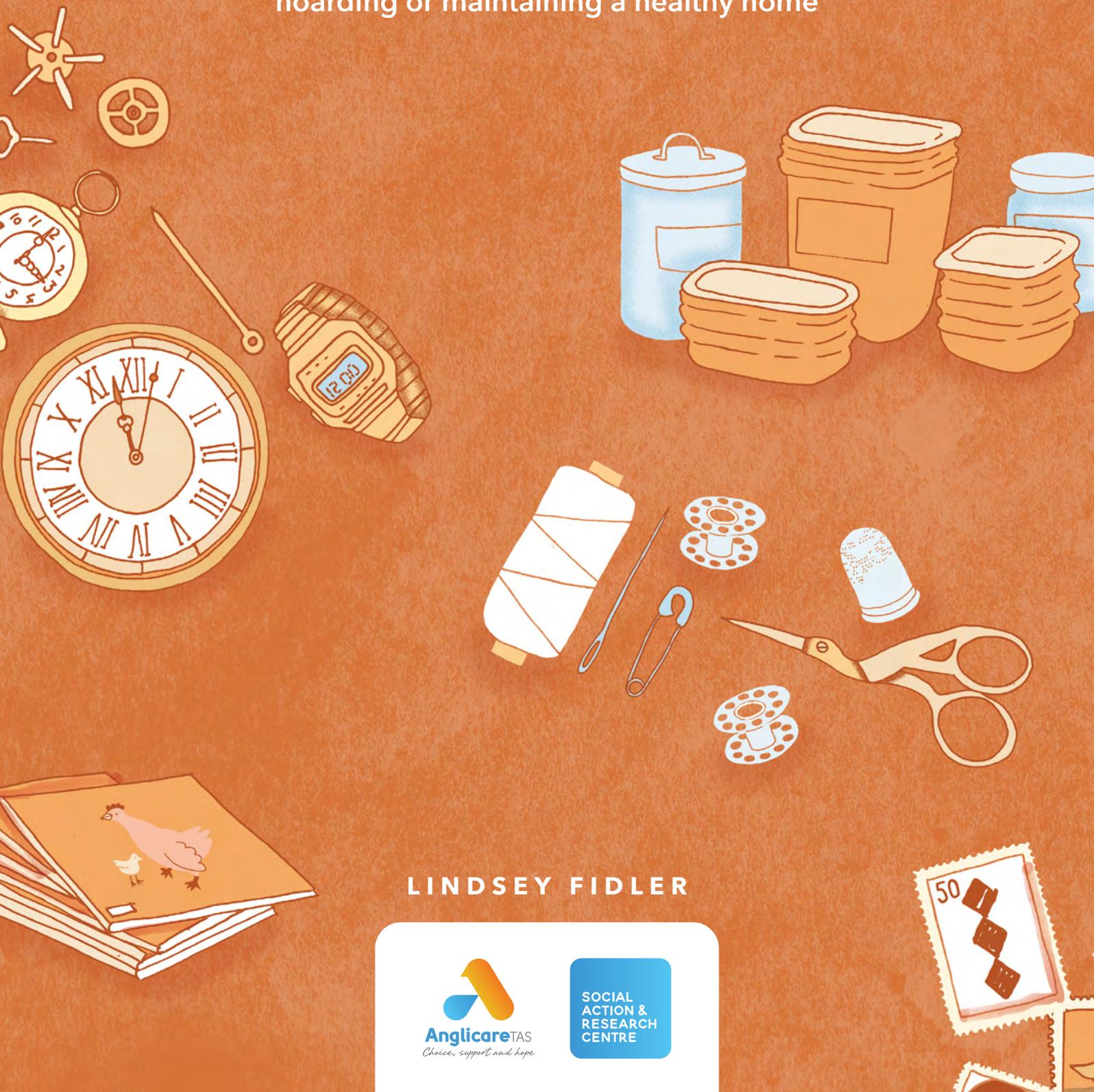


Treasured Lives

Enabling independent ageing for older Tasmanians living with challenges related to hoarding or maintaining a healthy home



LINDSEY FIDLER





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Treasured Lives

Enabling independent ageing for older
Tasmanians living with challenges related to
hoarding and/or maintaining a healthy home

PHASE 2: THE POLICY AND SERVICE ENVIRONMENT

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Acknowledgements

The fieldwork for Phase 2 of *Treasured Lives* was undertaken at a time of unprecedented demand on Tasmania's health and community services. COVID-19 was anecdotally reported to be exacerbating social isolation for many; meanwhile Tasmanians who were more present around their homes were reaching out to services and environmental health officers with concerns about elderly relatives and neighbours, as they had more time to notice. Increased unemployment, poverty and sudden opportunities to travel after lockdown had reportedly combined to increase animal surrenders. It was also a period of significant social policy reform in aged care, disability and mental health and adult community care. Many potential participants were busy, but willingly gave their time to share with me their deep concerns around one of Tasmania's most vulnerable older cohorts and demonstrated their commitment to addressing an enduring and complex Tasmanian blind spot. I am extremely grateful to all who took time out of their busy lives to share their thoughts with me.

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Once again, I'd like to thank Selina Claxton. The Treasured Lives resources lists and website are a testament to her endless attention to detail and ability to reach the far corners of our digital world. And thanks to Ellen Nicholson, who has as always provided excellent supervision, survey data management and logistics.

And importantly, I would like to acknowledge our Tasmanians and their families living with hoarding and challenges maintaining a healthy home. We sincerely hope that this project will help us move closer to recognising your needs and supporting you to age well at home.

LINDSEY FIDLER

CHAPTER ONE

About the research



1.1 Before Treasured Lives ...

The starting point for the Treasured Lives project came from conversations with Tasmanian clinical and community sector service providers about Tasmanians living with hoarding or challenges maintaining a healthy home (CMHH), which are familiar cohorts to many organisations working in local communities.

In 2012, a multidisciplinary *Hoarding and Squalor Forum* formed in northern Tasmania, led by Partners in Recovery (PIR)¹. It brought together those services needed to case-manage people who were living with hoarding or CMHH across the region. This was a voluntary group and included mental health service providers, housing support services and providers, emergency services, councils (local government) and animal welfare services.

Approximately 80% of Tasmanian PIR Facilitators reported working with at least one person who hoarded or had CMHH. They said supporting these people required more time than their other cases, and the lack of referral options for specialist therapeutic or practical supports in Tasmania made support coordination very difficult. They also reported that positive changes in the wellbeing of those they worked with were challenging to realise. Anglicare Tasmania's Housing Connect Support Workers and Disability Support Workers reported similar challenges (H&SWG 2017).

The void in targeted policy, programs and practice guidance that these Tasmanian services were working with led them to form the Northern Hoarding and Squalor Working Group, which produced a policy paper in 2017 (H&SWG 2017). The recommendations were to fund a research project to inform state government about the extent of these issues and resource planning, and that state government should develop a framework to guide practice, along with a therapeutic program to support those identified as at risk of hoarding and CMHH (H&SWG 2017).

Inevitably, without dedicated resources to continue case management across the Tasmanian north and to advocate for these recommendations, the working group disbanded and specific investment has not materialised.

Tasmania still lags behind most other Australian jurisdictions in its strategic response to hoarding and CMHH across household types. In contrast to other states, such as Victoria, New South Wales and South Australia (DoH [Vic.] 2012, 2013; Stark 2013; DoHA [SA] 2013), Tasmania does not currently have the appropriate social policy, program and practice settings to facilitate this challenging work. There are no specialist services who specifically work with Tasmanians or their families and carers who have issues around hoarding/CMHH to holistically address the underlying causes, the hoarding behaviour itself and its environmental, social and personal impacts. The challenges and needs identified in the Working Group's policy paper have remained unaddressed and are echoed by professionals participating in Treasured Lives.

1 Partners In Recovery (PIR) Tasmania was a pre-NDIS consortium between five agencies: Anglicare Tasmania, Colony 47, Richmond Fellowship Tasmania, Relationships Australia Tasmania and Wellways. PIR Tasmania assisted people with severe and persistent mental illness and complex needs to access required supports and services. Where these supports were unavailable or inaccessible, PIR worked to build capacity by identifying and addressing gaps and barriers. PIR employed support facilitators in every local government area of Tasmania. They worked with sensitivity and flexibility with each person, their family, friends, carers and other services to facilitate a coordinated response to both clinical and community living needs.

1.2 The costs of not caring: why this is a Tasmanian priority right now

Tasmania has the highest proportion of the population of any Australian state or territory aged over 65, at 19.4% (nearly 100,000 people). By 2037, it is predicted that a quarter of the state's population will be over 65, and over 40% in some local government areas (COTA Tas 2018).

One of the “pillars” within the Royal Commission into Aged Care Quality and Safety's much-anticipated report was concerned with how we enable more older Australians to age well in place with ‘respect, care and dignity’ (Royal Commission 2021). The report describes how care should ‘Support people living at home to preserve and restore capacity for independent and dignified living, and prevent inappropriate admission into long term residential care’ (Royal Commission 2021).

The Commissioners focused on the importance of an integrated care model to enabling this goal. An integrated care model brings together practical supports, such as personal care and domestic assistance, with clinical and allied healthcare that can support a wide range of physical and mental health challenges. These are further combined with supports that encourage or enhance older Australians' social connections and supports to address other personal and structural vulnerabilities, such as insecure housing and risks of homelessness (Royal Commission 2021).

Older Australians living with hoarding or CMHH are amongst those most vulnerable to not being assisted to age well at home. Due to the complexity and diversity of their potential needs across clinical, psycho-social and practical supports, they are amongst those most likely to require a suite of integrated supports as described by the Royal Commission. In the absence of such care, these older Australians are particularly vulnerable to poor outcomes in aging. Risks include social isolation and poor mental health, increased risks to their health and safety (including trip and fall hazards, blocked exits and cluttered environments leading to fire risks, and poor access for emergency services), housing insecurity due to threatened tenancies, financial vulnerability, self-neglect and disrupted and often broken family relationships (Park et al. 2014; Tompkins 2011; Wilbram et al. 2008).

Despite hoarding behaviour being recognised as a designated psychiatric condition by both the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed, DSM-5) and the World Health Organisation (APA 2013; WHO 2018), and in the face of analysis highlighting that ‘late life hoarding is a serious psychiatric and community problem that warrants considerable attention’ (DoH [Vic.] 2012), Australia lacks a national strategy, suite of investments, or a practice framework to address the needs of older Australians living with these challenges (CCS 2014; Fidler 2021).

There is very little national or international literature to inform such a strategy or framework. Research that directly explores the **experiences and needs** of those living with hoarding and CMHH is rare, and there is even less relating specifically to the experiences of older people.²

² Literature tends to focus on participants' diagnoses and behavioural descriptions, rather than exploring their lived experience through their own reports (see Ayers et al. 2013; Guinane et al. 2019; Roane et al. 2017), although there is a sprinkling of valuable first person accounts emerging within digital media and books (see Appendix 4).

Coupled with this, those living with hoarding or CMHH are typically amongst those unlikely to seek supports (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011). This makes their needs both knowingly complex and unknown and are amongst older Australians who are most likely to challenge the current consumer-directed approach inherent within the aged care model (Bozinovski 2008; Gunstone 2003; Mixson 1991; Moody 1988; Simmons & O'Brien 1999).

These factors make designing relevant services and supports for older Australians living with hoarding or CMHH at best challenging, and at worst left in an unusual policy space – one that is understood to be “hard to address”, or a “wicked issue” (Head 2008; McConnell 2016; Hoornbeek & Peters 2017).

Right now, there is an opportunity to inform Australia’s and Tasmania’s social care agendas. Australia’s aged care is in transition as the federal Department of Health (DoH [Au]) works out how best to respond to the Royal Commission’s recommendations. The new aged care model plans to combine the current Commonwealth Home Support Program (CHSP) with Home Care Packages (HCPs) into a new Unified Support at Home Program (USHP) from 2023 (DoH [Au] 2021). In parallel, there is an opportunity to inform the ongoing redevelopment of the federal National Disability Insurance Scheme (NDIS), the Tasmanian state mental health strategy *ReThink* (DoH [Tas] 2015b, 2020a) and Tasmania’s Health and Community Care (HACC) reform for adult social care.

Catholic Community Services (CCS) have estimated that it costs the Australian government about **\$56,800** to support one household living with hoarding or CMHH through emergency and critical care responses (CCS 2014), and that costs are likely to grow over time if we don’t intervene with national and state specialist policies, services and supports. Based on these CCS estimates, the Tasmanian government may be spending over **\$280m** on older Tasmanian households living with hoarding or CMHH through emergency and critical care.³ The social and economic costs for older Tasmanians, their families and the Tasmanian community will grow exponentially if not addressed.

Tasmania has a clear incentive to lead thinking about how to age well and is well-placed to lead innovations that ensure people who are nearing retirement age with acute challenges to wellness and reablement are supported to plan for and live their older years with as much independence and dignity as is possible. Tasmania is also well-placed to lead supports for those already eligible for aged care to age well at home. As the Council on the Ageing (COTA) Tasmania’s CEO has highlighted, ‘Tasmania could be the experts for age-friendly planning, if it grabs the opportunity with two hands’ (COTA Tas 2018). There are a number of federal and state policy reforms that make this an opportune time to consider how to support those most vulnerable to poor outcomes in later years.

Treasured Lives aims to support the Tasmanian government to recognise and prioritise this important group of elders and their families and, drawing on local evidence and international practice, start to co-design Tasmania’s framework for supporting our older people living with hoarding or CMHH to age well with proactive compassionate care.

3 These figures are estimates. They apply the estimated costs of critical support to one household provided by Catholic Community Services (2014) to an estimated 5000 older Tasmanians living with hoarding. See Chapter 2.7 and Appendix 3 for more details.

1.3 About the Treasured Lives project

Treasured Lives wants to acknowledge the important work of Tasmania's Northern Hoarding and Squalor Working Group on identifying this hidden and stigmatised cohort of Tasmanians and the tremendous work the group did in bringing together a broad group of agencies to address their needs.

The project has aimed to build on this work by providing the research needed to inform a federal and state government response for a specific group amongst those identified by the Working Group – older Tasmanians and their families and carers.

This project investigates:

- what information/data exists about the prevalence of these challenges amongst older Tasmanians
- the experiences of the families and carers of people living with hoarding or CMHH
- the experiences and challenges of clinical and community service providers, emergency services and the local, state and federal government agencies that design policy and programs to support such older Tasmanians and their families and carers
- good practice in supporting older people and their families and carers across other Australian jurisdictions and internationally.

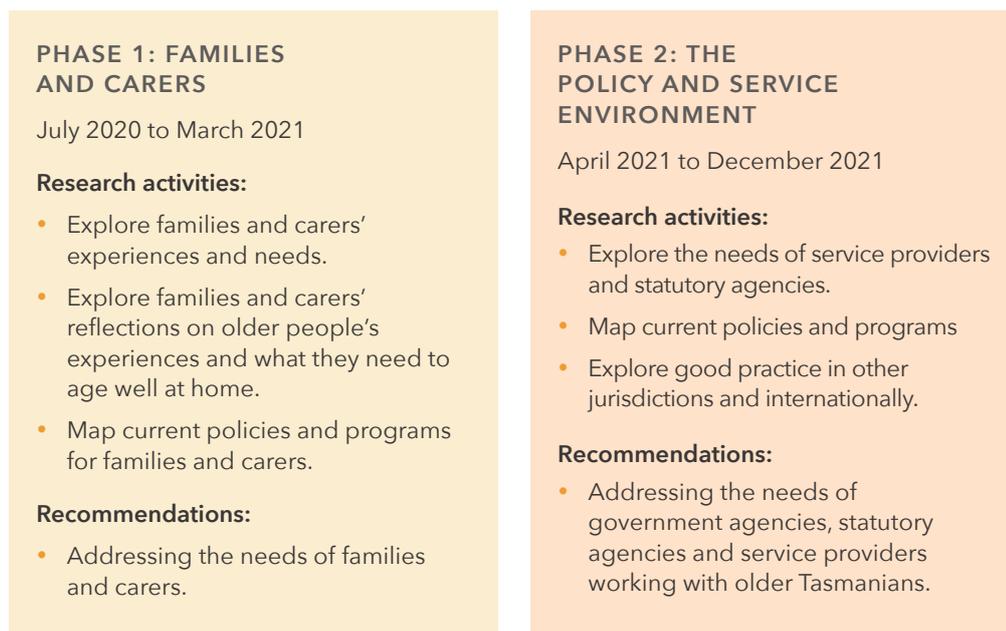
The project has utilised an inductive approach (Giddens 1982; Sarantakos 1998; Seale 2001) with a focus on understanding participants' experiences, relationships, needs, enablers and challenges, from which the framework for responding has emerged. It received research ethics approval from the University of Tasmania's (UTAS) Human Research Ethics Committee.⁴

Given the complexity and sensitivity of these issues and the breadth of stakeholders with an interest in this area, the project has been divided into two phases (see Figure 1). The first investigation was into the experiences and needs of families and carers of older people living with hoarding and/or CMHH (Fidler 2021). The second phase has been focused on the service providers supporting such older Tasmanians and their families and carers (see Figure 1).

The project received research ethics approval from UTAS' Human Research Ethics Committee to undertake a further research phase. This would have enabled older Tasmanians living with these challenges who were engaged with Older Persons Mental Health Services South to share their experiences and needs. However, this phase has not been able to proceed, due to the capacity of the Tasmanian Department of Health to complete the paperwork associated with their internal research governance requirements.

This unique insight into the views of older Tasmanians living with these challenges would have provided us with a holistic understanding of needs across the three significant stakeholders groups in Tasmania. However, the absence of Phase 3 does not undermine the validity of experiences and needs expressed by families and carers during Phase 1, nor those reported by professionals in Phase 2. The complimentary recommendations within these two reports were tested with research participants and are designed to meet their needs in supporting older Tasmanians, as well as meeting their own support needs.

4 Project no. 18686.

FIGURE 1: TREASURED LIVES PHASES AND TIMELINES

1.4 Phase 1: Families' and carers' needs

The first phase focused on the experiences and needs of families and carers. The research supported previous research findings, describing families and carers as 'team players' and 'support contractors' (Tompkins et al. 2011). It expanded our understandings of what this means within a Tasmanian context:

The report described how families and carers played key relational, practical and emotional roles in the lives of those they cared for:

- relational elements such as navigating stigma, family and community relationships and maintaining trust and privacy for those they cared for, often being the only person who visited or had contact with the person/people they were caring for
- practical elements such as negotiating and maintaining a degree of safety in the home of those they cared for, with no or very little input from professional support services
- emotional factors such as balancing other care responsibilities and maintaining often fragile and fractious relationships with little support for themselves.

The majority of families and carers had had at least some discussions with those they cared for about how and where they would like to age. There was an overwhelming desire amongst those they cared for to age at home. But families and carers expressed significant concerns about how ageing well at home could happen, given not only their care recipients' attachment to place, but their attachment to the collections within that place. There was a common concern that those they cared for would not be able to stay living in their home unless it was made safer for them and that, ultimately, the care recipient would be forced to leave their home and enter residential care.

Barriers to accessing supports reported by families and carers included:

- **a lack of recognition amongst those they cared for that supports were needed**, due to reportedly low insight into their challenges and their impacts
- **stigma and shame being perceived to inhibit help-seeking** and driving some of the demand for privacy amongst those living with hoarding and/or CMHH
- **those they cared for being wary of intervention**. This was not only because of low insight into challenges, or shame or judgement, but also because they were wary of what would happen if support services intervened. This may have been driven by the need to control and protect their current living environment, or because they perceived that services would want different outcomes from support interventions than they themselves did (Tompkins et al. 2011)
- **a lack of knowledge about what services (if any) were available** to them regarding hoarding and CMHH in Tasmania.

The Phase 1 report identified that care recipients are most likely to engage with services due to critical incidents such as hospitalisation, fire, risks to tenancies, or neighbourhood complaints. When they engaged, there was an opportunity to create pathways for them and these “first responder” services to connect with specialist clinical, psychosocial and practical supports. Such pathways to social care would support not just the presenting issues, but the underlying causes of challenges. Secondly, the report identified that there was an opportunity to link families and carers and those they cared for to specialist clinical, psychosocial and practical supports when conversations arise around what is needed for them to age well at home. Currently, these pathways to support do exist in Tasmania (Fidler 2021).

In Phase 2 of Treasured Lives, we have further explored these prospects with those who work with older Tasmanians living with these challenges.

1.5 Phase 2: The needs of services and agencies that support older Tasmanians

The focus on the experiences and needs of families and carers in Phase 1 of Treasured Lives was a crucial part of piecing together what needs to be in place to support older Tasmanians living with hoarding or CMHH to age well in Tasmania.

However, we are conscious that not all older Tasmanians living with hoarding or CMHH have family or carers around. They are often socially isolated, reluctant to seek help and distrusting of intervention (Ayres et al. 2010; Chabaud 2020; DoH [Vic] 2013; Neziroglu et al. 2020; Roane et al. 2017; Tompkins 2011; Tolin, Fitch et al. 2010). We do not have Tasmanian statistics to inform this view. But anecdotal reports from service providers before this project began and from research participants perceived that many – perhaps the majority – of older Tasmanians they are working with are not in contact with family and do not have a designated informal or formal carer.

Research questions

Phase 2 of Treasured Lives has been focused on exploring not only what supports would help older Tasmanians to age well at home, but also exploring the experiences and challenges for service providers and statutory agencies in Tasmania systemically, structurally and on an interpersonal basis with older Tasmanians living with these challenges:

SYSTEMIC:

- What information/data exists about the prevalence of these challenges amongst older Tasmanians?

STRUCTURAL:

- What does the Tasmanian policy and service landscape offer those supporting older Tasmanians living with hoarding and CMHH to age well?
- What can we learn from practice elsewhere in supporting older people and their families and carers?

INTERPERSONAL:

- What are the experiences and challenges of clinical and community service providers, emergency services and the local, state and federal government agencies that design policy and programs to support such older Tasmanians and their families and carers?

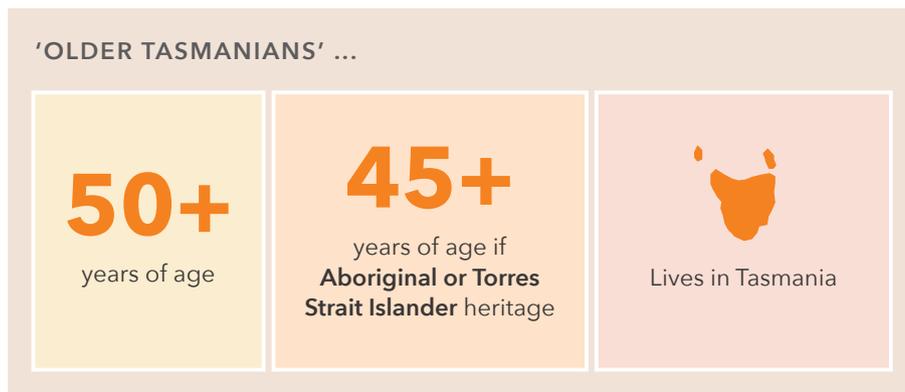
Methodology

AN EXPLORATION OF CURRENT POLICIES AND SERVICES

Semi-structured one to one and group interviews were conducted with clinical and community service providers and statutory agencies that offer services and support for older Tasmanians who may live with hoarding and/or CMHH. By “older Tasmanians”, we mean those who:

- **are aged 50** or over (or 45 or over if they are of Aboriginal or Torres Strait Islander heritage)⁵
- are having, or had had, **challenges with hoarding and/or maintaining a healthy home**
- **live in Tasmania.**

5 We are defining “older age” as 65, or 55 for people of Aboriginal or Torres Strait Islander background, in line with the Australian Department of Health’s aged care programs. This recognises that supporting hoarding and CMHH is a slow and long-term process. The project wanted to consider what supports could help people prepare for “older age”, as well as what is needed once people reach that age.

FIGURE 2: KEY DEFINITIONS – “OLDER TASMANIANS”

Organisations who could not participate in an interview were encouraged to complete an online survey.

Both the interviews and the survey asked participants to describe how they encountered people living with such challenges, the nature of the challenges they observed for those older Tasmanians and the impacts, the challenges faced by them as service providers, and what they would need to effectively provide support for such older Tasmanians to remain living at home as they age.

These organisations either incidentally or directly encountered people living with hoarding and/or CMHH. They included home-based aged care services, adult and older person’s clinical and community-based mental health services, disability support services, housing providers and specialist homelessness services, animal welfare and management services, emergency services and council environmental health and planning services.⁶ Some were state-wide service providers, while others offer specialist services for specific cohorts, or on a regional/local basis. Chapters 4-7 explore these experiences.

AN EXPLORATION OF RELEVANT INFORMATION SYSTEMS

Initial discussions with services and agencies in developing the research had indicated that there is no robust collection of data in Tasmania that might inform policy and service planning. Therefore we did not ask for data as part of the service provider and statutory agency interviews and survey.

We did ask what their information systems record around people they worked with who lived with hoarding or CMHH and what would be useful to them for designing and planning future support services. Chapter 7 explores this current data landscape and what consideration needs to be given to Tasmania’s information systems to help understand and plan policy and services going forward.

⁶ We were unable to interview services funded via the Tasmanian Department of Health, outside of Older Persons Mental Health Services South, due to changes to the Department’s research ethics approval processes since the project was initially designed.

AN EXPLORATION OF WHAT HAPPENS ELSEWHERE

We undertook desktop research on policies, programs and practice that are offered elsewhere in Australia, in North America and in England and Wales, UK.⁷ These areas were chosen due to their longevity of policy and practice in supporting those living with hoarding and CMHH, and for both their commonalities and diversity in approaches. Chapters 8 to 10 describe the general trends in policy, program and practice design and showcase how such content operates through featuring a series of national and international case studies.

These elements of policy, programs and practice were then compared to what Tasmania offers. This exercise enabled us to identify what elements of a policy, program and practice framework are missing in Tasmania.

Given Tasmania does not have a cohesive framework of supports for those living with hoarding or CMHH at the moment, the project has attracted a considerable amount of attention from professionals seeking support for their clients, families and neighbours seeking support for those they care for and older Tasmanians themselves living with hoarding and CMHH. To address the demand for information and support, we decided to construct a **selected** list of resources that may be useful for those living with hoarding, families and carers of those living with hoarding and/or CMHH and those working with these two groups (see Appendix 5). It was compiled by the Treasured Lives project team based on the resource/program:

- offering a responsible coverage of the context for hoarding and/or CMHH, based on an understanding of both aetiology and impacts
- explaining the approaches to support within that context
- raising awareness and positive engagement about hoarding and/or CMHH.

This has been made available on the Treasured Lives website to provide an interim information hub whilst this project is conducted.

PARTICIPANT-LED RECOMMENDATIONS

The draft report and recommendations were provided to all interview participants, as well as the reference group, for feedback before finalisation.⁸

7 Local authorities in the four countries that constitute the UK have different administrative and legislative frameworks. We focused on responses in English and Welsh local authorities, rather than those across the UK. We wanted to examine the specific duties that English and Welsh local authorities have in relation to responding to self-neglect.

8 The Treasured Lives Reference Group includes members representing consumer voices (older Tasmanians, people living with mental health challenges); peak bodies representing families and carers; key federal and state government agencies with policy portfolios related to adult, disability and aged care, as well as mental health and housing; agencies with statutory responsibility for emergency services and public health (local government); and key areas of service provision, including clinical and community sector mental health services, aged care services, housing support services and disability services across Tasmania.

CHAPTER TWO

Understanding hoarding and challenges maintaining a healthy home and their impacts



2.1 Key messages

- **Self-neglect:** Countries such as the UK and North America have incorporated policy and service responses to hoarding and CMHH within a broader understanding of self-neglect.
- **Hoarding disorder** is a psychiatric condition which can be comorbid with another mental health condition, personal trauma and negative self-constructs. Effectively supporting a person living with hoarding behaviour requires an understanding of their cognitive, psychosocial and contextual challenges and their attachments to items and animals.
- **CMHH** often present as secondary conditions to a range of medical and psychiatric conditions and drug and alcohol use. Loss of a domestic partner and the lack of skills to maintain a sanitary environment can exacerbate challenges (Guinane et al. 2019). Supporting a person living with CMHH requires an understanding of this context to address underlying causes as well any presenting risks to health and safety.
- **Prevalence and demographics:** Given the hidden nature of much hoarding and CMHH, there is no consistent Australian data about the extent of these challenges or demographic profile of those living with these challenges:
 - » International estimates suggest 2.5% of the adult population lives with hoarding (Postlethwaite et al. 2019). This would suggest that there are approximately 5,000 older Tasmanians (50+) living with hoarding behaviour.
 - » North American data shows that the mean age of patients diagnosed with hoarding disorder is between 53 and 67 years old (Ayres et al. 2013; Dimauro et al. 2013, cited in Guinane et al. 2019). Animal hoarders tend to be female and living alone (Lockwood 2018). The limited data around older self-neglecters suggest they are more likely to be male, low income and living alone (Abrams et al. 2002).
- **Personal and social impacts:** The risks of living with hoarding and CMHH to residents' health, safety and functioning tend to accumulate with a person's age, due to decline in physical health and neurocognitive decline, including the increased likelihood of dementia (Snowdon et al. 2007). These may include:
 - » Personal: poor mental and physical health; self criticism and shame; increased risk of premature death or injury; risk of premature entry into residential aged care; financial strain
 - » Social: social isolation; stigma and judgement; strained family relationships; reduced help-seeking
 - » Environmental: increased risks of injury (trips and falls); reduced access to kitchen and bathroom for self-care; reduced access to social care support and emergency services; housing insecurity
 - » Animals: risk of zoonotic diseases; poor health and nutrition for people and animals; stress and trauma amongst animal welfare staff.
- **Costs to the Australian economy** of supporting one household living with hoarding or CMHH through emergency and critical care responses has been estimated to be \$56,800. This cost has been estimated to drop to \$3000 per household with adequate preventative and response supports in place (CCS 2014).

The World Health Organisation's acknowledgement of hoarding disorder as a standalone mental health disorder was expected to improve public understanding of the condition and reduce stigma (Heffer 2018; Robertson 2018). This is based on the assumption that such acknowledgement would reassure individuals living with such challenges and the community that 'help can be given and they are not alone' (Robertson 2018). However, the increasing number of reality TV programs featuring those living with hoarding and/or CMHH may have reached deeper into the public consciousness than the WHO messaging.

People living with hoarding and/or CMHH and their families are more often judged than understood. The visibility of their condition often defines them in the community and promotes responses of self-criticism, shame and social withdrawal (Chou, Tsoh et al. 2018; Danet & Secouet 2018; Tompkins 2011). Such stigma and stereotyping can lead to families further retreating from the communities in which they live and tends to result in low help-seeking (Tompkins 2011).

Shaping appropriate support responses for older Tasmanians living with hoarding and/or CMHH and their families and carers demands that we understand the nature of the challenges, their root causes and their personal, social and environmental impacts (Bozinovski 2008; Chou, Tsoh et al. 2018; Frost et al. 2000; Gunstone et al. 2014). It also requires a shared understanding of when it is appropriate to offer support or intervene in such private matters as how a person chooses to live.

Although hoarding behaviour and CMHH are often considered together, they do not always go hand in hand. Understanding this distinction is important in shaping appropriate clinical and community-based supports to complement practical supports available for older Australians, as is understanding the relationship and trajectory between these two challenges as people age (Guinane et al. 2019; Lee et al. 2017).

Here, we offer a brief overview of what academic and grey literature tell us about the nature of self-neglect, hoarding behaviour and CMHH, what we know about prevalence and the characteristics of those living with these challenges and the personal, social and economic impacts.

In Chapters 5-11, we will draw on this understanding to consider implications for policy and service responses and professional practice.

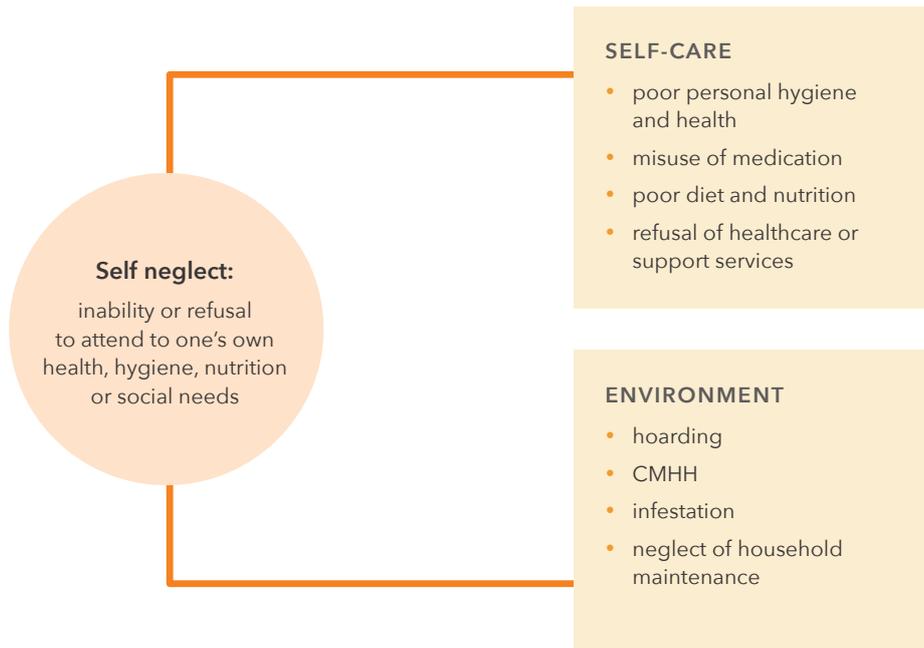
2.2 Elder self-neglect

Broader than hoarding behaviour or CMHH, "self-neglect" is a behaviour described as the 'inability or refusal to attend to one's own health, hygiene, nutrition or social needs' (Abrams et al. 2002). It provides a broader context in which policy and service responses for older people living with hoarding behaviour or CMHH can be framed. In fact countries such as the UK and North America have incorporated responses to hoarding and CMHH within a broader social policy framework of self-neglect (see Chapter 8).

Understanding elder self-neglect is emerging as an important area of compassionate clinical care for elderly Australians (Abrams et al. 2002; Bozinovski 2008; Gunstone et al. 2014; Micallef 2021). It considers risks and concerns around self-care (such as

poor personal hygiene or health, refusal of healthcare or support services) and/or the environment (hoarding, CMHH, infestations, neglect of household maintenance) (Bozinovski 2008) (see Figure 3). The extent to which elder self-neglect should be seen as inevitable or unavoidable, and consequently, when it is acceptable to intervene in a person's decision-making or actions around their most intimate environment and personal space, continues to be an unresolved professional ethical dilemma.

FIGURE 3: KEY DEFINITIONS – “SELF-NEGLECT”



Sources: Abrams et al. 2002; Bozinovski 2008; Micallef 2021

Self-neglect, similar to hoarding behaviour and CMHH, is likely to increase in severity with age (Abrams et al. 2002). Again, similar to hoarding behaviour and CMHH, it is a complex, not very well-understood concept (Bozinovski 2008). There is very little research from the perspective of those with lived experience. As a concept, it can be viewed through different prisms by clinical and community support professionals.

Analysis of self-neglect traditionally assumed that this behaviour resulted from mental, physical and social challenges, and that self-neglect itself increased such challenges (Abrams et al. 2002). Depressive symptoms and/or cognitive impairment may increase the likelihood of self-neglect amongst older adults (Abrams et al. 2002). Evidence also suggests that self-neglect increases frailty and cognitive decline beyond the normal ageing process (Abrams et al. 2002).

In a rare study, Bozinovski worked alongside a number of elders living with self-neglect to understand more about the psychosocial motivations behind such behaviour. This study explained behaviour that is often perceived as self-neglect brought about by physical and mental decline in functioning as being a much more proactive set of behaviours on the part of older people. The research reported this behaviour as a way for older people to 'maintain continuity' as they age (Bozinovski 2008).

Bozinovski describes the fraught interactions that many older people have with family members, external professionals and community members around their living environment, similar to those described in Phase 1 of *Treasured Lives* (Fidler 2021). She argues that interactions around bodies, behaviour and living environment become the main threats to both elders' personal identity and their sense of personal control. Viewed in this way, maintaining continuity, 'goes beyond being just an adaptive strategy. It is a motivating force and also a continuous life goal' (Bozinovski 2008).

In other words, what others are observing as self-neglect (sometimes including living in a cluttered or unsanitary environment) may not be a way some older people have adapted to their decreasing capacity to self-care and/or clean and sort their living environment. Bozinovski would argue it may be more about older people's continuous attempts to maintain control of their bodies, their behaviour and their living environment as they age. Viewed this way, for older people living with hoarding or CMHH who had these challenges when they were younger, any external attempts to support them around their living environment (whether via family, voluntary carers or professionals) may be seen as a significant threat to their assertion of control and continuity.

2.3 Hoarding

Since 2013, hoarding has been classified as a standalone psychiatric disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and was added to the World Health Organisation's (WHO) International Classification of Diseases 10 in 2018 (Whomsley 2020). Hoarding disorder involves challenges with acquiring, sorting and/or discarding items or animals (Frost & Hartl 1996, cited in Buscher et al. 2014). It is defined as 'The accumulation of a vast amount of possessions which compromises living spaces and causes impairment in social and occupational functioning' (Tolin et al. 2011, cited in Guinane et al. 2019). Excessive collections can consist of anything, but common items include newspapers, food packaging, clothing, electrical appliances and animals (DoH [Vic.] 2012; Stark 2013). There are varying accounts of whether item and animal collections usually coexist (Dozier et al. 2019; Snowden et al. 2019). The reality is likely to be that collections and the reasons behind them are specific to the individual.

FIGURE 4: KEY DEFINITIONS – "HOARDING"



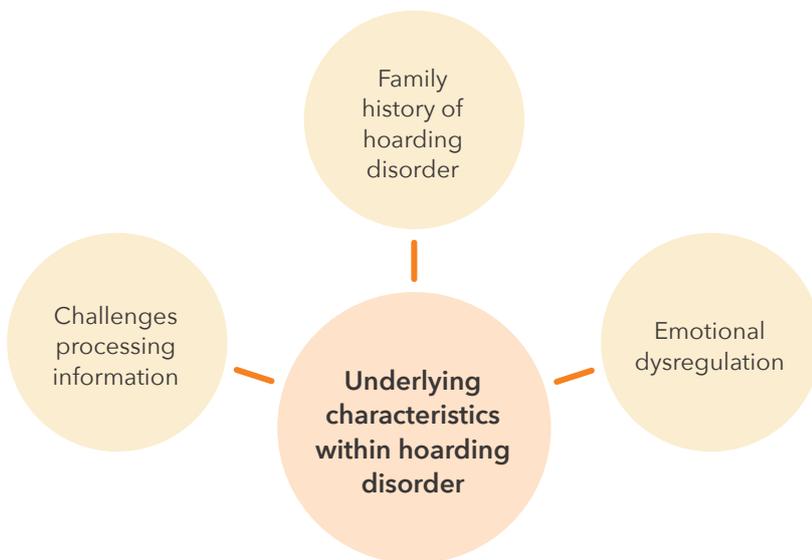
HOARDING

- Challenges with acquiring, sorting or discarding items or animals
- Attaching significant meaning to items, which impedes ability to discard
- May be a diagnosed disorder (DSM5), or co-morbid with mental health or other conditions
- Leading to a cluttered living environment and impeding the use of rooms for their intended function, the health and safety of residents, and/or leading to an animal welfare concern

An important element of hoarding disorder is holding meaning or emotional attachment to items that others would see as not valuable (Danet & Secouet 2018). This attachment leads to significant emotional struggles in thinking about or actually discarding items. Understanding this attachment and how it may have developed is crucial to understanding how to support a person to sort and discard.

Contemporary understandings of hoarding behaviour focuses on cognitive drivers (Chou, Tsoh et al. 2018; Frost and Hartl 1996, cited in Buscher et al. 2014). Hoarding disorder is understood to be associated with a range of potential underlying characteristics: emotional dysregulation, difficulties processing information, and comorbid mental health challenges (Snowdon et al. 2019; Stark 2013). Studies also suggest that there may be strong hereditary factors (Mathews et al. 2007, cited in DoH [Vic.] 2013; Grisham & Norberg 2012, cited in Stark 2013). Up to 85% of people with hoarding behaviours can identify another family member who displays similar behaviour (DoH [Vic] 2013) (see Figure 5).

FIGURE 5: HOARDING DISORDER – COMMON UNDERLYING CHARACTERISTICS

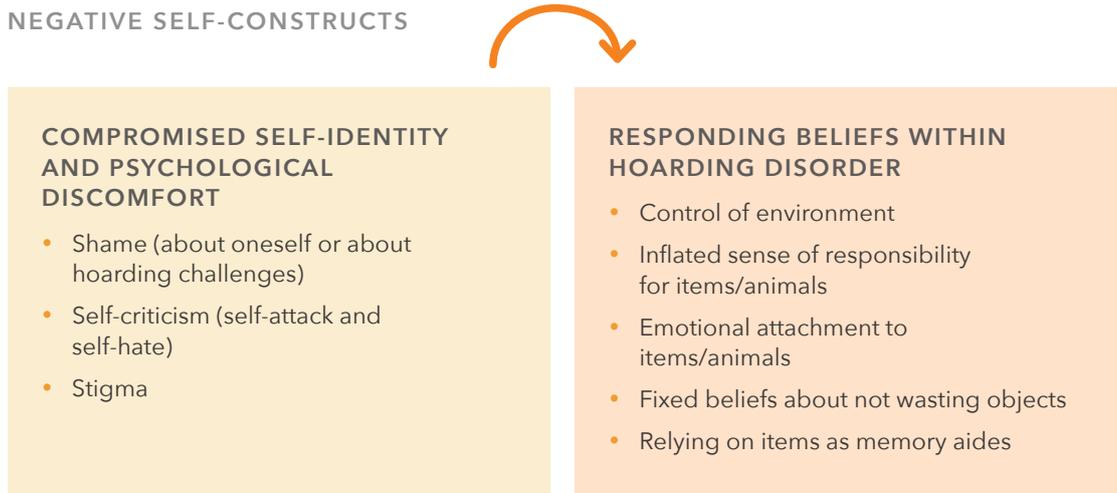


Source: Stark 2013

Hoarding behaviour is understood to be a way that some people compensate for compromised self-identity and the psychological discomfort (shame and self-criticism) that result from their view of themselves (Brown 2011; Chou, Tsoh et al. 2018; Frost et al. 2007). The severity of hoarding behaviours is understood to be negatively related to specific elements of cognitive constructs around self-identity (Chou, Tsoh et al. 2018). In particular, stronger feelings of self-criticism (self-attack and self-hate) and shame (about oneself as a person and/or about one's hoarding issues) appear to be 'underlying vulnerabilities affecting Hoarding Disorder pathology' (Chou, Tsoh et al. 2018) (see Figure 6).

There are reported to be a number of beliefs that potentially drive hoarding behaviours. An inflated sense of responsibility for items or animals is thought to be the belief most closely related with self-criticism and shame. Other beliefs include intense emotional attachment to items or animals, a desire to control their living environment, fixed beliefs about not wanting to waste objects and/or utilising items as memory aides (Chou et al. 2014; Stark 2013).

FIGURE 6: THE DOMAINS OF HOARDING BELIEFS AND THEIR RELATIONSHIP WITH NEGATIVE SELF-CONSTRUCTS

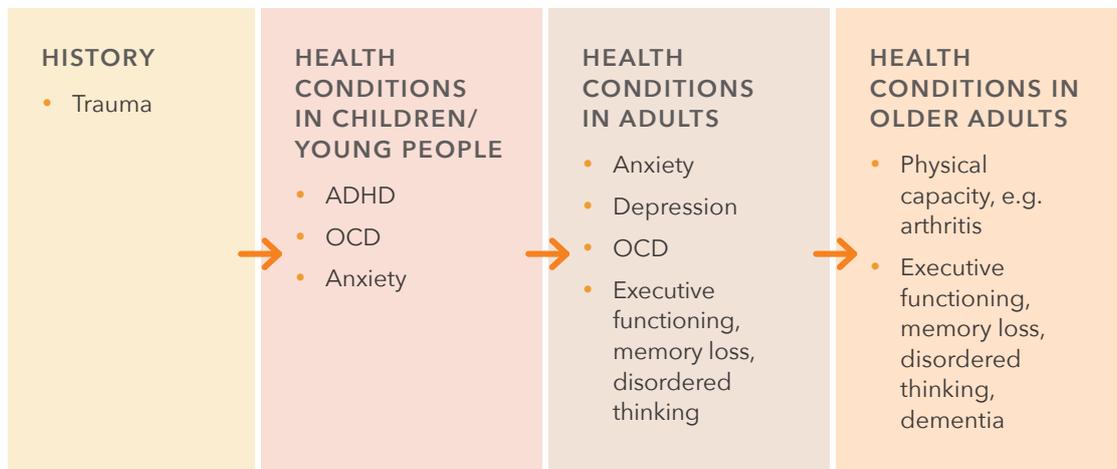


Sources: Chou, Tsoh et al. 2018; Stark 2013

People living with hoarding disorder commonly (but do not always) have comorbidities related to their mental health (see Figure 7). Common comorbidities include depression and/or anxiety (Frost et al. 2011, cited in Ayers et al. 2013; Frost et al. 2000; Guinane et al. 2019; Roane et al. 2017), a history of trauma (Brown & Pain 2014; Chou, Mackin et al. 2018; Roane et al. 2017), and/or issues with executive functioning (working memory, mental control, inhibition and set shifting), especially for those living with late-life hoarding (Ayers et al. 2013; Gleason et al. 2021; Roane et al. 2017).

The literature also suggests that hoarding behaviour in children is most likely to be comorbid with Attention Deficit and Hyperactivity Disorder (ADHD), and has lesser comorbidities with Obsessive Compulsive Disorder (OCD) and anxiety (Hojgaard & Skarphedinnsson 2020; Whomsley 2020). Amongst older people with hoarding disorder, impairment due to vascular dementia is common, as is arthritis and sleep apnea (Guinane et al. 2019; Roane et al. 2017) (see Figure 7).

FIGURE 7: HOARDING DISORDER – COMMON COMORBIDITIES IDENTIFIED IN PEOPLE’S PERSONAL AND HEALTH HISTORIES



Sources: Ayers et al. 2013; Brown & Pain 2014; Chou, Mackin et al. 2018; Frost et al. 2011, cited in Ayers et al. 2013; Frost et al. 2000; Guinane et al. 2019; Roane et al. 2017

A recent analysis of animal hoarders in New South Wales reported that mental health factors contributed to animal hoarding in over half of the 50 cases (Snowdon et al. 2019). However, as Snowdon et al. highlight, it is rare for “hoarding disorder” to be a primary mental health diagnosis. It tends to be other presenting psychiatric or psychological challenges that are assessed and “treated” (Snowdon et al. 2019).

There is a growing literature around hoarding amongst children (see Whomsley 2020 for a comprehensive overview). This suggests that hoarding disorder may be present, although likely to be undiagnosed, amongst children and may develop in early adolescence (see Tolin, Meunier et al. 2010, Whomsley 2020). However, hoarding tendencies are often suppressed by parents’ sorting and discarding efforts and may be escalated either due to a traumatic event (for example a loss or bereavement), or once children gain more independence (Whomsley 2020). So, although studies to date suggest the average age of onset may be 16.5, there is significant speculation that onset is likely to be earlier than this (Hojgaard & Skarphedinsson 2020).

Such evidence suggests that many older Tasmanians living with hoarding may have done so for a significant number of years. To address such behaviours requires a focus on cognitive and psychosocial therapy.

Animal hoarding

Since 2013, animal hoarding has been categorised as a ‘special manifestation of hoarding disorder’ by the American Psychiatric Association (Dozier et al. 2019). However, there is an emerging body of knowledge that suggests that animal hoarding may be a distinct disorder (Ferreira et al. 2017, cited in Dozier et al. 2019).

It is defined as an accumulation of a large number of animals that overwhelms a person’s ability to provide a minimum standard of nutrition, sanitation and veterinary care (DoH [Vic.] 2013). The American Hoarding of Animals Research Consortium (HARC) developed the definition to include ‘a denial of one’s inability to provide care to animals and urges to accumulate animals.’ (HARC 2002, cited in Dozier et al. 2019). The most common animals collected are cats, dogs, birds and small mammals (HARC 2002, cited in Dozier et al. 2019; Dozier et al. 2019).

Patronek et al. (2006) describe four common characteristics of those living with animal hoarding – see Figure 8. These characteristics highlight the challenges in supporting those living with animal hoarding. The potential impacts on the health and wellbeing of people, animals and the environment surrounding them are significant.

FIGURE 8: KEY DEFINITIONS – “ANIMAL HOARDING”



ANIMAL HOARDING

- Failure to provide minimal standards of sanitation, space, nutrition and veterinary care for animals
- Inability to recognise the effects of this failure on the welfare of the household and the environment
- Obsessive attempts to accumulate or maintain a collection of animals in the face of progressively deteriorating conditions
- Denial or minimisation of problems and living conditions for people and animals

Source: Patronek et al. 2006

There are three ‘types’ of animal hoarders – overwhelmed caregivers, rescuers and exploiters (Patronek et al. 2006), each recognised as requiring specialist supports (Castrodale et al. 2010; Dozier et al. 2019; Lockwood 2018; Patronek et al. 2006; Snowdon et al. 2019). But the underlying approach to understanding and supporting those with hoarding behaviour with or without animals present is essentially the same – understanding a person’s reason for collecting animals or items, understanding any underlying causes and comorbidities, assessing to what extent there are risks that need addressing for the human and animal residents and working out how best to support people living with this disorder to understand and address any risks to their own or others’ health and safety.

2.4 Challenges maintaining a healthy home

Challenges maintaining a healthy home describes an unsanitary environment that has arisen from extreme or prolonged neglect and poses health and safety risks to the people and/or animals living there, as well as others within the community (DoH [Vic.] 2013; Dozier et al. 2019; Snowdon et al. 2019). This describes an environment, not the people living in it. It is not a “diagnosis”, but ‘a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group are living in such conditions’ (DoH [Vic.] 2012).

“CMHH” are often referred to as “severe domestic squalor” by Australian federal and state government agencies, support professionals, and broadly within the international research community (DoHA [SA] 2013). In agreement with the University of Tasmania’s Human Research Ethics Committee approval conditions for Treasured Lives, we are referring to “squalor” as “challenges maintaining a healthy home” in all fieldwork and communication with research participants and in our reporting, outside of discussions centred around exploring language. This is in response to many with lived experience finding the term “squalor” loaded with judgement, offensive and disrespectful. “CMHH” will be a working term during this project.

FIGURE 9: KEY DEFINITIONS – “CHALLENGES MAINTAINING A HEALTHY HOME”



CHALLENGES MAINTAINING A HEALTHY HOME

- “Severe domestic squalor”/unsanitary environment
- Accumulation of rubbish, decomposing food, excessive grime, dust or mould
- The environment jeopardises the health and wellbeing of those who live there

Source: DOHA [SA] 2013

Similar to hoarding, the risks to health, safety and functioning tend to accumulate with a person’s age. This has been attributed to the neglect of personal hygiene and the living environment due to frontal lobe changes and the increased likelihood of dementia (Gleason et al. 2021; Snowdon et al. 2007).

CMHH often present as secondary conditions to a range of medical and psychiatric conditions. There is a strong association with impaired frontal executive function (Lee et al. 2017), with 72.3 years as the mean age of diagnosis (Lee et al. 2017, cited in Guinane et al. 2019). Studies have shown that between 20% and 60% of people who live with CMHH also have challenges with hoarding behaviour (Snowdon & Halliday 2011, cited in Lee et al. 2017). For some, prolonged or extreme hoarding may lead to CMHH. Those whose living environment has deteriorated into CMHH tend to present for support at an older age (the mean age being 76), often due to the loss of a domestic partner or onset of frailty or neurocognitive disorders (Lee et al. 2017, cited in Guinane et al. 2019) (see Figure 10).

It is important to note, however, that there are many people who live with CMHH but do not hoard (Lee et al. 2017, cited in Guinane et al. 2019). Profile analysis of those living with CMHH has indicated that 'vascular and Alzheimer's type neurodegeneration were significantly more common' in those who also presented with hoarding behaviours, compared with those who only presented with CMHH (Lee et al. 2017) (see Figure 10).

FIGURE 10: CMHH WITH AND WITHOUT HOARDING DISORDER – COMMON COMORBIDITIES IN PEOPLE'S PERSONAL AND HEALTH HISTORIES

CMHH WITHOUT HOARDING DISORDER	CMHH WITH HOARDING DISORDER
<ul style="list-style-type: none"> • Range of medical and psychiatric conditions (see Gleason et al. 2021) • Executive functioning, memory loss, disordered thinking • Alcohol and other drug-related impairment 	<ul style="list-style-type: none"> • Likely to be older than those living without hoarding • Loss of domestic partner • Onset of frailty • Neurocognitive disorders • More likely to have vascular and Alzheimer's type neurodegeneration

Sources: Lee et al. 2017; Gleason et al. 2021; Guinane et al. 2019

2.5 Prevalence and demographics

Given the hidden nature of much hoarding and CMHH, there is no consistent data collection across Australian jurisdictions to inform us about the extent of these challenges nationally. A recent systemic review of international data on hoarding disorder has estimated that 2.5% (range=1.7% to 3.6%) of the adult population live with hoarding disorder (Postlethwaite et al. 2019). Estimates also suggest that the prevalence of hoarding disorder in older adults is triple that found in the general population (Cath et al. 2017, cited in Pittman et al. 2020; Roane et al. 2017). Further research has estimated that hoarding occurs for 2% of adolescents (Ivanov et al. 2013, cited in Hojgaard & Skarphedinsson 2020; Whomsley 2020).

Other research has suggested that 1 in 1000 older people live in environments that would be considered as needing intervention (Snowdon & Halliday 2009; Snowdon et al. 2012, cited in Lee et al. 2017).

The Hoarding and Squalor Working Group (Northern Tasmania) (H&SWG) provided a snapshot of the extent to which hoarding and/or CMHH were present for people accessing psychosocial supports in northern Tasmania. Their survey of housing, mental health, disability and family support services working in the north of the state suggested that 80% of Tasmanian Partners In Recovery Support Facilitators were working with at least one person who hoarded and/or lived with CMHH (H&SWG 2017). This survey did not ask for the age of people receiving supports.

Postlethwaite et al.'s figures would suggest that there are approximately 5,000 older Tasmanians (50+) living with hoarding behaviour (see Table 1).⁹ However, there is no way to confirm the prevalence of hoarding or CMHH in Tasmania at the moment and we may never know the real extent due to the hidden nature of these challenges and low help-seeking.

TABLE 1: ESTIMATED RANGE OF OLDER TASMANIANS AFFECTED BY HOARDING OR CMHH

	Tasmanian Population*	Estimated no. of adults living with hoarding behaviour**	Estimated no. of older Tasmanians living in environments needing intervention***
		@ 2.5%	@1 in 1000
Aged 20-49	182,239	4556	/
Aged 50 to 64	107,694	2692	107
Aged 65+	98,753	2469	99
Total 50+	206,447	5,161	206

*Source: ABS 2016 Census QuickStats

**Based on Postlethwaite et al. 2019

***Based on Ivanov et al. 2013, cited in Hojgaard & Skarphedinsson 2020; Whomsley 2020

CMHH are often – but not always – present in cases of animal hoarding. This is due to the likely presence of animal faeces, urine and animal carcasses (Dozier et al. 2019). For example, severe CMHH were reported in 52% of animal hoarding cases involved in a recent New South Wales study (total n=50), with a further 21% reported to have moderate CMHH (Snowdon et al. 2019).

We do not know whether older people living with hoarding or CMHH are disproportionately represented in social and healthcare services. There is some information from assessment agencies and service providers about prevalence within their caseloads, but prevalence amongst older Australians is difficult to pinpoint. An analysis of patients referred to the Aged Care Assessment Service (ACAS) in Western Melbourne found that only 0.005% of the referral base between 2009 and 2015 had challenges with hoarding and/or CMHH. The study itself points out that such a small proportion was likely to be a significant under-representation, even amongst those referred to ACAS, due to the hidden nature of many challenges (Guinane et al. 2019).

⁹ Note that this would include those who do not themselves identify with such behaviour and are unlikely to have been officially diagnosed as living with hoarding disorder.

Australia currently has no comprehensive data on the age profile of those living with hoarding or CMHH nationally. North American data shows that the mean age of patients diagnosed with hoarding disorder is between 53 and 67 years old (Ayres et al. 2013; Dimauro et al. 2013, cited in Guinane et al. 2019). Further studies suggest onset from 40, which increases in severity after middle age, with others suggesting a bimodal onset, with a second spike after 50 (Roane et al. 2017). Further research confirms that hoarding disorder increases in severity (Dozier et al. 2016, cited in Pittman et al. 2020) and prevalence with age (Cath et al. 2017, cited in Pittman et al. 2020).

Due to the mainly opportunistic samples used within studies, there is no consistent evidence around gender and hoarding and/or CMHH (Danet & Secouet 2018; Roane et al. 2017). However, the limited data available in this area suggests that animal hoarders tend to be female and living alone (Lockwood 2018). The limited data around older self-neglecters suggest they are more likely to be male, low-income and living alone (Abrams et al. 2002).

2.6 Personal and social impacts

Research indicates that challenges with hoarding and/or CMHH may significantly impact older Australians' pathways to wellness and ageing in place. As well as personal risks, there may be environmental, social, safety and public health risks for themselves, their families and carers (Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin, Fitch et al. 2010; Tolin, Frost et al. 2010; Tompkins 2011; Roane et al. 2017; Wilbram et al. 2008).

Hoarding and CMHH can occur regardless of socio-economic status (Koenig et al. 2014; Roane et al. 2017). However, its association with early life adversity (Tolin, Meunier et al. 2010), work impairment (Tolin, Fitch et al. 2010), potential financial burden and comorbid mental health challenges present significant obstacles for sustaining labour force participation and maintaining income (Baldwin et al. 2018). Additionally, housing insecurity is likely to increase with lower socio-economic status. Hoarding in particular is also likely to intensify financial stress for residents due to the ongoing purchase of items and/or the devaluation of the property (DoH [Vic] 2013; H&SWG 2017; Tolin et al. 2014).

It is common for people living with hoarding and/or CMHH to have poor insight into the risks their living environment presents for them personally, socially or environmentally. Insight tends to be lower amongst those living with hoarding, compared to those living with CMHH (Tompkins 2011). The social stigma and judgement faced by this cohort can intensify social isolation, cause considerable family friction and alienation and can exacerbate poor mental health, self-criticism and shame (Buscher et al. 2014; Chabaud 2020; Chou, Tsoh et al. 2018; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Roane et al. 2017). This often reinforces a person's reluctance to seek help for any personal, social or environmental risks they may face (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).

Older Australians living in such environments are likely to have significant barriers accessing the basic facilities needed for self-care (i.e. washing, sleeping, eating) (Ayres et al. 2010; Kim et al. 2001; Tolin, Frost et al. 2010). Older Australians living with hoarding and CMHH may be at higher risk of injury due to falls, trips and/or falling over displaced items (Ayres et al. 2010; Roane et al. 2017; Kim et al. 2001; Tolin, Frost et al. 2010).

If accommodation, health and personal needs are left unaddressed, this can lead to a deteriorating living environment, increasing self-neglect, deteriorating mental and physical health, disengagement with support services, increased risk of losing tenancies, structurally unsafe dwellings and ultimately eviction due to public health concerns, leading to long term homelessness or premature entry into residential aged care (Visvanathan et al. 2019).

FIGURE 11: PERSONAL, SOCIAL AND ENVIRONMENTAL COSTS OF HOARDING AND CMHH



Sources: Ayres et al. 2010; Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Dozier et al. 2019; Frost et al. 2000; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Snowdon et al. 2019; Kim et al. 2001; Tolin, Fitch et al. 2010; Tolin, Frost et al. 2010; Tompkins 2011; Roane et al. 2017; Wilbram et al. 2008

In the case of animal hoarding, the impacts on animal welfare can be significant. Major concerns include infectious diseases, poor health and nutrition and death (Dozier et al. 2019; Snowdon et al. 2019). There can also be major impacts on the mental health of animal welfare and veterinary staff who retrieve and treat animals (Patronek et al. 2006).

Such living environments present enhanced risks to health and safety not only for residents, but also for families and carers, support workers, and emergency services. Hoarded environments are hugely problematic for emergency services (Frost et al. 2000; Tolin, Frost et al. 2010; Tolin et al. 2008); there is often limited access to properties in the case of fire or when responding to a critical health incident (Bratiotis 2013; DoH [Vic] 2013; Kysow et al. 2020; McGuire et al. 2013). This means there is an increased risk of premature death for residents and, in the case of fire, for the surrounding community (Clark et al. 1975, cited in Guinane et al. 2019; Visvanathan et al. 2019). Fire service data shows that 25% of deaths from fires in homes occur in the homes of people living with hoarding challenges (Lucini et al. 2009).

2.7 Economic costs

Investing in preventative services is normally a smarter and less costly investment than responding to crises. But because people living with hoarding or CMHH often do not seek help, they are a challenging cohort to engage in preventative or early intervention support services. They often do not come to the attention of services until there is a critical need or a crisis (CCS 2014; Fidler 2021). For example, their living environment may be “discovered” through a residential fire, or they may be subject to a delayed discharge from hospital due to the home environment being deemed unsuitable. They may be assessed as needing to “act” around their living environment due to a tenancy inspection, or a neighbourhood complaint to a council, or an animal welfare complaint.

Costs to the Australian economy of supporting **one** household through emergency and critical care responses has been estimated to be \$56,800, or up to \$34 billion nationally based on 2014 costings (CCS 2014) (see Appendix 3).¹⁰

Economic costs associated with hoarding may include (Bratiotis 2013; CCS 2014; Frost et al. 2000; Kysow et al. 2020; Lacombe & Cossette 2018; McGuire et al. 2013):

- increased residential fires
- increased hospitalisations
- delayed discharge from hospital due to the home environment being deemed unsuitable
- repairs and cleanups, borne by councils, public and social housing providers and landlords
- tenancy tribunals and other legal processes
- crisis accommodation
- housing and homelessness support provision
- emergency welfare payments
- premature entry into long-term residential aged care.

¹⁰ This is based on Catholic Community Care’s estimates. They estimated that there are approximately 600,000 people living with hoarding across Australia.

Based on these CCS estimates, the Tasmanian government may be spending over **\$280m** on older Tasmanian households living with hoarding or CMHH through emergency and critical care.¹¹

UK estimates of the costs related to managing households who live with hoarding and/or CMHH are also striking and make a strong case for an early intervention approach. Housing trust (similar to Australia social housing providers) estimates suggest the costs over the lifetime of a tenancy where they have a resident living with hoarding or CMHH are between £35,000 and £45,000 (RRR Consultancy 2018).

It has been estimated that the costs to Birmingham City Council's Environmental Health Service, combined with the 120 severe hoarding cases supported by the West Midlands Fire Services during 2014/15, reached between £5.53m and £7.11m (RRR Consultancy 2018).

This cost has been estimated to drop to \$3000 per household with adequate preventative and response supports in place, including having a case worker, ongoing mental health and practical supports and access to first response services when needed (CCS 2014) (see Appendix 3). For the Tasmanian government, this would be an outlay of **\$15m** if resources were channelled into effective response supports.¹²

In addition, for those people living with hoarding and/or CMHH who are still in the workforce, there may be lost days of productivity, with one study citing a mean of seven days off work per month for those living with hoarding disorder (Tolin, Fitch et al. 2010).

CCS has warned that these costs are likely to spiral over time, given Australia has an ageing population and there is currently no concerted effort to address supports for hoarding or CMHH on a national basis (CCS 2014).

These costs encourage us to consider what a preventative support framework would look like and to see the costs of such a framework as a priority investment for households and for the economy.

11 These figures are estimates. They apply the estimated costs of support provided by Catholic Community Services (2014) to an estimated 5000 older Tasmanians living with hoarding. See Appendix 3 for more details.

12 These figures are estimates. They apply the estimated costs of support interventions provided by Catholic Community Services (2014) to an estimated 5000 older Tasmanians living with hoarding.

FIGURE 12: ELEMENTS OF COSTS FOR EARLY INTERVENTION AND CRITICAL/ EMERGENCY CARE

EARLY INTERVENTION COSTS

- Therapeutic mental health supports
- Cognitive Behavioural Therapy
- Psychosocial supports
- Domestic support
- Personal care

CRITICAL AND EMERGENCY CARE COSTS

- Hospital bed-blocking due to delayed discharge
- Responding to residential fires
- Accommodation clean up costs (Housing provider or local government environmental health)
- Animal welfare removal, desexing, veterinary and re-homing costs
- Tenancy tribunals
- Crisis accommodation
- Emergency welfare payments
- Premature transfer to residential care

Sources: Bratiotis 2013; CCS 2014; Frost et al. 2000; Kysow et al. 2020; Lacombe & Cossette 2018; McGuire et al. 2013

CHAPTER THREE

Who participated in the research



Semi-structured interviews were conducted with a snowball sample of clinical and community service providers offering services and support for older Tasmanians who live with hoarding and/or CMHH. Interviews were also conducted with a range of statutory agencies who encounter older Tasmanians living with these challenges as part of their duties. Some were couple interviews containing participants who work in the same or different organisations, and others were focus groups with staff working in the same organisation across different program areas.

Service providers and statutory agencies could also participate by completing an online survey.

We decided not to pursue interviews with federal and state government public servants with relevant policy portfolios. This was a pragmatic decision. We were conducting fieldwork during a period of considerable policy reform across aged care, mental health and disability supports, and within a shifting work environment due to COVID-19. This meant that federal and state government staff availability to participate in research was limited, as their priorities lay elsewhere.

The majority of services funded via the state Department of Health were unfortunately unable to participate in interviews. This was due to changes to the Department's research ethics approval processes which occurred whilst the fieldwork was in progress.

TABLE 2: RESEARCH PARTICIPANTS

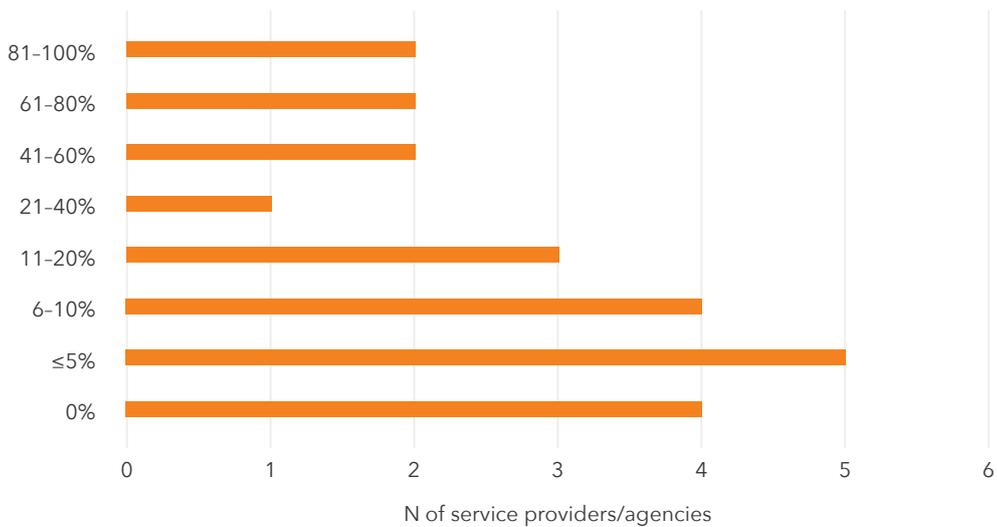
Number of research participants: completed interviews and surveys			
Participant type	Interviewed	Surveyed	Total included
Service providers	40	7	47
Statutory services	6	2	8
Total participants interviewed	46	9	55

55 professionals from eligible service providers and statutory agencies participated (see Table 2). The majority were service providers who either incidentally or directly encounter people living with hoarding and/or challenges related to maintaining a healthy home.

78% of the survey participants indicated that had worked with Tasmanians living with hoarding. The overwhelming majority of interview participants also worked with this cohort. 89% of survey participants indicated they had worked with Tasmanians with CMHH and all of the interview participants had encountered this cohort.

Of the service providers and agencies who were able to estimate the proportion of their clients over the past 12 months who were living with hoarding or CMHH, 10 reported 11% or more, 11 reported 10% or less, and 4 reported that they had not had any clients in the last 12 months with these challenges (see Figure 13). The higher estimates tended to be amongst housing providers, mental health service providers and animal welfare and management services. This reflects the pathways to services where people living with such challenges are likely to show up.

FIGURE 13: PROPORTION OF CLIENTS LIVING WITH HOARDING AND/OR CMHH

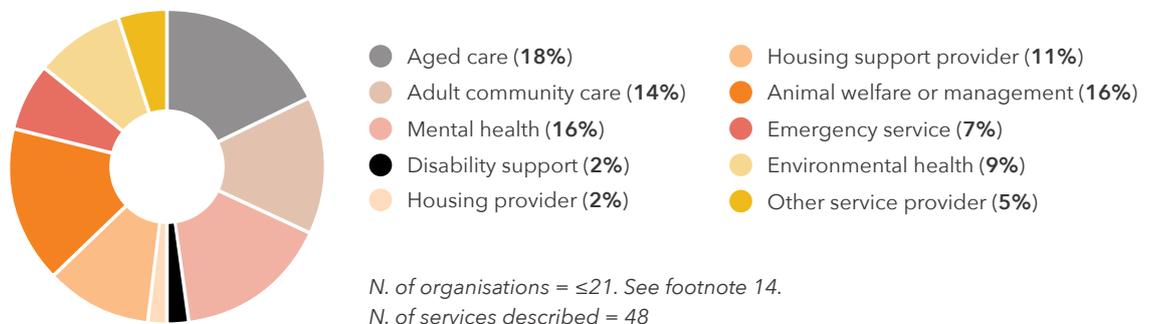


N. of organisations = ≤21. See footnote 14.

Participants collectively worked for approximately 21 organisations¹³ and reflected on their experiences across 48 areas of service provision. These covered a range of services:

- 55% of the services provided were clinical and social care services for older Tasmanians living with hoarding or CMHH. These services included:
 - » aged care services through CHSP or HCP
 - » adult and older people’s clinical and psychosocial mental health services delivered through NDIS, state-based or Primary Health Tasmania funded services
 - » disability support services
 - » other community and mental health services.
- 13% of services were housing provision or housing and homelessness support services that encountered older Tasmanians living with hoarding or CMHH.
- A further 32% of services were related to either animal welfare and management, environmental health and building compliance and emergency services, all of whom regularly encountered older Tasmanians living with hoarding or CMHH (see Figure 14).

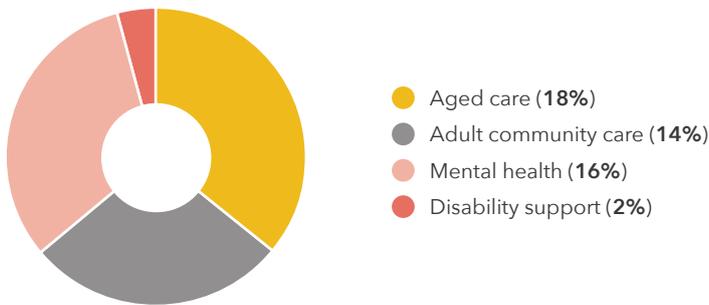
FIGURE 14: PARTICIPATING ORGANISATIONS BY TYPE OF SERVICE



13 To provide anonymity, we asked survey participants the type of service they worked in and their role. We did not ask them which organisation they worked for. There may be some overlap in organisations between survey and interview participants that we are unaware of.

Just over a quarter of services were provided statewide. The remaining were regionally targeted: 35% in the south of Tasmania (some across the region, others targeted within specific southern areas), 28% focused across or within specific areas of the north or northwest of Tasmania, and 10% focused in Tasmania’s midlands (see Figure 15).

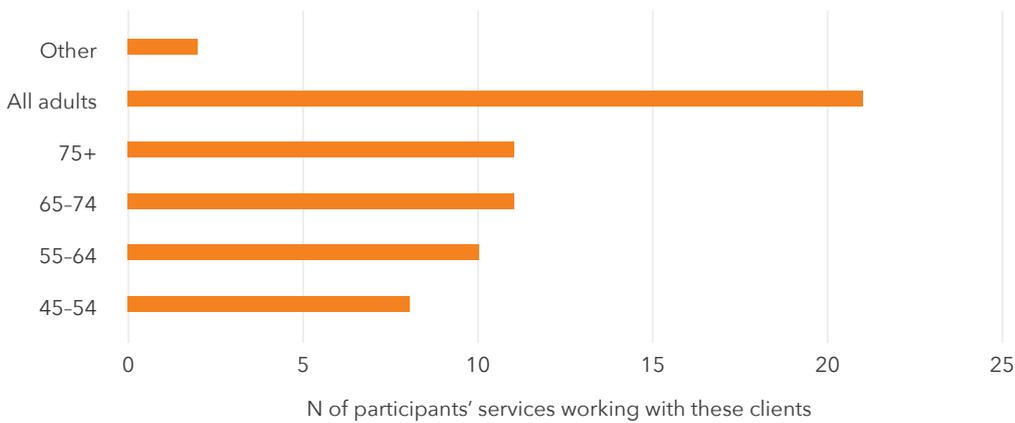
FIGURE 15: PARTICIPATING ORGANISATIONS BY SERVICE AREA COVERED



*N. of organisations = ≤21. See footnote 14.
N. of services described = 48*

There was a spread of service providers and agencies who worked across all adults, those who worked in aged care (i.e. those aged 65 and over) and those who focused on older adult care (i.e. those aged under 65) (see Figure 16).

FIGURE 16: PARTICIPANT ORGANISATIONS BY CLIENT AGE GROUP

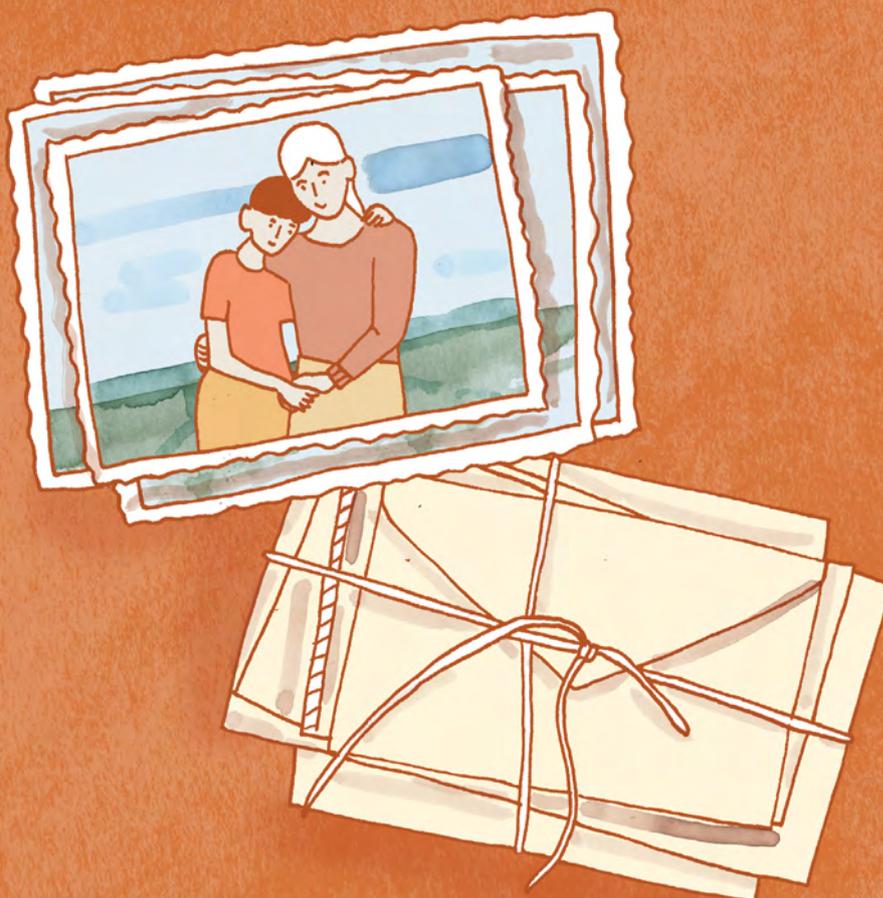


*N. of organisations = ≤21. See footnote 14.
N. of services described = 48*

The range of service providers and agencies that participated has provided a useful point of comparison across type of service, their target client populations and the geographical coverage. However, the sample is not large enough to consider whether differences in experiences are significant.

CHAPTER FOUR

Clients' risks and goals



4.1 Key messages

Many participants felt they did not have a clear understanding of their clients' circumstances. It was common for participants to report they had not yet entered some of their clients' homes, due to trust still developing, the client being embarrassment, or health and safety issues.

- **Clients' living environments:** Participants described some clients who had very ordered collections that simply presented a cluttered space in which to function and age. Others described cluttered environments combined with unsanitary conditions that may pose more health risks. The more commonly described concerns around clients' CMHH were mould and grime, rotting food, faeces and contaminated objects on the floors. No utilities and structural concerns were also mentioned. For those with challenges related to animal hoarding, our participants reported many "overwhelmed caregivers" and "rescuers" as described within other research (Patronek et al. 2006).
- **Perceived client need:** It was common for participants to acknowledge that their clients' living environments, particularly those living with hoarding, could provide a source of familiarity and comfort for them. Some participants offered reflections on clients' personal circumstances they felt may have either led to or were exacerbating their current challenges. These included poverty and social isolation, trauma, mental and physical health conditions, and cognitive and physical decline, including dementia. Participants described a number of perceived negative impacts their living environment had for their clients' wellbeing. These included social isolation and fractious relationships with family and neighbours, negative impacts on physical and mental health, increased risks of trips and falls, housing insecurity, financial strain and decreased prospects of ageing well at home. Many participants described how their clients' living environments compromised their activities of daily living (ADLs), such as toileting, cooking and sleeping. Some participants highlighted that hoarding or CMHH may have led to their clients' insecure housing situation or current homelessness.
- **Goals around ageing in place:** Many participants had not had the opportunity to discuss clients' desires about where and how they would like to age. Social care service providers, particularly aged care providers, were most likely to have held such discussions. Participants who had held such conversations reported that their clients overwhelmingly wanted to age in place, but participants voiced concerns that there were multiple hurdles to this happening. These included a lack of insight into the severity of the challenges their living environment posed for them, and their reluctance to allow services to address health and safety concerns within their living spaces.
- **Tensions between client goals and organisational concerns:** Both service providers and statutory agencies highlighted their most common challenges were supporting clients to developing insight into the risks, their challenges or code violations, gaining cooperation, and mutual goal setting. Client control was frequently mentioned as both an approach to achieving any personal or environmental changes and as a goal in itself. There were many reflections on how complex and fragile this goal could be when they were working with involuntary clients, or when the initial hurdle with clients was developing insight.

Many participants felt they did not have a clear understanding of their clients' circumstances. It was common for participants to report they had not yet entered some of their clients' homes, due to trust still developing, the client being embarrassed, or health and safety issues. Even when they only had partial assessments of their clients' circumstances, there was consensus amongst participants that without additional supports, their clients' prospects of ageing well at home were not great. This painted a picture of extremely vulnerable older Tasmanians, who were unlikely to be supported on a pathway to ageing within the Royal Commission's vision of independence, dignity and respect.

4.2 Clients' living environments

Some participants described clients with ordered collections that simply presented a cluttered space in which to function and age. Others described cluttered environments combined with unsanitary conditions that may pose more health risks. They described the full range of hoarding behaviours – challenges with acquiring excess items through to issues with sorting and discarding.

No real theme in what is collected, just many items with the issue being that clients do not seem to be able to throw things away, therefore accumulating more and more things. Most also seem to be compulsive shoppers and have issues with debt and paying other bills.

SURVEY RESPONDENT

Lots of antiques & curios from deceased relatives; lots of belongings left behind from associated transients who come and go from their places (frequently drug paraphernalia and stolen items). Lots of rubbish too – broken TVs, old cask wine boxes, cigarette packets....

SURVEY RESPONDENT

The more commonly described concerns around clients' CMHH were around mould and grime, rotting food, faeces and contaminated objects on the floors. And to a lesser extent, no utilities and structural concerns:

There's no running water in the house. ...Like I said I haven't been in there, but I know there is a lot of pets. There's also a bunch of possums that live in there. I get the feeling it's probably quite difficult to live, at the same time there's bonuses like it's really cold in in the house in summer... The house itself on the outside is in disrepair. There's lot of things outside the house as well... The doors are broken as well, they're missing panes and probably not really lockable.

INTERVIEW PARTICIPANT

With the people that I'm working with that are on the NDIS in particular, that's a pretty common challenge. You know, not necessarily the hoarding, but definitely the maintaining of the healthy home and possibly some clutter and then sort of a smaller proportion that you'd say of that's definitely hoarding.

INTERVIEW PARTICIPANT

Participant 1: *The younger ones that ... I've dealt with, with squalor, that come to mind, it's been through lack of education, lack of knowledge -*

Participant 2: *Intellectual disability.*

Participant 1: *No, I wouldn't say intellectual disability, no. No. Not the ones I'm thinking of. I think it's just ... that's how the mum lived ... You know, they have animals, but the dog is inside or two dogs inside. And ... they poop and urinate all through the unit. And even while I was there, the dog was just weeing on the carpet, and she did not say boo. And walking up a dark hallway, I could feel something tack on the end of my shoe, and I said, "Oh, is there a light?" Oh, it blows them, I'll open the back door. And I'd been kicking dog poo, but it was so dry, in the bathroom. So, she allowed her dogs just to pee and poop all through -*

Participant 2: *I just think, again, must have some depression level - maybe not the anxiety, but more depression. Can't seem to get out of the bed, don't have a big disposable income - tend to smoke, tend to eat poorly. I mean, I've got clients that live in squalor, that they're sick of it.*

FOCUS GROUP PARTICIPANTS

For those with challenges related to animal hoarding, our research participants reported many "overwhelmed caregivers" and "rescuers", as described within other research (Patronek et al. 2006). For example, all participants involved with cat management and welfare described how some people they worked with accumulated cats deliberately; some were breeders who had become overwhelmed when they could not sell sick litters, whilst others were nurturing outdoor cat colonies:

There's probably a dozen that are not necessarily what I would call 'hoarders', but they're feeding... the cat colony... So they're not in their house... We've got a dozen... people that actually have a hoarding situation where the cats are living in their house. And they're their cats and they will acknowledge the fact... but realistically, we've got another dozen... That pretty much say, "Oh, no, they're not mine..." But they've been feeding them for the last five years.

INTERVIEW PARTICIPANT

4.3 Perceived client needs

It was common for participants to recognise that their clients' living environments, particularly those living with hoarding, could provide a source of familiarity and comfort for them.

I was hesitant to tick the box "provides a space they can control" as a positive factor so I'll explain. I think that hoarding is the "seeking" of a sense of control, to assuage a sense of lack of control (whether that be over one's circumstances/emotions etc.), but is ultimately unsuccessful and doesn't provide what they are seeking.

SURVEY PARTICIPANT

Some participants offered reflections on clients' personal circumstances that may have either led to or were exacerbating their current challenges. These included poverty and social isolation, trauma, mental and physical health conditions, and physical and cognitive decline, including dementia. These were the contexts they understood to be – or speculated may be – shaping their clients' current needs:

There is nearly always an element of poverty. There is nearly always an element of cognitive impairment. There is nearly always an element of mental ill-health.

SURVEY PARTICIPANT

I guess there's sort of different spectrums of different mental health and how they might present. But it could be, you know, just really depressed and unable to clean or to shower, to do basic things around the home. Or it could be the real sort of more anxiety based, you know, inability to throw anything out or to declutter or to rationalise what's in their home or to make decisions. I think making decisions about things is a big one across the board. And just where to start and what to do, and there's a lot of barriers, I think, too it's not just as simple as just getting rid of a handful of things. It's a lot more complicated for people than that. Otherwise they would just do it.

INTERVIEW PARTICIPANT

Yeah, there's there's a few patterns. So there seems to be a difference between people who have an underlying psychotic illness and people who don't. So one gentleman in particular... he appears to have strong suggestions of an underlying untreated psychosis and I've referred him into Old Persons' Mental Health. He's pretty uncooperative. And he and others within his cohort seem to be more prone to collecting things which don't hold any intrinsic meaning for the rest of us. So empty medication packets are stacked in great towers, for example. But they can't be moved. Or other objects, such as newspapers, can be stacked and not taken away, but they're not actually referred to or anything like that. So that seems to be the pattern there. And that can exist without actual squalor.

Apart from that, squalor does seem to be very much more the case where there is actually sort of, you know, what we used to call Axis 1 diagnosis. I guess negative symptoms of psychosis. So it's more born in that setting. And the acquiring things and the animal hoarding. Doesn't seem to occur in that setting quite as much. That's more I've noted it just recently.

INTERVIEW PARTICIPANT

These vulnerabilities were intensified by the impacts of their living environment. Participants reeled off a number of perceived negative impacts their living environment had for their clients' wellbeing, those who lived with them and the surrounding community. These included social isolation and fractious relationships with family and neighbours, negative impacts on physical and mental health, increased risks of trips and falls, housing insecurity, financial strain and decreased prospects of ageing well at home. Many participants described how their clients' living environments compromised their activities of daily living (ADLs), such as toileting, cooking and sleeping.

I don't know if these are healthy places to live. I mean, the one who doesn't have, whose place is knee deep in, like they can't really use their kitchen. So she doesn't get sick, but I think that it would impact their ability to cook meals. So I think they might just buy stuff. And I think that would be quite expensive. And easy-to-prepare meals, I think, [in] their microwave and that's it... Sleep, I mean, her bed's broken. So I don't think she gets very good sleep.

INTERVIEW PARTICIPANT

Fire risks due to no space to safely run a heater. Health implications for being in a cold home. Issues with neighbours after one client was forced to defecate in the yard because they were not able to access the toilet. Often unable to access a safe place to sleep. Unable to prepare food due to space restrictions.

SURVEY PARTICIPANT

I often have to deal with the risk surrounding medicine hoarding. I often care for older people who have amassed unbelievable quantities and variety of prescription and OTC medicines which is dangerous for obvious reasons.

SURVEY RESPONDENT

It's usually reported as being an unhealthy premises... Often overgrown outside, so that gets the attention. It's probably because hoarding by virtue of its nature presents a fire hazard. An example is a [person]—lovely old [person], in a flat. This is very low budget accommodation flats—barely maintained. Now we went into [their] property, and it smelt really bad to us. But to [them] it was probably normal. [They] had a single lane of about probably that wide to get to the kitchen sink, and the toilet. The shower was—you'd have to move stuff to use the shower. I guess [they weren't] using the shower very often. It was there. And [their] bed the same. There was a strip on the side of a double bed about three to 400 millimeters wide, where [they] slept. Everything else was stacked to the ceiling. The whole room. Just stuff. Newspapers, bits and pieces, and treasures, but to [them]. And there were little rabbit warrens, scurry ways, where you could get around some of these things to some of these. So there was most of the place was occupied. So the only space [they]—and I don't think [they] even had a sitting chair. I think the only space [they] had was that little strip on the side of [their] bed. And that can't be healthy. You can't enjoy your house when—and we're talking ceiling high—everything was stacked up. So it was like walking in this room, but only having that chair available. And everything else was just, well, you can imagine... Lovely old [person]. To add to that burden,...the [neighbour] above and offset often left [their] stove and things going. She also suffers mental health. Every now and then she'd just break all the windows out of the place because she felt she was being trapped or something or other... Now you've got... an unstable person in that unit... and then you've got this great source of fuel under there. So there's potential for a disaster... and these are old buildings, they're old weatherboard buildings. They've never ever been fire separated. So if one flat burns, they all burn.

INTERVIEW PARTICIPANT

Some participants highlighted that hoarding or CMHH may have led to their clients' insecure housing situation or current homelessness. They were mindful that although their clients may not currently be living in an environment where these were challenges, their issues still needed to be supported and addressed. Without this, securing future housing that may enable them to age well in place would be unlikely:

Struggle with routine housing inspections; Low expectation of ever receiving Bond back upon leaving properties (often a cleaning bill left for the Public Trustee to sort). Often my clients believe their houses not to be dirty (as others they know live in similar squalor).

SURVEY RESPONDENT

I see mental health as being the root cause of a lot of these problems, and also a lot of the problems that end up in homelessness.

INTERVIEW PARTICIPANT

You can't hoard if you don't have a home.

And I've seen some people who ... will carry around everything from their childhood. They have nothing, but they're hanging onto those things. And if they had somewhere to live, they would probably hoard. Because control has been taken from them their whole life. So that's a little mental health issue. To me, you can't really band-aid it, because it's got to be done in a way that gives them a sense of control back. Does that make sense?

INTERVIEW PARTICIPANT

Others offered a longer term look at risks and impacts. They saw the intergenerational impacts of growing up in living environments that were cluttered or had CMHH. They were clear that more early intervention supports are key to preventing the personal and environmental impacts others described from escalating as they aged:

Participant 1: *I believe that the younger the client is, the worst prognosis for the client's quality of life.*

Participant 2: *If they don't get the appropriate help.*

Participant 1: *And it's not just the long – the long life that they might live. It's the interventions they'd need along that pathway, that are going to be very, very costly ... I know the Royal Commission into Aged Care are talking about people over 65, but I see a much, much greater need ...*

Participant 2: *For the younger ones.*

Participant 1: *... to get early intervention to ... younger people. Because older people now, they're not – you don't have young children living at home. It would seem generational hoarding and squalor and lifestyle choices that are not far from perfect for young kids to grow up in. And ... an increase in – well, maybe not an increase, but quite a lot of depression ... with younger families, as well. Even before COVID. And that get into a cycle that they can't get out of.*

Participant 2: *And the risk of homelessness for those people.*

4.4 Goals around ageing in place

Many participants had not had the opportunity to discuss clients' desires about where and how they would like to age. Social care service providers, particularly aged care providers, were most likely to have held such discussions.

Have tried to get clients to think about and plan for this but it's too scary and difficult for them to deal with.

SURVEY PARTICIPANT

Participants who had held such conversations reported that their clients overwhelmingly wanted to age in place, but participants voiced concerns that there were multiple hurdles to this happening. These included a lack of insight into the severity of the challenges their living environment posed for them, and their reluctance to allow services to address health and safety concerns within their living spaces:

People overwhelmingly want to age at home but don't put a lot of thought into how they will achieve that as they become infirm or unwell. Many living in squalor have told me they wish their living situation could be improved, i.e. "tidied up" or that they could have some help with sorting through their belongings, cleaning and maintaining their home. Our service often refers on to community service providers that can provide these services but somehow things don't seem to change and I wonder where the breakdown is.

A lot of my patients will know and admit they need help and even ask for it, then turn the service providers away at the door. Sometimes the level of squalor is so extreme perhaps the funding required to rectify it is insufficient. That said, many will argue until they're blue in the face that they're very happy with how things are... The argument that their situation is unsafe or upsetting for others is meaningless to them... They want to continue to receive community nursing services at home, for example, even though the home environment is an unsafe environment for nurses to work in.

SURVEY PARTICIPANT

Some are okay and cope well in other living environments such as hospital, respite and interim care beds. But others are terrified of having to go into aged care, so decline support for fear they will be forced to go.

SURVEY PARTICIPANT

These concerns led most participants to conclude their clients' trajectory was not a positive one. If nothing changed within the supports their clients received, they predicted that most of their clients would have to enter residential care prematurely, or by force, due to a hospitalisation or another crisis such as a fire. They were at high risk of ageing in homelessness.

More frequent hospitalisations, forced into aged care or statutory intervention (such as Guardianship and Administration)

SURVEY PARTICIPANT

There was also lots of speculation about declining mental health, social isolation and premature death without additional support services as they aged.

Would definitely encounter Police more. And more requiring protective custody due to ongoing mental health crisis.

SURVEY PARTICIPANT

Lonely. Declining physical and mental health.

SURVEY PARTICIPANT

High likelihood that many will die prematurely (combination of illness, medication & lifestyle factors). One of my more fortunate clients is able to live in a rural, family owned property, on acreage for as long as he likes... He is extremely content, in a cluttered property, and will most certainly die there.

SURVEY PARTICIPANT

Oh, well, things'll just get worse for them because they'll become more frail and less mobile and less healthy. In an environment which is unsuitable for them to be living in.

INTERVIEW PARTICIPANT

However, there were participants who had another vision for their clients' end of life goals. These were mainly participants who worked in the aged care space. For them, there was an opportunity to draw on a cluttered living environment as a way to ensure that clients were in control of their end of life planning. The goal here for clients was creating opportunities for clients to reminisce about their lives through exploring their collections with them. This, they argued, could promote a sense of cognitive stimulation, wellness and reablement for those in their later years:

There's that element, as we get older, the letting go. And... that letting go of insignificant stuff. Working towards end of life in a healthy way, because everybody is going to die. But the letting go is clutter... Some people, with a healthy view to end of life start to look at the things that are really important to them, and they give it away to the people they love, while they're still alive. And that's a healthy progression to knowing that life's going to end, one day. For a hoarder, they never get into that space, because their life is so consumed with stuff. And that freedom of thinking and – your whole – because the end of life can be really quite an acceptance space to be. But, I think, for some older people that live like that, they're so consumed in that space...

It's about reflection. Like, if there was a mental health worker working with someone that was – didn't have long for this world, and it was around reflecting on a good life, and the things that were – you had achieved, and the reminiscing, and all of that sort of stuff, I wonder sometimes if we could make an impact in that space for healthy wellness and reablement of older people. Because... a lot more people will start living until they're 100. And so, we're talking about wellness from 80 to 100. I mean, that's another 20 years. And if they're stuck in that hoarding and – and not nice mental health space, that last part of their life will be – it'll be institutionalised care. And I... do believe that... hoarding does not allow people to have healthy thoughts and practices. But I have no evidence of that, but it's just the people I've spoken to in this work. I feel them stuck in that space.

INTERVIEW PARTICIPANT

4.5 Tensions between clients' goals and organisations' perceived risks: negotiating insight

Many participants described that they were working with clients who had been referred to them because of someone else's concerns – an observed case of clutter or risks to sanitation by an emergency service, or a concerned family member, or another organisation that was concerned about the residents' risks. It was not usually voluntary client engagement, at least to begin with.

The majority are in Housing properties, Housing Tasmanian properties. And then usually a big part of why I've been called in is that Housing Tas are extremely unhappy and threatening to kick them out. And so, and that's sort of where it starts, I think, is that they are sort of constantly threatening that. There's usually a big list of things that Housing Tas want done and want changed, and yeah.

INTERVIEW PARTICIPANT

You'd get them from the firies, where they'd been called out to something and they'd seen it as a risk. And then they would send it across as a notification for further investigation. And it also happens with the police from time to time where the police have rang up and said, you know, we're concerned, and I know I have, from a building perspective, someone is living in some location or building which we don't think is legal, or safe. And quite often it can be because the police have been out there because of domestic disputes, or just stuff they're growing in their backyard, or whatever the case may be.

INTERVIEW PARTICIPANT

Supporting clients to develop insight into the risks, challenges or code violations, gaining cooperation and mutual goal setting were all highlighted as common challenges both service providers and statutory agencies faced:

I find it very challenging, but the goal would be to have a plan that is agreed upon from both that person with the situation and with us. But I guess that's probably the hardest part... getting them to agree to a plan and then sticking with the plan. And that's where we find that there's a challenge because it's just us working with someone who obviously has some mental health issues. So there's like a bit of a brick in between us assisting them allowing us to assist.

INTERVIEW PARTICIPANT

Client control was frequently mentioned as both an approach in achieving any personal or environmental changes and as a goal in itself. But there were many reflections on how complex and fragile this goal can be when they are working with involuntary clients, or when the initial hurdle with clients is developing insight.

I think they often just feel incredibly overwhelmed and it just seems like the biggest, most impossible job in the world. Where do I start? I have rooms filled with things that all seem incredibly important to me. And, you know, it's overwhelming and I don't know where to begin and what to do. And it's all too hard, so. Yeah, I think, I try and I guess get them to identify maybe a room or a shelf or a specific space that maybe they want to have work a little bit better. And it's definitely about starting small and starting somewhere a bit achievable and just testing the waters and seeing how they feel about things and – Just you can't go too fast and you've got to have their trust, which you have to kind of earn and work on, that relationship is absolutely vital. They've got to know what you're doing, what other people that are coming into that home are doing, where things are going. They've really got to be in control.

INTERVIEW PARTICIPANT

Client control and dignity of choice remained key principles of engagement. When clients did not share those concerns around their living environment, addressing them may have been de-prioritised, although maintaining engagement was not:

Lindsey: *So what would their pathway to you look like? And what sort of services might you be offering them?*

Participant: *Well, it's interesting that you say that. I would say that I have at least three people who fit that description on my caseload and one of them, I believe, was referred to me specifically for the hoarding behaviour. And that was referred through their aged care sort of provider. Because obviously from their perspective, it's really hard for them to have workers in. The difficulty for me is that the client in that case is not particularly interested in, well, she is, but, if I was to name what her goals were, I don't think it would be what she wants to do with the time with me. I wouldn't say that it's necessarily getting the house in a state that is more comfortable for the workers that come in for her.*

Lindsey: *So how have you negotiated that with her? I mean, what goals have you landed,*

Participant: *Well I'm here for the client, not the referrer. So it's really up to her. And we did look at it initially because that was what she said she wanted to do. And – but it isn't really so what we did in the end was, what I did in the beginning was I actually did a workshop on, on hoarding.*

INTERVIEW PARTICIPANT

Time, and lots of it, was identified as one element needed to support clients to develop insight and engagement. Participants also flagged that this stasis in participants' situations was maintained by two other structural barriers within the Tasmanian service landscape – the lack of specialist knowledge and services and organisational risk tolerances. We explore these in Chapters 5 to 7.

CHAPTER FIVE

'We don't have time': service providers' and statutory agencies' experiences of engaging older Tasmanians



5.1 Key messages

- **It's about time, not numbers:** Across enabling and code-enforcing agencies, Tasmanian service providers are working with different proportions of older clients living with hoarding and/or CMHH (from 5% to 100% of their caseload). But they are all clear that it is not the proportion of their client base, it is the significant amount of time needed to work with them that is important to recognise and cater for.
- **Investing time to understand:** Understanding the underlying causes, so that service providers and statutory agencies were not simply addressing the presenting issues, was described as a complex and protracted activity that was not necessarily accounted for in their service design or role.
- **Investing time to build trust and rapport:** Every person interviewed talked about the need to build trust and rapport with the people they are working with, and that this is a goal in itself that takes time with older Tasmanians living with hoarding or CMHH. They described how trust and rapport were often not easily gained and, due to the need to provide holistic supports – clinical, psychosocial and practical – supporting older Tasmanians living in such environments requires more than a short intervention. It is long term and evolving work.
- **Gaining entry to assess risks and needs:** Many participants – across social care and code-enforcing – talked about needing to build that relationship from outside the person's house. This means that professionals were often (at least initially) assessing environmental risks and needs for older Tasmanians that they could not see. They described how entering the property was a significant trust stage that in itself could take a while to achieve.
- **Working with voluntary clients around dignity of choice and risk:** A number of participants who were working with older Tasmanians on their living environment described the time it takes to sensitively work on insight, goal setting and the process of acting on these goals, at a client's pace and with them in control of the process. Challenges building relationships were often compounded by the limited scope or funding structure of the particular service/program they were working within. Program design based on hours rather than consumer outputs exacerbated challenges for social care services who needed more time, as well as budget, to support clients living with hoarding and CMHH.
- Another element of supports that participants described as time-consuming was the process of **preserving clients' dignity of choice and risk as long as is feasible**. Working through the process of guardianship, where this was deemed necessary, could also require lengthy time frames.
- **Engaging with non-voluntary clients:** Working with non-voluntary or refusing clients was commonplace amongst housing service providers and the statutory agencies responsible for investigating code violations, such as animal welfare and management, environmental health and building compliance. Common across non-voluntary clients they described was a lack or low level of insight into any risks to health and safety their living environment may be posing for themselves, the people and animals they lived with and the environment around them. This meant that staff were needing to gain trust, understanding and relationships as the first goal, where possible. It could be some time down the track before discussions were held about the nature of any challenges the living environments posed.

What's needed:

- The need for services that are able to build long-term relationships and move with the ebb and flow of voluntary and non-voluntary clients' engagement is very clear. Such services need to sit outside of a consumer-driven fee for service model and need to be based on long-term positive outcomes (which include building relationships and engagement), rather than hours of service.

The proportion of people living with hoarding or CMHH that participants encountered varied, but was high amongst those responsible for certain areas, such as tenancy support and animal welfare and management. All participants reflected that, even if they did not encounter many clients living with these challenges, when they did the time needed to support them was disproportionately high compared to many other clients they might work with.

Most participants reflected on the importance of having time to understand the challenges faced by their older clients living with hoarding or CMHH and time to build a relationship that would eventually engage them in positive supports. This was seen as particularly important given that many of the older Tasmanians they encountered had low levels of insight into the health and safety risks their living environment posed to themselves and others they lived with. In some cases, they also had declining physical and cognitive capacity to address the environmental risks they were living with.

Participants across social care and code-enforcing organisations reflected that they did not have the time needed to build these foundational elements with people. They described how they were confined by the limits of their roles and/or service provision. There was a common sense of regret and frustration amongst service providers and statutory agencies that the limitations on the time they could spend with older Tasmanians living with hoarding or CMHH and the scope of their particular service meant there was often a loss of momentum towards any progress – whether that be progress in building trust and relationships, working towards a mutual understanding of client risk, setting goals and/or supporting them in achieving goals.

The reasons for needing additional time were multiple. Those most commonly mentioned were:

- the time it takes to **understand what's happening** for clients holistically and understanding their needs
- the need for a long process of **building relationships**, supporting clients to build insight into challenges/code violations, enabling them to develop goals and supporting them to work through those goals at their own pace
- the need for **flexibility and changing approaches as the level of engagement changed** with clients
- the need for a long process of **enabling dignity of choice and risk**, assessing capacity and applying for restrictions in autonomy where this is deemed to be absolutely necessary.

FIGURE 17: PARTICIPANTS' CHALLENGES AROUND INVESTING TIME WITH CLIENTS



5.2 It's not about the numbers, it's about the time

Most services and statutory agencies did not keep data related to the proportion of their clients who live with hoarding or CMHH, nor the proportion who would be classed as "older Tasmanians" under this project's definition. Participants offered estimates when asked during interview or survey.

The proportion of people who participants estimated they encountered living with hoarding or CMHH varied from 5% to 100% across those interviewed and surveyed. It was noticeable that amongst those responsible for certain areas, such as tenancy support and animal welfare and management, the proportion of people living with hoarding was high and the proportion living with CMHH was even higher:

I would say it's a good 35%, maybe 40% of my clients are hoarders. And that's their issue as far as maintaining their home. There'd be varying issues with the lot, with every one of them. I've got 41 clients at the moment. And I would say each and every one of them have an issue with that, at varying levels.

INTERVIEW PARTICIPANT

The vast majority of service providers and statutory agencies reported that most of the cases they worked with were people over 50, particularly those living with hoarding. Reflecting other studies, participants working within animal welfare and management observed that the majority of the people they encountered were female and over 50. This gender divide was not reflected across all service areas though.

Research participants reported that their hoarding clients without animals mainly lived on their own. For those living with CMHH, the profile was much more varied – both in terms of having younger clients and those with children.

Many service providers also highlighted that they are working with many clients who may be living with hoarding or CMHH, but this is not an identified challenge or goal for the client:

I was just sort of thinking about it before and sort of trying to come up with a number of how many sort of situations there's been. And to be honest, it has been quite small. But I think from memory, I think I've really only had the one person who's contacted us for that specific purpose ... I have been where I've sort of rocked up for a home visit and it's sort of, I guess, apparent to me that that may be an issue for the person. But in the examples that I'm kind of thinking of, that actually hasn't been the client's priority. So I have been very careful about how I sort of talk about the options out there, so that it's not confrontational. So that I'm not being offensive or being presumptuous. And so I suppose sort of trying to mention it in a delicate way, that there might be some supports there. But if that's not their priority, then I haven't in any way pushed it if that makes sense.

INTERVIEW PARTICIPANT

Others were aware that hoarding or CMHH had been problems for their clients in the past and may have contributed to their current vulnerable circumstances, including being homeless. For these service providers, supporting clients around these issues was often not a current issue, but one that they felt should be addressed in order to provide sustainable positive outcomes for clients:

I think a lot of the time we see clients who have had hoarding and squalor issues, and then they've lost their tenancy and they're staying with family, and they've got a housing debt because of it. It's an issue of the past, but once they get a property it'll come back again.

INTERVIEW PARTICIPANT

A number of service providers also highlighted how difficult it is to know the extent of hoarding and CMHH for Tasmanians they are working with, given that their services, or at least initial assessments, were not home-based:

If it's not self-disclosure, we're unable to identify those challenges, because when we're talking to our folks in intake, they're only disclosing to us what they think we should know. And unless we're physically going out and visiting...

INTERVIEW PARTICIPANT

Across all of these reflections was a clear message. **Challenges working with this cohort were not as much about the number of clients as they were about the time and complexity of working with such clients.** All participants reflected that even if they did not encounter many clients living with these challenges, when they did the time needed to support them was disproportionately high compared to many other clients they might work with.

Look, other people can be time consuming in different ways... So probably the most the second most time consuming thing after hoarding are clients who for various reasons, don't like just appointments. So for quite often there's an anxiety driving it. So, you know, something will crop up and they simply can't wait to be seen at the appointment that you have with them. They need to see you today... So those people become very time-consuming as well and it's not related in any way to hoarding... I think probably across all clients I think the Pareto principle of the 20:80 is probably pretty accurate. That 20% of your clients will take up 80% of your time... But in terms of hoarding people, look, they would in some cases take many times the time of a person who doesn't have a hoarding issue.

INTERVIEW PARTICIPANT

So it's a small percentage of our work but it's a vast kind of a power and with not doing it very often it can also be very confronting for the team.

INTERVIEW PARTICIPANT

Our participants involved in animal welfare and management often returned to this point. What might present as an animal hoarding challenge, often referred to a welfare or management agency through a neighbourhood complaint or family concern, often escalated or spread into a wider environmental health challenge. They described the impacts of animal hoarding as often being vast – on the welfare of the animals, the health of people living in the property, on the neighbourhood environment and relationships:

It's just one aspect of what we're dealing with really. I mean it's a minimal portion of what we deal with. But it's such a massive impact. And I say that, for instance, because the fallout of one [client] ... has now sparked probably three other trap situations for just normal people.

INTERVIEW PARTICIPANT

This meant that cases often became much more complex, time-consuming and beyond the scope of animal welfare and management agencies.

Quantifying that additional time was challenging for service providers and statutory agencies. Only a couple of participants were prepared to offer an estimate:

So ... you might have 10 people with more straightforward depression who are about as much work or need as much as that one person with hoarding and squalor.

INTERVIEW PARTICIPANT

The additional time depended on the person and the context – whether this was a situation where the client had voluntarily engaged or not, the range of challenges being addressed, their level of insight into their challenges, the goals the client set and the level of trust and engagement. The **sensitivity and fragility** of the relationship and support process was clear.

5.3 Investing time to understand and build insight

Service providers and statutory agencies described how they were often working with older Tasmanians who had complex needs. Participants were acutely aware that their working relationship had to be led by the individual, rather than assumptions about their cacophony of symptoms and circumstances:

Oftentimes when I work with people, I suppose I get the referral form through. I'll have a little look to see what it is that they might like support around, and will identify their official clinical diagnosis... Generally I just meet the person and sort of work with the person, because I'm not clinical support, so I don't have to focus so much on the diagnosis. But it has been interesting in that for the people that I have worked with that have had goals around hoarding, quite oftentimes there has been a diagnosis of Post-Traumatic Stress Disorder. So significant trauma. Varying levels of reflection from different people around the hoarding behaviours and how that then links in with their mental health and their coping strategies, and yeah, things like that... How I would work with the person just depends on the person... So I suppose one thing I really like to do is stress that a person that I'm working with is in the driving seat of where that goal is at. And how fast or slow things go around that.

INTERVIEW PARTICIPANT

Understanding the underlying causes, so that service providers and statutory agencies were not simply addressing the presenting issues, was described as a complex and protracted activity that was not necessarily accounted for in their service design or role:

Understanding the root of the issue is very difficult—the reasons for people's unsafe/unsanitary homes are myriad and complex. It is very difficult to tease out poverty, trauma, motivations etc, and I do not have the time with people to establish the necessary rapport to raise the issue... Often people will acknowledge there is an issue but they are unable to grasp the seriousness of it. I once had a patient breezily apologise for the "dust" in a room that contained the long-dead corpse of a cat and cat faeces on almost every surface. It is very difficult to respectfully communicate the seriousness of a situation without upsetting the individual, which is counterproductive.

SURVEY PARTICIPANT

5.4 Building trust and rapport takes time

Every person interviewed talked about the need to build trust and rapport with the people they are working with, and that this is a goal in itself that takes time. Building such relationships requires a great deal of time when working with any client, but for those living with hoarding or CMHH, research participants were clear that trust and rapport were often not easily gained. Due to the need to provide holistic supports—clinical, psychosocial and practical—supporting older Tasmanians living in such environments required more than a short intervention. It was long term and evolving work:

Basically, it takes time. I don't rush that along. I've walked into people's homes who hoard and I haven't mentioned the hoarding for the first probably four visits over six to eight weeks. I don't even bring it up, you know, apart from letting them know ... I assess the client, I talk to them about what their support needs are, what support needs have been met, how that's going for them or, if it's not going for them so well, provide them with other options, or encourage them to engage at a higher level with the service provider.

Also, on the other side of that, I would get to know about what their underlying, or I suspect an underlying, mental health issue, that either hasn't been diagnosed, or that has been diagnosed and they've stopped taking their medication, for example. So I take a fairly in-depth look at all that sort of stuff. And I do that over a number of visits ... First thing is to win their trust, you know? Understand where I'm coming from and I'm actually able to help and not hurt. If that takes a while ...

INTERVIEW PARTICIPANT

You've got to develop a real sense of trust. And I let them know that we're not going to go into any rooms or touch anything at all that they don't want us to touch. It depends on the client. Sometimes what I try and do is get a trusted worker to go in and do a series of two hour cleans with them. And it might be that the worker goes in and, you know, boxes up things that I don't want to throw out, but I want to keep because it's very hard to get them to throw anything out.

INTERVIEW PARTICIPANT

It's clear that trust is much easier to gain and goals are easier to establish and act on around hoarding and CMHH where the relationship is a voluntary one and where the client already has a level of insight into challenges and goals:

It really depends on the person. One person that I worked with around some hoarding behaviours [was] very warm, very welcoming, just a really bubbly sort of person. So for building trust with that particular person didn't take too long at all. It was probably a couple of months in and I was like, 'Oh yes, I can tell that there is a good therapeutic relationship here where ... I can ask some questions that are quite open and honest to make sure that I'm best supporting her with these goals. And we can start going through rooms in the house and things like that.' Because a big part of it was that she was in this space where she was ready to do that. This was a goal that the client had identified they would like support with at the beginning of us meeting. So it wasn't just on me. It was with her and where she was at as well.

But I've worked with another person where engaging in a service was really challenging. Asking for any kind of support from absolutely anyone was just momentous. So I'd probably say having sound rapport took at least six plus months.

Yeah. It sounds so funny, I mean but yeah, I think that the markers of that... trust and rapport are different with everyone, because everyone is so different.

INTERVIEW PARTICIPANT

Whilst this may present as a reasonably logical argument, the challenge is in how professionals are enabled to develop such a trusted relationship and rapport. Because there are no specific support services for this cohort, the ability of professionals to work at this pace is often person-, funding- and role-dependent.

5.5 Gaining entry and evolving insight: investing time to assess risks and needs

All participants were able to describe the types of personal and environmental risks that their clients may generally face:

The fact that someone's living that type of situation increases risk, because of many factors—around how they're cooking, what they are using for cooking, how they are using electricity and power. Their behaviour—are they still smoking? ...Plus... if they don't have a fire alarm... [Or] it may be in a room they can't hear anymore, because of the amount of fuel load buffers the sound of the smoke alarm. It's their ability to escape quickly... They've more of a chance of being a fire fatality if a fire was to happen in that home, because it's a bigger fire, more toxic. The potential of tripping over and stuff going on top of them.

INTERVIEW PARTICIPANT

Understanding what is happening for such older Tasmanians, who may be leading relatively isolated lives—whether by design or circumstances—presents a number of support dilemmas around ageing well at home. Many participants—across social care and code-enforcing—talked about needing to build that relationship from *outside* the person's house. This means that professionals were often (at least initially) assessing environmental risks and needs for older Tasmanians that they could not see. They described how entering the property was a significant trust stage in itself. A couple of case examples illustrate well the challenges professionals have in getting started with assessing risks with the client:

[They] want to clean [their] house... [They] feel quite ashamed. And [they] say that [they] don't want to go into the house because [they] don't want me to see. So I mean when I'm with [them], we talk on the veranda. Again, it's hard to get started. [They] does have a number of chronic health conditions - ...Diabetes and... [they've] got... mental health conditions, as well. Which I don't necessarily think fed into this...I don't know... what's happened in the past, but [they've] certainly had a lot of trauma and definitely [they] feel like [they've] let the house to get away from [them].

INTERVIEW PARTICIPANT

Participant 1: *A lot of [the client's] items appear to be tools and things for professional use. Interestingly ... [they] call it work. [They] go to a ... company ... and [the company] pay[s] [them], so [they] say, in items as opposed to money. ... I've only been in the property once. I have to say that, because all the other times [they] met me was out in the front. But there were all the safety goggles that you wear, but there would have been between six and 10 pairs hanging in the kitchen. They were all in good order. They were all clean and tidy... And then there was another box full of screwdrivers that I noticed. Then I looked out into the backyard and [their] backyard is completely full of things, couldn't really identify them. [They] report to be keeping these items in the house because they're not safe out of the house ... The lights were off and the blinds were down. It was quite hard to tell what was in there... The kitchen had a pathway into the sink [they] could use, but was pretty much stacked up with items that I don't know what they were. I mean ... there wasn't like old food items or things that you would say would be dirty as such. Yeah. It was just a lot of stuff...*

Participant 2: *And to add to that ... I actually went out to see this person. And I think it speaks volumes that [they] let me into [their] house. I think the work that [Participant 1] has done so far has meant that [they] feel quite comfortable with [the service] ... And [they] sort of, you know ... acknowledge ... [They] say to me, you know, 'People think that this is all just junk, but it's really useful. They're really useful items.' ... So, again, it was quite dark in there when I went in there. But, you know, there are certain pathways ... And ... yeah, it doesn't smell like there's things in there that are unsanitary, it's just these items that [they're] placing everywhere.*

INTERVIEW PARTICIPANTS

5.6 Working with voluntary clients around dignity of choice and risk

A number of participants who were working with older Tasmanians on their living environment also described the time it took to sensitively work on insight, goal setting and the process of acting on these goals at a client's pace and with them in control of the process:

I think there's been some people that I've worked with, that if we've gone through different rooms, I'll ask them 'Okay, well, how are you feeling today? Are you feeling prepared to do this? And what is that red light for me?' So kind of talk to them before we start the process, to check in and see how they're feeling on the day. And then I can ask them how much they would like for me to challenge them with sorting through belongings.

And like with certain people I've agreed upon 'Okay, well, how would you like me to challenge you? Like what kind of language are you going to be comfortable with me using that isn't going to be confronting for you in that space?' So an example of that would be, I was going through some belongings with the person. And we had three questions so that I could ask that person to see that they were comfortable with keeping a possession or throwing away – was, What is it used for? Where can you put it? Does keeping this item align with your goal of creating a happy and healthy home?

So it was 'Purpose?' Like the actual practicality. And 'Does it have somewhere it can live?' Like does this fit in the space? And then... even if it was like, 'Yup, it's totally fine, I use it for this, it goes in this spot.' And it's like, 'No, no like I totally need it.' ... The last question would be ... a little bit more challenging ... 'Does keeping this align with your goal of having a house that is, you know, safe for you and workable for you?' And then if they were like, 'Yes, yes' I'd be like, 'Okay, cool.' So we put it to one side, and we move to the next item.

But it's different for each person ... But we have a lot of trust and rapport ... for me to be able to do that. Yeah.

INTERVIEW PARTICIPANT

I would definitely say that the clients with these struggles need a lot more time. They really need a lot more of you and a lot more of your time. And you can't be rushed. So you've got to give a client that – other clients you might see for an hour and that might be plenty. You know, these would be an hour and a half, two hours, and that might just be to just do a couple of small tasks together. Because it does take time and you've got to sort of connect with them about what's going on and where they're at. Some days are good days and they might feel more able to get some things done, and some days are really hard days and you just would not necessarily push ahead with what you'd planned the last time you met. So it's constantly kind of connecting with where they're at and kind of adjusting, I guess. But yeah, time is definitely a good one.

INTERVIEW PARTICIPANT

It is a process that required an infinite amount of time.

Challenges building relationships were often compounded by the limited scope or funding structure of the particular service/program they were working within. Program design based on hours rather than consumer outputs exacerbated challenges for social care services who needed more time, as well as budget, to support clients living with hoarding and CMHH:

We see quite number of clients, more so clients... without case management, that have the hoarding, squalid, clutter type issues... In the absence of case management for under 65s, to have... a time to bring services together, to have case meetings etc, is non-existent, really.

INTERVIEW PARTICIPANT

The difference... is the conditions of funding. So a Commonwealth Home Support [Program] client is measured as an output. And an output is an hour. So that's how we deliver. For that client. Whereas the [Home Care] Package... clients have got a budget. So... we can buy services that would make their home a lot better, because we've got the flexibility. We can do home modifications. We can do repairs. But in the CHSP, when we come across those issues with clients... it's very hard... for us to do anything that's innovative... because the funding doesn't allow it.

INTERVIEW PARTICIPANT

Another element of support that participants described as time-consuming was the process of preserving clients' dignity of choice and risk as long as is feasible, and working through the process of guardianship where this was deemed necessary. This was particularly raised by those working in acute mental health environments and those who encountered non voluntary cases within statutory roles:

Participant 1: *Oh, they take hours. Because, you know, first of all, well often with ours you're doing guardianship. So that's quite against their will... And then the amount of time we spend with them trying to get them to change or to do something about this. And then the amount of time we spend discussing, 'Do we bring them into the Roy Fagan Centre?'¹⁴ Do we keep them in their home?*

14 The Roy Fagan Centre is a state government residential mental health service for older Tasmanians living with acute mental health challenges.

Participant 2: Like all the meetings we have to have with all the providers.

Participant 1: Yeah, because we have to try the least restrictive approach possible. We can't go in boots and all with guardianship straight off. You've got to try. And that process itself will take months to see if it's going to work

And then if that's not going to work, then you do need to, you know, ask the [Guardianship] Board to take some autonomy away. That's for them a few more months. And then you start the work. So it can be very protracted process. Sometimes without achieving much.

Participant 2: And quite often... if we're not doing a lot, we're just observing and we're probably seeing them every week, because then there's also that sort of risk that we're sitting watching. But we've got to make sure we are watching.

Participant 1: So people at high risk of falls, you know, death at home. So they sort of just take time and lots of time to build relationships, so that they'll let you do what you need to do.

TWO FOCUS GROUP PARTICIPANTS

5.7 Working with non-voluntary clients and evolving engagement

Working with non-voluntary or refusing clients was commonplace amongst the housing service providers and the statutory agencies responsible for investigating code violations, such as animal welfare and management, environmental health and building compliance.

Many service providers and code-enforcers reported cases where clients had ended services or dialogue around safety concerns once these were raised by the professional:

A... [client] who is in [their] late 80s, and [their] house was unsanitary and it was unsafe... It was really bizarre because [their] son worked in the... fire [service]... And yet this [person] had newspapers absolutely everywhere, had woodwork that [they] would do inside the house. And so there was wood everywhere through the house, wood outside the house. It was such a fire hazard. [They] had an open fire as well. And yet [their] son let [them] stay with that situation. And then when the caseworker... actually approached the subject with [them], [they] cut off service.

INTERVIEW PARTICIPANT

Common across non-voluntary clients they described was a lack of or low level of insight into any risks to health and safety their living environment may be posing for themselves, people and animals they lived with and the environment around them. This meant that staff were needing to gain trust, understanding and relationships as the first goal, where possible, and it might be some time down the track before discussions were held about the nature of any challenges living environments posed:

We consider the big stick as an essential part of our toolbox, but it's the last resort part of the toolbox. Initially, we're about working together, trying to build a rapport with people.

And trying to build a trust and an understanding in them of what we need to do and we're actually here to work with them to get an outcome.

INTERVIEW PARTICIPANT

You've got to really dig deep... I find with people that hoard, it's my belief that they hoard for company. So... I had... a lovely old guy, and his deal was junker dogs. And again, you had to build a rapport with him... They're always cranky when you start. You've got to go back and really be consistent, harness anything you can. So I was able to build a rapport with him. With this lady that I'm dealing with at the moment, I've been able to, I guess, build a bit of trust with her... Like, one day I took her out a council pack with stickers and just said, 'Thanks very much for organising to have the front part of the lawn cut. This is my name, this is my number, I only work on certain days, but if you want to talk to me late at night, that's fine.' So coming in at their level, not coming in from an authoritarian approach. Come in more from, 'I'm here to help and I can kind of be here for you at a time that suits you.' Not just what suits me.

INTERVIEW PARTICIPANT

Code-enforcers in tenancy support roles and council environmental health and building compliance roles reported having to revisit or adapt the time scales for dealing with issues of concern or code violations to accommodate the need for a slow-burn relationship and often changing levels of engagement. For them, keeping a focus on what the end goal was, rather than the time it took, was key:

I had talked to my manager about this and I just said, look, you know, we're not going to get there overnight. It's destined to fail. It requires some sort of authority, which I don't have, and we're not a statutory authority. You know, we don't tell people what to do. So it's more a conversation. It's more a journey. And if it takes two years for them to get there, well, then if it takes two years to get them back to where they need to be, so be it. You know, so long as there is some form of progress, or that you have a given level of buy-in from a tenant. If they disengage, well then so do I.

INTERVIEW PARTICIPANT

5.8 Service providers' and statutory agencies' needs: relationship-focused investment

The need for services that are able to build long-term relationships and move with the ebb and flow of voluntary and non-voluntary clients' engagement is very clear.

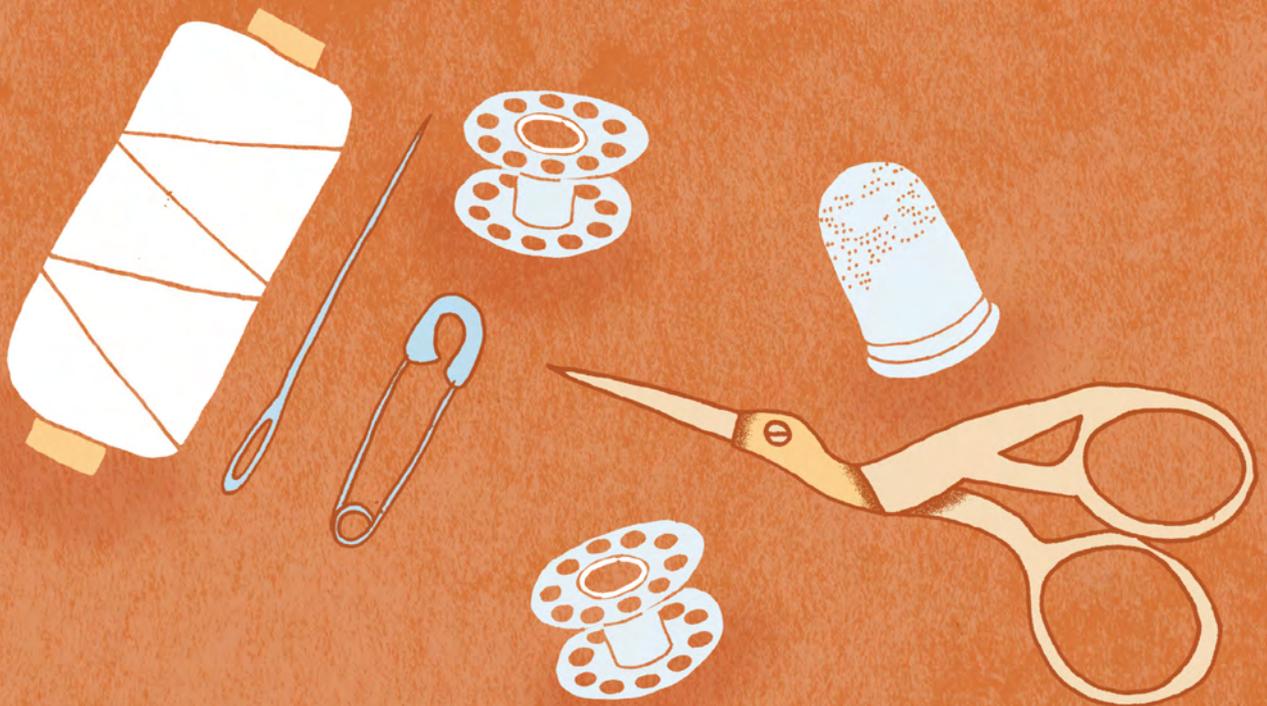
Any supports need time and flexibility to build relationships, trust and rapport with clients on a long-term basis. They need to be easily accessible to those on low incomes and complimentary to existing supports, such as the Australian Government's aged care system and NDIS.

You've gotta build trust and build rapport with the person so that, you know, they can work with you. So all this takes time and people can't be expected to work for nothing. So we need funding.

INTERVIEW PARTICIPANT

CHAPTER SIX

'Everyone's problem, no one's responsibility': experiences of collaboration and supporting clients



6.1 Key messages

- **Nowhere to turn to:** There were great examples of collaborative work amongst the Tasmanian service providers and code enforcers who participated, particularly with Tas Fire Service's Community Safety Program. However, all service providers and statutory agencies encountered the same hurdle when it came to seeking out other collaborative supports that might address their clients' needs: there were other interested agencies, but none who had the resources to coordinate a network and no specialists to provide the clinical, psychosocial and practical supports their clients needed.
- **Current supports insufficient to meet clients' needs:** Participants working in social care highlighted that current mainstream programs did not offer enough hours, nor the intensity and range of supports needed to keep on top of their clients' practical support needs. Additionally, the current workforce were not trained to provide the emotional or specialist psychosocial supports clients needed.
- **Case management keeping clients in a holding pattern:** Participants described how services that offer this cohort case management are often working with clients in a holding pattern. There are no specialist services to address the environmental and personal risks their clients face and the brokerage funding available in most case management services was simply not enough to fund clinical, psychosocial and practical supports, even if they were available. This meant most clients' challenges went unresolved.
- **No pathway from crisis to positive engagement:** Unplanned or crisis-driven incidents were often when older Tasmanians living with hoarding or CMHH encountered engagement with services. These were mainly negative interactions, often with the threat of a sanction – the loss of a tenancy, property or beloved animals if clutter and/or CMHH were not addressed. Participants described their limitations in addressing presenting concerns, because they were unable to access partnerships with social care providers who could support residents to address any underlying causes of their challenges. Participants within animal welfare and management, environmental health and fire safety commonly reported people with whom they had a long-term, "repeat" relationship around concerns that they felt would only ever be at best partially resolved, or not addressed, because their underlying complex challenges could not be supported by current services within Tasmania.
- **Beyond help? Service stalemate and transfer of risk:** First responders clearly faced high levels of risk in entering cluttered or unsanitary living environments. Agencies like Tas Fire Service were focused on reducing such known risks. Similarly, animal welfare organisations and council environmental health and building compliance officers described entering living environments that contained high risks to their own health and safety. Many participants working in health and social care described situations where they could not work with a client in their home because of health and safety risks that lay outside their organisation's risk tolerance levels. This left clients with the highest risks, being referred through a number of services who were unable to work with them, and led to unresolved challenges and no service options. Participants reported that these clients were falling through the safety net of social care.

What's needed:

- » **regional professional networks** for services and agencies supporting older Tasmanians living with hoarding and CMHH more holistically
- » **a specialist case management service** that can offer a lead role for clients who are not engaged in an existing program of support coordination. Also an advisory and referral service for case managers within existing programs such as aged care's HCP and CHSP, NDIS and Tas HACC who are looking for specialist support services
- » **regional targeted programs** to support Tasmanians living with hoarding and/or CMHH and their families and carers. These programs should offer a range of core clinical, psychosocial and practical support services that could be bolted onto the supports already provided through more mainstream care and could be accessed through referral to a specialist case manager, who could coordinate a specialist package of supports
- » **consideration of a provider of last resort model** for self-neglecting older Tasmanians who cannot be provided services due to their needs being beyond organisational risk tolerances.

Every participant recognised their limited capacity to support older Tasmanians living with hoarding or CMHH alone. They all flagged their need to work collaboratively across a range of services if they were to effectively support their clients, and reported there was no clear pathway to positive engagement and holistic supports for clients who encountered services through a crisis. They all expressed the same problem – they had no lead agency to refer cases to and no specialist services that could advise them or work with them. All research participants were aware that other services were in the same position as them. This led to an overwhelming feeling that supporting older Tasmanians living with hoarding or CMHH was everybody's problem, but nobody's specific responsibility.

Participants observed impacts on their clients, including:

- older Tasmanians' living environments being barely maintained where domestic support services could provide supports, but the challenges and risks inherent in their living environments not being tackled
- older Tasmanians often being left in a holding pattern with case managers and mainstream service providers, as they could not find relevant services to address their needs holistically
- there being a significant cohort of older Tasmanians who were not being supported because their living environments were beyond the risk tolerances of services. Risks had been transferred entirely to this particularly vulnerable group of elders, with no clear path to service options that could resolve the stalemate.

FIGURE 18: PARTICIPANTS' CHALLENGES AROUND COLLABORATION AND SERVICES

6.2 Nowhere to turn to: no systematic collaboration, specialist case management and services

Collaboration: commitment without infrastructure

There were great examples of collaborative work amongst Tasmanian service providers and code enforcers who participated. Tas Fire Services' Community Safety Program was frequently mentioned as a valuable collaborator (see Case Study 15). Reflecting the way taskforces elsewhere operate, participants reported that it was useful to have a partner who could bring a 'different angle' to the conversation they might be having with their client about risks. Discussing fire safety was viewed as a relatively neutral conversation that could improve their clients' insights and engagement.

There were also strong collaborative networks within certain sectors, such as animal management.

Statutory agencies across animal welfare and management, environmental health and building compliance spoke about the challenges of working with non-voluntary or refusing clients. They were all acutely aware of their need to work in partnership with a professional who could support residents psychosocially.

The ultimate goal is obviously to get them to a number of cats that is manageable... There isn't necessarily someone we can contact to come out with us that has the capacity to deal with the mental health aspect. And to be able to convince them that it is a mental health issue that they are potentially dealing with. Yeah, a lot of times they don't see that it's a problem at all. And that's very, very common.

INTERVIEW PARTICIPANT

These situations are not ideal by yourself. The mental health is such that if provoked they become defensive, and when they're defensive they'll do what's necessary. So not the best situation for ourselves. And to be honest, some of the... officers would find it difficult to talk to people and ask the hard questions, you know—I need to look inside; can you show me? ...But my thoughts are, you know, you need some help. I just want to make sure you've actually got a decent place to take your shower and keep yourself clean.

INTERVIEW PARTICIPANT

Many service providers and statutory agencies encountered the same hurdle when it came to seeking out other collaborative supports that might address the needs of their clients. They found other interested agencies, but none who had the resources or specialisms to provide the clinical, psychosocial and practical supports to clients.

Because the biggest thing is when you do identify needs for a client, the wait time, the chasing, and no one getting back to you, and you're just going around in circles. So the client is not getting anywhere. But if there's a task force, where everyone's collaborating on the one client. Let's get things done, not wait three years for it. And that's what's happening. Like, you can reach out to mental health, drug support, anything like that, but there's always a waiting period. And you've got to seize the moment when the client needs it and when they're saying yes.

INTERVIEW PARTICIPANT

Existing service delivery: touching the surface

Amongst service providers, particularly in aged care, there was an observation that regular intervention, for example through HCP domestic supports, could keep living environments maintained. But for those older clients who were not receiving HCP, or other regular domestic assistance, their living environments were generally observed to be less healthy:

So would you say that the clients who are on packages, their sanitation is okay simply because they do have that regular cleaning going in. Whereas I think, so a CHSP client that I worked with a couple of years ago, his house certainly wasn't sanitised. And obviously, you know, he hardly had anybody going through the house except for his son, but his son didn't do much for him either. So I think it's when they've got the packages and they've got regular services, it's okay. But CHSP clients, I think they're hoarding and they're [living with CMHH].

INTERVIEW PARTICIPANT

However, those working in social care and domestic supports also highlighted the limitations of current services across aged care and Tas HACC. They described that these programs did not offer enough hours, nor the intensity of domestic supports that could address environmental concerns. Additionally, the current workforce was not specifically trained to provide the emotional or psychosocial supports needed for clients. Some participants reflected that this led to unrealistic expectations of what aged care and adult care services, such as Tas HACC, could deliver for those living with hoarding or CMHH:

I think sometimes... just from experience, there could be that expectation that the support worker is going to come in and solve all the problems for the children to deal

with their parent. And expect too much from the support worker who would be dealing with the same behavioral stuff that's coming at them... Maybe even more so, because they're an outsider coming in... wanting them to, you know, address these sanitary things... Maybe it's not possible, even for the support worker to do it, to the detail that the family is actually really wanting to happen. Yeah.

INTERVIEW PARTICIPANT

So you know, I can send a worker in. But you're talking about someone with a Cert III who's getting paid barely anything to work their guts out. And they're not really going to understand the psychology behind what the actions are that they're taking in order to give the right type of support that's needed for this person who is keeping all of these objects. Or living in this environment. Yeah.

INTERVIEW PARTICIPANT

Lindsey: So what would need to be in place to ensure that they could age well at home? Or do you think that there's an inevitability about entry into residential care?

Participant 1: Well, I think that, I'm just thinking about a [client] who went from [their] home which was full of stuff into a supported living unit. And then that became full of stuff as well. Yes. I don't, I think obviously keeping people at home is better for them generally speaking. Yeah, so I think, you know, obviously... there's not enough support. There's Commonwealth Home Support, which is generally inadequate and doesn't address the problems that we're discussing because there's no case manager or person is dedicated to that individual. So I think, basically I think we need a well-educated professional workforce that has the time and skills to sort of look after people. And I don't think we've got that at the moment in aged care.

INTERVIEW PARTICIPANT

Commonly, services commented that clients' needs were left unresolved and they were not aware of the appropriate specialist services to work with locally.

Yeah, so in terms of the psychological interventions, the specialist psychologists who work in this area... need to be paid... Basically there are a couple of, at least one very good hoarding and [CMHH] specialist psychologist in Melbourne, who can do zoom meetings or whatever... I've heard her speak on a couple of occasions, at courses and so forth... That's through the Hoarding Hub. But basically she's set up to be paid by the NDIS and if you're still waiting for a plan to be built, you can't hire her because there's no NDIS funding. So I guess that's where the only other option is a GP mental health plan. And not all psychologists are really able to, you know, it's not part of broad psychology, I don't think. So, yes, not a huge amount we can do about that in terms of specialist referrals, because we don't have the funding to purchase those if the plan isn't there. But we will talk to people about, you know, "This is not sustainable." You know, "We have to do something. Otherwise, you know, there will be a consequence that will happen, regardless of whether we like it or not. You know, we don't have a problem with you. It's not about my personal judgment. It's about the fact that Housing Tasmania is saying, look, you know, you're breaching your lease in terms of the condition of the property."

INTERVIEW PARTICIPANT

Acknowledging the complexities of clients' needs, the different stages of contemplation clients were at and the different knowledge and skills support professionals brought, participants often suggested the need for a continuum of care in Tasmania. They envisioned that this would create a pathway of support wherever clients were on that contemplation path. A single point of entry into information and referral would also be required:

I mean, I guess for mine, it's, you know, a clear pathway to different tiers or different levels of support that... are in line with what stage of contemplation, I suppose. So, you know, whether that's just some information or some counselling or whether it's, people are very clear that "No, no, I do want to, I'm at a point where I do want to do something about this" and "I am open to having someone come in and have a look and talking through what needs to happen." Not just so that it's sort of one big clear up and then that's done. Then the problem starts again. But the ongoing sort of support and a real – and assistance to work out, you know, to talk about a strategy and a way forward that's not just around, you know, "You need to change and you need to, you know, address your behaviour." But, yeah, something that's really practical for people, I suppose."

INTERVIEW PARTICIPANT

Case management – a holding pattern

Given there is not a central specialist support hub in Tasmania, many felt unsure about whether they were simply missing supports. This in turn led to a common desire for there to be a central information hub around hoarding and CMHH, so they might at least know where to check what's available (see Chapter 7).

There are a number of case management services currently available for older Tasmanians living with hoarding or CMHH (for example through aged care HSPs, CHSP ACH Program, Tas HACC, NDIS, PHT-funded psychosocial support programs outside of NDIS, and state Adult and Older Persons Mental Health Services). Case-managing participants reported that they usually work with voluntary and non-voluntary clients referred through a broad range of agencies, including aged care assessment processes (ACAT and RAS), emergency services, housing and other health and social care services.

Case-managing participants described how their services for this cohort of clients were often left in a holding pattern. There were no specialist services to work with to support their clients to achieve their goals, or to address the environmental risks identified by other agencies, and the brokerage funding available in most case management services are simply not enough to fund clinical, psychosocial and practical supports. Again, case-managing participants reported that usually clients' challenges were unresolved.

Case-managing participants commonly talked about needing specialist advice on supporting clients on a case management basis and needing guidance around local specialist services they could draw on to put together a relevant support package.

Participants who delivered other services and statutory agencies who encountered older Tasmanians living with hoarding or CMHH expressed a clear desire to be able to refer clients to a specialist case management service. They perceived a need for a service that offered professionals who were trained in working with and supporting people living with these challenges and that could then bring all the relevant support services together to

address immediate concerns and longer term client needs. This service needed to support them to offer points of interaction that were **enabling**, rather than negative.

I think there needs to be sort of, you know, a coordinator with a specialisation in hoarding or with that type of behaviour. Who can speak to the consumer and sort of direct what that next part is going to be of the practical side of the de-cluttering, I suppose, yeah.

INTERVIEW PARTICIPANT

Without that component of case management, if [federal DoH are] going to recognise that it's a group needing support, that's the bit they need to fund.

INTERVIEW PARTICIPANT

Participant 1: *But what you're doing is as you work through your process, you determine whether he's best handled through our regulatory process, or through your other contacts. And those other bits become other people because they've got better skills than us.*

Participant 2: *Oh yeah, I get that.*

Participant 1: *It allows us to get off the regulatory roundabout, onto a conciliatory roundabout, or a proactive roundabout. If it needs to come back into process, back to us because they find that there's another issue there, then it comes back to us, but at least it's guiding us through the path, we're finding an option to get onto a good option.*

Participant 2: *But how would you ever come across a hoarder in a proactive space?*

Participant 1: *No, we're gonna come across them in these reactive spaces, but the process we need is going to guide us as to how we can get off that reactive, into -*

Participant 2: *Correct. Appropriate referral.*

Participant 1: *Yeah. Yeah.*

Participant 2: *That's it, appropriate referral*

FOCUS GROUP PARTICIPANTS

6.3 No pathways from crisis to positive engagement: repeat encounters

It was clear from participants that unplanned or crisis-driven incidents were often where older Tasmanians living with hoarding or CMHH encountered engagement with services, as reflected in other research into these issues (Bratitotis 2013; Kysow et al. 2020; Brown & Pain 2014; Neziroglu et al. 2020; Roane et al. 2017; Stark 2013). For example, hospitalisation that required homes to be made "safe" before people could be discharged, neighbourhood complaints to the council environmental health and building compliance officers, or an animal welfare concern raised with animal welfare and management services. Also commonly reported were condition of property inspections that had raised a concern with a public, social or private landlord, or a fire safety concern reported by a visiting first responder (see Figure 19).

These were mainly negative interactions, often with the threat of a sanction – the loss of a tenancy, property or beloved animals if clutter and CMHH are not addressed. As described above, these “code-enforcing” participants usually found that there was a limit to what they could do to support the presenting environmental concerns, since they could not secure assistance anywhere in Tasmania from social care providers with expertise in supporting people with complex mental health challenges.

Participants described how there was only so far they could go within their scope and powers to support residents with their concerns. This meant that issues were often left only partly resolved; many described how they had long-term relationships with “repeat” clients as the challenges with their living conditions ebbed and flowed. They talked about how there may be gradual progress with an immediate concern / code violation, but they were conscious that they were not addressing the underlying mental health challenges or long-term support needs residents had. This often led to repeated incidents. Once clutter became more visible, or the number of animals on a property escalated again, it would likely lead to another neighbourhood complaint, or another fall and hospitalisation would lead to another delayed hospital discharge. Many participants within areas of code violation, such as animal welfare and management, environmental health and fire safety had known cases – people with whom they had a long-term relationship, or at least they were aware of in a local community.

Participant 1: *In practice, how do we pacify a neighbour? How do we try to keep the community safe and healthy? But how do we also...*

Participant 2: *Meet this [resident's] needs?*

Participant 1: *...manage to walk down that path of conciliation with this [resident], to get an outcome, which is suitable for [their] environment? And it's not going too far against what our obligations are, but... sometimes we're better off not to step on the [regulatory] treadmill, than we are to step on and knowing we're going to ruin a life in the process of doing it. And I know that's all a bit complicated.*

Participant 2: *They are complicated matters.*

Participant 1: *If we could do it really simply, we should give notice to vacate the place, but to make this really, really complicated... there's a lot of, bunch of moral things going wrong there. Where it gets awkward... is where we don't do anything and the darn place burns down. Who's looking over our shoulder and how are we defending ourselves?*

Participant 2: *The media will get their hands on it and will swing straight around on us. So that's in the back of our mind all the time.*

Participant 1: *But if we kick [the resident] out, all the same stuff can happen.*

Participant 2: *Yes. Correct.*

Participant 1: *So then it really gets back to, "Okay, it's not about protecting our bum, it's about what's best for this resident?"*

Participant 2: *It's for them. Correct.*

Participant 1: *And sometimes, leaving well enough alone is probably best. But when we've got a fire burning next door we're trying to manage, we've got to try and find a way to help this [resident], but very sensitively and very carefully. And walking a bit blind, with a bunch of compassion, but a lot of unknown answers.*

However, it is important to note that these interactions are moments of opportunity. They potentially open a moment of contemplation on the safety risks posed by the home environment. They also offer the opportunity to turn a negative engagement into a longer term positive engagement that addresses the needs of self-neglecting elders holistically. However, as previously described, professionals such as environmental health officers, building compliance officers and animal welfare and management staff were clear that they did not have the scope or skills to work sensitively with residents living with complex mental health challenges.

I think there has to be a recognition that hoarding definitely is a mental health problem, and better access to services. And maybe some of the services need to be applied earlier.

INTERVIEW PARTICIPANT

Participant 1: *So I guess there's a bit of a grey area there, which benefits both us and the [resident] of the house, while we don't know. But once we put our foot in there, we've got to do something.*

Participant 2: *We've got to act. We've got a duty of care.*

Participant 1: *That's where we're really, and it's really out of the realms of the council to be delving this far down. We want to, but it's really way out of our comfort zone and way out of our scope and...*

Participant 2: *...Expertise.*

Participant 1: *Yeah, expertise. And that's where you need to call on someone else, that we can say, "Hey, can you please take over this and give us some guidance when you can?" And let someone else run with it.*

Participant 2: *I think someone from a specialist mental health service for older persons, is what is needed here. I know in New South Wales I also worked in an after-hours capacity in a mental health institution. And there are specialists, so it's... specialist medical practitioner for older persons. So someone that's working just in that space, I think is what the next step here, once we can engage with [the resident]. And I think I would want to have that service set up, that person well-briefed when I made that initial contact. And the other thing I would focus on is the welfare of the cats because that, to me, is apart from the hoarding, that I believe is going on, and the police officer has alluded to, the cats are the critical thing there.*

FOCUS GROUP PARTICIPANTS

FIGURE 19: CLIENTS' MAIN POINTS OF ENGAGEMENT WITH SERVICES AND AGENCIES AROUND CRISES AND TIME-CRITICAL CONCERNS



6.4 Beyond help? Service stalemate and transfer of risk

Organisational risk tolerances

Most services used health and safety risk assessments that were designed to assess the risk levels for service delivery, rather than risks for residents. Participants described different organisational risk tolerances.

Commonly identified barriers included unacceptable fire risk without smoke alarms due to high fuel loads, unsafe use of electrics, cooking and heating; concerns around trips and falls amongst service providers due to clutter, and the heightened risks of staff illness due to unsanitary environments. The combination of such risks meant that some organisations were not prepared to enter a client's property to provide a service, or might have to cease services where risks to staff due to either the living environment or behaviour had escalated. However such risk tolerances differ and there was no clear or shared information around who will work with clients in certain circumstances.

I've been in a home where the occupant simply discarded their used insulin needles on the floor after use. There were contaminated sharps scattered throughout the house on the floor, which was also mostly covered with human excrement as the result of

incontinence. I've also been in a home where the occupant collected and kept weapons (firearms, axes, large knives etc) concealed around the house which was a risk to their own health and safety as well as visitors.

SURVEY PARTICIPANT

Lindsey: How do you ensure that health and safety?

Participant: That's why we have that intake – their visit first. Because, first and foremost, it needs to be safe for the staff to work in, otherwise we don't go in. And we – we've got one recently, that came to us as a [Home Care] Package client, and... it's like a shack. A great big concrete step up onto the front veranda, and there were some pavers, but they're all – it's not safe. And the step's too high. There's tiles missing on the flooring, so they're trip hazards. There is no fire alarms in the house, and it's an old... There's tiles falling off everywhere in the bathroom. I said, "I can't... safely have my staff..." ...and I understood both of them were elderly. And she said, "Yeah, I'm falling down there." And I said, "But we're legislated to provide a safe workplace, so I'll get my son-in-law to come and do something with the step, or they can come in the back." And I said, "Oh, well, actually, they can't. Because there's a bit of a floorboard missing." [The resident said] "Oh, we just step over it." [I said] "That's okay for you. It's not good for you, but I can't ask staff to step over a hole in the floor." And so, it was sort of like, "Well, you can come on as a client, but this has to be fixed." And we have to get the – a fire department there, to put smoke alarms in... They were round there almost straight away. Put three in. Because he's got bad dementia. And he will stoke the fire in the middle of the night, and do crazy things.

INTERVIEW PARTICIPANT

First responders clearly faced high levels of risks in entering cluttered or unsanitary living environments. Agencies like Tas Fire Service were focused on reducing such known risks:

When it comes to... firefighters going in, they may not be able to find them quickly... Also, when it comes to firefighters, it's a work health and safety issue... because they don't know what they are going into... Part of their training is being prepared for the worst. But sometimes they don't know. That's beyond the worst to them... But after a conversation they say they see a lot and they've been seeing it through the years, just incredible issues with it. But, you know, they go in with lots of head gear on... they have limited vision. They do have a torch on the top. But because... they're going into a fire, it's smoky, it's dark. They may have to get low. So the potential for them is tripping, falling, their breathing apparatus being dislodged, having equipment... clutter and whatever's being hoarded falling on them. Stepping in things that potentially aren't very nice, healthy... And also being trapped themselves in a fire because, you know, if something falls on them and they can't get out... And then there's also the potential of a big fire... spreading beyond to other buildings. So, if it's a block of flats, it's other units in those flats, or if it's a residential area with lots of houses close by.

INTERVIEW PARTICIPANT

Similarly, animal welfare organisations described entering living environments that contained high risks to their own health and safety, as did council environmental health officers:

Participant 1: *Risk awareness – definitely need to be aware of risks in terms of identifying what not to touch.*

Participant 2: *Yeah*

Participant 1: *Like huge, huge.*

Participant 2: *It's not until afterwards that I go, oh, I really put myself in danger in that house, like that house could have fallen on me. There was a tree growing in the kitchen, like through the roof of the kitchen. And I really put myself at risk without even really being aware of it because I just went in to rescue. And it wasn't until afterwards. And when I went back there during the day... my husband... was like... "What are we doing in here?"*

Participant 1: *What are you doing in there, yeah.*

Participant 2: *And I was like, well, I couldn't see, I just had torches. So it's not until you go there the next day that you go, "Oh my God, I can't believe I was in this room."*

INTERVIEW PARTICIPANTS

Many staff reported they entered households that they suspected were beyond their organisation's risk tolerance, but occasionally made the judgement to enter to achieve a support goal:

I do worry about fire. I've talked to her about what would happen in a fire... I think I've talked to all of them about that. And I mean, there's not really, there's not really a lot she can do... I don't even know if there are smoke alarms. So that's kind of what, that's my impression of the house. The house itself on the outside is in disrepair. There's lot of things outside the house as well. There is a warning tape around it. And the windows, the doors are broken as well, they're missing panes and probably not really lockable. Yeah. I don't know if work would be happy if I went to that house anyway.

INTERVIEW PARTICIPANT

The pathway is through My Aged Care... And it's usually a referral for domestic assistance... And it's usually that we don't know how bad the situation is until we go and do a home safety check... They might have been living with this issue [hoarding and/or CMHH] for a long time, but they present as low level, because not given a home visit when they have the assessment from My Aged Care [Regional Assessment Services].

INTERVIEW PARTICIPANT

However participants working in social care and other areas of code enforcement regularly described situations where they could not work with a client in their home because of health and safety risks that lay outside their organisation's risk tolerance levels. They could not find any way of addressing these risks through collaboration with another organisation.

The home environment increases the risk of falls. The home environment is deemed unsuitable for clinical care and this means the client has to attend clinic instead at an added cost burden to them. Provision of other services such as domestic assistance or personal care is unable to be provided due to the unsafe working environment in the home, thus further impacting on the person's health status.

SURVEY PARTICIPANT

Wouldn't it be really good if we had—we could work with a mental health worker for some of those clients that we—we're almost at the stage of saying no to. But... I don't have the confidence that that would be easy to get, ongoing, in the right way. So it's not a solution. I'm seeing it as a little bit of a barrier, but it's always been on my agenda... I've spoken about it for so many times, about what we could do better internally.

INTERVIEW PARTICIPANT

There were occasional reflections from participants about the challenges of managing risks when working within the framework of consumer choice and dignity of risk. This was not a resolved issue for any participant, but many offered examples of where they felt that clients had fallen through the safety net of social care because the risks associated with their living environment had been transferred back to them by organisations:

Some people will kind of look the other way and say, "Oh, it's their choice." Because there's a lot of stuff about choice, especially in areas like disability... I remember working with someone once... This was squalor, hoarding, it was unsafe, and unhygienic. But [the service provider] just looked the other way and said it was her choice. But the fact was, no one was engaging with her, let alone engaging in a way that fostered trust or dignity or anything else, and it was just left to get worse and worse.

You have to look at it in a holistic way, because you've got to look at everything that's going on in their life, and see, "Do they really have control over this? Are they managing it? Or is their daily functioning affected?" So when you look at all of those factors and actually talk to them about what's going on in their life, you can work it out

INTERVIEW PARTICIPANT

Observations like these bring into focus our responses to self-neglect in Tasmania. As explored in Chapter 8, unlike countries such as England and Wales, Australia does not include self-neglect in our concept of elder abuse. In Tasmania we do not have a clear response to observations of self neglect outside of the social care framework of dignity or choice and risk. Where older Tasmanians living with hoarding or CMHH have expressed a desire to age at home, how can we support them more effectively to minimise severe personal and environmental risks? It appears that without investment in a suite of supports that will work with them along a spectrum of need and risks, our older Tasmanians are not in a position to exercise their choice and dignity of risk. Tasmania is not providing some of our most vulnerable older Tasmanians a relevant continuum of care.

Transfer of risk

In scenarios where organisations could not work with clients due to organisational risk tolerances, the risks were transferred solely to the client. This reflects a situation described in self-neglect literature, where dignity of choice and risk is argued to, in practical terms, transfer risks and responsibilities from partly being held by an organisation, back to the client (Bozinovski 2008). It meant that some older Tasmanian clients were being suspended in limbo in the Tasmanian service landscape. They were being referred from one service provider to another to see who was able to address health and safety concerns to a level that meant other services could send in staff, or recommence services. Participants reported that during this process, clients were often either disengaging, or holding an escalating level of risk to their personal and environmental safety:

So the referral came through for a [person] who lives with [family] and hoarding was identified as an issue. So I've only been into the family home once with [a colleague]. I've had some phone contact since then. And it was, so the hallway was clear, but there's lots of papers and stuff in the lounge and we weren't able to sit down or anything. And the bathroom was falling apart really, wasn't it? But, for me, what was interesting was, so the reason the referral came through to us was the woman was getting some personal care assistance through another agency and they stopped because it was a health and safety issue for their staff.

INTERVIEW PARTICIPANT

[Client] is unable to access support services, such as domestic assistance or personal care, to live independently due to the state of the home.

SURVEY PARTICIPANT

I have several who have run out of supported accommodation options in Launceston (having been to them all). These are all operated by non-government/private agencies, and my clients are deemed too high need. As a direct result of this I have a man, on the Housing list, who is into his 13th week in a tent.

SURVEY PARTICIPANT

The common impact of transferring risk is that clients' core personal and environmental challenges are unlikely to be addressed. Many service providers and statutory agencies mentioned a degree of "recidivism" or return clients due to this issue.

Participants commonly raised lingering concerns about clients' risks where they felt they had been unable to address code violations, or clear health and safety concerns. Transferring risk back to the client did not necessarily mean that the emotional load associated with that concern was transferred.

So with [a particular resident], and since I've had this and knowing that we've had some house fires in Launceston... I'm thinking about it at home now. So then that's saying to me, I'm worrying about it.

INTERVIEW PARTICIPANT

Participants were also often acutely aware that the risk transfer that had been passed back to clients meant that their situation may be worsening and risking their ability to live independently:

On occasion our clients would rather be in the Mental Health inpatient unit or prison, as in a sense this is structured, supported accommodation for them. Three meals a day, with no need to conserve/manage money for rent & food. Some remember professionally operated large residential centres (i.e. institutions – Royal Derwent and interstate hospitals such as Rozelle Hospital; Howard Hill in Longford).

SURVEY PARTICIPANT

This clearly raised an issue around employees' wellbeing, and it focused participants' minds on the clear need for specialist supports for those living with hoarding and CMHH:

It's also where one of my other bits of hats comes in, is I need to look after [staff's] welfare. And if I – if you get too deep into this, it potentially is going to take you down, if you can't get an outcome. And that's where we really need to be able to share the love with the people that know their stuff. And because I'll need to look after [staff], as well as we need to look after [residents]. So that's where I think we really need, we do the very, very best we can, but we need to call on some experts that can take it and run with it.

INTERVIEW PARTICIPANT

6.5 Their needs: collaboration, case management and services

Without the provision of services, any specialist support services designed for this cohort has to be able to provide for the market-driven elements of social care, such as NDIS and many elements of aged care. However, they also have to offer those not engaged in these consumer-directed programs access to a full suite of supports. Such supports need to be able to sensitively accompany older Tasmanians living with hoarding or CMHH through a journey, one that may include periods when they refuse to engage, engage in a non-voluntary manner or are voluntary partners. Where the market for services is thin or non-existent, as is currently the case for Tasmanians seeking supports for hoarding or CMHH, it is also crucial that government agencies consider how consumers can exercise their choice or dignity or risk.

Bearing in mind these complex policy design issues, most participants chose to describe the types of supports they needed, rather than where these should sit within the Tasmanian policy landscape. Participants described a common suite of services that they felt would support them in ensuring this vulnerable cohort of older Tasmanians have an increased chance of ageing well at home.

Regional multidisciplinary collaboration networks

Service providers and statutory agencies flagged the need for a systematic way of coming together to support older Tasmanians living with hoarding and CMHH more holistically. They felt that this would significantly help them to understand what services are available across the clinical, psychosocial and practical service landscape and would help to identify gaps in services that need investment. Participants also identified that this would help build a consistent approach to support and an agreed set of service goals.

Although local government areas were where more familiar community relationships were based, it was not considered practical to develop 29 networks. Most participants felt that bringing together supports on a regional level would be most appropriate:

I don't think [a network] could sustain itself – not really knowing how those services and networks are – if it were less than a regional scale. But... sometimes when you do scale up and it gets centralised there's a loss of connection with what it's like out there, it's a bit of a challenge... It's not just the hoarding and the [CMHH] stuff of course. But, yeah, just having there are social services networks and having them well connected and having them connected... then [there] can be a connection point here that... appreciates the place and then can connect to a regional capacity that can come out and support activity. Yeah, that might be a way of working it.

INTERVIEW PARTICIPANT

However, it was also widely recognised that bringing existing services together would not in itself ensure that older Tasmanians and their families were supported. Participants all voiced the need for a suite of specialist investments in clinical, psychosocial and practical services including case management and advice to mainstream services. These would need to both work with existing, more "mainstream" Tasmanian services and agencies and act as a specialist program that cases could be referred to.

Specialist case management service

There is clearly the need for a specialist case management service that can offer a lead role for clients who are 50¹⁵ or over not engaged in an existing program of support coordination.

Such a case management service would provide that key link into positive engagement for older people who may have found themselves facing a neighbourhood complaint, delayed hospital discharge, or are facing homelessness due to a tenancy risk or fire. Similar to the Brotherhood of St. Laurence's Critical Interim Support Program, this would ensure that older Tasmanians are compassionately led from addressing immediate crises and personal or environmental concerns into a longer term package of supports.

Additionally, there is a need for an advisory and referral service for case managers in existing programs such as the My Aged Care assessment process, aged care's HCP and CHSP, NDIS and Tas HACC who are looking for specialist support services. How these roles integrate is an issue that current program reviews should consider.

15 Or 45 and for those older Tasmanians of Aboriginal or Torres Strait Islander heritage.

This combination would have the potential to free clients from their existing holding pattern and help to minimise client disengagement. However, without a suite of specialist programs and services to work with, case management itself will not provide a Tasmanian service landscape that can facilitate aging well in place.

Specialist suite of supports – clinical, psychosocial and practical: consumer-informed

There was universal agreement amongst participants that Tasmania needs to invest in a targeted program to support Tasmanians living with hoarding or CMHH and their families and carers. To fit with the desire for regional networks, service provision on a regional level was considered the most appropriate, to ensure that there is state coverage.

Participants described a range of core clinical, psychosocial and practical support services that could be bolted onto the supports they are already providing through more mainstream care. Participants talked about a need for access to clinical, psychosocial and practical program elements they could broker as part of their existing case management, or could be accessed through referral to a specialist case manager who could coordinate a specialist package of supports.

Lindsey: *How would you see that working...? How would you see the emotional support working alongside the practical support?*

Participant: *Yeah, I think it would almost have to be either they go there and one of the trusted workers is there at the same time, and they almost would have to go through objects with the client almost, I suppose. Would be a real, it's difficult because you know, we can talk about all the ideas behind it. But like I said before, the practicality of it is what's difficult.*

INTERVIEW PARTICIPANT

I think for older people... I think you could get runs on the board much, much easier, because the intervention, I don't think you'd be pulling in so many different disciplines. I think with older people, particularly over 70, you'd be dealing with an experienced counsellor type mental health person that could do the gamut across that cohort. But with the younger people, where you've got an influence of the drug/alcohol/gambling, it's much more prevalent in those – the younger age group. You're going to have to have some expertise in that other area... and maybe a multi-disciplinary mental health person. You wouldn't be able to do all of it, but we'd do some of it. But liaise with other disciplines. Whereas... with the older one[s], I think a mental health counselling type person could certainly be embedded in an aged care service to manage a lot of that. Because the skills you'd be looking at are things like the reminiscing, and the – the stuff that I talked about. Those things to make the end quality of life indicator, the end of life, be really good.

INTERVIEW PARTICIPANT

Many participants were reluctant to offer up detail of what those supports should contain. From the review of what works elsewhere (see Chapter 9), it is clear that any Tasmanian supports need to consider:

- a clear and timely referral pathway to specialist clinical supports, either through state mental health services or a specialist clinical service within a program targeted for those living with hoarding or CMHH. This service could consider underlying cognitive challenges and trauma that may require a pharmacological and/or therapeutic approach
- a specialist program of psychosocial supports that offer:
 - » a therapeutic element of supports that addresses root causes of behaviours
 - » elements of cognitive rehabilitation that may be needed for older Tasmanians to prepare them to engage in thinking about and controlling change within their living environment. San Diego's CREST Program would be a useful model to consider (see Case Study 11)
 - » sensitive and paced psychosocial supports for older Tasmanians to be able to address changes to their living environment
- specialist sorting, discarding and cleaning services that are able to work with older Tasmanians in a sensitive and agreed approach with the case manager.

Consideration of providers of last resort

The services we are considering are for some of the most vulnerable older Tasmanians living in environments of high risks to their own health and safety. These living environments also pose high risks for those people and animals who live with them, around them and who endeavor to work with them. This needs to be acknowledged and addressed in any model of support. How can we ensure there is a safety net service – or services – across Tasmania, if an older Tasmanian's situation has escalated to the extent that no other services are willing or able to provide supports? It is worth investigating the extent to which the "service of last resort" model, or something along those lines, could be considered.

In the National Disability Insurance Scheme, where there are thin markets for services, or no services can or will provide supports to participants with complex needs, there is provision for NDIA to consider a 'provider of last resort' (NDIA 2016). This is where the funding agency considers contracting with a local provider to offer safety net supports.

Such a model could be considered for self-neglecting older Tasmanians. This would ensure that, where risk has been transferred back to older Tasmanians living with hoarding or CMHH, there is a clear process to ensure that every avenue has been explored within a framework of dignity or choice and risk. Beyond that, it would ensure a sensitive approach to minimising further self-neglect. Given this cohort spans market-led support models such as NDIS and My Aged Care and sit outside of these programs, it would be worth considering such services within revised models of NDIS and aged care's UHSP, but also a state-government based provider of last resort.

CHAPTER SEVEN

'We're not prepared for this':
the search for shared
approaches



7.1 Key messages

- **Opening the door to clients' needs – government recognition in policy reforms:** Many participants were unclear whether their clients' needs were being considered within current government reforms in aged care, mental health, disability and Tas HACC. They expressed concern that there seemed to be no government agency taking the lead role to ensure this vulnerable cohorts' needs were being met.
- **Where's the information we need? Developing shared information and practice:** There is no Tasmanian information portal for people living with hoarding and/or CMHH, or for those who seek to support with them. Nor is there a shared practice framework. Service providers and statutory agencies struggled to find the information they needed to support their clients. This included information concerning other services they might work with, how they might assess their clients' needs and ways to approach their support work. This left participants feeling unprepared and unclear about whether there were resources they simply hadn't discovered.
- **Missing data – understanding needs and mitigating risks:** There were four participants whose agencies were collecting data specifically around clients or addresses where hoarding or CMHH had presented concerns for their area of interest. Three agencies were using their data to proactively plan risk prevention and interventions. However, there is no systematic data collection around hoarding or CMHH in Tasmania that can help us to begin to understand the prevalence of hoarding and CMHH, clients' needs and to support risk mitigation for first responders. There were different perspectives on data sharing offered amongst participants, depending on the legislation and policies a service or agency was working under. Health and social care providers were often unsure or unclear about whether sharing data in a collaborative network would be possible under Tasmania's current statutory frameworks.

What's needed:

- Tasmania needs to identify a **lead state government agency** to develop a shared practice framework, as has happened in some other Australian jurisdictions.
- Service providers and statutory agencies need a **specialist, digital information hub** around hoarding and CMHH in Tasmania that would provide them with all the information, tools and resources they might need when supporting clients. This would provide more service efficiency.
- Service providers and statutory agencies require a **practice framework** that provides shared guidance on a number of areas. Elements need to include information about the nature of hoarding and CMHH to help their understanding of the role they could play and what they might need from others; a common approach to support clients; guidance on assessments and tools to develop a shared approach to assessing clients' risks, needs and the severity of the situation in a non-judgmental way and make support decisions and referrals; and how they could access professional development and advice to enhance their current practice.

The final theme in participants' reflections related to the need for state leadership in policy and guidance. They described how they struggled to locate hoarding or CMHH in any policy and practice frameworks. This, they felt, led to the lack of recognition of this cohort's needs and the lack of investment in supports for them. With no state leadership around this issue, they highlighted the critical need for a hub for social policy and legislation, information, references and resources and approaches to their practice – what other jurisdictions have called a practice framework, guidance, and/or an information hub (see Chapter 10).

There were four elements in participants' conversations that could contribute to a Tasmanian practice framework: where to turn to for information and services, developing a shared understanding of how to work with clients across different service areas, developing a shared set of tools for assessment and working, and what sharing data in this area might look like and for what purposes.

FIGURE 20: PARTICIPANTS' CONCERNS AROUND SHARED KNOWLEDGE, PRACTICE AND DATA



7.2 Opening the door to clients' needs: government recognition in policy reforms

Many participants commented that they felt the needs of older people living with hoarding or CMHH was not being recognised by the federal and Tasmanian state government. The complexity of addressing challenges, and the fact that they spanned a number of social policy and legislative areas, meant that no one federal or state government department had taken leadership over this issue. As a result of this, participants offered reflections on how their clients' needs were not really recognised adequately by any particular support program. The benefits of addressing the significant challenges faced by older people who were living with hoarding or CMHH had been overwhelmed by bigger agendas, such as the state of aged care in general.

Some participants felt it was timely to revisit this. Given current reforms within aged care, NDIS, Tas HACC and state mental health, they believed the time had come for state government to recognise hoarding and CMHH as an area worthy of attention. The keys to leadership, they suggested, were:

- federal and state government recognition of the needs of people living with hoarding or CMHH
- understanding the risks and impacts on people, animals, the environment and the services that seek to support them
- understanding how targeted supports could improve Australians' quality of life and the cost benefits for governments
- lead federal and state government agencies to develop a strategic approach to an enabling set of social policies, investment and collaborations.

I think it needs to be recognised as – it needs to be recognised as a condition worthy of help. Worthy of support, that it's not – I mean, people would say to you – but wouldn't say it about squalor – but they'd say it about hoarding, "It is just hoarding, no big deal, you know?" But when hoarding impacts so significantly on your safety at home... and the safety of others, it needs to be recognised as a condition in its own right. And I don't think we've got to that space in [aged care]... We've given it [a] much lighter touch... If we recognise it in the legislation, and if the Royal Commission have come out with a recommendation that [they]... believe it to be an... issue worthy of funding, I think that's where it starts... Because, at this stage... they like to read about it, but no one's going to take responsibility for it... Because there's much more pressing other things. But if [government agencies] could look at it from a cost saving, quality of life... I mean, if it stopped people falling... if it stopped homes from having fires... if it improved their health, because they could actually cook on the stove, because their stove is so cluttered, you couldn't find it... they can eat properly. If they could see some cost benefits, as well as an increase in the quality of [life]... Because, at the moment, they're not able to measure quality of life indicators, really. Not really... So, I – I think, from a legislative point of view, if there was some ownership that these people have a right to support in that space, that would be a good start. Because it's not a conversation many people have, because they're generally – generally the door is closed on those clients.

INTERVIEW PARTICIPANT

7.3 Where's the information we need? Developing shared information and practice

An information hub: a shortcut to information and collaboration

Participants often mentioned that clients living with hoarding or CMHH were an occasional element of their caseload, but needed a lot of time (see Chapter 5). They were conscious that support needed a complex level of understanding and response that they felt they did not have. Most participants longed for a specialist information hub around hoarding and CMHH in Tasmania. They described a digital hub they could access that would provide them with all the information, tools and resources they might need when supporting clients. This would provide more service efficiency – knowing that all specialist information and services were in one place would save them a lot of time in researching approaches and seeking other services they were not sure existed.

Oh, I think you feel like you can never do your job well enough basically. And that you're always chasing your tail. You're not sure what to draw upon. There's no sort of guidebook for hoarding.

INTERVIEW PARTICIPANT

Practice framework: the missing elements

Participants talked about a number of practice areas where they would appreciate more guidance. These included:

- a common understanding: information about the nature of hoarding and CMHH to help their understanding of the role they could play and what they might need from others
- a common approach: understanding the complexity of clients' needs and how they could work to support them with others
- guidance on assessments and tools: how they might assess clients' risks, needs and the severity of the situation in a non-judgmental way and make support decisions and referrals
- access to workforce development: how they could access professional development and advice to enhance their current practice.

A COMMON UNDERSTANDING AND APPROACH

There were a few participants who had undertaken training in hoarding and CMHH, usually prompted by seeing cases within their client group. They reported that this had helped them to understand that they needed to look beyond the living environment in thinking about supports.

However, most participants commented that they were not clear on what hoarding and CMHH were. They were aware of them as complex challenges for clients, but commonly

talked about not having the time or scope to look at this in depth. Many participants also raised a need or desire to understand more about the nature of hoarding and CMHH.

Many participants mentioned the need for advice on developing clear and shared approach to how to work with Tasmanians living with hoarding and CMHH. This included shared goals and how to work respectfully with their clients in a non-judgmental manner. In particular, they needed advice on how to get started with clients who have no insight into challenges, or are non-voluntary.

I mean, for those that are definitely going to be on the ground, it wouldn't hurt to have some form of engagement training. So that social interaction training and because, again, it's mostly been winging it, it's mostly been based on personal experience of how to deal with people. That's how we gauge our response. Whereas if there were specific markers or something that would be specific to people that are dealing with hoarding and squalor that we can identify through an hour training would be, I imagine, useful so that we can identify or start to figure out ways if we happen to be the ones that have first contact to see if they are engaging and want to receive help. Or, I don't know if I imagine that there's some sort of step, step wise manner that people that are in that field, psychologist or yourself, have been taught how to engage in what questions to ask. So even... a something like a template sheet. Like a template of what are we running through, what information do we need to gather so that I can take that back to said hoarding and squalor coordinator, that sits at the top. Yeah, I guess that would be useful.

INTERVIEW PARTICIPANT

I don't go into there and say, "you've got some hoarding issues." No. It's funny, though, because on the risk assessment, it specifically uses that terminology. On our risk assessment, it says, "Is there hoarding or squalor?" So what I would say is, I sort of just talk about it in a much more general term... Like with this lady, I talked about, "The workers are having difficulty getting in, because you've got a lot of things. Um, you collect a lot of things. And how do you feel about that? ...In the referral you wanted to look at this and is that something that you'd be interested in working together on?" So it's kind of general, it's a little bit vague.

INTERVIEW PARTICIPANT

TOOLS

A minority of services made use of the Clutter Image Rating (CIR) to assess the severity of clutter within resident's homes. Two agencies were currently trying to create a shared use of this tool to assess resident risk across enabling and enforcing agencies. Participants who used this tool felt that it had taken the "judgement" out of their conversations with their clients and they were able to work with them to identify current living environments, risks and goals. This in turn seemed to have had a positive impact on insight and engagement with some of their clients:

It's definitely improving communication between tenants and property officers. It's definitely helping us to identify the areas where we do need to actually pay close attention or provide a higher level of support. And it's also providing early intervention for us as well.

INTERVIEW PARTICIPANT

Some services drew on the CIR, but for them it was in the context of other assessments, such as Activities of Daily Living. Importantly, they were not looking as much at levels of clutter, but at what had changed for a particular individual:

And a lot of it is also based on if we can get collaborative history. So if you have always lived in interesting circumstances, what has changed and why? You know, this has been your choice in life, whereas I met a lady, she'd gone blind. And from what I had heard, her home had previously been immaculate. And now that was human and dog faeces everywhere. All over the floor, it was filthy. So what's changed? That's not been her way of living. So between both being blind and having dementia, she was now living in circumstances she would not have chosen.

INTERVIEW PARTICIPANT

Many participants who did not use this tool, or others such as the ECCS, were interested in doing so.

Others talked about the need for decision-making frameworks and case management documents to help with collaborative working. They suggested such tools would direct responsibility for a case based on whether the main concerns lay with a statutory agency or not:

Well, it would be good if we did maybe have a suite of shared assessment tools so that if we're talking to somebody, we're all on the same page because we've certainly had that happen where if you've never been into a squalor house, you can think a slightly more messy house is squalor. We've had that and then we've had other people under-rate when they go in. And you go in and you go okay, this isn't quite what we were expecting.

INTERVIEW PARTICIPANT

Given the likelihood of recidivism in the animal welfare and environmental health spaces, having access to shared case notes was also seen as useful:

Participant 1: *The three questions are, is it an offence, am I delegated under the powers of the legislation that I work with, and if so, then what is the course of action?*

Participant 2: *And then what—hopefully ... I think there's only one tool we need out of this, and that is a really detailed document you process on how we work our way through it. That's kept up to date because it's effectively housed online. And it's kept up to date so that contact details and all that are on there.*

INTERVIEW PARTICIPANTS

That's the sort of person that would be great on the ground to just be talking to them and then occasionally throwing a question to pull information that they're wanting, so that they can build a plan more broadly. So we can assist them and we can deal with the animal welfare side of things. And then they can somewhat draw up an ad hoc plan on the ground for how this should look going forward.

INTERVIEW PARTICIPANT

However, some participants referred to the need for clarity around data sharing before a shared case management approach could confidently be implemented across agencies.

7.4 Missing data: understanding needs and mitigating risks

There is no systematic data collection around hoarding or CMHH in Tasmania. There were four participants whose agencies were collecting data specifically around clients or addresses where hoarding or CMHH had presented concerns for their area of interest. These were all agencies who were encountering clients due to critical concerns, such as animal welfare, fire risks, environmental health and tenancy risks. Not all of these information management systems contained specific categories for hoarding or CMHH, but cases were discoverable through a specific enquiry.

Three agencies were using their data to proactively plan risk prevention and interventions:

We've realised we need to try and identify that earlier. So all the shelters, ah, cat management facilities, use a shelter management system.

INTERVIEW PARTICIPANT

We've... incorporated a review analysis capacity into [our management information system]... So we have an electronic system here that we use to manage our tenancies, including property inspections. And so there's quite specific notes that need to be recorded. You know, to a specific language... And so now... for example, in 12 months' time, we'll be able to mine some data and just have a look at the percentages of properties that sit within levels 1, 2 and 3 of the [clutter image] rating scales. You know, what was done at that time, what worked, what didn't work. Perhaps what we should have done, or didn't do. You know, that type of thing. Escalation, you know. So over a twelve month period we might go from a level 1 to level 3 issue of some nature. We'll be able to plot that. For example, an issue that develops from level 1 at one inspection, and becomes level 3, rating 9 at the next inspection twelve months later, that's a significant turnaround, which would be a strong indicator towards an unmet support need of some nature. Or perhaps the need for us to strategise, to think about what could we have done at some point to intervene there? What were the signals for us? What we could or should have seen? All that sort of stuff.¹⁶

INTERVIEW PARTICIPANT

The power of collecting such data across Tasmanian services who encounter clients living with hoarding or CMHH would be clear. Planning for prevention and early intervention in Tasmania could be undertaken from a more informed perspective. It would also help emergency services to be aware of and prepared for risks they may encounter when entering such properties, and case management and support services could be targeted and reviewed in a multidisciplinary manner.

There were different perspectives on data sharing offered amongst participants. This depended on the legislation and policies a service or agency was working under. Health

16 This participant's organisation had divided the Clutter Image Rating into three levels: Level 1 (images 1 to 3) indicated no concern, Level 2 (images 4 to 6) indicated concern, Level 3 (images 7 to 9) indicated action should be taken.

and social care providers were often unsure or unclear about whether sharing data in a collaborative network would be possible under Tasmania's current statutory frameworks. Investigating this is beyond the scope of this report, but it is clearly an issue that requires investigation. Being able to share a level of information and data regarding cases would be useful within a collaborative approach to supporting older Tasmanians living with hoarding and CMHH.

The Tasmanian Fire Service were clear on their data sharing provisions. They were not asking for personal data, just addresses and risks. This was to enable first responders to be better prepared when they attended an emergency at a property that was known to be hoarded or had severe CMHH. Under their operating legislation, it was possible and permitted to request data from other organisations if it was for the purpose of risk reduction. However, they were encountering hesitancy amongst health and social care providers about what could be shared:

So it's just the address and the hazard. So some services, even though we say in the info pack that we don't collect people's personal information to identify them, that we don't share any information with anyone else, it's secure with us and us only, and... we have to abide by the Privacy Act and securing our data as well... When I've talked about it, some people go, "I probably have to tell, I'd probably have to get their permission to have them on this system." And I said, "Well, look, that's entirely up to you." Because as far as we're concerned, our firefighters especially, cause we're under the Fire Services Act, we work under a different act than health does. So with health... they may... legally have to get permission. But that's something for them to work out. But for us, under our Act, we can actually acquire and utilise anything if it's deemed a risk... So I've had it checked with our legal team. So that has been a little bit difficult because, you know, people working under different acts and some are not sure. Because they're not referring.

INTERVIEW PARTICIPANT

There is clearly potential for planning, review, reducing risks and case management if data could be shared across agencies around either people or their living environments where there is hoarding or CMHH. Having a clear idea about the use of such data in Tasmania would be a conversation starting point and investigating an enabling statutory framework for data sharing in this space would be a useful exercise.

7.5 Their needs: a shared practice framework

Tasmania needs to identify a lead state government agency to develop a shared practice framework, as has happened in other Australian jurisdictions that have adopted frameworks. In NSW and Victoria, the lead department has been the Department of Health. Their role has been around strategic coordination and acting as an information hub, but work in developing information, practice approaches and investment in services has been a partnership across state government agencies, with the health and community sectors and consumer groups.

Clinical and psychosocial supports and public health have critical roles in effectively working with older Tasmanians living with hoarding or CMHH. Given the Tasmanian Department of Health has responsibility within these areas, it would be sensible for state DoH to take the lead agency role in a state system to meet the needs of those living with hoarding and CMHH.

Participants clearly need a specialist digital Tasmanian information hub around hoarding and CMHH. This hub needs to include a shared Tasmanian policy and practice framework, when this has been developed. This could be similar to New South Wales' hub, Pathways Through the Maze (see Case Study 4). Such guidance should include a shared understanding and approach to working with those living with hoarding and CMHH and a set of shared tools to guide service providers and statutory agencies in their assessments and decisions (see Appendix 4 for examples of such tools).

State DoH also needs to lead a review exploring the feasibility of a shared framework for data collection and sharing. This would greatly enhance Tasmania's capacity to understand and plan for early intervention and shape critical responses for Tasmanians living with hoarding and CMHH. It would also support emergency and statutory services to minimise their risks when attending incidents at properties that are hoarded or have concerns around CMHH.

CHAPTER EIGHT

What happens in
Tasmania and elsewhere:
policy and purpose



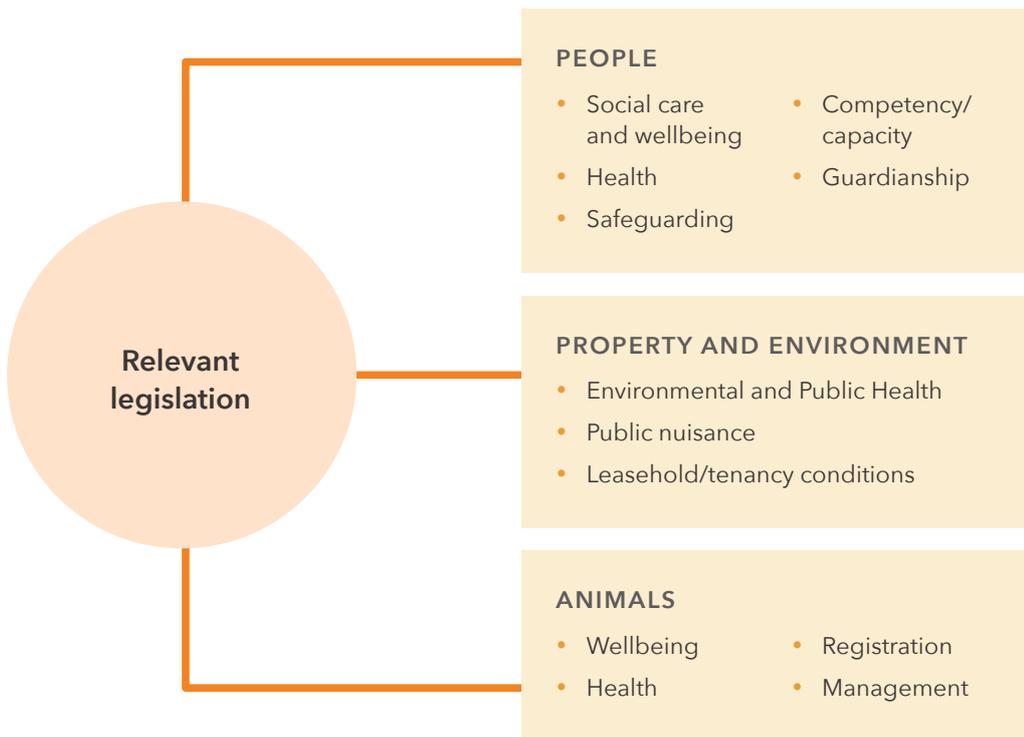
8.1 Key messages

- Where there are effective, supportive responses for those living with hoarding and/or CMHH, government leadership has managed to frame public and political thinking about hoarding and CMHH as **a complex community policy issue** which impacts on personal wellbeing and community safety.
- Effective social policies in North America, England, Wales and some Australian jurisdictions that guide professionals and supports for those living with these challenges:
 - » bring together social policies and approaches related to **people, animals and property** into a consolidated and focused directive
 - » establish a **lead government agency to convene a collective approach to addressing supports for those living with hoarding and/or CMHH**. This lead body shapes targeted policy, develops a collective practice framework, invests in a specialist case coordination and intensive case management system, and steers investment in long-term specialist clinical, psychosocial and practical services and multidisciplinary workforce development.
- There may be some lessons for Australia in examining the UK's concept of **self-neglect as part of our safeguarding approach to elder abuse**.
- **Tasmania has no social policy leadership** in place either federally or at a state level that guides a collective approach to supporting older people living with hoarding and/or CMHH. This means there is no shared approach across agencies to guide how they understand and support those living with these challenges.
- There is an opportunity for current policy reviews in federal Aged Care, state mental health and Home and Community Care to **consider how to develop a shared social policy and practice approach** to supporting older Tasmanians living with hoarding and/or CMHH.
- Tasmania's policy landscape is missing:
 - » **a lead government agency** overseeing a vision and approach to supporting those living with hoarding or CMHH
 - » specific social policy outlining hoarding and CMHH as **a complex community issue, requiring a multi-agency response**
 - » guidance outlining **agencies' responsibilities and powers as a collective**
 - » **social policy implementation overseeing and directing investments** in code enforcement and social care related to people, animals and property/environment.

Places where there are effective, supportive responses for those living with hoarding and/or CMHH have managed to shift public and political thinking about the "problem" from being one about the mental health of individuals, or a code enforcement challenge, to being an issue treated as a "**complex community problem**" (Kysow et al. 2020; McGuire et al. 2013; Pittman et al. 2020).

Thinking about hoarding and/or CMHH as a community concern enables us to shift the focus from individuals needing “to clean up their act” (Kysow et al. 2020; Brown & Pain 2014; H&SWG 2017) to framing our response as one that requires a considered set of policies and resources that both **protect communities** and **enable the wellbeing of those living with such challenges**. In different locales across North America and the UK, the “community challenge” has been framed as minimising community fire risks, addressing housing instability, or enabling vulnerable community members to age well; in other locales it has been a combination of these goals (Bratiotis et al. 2018; Kysow et al. 2020; NSAB 2019; Robertson 2018; RRR Consultancy 2016; Pittman et al. 2020). Such a shift in thinking has enabled ‘legitimacy and community buy-in’ (Bratiotis et al. 2018) in a range of communities across North America and the UK. To a lesser extent, this shift has been occurring in Australia, led by Victoria, New South Wales and South Australia (Bratiotis et al. 2018; CCS 2013; DoHA [SA] 2013; DoH [Vic] 2012, 2013; Stark 2013). Such “buy in” has helped this challenge to be seen as a priority for public investment.

FIGURE 21: PEOPLE, ANIMALS AND PROPERTY – THE THREE POLICY DOMAINS THAT STEER SUPPORT FOR HOARDING AND CMHH



This collective ownership demands a collaborative and local policy response (Bratiotis 2013; Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016; Kysow et al. 2020; RRR Consultancy 2016; Stark 2013). Such a response spans a number of human and environmental policy portfolios that might not typically, or regularly collaborate: portfolios around people (such as health, ageing, disability, homelessness, child safety, justice, social inclusion); property (such as housing, public health, environmental health, planning); and animals (welfare and management) (see Figure 21). These portfolios may, as they do in Australia, span federal, state and local government jurisdictions. This can lead to no one government agency taking the lead in developing and auspicing an approach to

supporting those living with hoarding and CMHH (Stark 2013); this is the case in Australia, where there is no national government leadership (CCS 2014; HSWG 2017; Robertson 2018; RRR Consultancy 2016; Stark 2013).

In the absence of national leadership, it is common for local responses to emerge. These are often sparked by local fire fatalities or critical incidents involving those living with hoarding or CMHH that galvanise local services into a need for action and organisation (see Bratiotis 2013; Bratiotis et al. 2018; Kysow et al. 2020; Stark 2013 for examples). Others are initiated by concerned professionals, frustrated by the lack of local knowledge, leadership and/or resources (see, for example, Bratiotis 2013; Bratiotis et al. 2018; CCS 2014; H&SWG 2017). If this response is community-led, driven solely by a cluster of concerned organisations or individuals, like Tasmania's Northern Hoarding and Squalor Working Group, it often has a shelf life, as individuals move on to other roles, the capacity of organisations to self-fund initiatives dwindles, and/or the resources available are deemed too limited to effectively support those living with these challenges.

A sustainable local approach works best where a government agency has recognised that not only are hoarding and CMHH community concerns, they require **sustained and resourced leadership** to co-ordinate ownership of the issues, and the policies, programs and practice that are needed (Bratiotis 2013; CCS 2014; Kysow et al. 2020; Robertson 2018; RRR Consultancy 2016; Stark 2013). There are many examples across North America, the UK and to a lesser extent, Australia, to illustrate this.

8.2 North America

"Hoarding taskforces" have been an increasing part of the US and Canadian local service landscape since 1999 (Bratiotis 2013). These are collaborative groups of professionals who have come together to support those living with hoarding and CMHH. Many have a stated purpose around 'understanding the problem of hoarding and CMHH, developing and coordinating a response and improving intervention outcomes' and have garnered around a harm minimisation approach (Bratiotis 2013).

Given Northern American coalitions are amongst the oldest we are aware of, their model is worth examining and learning from. Many North American taskforces have had successes in coalescing disparate services around a common goal and a collaborative case management approach (Bratiotis 2013; Bratiotis et al. 2018). But many have struggled with sustainability, particularly where they have been led by the passions of individuals, as opposed to through organisational or governmental leadership (Bratiotis 2013; Bratiotis et al. 2018; Stark 2013). It is reported that professionals have struggled to offer effective support due to time commitments where this is not their mandated role, and the lack of trained mental health providers to work with has been a challenge (Firsten-Kaufman & Hildebrandt 2016).

Vancouver provides a good example of a taskforce that has benefited from local government-led backing (Kysow et al. 2020). The City of Vancouver brought together Public Health and the Fire Department to form the Hoarding Action Response Team (HART) (see Case Study 1). Operating under a harm minimisation approach, HART has the dual

goals of **tenancy preservation and clutter reduction** for Vancouver residents living with hoarding or CMHH (Kysow et al. 2020). What is notable about Vancouver's HART is that it has developed its scope and grown its staff capacity in liaison with the City of Vancouver as its backbone organisation over a number of years (Kysow et al. 2020).

CASE STUDY 1: COLLABORATIVE COMMUNITY APPROACH – HOARDING ACTION RESPONSE TEAM (HART), CITY OF VANCOUVER, CANADA

Hoarding Action Response Team (HART), Vancouver

LOCATION:

Vancouver, Canada

DATE:

2011 – present

AGENCIES:

Partnership between City of Vancouver Fire Department and Vancouver Coastal Health

TARGET GROUP:

Homes that are severely hoarded (Clutter Image Rating of more than 6) and represent a fire hazard, or more moderate hoarding if there are concerns about the occupants' physical or mental health.

GOALS:

Promote public safety by reducing clutter to a safer level, improve quality of life by making referrals to relevant health services, including mental health, and preserve tenancy. The aim is not to eliminate hoarding behaviour but to improve safety.

PATHWAYS:

Potential cases are referred from a variety of sources, typically health, social service or housing providers, but also neighbours and emergency services.

APPROACH:

The HART team consists of two fire prevention officers and two mental health workers. Together they make assessments, develop an intervention plan, and maintain contact through phone calls and home visits. They serve as a liaison with family, health workers and housing managers. The program is not time-limited and the case will remain open until goals are met, the client withdraws engagement or the client moves, dies or is evicted. If the client does not make progress or fails to engage, the team has the power to escalate legal action in some cases.

Sources: Kysow et al. 2020; City of Vancouver 2021

8.3 England and Wales

In England and Wales policy leaders are often Local Authorities (LAs), through their adult safeguarding boards, their environmental health teams, or both. LAs hold more social as well as environmental policy and service portfolios compared to those in Australia. For example, they hold responsibility for child safety, adult care, education, social inclusion and community cohesion, as well as housing, planning and environmental health.

Brown and Pain report that many UK LAs have traditionally handled hoarding and CMHH as an issue that, 'languish[ed] in between housing, environmental health and adult social care, while the problem worsened' (Brown & Pain 2014, p. 215). But English and Welsh LAs have shifted their thinking. More LAs are taking a person-centred approach – they are treating challenges as a complex area of adult care that requires a coordinated **public health and safeguarding response** (Brent Safeguarding Adults Board 2020; Brown & Pain 2014; NSAB 2019; Robertson 2018).

The Care Act (2014) introduced responsibilities for LAs and their partners in health, housing, welfare and employment services to initiate preventative steps or early intervention to care and support local people. This included a new indicator of abuse and neglect within adult safeguarding – self neglect (Brent Safeguarding Adult Board 2020; NSAB 2019; RRR Consultancy 2016). This is defined as 'a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings' (RRR Consultancy 2016) and includes hoarding behaviours and CMHH. Statutory guidance requires agencies who encounter local residents at risk of self-neglect to refer the case to a multidisciplinary board that will consider care or safeguarding options. Across England and Wales, Early Help Hubs are the "front door" responding to the preventative and early intervention needs of local people, including those who are at risk of self-neglect. They bring together local agencies and services across care, housing, employment and other welfare agendas, so that complex cases can receive appropriate referrals and supports to address risks.

There is no standard approach, but this shift in thinking and statutory responsibility has led to local and county councils in both urban and rural areas formulating information hubs, practice guidance and case coordination services, which are shaped around their duty of care to safeguard adults and children, together with their duties under environmental health legislation. Notable examples include Birmingham City, Kent and Medway, the London boroughs of Brent, Hammersmith and Fulham, and Islington, Norfolk County Council, Nottingham City, and Nottinghamshire County Councils (Birmingham City Council 2020; Brent Safeguarding Adults Board 2020; Brown & Pain 2014; Kent and Medway Safeguarding Adults 2019; NSAB 2019; Nottinghamshire Safeguarding Adults Board n.d.; Robertson 2018).

The policy guidance documents emphasise the need for a person-centred approach, set out the legislative and practice frameworks, usually provide a mechanism to bring stakeholders together and provide details of all relevant services. They most commonly encourage partnership working across social services, mental health services, safeguarding, fire services and pest control (Birmingham City Council 2020; Brent Safeguarding and Adults Board 2020; Brown & Pain 2014; Kent and Medway Safeguarding Adults 2019; NSAB 2019; Nottinghamshire Safeguarding Adults Board n.d.; Robertson 2018) (see Case Study 2).

Positioning hoarding and CMHH within the broader concept of self-neglect, as defined within the UK's Care Act 2014, provides adult safeguarding boards with a clear remit to lead a person-centred approach to supporting those living with these challenges. Even when the trigger is a fire safety, animal welfare, environmental health or condition of property code violation, coalescing around this duty of care keeps responses holistically focused around the support needs of the person, animals and community. This creates a continuum of care across prevention, early intervention and crisis management. Furthermore, positioning collaboration within LAs lends itself to creating a more sustainable and resourced model of support, rather than it being a response led by concerned local professionals.

CASE STUDY 2: COLLABORATIVE COMMUNITY APPROACH – NORFOLK ADULT SAFEGUARDING BOARD, ENGLAND, UK

Norfolk Adult Safeguarding Board and Early Help Hub

LOCATION:

Norfolk, UK

DATE:

2013-present

AGENCIES:

Partner agencies include senior representatives from acute hospitals, adult social services, NHS, Norfolk Fire & Rescue, police, district councils, public health and the University of East Anglia

TARGET GROUP:

Adults who have need for care and support and are experiencing or are at risk of abuse and neglect.

GOALS:

To ensure adults in the community are safeguarded from harm and can live their lives independently and free from abuse and neglect. Norfolk Safeguarding Board conducts awareness raising and training activities to reduce the risk of harm as well as responding to and managing concerns and enquiries.

APPROACH:

Norfolk Safeguarding Board has published a Self-Neglect and Hoarding Strategy and a Practitioner Guide, which mandate a multi-agency approach coordinated via local Early Help Hubs. These documents promote a shared understanding of the issues involved and a person-centred approach under the Making Safeguarding Personal program. Each partner agency is required to identify a senior officer who has responsibility for ensuring effective multi-agency cooperation.

Sources: NSAB 2019, 2021

8.4 Elsewhere in Australia

Responses to matters of hoarding or CMHH do not have an Australian legal or policy framework to compel a response or duty of care at a federal, state or local level. Australian adult safeguarding legislation does not include the concept of “self-neglect”.

In the face of this void, there have been three Australian state governments who have taken a policy lead in this field. The Victorian Department of Health’s Ageing and Aged Care Branch published a discussion paper on hoarding and CMHH in 2012, recognising the complexities of supporting those living with such challenges, setting out the need for a **purposeful and coordinated community response** and the need for that response to be localised (DoH [Vic] 2012).

This was followed in 2013 by DoH Victoria’s comprehensive guidelines for agencies and service providers. It offers service providers a shared practice framework with a common understanding about the nature of hoarding and CMHH, assessment and case management tools, guidance on when to intervene and lists of relevant legislation and services (DoH [Vic] 2013).

The South Australian Minister of Health and Ageing published the *SA Public Health (Severe Domestic Squalor) Policy* in 2013 (DoHA [SA] 2013). This sets out a clear definition of CMHH to support professionals—especially Environmental Health Officers and Housing Support Officers—to have a shared understanding of when and how to intervene in cases of community complaint, condition of property issues and other environmental risks. This policy followed the SA Department of Health’s guidance, *A Foot in the Door* (DoHA [SA] 2012), which provides a practice framework for professionals working in this space.

Neither the Victorian nor the South Australian governments have funded a coordinated specialist case management group, or a coalition of specialist professionals who can respond to cases. However, both emphasise the need for an agreed interagency approach to support centred around their guidance (DoHA [SA] 2012; DoH [Vic] 2012, 2013; Stark 2013).

Older people living with hoarding or CMHH are recognised as a group with specific needs within the New South Wales’ Older People’s Mental Health Services Service Plan (NSW Health 2017). The plan emphasises the need to address challenges across agencies and highlights the central role of Older People’s Mental Health Services within this partnership:

Interagency cooperation and a collaborative, coordinated approach is crucial to successfully resolving and working with people who are hoarding and/or living in severe domestic squalor, with mental health services working in partnership with other agencies as required. OPMH services will have a role in performing mental health and cognitive assessments, assessing capacity, and treating any underlying psychiatric conditions, and should be guided by relevant local and state frameworks and guidelines.

(NSW HEALTH 2017)

To complement this, the state government has worked with Catholic Community Care to fund a specialist hoarding and CHMM hub, based in Sydney. *Pathways through the Maze* coordinates a partnership response to hoarding and CMHH. Again, the response is framed as being whole of community concern (see Case Study 4).

8.5 In Tasmania

Both federal and state strategies for older Australians promote a vision of healthy ageing, at home where possible. Federally, this vision is driven by the Australian Government's aged care support system, recently under the spotlight of the Royal Commission into Aged Care and Quality. The Commonwealth Home Support Program (CHSP) and Home Care Packages (HCPs) offer different levels of support for Australians to age well at home once they reach "older age" at 65 or 55 for Aboriginal and Torres Strait Islander people (DoH [Au] 2021). These consumer-led aged care programs encourage service providers to work within an approach that promotes wellness and reablement (see Figure 25). At a state level, the Tasmanian Government's *Strong, Liveable Communities Plan* outlines the state's vision for active ageing, where our older Tasmanians are valued, engaged and healthy (DPAC 2017) (see Figure 25).

However, as we have explored, responding to those living with hoarding and CMHH requires a specific social policy response that brings together people, animals and property (see Figure 21). Tasmania lags behind Victoria, New South Wales and South Australia in offering a strategic response to supporting those living with hoarding and CMHH. Tasmania does not currently have an overarching social policy and practice framework to facilitate this challenging work (H&SWG 2017; Fidler 2021).

This means that services supporting older Tasmanians living with hoarding and/or CMHH have to examine the policy and legislative landscapes in all three domains (people, animals and property/environment) sitting across federal, state and local government to understand their duties and the scope of what they can do to support older Tasmanians living with hoarding or CMHH.

People

We need to consider the policy settings that "enable" Tasmanians to age well at home, such as adult and aged care, mental health services in and outside of the National Disability Insurance Scheme (NDIS) and housing support services. There are also those frameworks that help Tasmanian service providers consider a client's capacity to make decisions and choices about their life, such as guardianship.

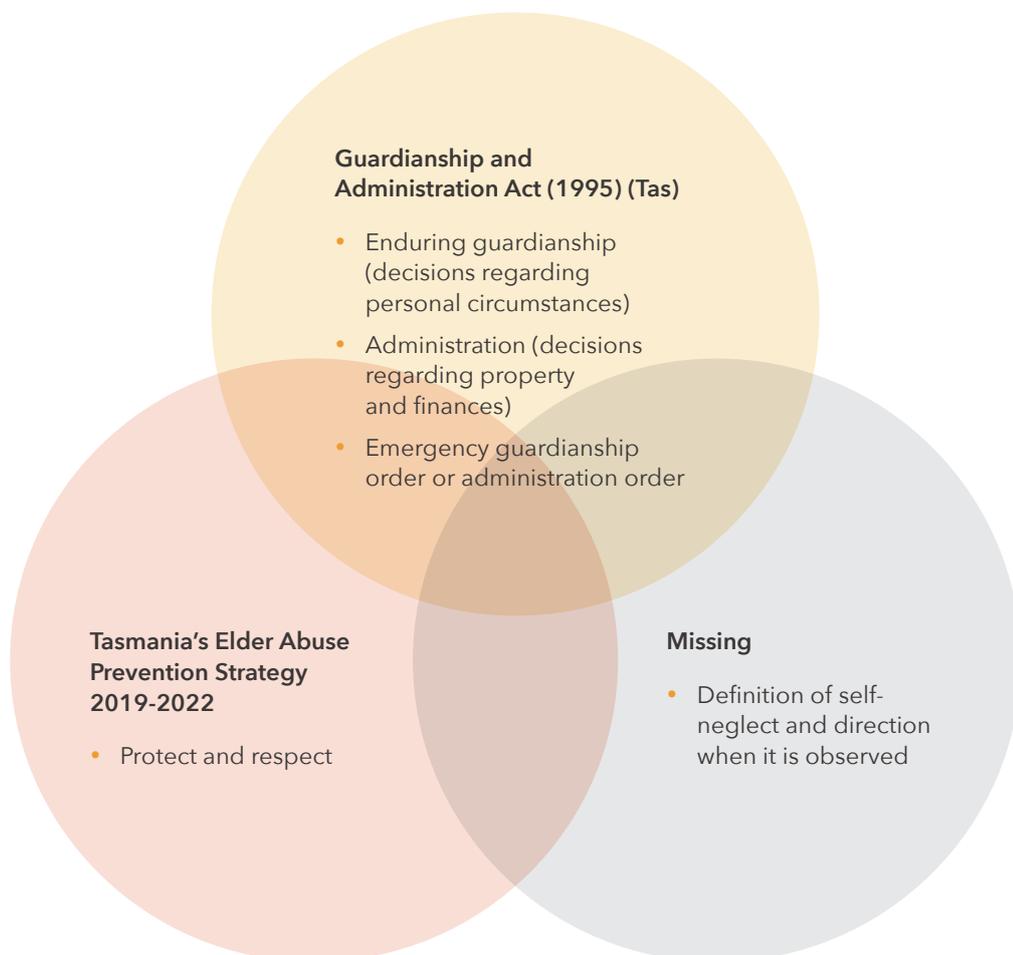
ADULT SAFEGUARDING

Tasmania's Elder Abuse Prevention Strategy seeks to 'protect and respect' older Tasmanians (DoC [Tas] 2019) (see Figure 22). It focuses on recognising and addressing acts of abuse and neglect by others of older Tasmanians. The concept of self-neglect is not recognised in Australia's adult safeguarding policies, as it is in the UK. This means professionals supporting those living with hoarding and CMHH are not compelled to act when they encounter what they observe to be hoarding or CMHH.

The only other Tasmanian adult safeguarding framework is the Guardianship Board. However, this is a route of last resort, given that it essentially transfers the powers of a person to make decisions about their own circumstances to either another individual or the Public Trustee (see Figure 22).¹⁷

This leaves somewhat of a void for professionals who encounter older Tasmanians who are living with hoarding or CMHH, where they observe the living environment to be having a detrimental impact on their wellbeing or the wellbeing of others or the community. It becomes a balance between respecting an individual's dignity of choice and risk, and the health and safety of themselves, the humans and animals they live with and the environmental health and safety of the surrounding community. There is no shared understanding of where this balance lies.

FIGURE 22: TASMANIAN ADULT SAFEGUARDING – CURRENT PROVISION



Sources: DoC [Tas] 2019; Department of Justice 2019

¹⁷ Professionals can refer clients to this board to assess their capacity to make decisions about their life ("enduring guardianship") and/or finances and property (administration). They can also apply for emergency guardianship in critical cases.

SOCIAL, WELLBEING AND HEALTH: DIGNITY OF CHOICE AND RISK

In the absence of specific social policy guidance for those supporting people living with hoarding and/or CMHH, Tasmanian professionals are mainly directed by the consumer-led approach inherent within the design of most Australian social care. The guiding principles within Tasmania's Elder Abuse Strategy include respecting older Tasmanians' dignity of choice and ensuring older Tasmanians have access to standards of living and care that will ensure they can live where they wish with the supports they need to do so (DoC [Tas] 2019).

Australia's federal aged care system and its disability support system, the National Disability Insurance Scheme (NDIS), also encourage consumer choice and risk tolerance. Dignity of choice and risk are key concepts within the current social policy and program settings and quality standards framework for the aged care system (DoH [Aus] 2021).¹⁸ In fact, they form a key part of the aged care quality standards, as the Aged Care Quality and Safety Commission highlight within Standard 1:

These concepts recognise the importance of a consumer's sense of self. They also highlight the importance of the consumer being able to act independently, make their own choices and take part in their community. These are all important in fostering social inclusion, health and well-being.

ROYAL COMMISSION 2021

Outside of the NDIS, older Tasmanians may access statewide clinical mental health supports and psychosocial supports funded by Primary Health Tasmania. Whilst neither of these schemes are a fee for service model, both are driven by the Tasmanian mental health strategy's recent reforms – *Rethink 2020* and its recent implementation plan (DoH [Tas] 2020a) – to ensure that Tasmanians have access to the best mental health and wellbeing (see Figure 25). The strategy aligns with the concepts of dignity of choice and risk, as well as promoting independence, self-determination and social participation. These goals are also reflected in the state Health and Community Care (HACC) program supports for frail older adults (DoH [Tas] 2020b).

Tasmanian social care professionals supporting those living with hoarding and CMHH have to assess the boundaries of consumer choice and risk tolerance within their own organisational risk management framework. As the Aged Care Quality and Standards Commission describes, facilitating dignity of choice and risk is a subjective balance (Royal Commission 2021). Professionals supporting those living with hoarding or CMHH need to consider whether the consumer's choices around hoarding or CMHH will negatively impact on others – either those they live with, or their surrounding community. They also need to consider the impacts that consumers' risk tolerances have on employees' health and safety and whether these are risks an organisation can work with.

18 Requirement 3c of the Aged Care Quality and Standards states that 'Each consumer is supported to exercise choice and independence' (Royal Commission 2021, p. 17) and requirement 3d states that 'Each consumer is supported to take risks to enable them to live the best life they can' (p. 20). The purpose of Australia's disability supports is to, 'maximise their potential and participate as equal citizens in Australian society' (Commonwealth of Australia 2011). The National Disability Insurance Scheme strives to maximise consumers' potential and participation. Similar to the Australian government's aged care system, the NDIS Act (2013) states that 'People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports' (section 4[4]).

Animals

Tasmania's Royal Society for the Protection of Animals (RSPCA) is funded by the Department of Primary Industries, Parks, Wildlife and Environment (DPIPWE) to enforce the Animal Welfare Act 1993 in domestic settings. The Inspectorate investigates reports of animal cruelty, including those received through their cruelty hotline. Officers have power to enter and search premises where there is a reasonable belief that an offence has or may be committed against an animal. Inspectors may provide information and advice to animal owners, or issue legal instructions and infringement notices if action to address concerns is not undertaken. Only the inspectorate function within the RSPCA is funded by state government. Follow up or support activities are not.

Local government has responsibility for managing dogs within their area under the Dog Control Act 2000. This includes ensuring they are registered, that there are no more than two dogs within a domestic dwelling and behaviour is managed appropriately.

Tasmania's Cat Management Act 2009 has introduced proactive measures to control the state's domestic, stray and feral cat population. From 1 March 2022, Tasmanians must not keep more than four cats over the age of four months on an individual property. Authorised persons under the Cat Management Act 2009 will have powers to enforce compliance of this limit. Three Regional Cat Management Coordinators representing different regions of Tasmania work collaboratively with a range of stakeholders, including local and state government, animal welfare organisations and other relevant partners, to improve cat management and welfare. One aspect of the regional coordinators' role is to coordinate organisations and services who need to work together on a specific case and sometimes mediating between animal owners and the agencies.

Tasmanian animal welfare and management professionals acting under such statutes only have tools to sanction, rather than support, the households they encounter who are living with animal hoarding. There are no mechanisms for agencies to work with others to support the people involved in concerns around animal welfare, or to address any concerns around the property.

Property and environment

Tasmania's 29 councils have responsibility for environmental health under Tasmania's Public Health Act 1997 and the Environmental Management Pollution Control Act 1994. Under Tasmania's Building Act 2016 and the Land Use Planning and Approvals Regulations 2014, they also have responsibility for building compliance across all domestic properties (for example, structural integrity and health and safety) and compliance with fire safety for flats.¹⁹ Between these two functions, they are responsible for receiving and following up public complaints and agency referrals (for example, from Tasmania Fire Service and Tasmanian Police) concerning "unhealthy housing", including environments that are thought to be inhibited by clutter or CMHH, and properties that are thought to be "dangerous", either due to being structurally compromised or posing a fire safety risk.

¹⁹ Private dwellings, such as houses, do not fall under local government's remit for fire safety, although houses do need to comply with the National Construction Code.

Similar to Tasmanian professionals working within animal management or welfare, council Environmental Health Officers and Compliance Officers acting under such statutes only have tools to sanction rather than support the households they encounter who are living with hoarding or CMHH. There is no structure that facilitates councils to work with social care providers and animal welfare agencies to support the people involved in concerns around animal welfare or management.

Social policy reform

Australia's aged care is in transition while the federal Department of Health works out how to best respond to the Royal Commission's recommendations. The new aged care model plans to combine the current Commonwealth Home Support Program (CHSP) with Home Care Packages (HCPs) into a new Unified Support at Home Program (USHP) from 2023 (DoH [Au] 2021). It is promising that the Royal Commission has recognised the need for grant-based supports within the USHP to support those living with hoarding, as well as a way to integrate aged care supports with healthcare (Royal Commission 2012). It is also promising that the federal government has accepted the RC's recommendation (DoH [Aus] 2021).

In parallel, there is an opportunity to inform reforms to the NDIS and the ongoing redevelopment of the Tasmanian state mental health strategy, *ReThink* (DoH [Tas] 2015b, 2020a). The state government plans to release an annual plan in response to local needs. Tasmanian HACC is also undertaking a rolling review of policy and provisions.

Tasmanian public and social housing management is also undergoing a transformation. Under the Community Housing Growth Program, the management of more public housing stock is being transferred to social housing providers from September 2021 (DoC 2021). This means that there are a number of tenancy management models across the state, each of which may approach concerns with hoarding and CMHH differently. However, there is an opportunity to provide a coherent framework for supporting tenants living with hoarding and CMHH within which they can operate.

Inherent in these reviews needs to be consideration of how supports for older Tasmanians living with hoarding and CMHH are conceptualised, designed and delivered. Specifically:

- What are the goals we want to achieve in Tasmania by supporting those living with hoarding or CMHH?
- Where would supports best sit within the framework of supports for people, animals and property/environment?
- How do we ensure all of the services that have a role in supporting these outcomes have a shared understanding of what needs to happen, how it should happen and who is responsible for implementation, including consumers who are voluntarily participating, involuntarily participating or refusing to participate?

8.6 What’s missing in Tasmania’s policy landscape

Tasmania does not have a lead government agency that takes responsibility for overseeing a vision and approach to supporting those living with hoarding or CMHH. This has led to there being no cohesive and strategic approach. Strategic elements of Tasmania’s policy landscape that are currently missing (see Figure 23) include:

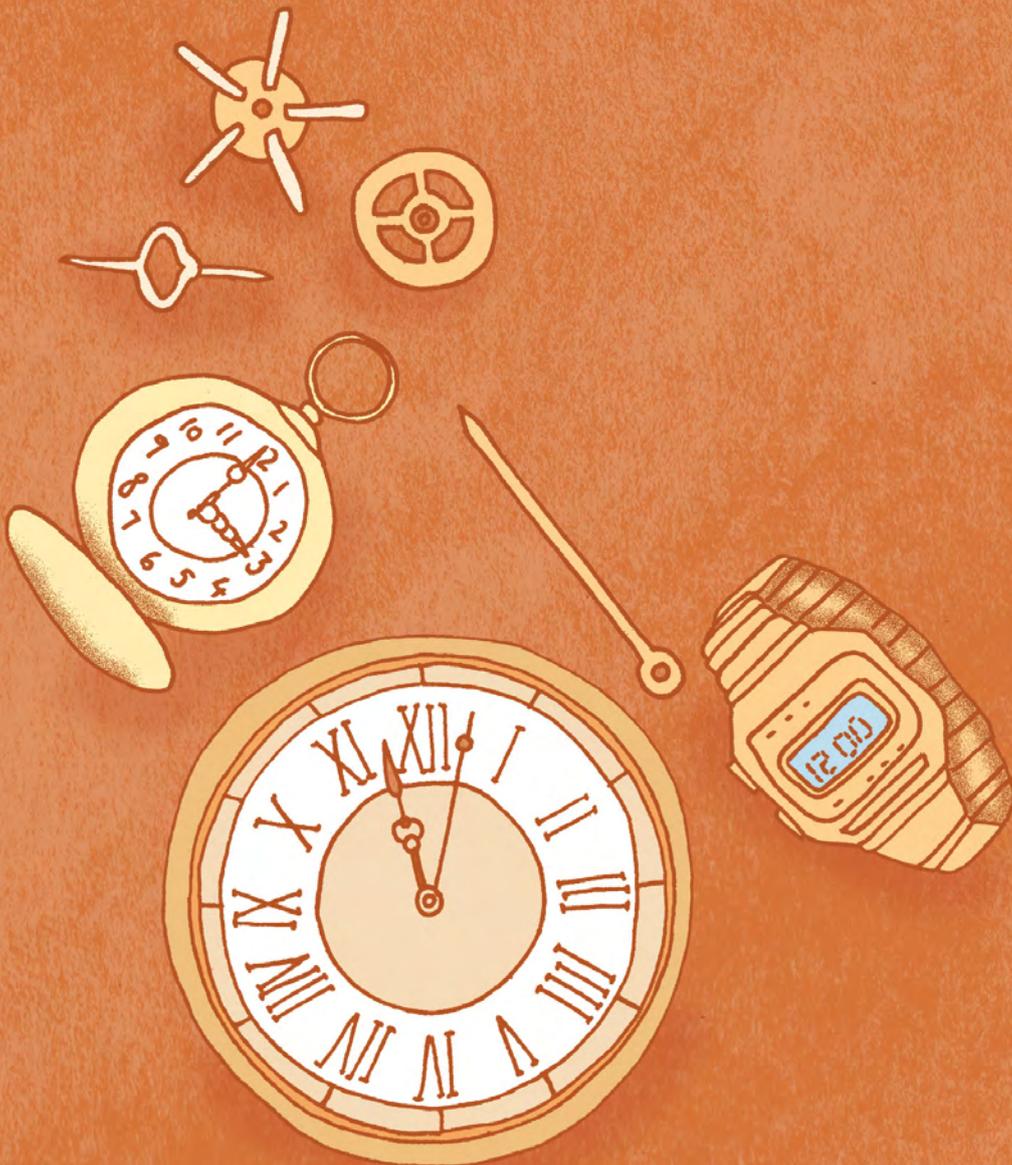
- Tasmanian social policy outlining hoarding and CMHH as a complex community issue, requiring a multi-agency response
- Tasmanian guidance (or regulations or social policies) that outlines agencies’ responsibilities and powers (individually and collectively) related to people, animals and property/environment around challenges with hoarding and CMHH.
- Tasmanian social policy implementation overseeing and directing investments in code enforcement and social care related to people, animals and property/environment involved with these challenges.

FIGURE 23: SUMMARY OF CURRENT TASMANIAN SOCIAL POLICY AND LEGISLATION SURROUNDING HOARDING AND CMHH AND WHAT’S MISSING



CHAPTER NINE

What happens in Tasmania
and elsewhere: collaboration
and services



9.1 Key messages

- Successful models manage to bring together policy remits concerning people, animals and property/environment under two approaches: addressing hoarding disorder as a **chronic illness management model**, which addresses client self-care, care coordination and consistent follow-up; and/or under a **harm minimisation model**, which focuses on 'managing and mitigating the negative impact rather than eradicating the hoarding behaviour entirely' (Stark 2013).
- Successful models tend to have five key foundations (see Figure 24):
 - » **a multidisciplinary professional network** that brings together the expertise of local clinical supports and social care providers (such as mental health services, aged care providers, disability support providers, housing support) with "code enforcers" such as the fire service, council environmental health and building compliance officers, animal welfare and management and housing providers
 - » **a case management approach** with a lead case manager, usually a social worker or clinical nurse, who can ensure appropriate assessments happen, work with the client around goal setting, and coordinate and broker supports
 - » **investment in an enabling client/worker relationship** grounded in trust that forms the foundations for any clinical, psychosocial and practical supports
 - » **a clear response to crisis intervention** with processes and partnership arrangements for crisis and time critical incidents such as fires, hospitalisations and condition of property concerns, that include collaboration between code enforcers and social care providers
 - » **specialist supports** that can work in an informed way with clients and their families and carers to identify and address clinical, psychosocial and practical needs.
- **Cognitive therapy** for older people living with hoarding or CMHH needs to be considered to ensure that supports are effective and outcomes sustained.
- There are **areas of developing good practice in the Tasmanian program landscape** that have the potential to support older Tasmanians to age well at home when they are living with hoarding or CMHH. Notable examples are Tasmania Fire Service's Fire Safety Project and Housing Tasmania's condition of property assessments and tenancy supports. However, there are huge gaps in Tasmania's case management and service landscape compared to what we know works elsewhere. Significantly, Tasmania lacks:
 - » a specialist multidisciplinary coordinating group that can also provide a central point of information and workforce development
 - » programs that facilitate specialist case management outside of the fee for service model with appropriate brokerage funds
 - » programs that facilitate investment in building trusted relationships with those living with hoarding and CMHH
 - » a clear response to crisis intervention across people, animal and property agencies
 - » a set of specialist supports to address the clinical, psychosocial and practical support needs of older Tasmanians living with hoarding or CMHH.

International evidence suggests that successful policy models manage to bring together the required programs under two approaches: addressing hoarding disorder as a **chronic illness management model**, which addresses client self-care, care coordination and consistent follow-up; and/or under a **harm minimisation model**, which focuses on 'managing and mitigating the negative impact rather than eradicating the hoarding behaviour entirely' (Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016; Kysow et al. 2020; Stark 2013; Tompkins 2011).

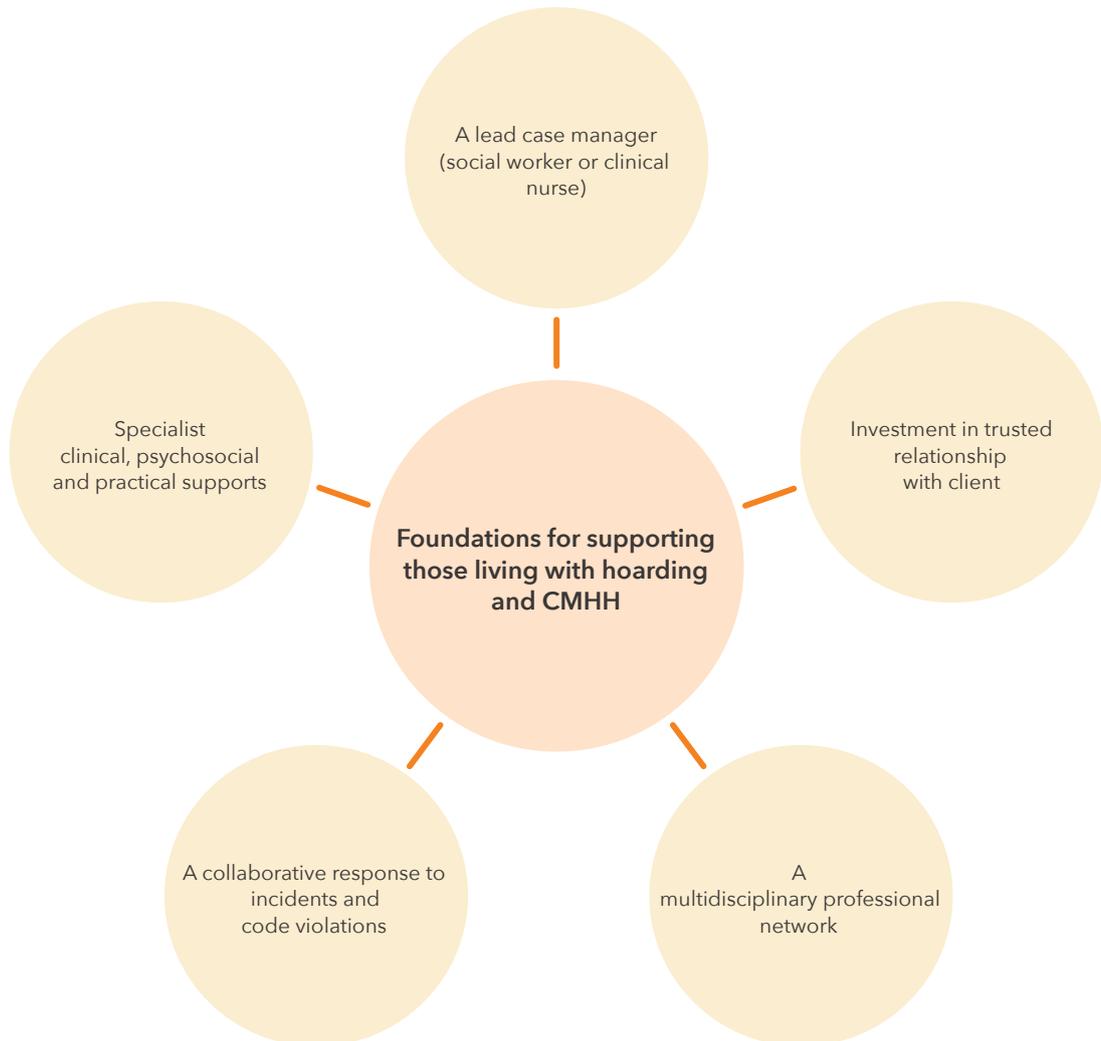
But a common policy goal or approach does not necessarily make things happen. Similar to successful domestic violence initiatives (Bratiotis 2013; Stark 2013), it needs government leadership and organisation. International evidence suggests that successful interventions in supporting those living with hoarding or CMHH are led by government agencies with a human services focus (Bratiotis 2013; Brown & Pain 2014; Kysow et al. 2020; Stark 2013) – health or human services, ageing or disability services – and are most successful when there is a mental health case leader (Firsten-Kaufman & Hildebrandt 2016).

Successful collaborative interventions tend to have five key foundations (see Figure 24):

- a multidisciplinary professional network
- a case management approach, led by a social worker or clinical nurse
- investment in a supportive client/worker relationship
- a collaborative response to crisis intervention
- specialist clinical, psychosocial and practical supports.

We explore these foundations here with examples of how they are implemented in North America, England and Wales and other Australian jurisdictions. We then explore which elements are present and missing in the Tasmanian service landscape.

FIGURE 24: COLLABORATIVE GROUPS – STRUCTURAL ELEMENTS FOR SUPPORTING THOSE LIVING WITH HOARDING AND CMHH



Sources: Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016

9.2 A multi-disciplinary professional network

An essential element of the support infrastructure for those living with hoarding or CMHH is having a collaborative group, sometimes called a local taskforce, coalition, action group, coordinating council, case coordinating group or network (Bratiotis 2013). This group brings together the expertise of “enablers” or support services, such as clinical supports and social care providers (mental health services, disability supports, housing support services, aged care), with the expertise of “code enforcers”, such as the fire service, environmental health officers, animal welfare and management (Bratiotis 2013; Bratiotis et al. 2018; Brown & Pain 2014; Firsten-Kaufman & Hildebrandt 2016; Frost et al. 2000; Kysow et al. 2020; McGuire et al. 2013; Pittman et al. 2020).

These groups are a great way for local stakeholders to work together to achieve community, as well as individual level change (Bratiotis 2013). They are widely argued as an efficient means of dividing up labour and responsibilities, managing limited budgets, avoiding duplication of services and enabling the cross-pollination of ideas and approaches (Bratiotis 2013; Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016; Frost et al. 2000; Kysow et al. 2020; Pittman et al. 2020; RRR Consulting 2016). See for example the City of Vancouver's HART Program (Case Study 1).

**CASE STUDY 3: TARGETED FOR OLDER PEOPLE –
GATEKEEPERS PROGRAM, HAMILTON, ONTARIO, CANADA**

Gatekeepers Program, Catholic Family Services of Hamilton

LOCATION:

Hamilton, Ontario, Canada

DATE:

2005–present

AGENCIES:

Catholic Family Services

TARGET GROUP:

adults over 60 years of age who are living in severe self-neglect (Diogenes Syndrome)

GOALS:

improve quality of life and increase overall health and wellbeing; “open the gate” to support services; decrease isolation; increase safety within the home.

PATHWAYS:

Gatekeepers does extensive outreach in the community to teach people who may come into contact with vulnerable seniors to recognise the signs of self-neglect. It receives referrals from members of the community including friends and family, neighbours, landlords, delivery people and home repair contractors, as well as health, housing and social service providers.

APPROACH:

Case managers serve as client liaison with frequent home visits. A care plan is created with the client and goals are set with a focus on health and safety. Intensive case management teaches problem-solving and decision-making. In addition there is a clinical treatment group run by a psychologist specialising in anxiety disorders.

Source: Bratiotis et al. 2018; Boule et al. 2018; Catholic Family Services of Hamilton n.d.

Furthermore, a collaborative group also makes it possible for services with very different goals to coalesce around a shared approach and set of objectives, i.e. harm minimisation and person-centred care (Bratiotis et al. 2018; Kysow et al. 2020). They are also reported to provide collegial support in what are sometimes very complex and challenging support relationships. They offer a means to develop a comprehensive needs assessment for individuals, animals and communities involved in cases whilst maintaining a person-centred perspective (Bratiotis 2013; Bratiotis et al. 2018).

The form of these collaborations differs across jurisdictions; they may be in the form of US “taskforces” (see Case Studies 1 & 5), Canadian community collaboratives (see Case Study 12), English and Welsh adult safeguarding groups (see Case Studies 2 & 6) or help hubs, or Australian industry groups (see Case Study 4). But there are a number of core elements that appear to lead to a sustainable and effective approach to supporting those living with hoarding or CMHH.

Collaborating groups are most effective when they have information, data collection and capacity building elements (Bratiotis 2013; CCS 2014; Kysow et al. 2020). These elements include:

- providing an information hub for people living with hoarding and CMHH and their families/carers, and for professionals seeking to support them. This might include information about the nature of hoarding and CMHH and the local services that can support them
- offering workforce development opportunities for professionals
- collecting and reviewing data about the local prevalence of challenges and the impacts of interventions on those living with hoarding and CMHH, their families and carers and service providers
- providing and reviewing the collaborative practice framework regularly to ensure that it is up to date and relevant to all parties
- identifying gaps in local service provision and advocating for investment in relevant services and skills where needed.

These are significant tasks that require resourcing.

In New South Wales, Catholic Community Care has successfully fulfilled many of these roles with *Pathways through the Maze*. This initiative followed their initial advocacy with DoH NSW about the need for specialist supports (CCS 2014). The NSW government used to fund a Squalor Hotline as a central information and advice service for anyone seeking support. It now funds Catholic Community Care’s *Pathways through the Maze* to provide an information hub and training. (Stark 2013; CCS 2014). *Pathways through the Maze* also facilitates an industry group, which not only brings services together around cases, but also considers workforce development needs (see Case Study 4).

CASE STUDY 4: COLLABORATIVE APPROACHES – PATHWAYS THROUGH THE MAZE, NEW SOUTH WALES, AUSTRALIA

Pathways through the Maze, Catholic Community Services, New South Wales

LOCATION:

New South Wales, Australia

DATE:

2012–present

AGENCIES:

Catholic Community Services (lead agency), representatives from Sydney Local Health District; South Eastern Sydney Local Health District; NSW Ministry of Health; NSW Trustee and Guardian; Housing NSW; City of Sydney Council; RSPCA NSW; NSW Fire and Rescue; University of Sydney, School of Psychology; University of NSW, School of Social Sciences; Mental Health Coordinating Council; Local Government NSW.

GOALS:

To develop a shared understanding of the challenges and approach to supporting people living with hoarding or CMHH and the families and carers. To provide a central information hub for the public and professionals. To provide a referral pathway into specialist supports for those living with hoarding or CMHH, their families and carers. To build the capacity of professionals to support those living with these challenges.

APPROACH:

Pathways through the Maze facilitates a collaborative approach to public education, consumer, carer and professional support, professional and carer capacity building and systemic change. Clinical, psychosocial and practical supports take a harm minimisation approach to consumer goals and encourage consumer-paced behavioural change, drawing on cognitive behavioural therapy (CBT). The industry taskforce has promoted collaborative working, considers workforce development issues and undertakes advocacy for systemic change.

Source: CCS 2021

9.3 A case management approach

Case management as part of a collaborative group may include a number of elements (Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016; Mas-Exposito et al. 2014).

Finding cases and/or receiving referrals from other agencies

This is a core role for any specialist collaborative group. For example, the City of Vancouver's HART (Case Study 1) has a case manager based in adult care services who has a specific goal around tenancy preservation and harm minimisation. They work in partnership with the Fire Safety Officer. The case manager will both actively seek older people at risk of safety concerns or self-neglect and receive referrals from other agencies, particularly housing providers who need access to additional supports for tenants who may have significant condition of property challenges (Kysow et al. 2020).

Home visits, assessment of needs, case co-ordination and intensive case management.

There will usually be a standard set of assessments agreed on and understood by the collaborative group. Usually these will take into account the person's wellbeing and functioning and environmental risk assessments (see Appendix 4 for more on these tools).

There will usually be a shared agreement around what constitutes moderate and severe levels of concern that will spark action. Goals and an action plan will be determined on a case by case basis. The case manager is likely to be liaising closely with and drawing on the expertise of fire safety, animal welfare and environmental health staff to co-ordinate the case, ensuring the goals are appropriate to address any code concerns and any partnership work is arranged with the resident. For example, Hamilton's Gatekeeper's Program (Case Study 3) works closely with the Housing Help Centre to provide supported housing and housing related services. But the most important aspect of a collaborative case management approach is ensuring that goals are developed with the person concerned and relate to their care, as well as any code violations.

The case manager is usually also responsible for brokering clinical and therapeutic practical services and supports.

Implementation of the chosen interventions.

There will usually be a link to a program of support that involves clinical, psychosocial and practical supports. For example, the CREST Program specifically provides a suite of such supports for older people (see Case Study 11). These elements of support are described in Chapter 9.6.

Personal advocacy, monitoring and case closure.

This may include liaising with agencies to ensure that “conditions” or “concerns” are met. For example, the case manager may be liaising with hospital staff if a person’s discharge home is being delayed to ensure health and safety concerns can be addressed and ongoing care provided. They may be liaising with housing providers to ensure that conditions of property concerns can be met, but also to establish ongoing supports that will ensure the tenancy is sustained and care needs addressed. This is the case for a number of housing-focused collectives, such as Boston’s Hoarding Intervention and Tenancy Preservation Project (see Case Study 5) and Onward Home’s Outside the Box (see Case Study 9). Where there is a concern around impaired judgement, or capacity to make decisions, the case manager will liaise with families, mental health, safeguarding and guardianship agencies to ensure appropriate assessments are conducted and the client’s interests are protected.

CASE STUDY 5: HOUSING-LED APPROACHES – HOARDING INTERVENTION AND TENANCY PRESERVATION PROJECT, GREATER BOSTON, MASSACHUSETTS, USA

Hoarding Intervention and Tenancy Preservation Project

LOCATION:

Greater Boston, Mass., USA

DATE:

2010-

AGENCIES:

Metropolitan Boston Housing Partnership (non-profit working in homelessness prevention and housing assistance) and Boston Tenancy Preservation Project, a program of Bay Cove Human Services. Funded by the Oak Foundation, a philanthropic organisation.

TARGET GROUP:

People at risk of eviction or loss of housing subsidy. Most participants are required to participate in the program to avoid sanctions.

GOALS:

Reduce evictions and prevent homelessness.

PATHWAYS:

Referrals mainly come from property managers and inspectors, but the program has done outreach with a wide range of services to increase awareness and open referral pathways.

APPROACH:

Harm reduction and CBT strategies and tools. Individualised case management plan and weekly home visits from case managers. Referrals to relevant outside agencies where appropriate. Liaison with landlords and other agencies. Ongoing monitoring for 1-2 years after meeting compliance standards. Open ended, but on average participants take 6 months to pass inspection.

Source: Bratiotis et al. 2018; Metropolitan Boston Housing Partnership 2015

9.4 Investment in a supportive client-helper relationship

Interventions can be time-consuming, lengthy and costly. The need to build a trusting relationship and engage the client is absolutely critical to success, given that any intervention is focused on the most intimate elements of a person's life – how they live (Bratiotis 2013; Brown & Pain 2014; Firsten-Kaufman & Hildebrandt 2016; Gleason et al. 2021; Kysow et al. 2020; McGuire et al. 2013; Pittman et al. 2020).

Building trust takes time. Strategies often include a motivational, strengths-based and therapeutic approach, focusing on harm reduction, improving personal safety, addressing social isolation, education (predominantly around health and safety initially), and empowering the person to make choices and decisions (Firsten-Kaufman & Hildebrandt 2016).

Both social work and nursing are viewed as good fits for working with those living with hoarding and CMHH. Both professional frameworks are adept at working with non-voluntary clients (Bratiotis et al. 2018; Koenig et al. 2014).

The UK's London Borough of Hammersmith and Fulham (LBHF) operates with a social work lead. Designated social workers from the borough's Adult Community Social Work Team accept and lead cases in partnership with the London Fire Service (Brown & Pain 2014). This approach draws on social work paradigms including putting relationship building and empowerment at the centre of the work, drawing on the values of 'unconditional positive regard, mutuality and dialogue' (Murphy et al. 2013, cited in Brown & Pain 2014) and assessing and managing risk. Brown and Pain highlight that such relationship building should be the first priority, but should then form the foundation for 'future work rather than as an end in itself' (Brown & Pain 2014; see Case Study 6).

CASE STUDY 6: COLLABORATIVE COMMUNITY APPROACH – LONDON BOROUGH OF HAMMERSMITH AND FULHAM'S ADULT CARE TEAM, ENGLAND, UK

Hammersmith and Fulham Adult Care Team

LOCATION:

London, UK

DATE:

2010-present

AGENCIES:

London Borough of Hammersmith and Fulham Adult Social Care Team

PATHWAYS:

Referrals come from agencies including London Fire Brigade, housing associations, the London Ambulance Service, council housing department, general practitioners and community nurses.

APPROACH:

A strategic decision was made to make the Adult Social Care Team the lead agency to work with all hoarding cases. A social worker is allocated and a home visit and assessment is made. The social worker may call a case conference with all agencies involved, and where possible with the service user, to develop an action plan. Relationship-building may take several months before any practical work is done. The Borough has established a local hoarding panel that can discuss ongoing cases and share information.

Source: Brown & Pain 2014

Other models draw on a clinical nurse lead as the relationship builder and case manager, such as the City of Vancouver's HART (Case Study 1) and San Diego's CREST's Program (Case Study 11) (Fleury et al. 2012; Kysow et al. 2020; Stark 2013). The skills and knowledge needed to work with those living with psychiatric mental ill health and establish a rapport have proven to be effective in establishing the trust and cooperation needed to engage clients. It is reported that HART has been able to develop both crisis intervention and longer term supports to preserve tenancies and minimise risks to the individual and community (Kysow et al. 2020).

It is important to note here that building a trusting relationship does not always lead to a reduction in clutter or CMHH (Kysow et al. 2020), but is widely acknowledged to be an absolute foundation of any therapeutic or practical support.

CASE STUDY 7: TARGETED FOR OLDER PEOPLE – CRITICAL INTERIM SUPPORT PROGRAM, BROTHERHOOD OF ST. LAURENCE, MELBOURNE, AUSTRALIA

Critical Interim Support Program

LOCATION:

Melbourne, Australia

DATE:

September 2020-

AGENCIES:

Brotherhood of St. Laurence.

TARGET GROUP:

Vulnerable and socially isolated older Melbournians who are eligible for aged care services under My Aged Care (65+ years, or younger if qualifying for access under the premature ageing guidelines). In particular those who have no or limited social supports, socio-economic disadvantage and do not have immediate access to supports through My Aged Care due to non-engagement, extended package waitlists, or complex assessment processes. Clients often live in highly complex and varied psychosocial circumstances. They are often hidden from view due to the nature of their isolation, and often mistrusting of authorities with histories of trauma, self-neglect behaviours and elder abuse. This target group includes those living with hoarding or CMHH.

GOALS:

To provide system navigation and case management supports that connect older Melbournians to ongoing service systems. The goal is to reduce their isolation, reduce the need for critical physical and mental health care, reduce the likelihood of premature entry into residential aged care, and prevent their wellbeing further declining while they await supports through My Aged Care.

PATHWAYS:

Pathways into the program are flexible. Current referrals tend to be through health services (hospital discharge and emergency departments, Ambulance Victoria), councils, local community services and My Aged Care assessors (ACAT and RAS).

APPROACH:

Assertive outreach is used to establish contact with clients. Case managers work within a framework of compassionate care, foregrounding dignity of choice and risk, and are not time limited. They prioritise building trust and relationships with clients. They then work with the client to address initial crises, guide and support them through the Australian Government's My Aged Care assessment process and connect them with essential ongoing services. This may include multiple support services that will address their physical and mental health needs, domestic support needs and social connection. For those living with hoarding or CMHH, this will include access to specialist programs of support to work with clients around clinical, psychosocial and practical support needs.

This is a two year pilot program, enabled through philanthropic funding. It is being evaluated by BSL's Research and Policy Centre.

9.5 A clear and planned response to crisis intervention

The ability to respond to critical incidents (such as hospitalisations or fire) and time-critical cases (such as tenancies threatened by condition of property concerns, environmental health concerns, animal welfare code violations, concerns about fire safety, or delayed hospital discharge due to concerns about the home environment) tests any person-centred support model (Bratiotis et al. 2018).

Responses require skills and supports beyond the mandate of most code-enforcing agencies. Often crisis-driven interventions do not (or are unable to) offer appropriate support for the resident's deep anxieties around discarding precious items; time constraints, code requirements and professional skills may mean it is challenging to ensure that a resident is in control of decisions about what happens to their items, or ensure that the resident's underlying and presenting mental health challenges are supported before, during and after sorting and discarding occurs (Brown & Pain 2014; Kysow et al. 2020; RRR Consultancy 2016; Stark 2013). Such restricted remits or capacities can lead to services addressing the presenting issue (i.e. the clutter or unsanitary environment) rather than the underlying causes (i.e. underlying mental health challenges). Such "clean-outs" without resident support or control usually leads to clutter or concerns around domestic sanitation or structural issues re-escalating in subsequent weeks and months. It can often lead to a deterioration in the resident's mental health and can further damage their willingness to seek help and support in future (Brown & Pain 2014; Buscher et al. 2014; Neziroglu et al. 2020; Roane et al. 2017; Koenig et al. 2010).

Canadian, English and Welsh collaborative groups have benefitted enormously from bringing together the expertise of code enforcers (such as fire safety officers, environmental health officers, animal welfare officers and housing providers) who can understand and leverage action from their statutory powers and responsibilities, with "enablers", such as social workers and clinical nurses (Bratiotis et al. 2018; Brown & Pain 2014; Kysow et al. 2020; Pittman et al. 2020; RRR Consultancy 2016; Stark 2013). Code enforcers usually reach the limits of their scope and powers without resolving concerns when they are working with people living with hoarding or CMHH (Bratiotis et al. 2018; RRR Consultancy 2016). Their remit is usually to address a structural, environmental or animal welfare concern, even though they are often presented with a person who needs significant supports around their mental or physical health in order to engage and address the presenting concerns. They are often working with people in a non-voluntary capacity, but need a tangible resolution in order to "close the case" (Bratiotis et al. 2018).

CASE STUDY 8: FIRE RESCUE VICTORIA HAZARD NOTIFICATION SYSTEM**Fire Rescue Victoria Hazard Notification System****LOCATION:**

Victoria, Australia

GOAL:

To enhance the preparedness of emergency responders in the event of fires in cluttered properties.

AGENCIES:

FRV At Risk Group Team and CFA in partnership with emergency and community sector services.

APPROACH:

Fire Rescue Victoria maintains a Hoarding Notification System. This is a register of known hoarded properties (usually level 5 or above on the Clutter Image Rating), so that if there is an emergency incident, the Communications Team can alert responders to increase their preparedness and safety (for example, extra personnel and vehicles allocated). Firefighters undertake tests and training in hoarded environments to prepare them for the unique challenges this poses. These initiatives are supported by the Victorian practice guidance on hoarding and squalor (DoH[Vic] 2013).

Source: Fire Rescue Victoria 2017

Collaborating with social care providers utilising a harm minimisation approach is much more likely to result in individuals engaging and seeing progress towards resolving issues of concern (Bratiotis et al. 2018; Brent Safeguarding Adults Board 2020; Brown & Pain 2014; Kysow et al. 2020; NSAB 2019; Nottinghamshire County Council n.d.; RRR Consulting 2016). Also, having practical arrangements that consider an individual's wellbeing whilst critical interventions occur can be vital to sustaining engagement and progress. For example, Boston's Hoarding Intervention and Tenancy Preservation Project enables clients to access emergency housing to provide respite from their living environment whilst safety concerns with hoarding and CMHH are addressed, if this is a path a resident chooses (Bratiotis et al. 2018; see Case Study 5).

In cases of animal hoarding, there are a number of elements to consider. These include:

- **What is the concern?** Animal welfare is concerned with protecting animals from neglect or cruelty, ensuring they are well cared for and have medical treatment when needed, and educating humans around responsible pet ownership. Animal management is concerned with ensuring people are complying with ownership requirements (registration and limits) and population concerns outside of domestic dwellings. Both elements may need to be part of a response and may involve different agencies.

- **What are the short and long term goals?** Where the code violation may be neglect, rather than cruelty, or having excess animals, limiting animals may be the ultimate goal over abstinence. However, attaining such a goal should be seen as longer term, if that is possible within local codes. The initial goals need to be engaging the resident(s) and encouraging them to identify short term, achievable goals (Frost et al. 2015).
- **Who should be involved?** In order to achieve such engagement and goal setting, it is crucial for a multidisciplinary team to work together, drawing on social care and code enforcement, as identified in Chapter 9.2 and .3. Research highlights that both mental health challenges and CMHH are likely to be present in cases of animal hoarding (Snowdon et al. 2019). It is recommended that specialist clinical services work alongside animal welfare inspectorates and animal management agencies to assess and where appropriate treat residents' mental health challenges. Without such partnerships, the likelihood of recidivism is extremely high (Ockenden et al. 2014; Snowdon et al. 2019).

9.6 Specialist supports

There is a strong argument for investing in local specialist support programs for those living with hoarding and/or CMHH, particularly to support older residents (Bratiotis et al. 2018; Firsten-Kaufman & Hildebrandt 2016). Best practice support models have one element in common – they are person-centred in their approach.

CASE STUDY 9: OUTSIDE THE BOX, LIVERPOOL, ENGLAND, UK

LOCATION:

Liverpool, UK

AGENCIES:

Onward Homes (formerly Liverpool Housing Trust), a social housing provider, with Talk Liverpool, a government-funded mental health service

TARGET GROUP:

Tenants of Onward Homes

GOALS:

To provide long-term solutions to clients with a hoarding problem

APPROACH:

Practical support provided by Onward Homes is linked to therapeutic support provided by mental health services and peer support groups. Specialist support workers employed by Onward Homes act as "co-therapist", supporting clients in between their psychological therapy sessions and peer support group meetings. The Outside the Box toolkit separates the property into smaller, less intimidating areas for sorting and is accompanied by a relapse prevention plan and "Boxed Off Pledge" to provide a structured program of gradual exposure and CBT-based thinking.

Sources: RRR Consultancy 2016; McPhillips 2015

The agencies, strategies and methods used in support programs may vary, but there are usually core elements to support. There are often **clinical elements**, designed to address underlying mental health or cognitive challenges (such as depression, anxiety) through pharmacological, talk therapies and/or occupational therapies (Snowdon & Halliday 2009).

There are usually psychosocial cognitive and behavioural elements, designed to work with the person around their understandings and relationships with items and animals, their sense of themselves, stigma and shame, their insight into what's needed to ensure they are safe and their ability to make decisions about what they would like to do with their living environment or in response to any code violation. And there will be some form of practical support that will help them to act on their decisions around sorting and discarding items or animals. The practical elements may be an extension of the therapeutic supports, but if they are a separate part of the process, they too need to be delivered in a person-centred approach that draws on and is connected to the other supports.

Below, we have highlighted some of the common forms of psychosocial, clinical and practical elements of support.

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy is seen as the most effective clinical method of supporting people to review their relationship with their items/animals and their living environment and helping them with strategies to sort and discard (Firsten-Kaufman & Hildebrandt 2016; National Housing Federation 2015; RRR Consultancy 2016; Steketee & Frost 2013; Tolin et al. 2014).

Through a series of sessions with a therapist, either outside or inside their home, CBT utilises **exposure, cognitive restructuring and motivational interviewing**. These therapeutic interventions will support the individual to challenge their underlying beliefs about items or animals, develop their own decision-making process, and learn practical strategies to sort and discard in the long term. There is no element of persuasion to discard, as this can lead to strengthening beliefs about the importance of such items (RRR Consultancy 2016).

Program evaluations using this approach have shown a decrease in hoarding severity, particularly the ability to discard items, amongst most people who engage. Outcomes are reported to be best for younger people, those who have more home visits (either by professionals or peer workers) and those who attend more CBT sessions (Firsten-Kaufman & Hildebrandt 2016; Tolin et al. 2014; Williams & Viscusi 2016). Better outcomes are also reported when individuals participate in peer-facilitated support groups and are supported in the home by a non-clinical support worker (Firsten-Kaufman & Hildebrandt 2016).

Treatment gains are often maintained post-intervention, although there is often still heightened levels of hoarding behaviour compared with normative behaviour (Firsten-Kaufman & Hildebrandt 2016). It should be noted that for some participants, the change in hoarding severity can be modest.

The widely-used *Buried in Treasures* workbook uses this method (Tolin et al. 2014), as do a number of hoarding support programs, such as the London Hoarding Treatment Group, Onward Home's Outside the Box, Sydney's Pathways through the Maze and Mission Australia's Room to Grow (see Case Studies 9, 4, 10).

CASE STUDY 10: ROOM TO GROW, MISSION AUSTRALIA, SYDNEY, NSW, AUSTRALIA

Room to Grow, Mission Australia

LOCATION:

Central and eastern Sydney

DATE:

July 2015-June 2016

AGENCIES:

Mission Australia, funded by National Partnership Agreement on Homelessness through NSW Department of Families and Community Services

TARGET GROUP:

Vulnerable individuals, mostly in public and social housing, experiencing hoarding disorder and/or CMHH.

GOALS:

Reduce the risk of tenancy loss by addressing the physical, cognitive and psychological factors contributing to the situation

PATHWAYS:

Clients were referred from housing and mental health support services (Common Ground Camperdown Support Service, Eastern Sydney Partners in Recovery and Housing NSW)

APPROACH:

Individual case coordination plan with referrals to external services where appropriate. Intensive case management, including the development of organisational and decision-making skills, assistance with daily living activities, and guidance with decluttering. Adapted CBT and Buried in Treasures group workshops, over two programs of 12 sessions each. Cognitive rehabilitation program of twice-weekly 2-hour sessions for 6 weeks, to provide strategies to enhance functional cognitive skills. In response to participant demand, a facilitated peer support group during the final two months of the program.

Source: Mission Australia 2016

Working with older people: Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST)

Catherine Ayres, a prominent figure in geriatric hoarding disorder, has highlighted that CBT may be less effective with older clients, due to their compromised capacity for cognitive change (Pittman et al. 2020). It has been reported that for older adults, CBT combined with cognitive rehabilitation strategies targeting memory, organising, problem-solving and cognitive flexibility (i.e. our ability to adapt our thinking and behaviour to an environment) double treatment response rates (Firsten-Kaufman & Hildebrandt 2016; Pittman et al. 2020).

CREST is a community-based intervention specifically designed to support older adults living with hoarding disorder. It has been designed to specifically address cognitive deficits experienced by older adults and has been evaluated as the most effective treatment of older people (Pittman et al. 2020) (see Case Study 11).

CASE STUDY 11: TARGETED FOR OLDER PEOPLE – COGNITIVE REHABILITATION AND EXPOSURE/SORTING THERAPY (CREST), SAN DIEGO, USA

Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST)

LOCATION:

San Diego, California, USA

TARGET GROUP:

Adults over 60

GOALS:

To reduce hoarding severity amongst older residents

APPROACH:

The San Diego County Health and Human Services Agency funded CREST with a multi-disciplinary, mobile team. The team consisted of three psychologists, two social workers, one marriage and family therapist and a peer support specialist. Resources were also dedicated to program administration, including clinical and administrative supervision and regulatory oversight, clinical care and outreach. In recognition that this support work is time consuming and would involve significant travel, caseloads were capped at 15 individual clients per FTE. The goal was to support 30 individuals in a year.

CREST INVOLVES:

Compensatory cognitive training: The “Cognitive Rehabilitation” element addresses cognitive impairments commonly experienced by those living with hoarding disorder – the ability to carry out intended activities, prioritising, problem-solving, planning and cognitive flexibility. Developing these skills helps participants prepare for treatment, helps them develop the skills to attend treatment sessions and complete homework tasks and plan strategies that will prevent relapses.

As Pittman et al. explain, 'CREST aims to help clients form new habits and automate tasks, thereby reducing the active cognitive effort required for effective performance' (2020).

Exposure Therapy: the "Exposure/Sorting Therapy" element supports individuals to move from continuing to acquire items and avoidance of sorting and discarding, to gradual and supported exposure to these tasks. Participants develop a list of spaces that evoke progressively more distress for them when they think of discarding (it might be increasing levels of clutter, specific types of items, or environmental elements). The participant creates these "fear hierarchies" with their therapist and then chooses a mild to moderate space to begin their exposure exercises. Participants will receive between 20 to 40 sessions, based on their needs and severity of their environment.

Source: Pittman et al. 2020

Challenging negative self-constructs: one to one clinical counselling

Chou et al's work encourages us to extend this cognitive focus. They argue that challenging negative self-constructs requires a therapeutic approach that supports individuals to reconsider their relationship to their self-identity in a more positive framework. They argue that such therapy needs to tackle issues of shame – about themselves and their hoarding behaviour, if this is relevant (Chou, Tsoh et al. 2018). Some support approaches include one to one therapy to address underlying mental health challenges and any medical needs.

Group work and peer support groups

Group work for people living with hoarding or CMHH can be extremely beneficial in reducing people's isolation, supporting them to feel "recognised" by a similar group of people, and reducing the sense of shame and stigma around their challenges (Frost et al. 2003; RRR Consulting 2016; Whitfield et al. 2012). They can be an effective means of sustaining new thinking and actions.

Group CBT has been shown to be effective in supporting changes in discarding and decision-making, but not as effective as one to one sessions (Firsten-Kaufman & Hildebrandt 2016). Programs such as Pathways through the Maze (Case Study 4) and Mission Australia's Room to Grow (Case Study 10) have utilised group sessions for teaching and modelling that provide the clients with psychosocial education about the nature of hoarding and CMHH, the tools to assess challenges and needs, and the skills to problem solve and make decisions. Peer groups create an environment for recovery for the clients.

Peer support groups are an often requested part of specialist programs, including Pathways through the Maze and Room to Grow, and go a long way to addressing social isolation and reducing stigma for those living with hoarding or CMHH. This in itself can prompt help-seeking. It has been a strength of Edmonton's This Full House program (see Case Study 12). This program, targeted at older residents who are socially isolated and at risk of losing their home due to hoarding or CMHH, has received strong feedback that community engagement has reduced social isolation (Whitfield et al. 2012).

CASE STUDY 12: TARGETED FOR OLDER PEOPLE – THIS FULL HOUSE, SAGE, EDMONTON, CANADA

This Full House, Seniors Association of Greater Edmonton (SAGE), Edmonton

LOCATION:

Edmonton, Canada

DATE:

2007-present

AGENCIES:

Program delivered by Seniors Association of Greater Edmonton, in association with a community collaborative that includes social workers, home care nurses, a geriatric neuropsychologist, fire and safety investigators, public health practitioners and environmental health and safety officers.

TARGET GROUP:

People aged over 55 in the Greater Edmonton area with hoarding behaviour

GOALS:

To prevent eviction and keep seniors in their homes for as long as possible, to improve health and wellbeing, to encourage positive social contacts and contribute to a health community.

PATHWAYS:

Referrals from professionals including community services, medical practitioners etc., or from self, family or neighbours.

APPROACH:

An initial home visit to assess the situation and identify safety issues. An Action Plan is made according to the client's vision of how they want to work and live in their home. Staff regularly check on progress and provide ongoing support. A professional organiser usually assists with practical aspects. There is also a monthly peer support group.

Source: Whitfield et al. 2012

Practical supports

In-home support to practice and reinforce skills and behaviour is a key element of any support program. Programs approach this in different ways, depending on the makeup of coordinating groups, local skills and resources and timescales for action. For example, programs like CREST (see Case Study 11) offer continuity of support with a therapist, who accompanies an individual into the home to practice thinking and behaviour learnt during psychosocial and clinical sessions (Pittman et al. 2020).

Programs like Boston's Hoarding Intervention and Tenancy Preservation Project (see Case Study 5), Edmonton's This Full House (Case Study 12), Sydney's Pathways through the Maze (Case Study 4) and Room to Grow (Case Study 10), and Liverpool's Outside the Box (see Case Study 9), offer regular home visits from a case manager. In such models, the case manager may work with the resident to set and act on their goals through regular home visits, or work with another service to do so.

Where there are concerns about unhealthy premises, other practical services might include professional organisers or therapeutic cleaners. Achieving the goals must remain client-led. It is important that the client participates in achieving the goals, draws on psychosocial therapy and practices their skills regularly. There is some evidence that home visits by professionals who are not therapists may be more successful (Pittman et al. 2020). This supports the use of peer-led and family models of home support. However, older clients are less likely to sustain goals without ongoing supports in place due to cognitive decline.

9.7 In Tasmania

There are very few specialist services who specifically work with Tasmanians or their families and carers who have issues around hoarding and CMHH. None are able to offer supports that will holistically address the underlying causes, the hoarding behaviour itself and its environmental, social and personal impacts (H&SWG 2017; Fidler 2021). The pockets of case management and services that are available are a valuable start to creating a network of support, but they are all limited in their scope and capacity for older Tasmanians to be able to address both personal and community safety concerns.

FIGURE 25: FEDERAL AND TASMANIAN SOCIAL CARE POLICIES AND PROGRAMS FOR OLDER TASMANIANS LIVING WITH HOARDING OR CMHH

HOME AND COMMUNITY CARE

Purpose: Support Tasmanians under 65/50* to be more independent at home and in the community to enhance quality of life or delay an acute health event

- Case coordination
- Clinical and non-clinical care and support
- Maintenance
- Transport
- Support for carers

RETHINK 2020 TASMANIAN MENTAL HEALTH IMPLEMENTATION PLAN

Purpose: a Tasmanian community where all people have the best possible mental health and wellbeing

- Statewide Mental Health Services
- Clinical mental health supports and services
 - Alcohol and drug services
- Primary Health Tasmania
- Psychosocial supports outside of NDIS
 - Support for carers

STRONG LIVEABLE COMMUNITIES: TASMANIA'S ACTIVE AGEING PLAN 2017-2021

Purpose: Older people making informed choices about their lives

AGED CARE

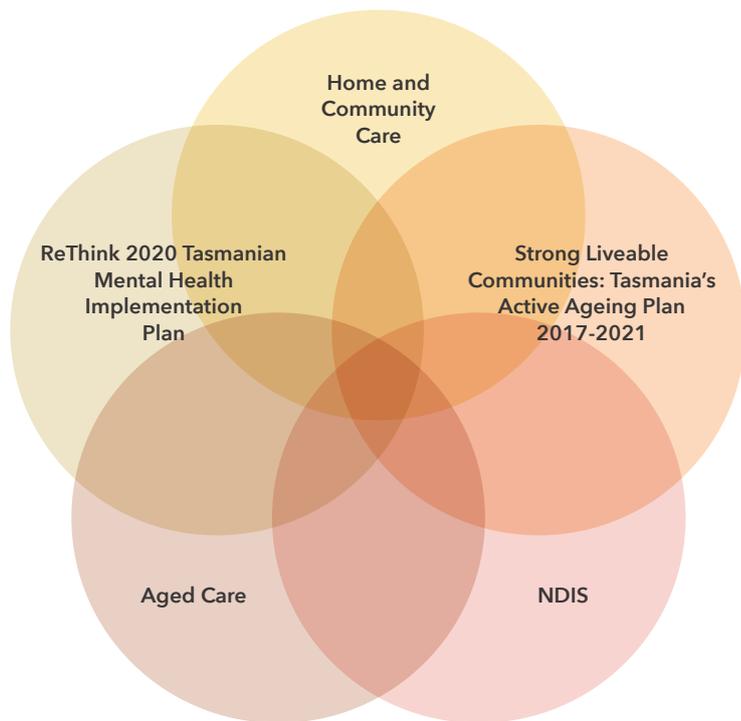
Purpose: Wellness and reablement for Tasmanians 65/50* and over

- Domestic and social care
- Mobility aides
- Support for carers

NDIS

Purpose: Maximise potential of disabled persons and allow them to participate as equal citizens.

- Non-clinical supports judged reasonable and necessary and not supplied through the aged care system
- Support for carers



People: personal wellbeing and ageing well at home

ASSESSMENT AND CASE COORDINATION

My Aged Care assessments are undertaken by either Aged Care Assessment Teams (ACATs) or Regional Assessment Services (RASs), depending on the level of package older Tasmanians are eligible for.²⁰ They can recommend and refer clients to a range of services in Tasmania offering case management and support services.

The Commonwealth Home Support Package's sub-program for Assistance with Care and Housing (ACH) funds two programs within Tasmania that can support older people living with hoarding or CMHH, if they are at risk of homelessness. The Salvation Army and Catholic Care's Home and Housed offer case coordination and a small amount of brokerage funding (see Case Study 13). There is also the opportunity for younger Tasmanians²¹ to receive case management through the Tasmanian Home and Community Care (HACC) Program.

Tasmanian state Adult and Older Persons Mental Health Services and Primary Health Tasmania-funded psychosocial supports may also offer case coordination services for adult Tasmanians. Similarly, Tasmanian consumers eligible for NDIS can commission case coordinating services through a support coordinator. They can also commission a package of supports that include psychosocial and practical help with challenges related to hoarding and CMHH.

For all of these programs, staff are in a position to case manage older Tasmanians, but are limited in their capacity to effectively work with clients who have challenges related to hoarding or maintaining a healthy home by various factors.

Fee for service models, such as NDIS and aged care packages, have the initial challenge that clients need to have actively recognised, identified and acted upon their challenges related to hoarding or CMHH in order to design a package of supports to address them. Secondly, there is the challenge of having the time and capacity to effectively build the trusting relationship and level of insight needed to effectively work with people who may have shunned services up to this point.

Thirdly, there is the challenge of case coordinating without the range of services available to effectively work with older Tasmanians living with hoarding and CMHH. As we will describe below, the Tasmanian market is at best thin in terms of specialist clinical, practical

20 RASs assess lower level support needs under the Commonwealth Home Support Package (CHSP). Such supports may include domestic assistance, personal care assistance, allied health, garden and lawn maintenance, home modifications, transport and social support.

ACATs undertake a more comprehensive assessment for higher level coordination and support needs under the Home Care Package (HCP).

21 The Tas HACC target population is defined as, 'People who live in the community who, without basic core maintenance and support services provided under the scope of the Program, whose capacity for independent living is at risk due to an acute health event, moderate functional impairment or deterioration of an ongoing condition including:

- younger persons (aged less than 65 years and less than 50 years for Aboriginal people).
- such other classes of people as are agreed upon, from time to time, by the Department of Health.
- the unpaid carers of people assessed as being within the Program's target population.' (DoH [Tas]) 2020b

and psychosocial supports available for older clients living with such challenges. RAS and ACAT assessments may identify support needs during client assessments, but there are often no specialist services they can refer clients to.

And fourthly, in the case of ACH and Tasmanian HACC programs where the “market” is meant to be supplemented by grant-based brokerage supports, there are insufficient brokerage funds to be able to address the often significant clinical, psychosocial and practical challenges their clients have, even if there were services available within Tasmania

CASE STUDY 13: TASMANIAN CHSP ASSISTANCE WITH CARE AND HOUSING PROGRAMS – THE SALVATION ARMY

Assistance with Care and Housing for the Aged Program (ACHA), The Salvation Army, Tasmania

LOCATION:

Tasmania, Australia

AGENCIES:

The Salvation Army, funded by the Australian Government Department of Health under the Commonwealth Home Support Program (CHSP).

TARGET GROUP(S):

People aged 50 and over, or 45 and over if they are of Aboriginal or Torres Strait Islander heritage. They must be on a low income and be homeless or at risk of being homeless.

GOALS:

To support those who are homeless or at risk of homelessness to access appropriate and sustainable housing as well as community care and other support services

PATHWAYS:

Referrals from My Aged Care Regional Assessment Teams, hospitals, Housing Connect, community services, medical practitioners, family, neighbours and self-referrals.

APPROACH:

The Salvation Army provides goal-focused case coordination and links clients with services. They can offer three types of service – assessment and referrals, financial and legal advocacy, and supports to address hoarding and CMHH. Services may include developing a client plan; one-off clean-ups; reviewing care plans; and linking clients to specialist support services. It is expected that case managers will invest significant time in developing a trusted relationship with the client and

may stay connected with them after they begin accessing support services that address their needs. This is expected to aid transition and prevent a swift return to homelessness or the risk of homelessness.

The current program extended case management services to include support for hoarding and CMHH, but did not expand the funding to support the delivery of this function. In Tasmania, there are no specialist clinical, psychosocial or practical support services for ACH to refer clients to. The program has few options to holistically support such clients in insecure housing outcomes.

Source: DoH [Aus] 2020

SPECIALIST SUPPORTS

Tasmania does not have any specialist clinical or psychosocial supports for people living with hoarding or CMHH that draw on the approaches outlined in this chapter.

The Tasmanian HACC program funds a range of basic core support services targeted at younger people who live in the Tasmanian community and whose capacity for independent living is at risk due to an acute health event, moderate or mild functional impairment or deterioration of an ongoing condition. "Younger persons" are people aged less than 65 years and Aboriginal people aged less than 50 years. Tas HACC guides services to prioritise those clients vulnerable to further deterioration and assessments to consider those at risk of premature entry into residential or acute care (DoH [Tas] 2020b, p.13-5).

The Tas HACC program has funded Anglicare Tasmania to support people living with hoarding or CMHH with domestic, practical supports across the state. This service is limited to offering practical supports, such as sorting, discarding items and cleaning. Staff delivering these supports are part of Anglicare Tasmania's Home Care Support Team. They are aware of the sensitivities and complexities within which they are delivering supports, but are not trained specialists. Although they offer case management, there are no clinical or psychosocial supports that they can work with to provide a wrap around service (see Case Study 14).

CASE STUDY 14: TASMANIAN HOME AND COMMUNITY CARE DOMESTIC SUPPORTS, ANGLICARE TASMANIA

Home and Community Care (HACC) Domestic Support, Anglicare Tasmania

LOCATION:

Tasmania, Australia

AGENCIES:

The Tasmanian Department of Health Home and Community Care Program funds this service. It is a free-to-access domestic support service, delivered by Anglicare Tasmania's Home Care Services. It is designed to secure independent living and housing outcomes for younger vulnerable adults.

TARGET GROUP(S):

People aged under 65, or under 50 if they are of Aboriginal or Torres Strait Islander heritage whose capacity for independent living is at risk due to an acute health event, moderate functional impairment or deterioration of an ongoing condition.

GOALS:

To assist clients maintain their home.

PATHWAYS:

Tasmanian Community Referral Service or direct referral to Anglicare Home Care Services.

APPROACH:

The team works within a wellness framework, partnering with clients to support their independence.

<https://www.anglicare-tas.org.au/home-and-community-care-hacc/>

OTHER ADULT, MENTAL HEALTH AND AGED CARE SUPPORTS

Given Tasmania's older demographic profile, the state has a range of aged care providers offering supports through CHSP and HCP. These will include domestic assistance, personal care assistance, allied health, garden and lawn maintenance, home modifications, transport and social support and case coordination. To support older Tasmanians and their families to find the right supports for them, Tasmania's Council on the Ageing (COTA Tas) offers Aged Care Navigators.

There is also an array of psychosocial supports available through and outside of NDIS. Within NDIS, these can include purchasing specialist supports to address cognitive and behavioural challenges related to hoarding and CMHH. Clinical supports are available through Adult and Older Person's Mental Health Services. Tasmania is also expanding at-home health services through programs such as Hospital in the Home and Mental Health in the Home. Wintringham has an expanding presence in Tasmania, working with Tasmanians aged 50 and over who are experiencing homelessness or are at risk of experiencing homelessness to achieve stable homes so that they may age well in place.

All of these services have the potential to support older Tasmanians living with hoarding or CMHH to age well in place if they could access specialist supports to complement what they offer. However, the lack of specialist case management and clinical or psychosocial services, like those described in Chapter 9.2 - .6, prevents any progress being made with clients around these challenges.

Animals

For cases of animal hoarding in Tasmania, there are a number of agencies that may be involved, as described in Chapter 8.5. There are also a number of specialist not-for-profit animal welfare organisations, such as the Dogs Home of Tasmania, Ten Lives and Just Cats who will work with the RSPCA and animal management entities to ensure the welfare of animals and accept animals for care and rehoming.

However, given the lack of a specialist coordinating group, case management and specialist clinical and psychosocial support services to work alongside these organisations, as described in Chapter 6, it is likely that most households they support will return to animal hoarding behaviour.

Property/environment

There are two agencies working within portfolios concerned with property and environment that have developed specific approaches to working with Tasmanians living with hoarding and CMHH. However, both are hampered in achieving their support aims due to the lack of specialist case management and clinical, psychosocial and practical support programs.

HOUSING

Housing Tasmania has developed a standard approach to assessing condition of property and assist Housing Tasmania tenants to stabilise their tenancy when it is at risk due to concerns around hoarding or CMHH (see Case Study 18). Since January 2021, this approach has been rolled out statewide for properties managed by Housing Tasmania. The approach is also being shared with social housing providers across the state.

Similar to those agencies undertaking case management in Tasmania, the challenge for property managers is the lack of specialist services to refer tenants to.

This is also a challenge for Tasmania's Housing Connect support workers. This service offers a gateway to housing applications and housing support services. However, where they encounter clients living with hoarding or CMHH, or those who are at risk of homelessness due to those challenges, there are no specialist services to refer them to across Tasmania.

ENVIRONMENTAL HEALTH AND PLANNING

In Chapter 8.5, we outlined the responsibilities local government has for investigating unhealthy and dangerous premises. Environmental health officers and building compliance officers will often work together to address a concern. Environmental health officers have power to enter a property to investigate a complaint/referral. Their remit is to decide whether a premises is "unhealthy" – specifically, does it need to be fixed and can the premises be lived in. The Tasmanian Department of Health's Population Health Unit has worked with councils to develop a guide to support assessments (DoH [Tas] 2015a). As is made clear in the *Guide to Assessing Unhealthy Premises*, environmental health officers are not responsible for assessing any of the human elements, such as how the situation has arisen and what steps need to be taken to ensure the residents are appropriately supported.

However, to address any environmental health or structural concerns, both building and environmental health officers need to be able to work with health and social care providers in order to address the practical elements of supports, as well as any clinical or psychosocial supports needed. There are no options within Tasmania for them to draw on.

FIRE SAFETY

The Tasmanian Fire Service (TFS) is a leader in recognising the risks and needs of Tasmanian residents living with hoarding and CMHH. Drawing on good practice in Victoria (see Case Study 8) and New South Wales, the TFS is offering a pilot project to enhance community fire safety and the safety of firefighters (see Case Study 15).

Following a successful trial in southern Tasmania, project funding and scope has been extended for a year from 1 July 2021. This project is an excellent example of drawing on best practice in constructing a support system for Tasmanians living with hoarding and/or CMHH. However, the project cannot support this cohort on its own. To address any fire safety concerns, the TFS needs to be able to work with health and social care providers, animal welfare staff and building and environmental health officers in order to address any clinical or psychosocial supports, as well as any practical supports such as clearing entry and exit points, clearing routes through the house and addressing any unsafe electrics or other fuel loads. However there are no options within Tasmania for them to draw on.

CASE STUDY 15: TASMANIAN FIRE SERVICE HOME FIRE RISK MITIGATION PROJECT

Tasmanian Fire Service Home Fire Risk Mitigation Project

LOCATION:

Tasmania, Australia

GOALS:

Reduce residential fire injuries and fatalities in the Tasmanian community, including amongst those living with hoarding and CMHH. Enhance the preparedness of emergency responders in the event of fires in cluttered properties.

AGENCIES:

Funded by the State Fire Commission, this project enables the Tasmanian Fire Service's Community Development and Education Unit to work with any organisation to support the most vulnerable in the community to minimise residential fire safety risks. It also enables the Unit to work with other TFS units, such as the Fire Fighters and Fire Investigators in Operations, to increase preparedness and reduce risks to first responders in the event of a fire or other emergency.

TARGET GROUP(S):

Tasmanians who are most vulnerable to being a residential fire casualty, including those living with hoarding and CMHH.

PATHWAYS:

Any assessment or service organisation, or member of the general public, can contact TFS's community safety project officer to discuss a potential case or arrange an assessment.

APPROACH:

Using a community development approach, the project educates and encourages a harm minimisation approach to minimising fire risks due to hoarding and CMHH. The Home Fire Mitigation Project Officer facilitates partnerships and collaborations to minimise residential fire risks. The role acts as a liaison between Operational Firefighters and the health and community sectors to address home fire risk trends and emerging issues, provide training, resources and intervention advice, and encourage sectors to submit hazard notifications to TFS.

Home fire safety risk assessment and risk reduction training

The project offers free home fire safety training sessions to people working in the aged, disability, community, health services and social housing sectors and a Residential Hazard System Information Pack. These resources include how to

identify risks, the Clutter Image Rating Scale assessment tool, how to mitigate risks and what TFS can provide. This training promotes TFS's home fire risk mitigation referral and notification systems. The training aims to build sector capacity to reduce residential fire casualties and increase engagement and relationships with network contacts across the emergency services, health and community care sectors.

Fire Safe at Home referral program

Aged care, community health and disability services or agencies can refer clients who have no reasonable means of installing smoke alarm/s themselves to the [FireSafe@Home](#) project. Referrals for a home fire safety check are received via an online webform and must be completed by the referring agent.

Statewide Residential Hazard Notification System

The project is compiling a discreet, anonymous [Residential Hazard Notification System](#). Service providers can notify TFS about residential environments they encounter that are rated 5 or more using the Clutter Image Rating Scale. The information provided does not identify the residents. In the event of a fire or other emergency at that address, responding crews are notified that the property has safety risks to firefighters, other emergency responders and neighbouring properties. The aim of this system is to increase firefighter preparedness and reduce risks to firefighter and community members.

Research

In 2021-22, an epidemiology study by the University of Tasmania's Menzies Institute, in partnership with TFS Community Fire Safety, the Royal Hobart Hospital Burns Unit and the Tasmanian Health Service will investigate the risk profiles for residential fire injuries or fatalities and relevant health service utilisation. The research, titled *Prevalence, incidence, risk profiles, and health impacts of residential fires in Tasmania: 2010-2020*, will provide a better understanding of the impact of residential fires injuries on government services. This data will inform and influence policy and planning to mitigate risks and reduce fatalities.

Source: Tasmania Fire Service 2021

9.8 What's missing in Tasmania's program landscape?

There are clearly areas of developing good practice in the Tasmanian program landscape that have the potential to support older Tasmanians to age well at home when they are living with hoarding or CMHH. Notably, these are in areas related to property concerns and crisis intervention – TFS's fire safety project, and Housing Tasmania's condition of property assessments and tenancy supports. There are also opportunities for older Tasmanians to access case management services, particularly through My Aged Care assessments

into CHSP services and HCPs, through NDIS support coordinators and through other case management services, such as Adult and Older Person’s Mental Health Services and tenancy support programs.

However, there are **huge gaps in Tasmania’s case management and service landscape** compared to what we know works elsewhere. Significantly, Tasmania lacks (see Figure 26):

- a specialist multidisciplinary coordinating group that can also provide a central point of information and workforce development
- programs that facilitate specialist case management outside of the fee for service model with appropriate brokerage funds
- programs that facilitate investment in building trusted relationships with those living with hoarding and CMHH
- a clear response to crisis intervention across people, animal and property agencies
- a set of specialist supports to address the clinical, psychosocial and practical support needs of older Tasmanians living with hoarding or CMHH.

FIGURE 26: SUMMARY OF TASMANIAN PROGRAMS AND SERVICES AND MISSING ELEMENTS



CHAPTER TEN

What happens in Tasmania and elsewhere: the practice framework



10.1 Key messages

- The purposes of developing a shared practice framework around supporting people living with hoarding or CMHH are many, including creating a shared understanding of hoarding behaviour and CMHH, confirming a common language, systems and tools that can be utilised by services, and understanding what agencies and services are available to draw on. This creates transparency for local residents, their families and carers and the professionals supporting them.
- There are key elements in existing practice frameworks:
 - » **a shared understanding and approach to working:** what we understand about hoarding and CMHH and the shared goals, practice principles and approach professionals are using to support people, animals and property
 - » **processes and roles:** referral pathways into case coordination/management and describing the roles of local relevant services/agencies
 - » **shared assessments and tools:** assessments around client wellbeing, animal wellbeing and the severity of concern around the living environment, and guidance on approaches when working with non-voluntary clients within a framework of dignity of choice and risk
 - » **legislation and data management,** including a description of the relevant legislative frameworks, what data needs to be collected, management information systems, and frameworks around privacy and data sharing.
- Tasmania lacks most of the elements required for a comprehensive practice framework, including a shared understanding and approach to working, shared processes and roles, shared assessment tools and decision-making frameworks, and a shared understanding of legislative and data frameworks.
- TFS's *Residential Hazard System Information*, *Housing Tasmania's Guide for evaluating and responding to clutter, squalor and property damage* and the Tasmanian Department of Health's *Guide for assessing unhealthy premises* are useful frameworks within their limited scope of assessing fire risk, condition of property and environmental health issues. However, they do not offer a holistic assessment of the needs of people, animals and property.
- The lack of a multi-agency practice framework is problematic on a policy and planning level for understanding what the nature and scope of challenges are for Tasmanians and how and where to plan for support services. It presents obstacles to offering Tasmanians, their families and carers a clear and transparent approach to addressing such complex and multifaceted issues. It also means there is no common reference point for professionals.

Aged care professionals are guided to 'take the time to listen to and understand each consumer's personal experience. They need to work with consumers in an inclusive and respectful way, using a consumer-focused approach' (Royal Commission 2021). Research tells us that the reality amongst professionals working with older clients where they observe elements of self-neglect, including hoarding and CMHH, is that decisions often come down to broader factors (Woolford et al. 2017). What tends to dominate decisions is:

- the assessment of risks to others, as well as the legal boundaries of decisions
- the specific context—factors such as individual capacity to handle risks and consequences, what other supports are around the person
- transfer of risk (how much risk a professional is willing to absorb to enable a client to act in ways that are perceived as risky to themselves).

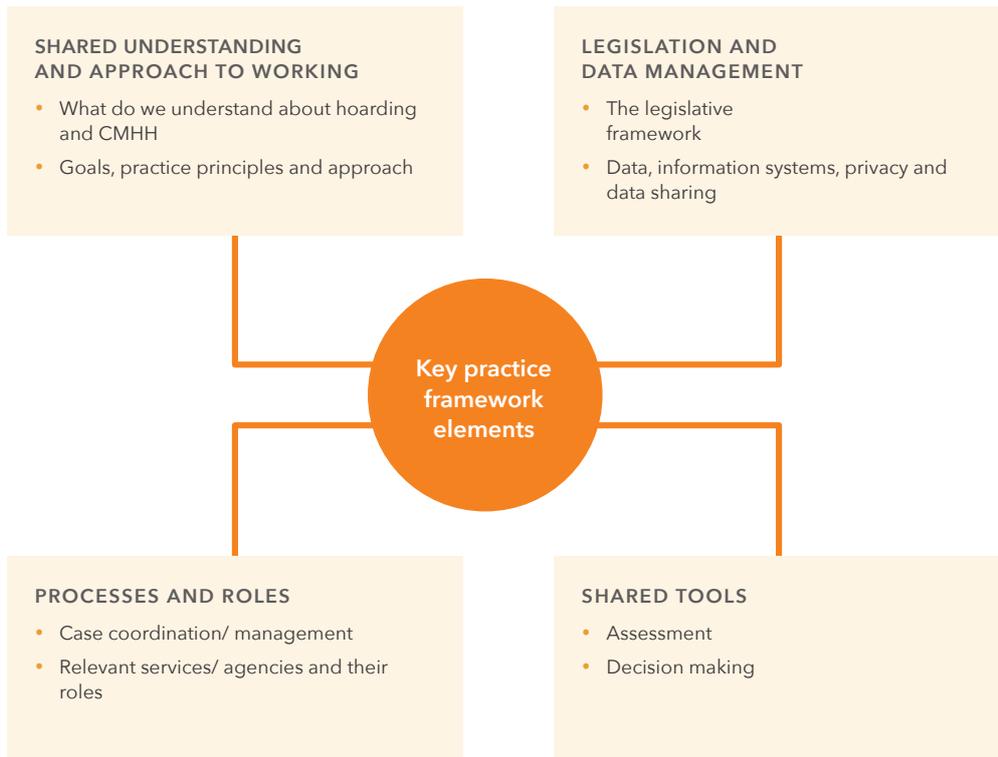
Given the complexities of such assessments, a shared practice framework is a key resource for the range of services and agencies working with clients living with hoarding and/or CMHH. The purposes of developing a shared practice framework are many, including:

- creating a shared understanding of hoarding behaviour, CMHH and the approaches needed to support people living with these challenges
- providing a structure for collaborative working
- placing the person, human dependents and animals first in a planned response, ensuring they are safe and risk is minimised
- confirming a common language, systems and tools that can be utilised by services
- presenting information about service types, what they do and how to contact them.

Perhaps the most comprehensive Australian practice framework is offered by the Victorian Department of Health (DoH [Vic] 2013) (see Case Study 16), but there are many others that cover some or all of the same content (Birmingham City Council 2021; Brent Safeguarding and Adults Board 2020; Brown & Pain 2014; DoHA [SA] 2013; Kent and Medway Safeguarding Adults 2019; NSAB 2019; Nottinghamshire County Council n. d.; Robertson 2018; Stark 2013).

There are some key elements in these existing practice frameworks (see Figure 27). These are described below.

FIGURE 27: KEY ELEMENTS IN PRACTICE FRAMEWORKS AROUND HOARDING AND CMHH



CASE STUDY 16: VICTORIAN HOARDING AND CMHH PRACTICE FRAMEWORK

LOCATION:

Victoria, Australia

DATE:

2013-present

AGENCIES:

Department of Health Victoria

TARGET GROUP:

Government-funded and private services that may become involved in responding to hoarding and CMHH situations

GOALS:

To provide direction and strengthen the capacity of non-specialist services to work together in responding to cases.

APPROACH:

The practice framework covers all stages from initial contact to long-term maintenance. It presents a planned response that covers all aspects of hoarding/ CMHH and gives services common tools and language. There is a key requirement that services and agencies coordinate their responses with a high level of communication in order to achieve lasting improvements in people’s lives.

Source: DoH (Vic.) 2012

10.2 Shared understanding and approach to working

These elements create a shared understanding of what the challenges are likely to be for people living with hoarding or CMHH and create an informed, shared approach to supporting the people, animals and property involved.

What we understand about hoarding and CMHH

This is an important part of building the shared knowledge and capacity of local workforces across disparate sectors. It usually creates a shared reference point around the nature of hoarding behaviour and CMHH and the challenges and impacts for people, animals and property/environment, similar to those described in Chapter 2. It may include any local understanding about particular demographics of concern and their specific needs – perhaps older residents, or those in insecure accommodation.

Goals, practice principles and approach to support

This places the person, human dependents and animals first in a planned response, ensuring they are safe and risk is minimised. It clarifies what agencies are aiming to achieve and how they will achieve it and it shapes a common set of practice principles across a disparate group of agencies.

GOALS

As discussed in Chapter 9, most coordinating groups and programs are brought together around focused goals. For example, the focus may be preserving tenancies and homes for all or older local residents living with hoarding or CMHH, as it has been for the City of Vancouver's HART (see Case Study 1), SAGE's This Full House in Edmonton (see Case Study 12), and the London Borough of Hammersmith and Fulham's Adult Care Team (see Case Study 6) (Brown & Pain 2014; Kysow et al. 2020; Whitfield et al. 2012). Or the goal might be maximising wellbeing or ageing well in place, for example the Brotherhood of Saint Laurence's Critical Interim Support Program (see Case Study 7) and many of the English and Welsh adult safeguarding boards (Birmingham City Council 2021; Brent Safeguarding and Adults Board 2020; Brown & Pain 2014; Kent and Medway Safeguarding Adults 2019; North Wales Safeguarding Board 2021; NSAB 2019; Nottinghamshire County Council n. d.). These goals set the focus of activities, decisions about when or how intervention is appropriate and how progress and success might be evaluated.

Practice principles

Given the pathways to services for people living with hoarding or CMHH are often not by choice, it is critical to have a shared set of principles for services around person-centred care to guide their decisions, approach and practice. These principles support the coordinating group to collectively balance consumer choice and risk with the safety of other humans, animals, the wider community and professional health and safety. They are usually framed within a consideration of clients' personal safety and that of the people

and animals who live with them and around them and the workers and carers who are supporting them. There are usually pointers to potential code violations and assessment tools to support risk analyses. It is often where the “enforcer” and “enabler” roles within any network need to work together closely and consistently.

Common areas that these cover are:

- dignity of choice and risk
- working within a harm minimisation framework
- incorporating a trauma-informed approach at every stage of assessment, investigation and support
- ensuring that support staff and peer workers are skilled and committed
- worker safeguarding and ensuring staff and peer worker mental and physical health and safety, bearing in mind that this is often emotionally and physically challenging work.

When guidance is developed in partnership with a coordinating group, this may lead to a regular assessment of workforce development needs and a provider offering regular training or updates. Pathways through the Maze offers such training (Case Study 4).

10.3 Processes and roles

This element of the guidance will focus on describing any formal working processes. There might be referral processes for organisations / the public into a program of case management and they might outline what the case coordination or management model offers. It may outline or contain any assessments and paperwork that are needed or encouraged as part of a referral.

However formal or informal local networks are, guidance will also usually provide information about the roles, responsibilities and contact details of all local services who may be able to support people living with hoarding or CMHH. This is obviously an organic element of any guidance, as new agencies and services may emerge. Given this, some guides will either have a regular review date, or provide this element online to enable updates, such as [Pathway through the Maze’s information hub](#) for New South Wales and the Government of South Australia’s guidance for environmental health officers encountering “severe domestic squalor” (see Case Study 17).

CASE STUDY 17: GOVERNMENT OF SOUTH AUSTRALIA'S 'A FOOT IN THE DOOR'**LOCATION:**

South Australia

AGENCIES

South Australia Health

TARGET GROUP:

Environmental Health Officers who may become involved in responding to hoarding and CMHH situations

GOALS:

To provide direction and strengthen the capacity of non-specialist services to work together in responding to cases of hoarding and CMHH in SA.

APPROACH:

This digital hub provides Environmental Health Officers and other interested parties with a comprehensive set of information, tools, practice approaches and service contacts. It includes policies, legislation and powers, background papers, presentations that can be used as information or for training, assessment tools, guidance on approaches to practice and links to potential partner agencies.

The policy and practice guidelines offer an extensive framework for dealing with cases of hoarding and CMHH, including the formation of interagency teams, worker health and safety, assessment tools, information sharing and use of legislative powers.

Source: DoHA (SA) 2013; SA Health 2021

10.4 Assessments and tools

This element of the guidance provides a structure for collaborative working. It also confirms a common language, set of systems and tools that can be utilised by services, even in the most informal of networks.

Having a shared understanding across such disparate professions about when to intervene and how is a critical element of any guidance, but not necessarily straightforward. As we have already discussed, supporting someone living with hoarding or CMHH is complex, sensitive and challenging. Intervening in how someone chooses to live goes against many elements inherent in professional codes and service models. It challenges concepts of care being consumer-led, and focused on dignity of risk.

Assessment tools

To support groups in making those assessments and decisions to act, there are a range of tools (see Appendix 4). Some guidance points to a range of tools for groups to draw on, such as the Victorian Government's practice framework (DoH [Vic] 2013). Others prescribe a set for the group to share.

Assessment usually involves drawing on tools that focus on two assessment subjects – individual wellbeing and environmental risk.

ENSURING THE CLIENT'S PERSONAL SAFETY AND WELLBEING.

Considerations can include:

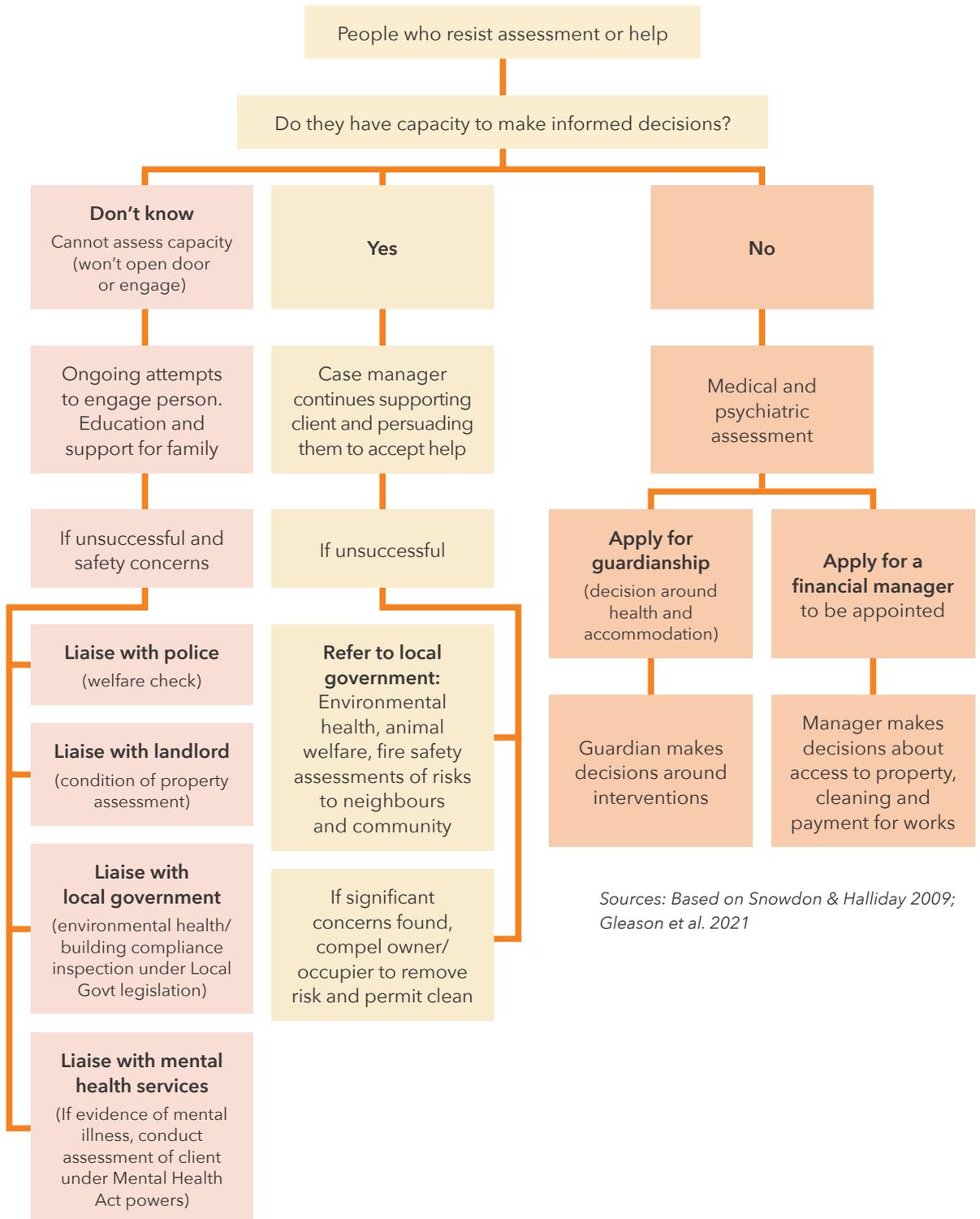
- **whether a person has the skills needed to care for themselves**, such as eating, bathing, toileting, dressing, mobility and continence, or Activities of Daily Living (ADLs)
- **scales to assess whether and to what degree an individual can be seen to exhibit hoarding disorder behaviours and their degree of insight.** Amongst these are assessments that rely on self-reporting by the person concerned, preferably in their home, such as the Saving Inventory – Revised© (Frost et al. 2004). There are also assessments that combine self-reporting via a semi-structured interview with the person concerned and a clinical assessment by the professional administering the tool. Examples include the Hoarding Rating Scale Interview (HRS-I) (Tolin, Frost et al. 2010), the Structured Interview for Hoarding Disorder © (Nordsletten et al. 2013) and the UCLA Hoarding Severity Scale (Saxena et al. 2016). It is beyond the scope of this report to assess the efficacy of these tools in assessing hoarding disorder and its impacts, but there are reported benefits of utilising a tool that combines self-reporting with a clinical assessment, as it goes beyond reliance on a person's perceptions of their challenges and the risks their environment may pose. Given we know that those living with such challenges are likely to have poor insight and under-report impacts, there have been arguments that a combined self-reporting and professional reporting tool is more reliable (Saxena et al. 2016), and these tools are usually used in combination with other assessments as described here.
- **the presence of any comorbid mental health challenges**, such as anxiety or depression. Clinical assessments may include standard clinical depression, anxiety and stress scales and psychiatric comorbidity (Pittman et al. 2020).
- **their relationship to their living environment and their awareness of any risks to their health and safety.** There are a number of assessments that service providers can use for this, including Bratiotis' Health, Obstacles, Mental Health, Endangerment, Structure and Safety Assessment (HOMES)© (Bratiotis 2011).
- **risks to their wellbeing as a result of their living circumstances**, such as the risk of homelessness due to having an unstable tenancy or a condition of property warning (Pittman et al. 2020).
- **whether the person is calling in services to meet their needs**, through assessments such as the Service Utilisation Questionnaire (SUQ) (Pittman et al. 2020). This can be particularly useful where there is a local concept of self-neglect that includes not accessing services to enhance your wellbeing.

ASSESSING THE SAFETY OF THE SITE AND THE SEVERITY OF CONCERNS AROUND HOARDING AND/OR CMHH.

The most common assessments used are the Environmental Cleanliness and Clutter Scale (ECCS) and the Clutter Image Rating (DoH [Vic] 2012). These can be administered by service providers and/or with residents. The CIR is a visual representation of the level of clutter in each room, which can be a very useful tool in assessing residents' perceptions and provide a non-judgmental common language through which to set goals for decluttering.

For coordinating groups, the critical issue is the point at which the assessments raise moderate or critical concern about the health and safety of residents, animals and community. For example, moderate concern around clutter is often agreed to be around 4 to 5, and critical concern at around 6 and above (see Case Studies 1, 15, 18).

FIGURE 28: DECISION-MAKING FLOW CHART FOR NON-VOLUNTARY PEOPLE LIVING WITH HOARDING OR CMHH



Sources: Based on Snowdon & Halliday 2009; Gleason et al. 2021

Working with non-voluntary clients

Most of the enabling and enforcing professions within the coordinating group will be used to reaching out to people who have not requested support or intervention. Having a shared approach to responding to this behaviour ensures that services have done everything they can to build trust and support individuals to address the issues of concern.

Most guidance suggests a number of pathways to consider. For example, Snowden and Halliday developed a flow chart to support professionals in their decision-making with non-voluntary people (see Figure 28). This has been taken up by the NSW government in the state practice guidance (Stark 2013).

Snowdon and Halliday (2009), and Gleason et al. (2021), outline different possible pathways, based on whether the person is known to have cognitive or decision-making challenges and whether they are refusing engagement. For those people whom professionals know to have capacity, they encourage a continued relationship-building approach. If the individual continues to refuse supports, they suggest involving the police, fire service or animal welfare services to assess whether there are any code violations with a view to action planning based on that. They suggest the lead professional continues to focus on safety issues with the aim of working towards the person accepting support with those concerns. For those people whom professionals suspect to have cognitive or decision-making challenges, where there are high health and safety risks, they suggest involving a medical or psychiatric assessment. Where individuals are known to have challenges with cognitive or decision making, the authors recommend a referral to the guardianship process (Firsten-Kaufman & Hildebrandt 2016; Gleason et al. 2021; Snowden & Halliday 2009)

10.5 Legislation and data

The legislative framework

Given how many issues hoarding and CMHH intersect with, most guidance lays out the relevant local legislative landscape. This usually includes three areas of legislation as described in Chapter 8 (RRR Consultancy 2016; Stark 2013) (see Figure 21):

- **the people.** This will cover elements such as health and wellbeing (for example, requirements under the mental health legislation, concepts of abuse, self-neglect and safeguarding, and the conditions, processes and procedures for assessing competency to make decisions and guardianship).
- **the animals.** This may cover local animal welfare and management legislation, for example limits on domestic animals, welfare standards, the powers and limits of intervention for animal welfare organisations, and registrations. Coordinating groups will usually include those agencies locally responsible for monitoring and enforcing these statutory instruments.
- **the property and environment.** This will cover issues such as public and environmental health standards and the powers and limits of statutory agencies, fire safety codes, public nuisance and leasehold conditions. Coordinating groups will usually include representatives from all the professions holding expertise in these areas.

This exercise also helps to identify any gaps in the legislative framework that might be needed to support residents, animals or community concerns around environmental health.

Data, information systems, privacy and data sharing

This element of the guidance is designed to create a shared **local** understanding of hoarding behaviour and CMHH, provides a structure for collaborative working and confirms a common information system that can be utilised by services. Having agreed protocols and systems around data, sharing data and data management is extremely beneficial for planning and evaluation, by identifying (Stark 2013):

- where clinical and other supports services are needed and planning for those supports
- the true costs of supports
- where prevention and early intervention supports may be possible to prevent severe cases from developing
- workforce development needs
- impacts or interventions and engagements.

Practice frameworks often outline the local legal and practice parameters for data sharing between services, including procedures to ensure clients' privacy, whether or how client information management systems can talk to each other and whether there is a shared information system the network can utilise. Others may include protocols on how progress and success will be measured and reported.

10.6 In Tasmania

Tasmania has no shared practice framework to guide professionals working with older Tasmanians who live with hoarding or CMHH. Where appropriate, social care professionals can draw on individual program guidelines, such as those provided by the Australian Government's aged care system, NDIS and Tas HACC, to guide assessment and decision-making. However, these are not shared across all agencies that are likely to work with a client around such challenges.

There are three specific sets of guidelines available to sections of Tasmania's support network. As described in Chapter 9.7, TFS's *Residential Hazard System Information Pack* provides guidance on assessing fire risks and provides the CIR with thresholds of concern and referral (see Case Study 15). *Housing Tasmania's Guide for evaluating and responding to clutter, squalor and property damage* supports property officers to objectively assess living environments. It also offers thresholds of concern and referral (see Case Study 18).

Tasmania's Department of Health also offers *Guidance on assessing unhealthy premises* for local government (DoH [Tas] 2015a). This provides a set of assessments and decision-making flowcharts to guide councils on assessing clutter and some elements of CMHH, such as cleanliness and mould. It should be noted that these are different assessments to those recommended by TFS and Housing Tasmania. It also offers processes and templates for councils that pursue a statutory route to solving issues with residents.

All of these guidelines are excellent. However, they do not offer a holistic assessment of the needs of people, animals and property. It is out of their scope. There is no list of relevant agencies and roles to help professionals, families and the broader public to navigate case management and service provision. This limits the momentum of the excellent work that these two agencies can undertake to achieve their goals—fire prevention and secure housing for some of Tasmania’s most vulnerable independently living residents.

The lack of a multi-agency practice framework is also problematic on a policy and planning level. There is no framework for understanding what the nature and scope of challenges are for Tasmanians and understanding how and where to plan for support services. It presents obstacles to offering Tasmanians, their families and carers a clear and transparent approach to addressing such complex and multifaceted issues. It also means there is no common reference point for professionals.

CASE STUDY 18: HOUSING TASMANIA’S CONDITION OF PROPERTY ASSESSMENT AND SUPPORT PROCESS

Housing Tasmania’s condition of property assessment and support process

GOAL:

To provide a consistent and transparent approach to assessing condition of property and assist Housing Tasmania tenants to stabilise their tenancy where it is at risk due to concerns around hoarding or CMHH.

PATHWAY:

Used internally by Housing Tasmania Property Officers. Tenants are internally referred to the Tenancy Intervention Officer by Property Officers where there are concerns to address.

APPROACH:

Condition of property assessment

Property officers use a toolkit to assess their tenants’ condition of property. This guidance has been internally developed to ensure that assessments are conducted ‘objectively’, rather than being led by property officers’ values. It assesses levels of internal and external clutter, CMHH and structural damage through the use of image ratings. These are based on the Clutter Image Rating Scale and the Environmental Cleanliness and Clutter Scale (see Appendix 4 for more details about assessment tools). Since January 2021, property officers are being trained to use this tool statewide. Social housing providers are also being introduced to this tool.

Tenancy support

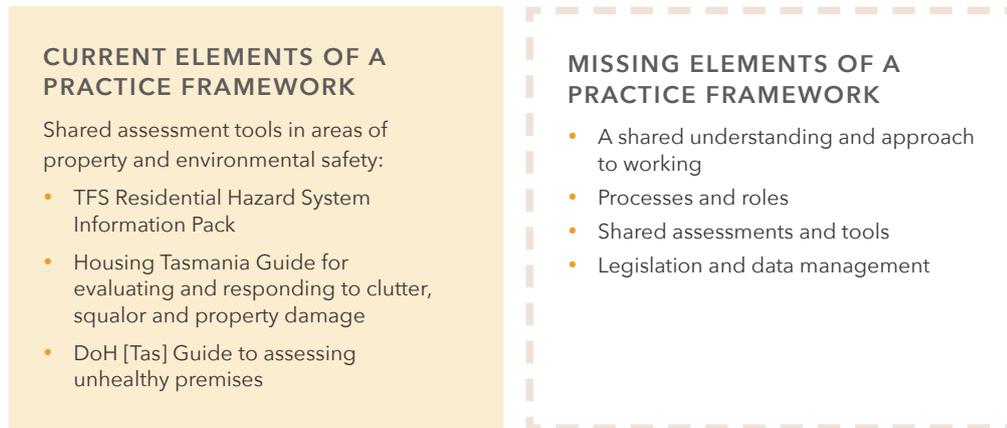
The tenancy intervention officer works with tenants over a period of time to address concerns around condition of property using a community development approach. They focus on building trust and relationship with the tenant and on building an understanding of what may have led to the current living environment. This includes building a picture of tenants' challenges with mental health, domestic circumstances and other issues that may require referrals to external support agencies. They will work with the tenant, utilising the assessment tools, to gain a shared understanding of the current condition of property and where the tenant needs to get to in order to stabilise their tenancy.

10.7 What's missing in Tasmania's practice framework?

Tasmania needs to build on the existing good practice offered within fire safety and tenancy support for residents living with hoarding or CMHH. Tasmania currently lacks most of the elements required for a comprehensive practice framework. These include (Figure 29):

- **a shared understanding and approach to working**, including a shared understanding of the nature of challenges and prevalence in Tasmania, a shared understanding of the goals services are aiming to achieve with Tasmanians living with hoarding or CMHH and the principles of practice when working with people and animals
- **shared processes and roles**, including referral pathways into specialist case management and supports and information about what services and programs are available
- **shared assessment tools and decision-making frameworks**, including common understandings of scales of concern that will trigger early intervention and crisis intervention, assessments and decision-making based on residents' contexts, level of engagement and capacity
- **a shared understanding of legislative and data frameworks**, including data sharing, systems and monitoring and reporting.

FIGURE 29: MAP OF TASMANIA'S CURRENT AND MISSING PRACTICE FRAMEWORK FOR SUPPORTING PEOPLE LIVING WITH HOARDING OR CMHH



CHAPTER ELEVEN

Recommendations



11.1 A lead state government agency

An appropriate lead state government agency should be appointed to oversee a Tasmanian policy and practice framework related to hoarding and CMHH. This agency should also oversee investments in a suite of specialist, multi-disciplinary supports and workforce development. Given the complexity and diversity of the policy, practice and services needed, the agency needs to work closely with a range of federal, state and local government stakeholders in aged care, primary healthcare, mental health, community services, housing provision and housing and homelessness services, disability support services, adult care, environmental health, building compliance, animal welfare and management, emergency management, guardianship, justice and any other government stakeholders. The agency should also work closely with those with lived experience and with the support services and statutory agencies that work with them.

11.2 A Tasmanian policy framework

Tasmania needs a **social policy framework** focused on hoarding and CMHH. The framework should include:

- **recognition of a cohort of concern with significant needs.** Similar to Victoria, New South Wales and English and Welsh local authorities, a Tasmanian policy framework needs to recognise that hoarding and CMHH is a complex community problem requiring a multidisciplinary response to care for people, animals and property/environment
- **an outline of the duties of care** for the Tasmanian state, statutory agencies and organisations to support those living with hoarding and CMHH within a framework of dignity of choice and risk. It may be useful to consider the English and Welsh responsibility to act around elder self-neglect
- **harm minimisation as the common purpose** for programs and interventions across all service types
- **an enabling statutory framework** for those living with these challenges. This should state the roles and powers of agencies with statutory responsibilities.

11.3 A Tasmanian practice framework

Tasmania needs a **practice framework** for supporting older Tasmanians living with hoarding and CMHH. This would provide Tasmanian service providers and statutory agencies with a shared resource and common approach. Elements should include:

- **a shared understanding and approach:** guidance outlining the nature of hoarding and CMHH and the approaches needed to support Tasmanians respectfully to age well at home. The guidance should also outline the policy framework described above.

- **recommended assessments, tools, thresholds and outcomes:** guidance and recommended tools to assess:
 - » health and wellbeing for consumers and the people and animals they live with
 - » health and safety and personal risks for residents, people and animals who live with them and those working with them
 - » consumers' needs and those of the people and animals they live with
 - » agreed severity thresholds for supports and intervention and risk tolerances
 - » consumer outcomes
- **data management guidance:** an agreed framework of data needs, confidentiality and sharing, so that we can understand more about the prevalence of hoarding and CMHH in Tasmania for the purposes of service planning and emergency service risk mitigation.

11.4 Regional Tasmanian collaboration and services

Tasmania needs **investment in specialist support infrastructure** to ensure that older adults living with hoarding and CMHH are enabled to age well at home, and the people and animals they live with are effectively supported. To enable effective service collaboration, there needs to be three regional Tasmanian service systems (south, north and north west) that provide:

- **multidisciplinary professional networks:** investment in the time and space for networks to meet for case planning, monitoring and reviewing, information sharing, workforce development and reviewing policy, practice and service needs. Models such as the North American hoarding taskforces should be considered
- **specialist case management services,** led by a social worker or clinical nurse practice approach. Case managers should be specially trained in supporting those living with hoarding or CMHH and able to accept referrals from a range of service providers and statutory agencies to either advise, co-manage or lead. The service needs to be focused on long-term, relationship-based support which is not time-limited
- **specialist clinical, psychosocial and practical supports** that can be accessed via the case management service or directly by other service providers. Consideration should be given to San Diego's CREST program as a model for supporting older Tasmanians living with hoarding or CMHH where there is cognitive decline. Consideration also needs to be given to how a continuum of care can be provided in relation to those who engage voluntarily, non-voluntarily, or refuse to engage
- **a clear response to critical incidents and a pathway to positive health and social care supports.** There needs to be strong referral pathways to specialist case managers and clinical, psychosocial and practical specialist supports for agencies focused on critical care, emergency response, animal welfare and management and environmental health. This would enable more older Tasmanians living with hoarding or CMHH to be engaged in long term supports that may reduce their risk of further decline and enable them to age well for longer at home

- **explore the potential of services of last resort** (similar to this model within disability services). These would be specialist clinical, psychosocial and practical services that are funded to work with Tasmanians living with hoarding or CMHH on a more temporary basis, when more mainstream consumer supports are ended due to conditions being beyond organisational risk tolerances. The aim of these supports would be to restore wellness and living environments to a threshold where other services could be recommenced
- **a workforce development plan** to ensure that Tasmania's workforce across healthcare, community development, animal welfare and management, environmental health and building compliance are able to access contemporary skills and knowledge as this emerging field of support develops
- **a digital hoarding and CMHH information hub**, similar to NSW's Pathways through the Maze. This hub could include:
 - » information about Tasmanian service providers and statutory agencies that can support those living with hoarding or CMHH, what they do and how to contact them
 - » the policy and practice frameworks outlined in the recommendations above
 - » available training and other useful documents
 - » a hub for any regional collaborative networks.

Consideration needs to be given to how recommended supports interact with existing and developing models. These include adult care (such as Tasmanian Health and Community Care), and fee-for-service, federal models such as aged care and the National Disability Insurance Scheme.

11.5 Consumer-informed

Any approach to supports need to be **tested and informed** by older Tasmanians living with hoarding or CMHH, and their families and carers.

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Appendix 1: Treasured Lives acronyms and definitions

ACAT

Aged Care Assessment Team. These are teams of medical, nursing and allied health professionals who assess the physical, psychological, medical, restorative, cultural and social needs of older Australians to help them and their carers to access appropriate levels of support for aged care.

CHSP

Commonwealth Home Support Program. This program helps older Australians with entry-level supports to live independently and stay at home. Supports may include those to keep people well and healthy, such as meals, personal care, nursing and allied health and respite care; supports to ensure their home is safe, such as domestic assistance, home maintenance and modifications equipment; supports to stay connected with community, such as transport and social support; and homelessness services for those who need it.

CMHH

Challenges maintaining a healthy home. The term used in Treasured Lives documents, fieldwork and reporting for domestic “squalor”.

Continuum of care

Also called “stepped care”, this describes a care system that encompasses different levels of support, from the least to most intensive.

COTA Tas

Council on the Ageing Tasmania. Peak body representing older Tasmanians.

DoC

Department of Communities Tasmania. This State Government department aims to create strong, active and inclusive communities. It oversees a range of strategies and services to deliver this, including housing and homelessness, disability and community support.

DoH

Department of Health (federal). It is the federal Government department that oversees aged care support.

OR

Department of Health (state). This State Government department manages government health services for the wellbeing of all Tasmanians. This includes the delivery of Ambulance Tasmania and public health services, and the planning, purchasing and performance management of key physical and mental health services delivered by other agencies, such as the THS.

DPAC

Department of Premier and Cabinet. This is the central agency for the State Government. Its services include delivering programs that improve the wellbeing of Tasmanians and leading and coordinating whole of government policies and strategies.

DSM-5

Diagnostic and Statistical Manual of Mental Disorders Five. This manual is used as a guideline to support the classification and diagnosis of mental health issues in Australia and internationally.

HACC

Home and Community Care. This program provides grant-based maintenance, support and care services for adults whose independence is at risk due to acute health events, moderate functional impairment or deterioration of an ongoing condition. The program will also support their carers. Adults are defined as people aged less than 65, or less than 50 if of Aboriginal or Torres Strait Islander heritage. It is funded through the Tasmanian Department of Health.

HCP

Home Care Package. This program helps older Australians to live independently home. It is for those who have more complex needs than those accessing CHSP. The range of supports is similar to those described for CHSP.

Hoarding

'The accumulation of a vast amount of possessions which compromises living spaces and causes impairment in social and occupational functioning' (Tolin et al. 2011, cited in Guinane et al. 2019).

Housing Connect

This service helps low-income Tasmanians to find or maintain appropriate and affordable homes either in the emergency, private, public or social housing sectors. The service also offers information, advice and referral to other agencies and financial support. They do not directly house people.

LA

Local Authority. In England and Wales a Local Authority may represent a county council, district council, unitary authority, metropolitan district or London borough. Most Local Authorities are responsible for social care and provide some aspects of transport, education and housing.

LGAT

Local Government Association of Tasmania. The peak body representing the interests of councils in Tasmania.

My Aged Care

This federal Government service is the information and assessment service to help older Australians find the right aged care support for them.

NDIS

National Disability Insurance Scheme. Provides funding for support for Australians with a permanent and significant disability who are under the age of 65.

PHT

Primary Health Tasmania is one of 31 similar organisations under the Australian Government's Primary Health Networks program. Primary Health Tasmania (Tasmania PHN) is a non-government, not-for-profit organisation working to fund initiatives that connect care and keep Tasmanians well and out of hospital.

RAS

Regional Assessment Services. They assess needs and eligibility for lower level CHSP clients.

Reablement

Reablement is one of the goals for home-based aged care. It emphasises assisting people to regain functional capacity and improve independence. Similar to rehabilitation, it is goal-oriented and aims at full recovery where possible. It seeks to enable people to live their lives to the fullest.

SARC

Social Action and Research Centre. This centre is fully funded by Anglicare Tasmania. It exists to undertake research, policy and advocacy towards achieving a just Tasmania.

Service provider

An organisation or agency providing community or health related service for children, adults and older people. They may be universal services (for example, GPs), or targeted services based on a specific need, such as mental health, disability or aged care services. The organisation may be a contracted agency of Government service delivery (such as the Tasmanian Health Service, providing statewide mental health services), a not for profit organisation from the community sector contracted to provide services to the community, such as Anglicare Tasmania or the Salvation Army providing housing and homelessness services or Home Care Packages, or a for-profit company contracted to provide services in the community and health sector, such as Oak Possability providing disability support services.

Self-neglect

Self-neglect is a behaviour described as the 'inability or refusal to attend to one's own health, hygiene, nutrition or social needs' (Abrams et al. 2002).

SHS

Specialist Homelessness Services provide more intensive help than Housing Connect for those who need it to find housing and other accommodation. They can also provide advice, advocacy and financial supports. SHS can only be accessed via Housing Connect.

Squalor

Domestic squalor is specifically describing an environment, not the people living in it. It is not a "diagnosis" but 'a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group are living in such conditions' (DoH [Vic.] 2012). Within Treasured Lives documents, fieldwork and reporting, this will be referred to as 'challenges related to maintaining a healthy home'.

Support services

Community or health related services for children, adults and older people. These include pre- and post-natal services, family support, disability services, housing and homelessness support, aged care, clinical and community-based mental health services.

TFS

Tasmanian Fire Service

THS

Tasmanian Health Service. The agency commissioned by the state Government Department of Health to deliver physical and mental health services.

Wellness

Wellness is one of the goals for home based aged care. It emphasises identifying needs, aspirations and goals. It acknowledges and builds on strengths and has a focus on integrating support services as a path to greater independence and quality of life.

Appendix 2: Phase 1 recommendations – meeting the needs of families and carers

Address stigma, raise awareness, generate respect

1. **Invest in positive community education campaigns.** Tasmania needs to foster an environment that breaks down stigma, builds understanding and respect for those living with hoarding and challenges maintaining a healthy home, and facilitates help seeking.

Develop a comprehensive framework of policies, practice and information

2. **Establish and invest in specialist regional Tasmanian taskforces that address hoarding and challenges maintaining a healthy home.** These should provide the focus for information, case management, support services and workforce development.
3. **Develop a shared practice framework for professionals who work with older people living with hoarding and/or challenges maintaining a healthy home and their families and carers.** This should include common tools for assessing and understanding needs, a shared understanding of appropriate points of intervention, and support and treatment options for people living with hoarding and/or challenges maintaining a healthy home and their families and carers.

4. **Provide an information portal with resources for families and carers to help them navigate supports for those they care for and for themselves.**

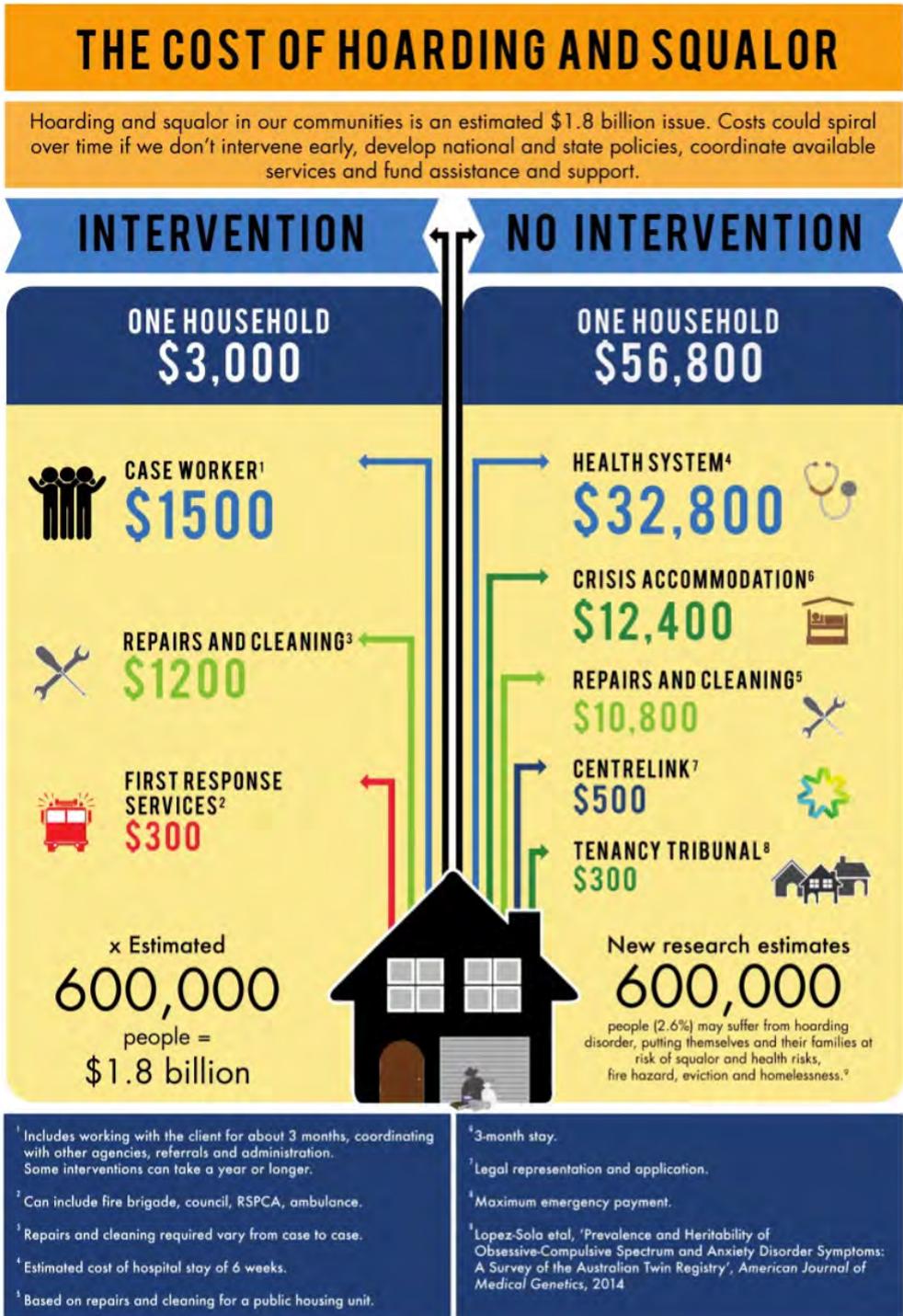
Invest in a continuum of care and support and services for families and carers

5. **Invest in a continuum of locally provided, specialist therapeutic, clinical, psychosocial and practical support services for families and carers.** This should include local online and face to face peer support for families and carers, specialist counselling support services, and specialist information, training and programs to enhance families' and carers' awareness and skills to support those they care for to age well at home.
6. **Within existing models of federal and state-based community supports, develop pathways to specialist advice for families and carers to support them in assisting those they care for to age well at home.** This should include consideration of how the reformed model of aged care gateway services, NDIS Local Area Coordinators and assessments for Home and Community Care can incorporate specialist information and advice services for consumers and their families.

Build our understanding of the continuum of care and supports needed for older Tasmanians living with hoarding and/or challenges maintaining a healthy home to age well at home

- 7. Undertake consumer-led design of the continuum of care and specialist support services for older Tasmanians living with hoarding and/or challenges maintaining a healthy home.**
- 8. Consider the opportunities offered by 'conversation gateways' to maximise help seeking amongst older Tasmanians living with hoarding and/or challenges maintaining a healthy home.** This includes primary healthcare such as GPs, hospitals and other healthcare services, animal welfare, and tenancy managers.

Appendix 3: Estimated costs to the Australian economy of supporting hoarding



Source: Catholic Community Services 2014

Appendix 4: Assessment tools for personal wellbeing, severity of hoarding and CMHH and code violations

Client wellbeing in the home

Self-report:

- Activities of Daily Living in Hoarding Scale (ADL-H) (Frost et al. 2013)
- The Hoarding Rating Scale (HRS-I) (Tolin, Frost et al. 2010)
- Compulsive Acquisition Scale (CAS) (Frost et al. 2002)
- Savings Cognition Inventory (SCI) (Steketee et al. 2003)
- Saving Inventory Revised (SIR) © (Frost et al. 2004)

Self-report and clinical assessment:

- Hoarding Rating Scale Interview (HRS-I) (Tolin, Frost et al. 2010)
- UCLA Hoarding Severity Scale (HSS) (Saxena et al. 2015)
- Montreal Cognitive Assessment Basic © (MOCA-B) (Julayanont et al. 2015)
- Structured Interview for Hoarding Disorder (SIHD) (Nordsletten et al. 2013)
- Depression Anxiety Stress Scales (DASS) (Lovibond & Lovibond 1995)
- Personal Wellbeing Index - Intellectual Disability (PWI-ID) (Cummins & Lau 2005)
- Mini International Neuropsychiatric Interview (Sheehan et al. 1998) for psychiatric co-morbidities

Service provider assessment:

- Health, Obstacles, Mental Health, Endangerment, Structure and Safety (HOMES)© (Bratiotis et al. 2011)
- Hoarding and Squalor Program Screening Tool (CCS 2021)
- Homelessness risk assessment as required

Animal welfare

- Tufts Animal Care and Condition (TACC) (Patronek 1997)

Environmental assessments

Service provider assessment:

- Environmental Cleanliness and Clutter Scale (ECCS) (Halliday & Snowdon 2009)
- Clutter Image Rating Scale (CIR) (Frost et al. 2008)

Appendix 5: Resources in Australia and internationally

This is a **selected** list of resources that may be useful for those living with hoarding, families and carers of those living with hoarding and/or maintaining a healthy home (CMHH) and those working with these two groups.

It is not a comprehensive list. It has been compiled by the Treasured Lives project team based on the following criteria:

The resource/program:

- offers a responsible coverage of the context for hoarding and/or CMHH, based on an understanding of both aetiology and impacts;
- explains the approaches to support within that context; and/or
- raises awareness and positive engagement about hoarding and/or CMHH.

We may add to this list as the project progresses. We would welcome feedback on the usefulness of this list, on the usefulness of resources within this list and any additional resources and programs that readers experience.

Please send feedback to:

- Lindsey Fidler:
lindseyf@anglicare-tas.org.au
- Selina Claxton:
s.claxton@anglicare-tas.org.au

Digital resources

[r/hoarding](#)

Target group: People living with hoarding, families and carers, service providers

Run by: Hosted by large social media platform Reddit, run by volunteer moderators. 34,000 registered members.

Description: Public discussion forum offering advice and support. Has a wiki with comprehensive info and resources.

[International OCD Foundation](#)

Target group: People living with hoarding, families and carers, service providers

Run by: Non-profit promoting awareness and providing resources and support for people affected by Obsessive Compulsive Disorder.

Description: Website with information and resource directory.

[Maroondah Hoarding and Squalor Network](#)

Target group: People living with hoarding, families and carers, service providers

Run by: Forum for agencies and community groups in the City of Maroondah, Victoria, Australia.

Description: Excellent introductory articles. Comprehensive resource guide for Maroondah locals and others

[Pathways through the maze](#)

Target group: People living with hoarding, families and carers, service providers

Run by: Catholic Community Services, New South Wales, Australia

Description: Basic information, resources and training

[Hoarding Disorders UK](#)

Target group: People living with hoarding, families and carers, service providers

Run by: Hoarding Disorders UK

Description: Resources and information for people affected by hoarding.

[Children of Hoarders](#)

Target group: Families and carers

Run by: Volunteer grassroots U.S. non-profit

Description: Biggest and best known online support for family members of hoarders. Resources, information and support.

Audio visual resources

[Hoarding Disorder playlist](#)

Target group: People living with hoarding, families and carers, service providers

Author: International OCD Foundation

Description: A Youtube playlist of short (2-3 minute) videos explaining hoarding disorder

[Clutter Chronicles](#)

Target group: People living with hoarding, families and carers, service providers

Author: Lori Koppelman

Description: Free podcast. An ongoing conversation with Mary, who calls herself a recovering hoarder.

[The Hoarding Solution Podcast](#)

Target group: People living with hoarding, families and carers, service providers

Author: Tammi Moses

Description: Free podcast. An exploration of how we as a community can approach this issue with compassion, kindness & awareness.

[Helping hoarders let go](#)

Target group: People living with hoarding, families and carers, service providers

Author: ABC Radio

Description: Archived radio broadcast. An interview with Jessica Grisham, a clinical and research psychologist at the University of NSW.

[The psychology of hoarding](#)

Target group: People living with hoarding, families and carers, service providers

Author: ABC Radio

Description: Archived radio broadcast. Interviews with Professor Randy Frost (co-author of *Buried in Treasures*), a support worker, and two people who hoard

Books

[Buried in Treasures](#)

Target group: People living with hoarding, families and carers, service providers

Date: (2nd ed. 2013)

Author: David Tolin, Randy Frost and Gail Steketee

Description: Self-help treatment program

Stuff: Compulsive hoarding and the meaning of things

Target group: People living with hoarding, families and carers, service providers

Date: 2010

Author: Randy Frost and Gail Steketee

Description: Case studies and exploration of the psychology of hoarding

Digging Out: Helping your loved one manage clutter, hoarding and compulsive acquiring

Target group: Families and carers

Date: 2009

Author: Michael Tompkins and Tamara Hartl

Description: Practical advice focusing on harm reduction and salvaging relationships

Children of Hoarders: How to minimize conflict, reduce the clutter, and improve your relationship

Target group: Families and carers

Date: 2013

Author: Fugen Neziroglu and Katharine Donnelly

Description: Aimed at helping adult children of hoarders manage their own emotions. Uses Cognitive Behavioural Therapy, mindfulness etc.

Understanding hoarding: Reclaim your space and your life

Target group: People living with hoarding

Date: 2021

Author: Jo Cooke

Description: An explanation of what hoarding is and an 8-step plan with practical steps to tackle the problem

Overcoming hoarding: A self-help guide using cognitive behavioural techniques

Target group: People living with hoarding

Date: 2016

Author: Satwant Singh, Margaret Hooper and Colin Jones

Description: Offers support, guidance and Cognitive Behavioural Therapy activities to help overcome hoarding

Reclaim your life from hoarding

Target group: People living with hoarding

Date: 2020

Author: Eileen Dacey

Description: Workbook with case studies, self-care strategies and an action plan

Dirty Secret: A daughter comes clean about her mother's compulsive hoarding

Target group: People living with hoarding, families and carers, service providers

Date: 2011

Author: Jessie Scholl

Description: Memoir of the daughter of a parent living with hoarding behaviour

Coming Clean

Target group: People living with hoarding, families and carers, service providers

Date: 2014

Author: Kimberley Rae Miller

Description: Memoir of the daughter of a parent living with hoarding behaviour

White Walls: A memoir about motherhood, daughterhood and the mess in between

Target group: People living with hoarding, families and carers, service providers

Date: 2016

Author: Judy Batalion

Description: Memoir of the daughter of a parent living with hoarding behaviour

Lessons in letting go: Confessions of a hoarder

Target group: People living with hoarding, families and carers, service providers

Date: 2010

Author: Corinne Grant

Description: Memoir by an Australian living with hoarding behaviour

Mess: One man's struggle to clean up his house and his act

Target group: People living with hoarding, families and carers, service providers

Date: 2015

Author: Barry Yourgrau

Description: Memoir and exploration of hoarding by a person living with hoarding behaviour

Training

Hoarding Home Solutions Family & Friends

Target group: Families and carers

Run by: Hoarding Home Solutions

Description: Online. Workbooks, video lessons, real life stories and resources and tools. 12 x 1-hour sessions. Fee to be paid

Understanding and treating hoarding disorder

Target group: Families and carers, service providers

Run by: University of Sydney

Description: Online; one 8-hour session. Covers etiology, assessment and therapy (Cognitive Behavioural Therapy). Fee to be paid

Virtual Hoarding Awareness Training

Target group: Families and carers, service providers

Run by: Hoarding Disorders UK

Description: Online. 4.5 hours over one day. Covers understanding hoarding, how to help and further knowledge. An advanced course is also available. Fee to be paid

Helping People Who Hoard: Alternatives to nagging, pleading, and threatening

Target group: Families and carers

Run by: Michael Tompkins via IOCDF

Description: Free 44-minute Youtube video. Covers dealing with people who refuse help and repairing damaged relationships.

Family as Motivators

Target group: Families and carers

Run by: Lifeline Victoria

Description: One 2-hour session per week for 10 weeks. 'How to encourage a person with hoarding disorder to seek help and look after your own wellbeing.' Free via GP referral

[Hoarding and squalor training in effective service responses](#)

Target group: Families and carers, service providers

Run by: Catholic Community Services

Description: Full day workshop. Unclear whether online or in person. Half day introductory workshop also available. Cost unclear.

[Understanding animal hoarding](#)

Target group: Families and carers, service providers

Run by: Animal Courses Direct

Description: Online. Study time 10 hours. Fee to be paid

[How to help someone who hoards](#)

Target group: Families and carers, service providers

Run by: Hoarding Home Solutions

Description: Free online. 40 minute video.

Support groups

[Hoarding and clutter support group](#)

Target group: People living with hoarding, families and carers, service providers

Platform: Zoom

Run by: ARC Victoria

Description: Free peer-led mutual self-help support group.

[Virtual Buried in Treasures](#)

Target group: Families and carers

Platform: Zoom

Run by: Mutual Support Consulting

Description: Paid, facilitated series of workshops based on *Buried in Treasures*. Must have a copy of the book.

[Online Hoarding Support Groups](#)

Target group: People living with hoarding

Platform: Chat

Run by: Steri-Clean

Description: One group includes professionals, the other is peer only

[Clutterers Anonymous virtual meetings](#)

Target group: People living with hoarding

Platform: Phone and Zoom

Run by: Clutterers Anonymous

Description: Virtual meetings following the Alcoholics Anonymous methods and traditions

[Hoarding/Cluttering Support Group](#)

Target group: People living with hoarding

Platform: Private Facebook group

Run by: Volunteer members

Description: Emotional, educational and psychological support, and a resource for understanding hoarding and cluttering

[The Clutter Movement Individual Support](#)

Target group: People living with hoarding

Platform: Private Facebook group

Run by: Unknown

Description: A peer community working together to share knowledge, experience, and ideas to affect sustainable change amongst themselves.

[Adult Children of Hoarders](#)

Target group: Families and carers

Platform: Private Facebook group

Run by: Volunteer members

Description: 'A place to get support, share experiences and feelings, and sometimes laugh at the absurdity of it all - without judgment'

[Family and Friends of Hoarders Support Group](#)

Target group: Families and carers

Platform: Private Facebook group

Run by: Volunteer members

Description: 'A safe place to be able to let out the frustration of living with a hoarder.'

[MYCOHP](#)

Target group: Families and carers

Platform: Groups.io

Run by: Volunteers

Description: 'A safe, understanding, peer support group for minors and youth living in hoards.'

[Children of Hoarders](#)

Target group: Families and carers

Platform: Groups.io

Run by: Volunteer members

Description: Peer support and information sharing.

[r/hoarding](#)

Target group: People living with hoarding, families and carers, service providers

Platform: Reddit

Run by: Volunteer members

Description: Public discussion forum offering advice and support.

[r/ChildofHoarder](#)

Target group: Families and carers

Platform: Reddit

Run by: Volunteers

Description: Public discussion forum offering advice and support.

[Arafmi Carer Support Group](#)

Target group: Families and carers

Platform: Zoom

Run by: Arafmi

Description: A wider support group of families and carers to talk about their feelings, explore alternative ways of coping, offer mutual support, or listen and observe.

[Safe Spaces](#)

Target group: Families and carers

Platform: Face to face and Zoom

Run by: [Mental Health Families and Friends Tasmania](#)

Description: A wider support group of Tasmanian families and carers to share experiences with others who understand.

Australian professional support services

[Fiona Mason – Ace of Space](#)

0437 772 097

Target group: People living with hoarding

Location: Hobart

Service: Professional organiser

About: Works with people wanting to declutter or downsize, and also works with NDIS and My Aged Care participants. Has training in hoarding.

[Dr Bethany Lusk – Archer Street Health](#)

0361 242 222

Target group: People living with hoarding

Location: Hobart

Service: Clinical psychologist

About: Has an interest in working with clients experiencing hoarding problems and has completed training

Dr Jan Eppingstall – Stuffology

Target group: People living with hoarding

Location: Melbourne

Service: Psychologist

About: Hoarding specialist offering therapy over Zoom as well as in-person

Julie Jensen – Changes in Between

0411 241 005

Target group: People living with hoarding

Location: Melbourne

Service: Counsellor

About: Primarily a grief counsellor with training and interest in hoarding. Offers phone and Zoom therapy as well as in person

George Turnure

0413 674 328

Target group: People living with hoarding

Location: Sydney

Service: Clinical Psychologist

About: Works frequently with hoarding and offers multiple telehealth options

