Treasured Lives

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

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Choice, support and hope

SOCIAL ACTION & RESEARCH CENTRE

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1. About Treasured Lives

One of the "pillars" of 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'.[1] Older Australians living with hoarding or challenges maintaining a healthy home (CMHH) are amongst those most at risk of not being supported to age well at home. Compared to Victoria, New South Wales and South Australia,[2] Tasmania does not have what is needed in relation to social policy, program and practice settings to support its older residents living with these challenges.

Treasured Lives is a two-year project[3] investigating:

- what information exists about who lives with these challenges in Tasmania

- the experiences of the families and carers of people living with hoarding or CMHH

- the experiences and challenges of service providers, emergency services and government agencies that design policy and deliver 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.

Treasured Lives has two phases:

- **Phase 1** explored the experiences and needs of families and carers of older people living with hoarding and/or CMHH.[4]

- **Phase 2:** This phase has focused on service providers and statutory agencies supporting such older Tasmanians and their families and carers.

We have defined "older people" as those who are aged 50 or over (or 45 or over if they are of Aboriginal or Torres Strait Islander heritage).[5]

2. Who participated in Phase 2?

55 service providers and statutory agencies from across Tasmania participated in interviews or an online survey. Participants worked in a range of settings, including aged care services, adult social care, adult and older people's mental health services, disability support services and other community and health services. Other participants worked within housing provision or housing and homelessness support services, animal welfare and management, local government environmental health and building compliance, and state emergency services.

3. About hoarding and challenges maintaining a healthy home

WHAT DO WE MEAN?

- **Hoarding disorder** is a psychiatric condition that involves challenges with acquiring, sorting and/or discarding items or animals.[6] Those living with this disorder hold meaning or emotional attachment to items that others would see as not valuable.[7] This attachment leads to significant emotional struggles in thinking about or actually discarding items. The condition can be comorbid with other mental health conditions, personal trauma and negative self-constructs.[8] Recent research suggests that animal hoarding may be a distinct disorder.[9]

- **CMHH (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.[10]

HOW COMMON IS HOARDING BEHAVIOUR?

International estimates suggest 2.5% of the adult population live with hoarding.[11] This would suggest that there are approximately **5,000 older Tasmanians** (50+) living with hoarding behaviour.[12]

WHAT ARE THE PERSONAL, SOCIAL AND ECONOMIC IMPACTS?

Impacts for those living with these challenges may include:

- **Social:** social isolation; stigma and judgement; strained family relationships; reduced help-seeking[13]

- **Personal:** self-criticism and shame; poor mental health, due to accompanying illnesses and/or social isolation and stigma; compromised physical health and increased likelihood of injury and hospitalisation, due to increased trip and fall hazards; reduced self-care, due to restricted access to kitchen and bathroom; increased risk of premature death or injury; risk of premature entry into residential aged care; financial strain and increased risks of housing insecurity and homelessness[14]

- **Animals:** poor health and nutrition for animals; stress and trauma amongst animal welfare staff [15]

- **Access to supports:** social care support and emergency services may not be able to enter a home safely due to clutter or insanitary conditions. [16]

The risks of living with hoarding and CMHH to residents' health, safety and functioning tend to get worse as a person ages.

Estimates suggest it costs government about $56,800 to support one household living with hoarding or CMHH through emergency and critical care responses. These estimates would suggest that the Tasmanian Government may be spending over **$208m** on older Tasmanian households living with hoarding or CMHH through emergency and critical care.[17] When adequate preventative and response supports are in place, this falls significantly.[18]

4. What did we find out? Participants' views of the challenges facing clients

Many participants said they had not entered some of their client's homes because they were still building trust, because the client was embarrassed, or because of health and safety issues. Similar to previous research, participants observed the impacts of hoarding and CMHH on clients' wellbeing as:

- **Social:** social isolation and difficult relationships with family and neighbours

- **Personal:** 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

- **Animals:** challenges with maintaining the health of their pets, and sanitation issues with faeces inside and outside the home.

Some participants could see that poverty and social isolation, trauma, mental and physical health conditions, and cognitive and physical decline, including dementia, may have led to or made their clients' current challenges more difficult.

Participants reported that most clients wanted to age at home but that there were many hurdles to this happening. These included that clients had difficulty understanding the severity of the challenges their living environment posed for them. They were also reluctant to allow services to address health and safety concerns within their home.

5. What did we find out? Barriers faced by service providers and statutory agencies in providing support to clients

"NOT ENOUGH TIME"

Service providers highlighted that the additional time needed to work with their clients was not recognised and invested in. When programs were based on hours rather than client outputs, the challenges for social care workers were exacerbated. They needed more time, as well as budget, to support clients living with hoarding and CMHH.

Time was needed to:

- build trust and rapport with the people they were working with

- gain entry into the home to assess risks and needs

- understand the underlying causes of their clients' challenges, so that service providers and statutory agencies could go beyond addressing the presenting issues

- sensitively work through client-led goal setting and supporting clients to act on these goals.

"EVERYONE'S PROBLEM, NO ONE'S RESPONSIBILITY": SUPPORTING CLIENTS WITH NO RESOLUTION

All service providers and statutory agencies faced the same barrier to collaborating with other services that might help their clients: there were other interested agencies, but nobody had the resources to coordinate a network and no specialists were available to provide the clinical, psychosocial and practical supports their clients needed.

Supporting clients was made harder because:

- current mainstream case management and services did not offer enough hours, nor the intensity and range of supports needed to keep on top of their clients' practical support needs or mental health challenges

- risk tolerance of organisations prevented workers from providing support to clients

- services were often encountering older Tasmanians through unplanned or crisis-driven incidents. These were mainly non-voluntary and negative interactions, such as tenancy threats, animal welfare or environmental health concerns. But first responders were unable to access partnerships with social care providers who could support residents to address any underlying causes of their challenges.

"WE'RE NOT PREPARED FOR THIS": THE SEARCH FOR SHARED APPROACHES

Participants felt unprepared to support their clients because they had limited access to information that could help them.

- Service providers and statutory agencies struggled to find the information they needed to support their clients. They weren't sure if there were no resources, or if they simply hadn't yet discovered them. Participants needed information about:

  » how to assess their clients' needs

  » ways to support their clients

  » services they might work with.

- There was no systematic data collection about hoarding or CMHH in Tasmania to help us understand the prevalence of hoarding and CMHH and clients' needs, and to support risk mitigation for first responders.

6. What happens elsewhere?

Evidence from North America, England and Wales and other Australian jurisdictions (Victoria, New South Wales and South Australia) describes four parts of effective systems for supporting those living with hoarding or CMHH:

- focused social policy

- a practice framework

- collaboration across services related to people, animals and property/environment

- specialist case management and services.

Effective responses have government leadership that has changed public and political thinking about hoarding and CMHH from seeing it as an issue of personal stigma which is too complex to address, to seeing it as **a complex community policy issue** which impacts on personal wellbeing and community safety. Effective government agencies bring together social policies and approaches related to **people, animals and property/environment** into a focused goal and way of working together, with investments in targeted supports.

Key elements of successful systems include:

- 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

- responding to hoarding as a chronic illness

- aiming for goals that minimise harm for clients and the people and animals they live with

- a case management approach, usually led by a social worker or clinical nurse

- investment in a client/worker relationship grounded in trust that forms the foundation for clinical, psychosocial and practical supports

- a clear response to crisis intervention such as fires, hospitalisations and condition of property concerns that includes collaboration between code enforcers (e.g. fire service) and social care providers

- specialist supports that work in an informed way with clients and their families and carers to identify and address mental health and practical needs

- a practice framework that provides support workers with a shared set of goals, a shared approach to assessing client need and thresholds for service responses, clear referral pathways for support and guidance on legislation and how services can share information.

7. Recommendations

A LEAD STATE GOVERNMENT AGENCY

Tasmania needs **a state government agency to lead** the development and implementation of a policy and practice framework related to hoarding and CMHH. This agency should also oversee investments in a suite of specialist, multidisciplinary supports and workforce development.

A TASMANIAN POLICY FRAMEWORK

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

- recognition that there is a cohort of concern with complex mental health challenges who have specialist support needs

- an outline of the duties of care for statutory agencies and service providers

- harm minimisation as the purpose of interventions for programs and services

- an enabling statutory framework that supports multiple agencies to work together within a framework of dignity and choice to deliver positive outcomes for older Tasmanians.

A TASMANIAN PRACTICE FRAMEWORK

Tasmania needs **a practice framework** for supporting older Tasmanians living with hoarding and CMHH. Elements should include:

- a shared understanding of challenges, approach to working and goals
- recommended assessments, tools, thresholds and outcomes
- data management guidance.

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 who meet for case planning, monitoring and reviewing, information sharing, workforce development and reviewing policy, practice and service needs
- specialist case management services
- specialist clinical, psychosocial and practical supports
- a clear response to critical incidents and a pathway to positive health and social care supports
- services of last resort (similar to this model within disability services) to provide older Tasmanians living with these challenges with a social care safety net
- a workforce development plan
- a digital hoarding and CMHH information hub.

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.

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.

For more information about the Treasured Lives project and the full reports, please go to the Treasured Lives website.

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Endnotes

1   Royal Commission into Aged Care Quality and Safety (Royal Commission) 2021, *Final report: Care, dignity and respect*, The Office of the Royal Commission.

2   Department of Health Victoria (DoH [Vic.]) 2012, Discussion Paper: Hoarding and Squalor, State Government Victoria.

     – 2013, *Hoarding and squalor: a practical resource for service providers*, State Government Victoria.

     Department of Health & Ageing South Australia (DoH[SA]) 2013, *A foot in the door: Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia*, Government of South Australia, Adelaide.

     Stark, D 2013, *Beyond overwhelmed: Identifying pathways to deliver more effective services for people and their pets affected by hoarding and squalor across NSW*, NSW Hoarding and Squalor Issues Paper, commissioned by the NSW Hoarding and Squalor Taskforce.

3   The project received research ethics approval from the University of Tasmania's Human Research Ethics Committee. Project n: 18686.

4   Phase 1, Fidler, L 2021, *Treasured lives: Phase 1 report*, Social Action and Research Centre, Anglicare Tasmania.

5   This is in line with the Australian Department of Health's My Age 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.

6   Frost & Hartl 1996, cited in Buscher, TP, Dyson, J & Cowdell, F 2014, 'The effects of hoarding disorder on families: An integrative review', in *Journal of Psychiatric and Mental Health Nursing*, vol. 21, pp. 491-498; Tolin et al. 2011, cited in Guinane, J, Bailey, D, Fuge, F & Sook, M 2019, 'Analysis of patients referred for aged care assessment with concerns related to hoarding or squalor', in Internal Medicine Journal, vol.49, pp. 1313-1316.

7   Danet, M & Secouet, D 2018, 'Insecure attachment as a factor in hoarding behaviours in a non-clinical sample of women', in *Psychiatry Research*, vol. 270, pp. 286-292.

8   Ayers, C, Loebach Wetherell, J, Schiehser, D, Almklov, E, Golshan, S & Saxena, S 2013, 'Executive functioning in older adults with hoarding disorder', in *International Journal of Geriatric Psychiatry*, vol. 28, no. 11, pp. 1175–1181; Brown, S 2011, 'Theoretical concepts from self-psychology applied to animal hoarding', *Society and Animals Journal* vol. 19, pp. 175-193; Brown, F & Pain, A 2014, 'Developing an approach to working with hoarding: space for social work practice', in *Social Work in Action*, vol. 26, no. 4. pp. 211-224; Chou, CY, Tsoh, J, Vigil, O, Bain, D, Uhm, S, Howell, G, Chan, J, Eckfield, M, Plumadore, J, Chan, E, Komaiko, K, Smith, L, Franklin, J, Vega, E, Delucchi, K & Mathews, C 2018, 'Contributions of self-criticism and shame to hoarding', in *Psychiatry Research*, vol. 262, pp. 488-493; Chou, CY, Mackin, R, Delucchi, K & Mathews, C 2018, 'Detail-oriented visual processing style: Its role in the relationships between early life adversity and hoarding-related dysfunctions', in *Psychiatry Research*, vol. 267, pp. 30-36; Frost et al. 2011, cited in Ayers et al. 2013 ibid.; Frost, R, Steketee, G & Williams, L 2000, 'Hoarding: a community health problem', in *Health and Social Care in the Community*, vol. 8, no. 4, pp. 229-234; Guinane et al. 2019 ibid.; Roane, D, Landers, A, Sherratt, J & Wilson, G 2017, 'Hoarding in the elderly: a critical review of the recent literature', in *International Psychogeriatrics*, vol. 29, no. 7, pp. 1077-1084.

9   Ferreira et al. 2017, cited in Dozier, M, Bratiotis, C, Broadnax, D, Le, J & Ayres, C 2019, 'A description of 17 animal hoarding cases from animal control and a humane society', in *Psychiatry Research*, vol. 272, pp. 365-368.

10   Department of Health Victoria (DoH [Vic.]) 2013, *Hoarding and squalor: a practical resource for service providers*, State Government Victoria; Dozier, et al, *ibid.*; Snowdon, J, Halliday, G, Elliott, R, Hunt, G & Coleman, S 2019, 'Mental health of animal hoarders: a study of consecutive cases in New South Wales', *Australian Health Review* vol. 44, pp. 480-484.

11   Postlethwaite, A, Kellett, S & Mataix-Cols, D 2019, 'Prevalence of hoarding disorder: A systematic review and meta-analysis', in *Journal of Affective Disorders*, vol. 256, pp. 309-316.

12   See the full report, table 1.

13   Buscher, TP, Dyson, J & Cowdell, F 2014, 'The effects of hoarding disorder on families: An integrative review', in *Journal of Psychiatric and Mental Health Nursing*, vol. 21, pp. 491-498; Chabaud, S 2020, 'Children in hoarded homes: a call for protection, prevention, intervention and compassionate care', in *Children Australia*, vol. 45, pp. 186-192; Chou, CY, Tsoh, J, Vigil, O, Bain, D, Uhm, S, Howell, G, Chan, J, Eckfield, M, Plumadore, J, Chan, E, Komaiko, K, Smith, L, Franklin, J, Vega, E, Delucchi, K & Mathews, C 2018, 'Contributions of self-criticism and shame to hoarding', in *Psychiatry Research*, vol. 262, pp. 488-493; Davidson, E, Dozier, M, Mayes, T, Baer, K & Ayers, C 2020, 'Family and social functioning in adults with hoarding disorder', in *Children Australia*, vol. 45, pp. 159-163; Garrett, C 2020, 'The perspective of children of hoarding parents (COHP)', in *Children Australia*, vol. 45, pp. 164-166; Neziroglu, F, Upston, M & Khemlani-Patel, S 2020, 'The psychological, relational and social impact in adult offspring of parents with hoarding disorder', in Children Australia, vol. 45, pp. 153-158; Park, J, Lewin, A & Storch, E 2014, 'Adult offspring perspectives on parental hoarding behaviour', in *Psychiatry Research*, vol. 220, pp. 328-334; Roane et al. 2017 *ibid.*

14   Ayres, C, Saxena, S, Golshan, S & Loebach Wetherell, J 2010, 'Age at onset and clinical features of late life compulsive hoarding', in *International Journal of Geriatric Psychiatry*, vol. 25, no. 2, pp. 142-149; Roane et al. 2017 *ibid.*; Kim, H-J, Steketee, G & Frost, R 2001, 'Hoarding by elderly people', in *Health and Social Work*, vol. 26, no. 3, pp. 176-184; Tolin, D, Fitch, K, Frost, R & Steketee ,G 2010, 'Family informants' perceptions of insight in compulsive hoarding', in *Cognitive Therapy and Research*, vol. 34, pp. 69-81.

15   Dozier et al. 2019 *ibid.*; Snowdon et al. 2019 *ibid.*; Patronek. G, Loar, L & Nathanson, J (eds) 2006, *Animal hoarding: Structuring interdisciplinary responses to help people, animals and communities at risk*, Hoarding of Animals Research Consortium.

16   Bratiotis, C 2013, 'Community hoarding task forces: a comparative case study of five task forces in the United States', in *Health and Social Care in the Community*, vol. 21, no. 3, pp. 245-253; DoH [Vic] 2013 *ibid.*; Kysow, K, Bratiotis, C & Lauster, N 2020, 'How can cities tackle hoarding? Examining an intervention program bringing together fire and health authorities in Vancouver', in *Health, Social and Community Care*, vol. 28, pp. 1160-1169; McGuire, J, Kaercher, L, Park, J & Storch, E 2013, 'Hoarding in the community: a code enforcement and social service perspective', in *Journal of Social Service Research*, vol. 39, pp. 335-344.

17   These figures are estimates. They use the estimated costs of support provided by Catholic Community Services (CCS) in CCS 2014, *Pathways to dealing effectively with hoarding and squalor in Australia*, report on the Pathways through the Maze Hoarding and Squalor National Conference. These costs are applied to an estimated 5000 older Tasmanians living with hoarding. See Fidler L 2021, Treasured Lives: the policy and service environment, Social Action and Research Centre, Anglicare Tasmania, for details of estimated population. Critical care costs may include 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; and premature entry into long-term residential aged care. Early intervention costs may include case management, repairs and cleaning, and first response services.

18   CCS 2014, *ibid*. Also, see Anglicare Tasmania's submission to the Tasmanian State Budget 2022-23, December 2021. Available at: https://www.anglicare-tas.org.au/research-category/state-budget/.