to being accurate, even if it is not exactly right.
If your home does not have one of the rooms listed, just put NA for “not applicable” on that line.

Room	Number of closest corresponding picture (1-9)
Living Room	_____
Kitchen	_____
Bedroom #1	_____
Bedroom #2	_____

Also, please rate other rooms in your house that are affected by clutter on the lines below. Use the CIR: Living Room pictures to make these ratings.

Appendix 6

Services and Agencies Supporting People Living in Severe Domestic Squalor

LOCAL GOVERNMENT SERVICES

It is the duty, under the Health Act 1956, of every local authority to improve, promote and protect public health within its district and for this purpose every local authority is empowered and directed under the Act to cause all proper steps to be taken to secure the abatement of a nuisance that exist or the removal of a condition that is likely to be injurious to health or offensive in its district.

The purpose of the provisions of the Building Act 2004, for local councils, is to reduce the likelihood of dangerous or insanitary buildings causing offence, illness, injury or death to persons. A building is regarded as insanitary if it is offensive or likely to be injurious to health of how it is situated or constructed; or of it is in a state of disrepair; or it has inefficient or defective provision against moisture penetration as to cause dampness; or it does not have a sufficient supply of potable water; or it does not have adequate sanitary facilities.

Health Act 1956 Nuisances

Section 29. Nuisances defined for purposes of this Act

Without limiting the meaning of the term nuisance, a nuisance shall be deemed to be created in any of the following cases, that is to say:

(a) where any pool, ditch, gutter, watercourse, sanitary convenience, cesspool, drain, or vent pipe is in such a state or is so situated as to be offensive or likely to be injurious to health:

(b) where any accumulation or deposit is in such a state or is so situated as to be offensive or likely to be injurious to health:

(c) where any premises, including any accumulation or deposit thereon, are in such a state as to harbour or to be likely to harbour rats or other vermin:

(d) where any premises are so situated, or are in such a state, as to be offensive or likely to be injurious to health:

(e) *[Repealed]*

(f) where any building or part of a building is so overcrowded as to be likely to be injurious to the health of the occupants, or does not, as regards air space, floor space, lighting, or ventilation, conform with the requirements of this or any other Act, or of any regulation or bylaw under this or any other Act:

(g) where any factory, workroom, shop, office, warehouse, or other place of trade or business is not kept in a clean state, and free from any smell or leakage from any drain or sanitary convenience:

(h) where any factory, workroom, shop, office, warehouse, or other place of trade or business is not provided with appliances so as to carry off in a harmless and inoffensive manner any fumes, gases, vapours, dust, or impurities generated therein:

(i) where any factory, workroom, shop, office, warehouse, or other place of trade or business is so overcrowded while work is carried on therein, or is so badly lighted or ventilated, as to be likely to be injurious to the health of the persons employed therein:

(j) where any buildings or premises used for the keeping of animals are so constructed, situated, used, or kept, or are in such a condition, as to be offensive or likely to be injurious to health:

(k) where any animal, or any carcass or part of a carcass, is so kept or allowed to remain as to be offensive or likely to be injurious to health:

(ka) where any noise or vibration occurs in or is emitted from any building, premises, or land to a degree that is likely to be injurious to health:

(l) where any trade, business, manufacture, or other undertaking is so carried on as to be unnecessarily offensive or likely to be injurious to health:

(m) where any chimney, including the funnel of any ship and the chimney of a private dwellinghouse, sends out smoke in such quantity, or of such nature, or in such manner, as to be offensive or likely to be injurious to health, or in any manner contrary to any regulation or Act of Parliament:

(n) where the burning of any waste material, rubbish, or refuse in connection with any trade, business, manufacture, or other undertaking produces smoke in such quantity, or of such nature, or in such manner, as to be offensive or likely to be injurious to health:

(o) where any street, road, right of way, passage, yard, premises, or land is in such a state as to be offensive or likely to be injurious to health:

(p) where any well or other source of water supply, or any cistern or other receptacle for water which is used or is likely to be used for domestic purposes or in the preparation of food, is so placed or constructed, or is in such a condition, as to render the water therein offensive, or liable to contamination, or likely to be injurious to health:

(q) where there exists on any land or premises any condition giving rise or capable of giving rise to the breeding of flies or mosquitoes or suitable for the breeding of other insects, or of mites or ticks, which are capable of causing or transmitting disease.

Contact Details:

Invercargill City Council
101 Esk Street Invercargill 9810
Phone (03) 211 1777
Urgent or outside office hours (03) 211 1679
Free phone 0800 422 435 .

Southland District Council
15 Forth St, Invercargill 9810
Phone: 0800 732 732.

Gore District Council
Civic Centre
29 Bowler Avenue
Gore 9710
Phone: 03 209 0330

Dunedin City Council
50 The Octagon, Dunedin, 9016.
Phone: 03477 4000

Queenstown-Lakes District Council
Regulatory and Finance
10 Gorge Rd, Queenstown. 9300
Phone: 03 441 0499

Waitaki District Council
20 Thames Street, Oamaru 9400
Phone: 03 433 0300

Southern District Health Board

Statutory Purpose:

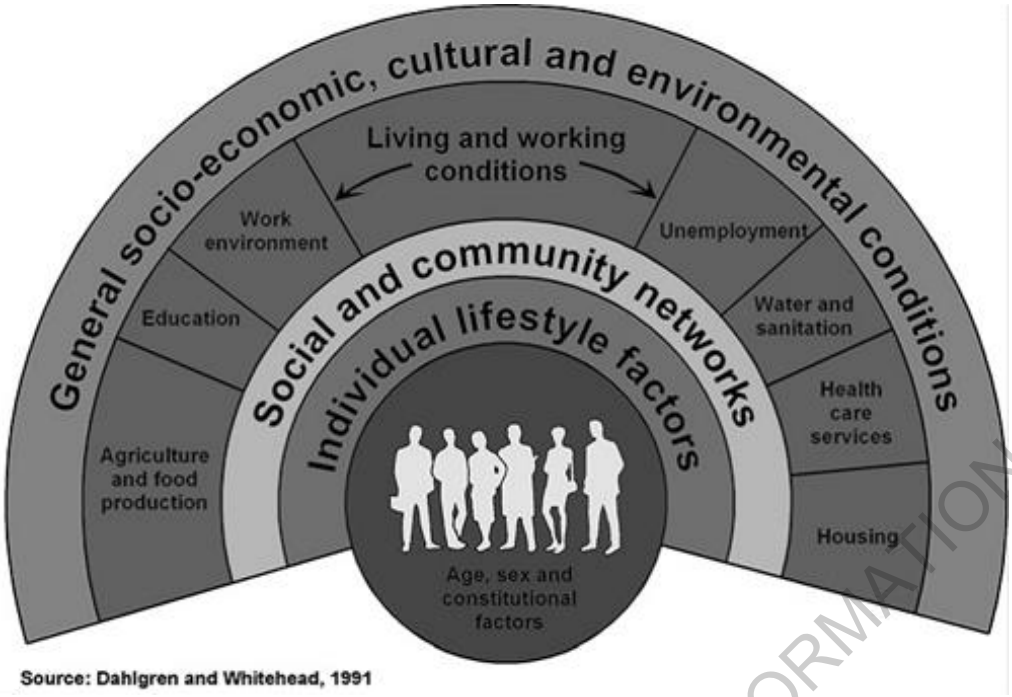
- Improve, promote and protect the health of the population
- Promote effective care and support for people in need of personal health or disability services
- Reduce health outcome disparities
- Manage national strategies for the specific health needs of our community
- We plan for the health needs of Otago and Southland communities based on the analysis of our population's health status
- We fund a range of health providers to deliver health services that will meet the identified health needs of our population.
- We provide hospital and mental health services from our own facilities (Southland Hospital, Lakes Hospital, Dunedin Hospital and Wakari Hospital)
- We service a resident population of 319,200 and have a land area of over 62,356 sq. kms and a coastline of nearly 5,000 kms including Invercargill City, Gore District, Queenstown Lakes District, rural Southland encompassing Fiordland, Stewart Island, the Catlin's, Dunedin City, Central Otago, Maniototo, Clutha District.

Public Health South
Public Health South is a service entity of the Southern District Health Board.

What is Public Health?
"Public Health is the art and science of preventing disease, prolonging life and promoting health through the organised efforts of society, organisations, public and private, communities and individuals"
(C E A Winslow 1920)

To have a healthy population we not only need to heal people who are sick, but we also need to make sure that the physical and social environment we live in supports the health and wellbeing of everyone. For example, a healthy population requires clean air and water, access to enough income to support a reasonable quality of life, healthy working conditions and knowledge about how to maintain wellbeing. The factors that impact on health are called 'determinants'.

Public Health Services are offered to populations rather than individuals and are considered a 'public good'. They fall into two broad categories – health protection and health promotion and aim to create or advocate for a healthy social, physical and cultural environments. Public Health practitioners utilise population data to identify health issues and develop appropriate services aimed at improving health gains. The overall goal of Public Health South is to be effective in preventing disease, minimising health risks and maximising health for the population in the region.



Contact:

Dunedin	03 476 9800
Invercargill	03 211 8500
Queenstown	03 450 9154

Community Support Service

Older Persons NASC – Needs Assessment & Service Coordination for people over 65 years.

The Southern DHB Community Support Service (Care Coordination Centre) is a needs assessment and service co- ordination (NASC) service that works with older people who have health or disability issues to help support them to live at home. The service supports people aged over 65 years, or those identified by CCC Unit Managers in conjunction with a geriatrician or psych geriatrician as required as being 'like in age and interest' (i.e. who have a condition or disability more commonly associated with ageing).

Every eligible person who wishes to receive disability support services funded by a District Health Board must have a needs assessment. The service uses the InterRAI assessment tools to assess a person's health and social needs and, from this, develops a care plan in partnership with the person and their family/whanau. The service also refers clients on to other services if needed e.g. to physiotherapy or district nursing services.

If the person has complex needs they will be assigned a Clinical Need Assessor (CNA) who will then complete a comprehensive assessment. The CNA is a registered health practitioner eg nurse, physiotherapist, who works alongside the person's GP and staff within Hospital and Specialist Services to ensure the person gets the best response possible. Non Complex clients are managed by the Home and Community Support Provider agencies whom complete Contact Assessments, care plans and package of care and refer on to CCC for more complex assessment if identified by assessment urgency outcome scales as requiring further assessment.

The CCC service identifies what support the person's family/whanau can provide and what support they might need in order to be able to help the person, goals are created and a care plan

sent to Home and Community Support Provider agencies to negotiate a funded package of care for the client.

Examples of funded support services include:

- Restorative services aimed at improving independence
- Home based support services
- Community and Residential Care-Based Day Programs
- Carer Support Services
- Long term residential care

The Community Support Service is available to older people aged 65 years and over, or those between 50 – 65 years who are considered to be "like in age and interest" (i.e. who have a health condition or disability more commonly seen in older people, such as dementia or stroke).

To be eligible for funded support services the person must have an aged-related disability which is likely to continue for a minimum of six months and results in a reduction of independent function to the extent that ongoing support is required.

Contact:

Mental Health Services for Older People (MHSOP)

The Mental Health Service for Older People (MHSOP) provides inpatient and community assessment, treatment, care and support for people in Southland who are over the age of 65 and experience significant mental health problems including dementia. People under the age of 65 who experience age related mental health problems may also supported by the team which is made up of personnel from several disciplines. People may be seen in outpatient clinics or their own homes.

Adult Mental Health Services

The Service aims to reduce health, physiological, financial, and social problems caused by Mental illness, by providing regular support and connection with community services which provide home based support.

The teams consist of health professionals employed by the SDHB to work in the area of Mental Illness. The teams consist of Psychiatrists, Psychologists, Registered Nurses, Social Workers, Occupational Therapists, and Needs Assessment and Service Coordination (NASC). The teams work closely with family and whanau to support clients to remain in their homes, and to maintain independence and a standard of living that other New Zealanders have.

Supported accommodation is available for clients that have been assessed and deemed in need of additional support and training geared towards returning to independence with additional skills.

Where squalor has been identified, we work with other agencies which carry out extensive cleaning and follow up with community agencies to maintain the clean environment.

Alcohol, and Drug Services

The Specialist Addiction Service (formerly CADS and DASS) is based at Southland and Wakari Hospitals. Staff are available between the hours of 8.30am and 5pm, Monday to Friday, excluding public holidays.

The Service aims to reduce health, physiological, financial, and social problems caused by alcohol and drug misuse by providing a range of quality treatment and education services.

The Specialist Addiction Service offers a range of services to adults over the age of 17 who are affected by their own or someone else's substance use problems. This includes providing support to individuals, families and groups who have been affected by drug and alcohol use. A group programme is available in Dunedin.

People can access the service as a referral in by a general practitioner, probation service, Child Youth and Family Services, SDHB Departments or other DHB's and community agencies by phone contact or walk in to be assessed by the intake worker.

The Service will support individuals and their families/whanau to access help and support from other providers by liaising, advocating and onward referral to empower them to make healthy lifestyle choices.

The team consists of health professionals employed by the Southern District Health Board to work in the area of alcohol and or other drug addictions. All clinicians provide comprehensive assessment, treatment planning, interventions to assist people to achieve their changes to their substance use and provide support to family/whanau and concerned others about someone's substance use. Specialist skills within the team include areas such as comprehensive alcohol and drug assessments, detoxification assessments for referral on to specialist regional services, comprehensive education about addiction and relapse prevention.

Opioid Substitution Treatment (OST) is provided to assist those seeking wellness from illicit opioid misuse and intravenous drug use.

Hospitalisation and Residential Care

In some cases, depending upon diagnosis and the level of risk, hospitalisation or transfer to alternative accommodation, such as residential care, may be required, e.g., where individuals have severe medical and psychiatric problems or disabilities.

If available, a brief period of hospitalisation or respite residential care can provide ideal temporary accommodation while cleaning is being carried out.

In the case of hospitalisation it can also provide an opportunity for full multidisciplinary assessment, including accurate diagnosis and treatment of medical and psychiatric problems. If hospitalisation is required the person's GP would arrange that with the appropriate service, but respite residential care can only be accessed by contacting the NASC/CSS care manager or team leader.

COMMUNITY SUPPORT SERVICE

Accessibility

Under 65S NASC - Needs Assessment & Service Coordination for people aged under 65 years.

Access Ability is an independent, not for profit organisation that provides Needs Assessment and Service Coordination (NASC) and Local Area Coordination (LAC).

To be eligible for Needs Assessment, Service Coordination and Local Area Coordination through Access Ability, clients must:

1. be between 0 and 65 years of age
2. have a disability that lasts longer than six months
3. Need support in some parts of their lives because of disability.

The disability could be:

- physical
- sensory: vision, hearing and Autism Spectrum
- Intellectual.

Needs Assessment

- We will talk with clients about thier goals, dreams and what they need to live well.
- This conversation enables us to find the best people, opportunities and supports in the community.

How does it work?

The first step is to apply for the Needs Assessment. Individuals can can apply themselves, or ask a family member, friend or a health professional to complete an application on their behalf. Clents will be advised when their application has been received.

The next step will be to check eligibility for a Needs Assessment. On the first occasion we may need a doctor or specialist to confirm disability.

Assuming eligibility a Needs Assessment meeting will be arranged.

During the Needs Assessment the client will be asked about their life, their goals, dreams and what they leave to live well. Clients can choose the place for meeting and are welcome to have whānau, a friend, a caregiver or an advocate with them. When the meeting is being arranged, we need to know if there is a need to engage with with one of our Māori or Pasifika staff. We can also arrange an interpreter, including a New Zealand Sign Language interpreter.

At the end of your meeting, a report will be put together. Clients will be shown a draft copy and asked to check it. Once it is OK clients are asked to sign it or if they are not able have a proxy to sign for them.

Assessments are reviewed with clients every three years although this can occur earlier if required.

Service Co-ordination

Service co-ordination is a separate process designed to find the best solutions to meet as many identified needs as possible. Coordinators will talk to clients about their Needs Assessment and the best way to meet those needs within the resources available.

These may include: Family and friends, Service agencies, Government funded support (e.g. Ministry of Health, Education, WINZ); and Non-Government organisations such as service groups, church groups, self-help groups or volunteers.

Funded Services may range from:

- Personal care
- Carer support
- Home help
- Supported living
- Residential care
- Other services based on your individual needs

Information and support will be given to access a range of supports available in your community.
For more information www.accessability.org.nz

Local Area Coordination
LACs connect clients with people and opportunities in your local community to help achieve thier goals.

LACs can work to:

- identify what goals for a good life
- develop a plan to achieve those goals
- find natural (unpaid) supports within the community, hapū and marae
- learn about opportunities near clients homes
- build connections with local people and places.

LACs also encourage and support local communities to be inclusive and welcoming to all. They work closely with local people, businesses, organisations and marae

Contact
Phone: 0800 758 700
Email: otago@accessability.org.nz
Access Ability: Ground Floor, Burns House, 10 George St, P O Box 966, Dunedin 9054
More information on: www.accessability.org.nz

KAINGA ORA

We focus on the efficient and effective management of state houses and the tenancies of those living in them, in order to meet demand from MSD's social housing register.

We own or manage around 63,000 properties nationwide. More than 184,000 people live in our houses or flats. It isn't just about getting a roof over people's heads - we also work closely with others to ensure our tenants have access to good support services.

Our Customer Services Centre (freephone 0800 801 601) provides national coverage for all enquiries Monday to Friday from 8am to 6pm. They also provide 24/7 support for urgent calls. Our trained housing advisors provide a range of services and can answer most questions on the spot.

Our Customer Services Centre can help with:

- getting a state house or flat repaired
- checking a tenant's account
- lodging complaints and providing feedback
- answering questions about damage and rental debts and credits
- getting in touch with organisations which can help a tenant with other issues.

The rest of our frontline staff operate from a combination of local Kainga ora offices and shared space offices located in facilities provided by other organisations, such as Work and Income.

Specialist teams deal with issues such as debt and Tenancy Tribunal matters.

Contact
Freephone 0800 801 601

Ministry for Vulnerable Children
Oranga Tamariki

Everyone has a role to play in keeping our children and young people safe. At Oranga Tamariki we partner with others to help protect, support and care for children. Together we can help our children be safe from harm and well cared for, strong as part of a loving family and whanau, and to thrive by helping children be the best they can be.
We support a multi- agency approach to families living in squalid conditions. We are committed to working alongside other agencies to respond to cases of hoarding and squalor where they involve children and young people.

If there are identified care and protection concerns identified a referral should be made to our call center 0508 FAMILY (0508 326 459). Ministry for Vulnerable Children, Oranga Tamariki

Invercargill: Henderson House, 93 Kelvin Street, Box 1305 , Invercargill

Dunedin: 144 Rattray St, Central Dunedin or 40 Elliot St, South Dunedin

SPCA (Society for the Prevention of Cruelty to Animals)

An SPCA Inspector can enter and inspect properties (ie outside of the house or dwelling) where they have received notification of suspected neglect or hoarding of animals.

To enter a house or dwelling the SPCA Inspector requires the consent of the owner. If there is reasonable evidence of neglect or abuse of animals and the owner does not give consent a Search Warrant may be obtained to enable the Inspector to enter the house or dwelling.

Southland SPCA
22 Harewood Road, Woodend, Invercargill
Phone: 03 2189 684
After hours emergency phone: 027 8829 379

Gore and Districts SPCA
5 Waiau Street, Gore
Phone: 03 208 5111

Otago SPCA
1 Torridon St, Opoho, Dunedin 9016
Phone: 03 473 8252
After hours emergency phone: 0800 682467

Alexandra SPCA
247 Blackman Road, Alexandra 9391
Phone: 027 512 0294

Oamaru SPCA
281 Thames Street, Oamaru 9400
Phone: 03 434 8196

NON GOVERNMENT ORGANISATIONS (NGOs)

Age Concern Southland and Otago

A free and confidential service that helps protect against abuse and neglect of elderly people, aged over 65 years. Age Concern provide information and support to older people to enable them to make their own decisions about their wellbeing and safety. We also assist the older person by advocating with family and service providers or refer to other organisations such as health / social services, solicitors and Police. Age Concern also provide support and information for carers.

Coordinators for Elder Abuse and Neglect Prevention
Dunedin Phone: 03 479 3053
Invercargill Phone: 03 218 6351

Salvation Army Corps

The Salvation Army Corporation Invercargill and Dunedin is an integral part of the Christian Church. We are a Church or Worship Centre along with a Community Ministries Centre. We are here to express our Christian faith in serving those within our community who need support in various areas. We look at the person's life with a holistic view to supporting them in the best way we can.

Our Community Ministries focus is on:

- Loving the marginalized
- Advocating for the voiceless
- Befriending those that have no friends
- Empowering those who are powerless[1]

Contact Salvation Army Corps:
Invercargill Phone: 03 218 3094
Dunedin Phone: 03 477 9852
160 Crawford St, Dunedin, 9016

[1] As written in the scriptures, Matthew 25:35-38

Appendix 7

ORGANISATIONS THAT CAN PROVIDE ASSISTANCE WHEN PEOPLE ARE UNWILLING TO ACCEPT ASSISTANCE

Local Councils

Territorial Authorities Regulatory Roles under the Health Act 1956 and the Building Act 2004:

A local authority may issue a cleansing order under the Health Act 1956 - to be served to the owners or occupiers of a premises to cleanse such premises, with the time specified, if it is of the opinion that the cleansing of such premises is necessary for preventing of danger to health or for rendering the premises fit for occupation.

A local authority may issue repair notices to the owners (or his agent) of premises requiring repairs, alterations, or works to be carried out with the time specified, where any dwelling house within its district is, by reason of its situation or insanitary condition, is likely to cause injury to the health of any persons therein, or otherwise unfit for human habitation.

Where any such notice is not complied with to the satisfaction of a local authority, the local authority may issue a closing order prohibiting the use of the premises for human habitation or occupation from a time to be specified in the order, until such repairs, alterations, or works as may be specified in the closing order, have been carried out to the satisfaction of the local authority.

A territorial authority may, under the Building Act 2004, if it is satisfied that a building is dangerous or insanitary, put up a hoarding or fence to prevent people from approaching a building nearer than is safe; attached a notice warning people not to approach the building; issue a written notice requiring work to be carried out on the building, within a specified time, to reduce or remove the danger or prevent the building from remaining insanitary.
A person failing to comply with this notice commits an offence and is liable to a fine.

Where an owner has failed to carry out the work within the time specified, a local authority may obtain a court order authorizing it to carry out the work.

Housing New Zealand Corporation (HNZC)

Housing New Zealand provides state houses for those in the greatest need, for their time of need. Housing New Zealand owns or manages more than 69,000 properties throughout the country, including about 1,500 houses used by community groups. Housing New Zealand also helps people make the move from renting to home ownership, by providing a range of home loans and home ownership services.

Housing New Zealand makes every effort to resolve problems in tenancies where unacceptable, unclean or hoarding behaviours are evident by referring clients to support services. These efforts are balanced against threats to tenant safety and the rights of neighbor's to have reasonable peace, comfort and privacy.

New Zealand Police

The Police are often the initial point of contact and the referring body. They are asked to check on an individual when neighbor's are concerned that mail is not being collected, or a person has not been seen for some time. Police are empowered to conduct checks on people and can gain

access, involving forced entry if necessary. There are however, some restrictions on their powers of entry.

Police work in collaboration with Mental Health services, particularly when dealing with mental health crisis interventions. Police have the responsibility to protect the safety of all parties, and to protect all persons from injury or death, while attempting to preserve the rights and freedom of individuals.

Fire and Emergency New Zealand

Fire and Emergency New Zealand (FENZ) has the right to enter buildings where it is believed that there is a fire, or where it is believed that a fire has occurred.

FENZ can take action to render the situation safe. However, FENZ cannot inspect residential premises, even if they suspect them to be a fire hazard, without the permission of the owner.

FENZ does not have official procedures for dealing with a squalor situation however they recognize that hoarding increases fire risk and potentially inhibits safe egress in the event of a fire and as such they would appreciate notification of any addresses where it has been discovered that hoarding is taking place. Fire Safety Officers would be happy to visit affected premises if the occupier is happy to allow this. Alternatively they would be happy to support staff working with these individuals with appropriate Fire Safety messaging.

Contacts:

Dunedin

Mark Bredenbeck mark.bredenbeck@fireandemergency.nz
DDI 03 467 7565 Mob: 027 221 5141

Invercargill

Mike Cahill michael.cahill@fireandemergency.nz
(until April 2019 when replacement will start, numbers will be the same)

DDI 03 214 3763 Mob: 027 433 3817

Central Otago/Lakes/Waitaki

John Smalls john.smalls@fireandemergency.nz
DDI 03 441 4550 Mob: 027 223 4901

Marty Jillings Marty.Jillings@fireandemergency.nz
DDI 03441 4551 Mob: 027 433 3816

South Otago

Scott Lanauze scott.lanauze@fireandemergency.nz
DDI 03 467 7565 Mob: 027 801 1834

Appendix 8

SUPPORTS FOR PEOPLE WITH IMPAIRED COMPETENCY

Protection of Personal and Property Rights Act 1991

The PPPR Act is the NZ statute which deals with issues of competence.

The Act aims to protect and promote the personal and property rights of adults who are wholly or partially incapable of managing their own affairs. Under the Act, it is presumed that everyone is competent to manage their own affairs unless proven otherwise, based on medical evidence.

Many people, when competent to do so, have granted an Enduring Power of Attorney (EPOA) to a person who then has the right to make decisions on their behalf in the event of them being unable to do so**.** The EPOA comes into effect with a medical statement of incompetence.

For those with no EPOA, and/or lack the capacity to appoint someone, the matter is directed to the Family Court.

Once the Family Court has demonstrated, with medical evidence, that competency is lacking, it then has the power to make orders authorizing certain actions, or appointing other suitable and available persons to manage the subject person's affairs.

Orders Available

The Court must make the least restrictive intervention possible.

The extent of need has to be assessed. Where there is significant incapacity, a more restrictive intervention may be necessary.

A medical assessment of competence is always required. This must be provided by a suitable Practitioner who is familiar with the concepts involved.

Personal Orders (S10 of Act)

These provide for a range of matters, including orders to attend a particular institution, and orders to be provided with particular living arrangements, treatment, or therapeutic services.
There are regulations regarding the type of order. Applicants may be:

1. the subject person
2. A relative or attorney
3. Social Worker
4. Medical Practitioner
5. Property Manager
6. Any other person with the leave of the court

Welfare Guardian

This allows the court to appoint a person as a Welfare Guardian, giving them the power to make decisions in relation to the subject person's personal care and welfare.

There are stipulations regarding applicants. Paramount consideration is to promote and protect the welfare and best interests of the subject person. They need to consult the subject person, their property manager and others who are involved, including the Court.

Property Manager (or Administrator, depending on the level of assets available)

A person appointed who can make decisions for the subject regarding property and assets.

Stipulations are similar to those regarding Welfare Guardianship.

In those situations where there is no family/whanau suitable or willing, the Public Trust may be appointed.

All orders have an expiry date, requiring review.

Applications

Applications need to be discussed with all relevant people, and appropriate legal representatives.

It is rare for **Southern** DHB to be an applicant.

The Family Court website at www.justice.govt.nz/family/what-familycourt-does/powers-to-act.asp is a useful source of information about applications under the Act.

In certain circumstances, there are other Acts that may be appropriate.

- Mental Health Act 1992
- Alcohol and Drug Addiction Act 1966
- Committal Orders under the Health Act 1956 (s126)

Circumstances leading to extreme hoarding and squalor are usually complex, and a comprehensive Multi Agency/ Multi-disciplinary approach is essential, particularly to aim to provide the least restrictive intervention.

Appendix 9

Case Studies

CASE 1

I received a referral for a man living alone in a flat, the referrer was concerned about his living conditions – she said his home was very run-down and dirty and she had noticed a marked deterioration in his physical well-being, his mobility was severely limited, he had no support services or agency involvement. While he was well known within the community he had no family support and had become very isolated. She had become aware that he had had no running water for at least one month– he explained he had been getting water from a business where he was previously employed.

When I visited this man it was very apparent that he was self-neglecting - his home was in a very poor state of repair and unclean, floorboards were rotten in places, he confirmed that he had been without running water until recently when the Landlord had visited his home and arranged some urgent repairs – there was to be a meeting regarding total refurbishment of the flat and reviewing his tenancy.

His mobility was severely impaired, he had been telling people he was waiting for surgery, but on investigation, he revealed he had not seen a surgeon and very seldom visited his Doctor. With his consent I spoke with his G.P. Practice Nurse explaining his circumstances and arranged an appointment for the next day. Although walking was very difficult he was able to drive. His G.P. made an urgent referral to see a Specialist and prescribed pain medication. He was referred to a Physiotherapist who provided him with a walking frame and other aids. I made a referral for a Needs Assessment and he now receives weekly domestic assistance. I liaised with the Landlord and an agreement has been reached that he will retain his tenancy providing he continues to have regular domestic assistance. A local person is now actively supporting him. His flat is to be completely renovated at the end of April, and he has made arrangements to stay locally while this occurs.

Case 2

'Mary', is a woman in her mid-70, living alone in her own home, she had been hoarding for many years. Her daughter had walked away, overwhelmed from trying to help her – their relationship had broken down and they were now estranged.

When initially approached Mary was pleasant although very reluctant to open the door more than a 'crack', she was well dressed and had her hair and make-up done. On each occasion she was just on her way out to an appointment, she declined any intervention.
A second referral came from the hospital, Mary had fallen and broken her ankle, hospital staff had visited her home to assess how she would manage when discharged, they were appalled at her living conditions.

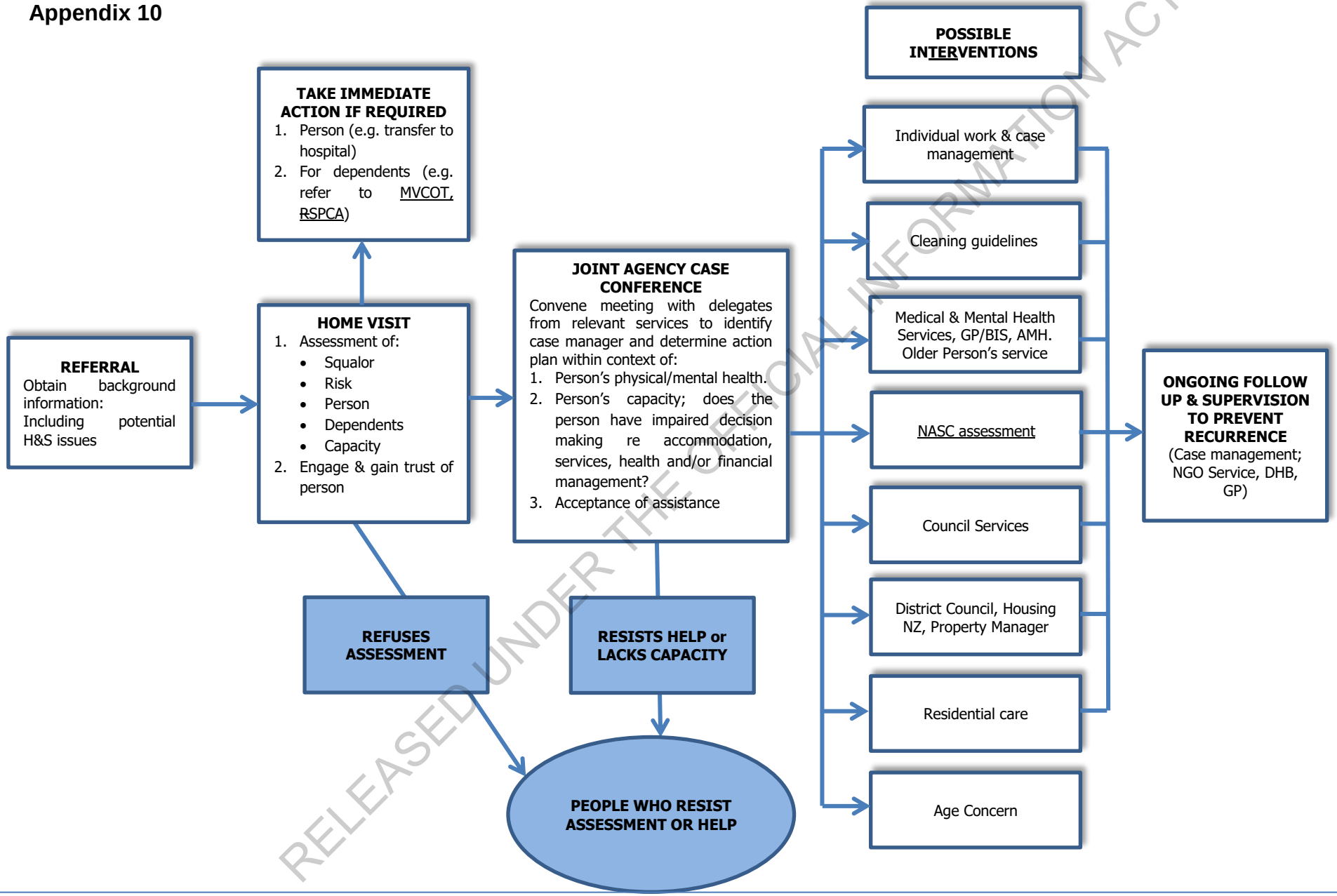
First impressions when entering Mary's home were good, the lounge was very tidy but all the other doors were closed.

Once past the public areas the hoard was extensive, the hallways were piled high with clothing, posing a safety hazard, the bathroom was unusable and the kitchen was over-flowing. Cupboards were open with contents literally flowing onto the floor, the stench was appalling. There were no free surfaces and no place where meals could be prepared or cooked. Mary would go out and buy bags of groceries but would leave them on the floor because there was nowhere to put them. Vegetables and food were rotting in bags, the freezer was so full the lid wouldn't close; Mary would take meat out of packs and stuff it into any gap she could find in the freezer.

Mary had no insight into the issues, although reluctant to engage, the hospital would not allow her to return until the issue had been addressed.

FLOWCHART 1 : ASSESSMENT & SUPPORT FOR PEOPLE LIVING IN SQUALOR

Appendix 10



FLOWCHART 2 : SUPPORT FOR PEOPLE WHO ARE UNWILLING TO ACCEPT ASSISTANCE