Anglicare Tasmania’s submission to the Royal Commission into Aged Care Quality and Safety:

Public hearing into accommodation held in Sydney 13th and 14th August 2020

Ageing in place for older Australians living with hoarding and challenges maintaining a healthy home

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# Introduction to Anglicare Tasmania

Anglicare Tasmania is a large community service organisation in Tasmania with offices in Hobart, Glenorchy, Launceston, St Helens, Devonport, Burnie, Sorell and Zeehan and a range of programs in rural areas. Anglicare Tasmania’s services include crisis, short-term and long-term accommodation support; NDIS disability and mental health support services; support services following a motor vehicle accident; aged and home care services; alcohol and other drug services; financial and gambling counselling; and family support. In addition, Anglicare Tasmania’s Social Action and Research Centre conducts research, policy and advocacy work with a focus on issues affecting Tasmanians on low incomes.

Anglicare Tasmania is committed to achieving social justice for all Tasmanians. It is our mission to speak out against poverty and injustice and offer decision-makers alternative solutions to help build a more just society. We provide opportunities for people in need to reach their full potential through our services, research and advocacy.

Anglicare Tasmania’s work is guided by a set of values which includes these beliefs:

* that each person is valuable and deserves to be treated with respect and dignity;
* that each person has the capacity to make and to bear the responsibility for choices and decisions about their life;
* that support should be available to all who need it; and
* that every person can live life abundantly.

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# Anglicare Tasmania’s experience in aged care and social research

Anglicare Tasmania provides a range of accommodation and personal support services to enhance the wellness and reablement of older Tasmanians, with the aim of supporting them to age well at home.

#### Aged care

Anglicare Tasmania delivers a range of aged care funded services

* Commonwealth Home Support Program (CHSP)
* Home Care Package Program (HCP)
* Veterans Home Care (VHC)

Anglicare has a state-wide Clinical Team who provide services including care planning, dementia care, palliative care, dressings and wound care, medication and pain management, chronic disease and diabetes management, continence support, nutritional support and dietary advice.

Anglicare also delivers self-funded home care services.

Anglicare provided services to 1,700 aged care clients last financial year.

#### Home and Community Care (HACC)

Anglicare Tasmania provides HACC services for approximately 400 people under 65 years of age, who require assistance to manage activities of daily living. Services include personal care, shopping, medication administration, domestic assistance, meal preparation, social support and respite.

Anglicare also provides services to a growing number of clients who are at risk of needing residential care or at risk of losing their tenancy due to clutter in their home.

#### About the Social Action and Research Centre (SARC)

Anglicare Tasmania’s Social Action and Research Centre conducts research, policy and advocacy work with a focus on issues affecting Tasmanians on low incomes.

SARC’s research agenda evolves from discussions with low income Tasmanians, clinical and community services working with them and the government agencies that design the policy and program environments that support them. Conversations with stakeholders indicate that older Tasmanians living with hoarding and/or challenges related to maintaining a healthy home[[1]](#footnote-2) are a cohort whose accommodation, health and personal support needs require attention and review.[[2]](#footnote-3)

There is presently limited research available to inform how to effectively support older Australians and their families and carers living with hoarding and/or maintaining a healthy home, despite analysis highlighting that ‘late life hoarding is a serious psychiatric and community problem that warrants considerable attention’ (C. Ayers, cited in Dept. of Health [Vic.] 2012). If accommodation, health and practical support needs are left unaddressed, or inadequately addressed, this can contribute to older Australians’ deteriorating mental and physical health, increased social isolation and ultimately lead to premature entry into residential aged care or death. (Clark et al. 1975 cited in Guinane et al. 2019; Visvanathan et al. 2019)

Previous research and advocacy by Anglicare Tasmania has highlighted the need to consider accommodation, care and support needs as a holistic support response for a number of particular cohorts of vulnerable Tasmanians, including unaccompanied homeless children (Robinson 2017a and b) and the support and accommodation needs of families involved in the child safety system (Hinton 2013, 2018, 2020; Fidler 2018).

Research now underway, *Treasured Lives: enabling older Tasmanians living with challenges related to hoarding and/or maintaining a healthy home to age well at home*, aims to inform the development of a policy, programs and practice framework to respond to the needs of older Tasmanians, their families and their carers.

## What will *Treasured Lives* tell us about approaches to innovative aged care?

### Why look at innovative aged care in Tasmania?

Tasmania has a clear incentive to lead thinking about how to age well. Tasmania has the highest proportion of any of Australia’s state and territory populations 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; over 40% in four Local Government Areas. (COTA Tas 2018).

Tasmania is well placed to lead innovations that both prevent people who are nearing retirement age with acute challenges to wellness and reablement from entering aged care, and support those already eligible for aged care to age well at home. As the COTA Tasmanian CEO has highlighted, ‘Tasmania could be the experts for age-friendly planning, if it grabs the opportunity with two hands’ (COTA Tas 2018).

There is limited research to inform how to effectively support older Australians and their families and carers living with hoarding and/or maintaining a healthy home, despite analysis highlighting that ‘*late life hoarding is a serious psychiatric and community problem that warrants considerable attention*’ (C. Ayers, cited in Dept. of Health [Vic.] 2012). It has been speculated that hoarding and dementia are the only two psychiatric disorders that increase in severity and prevalence during a person’s life-course (Dept. of Health [Vic.] 2012).

Tasmania lags behind most other Australian jurisdictions in its strategic response to hoarding and challenges related to maintaining a healthy home across household types. In contrast to other states, such as Victoria, New South Wales and South Australia (Dept. of Health [Vic.] 2012, 2013; Stark 2013; Dept. of Health & Ageing [SA] 2013), Tasmania does not currently have the appropriate social policy, program and practice settings to facilitate this challenging work. So, whilst in some states, there may be progress towards supporting this vulnerable cohort to age well in place, we do not have a national picture of this.

Tasmania currently has few options to holistically address the complex needs of this cohort: the underlying causes (trauma, depression, possibly OCD-related disorders, depression, anxiety); the hoarding behavior itself and its impacts (social isolation, health and safety issues for clients, families, carers and for workers; threatened tenancies, financial vulnerability, self-neglect); and potentially, any comorbid challenges, such as drug and/or alcohol use (H&SWG 2017). There are no specialist services who specifically work with Tasmanians who have issues around hoarding/maintaining a healthy home.

Furthermore, challenges with hoarding and maintaining a healthy home often remain ‘hidden’. Challenges are often ‘uncovered’ by a concern raised by someone else later in life (Roane et al. 2017), for example a public health concern, or a tenancy risk. The incidental and sometimes reluctant pathways to support services leads to difficulties in understanding the prevalence, as well as the nature of hoarding and challenges related to maintaining a healthy home in Tasmania. This is problematic for designing appropriate local service responses. Commanding effective multi-agency responses is particularly a challenge for older Tasmanians, their families and carers within such a small state. Consumer-driven aged care and disability support industries are often operating in thin markets. Layer this challenge with consumers who may have critical tenancy and/or public health needs in order to prevent early entry into residential care, and the need for a locally designed, innovative framework of support is clear.

### About *Treasured Lives*

*Treasured Lives* will be the first in-depth project able to inform a Tasmanian-specific framework to address challenges with hoarding and maintaining a healthy home. The research will investigate what information exists about the prevalence amongst older Tasmanians.[[3]](#footnote-4) It will also explore the experiences of people living with hoarding and / or challenges maintaining a healthy home and their families and carers. It will investigate 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. The project will also scan good practice across other jurisdictions and internationally.

Grounded in this analysis, and drawing on the feedback of the project’s reference group,[[4]](#footnote-5) the report will provide a set of recommendations on policy, programs and practice to support older Tasmanians to age well in place, when they are living with these challenges. The report is due for release in March 2021.

*Treasured Lives* will establish a body of knowledge to inform the deliberations of the Royal Commission on the future of ageing in place within a framework of wellness and reablement. This will include consideration of how current initiatives within My Aged Care, such as CHSP’s Assistance with Care and Housing (ACH) services, home support packages and HCPs could be more clearly directed to meet the needs of this cohort, their families and their carers. It will also make recommendations about innovations in accommodation, health and personal supports to provide a holistic response to some of the most vulnerable older Australians.

### Key messages

Given the project has recently commenced, this submission provides the Royal Commission with some of the key messages emerging from our initial consultations and from an initial scan of literature. In summary, those key messages are:

#### Prevalence and diagnosis

There is little information about the age profile of older Australians living with hoarding and/or challenges related to maintaining a healthy home. Exploring how to develop an information system to inform the prevalence and nature of accommodation, health and personal support needs would be a powerful step forward in shaping effective supports that enable older Australians to age well in place.

It is crucial that we understand the underlying aetiology and nature of challenges for this cohort. This includes understanding how hoarding and challenges maintaining a healthy home interact with other progressive conditions like dementia. Gaining such insight would enable an informed approach to designing innovative and appropriate accommodation, health and personal supports for older Australians living with such complex progressive conditions.

#### Understanding impacts

Understanding the impacts on those living with challenges related to hoarding and maintaining a healthy home, their families and carers and service providers is crucial for designing a holistic response to supporting this cohort of older Australians to age well in place.

#### Pathways to support, interagency collaboration, tiers of support

As the pathway to support is often non-consensual or incidental, there needs to be careful consideration of how to ensure this cohort can age in place within a clear practice framework for My Aged Care services which balances choice and dignity with personal safety.

Effective support is likely to require an interagency case management response, beyond the boundaries of My Aged Care, across accommodation, health and practical supports.

At a local level, consideration needs to be given to tiered support for older Australians living with challenges related to maintaining a healthy home, and for their families and carers. This tiered support needs to consider how to prevent older Australians entering aged care with unsupported challenges. It also needs to consider a spectrum of preventative to critical care needed through CHSP’s ACH services, together with clinical, community and practical supports.

### More information

*Treasured Lives* has been approved by the University of Tasmania’s Social Sciences Human Research Ethics Committee. Project ID 18686. Research Integrity and Ethics Unit: [ss.ethics@utas.edu.au](mailto:ss.ethics@utas.edu.au) | Phone: (03) 6226 2975.

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## What is special about the needs of older Australians living with hoarding and challenges maintaining a healthy home?

### Definitions and diagnoses

#### Older Australians with hoarding disorder

Hoarding 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 (Dept. of Health [Vic.] 2012; Stark 2013).

Animal hoarding is identified as a specific area of challenge. This is defined as an accumulation of large numbers of animals that overwhelms a person’s ability to provide a minimum standard of nutrition, sanitation and veterinary care (Dept. of Health [Vic.] 2013). Such behavior requires specialist support (Castrodale et al. 2010; Lockwood 2018).

Australia currently has no comprehensive data on the age profile of hoarders in Australia. 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).

Supporting people living with hoarding is a developing area of research and practice in Australia. There are a few local studies and some international work that can help inform diagnosis and shape general approaches to supporting those living with hoarding.

There can often be a hereditary link to hoarding behaviour. Up to 85% of people with hoarding behaviours can identify another family member who displays similar behaviour (Dept. of Health [Vic] 2013).

Since 2013, hoarding has been classified as a standalone psychiatric disorder in the Diagnostic and Statistical Manual of Mental Disorders Five (DSM-5). It is understood to be associated with four underlying characteristics: emotional dysregulation, difficulties processing information, intense emotional attachment, and fixed beliefs about not wanting to waste objects (Stark 2013). Studies also suggest that there may be strong hereditary factors (Mathews et al. 2007, cited in Dept. of Health [Vic.] 2013; Grisham & Norberg 2012, cited in Stark 2013).

People living with hoarding disorder commonly (but do not always) have comorbid mental ill health, particularly depression and/or anxiety (Frost et al. 2011, cited in Ayers 2013; Frost 2000; Guinane et al. 2019; Roane et al. 2017), a history of trauma (Brown & Pain 2014; 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; Roane et al. 2017). 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). Hoarding behavior occurs irrespective of a person’s financial means and their ‘standing’ in a community, but people living with hoarding are often socially isolated (Roane et al. 2017).

#### Older Australians living with challenges related to maintaining a healthy home

‘Challenges related to 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 (Dept. of Health [Vic.] 2013).

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’ (Dept. of Health [Vic.] 2012). Similar to hoarding, the risks to health, safety and functioning tend to accumulate with a person’s age.

Such living conditions often present as a secondary condition to a range of medical and psychiatric conditions. There is a strong association with impaired frontal executive function (Lee at el 2017). 72.3 years is the mean age of diagnosis (Lee et al 2017 cited in Guinane et al 2019).

#### The relationship between hoarding and challenges related to maintaining a healthy home as people age

Although these living conditions are often considered together, they do not always go hand in hand.

Studies have shown that between 20% and 60% of people who live with challenges maintaining a healthy home also have challenges with hoarding behaviour (Snowden and Halliday 2011 cited in Lee et al. 2017). For some, prolonged or extreme hoarding may lead to challenges related to maintaining a healthy home. Those whose living environment has deteriorated into challenges related to maintaining a healthy home tend to present for support at an older age (the mean age being 76), often due to the loss of a domestic partner, onset of frailty or neurocognitive disorders (Lee et al. 2017, cited in Guinane et al 2019).

But it is important to note that there are many people who live with challenges related to maintaining a healthy home but do not hoard (Lee et al. 2017, cited in Guinane et al. 2019). Profile analysis of those living with challenges related to maintaining a healthy home 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 just presented with challenges related to maintaining a healthy home (Lee et. al. 2017 p.1435).

Understanding this distinction is important in shaping appropriate clinical and community-based supports that may complement practical supports available for older Australians within their living environments, as is understanding the relationship and trajectory between these two challenges as people age (Guinane et al 2019; Lee et al 2017).

### Prevalence

Given the hidden nature of much hoarding and challenges related to maintaining a healthy home, there is no consistent data collection across Australian jurisdictions to currently inform us about prevalence.

US research has shown that hoarding in those aged between 35 and 94 years was 6.2% (Samuels et al 2008 in Roane et al 2017). It is estimated that 2% to 6% of the Australian population is affected by hoarding or challenges related to maintaining a healthy home (ANU 2016). Other research has suggested that 1 in 1000 older people live in environments that would be considered as needing intervention (Snowden and Halliday 2011, Snowden et al 2012, cited in Lee et al 2017).

There is some information from assessment agencies and service providers about prevalence within their caseloads. Fire service data shows that 25% of deaths from fires in homes occur in the homes of people living with hoarding challenges (ANU 2016). However, 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 maintaining a healthy home. 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) (see section 3.a).

Of those, just over half had challenges with both hoarding and maintaining a healthy home, just over a quarter needed support with hoarding only and the remaining 18% with maintaining a healthy home only (Guinane et al. 2019). This would indicate that challenges were not widespread. However, it does not tell us about the prevalence amongst older Melbournians who had not accessed aged care services. As we explore below, it is typical for this cohort to resist support.

The Hoarding and Squalor Working Group (Northern Tasmania) (H&SWG) provided a snapshot of the extent to which hoarding and challenges related to maintaining a healthy home 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 challenges related to maintaining a healthy home (H&SWG 2017). This survey did not ask for the age of people receiving supports.

Anglicare’s current research project, *Treasured Lives*, will explore what data is collected across a selection of Tasmania’s information systems. The project will also draw on practice in other jurisdictions and internationally, to consider what data needs to be collected and shared across services that support older Tasmanians to age well in place.

#### Key messages: prevalence and diagnoses

There is little information about the age profile of older Australians living with hoarding and/or challenges related to maintaining a healthy home. Exploring how to develop an information system to inform the prevalence and nature of accommodation, health and personal support needs would be a powerful step forward in shaping effective supports that enable older Australians to age well in place.

It is crucial that we understand the underlying aetiology and nature of challenges for this cohort. This includes understanding how hoarding and challenges maintaining a healthy home interact with other progressive conditions like dementia. Gaining such insight would enable an informed approach to designing innovative and appropriate accommodation, health and personal supports for older Australians living with such complex progressive conditions.

### Impacts on older Australians and their families and carers

Research indicates that challenges with hoarding and/or maintaining a healthy home may significantly impact on older Australians’ pathways to wellness and reablement in place. As well as personal risks, there may be safety and public health risks for themselves, their families and carers.

#### Older Australians

Given that people living with hoarding are often socially isolated and living with mental health challenges and/or executive dysfunction (Ayres et al 2010; Dept. of Health [Vic.] 2013; Roane et al. 2017; Tolin et al 2010), and that hoarding and/or challenges related to maintaining a healthy home often progress with age, 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; Steketee et al 2012; Tolin et al 2010).

Older Australians living with hoarding and challenges related to maintaining a healthy home 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; Steketee et al 2012; Tolin et al 2010). Such living environments present enhanced risks to the 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 el al 2000; Tolin et al 2010, 2008); there is often limited access to properties in the case of fire or when responding to a critical health incident (Bratiotis 2012; Dept. of Health [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).

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 risks of losing tenancies, structurally unsafe dwellings or eviction through public health concerns, leading to long term homelessness, or, premature entry into residential aged care (Visvanathan et al. 2019).

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) (Dept. of Health [Vic] 2013; H&SWG 2017; Tolin et al 2014).

#### Families and carers

Families and carers of those who live with hoarding and/or challenges related to maintaining a healthy home report a number of impacts on their own lives (Wilbram, Kellett & Beail 2008). These include their struggles to effectively support the person they care for to manage their living environment and their health, their difficulties understanding what’s happening for the person they care for and how to approach challenges, strains on their relationships and social connectivity, and their own marginalization due to associated stigma (Buscher et al 2014; Tolin et al 2008; Tompkins 2011; Wilbram et al 2008).

Although these impacts on people, their families and carers are generally accepted in the international research literature and are a useful starting point for designing tailored policy and service responses; Australian-specific insights are sparse.

Anglicare Tasmania’s Treasured Lives research project will explore the experiences and impacts of hoarding and/or challenges related to maintaining a healthy home on older Tasmanians, their families and carers. This will support a Tasmanian-specific response to designing an effective framework of policies, programs and practice.

#### Key messages: understanding impacts

Understanding the impacts on those living with challenges related to hoarding and maintaining a healthy home, their families and carers and service providers is crucial for designing a holistic response to supporting this cohort of older Australians to age well in place.

## Designing innovative supports for this cohort

The Commonwealth Government’s home-based aged care programs encourage service providers to work within an approach that promotes *wellness* and *reablement* (see Fig.1).

Fig 1: Wellness and reablement: definitions from the Commonwealth Home Support Program (CHSP) Good Practice Guide

*Figure drawn from that used by Nous Group 2018*

*‘Yoga’ icon by Chanut Industries from the Noun Project[[5]](#footnote-6)*

*‘Support’ icon by Massupa Kaewgahya from the Noun Project[[6]](#footnote-7)*

Although there is strong support amongst older Australians, carers and service providers to work within this framework, providers are at varying points of maturity in being able to deliver home care services within this approach (Nous Group 2018). There can be particular challenges when services need to work together in a cross-disciplinary model to meet consumers’ needs and choices (Nous Group 2018). Furthermore, where there are dilemmas over the degree of choice and consent an older person can exercise, the boundaries of this model of ageing are tested ethically, as well as practically (Dept. of Health [Vic] 2013).

Addressing older Australian’s challenges with hoarding and/or maintaining a healthy home to enable them to age well in place potentially tests the model’s design parameters.

Here, we explore some of the main design challenges for aged care and allied services already flagged through *Treasured Lives’* literature review.

### Pathways to support

Challenges with hoarding and/or maintaining a healthy home often remain hidden (Guinane et al 2019). People rarely self-identify as needing support, unless they feel there is a significant threat to either their health, their home, or their family (Lee et al 2017). More often, challenges are ‘uncovered’ by a concern raised by someone else later in a person’s life (Roane et al. 2017). For example, a public health intervention may be prompted due to a neighbour raising a concern about ‘mess’; a Child Safety investigation may be prompted due to a concern being raised by someone in the community; a home visit from Aged Care, Family, Disability or Mental Health Support Workers may flag a need for clinical and/or community support and practical intervention, or a home visit may be prompted due to a family member or carer contacting services to help ‘manage’ their relative’s living conditions. A social or private landlord’s tenancy inspection may flag a tenancy risk and prompt practical action; emergency or hospital services may raise a concern about being able to access a patient at home, or a concern about discharging a patient into an unsafe environment or an environment that continues to pose health risks.

Where people enter services through incidental pathways, such as housing support services, due to a tenancy risk, or local government, due to a public health complaint, the challenges multiply. Often issues need to be addressed within a set period or sanctions (often homelessness) will be imposed. They are often working to support people who may not be ready to or do not want to consent to addressing challenges. They often refuse support (Frost et al 2000; Kim et al, unpublished paper in Frost et al 2000; Lee et al 2017 in Guinane et al 2019; Snowden 2012). Furthermore, providing therapeutic services is likely to be outside of these services’ remit and hard to find in a timely manner, if they are available locally at all (DoH [Vic] 2013; Frost et al 2000; Lauster et al 2016).

The snapshot provided by the Hoarding and Squalor Working Group in northern Tasmania illustrated the impacts of this ‘incidental’ service landscape. Partners in Recovery (PIR) Support Facilitators described how a lack of referral options made support coordination extremely difficult. Support staff across PIR, Housing Connect and Disability Services described the significant amount of additional time needed to work with clients who present with hoarding and challenges related to maintaining a healthy home to try to keep their tenancies stable, provide in-home care and liaise within an inadequate service landscape (H&SWG2017).

The degree of choice and consent an older person can exercise in the supports they access, including when housing is at stake, tests the ethical and practical boundaries of consumer-led services, such as My Aged Care.

Advancing appropriate accommodation, clinical, community and practical supports around ageing in place for older Australians accessing NDIS, ACH services, home support and home care packages will require consideration of how to balance dilemmas and ethics around risk analysis, duty of care and guardianship with those of choice and dignity. See Dept. of Health [Vic] 2013 for a practical consideration of these issues. Consideration needs to be given to a clear framework of policy, programs and practice to guide decisions about providing support for this cohort.

### Interagency collaboration

The complexities of hoarding and challenges maintaining a healthy home require a range of clinical, community and practical services to coordinate support for individuals and their families and carers on a long term basis (Bratiotis et al. 2011; Dept of Health [Vic] 2013; H&SWG 2017; Moulding et al 2017; Stark 2013; Steketee et al. 2001).

These are likely to include supporting older Australians to address the underlying causes (trauma, depression, possibly OCD-related disorders, depression, anxiety); the hoarding behavior itself and its impacts (social isolation, health and safety issues for clients, families, carers and for workers; threatened tenancies, financial vulnerability, self-neglect); and potentially, any comorbid challenges, such as drug and/or alcohol use (Bratiotis 2012; Brown and Pain 2014; Dept of Health [Vic] 2013; Frost et al 2000; H&SWG 2017; Kysow et al 2020; McGuire et al 2013; Snowden and Halliday 2009; Tolin et al 2008). There are very few specialist services that specifically work with Australians in such a holistic manner.

Interagency coordination in itself can pose challenges for delivering effective and connected supports for older adults. However, older Australians living with hoarding and/or challenges related to maintaining a healthy home present consumer-directed services with an additional layer of challenge. Particularly given the mostly non-consenting pathways into potential support.

The CHSP’s ACH services recognise the need for targeted support for older Australians at risk of homelessness, or living in unstable housing. Both Federal and State-based services have the potential to support this federal response through health and community care. For example, in Tasmania, the State’s Home and Community Care Program (HACC) has been forward thinking in its provision of support for adults whose tenancy is at risk due to clutter (Dept. of Health [Tas] 2020).

It is important to consider how we can harness a holistic service response into local cross disciplinary case coordination frameworks that specifically focus on those living with challenges related to hoarding and maintaining a healthy home. (Bratiotis 2012; Brown and Pain 2014; Dept of Health [Vic] 2013; Frost et al 2000; H&SWG 2017; Kysow et al 2020; McGuire et al 2013; Snowden and Halliday 2009; Tolin et al 2008). Such a holistic response is more likely to a significant shift in service provision and outcomes for those living with such challenges.

### Prevention through to critical care

A multitude of services need to be considered to support wellness and reablement for older Australians with challenges related to hoarding and/or maintaining a healthy home. (Dept. of Health [Vic.] 2012, 2013; Stark 2013; Dept. of Health & Ageing [SA] 2013). These include services for adults across NDIS and other disability supports, aged care services, adult and older person’s clinical and psychosocial mental health services, occupational health services, health and community care (HACC), specialist homelessness services and housing support services, animal welfare, local government and emergency services.

A spectrum of support is required for this cohort of older Australians, their families and carers – from low level preventative support through to acute and crisis interventions (Bratiotis 2012; Brown and Pain 2014; Dept of Health [Vic] 2013; Fleury et al 2012; Frost et al 2000; H&SWG 2017; Kysow et al 2020; McGuire et al 2013; Moulding et al 2016; Snowden and Halliday 2009; Tolin et al 2008, Tompkins 2011).

Tiers of support is required that need purposeful thinking at each level. They require federal, state and local government collaboration to ensure that this cohort do not fall through the cracks of support. This also applies to the supports for families and carers.

There is an opportunity for considerable innovation to reform the CHSP, including within the ACH sub program, and current Home Support and HCPs to ensure that older Australians already eligible for home-based aged care and who are living with hoarding and/or challenges related to maintaining a healthy home can choose to access a suite of supports that enable them to age well in place. These innovations need to be considered alongside innovations in adult care that prevent entry into aged care unsupported.

#### Key messages: pathways to support, interagency collaboration, tiers of support

As the pathway to support is often non-consensual or incidental, there needs to be careful consideration of how to ensure older Australians living with hoarding and/or challenges related to maintaining a healthy home can age in place within a clear practice framework for My Aged Care services which balances choice and dignity with personal safety.

Effectively supporting older Australians with challenges related to hoarding and/or maintaining a healthy home to age well in place is likely to require an interagency case management response, beyond the boundaries of My Aged Care, across accommodation, health and practical supports.

At a local level, consideration needs to be given to tiered support for older Australians living with challenges related to maintaining a healthy home, and for their families and carers. This tiered support needs to consider how to prevent older Australians entering aged care with unsupported challenges. It also needs to consider a spectrum of preventative to critical care needed through CHSP’s ACH services, together with clinical, community and practical supports.

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1. ‘Challenges related to maintaining a healthy home’ is often referred to by Australian federal and state government agencies, program funders and support professionals, such as social workers, support workers and psychologists as ‘domestic squalor.’ In agreement with the University of Tasmania’s Human Research Ethic Committee approval conditions for SARC’s research, *Treasured Lives*, we are referring to ‘squalor’ as ‘challenges related to maintaining a healthy home’. This is in response to many with lived experience finding the term ‘squalor’ as loaded with judgement, offensive and disrespectful. [↑](#footnote-ref-2)
2. SARC conducted consultations across Tasmania with a range of stakeholders. These included consumer groups representing older Tasmanians, people living with mental health challenges, and peak bodies representing families and carers. SARC also undertook consultations with federal and Tasmanian state government agencies, emergency services and local councils. Additionally discussions were held with clinical and community sector service providers, including mental health services, aged care services, housing providers and housing support services, disability services across Tasmania. [↑](#footnote-ref-3)
3. For the purpose of the research, ‘older Tasmanians’ are defined as those aged 50 or over, or 45 or over, if they are of Aboriginal or Torres Strait Islander heritage. [↑](#footnote-ref-4)
4. Treasured Lives Reference Group includes members representing consumer voices – older Tasmanians, people living with mental health challenges, and peak bodies representing families and carers. There is also representation from 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 councils) are included. Additionally there is representation from key areas of service provision, including clinical and community sector mental health services, aged care services, housing support services and disability services across Tasmania. [↑](#footnote-ref-5)
5. The Noun Project is a collection of curated icons. Available from https://thenounproject.com/ [↑](#footnote-ref-6)
6. The Noun Project is a collection of curated icons. Available from https://thenounproject.com/ [↑](#footnote-ref-7)