Evaluation of the Hoarding Advocacy Support Service (HASS) EXTENSION Trial

September, 2021

Author Morag McArthur for Woden Community Service (WCS)

Morag McArthur (BSocSci (Hons), PhD) is a social work academic with over 30 years of teaching and research experience. She has worked with Commonwealth, State and Territory Government departments, non-government and community organisations on a wide range of research and evaluation projects.

Acknowledgments

Thank you to the clients of the service who agreed to speak with me about their experiences of the HASS trial. Thank you also to the members of the Hoarding Case Management Group (HCMG) who provided their perspectives.

TABLE OF CONTENTS

TABLE OF CONTENTS....................2

TABLE OF FIGURES AND TABLES....................2

GLOSSARY....................3

EXECUTIVE SUMMARY....................4

INTRODUCTION....................7

RESPONDING TO HOARDING AND DOMESTIC SQUALOR....................9

APPROACH TO THE EVALUATION....................13

FINDINGS....................16

DISCUSSION AND IMPLICATIONS....................29

CONCLUSION....................33

REFERENCES....................34

TABLE OF FIGURES AND TABLES

Figure 1 Coordinated interventions for hoarding and squalor.................... 12

Figure 2 HASS program logic.................... 13

Figure 3 Stages of the HASS trial case management model.................... 17

Figure 4 HASS inquiries.................... 21

Table 1 Number of complaints, Inspections, and other regulatory activity for HASS clients.................... 28

GLOSSARY

Hoarding Case Management Group (HCMG) was established to enhance the cross-government approach to the management of severe and complex hoarding and domestic squalor cases in the ACT. It is the multi-agency group that oversees the government response to complex cases of hoarding and squalor. It is the source of referrals for the HASS trial.

Hoarding Advocacy Support Service (HASS) provides targeted case management to work with, and advocate for, clients to improve their particular hoarding circumstances and to facilitate effective liaison and collaboration between the individuals, government regulators, government support services and community support services.

Case management model describes "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective care". (Case Management Society of Australia and New Zealand https://www.cmsa.org.au/documents/item/111)

Hoarding behaviour is the persistent accumulation of, and lack of ability to relinquish, large numbers of objects or living animals, resulting in extreme clutter in or around premises. This behaviour compromises the intended use of premises and threatens the health and safety of people concerned, animals and neighbours. (VicHealth 2013).

Squalor describes an unsanitary living environment that has arisen from extreme and/or prolonged neglect and poses substantial health and safety risks to people or animals residing in the affected premises, as well as others in the community. (Vic Health, 2013)

There is some overlap between the two situations, however accumulating items or waste because there is no motivation to discard or due to physical or cognitive impairment does not meet the criteria for hoarding disorder just as those who display hoarding behaviours may maintain clean and hygienic, though severely cluttered, living spaces. (Sydney City Mission, 2016).

Complex hoarding clients means the clients referred to WCS by the HCMG for HASS case management.

Lead agency means the government agency represented on the HCMG that has the primary responsibility for overseeing a hoarding case. There might be one or more lead agencies for a particular case.

EXECUTIVE SUMMARY

The ACT Government is required to respond to a small number of cases of severe hoarding and domestic squalor in the ACT. Severe hoarding and domestic squalor have profound impacts on the responsible individual, such as posing health and safety risks. It also impacts neighbours, including diminishing urban amenity and enjoyment of their home and property.

In 2015HCMG was established to enhance the cross-government approach to the management of severe and complex hoarding and domestic squalor cases. HCMG evolved from an identified need for a whole-of-government approach to the management of complex hoarding and domestic squalor cases. Recognising that severe and complex cases require the ongoing involvement of several agencies at any given time, an intensive case management model was implemented. HASS was initially trialled in 2019 for three months with an extension agreed to for a further 18 months. WCS was funded to implement and evaluate the HASS trial.

The purpose of this report is to present the findings from an evaluation of the HASS trial. The report provides an overview of the implementation of the HASS trial as well as an assessment of the effectiveness of the model for achieving the stated trial outcomes. In 2020 WCS commissioned Dr Morag McArthur to undertake the evaluation.

The evidence sources for the evaluation included a synthesis of case data, HCMG referral and meeting minutes, some regulatory data, interviews with HCMG members and with several clients. The evaluation concluded, based on these data, that the HASS fills a significant gap as a program that works with clients with complex needs in a range of flexible ways. The report calls for a reshaping and expansion of a hoarding and squalor program for the ACT. So as to not lose momentum, connections, and relationships it is important during any redesign phase to continue HASS in its current form.

Findings

Despite the small number of clients overall, limited complaint and inspection data and the impact of COVID 19 on the trial, all stakeholders interviewed for the evaluation saw the case management process as having a value in achieving outcomes for clients and the people working within the case management process.

Key service stakeholders were generally of the view that the HCMG plays an important role in coordinating government responses to the most complex hoarding cases. There was no strong consensus that the ‘right’ people attended meetings as some members were not always in a position to intervene and problem solve particular cases referred to the HCMG. Several stakeholders argued that the HCMG required more resources to support the committee for research, including more rigorous data collection and policy work to respond to systemic issues.

There is little doubt that most clients referred to the HASS trial meet the criteria of complexity identified by the HCMG. They are mainly people who have come to the attention of authorities due to the identification of hoarding or squalor that either impacted neighbours resulting in complaints or were assessed as unsafe or unsanitary by those attending the residence for other reasons. However, various stakeholders felt that there were many more clients who would benefit from a HASS type service.

Interviews with stakeholders and clients indicate those who engaged in the program are linked to services such as advocacy services, cleaning, gardening and repair services. Several were referred to My Aged Care for assessment and if successful were granted funding for a range of services. The evaluation identified a range of gaps and significant delays in accessing services that impact the effectiveness of the HASS. The clients interviewed felt that the HASS Coordinator (HC) was an ally, a navigator of helpful services and someone who understood their situation.

There is evidence from the number and nature of enquiries to WCS to indicate that the current small, restricted HASS program is not able to meet the needs of people who experience severe or moderate hoarding and squalor.

This report concludes by outlining possible enhancements to the model to respond more effectively to the needs of people affected by hoarding and squalor. The findings of the evaluation point to the need to develop a more comprehensive program. This means designing a program that coordinates services for clients with complex to moderate needs, as well as increasing the capacity across the service system to provide an earlier and more effective identification of people who live with hoarding and squalor challenges. The current model is not able to intervene with many complex and moderate cases. In addition, its size is not sustainable with its reliance on one experienced Co-ordinator.

Implications

- Understanding the scope and nature of the problem

Research indicates that more than 2 in 100 people in the community might meet diagnostic criteria for Hoarding Disorder with a higher rate of people who have issues with hoarding and squalor (Nordsletten et al, 2013, Postlethwaite et al, 2019). Stakeholders identified the benefits of services that intervene earlier and the number of enquiries to the HASS Coordinator over the life of the trial, without any promotion of the service, indicate there is a significant unmet need in the community.

Before decisions are made about the nature of an ongoing HASS, a needs assessment should be carried out to determine the extent and nature of hoarding and squalor across Canberra. A needs assessment is essential to develop an adequate and appropriate program for clients who experience moderate and complex hoarding and squalor conditions.

- Governance

Due to the uncertain ongoing funding, there has been limited policy and program documentation for HCMG and the HASS. There are HCMG terms of reference, but they remain in draft. The collaboration between directorates and services works on 'goodwill'. If the program receives ongoing funding, clearer articulation of the roles of HCMG and HASS will be required.

The HCMG is both a multi-disciplinary panel that discusses and responds to cases of hoarding and squalor as well as the oversight mechanism for the HASS.

To ensure the ongoing success of the inter-agency collaboration, a strong governance structure must be established. The HCMG could provide a more focused collaborative forum to discuss service delivery options for people who experience complex and challenging needs due to their hoarding behaviour – not just those who come to the attention of government authorities. It could also oversee the work of a broader focused HASS.

- Location of a new service

Any new iteration of the HASS should continue to be voluntary for participants and delivered by the community sector, recognising that hoarding clients often have limited trust in government services.

- Case management model

In redesigning HCMG and HASS, the roles and relationships between the different members of a designated care team must be clearly defined, processes articulated, and accountability mechanisms identified.

It is essential to recognise in any reshaping of the HASS there is no 'one-size-fits-all' approach appropriate for individuals experiencing hoarding and or squalor. Programs must be flexible to respond to the different, individual needs, capacities and goals of clients.

- Earlier intervention

There is evidence of the benefit to intervene earlier to respond to people with hoarding and squalor circumstances and widening the eligibility to the HASS.

Consideration in redesigning HASS that referrals can be accepted directly through that program to provide intervention at both the complex and more moderate end.

- Time and a trauma-informed framework

Once the focus of any new HASS is identified, establishing program guidelines and principles will be necessary. The principles would include what we know works best for people with complex needs and include a trauma-informed framework that recognises that many people who have hoarding and squalor issues have experienced trauma. Operationalising trauma-informed care into practice is also crucial, as is building this knowledge into policies and procedures. In the absence of trauma-informed care and responses, services are at risk of inflicting further harm.

Due to the nature of people who experience hoarding and/or squalor lives (e.g. anxiety, histories of loss or trauma, long-term social isolation) a lengthy period of rapport and trust-building between staff and clients is essential to be built into the model. Further, the model should allow for higher intensity and lower intensity service without clients having to disengage and reengage with different workers. It is therefore important that any new model of HASS be not too prescriptive as to the length of service provision and respond according to individual client needs.

In a new program or service, it must be informed by a trauma-informed framework recognising that many people who have hoarding and squalor issues have experienced trauma.

- Strategies for building capacity across the service system

Strategies include:

- Continuation of Buried in Treasures course and Families as Motivators
- Training for community groups and services with a focus on introductory and more advanced content
- The HASS playing a consultation role in one-off 'case based' discussions (secondary consultation) or to working directly with clients (primary consultations)
- The consideration that the new HASS develop and maintain a Hoarding and Squalor Portal with resources available to services and families
- The HASS arranging and facilitating a Communities of Practice on hoarding and squalor to build the capacity of the service system to identify and respond to hoarding and squalor situations more effectively.

INTRODUCTION

Purpose of the report

The purpose of this report is to present the findings from an evaluation of the HASS Extension Trial. The report provides an overview of the implementation of the HASS trial as well as an assessment of the effectiveness of the model for achieving the stated trial outcomes. In 2020 WCS commissioned Dr Morag McArthur to undertake the evaluation and aimed to answer the following questions:

- Has the HASS model been implemented as intended?
- Has the HASS trial, on balance, directly or indirectly contributed to:
  - increased client amenity, wellbeing and community engagement
  - decreased hoarding activity by the client (a measurable reduction in squalor, public health and public safety risks)
  - decreased interventions required by the regulator; and
  - decreased number of related complaints received from the public.

The project has the potential to inform the design of future responses to complex hoarding and squalor cases in the ACT. The focus of the evaluation is the trial period as defined in the original contract before amendments - 1 January 2020 to 30 June 2021.

Background to the project

The ACT Government is required to respond to a small number of cases of severe hoarding and domestic squalor in the ACT. Severe hoarding and domestic squalor have profound impacts on the responsible individual, such as posing health and safety risks. It also impacts on neighbours, including diminishing urban amenity and enjoyment of their home and property.

Hoarding and squalor are complex social issues that have many potential causes and can have a highly detrimental impact on the lives of those affected in the community. People displaying hoarding behaviours require skilled services to support them, including while they are facing enforcement action.

Due to the complexity of hoarding cases, mental health conditions, and often past traumas experienced by the clients, the management of complex hoarding cases is a specialised field. It requires a carefully managed approach, with appropriate skills, knowledge, and experience to support these clients without increasing trauma. Poorly managed interactions with residents in hoarding situations can exacerbate hoarding behaviour, and increase mental distress.

Numerous ACT Government directorates have legislative levers available to engage with hoarding and domestic squalor issues. In 2015 the HCMG was established to enhance the cross-government approach to the management of severe and complex hoarding and domestic squalor cases. HCMG evolved from an identified need for a whole-of-government approach to the management of complex hoarding and domestic squalor cases. Various ACT Government directorates have legislation that engages with hoarding and domestic squalor issues. However, much of this work was undertaken in isolation. It was determined that it would be more effective and better serve the ACT community for directorates to pool their resources and work collaboratively on complex hoarding and domestic squalor cases.

The HCMG acknowledges that each case of severe hoarding is different and there is no single regulatory approach that will effectively resolve all cases. Severe and complex cases require the ongoing involvement of several agencies at any given time. An individual living with a severe hoarding or squalor circumstance often has competing health and social issues which require multidisciplinary interventions and a cross-

sector approach to achieve optimal stability and better outcomes, including connecting with their community.

Individuals can be unreceptive to support offered by the government, who might be seen primarily in the role of regulator or law enforcement. Optimal resolution of complex hoarding cases may require regulatory action in conjunction with non-government support and case management. The introduction of an intensive case management model through the implementation of a HASS was trialled in 2019 for three months. During the short-term trial, some improvements were seen in the condition of the properties involved and in engagement between hoarding residents and support services.

Following that trial, HCMG requested funding for a longer-term trial to strengthen the evidence base for a long-term community-sector HASS. In November 2019 the Minister for Health announced he ACT Government would fund an 18-month extension to the HASS trial. Throughout this extended trial, HCMG identified and decided who was referred to HASS and monitored progress during the trial extension. WCS was funded to implement and evaluate the HASS trial.

During the period of the extended trial, the COVID-19 pandemic impacted the ability of HASS to provide intensive case management. There was no face-to-face interaction with clients for a few months. The service funding agreement was negotiated to reduce the services and hours for 6 months. During this time, the HASS trial focused on cases where a relationship was already in place with clients. HASS hours were increased in July 2020 and a new contract variation negotiated. As a result, the trial was extended until 31 August 2021.

The Hoarding Advocacy Support Service

The service intends to assist individuals to acknowledge the impact of their hoarding behaviour, the need to address it from health, behavioural, and social perspectives, the need to identify and overcome barriers to behaviour change, and then monitor the change. It is critical to gain the participants' agreement to work with HASS staff in this way to address the issues.

This approach requires intensive voluntary engagement with the HASS staff, to gain each participant's trust and develop a plan to address concerns. It is anticipated that participants will be aware of the concerns of the statutory authorities that need to be addressed. It is also acknowledged that participants may have been involved with authorities for some time with limited success, as the hoarding behaviour has remained substantially unchanged over time.

Further detail about the HASS Case management model is discussed below.

Although not a focus of the evaluation, WCS has also been funded to provide the following programs and services.

Buried in Treasures and Post Buried in Treasures Groups

Buried in Treasures (BIT) supports behaviour change for people with a hoarding disorder and provides practical and emotional support throughout the process as people gain insight and understanding into their situation. It is a 16-week course, facilitated by peers, that WCS has experience in delivering over the past five years. During the extended HASS trial, WCS reintroduced BIT to the ACT community and partnered with the ACT Recovery College to provide the peer support program during 2020.

Family as Motivators

Family as Motivators (FAM) is a new support group program specifically designed for those who care for someone with hoarding behaviours. Over 10 weeks, members of the group learn how to identify when a hoarding habit has become Hoarding Disorder, how to effectively encourage their friend or family member

to seek help and treatment, and how to ensure that caring for the person with a Hoarding Disorder does not negatively impact their health and well-being (https://lifelineh2h.org.au/get-help/groups/compulsive-hoarding-treatment-program/family-motivators/). WCS is in discussion with both Gregory S. Chasson and Lifeline, Hunter to Hawkesbury, NSW about the introduction of FAM group to the ACT and would establish this during the HASS trial. However, the timeline for delivery of this course has been affected by COVID-19 lockdowns.

Responding to enquiries

Although the HASS trial did not work with additional clients beyond those referred from HCMG, many services and potential clients often approached HASS for information and advice. WCS responded in the best way they could to these enquiries. A record of these enquiries was kept, tracking the sources of enquiries, repeat requests to assist with recommendations after the trial.

Sector Development

There is a much-needed role for training, support and mentoring of staff working in the hoarding area, as they are often isolated and inexperienced. Even experienced staff cannot source services to assist their client. Throughout the trial, the HASS coordinator (HC) provided a range of presentations and training to organisations, such as St Vincent De Paul to increase their understanding of hoarding and squalor. The HC has also provided a range of services and individuals with advice about responding to hoarding and squalor, making referrals, including to HCMG as appropriate.

RESPONDING TO HOARDING AND DOMESTIC SQUALOR

The following sections provide an overview of the literature describing hoarding and squalor as well as what is known to be affective in responding to people experiencing hoarding.

Hoarding and squalor

Hoarding and squalor are complex conditions, with a diverse set of underlying causes. As defined below, both conditions result in an accumulation of possessions or rubbish. Although sometimes similar, they are regarded as different conditions with overlapping situations. Hoarding behaviour has many causes but hoarding disorder is now listed as a mental illness, whereas squalor describes an unsanitary living environment, which may be the result of extreme domestic neglect or hoarding (Snowdon et al, 2007; Dozier and Ayers, 2017).

Hoarding and squalor can result in health and safety risks to the individual, as well as other household occupants including children, pets and neighbours. These include the risk of falls and other risks to themselves e.g. self-harm, acute medical illness, insects or rodent infestations, fire, and risk of eviction or homelessness. Increasingly the problems of hoarding and squalor are recognised as both a private mental health problem and a matter of public health and safety (Bratiotis et al, 2011). Legal enforcement of public health and safety regulations is an option that needs to be balanced between the interests of the community and/or property owners with those of the person who hoards (Slatter,2012).

Hoarding

Hoarding when excessive is regarded as a disorder that reduces space and impacts wellbeing and amenity. Hoarding disorder is typified by persistent difficulties in discarding possessions, which can result in significant clutter that obstructs the individual's living environment and produces considerable functional impairment.

People who experience hoarding disorder find it distressing to reduce the accumulation of possessions rather than simply having a lack of insight or poor motivation. Hoarding disorder can occur in the absence

of another physical or mental disorder and is now a distinct diagnosis in the DSM-5. The prevalence of hoarding disorder is difficult to assess but in a recent meta-analysis it is estimated that approximately 2 in every 100 people meet the hoarding disorder criteria. The prevalence rates were similar for both males and females (Postlethwaite et al, 2019).

Problems associated with serious hoarding behaviour commonly cause health and safety concerns for those who live in the home as well as for neighbours.

Hoarding disorder:

- Tends to begin early in life and has a chronic, progressive course (Dozier and Ayers, 2017; Tolin, Meunier, Frost, Steketee, 2010).
- Insight is limited in about half of cases.
- Around half are affected by a physical health condition. Arthritis and sleep apnoea is common in older people who hoard (Roane et al, 2017).
- Estimates of mental illness, such as mood, anxiety (e.g obsessive compulsive disorder) or attention deficit hyperactivity disorders, range from 56–85% in people who experience hoarding disorder (Nordsletten et al, 2013).
- Personality traits of perfectionism, indecisiveness and procrastination are associated with hoarding.
- People with hoarding disorder often have a low quality of life and poor function with a level of burden on their family (Tolin et al, 2007, Saxena, et al, 2006).

There is increasing understanding of the disorder with growing research that provides new insights into the complexities of hoarding, its co-occurring features, and the identification of promising interventions (Bratiotis, et al, 2011).

Squalor

Squalor describes an unsanitary living environment that has arisen from extreme and/or prolonged neglect and poses substantial health and safety risks to people or animals residing in the affected premises, as well as others in the community (Vic Health, 2013). There are two main pathways to squalor – domestic neglect such as failure to remove rubbish and hoarding such as excessive accumulation of items (Snowden, et al, 2007). People living in severe domestic squalor frequently refuse help, often withdraw socially and can have limited insight into their living circumstances. The majority of people who live in squalor often have other challenges such as Alzheimer, alcohol or other substance misuse, depressive disorders, intellectual disability or personality disorders.

There is some overlap between hoarding and squalor, however accumulating items or waste because there is no motivation to discard or due to physical or cognitive impairment does not meet the criteria for hoarding disorder, just as those who display hoarding behaviours may maintain clean and hygienic, though severely cluttered, living spaces (Sydney City Mission, 2016).

What is effective?

Due to the nature of hoarding behaviour, people who hoard may fail to recognise the dangers of hoarding. It is not surprising then, that those who hoard may not feel motivated to change the conditions in the home. Although there are legal responses available to enforce public health and safety concerns, balancing the rights of neighbours and/or property owners with those of the person who hoards can often lead to the risk of housing instability and homelessness (Slatter, 2012). As discussed above, hoarding disorder is evident in vulnerable groups who are often older and/or have physical or cognitive needs.

The most commonly used evidence-based approach to mental health treatment for hoarding is cognitive-behavioural therapy (CBT) designed to modify emotions, cognitions, and behaviours relevant to hoarding (Tolin, Frost, Steketee, & Muroff, 2015), however there are very few mental health providers who have the relevant expertise necessary to provide treatment for hoarding. Research in the use of other therapies such as Dialectical Behavioural Therapy (DBT) and Acceptance and Commitment Therapy (ACT) are starting to show promise.

Alternative ways of responding focus on the efforts around the conditions of the home and in reducing the impact of the hoarding on neighbours. There is some evidence that sanctions, or at least the threats of sanctions, for non-compliance may be useful to increase the motivation of people to change. However, In the case of hoarding, relying solely on legal sanctions often fails to achieve regulatory compliance and may create complications. For example, unintentionally, professionals who are working with hoarding clients may complicate matters by setting unrealistic deadlines for compliance; communicating inconsistent demands for changes in the home or paving the way for severe consequences such as eviction or forced cleans (Bratiotis and Woody 2020). This can lead to unintended outcomes such as extreme emotional responses from those affected which have long term repercussions for future compliance and engagement with helpful services.

As is seen across the hoarding literature, due to fluctuating awareness of the impact of their hoarding behaviour on others, many do not see their situation as unsafe or problematic (Steketee, Frost, & Kim, 2001; Tolin, Fitch, Frost, & Steketee, 2010). Sometimes people who hoard are unable to reduce the amount of 'things' in their homes, feeling overwhelmed, and although insight might be a motivator for change, it can also lead to shame and embarrassment, 'which leads to secretiveness, social isolation, and rejection of offers of help'. Being involved for longer periods, taking things slowly to build trust and understanding the emotional aspects of hoarding behaviour are all essential elements to achieving voluntary compliance (Kwok et al., 2018). Bratiotis and Woody (2020) reflect that 'unfortunately, most enforcement officers are not trained to take account of the emotional aspects of hoarding disorder that make it difficult to achieve compliance'.

Managing complexity

No one agency or service is likely to be able to respond to the multifaceted set of needs people who hoard have. There is a complex balance between concern over an individual's mental health and the health and safety of others. Due to the nature of the problem, a wide range of skills and knowledge is required, which includes professionals who know about the health and safety risks, child welfare, and aging, as well as mental health services and agencies that have the mandate and resources to assist in these different areas. There is a logistical challenge to managing the different perspectives and priorities which requires coordinating with others who have the expertise and resources to intervene (Bratiotis et al., 2011).

However, in any response to people with complex needs, several key elements need to be in place. This includes a shared recognition and understanding of the nature of the complexity and common criteria and language to identify people. It is recognised that people who experience hoarding and/or squalor who come to the attention of authorities require specific cross-portfolio/directorate integration which supports more coordinated responses across the key service systems and that can be diverse such as health, mental health, disability, housing, community services and child protection services. When conceptualised this way, a shared responsibility is required to respond because no single discipline has sufficient expertise or resources to respond effectively to the situation with hoarding and squalor (Bratiotis, Woody and Lauster 2018).

Integrated models are seen to improve outcomes in other circumstances of complex needs. Coordinated models are regarded as more efficient due to the complexity – and recognise that one service or service

system cannot address the range of complex needs (Maruthappu, Hasan and Zeltner 2015). Having integrated and coordinated services also helps to address the fragmentation that exists across service systems. Integration or coordination is the creation of structural links between separate services and requires clear and strong governance arrangements to be effective. They also require intensive case management responses which require small caseloads and long-term service provision. Having cross-disciplinary responses such as hoarding task forces or complex need panels are increasingly seen as a way to combine resources, to educate and support each other and collaboratively address cases that come to public attention (Bratiotis, 2013). The figure below is a summary of case management elements for hoarding and squalor [1] cited in Gleason, Perkes and Wand, 2021, p 82.

Figure 1 Coordinated interventions for hoarding and squalor

- **Coordination of services**: they need to work together to deliver a consistent approach. A case manager or key worker should be identified to lead the response. Ideally, there is one coordinated intervention plan across agencies to facilitate collaboration and clear communication (including clear goals, support and timeframes).
- **Match the assessment to specific specialist services and interventions**, including:
  - Treat comorbidity and the underlying causes of the hoarding and squalor.
  - Arrange for community services to support people with functional impairment. Some people may not be able to have their complex or high needs met at home and may need to enter a residential aged-care facility or supported accommodation. Occupational or functional assessment may assist.
  - Arrange for services to assist with cleaning.
  - Consider making a cleaning agreement with the person and actively involve them, where appropriate, to reduce trauma.
  - Arrange or notify services as indicated e.g. Child Protection Services, RSPCA, Ageing and Disability Abuse Helpline.
- **A Team Care Arrangement** may help keep track of the numerous referrals and agencies involved and review outcomes.
- **Support the individual, their carers and relatives**. Interventions are often experienced as very stressful and there may be multiple unsuccessful attempts. When someone is not ready for change, relatives may need support. Resources and strategies for families and carers may be found in the book 'Digging Out' by Michael Tompkins et al.,[31] or online e.g. Hoarder.org.
- **Arrange ongoing funding** source (e.g. National Disability Insurance Scheme, My Aged Care), with **ongoing home-visit-based case management and domestic assistance** for support and monitoring to ensure maintenance of treatment gains.

[1] There is a range of non-drug interventions including CBT and motivational interviewing that are seen as useful to reduce harm. Limited drug treatments are currently available.

APPROACH TO THE EVALUATION

An evaluation plan was developed in collaboration with WCS staff at the beginning of the trial of HASS in February 2020 and reviewed by the HCMG. The evaluation framework details the program logic of the HASS and the intended outcomes and indicators of the achievements of the HASS. It was planned that a process evaluation would be completed towards the middle of 2020 and an outcome evaluation mid-2021. Due to the COVID-19 pandemic and the extension of funding until the August of 2021, this report discusses both process and outcome evaluation questions.

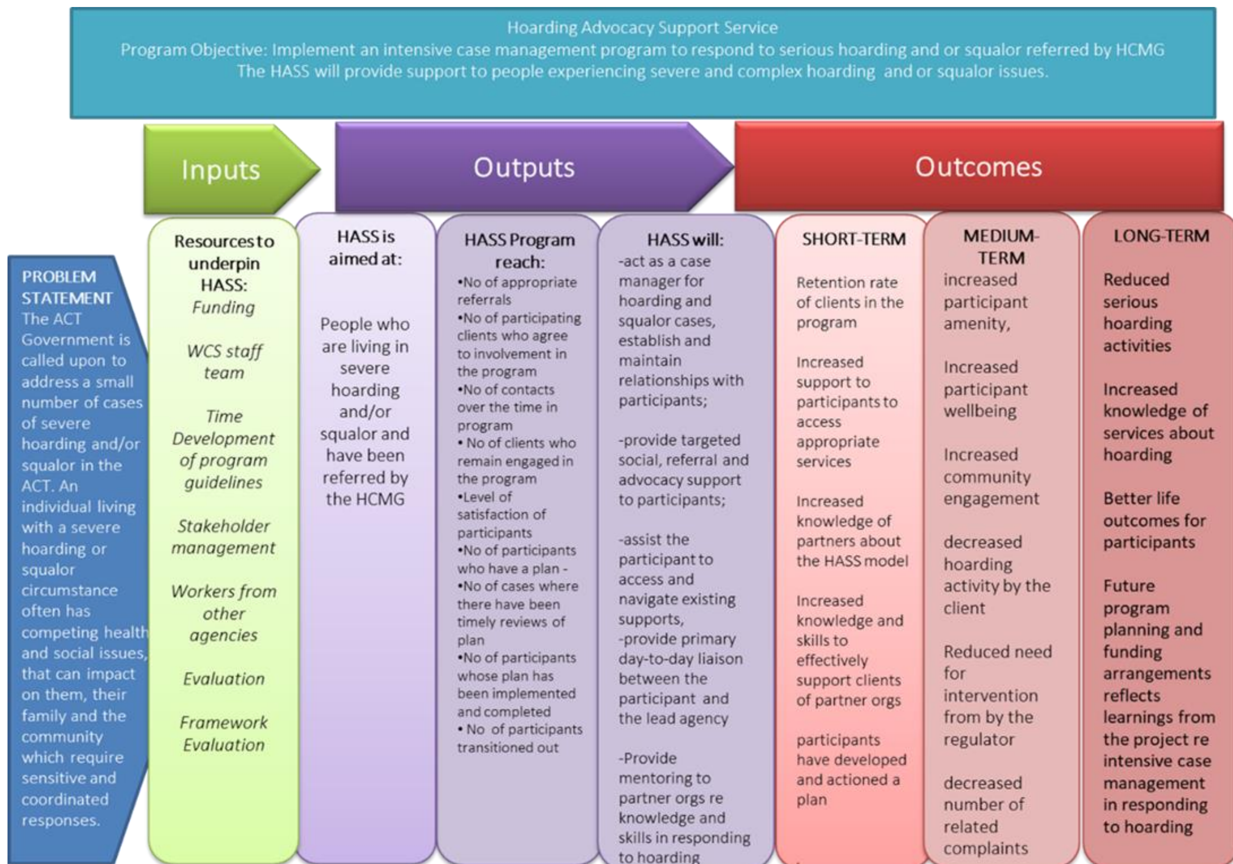
Objectives

The overall objectives of the HASS which reflects the requirements of the funding agreement with the Health Directorate are as follows:

> The key focus of the provision of targeted HASS case management is working with and advocating for, clients to improve their particular hoarding circumstances and to facilitate effective liaison and collaboration between the individuals, government regulators, government support services and community support services.
>
> HASS aims to assist individuals to acknowledge the impact of their hoarding behaviour and the need to address it from health, behaviour, social and financial perspectives, to influence the behaviour and to monitor change.

Program outcomes were identified in the WCS funding agreement and were based upon two main areas: outcomes for clients; and outcomes for the service sector. The outcomes are outlined in the Program Logic below.

Figure 2 HASS program logic



Methods

In this evaluation, an emphasis has been placed on gaining the perspectives of key stakeholders, that include clients of the HASS and services involved in HCMG on what has been achieved. The evaluation has relied on gathering multiple types and sources of evidence, both quantitative and qualitative where available.

Data Sources

Quantitative

- **HCMG data** – included referral information, some complaint and inspection data.
- **HASS inquiry data** – number and nature of enquires to HC over the life of the trial

Qualitative

- **Interviews with key stakeholders -** The participation level for key agencies was good with 12 interviews completed with stakeholders from a range of government services who sit on the HCMG. The HC and a senior staff member of WCS were also interviewed. Interviews with stakeholders were carried out either face-face, via telephone or online.
- **Interviews with clients –** 3 out of a possible 7 clients agreed to be interviewed for the evaluation. A family member was also invited but chose not to participate. An interview was also carried out with a family member whose parent was not accepted into the HASS trial.
- **Meeting Notes -** The notes from HCMG meetings held from December 2019 until June 2021 were utilised in the evaluation.
- **HASS Program data –** were used to present the nature of case coordination activities.

Data synthesis

Due to the small numbers, the quantitative data analysis was very basic, for example no statistical analysis was carried out but simply presented.

The qualitative data: interview summaries, minutes from HCMG and HASS case notes were used to answer the evaluation questions. The data were organised and synthesised according to the broad evaluation questions. Quotes from data sources are indicated and are used to illustrate particular points.

Several cases studies were developed by the HC which are presented in the report. These are illustrative case studies which aim to provide an explanation of common processes and outcomes. These type of cases studies are commonly used in evaluation research. Its purpose is primarily descriptive. In this type of case study, usually, one or two instances are utilized to explain what a situation is like in practice.

Limitations

There were several limitations associated with identifying the extent to which the HASS program contributed to improved wellbeing, connectedness and reduced regulatory activity using quantitative measures. The plan was to use a range of validated questionnaires [2] at the beginning and end of HASS

[2] Clutter Image Rating Scale (CIRS) – self-report pictorial rating system was found to be a reliable and valid screening tool for detecting the presence of clinically significant hoarding symptoms. The CIRS has also been found to be sensitive to treatment effects.

involvement to measure improvements. However, the HC reported that due to a range of reasons including not being able to enter the property to complete the scales and limited insight about the issues meant some clients were unable to complete the questionnaires. In other situations, a judgment was made by the HC that completing the questionnaire would impact on engagement. Therefore no data of this nature is available.

This is an extremely small but complex cohort of clients which lends itself to more qualitative approaches such as case studies rather than statistical analyses. Where possible the wider literature is used to strengthen conclusions with the limitation that generalisations to the wider population of people who experience hoarding, or squalor is not possible.

Evaluation of case management models such as the HASS is fraught with difficulties, particularly around attributing change to the program under evaluation. Many events, such as inspections and compulsory cleaning can impact the effectiveness of a program. The coordinated intervention provided services through different agencies and with workers from a variety of backgrounds working in different legislative contexts with different approaches and limitations.

The Clutter Quality of Life Scale (CQLS) has been designed by the Institute for Challenging Disorganization (ICD) to help people assess for themselves the personally felt impact that clutter has on their well-being.

Personal Wellbeing Index (PWI) – an international validated measure of wellbeing which contains seven domains of satisfaction, each one corresponding to a quality-of-life domain including standard of living; health; achieving in life; relationships; safety; community connectedness; and future security.

FINDINGS

The findings section of the report aims to answer the key evaluation questions as to whether the model of the HASS trial has been implemented as intended as well as whether the broad outcomes of increasing the wellbeing of individuals and decreasing the frequency of regulatory action outcomes have been achieved. It relies on written program data from the HASS trial, HCMG referral data, minutes from HCMG meetings as well as feedback from key stakeholders: services, clients and HASS staff gathered through interviews for the evaluation.

The findings are arranged by three key evaluation questions:

- To what extent has the program been implemented as intended?
- How effectively is the case management model working?
- To what extent has the HASS trial key outcomes been achieved?

Overview or key features of the HASS Case management model

Case management typically includes the establishment of a working/therapeutic relationship of trust, assessment, goal setting, individual care planning, coordination, linkage and referral, core tasks and interventions on the client-level and systems-level including advocacy, supportive counselling and monitoring of the client's health and mental health and the care plan. Case management can be defined as 'a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes' (CMSA, 2008).

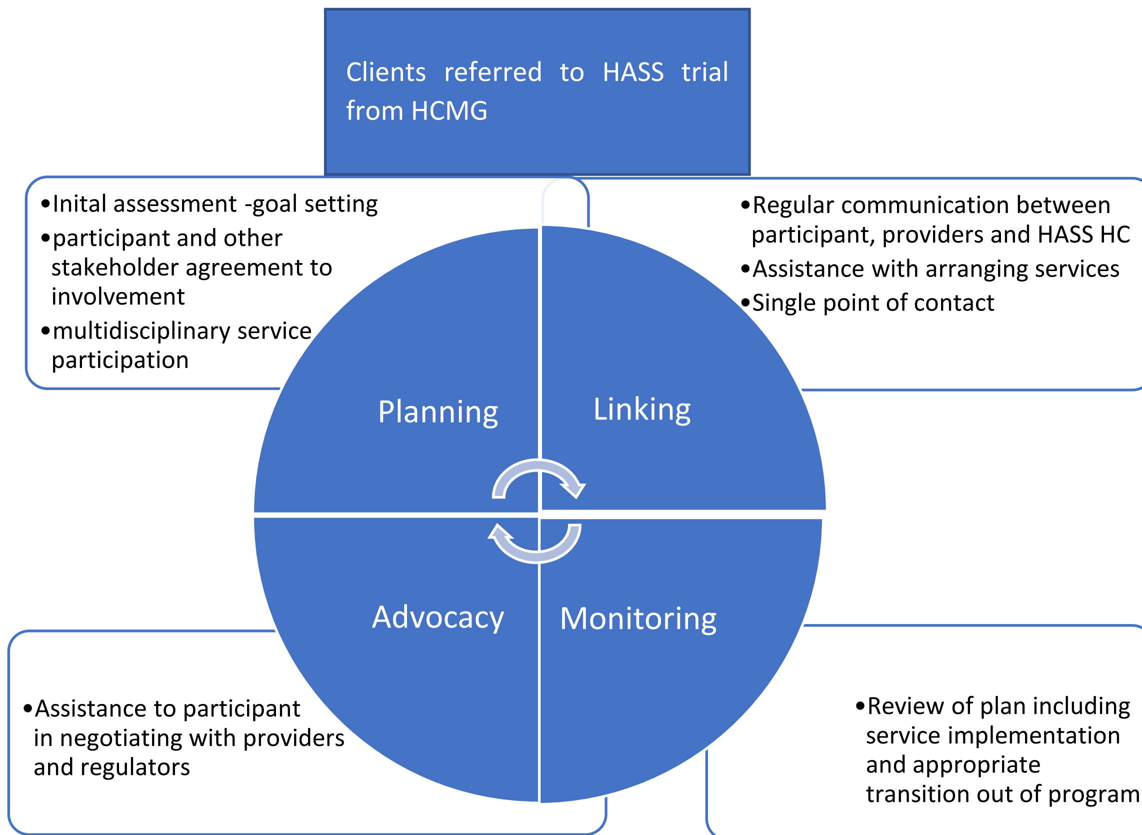
Program documents outline the intent of the trial which is to assist individuals to acknowledge the impact of their hoarding behaviour, to work and advocate for them to improve their particular hoarding circumstances and to facilitate effective liaison and collaboration between the individuals, government regulators, government support services and community support services. Over the trial it became evident that client’s natural supports should be included. Involvement in the HASS trial is voluntary with clients consenting to work with HASS staff to address the issues.

The HASS model used in the trial is a case management model with HCMG - a cross-disciplinary, directorate panel providing the referrals and overseeing its activities. (see discussion below).

The HASS trial model includes the following activities (as outlined by the funder)

- act as a case manager for hoarding and squalor cases overseen by the HCMG, in collaboration with the relevant lead government agency (lead agency);
- establish and maintain relationships with clients displaying hoarding behaviours;
- provide targeted social, referral and advocacy support to clients;
- facilitate the provision of domestic services (such as cleaning or gardening);
- assist the client to access and navigate existing supports;
- provide primary day-to-day liaison between the client and the lead agency.

Figure 3 Stages of the HASS trial case management model



To what extent has the model been implemented as intended?

This is a critical process evaluation question. It is essential in carrying out this form of evaluation to ensure that the model has been implemented in the way it was intended. If changes have been made over the time of the trial, they need to be considered in making any comments about the outcome of the trial. By answering this question, confident judgments can then be made about how effective the model (as implemented) has been in affecting outcomes for clients and other stakeholders. If it has not been implemented as intended, the evaluation will attempt to identify the reasons why and consideration of enhancements or changes to the model will be discussed.

To answer this broad evaluation question, several sub-questions are examined.

How effectively are the assessment and selection processes working?

HCMG Governance

The HASS trial is overseen by the HCMG. HCMG is the only source of referrals to the HASS trial. Understanding how this governance process works is important to answer whether appropriate cases were referred to the trial.

HCMG was convened by the Health Protection Service in 2015 in response to a clear need for cross-government collaboration and coordination on complex cases of hoarding and squalor. HCMG is chaired by the Executive Branch Manager of the Health Protection Service. Its key function is to oversee complex cases of hoarding and squalor which require a multi-agency and multidisciplinary approach. It is noted that HCMG responds to a range of cases that are not always referred to the HASS trial but are managed by members of the committee.

The HCMG assists in coordinating the government response to the most complex hoarding cases. It does not have the capacity to oversee all hoarding cases and mainly deals with those clients who have the most complex needs, where serious safety issues are identified and whose circumstances lead to complaints from neighbours. Panel models such as HCMG are commonly used with different foci such as education, disability and youth justice and in this case hoarding and squalor. They tend to have a common range of elements, including a single-entry point, eligibility defined in terms of complexity, holistic and comprehensive needs assessments, coordinated care planning and intensive case management, with access to brokerage funds to directly purchase services promptly. All of these elements are in place, to some extent, in the current HCMG and HASS model.

Current HCMG members include:

- Representatives from the Health Protection Service (including the HCMG secretariat),
- Canberra Health Services - Mental Health Services,
- ACT Mental Health Policy,
- ACT Fire & Rescue,
- ACT Ambulance Service,
- ACT Policing,
- Housing ACT,
- Transport Canberra and City Services (the Licensing and Compliance area, Domestic Animal Services and the Waste Regulation area),
- Access Canberra,
- Public Advocate and Public Trustee and Guardian,
- Child and Youth Protection Services - if there is a case involving children,
- Woden Community Service (providers of the HASS Trial), and
- Other services or organisations are invited to assist with particular cases as needed.

Although HCMG is not the focus of the evaluation, it is the key mechanism for referrals to the HASS trial. All members of HCMG were invited to participate in an interview for this evaluation. Members of the committee were asked to comment on whether the referrals presented at meetings and were referred to the HASS trial were appropriate. As they were also likely to be the services involved in responses to HASS clients, they were asked about the efficacy of the model.

For those who participated in an interview, most agreed that HCMG was a useful strategy for coordinating complex hoarding and squalor cases in the ACT and that HASS was critically important. Many talked about the ‘good will’ that drove the work of the committee activity. There was no strong consensus that the ‘right people’ attended meetings. Participants argued that the ‘right people’ means that not only do they represent their Directorate or Service, but they were in a position to make decisions about what to do. Those who were not confident that the ‘right people’ were on HCMG made comments such as this:

> We need people who can make decisions about what they can and can’t do for individual cases – weakness is that some people aren’t aware of the powers they have to intervene. (Interview Participant 1).

Other participants talked about how HCMG provides a good problem-solving venue, pointing out that the ‘networking is really helpful, making connections, knowing who to contact’.

Several participants talked about how the different perspectives on the social problem of hoarding and squalor influenced the work of the committee. For example, a clinician's view is that hoarding is a mental health issue requiring mainly 'voluntary' responses that are quite different to seeing the response as a 'regulatory' activity. However, most participants could see how both the 'stick' (legislation) and ‘carrot’

could be used to meet objectives if done in a purposeful way. One participant recognising the complexity of hoarding said – 'you can go in and do a clean, but it doesn't solve the problem'.

Several participants talked about how HCMG needed more resources to support the committee for research and systems reform. It was reported that a cross-government strategic policy project is being planned which will strengthen responses to people who experience hoarding and squalor.

Referrals to the HASS trial

Referrals to multidisciplinary groups/panels can occur at different points on the continuum of need, to cater for early intervention, emerging complexity, or responding to a crisis. Models may include a mandatory or statutory element. In this case, the focus of the intervention is that people referred to HCMG, or on to the HASS trial, are those that are complex cases of hoarding and squalor which have been identified as requiring a multi-agency and multidisciplinary approach. Possible clients have either come to the attention of the AFP, ACT Fire and Rescue, ACT Housing or their circumstances have resulted in complaints to various regulatory agencies. Referrals to HCMG have also been made by Mental Health Services and most recently by the Public Trustee and Guardian. The HC is not able to directly make referrals to HCMG.

HCMG meets every 2 months to discuss existing cases and to consider referrals for HCMG case management and suitability for the HASS trial. If there are urgent cases, they are dealt with out of session. Cases referred to HCMG are considered and a decision is made about whether HCMG will take on the case.

Separate consideration is whether the case would benefit from the HASS trial. If the HASS trial has the capacity to take on extra case/s, then HCMG discusses in the meeting whether HASS could assist with the case. Because each case is so different, there are no set criteria as to what prompts a referral to HASS. The group considers each case, whether they think the case would benefit from HASS and whether HASS would be appropriate.

The decision about whether the case would benefit from HASS might consider a range of factors, including whether the client already has supports in place and the complexity of the situation.

Even if HASS can take on cases, not all cases will be referred to HASS. For example, if HCMG takes on a case that is being managed by Housing ACT, the Public Advocate and ADACAS, then it may not become a HASS case. It is acknowledged that adding a new person to the case management team might be detrimental for the client who may have already built rapport with others.

In most cases, a referral form is completed which outlines the issues and where possible indicates the significance of the hoarding and squalor as well as the safety risks. Sometimes there are delays to decisions about referrals due to a lack of information from which to make decisions and/or the referrer has not been able to attend the meeting. This can lead to delays in cases being taken up and responded to.

During the life of the trial, 14 people were referred to HCMG (either formally or informally) with 9 being referred to the HASS. Of the 9 referred, two people who were offered HASS services did not accept assistance or stopped engaging with the HASS trial. Some of these cases were involved in the previous short-term HASS trial and a number had been known to HCMG, often for many years.

Is the HASS trial reaching the intended target group?

There is little doubt that most clients referred to the HASS trial met the criteria of complexity identified by the HCMG. They are mainly people who have come to the attention of authorities due to the identification of hoarding or squalor that either impacted neighbours resulting in complaints or were assessed as unsafe or unsanitary by those attending the residence for other reasons.

There were some inappropriate referrals where the judgment was made that the person was not living with hoarding – or where hoarding was not regarded as the main or most pressing issue. An example of this is where an individual was being evicted or a child was being removed. It is reported that some people who make referrals are not certain whether the issues they are observing are in fact hoarding. On one occasion, a referral to HASS was seen as a 'last chance' before mandatory action was taken.

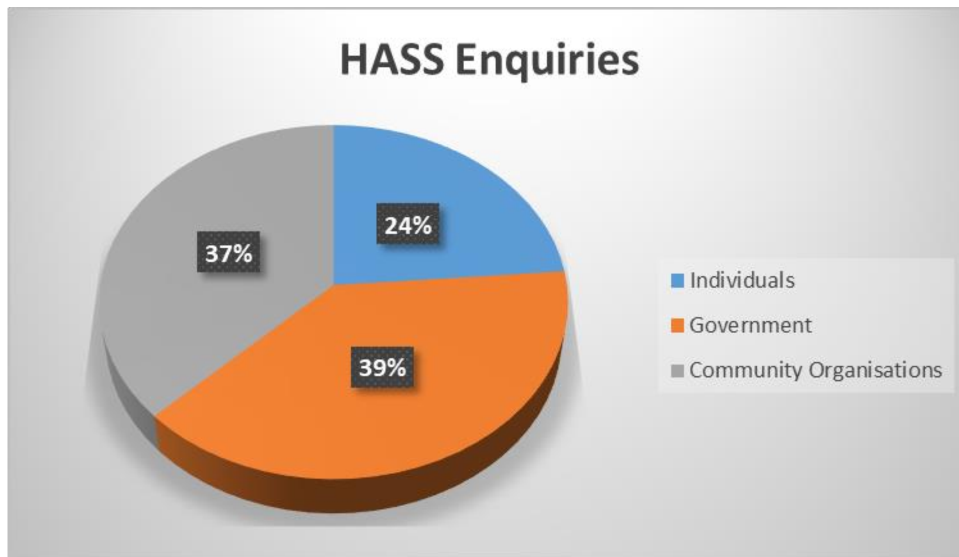
Due to the nature of hoarding behaviour, people who hoard often have limited insights and may fail to recognise the dangers or impacts of hoarding. It is not surprising then, that those who hoard may not feel motivated to change the conditions in the home. They also have often had very negative previous experiences with government services that means that engagement with supportive services, such as the HASS trial is also treated with suspicion. Two clients who were referred to the HASS trial agreed to initial meetings but subsequently, despite active attempts (the HC sent multiple texts and calls) did not engage in the service. Commonly the HC attends initial meetings with colleagues, usually the referrer and then spent considerable time trying to engage with the client. In two cases even with persistent outreach, she was unable to provide any help. Here is a description of what occurred in one situation.

> The client was suspicious of HASS's arrival at the property, the HC spoke to the client before the AFP arrived. He was nervous but welcoming. He said the inside of his house was cluttered which fitted with police reports. His front garden was very ordered and well cared for and he said it was where he felt safe and at peace. After the arrival of the police in uniform, his demeanour changed. The HC stayed on after the police left and discussed how HASS could assist, asked what his goals and his preferred contact method were. He was clear he would only meet and speak in the garden, so the weather had to be fine, but he was willing to engage with HASS. Over the next 6 weeks, appointments were made but cancelled for a range of reasons. The final interaction in October 2020 was the last. He did not re-engage in any way from this point. From late October to mid-December, HASS emailed 5 times offering support and practical assistance but there was no response. (HASS program notes).

The HC also fielded 59 enquires about help with hoarding behaviours during the life of the trial. These enquiries were from services, clinicians, self-referrals and family members.

Sometimes it is a matter of linking or suggesting a specific service, sometimes the HC provided advice as to what to try, several times the HC recommended contacting the HCMG secretary for a possible referral. The HC made referrals to the BIT program. On an ad hoc basis, the HC also attended staff meetings and provided training to organisations such as St Vincent de Paul to provide information about working with people who hoard. The figure below indicates the breakdown of enquires between government, community services and family members.

Figure 4 HASS inquiries



An example of the type of enquires is where a service provider is looking for advice for a client. The service provider described how the client had long term hoarding behaviour, with physical health conditions that impede her ability to clear out her house. The enquirer described how the house is clean and the client is willing and aware that the material in her house needs to be removed. The house is assessed as unsafe. From this description the HC assessed that the current hoarding behaviour was not 'high' enough for a HCMG referral. The HC suggested that the Community Assistance and Support Program [3](CASP) funding might be available to get immediate help to make the house safe and the enquirer could also assist the client with a NDIS application for ongoing support.

The nature and level of inquiries received by WCS during this trial, with no public promotion of the program undertaken, indicates that there is a gap in providing targeted support to service providers and family members to respond to hoarding behaviour.

The following case study is an example of someone who was not found to be eligible for HCMG and therefore not eligible for the HASS trial. It points to the need for an expanded focus of the HASS.

A family member contacted the HC directly to enquire whether her mother was suitable for the HASS trial. Her mother had completed the BIT course previously. Her mother had recently had a fire in the property which was attended by Fire and Rescue who suggested the family speak to the HC. The daughter reported that her mother's collecting had gotten worse which included hoarding food, her mother also has mobility issues. The daughter was worried as the neighbours were angry and complaining about the state of the property (including rodents). The HC had expected that Fire and Rescue would refer this property to HCMG for discussion. When this did not occur the HC attended the property and carried out an assessment, including the clutter image rating tool and identified a range of safety concerns. In her view, the nature of the hoarding and safety issues were similar to other HASS cases. The mother had returned to the house after the fire and its aftermath was still obvious.

Health Protection Services visited the property but the case was still not raised at HCMG.

In November 2020 the HC arranged a meeting of family members and HPS and Fire and Rescue to discuss what could be done to assist this family. As a result of the meeting, this property was not referred to the HCMG as it was felt that that the person with the hoarding behaviours was seen to be well supported by her family.

[3] To be eligible for CASP you must live in the ACT, be under 65 years and require home and community support for daily living activities due to a health issue.

In an interview for the evaluation, the daughter said "there is a big gap! I think it's great to help people who don't have social support, but it still leaves us in a difficult situation. We don't have anything to influence her to clean up - she is getting worse – she collects knives and forks and food, wherever she is, she has not got a working stovetop due to the rodents, she is declining. I would have liked to get mum the help now".

To what extent have participants been supported and linked to supports and services?

Program notes, interviews with stakeholders and clients all indicate those who engaged in the program are linked to services such as advocacy services, cleaning, gardening and repair services. Several were referred to My Aged Care for assessment and if successful were granted funding for a range of services. As one respondent described

> The HC works directly to build rapport with the client to improve their situation and to link them to helpful services – not just HCMG services (Stakeholder interview 10).

One of the benefits of a case management model is that the HC was able to ensure services, once arranged, are delivered and if there were problems with delivery, the HC can follow up. For example, one client who had services arranged but not delivered was able to rely on the HC to sort it out. The HC was also able to assist family members to access support services for their parent.

Several key service gaps were identified for HASS clients. In the HCMG minutes, this discussion was summarised.

> For some clients, there are no services available to assist. Even if a person has funding for services, those services do not have enough funding to carry out the intensive work. It is a consistent issue and worse than 2 years ago. The work does not really fit under My Aged Care or NDIS funding. Support workers want to help, but their business will not allow them to because of the intensive time required for these cases. Businesses are more likely to accept straightforward cases. (HCMG Minutes, February 2021).

Other service gaps identified in the interviews included mental health services for younger people and significant waiting lists for services under My Aged Care. For those clients eligible for NDIS funding, the services are also not provided in a timely manner.

Clients interviewed for the evaluation were able to point to services that were arranged due to their involvement in the HASS trial that they felt were helpful to them, although one participant felt that the people coming to clean were there for too long when it wasn't necessary.

How well has the HASS program developed and maintained partnerships and collaborations?

The basis of a case management model is collaboration and partnership working. It is an explicit but often not clearly defined component of the approach of programs and services.

In the collaboration literature, interagency relationships work best when the purpose of the collaboration is clear, where there are articulated shared outcomes and the difficulties of implementation and other context-related challenges are well understood (for example different legislative powers, different policies about health and safety) (Bratiotis, et al, 2018; Winkworth and White, 2011). Many service stakeholders interviewed for the evaluation indicated that there was generally a strong focus on working together to solve the issues for people with complex needs. The view was provided by several stakeholders that the HC had a high level of skill to work with clients who had traditionally been difficult to engage, had an expert level of knowledge about hoarding and squalor and comprehensive knowledge of services that might be available to assist clients. These are key attributes necessary to effective case management (Hudon, Chouinard, Pluye, et al., 2019). The nature of the relationship between the HC and the key agencies in each case was essential.

The development of partnership working for particular clients was also discussed. In the program description of the HASS trial, it is assumed that a lead agency would work with the HC to assist in developing a plan (in consultation with the client) to meet the agreed outcomes of reduced risk, increased safety and wellbeing and to arrange for services to be implemented to meet the client's needs. In some cases an explicit 'care team' was identified who met regularly to discuss implementing the plan for the client. Where it worked well, all stakeholders, excluding specific specialized services (e.g. like Pest Control), and family (where available) were identified and communication through an email group was used to ensure everyone was up to date with changes to service delivery, support and any regulatory action requirements. Multidisciplinary meetings could, if required, be called quickly to address issues. In some cases, family members are updated regularly and regarded as 'part of the team'.

There is no description in the program material of how the lead agency and the HC work together. As described above in some cases the 'care team' is clearly defined and processes put in place to work together to implement a shared plan, to have clear communication and to problem solve. This process did not occur in every situation with HASS clients. The key is to develop a system that supports essential functions of care coordination with clearly delineated roles and responsibilities including the role of the lead agency.

Several respondents felt the role of a care team required more explicit articulation. One interview respondent felt these smaller groups should be used to discuss clients and would be a way to ensure accountability, 'where people could find out where we are up to and the HC could provide specialized knowledge and advice about particular clients' (Stakeholder interview 5).

As the trial progressed it became apparent that the role of the HC was different in different circumstances in that they were not always the case manager. There were three different ways the model worked in practice. The first was the traditional case management model with the HC taking responsibility for the plan and the coordination of its implementation. The second is where there is close joint working between a lead agency and the HC. The third is where the HC has limited or no contact with the client, the work is carried out by another agency and the role of the HC is to provide advice and mentoring.

How effectively is the case management model working?

A systematic review of factors for effective case management indicates three main ingredients for success (Hudon, Chouinard, Pluye , et al. 2019). These are close partnerships between government and community service providers, the selection and knowledge/training of the case manager/coordinator and the coordination of care, support of client self-management and assistance to clients to navigate the service system. Case management specific to hoarding includes other activities such as problem solving for sorting and discarding possessions and activities unique to hoarding such as linking to organisations who provide skips or arranging intensive or forensic cleaning (Bratiotis, Woody and Lauster, 2018).

As discussed in the previous section, stakeholder interviews, including with clients, identified the skill and knowledge of the HC as an essential ingredient to any success attributed to the HASS trial. The HC works with clients to link them to services, problem-solve where possible and assist clients and families to navigate the service system to access helpful support services. A stakeholder described what they hoped would occur when clients were referred to the HASS trial.

> What you are hoping for with access to HASS, is they are adding value in cases that have multiple levels of complexity, not just their mental health, housing, self-care, transport, access to other services but across their whole life (Stakeholder interview 8).

However, Case Management models include various components that interact in nonlinear ways to produce outcomes that are highly dependent on context and other variables across settings. For example,

three assumptions about the availability of services and expertise underpin effective HASS case management however these assumptions are not always available in practice.

1. **Availability of funding** to purchase services identified as being needed. It can often take some time for clients to be assessed for funding packages to access services. It has been reported that some HASS clients will disengage from the process due to the nature of the intake/assessment process unless they have someone to assist and support them. Funding packages are often formulated based on hours for an 'average' person. The hours and requirements needed for hoarding clients are considerably higher for services. Funding often covers maintenance cleans, however there is no acknowledgement of what is required to get the property to a level that allows maintenance cleans to occur. This ignores a key step in the process of working with this client group. Some forensic cleans can cost $20,000 to $30,000.
2. **Availability of service providers** with capacity, capability and willingness to work with clients in this context. Currently, in the ACT there are very few providers who are trained to work with the HASS trial target group. There are no financial incentives for service providers, small businesses and individuals to carry out these more complex services under available funding models (e.g under NDIS and My Aged Care funding caps). Forensic and other cleaning activities, if not completed with care and understanding, can leave clients feeling shocked, traumatised and very distressed. As the HC said*: Service delivery under the funding systems is stretched to capacity. When faced with a disagreeable client and an offensive environment, few services would choose to clean here for the same payment as a less offensive environment.*
3. **Available services to provide long term case management** once the HASS trial has completed or has done what it can in the specific context. In the current funding environment, there is rarely funding allocated for long term intensive case management. Often services have a specific time limit for involvement with particular clients with hoarding frequently not recognized as an eligibility requirement for more targeted case management. There is limited knowledge and expertise available to work with hoarding clients in the long term with limited training available for the workforce and management in this area.

Across the interview groups, all reported that the HASS trial model of case management was essential to work with clients with complex needs. Most felt that the strength of the HASS case management model was that it involved an individual with the skills and knowledge to carry out this role and that it was located in the non-government sector recognising that many clients had limited trust in government services.

When asked what element of the model is most effective, many pointed to the HC as the significant factor. There was a shared recognition that the HASS model is not sustainable if its success is due to an individual. One stakeholder said

> If you wanted to strengthen HASS you need more than one person, if the current coordinator leaves or gets sick, it would be a problem as there is too much reliance on one person. The HC has been very generous with her knowledge. We need to build more capacity in the program then I think the risk that HASS is reliant on one person will reduce over time. (Interview stakeholder 3).

Another stakeholder said:

> One of the issues is the sustainability of HASS because it's based on an individual. If the program was broadened, with more HC, more like an agency, (it would be better) at the moment it is far too small to deal with the needs. We (agency named) need to be a bit more proactive; outcomes need to be measured, in particular where housing and clients are very unsafe. (Interview stakeholder 7).

Recognising this was an issue WCS recruited a part worker to extend the organisational expertise, and to provide support and cover to the HC. However the COVID lockdown impact on face-to-face service delivery effected the ongoing need for this position.

Building trust and relationships as the basis for intervention

Apart from the coordination function of case management models and the availability of services to refer to, the skill and expertise of the case manager is an essential element for the model to be effective. To work with highly vulnerable people, such as those in the HASS trial, requires the use of safe, nurturing and positive relationships to support change. Previous literature highlights the significant barriers to engaging clients who live with complex hoarding and squalor behaviours and points to how essential it is to develop trust and rapport as a basis for any successful intervention. Building trust through relationships was considered a fundamental element of the HASS.

The approach taken by the HC has some important elements. They describe it in the following way recognising the possible barriers.

> This approach requires intensive engagement by the HASS staff, to gain each participant's trust and develop a plan to address concerns. It is anticipated that participants will be aware of the concerns of the statutory authorities that need to be addressed. It is also acknowledged that participants may have been involved with authorities for some time with limited success, as the hoarding behaviour has remained substantially unchanged over time. (HC interview)

Several stakeholders talked about the need to 'take things slowly', to 'take a gentle approach which doesn't judge', 'allowing clients time to decide, and process' what might happen. They also talked about the contrast between this type of approach and the sometimes perceived-confrontational approach of regulators.

Other stakeholders also talked about how important it was for them to also build a relationship of trust to improve safety. For example

> We try to build a relationship trust – for example, we try to provide education about safety issues. It is bigger than just our perspective we are looking at the person's welfare or the welfare of others. We work with others – community-based organisations around Canberra – if they have a relationship with some of the clients (sometimes don't go in uniform to lower the heat). We have had success and let our staff in – removing the hazards is a different issue – we don't try to address that (Interview stakeholder 7).

The 3 clients interviewed all talked about how they appreciated the relationship they had with the HC.

> I like how she makes a time to see me before she comes and appreciates that getting my books and magazines cleared away takes time. I don't want to make the wrong decision about throwing out the wrong things and regretting it. She helps me appreciate other people's points of view (about the circumstances (Client 1).

> She is a tower of strength to me; she actually gave me a way to make a plan…such a useful service because people can get trapped and do not know what to do (Client 2).

> She provided advice about things I that miss, she helped by telling me what to expect in the system and the rules, ways around the rules, I am totally ignorant. (Client 3).

To what extent have the HASS key outcomes been achieved?

As stated above, there are two key outcomes for the HASS trial which are to

- increase the well-being of individuals and

- decrease the frequency of regulatory action.

As stated above in the limitations section, this is an extremely small but complex cohort of clients which lends itself to more qualitative approaches such as case studies rather than statistical analyses. It was intended to collect data using validated hoarding tools. However, this did not occur because of a range of reasons including: the HC not being allowed to enter the property to do the assessment or a professional judgment about the efficacy and impact of completing the tools with clients with low levels of insight into the problem.

Outcomes for clients - increase in wellbeing, amenity, and connections

The following section provides a description of changes that occurred in clients' wellbeing, amenity, and connections. It must be noted that most of these clients have been involved with government services for some time with limited success, as the hoarding behaviour has remained substantially unchanged over time. As is noted in the literature section of this report, working effectively with clients in this cohort takes considerable time, time to engage effectively to build trust and having the necessary services available promptly. As one stakeholder, interviewed for the evaluation said:

> You have to go slow while you can – before we did the literature reviews to understand hoarding behaviour better clinicians would want us to close the case – because something meaty isn't going to happen. However, you can be doing things in the background. One important thing is to have a harm minimisation approach. If there are safety issues where we feel that can't go slow – we do an assessment… HCMG is driven by environmental protection – we have to go softly softly – a big stick doesn't help. It takes a long time to get results. (Interview participant 2).

The 5 clients who engaged with the HASS trial have been linked to ongoing services. This has included assessments by My Aged Care for funding packages. Several clients were referred to or were already known to Older People's Mental Health Services who provide a mental health assessment and, if appropriate, ongoing support. The HC has arranged for clients to have cleaning, gardening and repair services, notwithstanding the limited number of services there are to do this work. Clients were connected to services such as ADACAS (a free advocacy and information service for people with a disability, mental ill-health, for older people and carers) and the Public Advocate to ensure their rights are protected. Family members were also supported by HASS by being linked to supportive services such as Next Step, a free cognitive behaviour therapy service available in the ACT, and kept up to date with what was happening with their family member and regulatory responses.

The HC commonly provided support to clients whenever there were inspections and cleans, recognising how difficult this can be for clients. One client, interviewed for the evaluation, described how upset he was to receive a letter from Access Canberra outlining a complaint. He was grateful that the HC was able to de-escalate the situation and explain what had happened. The three clients who were interviewed for the evaluation saw a significant outcome for them was the reduced interaction with regulators who they found were 'confrontational' or 'frightening'. Being involved with HASS meant they could better manage these interactions because the HC explained to them what was required and what was likely to happen if they didn't agree to interventions. They also felt it was important that HASS was located in a community sector organisation – that is it is 'not the government'. They appreciated this approach.

Below is a client case study that illustrates the nature and impact of the interaction with the HASS trial.

This client is an older man who lives alone with some family support. He has a range of complex physical and mental health issues. He is well known to regulators and to WCS over many years, due to ongoing complaints from neighbours about the smell and evidence of rodents around his property. His level of insight and awareness of the impact of his situation on others is limited leading to difficulties with engagement. He was referred to the extended HASS trial in January 2020 to:

- Facilitate and support the service providers who attend and access the property as a requirement of the court order.
- Provide support and advocacy to the client during the service providers visits
- Liaise with service providers and the client regarding dates, times of visits as well as and payment
- Develop a plan with the client for sustainable service delivery and the linking and support for engagement with other helpful services.

Although the HC had had a long-term previous professional relationship with this client, it was uncertain whether he would re-engage with supports. Rapport was re-established over several months and he then accepted assistance and support. He was keen to be involved in the HASS trial. After discussion with the client, goals for trial were identified which were to increase family involvement in facilitating support, source financial assistance due to significant debts and for the HC to support the client to meet the court ordered requirements.

Outcomes

Increased family involvement. The HC was able to engage with the client's daughter to involve her more fully in plans to support her father. For example, the client required funding for services and the daughter took responsibility for arranging this and became the contact point for My Aged Care funding.

Managing debt and payment of invoices. Payment of services with this client was an ongoing issue. He is reluctant to pay for services he feels are unnecessary and are forced on him but are required under court orders. The HC linked him to a financial advice service who worked through his existing debts with the client. The HC liaised with the My Aged Care funding with his daughter to identify whether any of the court requirements could be actioned through his funding package. This was agreed to, and his package is currently being coordinated through Community Service 1.

Support the client to implement the court ordered requirements. To do this the HC: created and coordinated a 'care team' to facilitate clear communication across the multiple service stakeholders; found appropriate providers who were willing to work with this client, (after HASS cleared the debt through brokerage), ongoing monitoring to respond to any barriers that emerged, kept in regular contact with the 'care team' to ensure the smooth implementation of the plan and provided advice about possible strategies to keep the client engaged.

Enablers for success. The ability of the HC to work long term with client to build rapport, create and support a clear care team, having flexibility to pay the debt allowing service providers to deliver services, having an appropriate service to transition the client to at the end of the HASS trial.

What else is required? The trial was focused on the immediate and pressing issues. However, the underlying health and mental health issues remain a barrier to this client's wellbeing. A comprehensive cognitive and mental health assessment carried out in his home could uncover the underlying cause of behavioural patterns. This has the potential to improve the client's wellbeing and to reduce the need for government intervention.

At the conclusion of trial: A handover from HASS to the ACT Health Older Persons Mental Health (OPMH) community team means that this client will still receive intensive case management and support to assist him to comply with the court order. Time will be needed to build up a rapport with the new case manager. The client still has outstanding payments with service providers and service provision is still at risk. He has self-referred to Care Financial to find a sustainable way to manage his finances.

Decreased frequency of regulatory action

One client talked about his experience with Health Protection Services and at the time of the interview said he had not had an inspection 'for some time'. This indicated to him that things were better and that the

regular cleaning was one of the reasons why they didn't need to come. He was disappointed that 'the money ran out' (for HASS) and the coordinator 'dropped out of the scene'. Although he did acknowledge that the HC had introduced him to practitioners from OPMH who saw him regularly. However, he felt that when the HC was involved, she could come into the house and she knew the situation with greater knowledge (about him and what needed to happen).

There are only complaints and inspections data for 4 HASS clients made available by Health Protection Services, noting they are not the only regulator. It is difficult from this data to conclude whether there has been reduced regulatory activity, although for 3 out of 4 of the clients there is now minimal interaction with HPS.

Table 1 Number of complaints, Inspections, and other regulatory activity for HASS clients

Client	Complaints		Inspections		Other activity	
	2020	2021	2020	2021	2020	2021
Client 1	1	1	Nil	1	-	-
Client 2	1	Nil	1	Nil	-	-
Client 3	-	Nil	Nil	1	-	-
Client 4	NA	NA	1	12	Expired Abatement order	Abatement order[4]

Regarding Client 4, HPS report that there has been ongoing engagement with the owner, and he has been subject to a number of enforcement notices over many years but there are no clearly logged complaints regarding this property. For a number of years, the inspection frequency was dictated by an enforcement approach which mandated the number of inspections, with concerns raised by surrounding neighbours often investigated throughout these enforcement inspections. The escalation of the enforcement approach taken by the HPS (seeking more onerous requirements for the property owner including monthly/fortnightly cleaning from 2018 onwards) required the involvement of HASS to attempt to manage (on his behalf) his requirements under the Orders and notices (notably from 2018 onwards in the first HASS trial). HPS services note that the HASS trial was of great assistance during these periods as HPS sought to mandate more ongoing arrangements (cleaners etc).

One stakeholder talked about the relationship between regulatory services and HASS and the progress that was being made in a specific case they were involved in.

> It started regulatory and HASS's role was to provide on the ground support to the client and other agencies. It is early days but seems to be going well with the state of the property, complaints from neighbours dropped off, neighbours are happy, other services, cleaners, pest control, gardening, are all in place. The separate group looks after funding, essentially if he (the client) stops paying – we may have to revert to the full regulation activity. His funding for these services is under My Aged Care. The HASS coordinator knew the systems to see what he was entitled to. She was the person who had that information and was able to sort it out. (Interview stakeholder 10).

[4] An abatement notice requires the person to clean up or remove or relocate excess waste. In extreme cases where there is a public health risk that hasn't been remedied by the property owner, the Chief Health Officer can apply to the courts for an abatement order to guarantee compliance with an abatement notice.

Discussion and Implications

This project aimed to evaluate the HASS Extension trial which was an attempt to build a more collaborative and coordinated approach to supporting people with severe hoarding and squalor issues. Case management models such as the HASS trial aim to use collaborative approaches to assist clients who have complex and interacting needs. The evidence sources for the evaluation included a synthesis of case data, HCMG referral and meeting minutes and interviews with HCMG members and with several clients. Based on these data, it is clear that the HASS fills a significant gap as a program that works with clients with complex needs in a range of flexible ways.

The findings of this evaluation reflect the complex (many types of intervention) and complicated (multiple agencies involved) nature of the HASS trial, meaning that the identification of causal strands between activities and outcomes is challenging (Rogers, 2008). This is accentuated by the small number of clients overall and limited complaint and inspection data. The trial was held over a relatively short period and was interrupted with the COVID-19 constraints. COVID-19 restrictions disrupted the ability of the HC to build the relationship with clients because no face-to-face contact was possible. There is clear evidence from previous research on how building rapport and trust is essential for change to occur and how long this can take.

Nonetheless, all stakeholders interviewed for the evaluation saw the case management process as having value in achieving outcomes for clients and the people working within the case management process. The clients interviewed felt that the HC was an ally, a navigator of helpful services and someone who understood their situation. Some features of the HASS model have emerged that provide important information for future developments to support people with complex hoarding and squalor circumstances.

Enhancements to the model

Based on the findings of this report, there is an argument for developing a broader hoarding and squalor program in the ACT. This means designing a program that coordinates services needed by clients with complex needs as well as building capacity across the service system to provide a more effective and earlier identification of needs for people who live with hoarding and squalor challenges. The current model is not able to intervene with many complex and moderate cases. In addition, its size is not sustainable with its reliance on mostly one individual’s expertise.

There is significant stigma and shame attached to hoarding and squalor and this can be a barrier to engagement. Similar programs have decided to use a less specific name for the program. For example, previously suggested programs were called 'Healthy Home, Healthy Me' and 'People over Possessions', and in NSW Mission Australia called their program 'Room to Grow'. A new program should be renamed for this reason.

The following are suggestions for enhancements to the model. It assumes that the HASS model and its focus on complex cases of hoarding and squalor that come to the attention of government services will continue as there is a need to have a coordinated response.

Understanding the scope and nature of the problem

The HCMG and the HASS trial is a response to an identified need. Apart from the HASS, there is no specialised hoarding and squalor program in the ACT. Historically there have been attempts to develop a program or service but with no long-term funding, these efforts have not been sustainable. Although only a small number of clients come to the attention of HCMG and subsequently referred to HASS, (because of the trial's capacity and guidelines), research indicates that more than 2 in 100 people in the community might meet diagnostic criteria for Hoarding Disorder with a higher rate of people who have issues with

hoarding and squalor (Nordsletten et al, 2013, Postlethwaite et al, 2019). The number of enquiries to the HC over the life of the trial, without any promotion of the service, indicate there is a significant unmet need in the community. So as to not lose momentum, connections, and relationships it is important during any redesign phase HASS is continued to be funded.

Before decisions are made about the nature of an ongoing HASS, a needs assessment should be carried out to determine the extent and nature of hoarding and squalor across Canberra. A needs assessment is essential to develop an adequate and appropriate program for clients who experience moderate and complex hoarding and squalor conditions.

Governance

Due to the uncertain ongoing funding, there has been limited policy and program documentation for HCMG and the HASS. There are HCMG terms of reference, but they remain in draft. The collaboration between directorates and services works on 'goodwill'. If it receives ongoing funding, clearer articulation of the roles of HCMG and HASS will be required.

To ensure the ongoing success of the inter-agency collaboration, a strong governance structure must be established. The HCMG is both a multi-disciplinary panel that discusses and responds to cases of hoarding and squalor as well as the oversight mechanism for the HASS. Several stakeholders argued that further attention was required to clarify the role of the HCMG and its membership. There was no consensus about whether the 'right people' were on the HCMG and most stakeholders regarded its focus as too narrow, and opportunities are missed to intervene earlier before problems are so deeply entrenched.

The HCMG could provide a more focused collaborative forum to discuss service delivery options for people who experience complex and challenging needs due to their hoarding behaviour – not just those who come to the attention of government authorities. HCMG’s role could include:

- Overseeing the work of a broader focused HASS.
- A problem solving and accountability role, to ensure that service blockages and issues for specific clients can be identified and resolved.
- A mechanism for closer working partnerships, improved communication and the monitoring and evaluation of the collaboration.
- Collecting data to identify and report systems issues to the various directorates for response and resolution.
- A focus on a clearly articulated and shared set of outcomes; this requires robust data to ensure that the shared approach is accountable for achieving real change for clients, families, and the community.
- Being responsible for reporting on joint activities and are likely to include options for building capacity within existing service providers, providing evidence of unmet need and broadening options to better serve the needs of this cohort.

The redefinition of the role of HCMG and any new HASS will be enhanced through the development of a cross directorate strategic policy for hoarding which is in development. As part of this policy project, it is expected that a clearer understanding of the extent and multifaceted nature of the needs of people who have issues with hoarding and squalor will be identified.

A voluntary service

Most stakeholders saw the benefit of continuing to locate the provision of a hoarding and squalor program in the community sector. This recognises that clients with hoarding and squalor behaviour often also have a strong distrust and fear of 'government' services. The voluntary nature of any interaction between clients

and community sector agencies ensures that clients have informed choices and actively consent to engage in developing a plan to assist them. Voluntary engagement of clients is preferred because mandated measures are often ineffective and unaligned with the therapeutic aims of case management approaches.

A voluntary service is not code for: 'we tried, they said no, or they wouldn't let us in, so we gave up'. A voluntary service requires resources to support respectful persistent outreach. People may also behave in ways that do not always meet desirable norms of behaviour (e.g., being polite, being at home when there is an appointment, accepting help in the first instance), so they are not followed up with any real effort (Deakin et al., 2020). The HASS trial has illustrated how much time is required to build relationships with people with limited trust and/or limited insight. Engagement is a therapeutic process in itself. It involves building trust and genuine relationships with potential clients. In reviews of ways to work effectively with people with complex needs, three empirically generated themes are identified as essential: collaboration, relationships (trust, connection) and empowerment-oriented practices such as involvement in decision making. These are important elements for any new program and are seen in the interactions between clients and the HASS.

Any new iteration of the HASS should continue to be voluntary and provided in the community sector recognising that hoarding clients often have limited trust in government services.

Case management model

Currently, there is limited understanding and expertise across the service sector about the social and health problems caused by hoarding and squalor and how best to respond to it. There is also nowhere to refer families for advice except if they happened to know that WCS and the HC have developed expertise. The HASS trial utilised a case management model with an identified lead agency to respond to referrals. Defining a care team with roles and responsibilities is an important element of case management models. Where this occurred in the trial, it worked well and ensured accountability, was an important communication mechanism and allowed for team decision making and problem-solving. Where it was not defined saw the HC with limited authority to implement the plan if services did not participate or deliver. In any ongoing HASS, a care team and their roles, should be clearly defined and articulated as part of the model. Currently, it is implicit and not always implemented.

In redesigning HCMG and HASS, the roles and relationships between the different members of a designated care team should be clearly defined, processes articulated, and accountability mechanisms identified.

It is essential to recognise in any redesign of the HASS that there is no one-size-fits-all approach appropriate for individuals experiencing hoarding and or squalor. Programs need to be flexible to respond to the different, individual needs, capacities and goals of clients.

Earlier intervention

More than a few people interviewed for the evaluation made the argument for widening the eligibility of cases to the HASS to reach more clients and for those with more moderate hoarding behaviours to be eligible for earlier intervention. It is understandable considering the evolution of the HCMG and the HASS trial that the focus was on those clients who come to the attention of authorities. There is no doubt there is a need for a response at the complex/crisis end, but stakeholders interviewed for the evaluation and the number of enquiries to the HC reflects an unmet need in the community.

Consideration in redesigning HASS that referrals can be accepted directly through that program to provide intervention at both the complex and more moderate end.

Time and a trauma-informed framework

The clients in the HASS experienced long-term disadvantages and complexity. These are people that require supportive, proactive, ongoing and coordinated service responses. Several HASS clients had been known to government services for many years. They are often people with interlinked problems who benefit from dedicated coordinated assistance to help them broker services over a longer period.

There were gains for some clients after the HASS intervention, but then crises had occurred subsequently which threatened those gains. This is a well-known situation when support is removed. It is unrealistic to expect that clients, particularly those with long term, multiple and complex needs, will be 'fixed' or the reversal of long-term patterns will be quick.

Once the focus of any new HASS is identified, establishing program guidelines and principles will be necessary. The principles would include what we know works best for people with complex needs and include a trauma-informed framework that recognises that many people who have hoarding and squalor issues have experienced trauma. Operationalising trauma-informed care into practice is also crucial, as is building this knowledge into policies and procedures. In the absence of trauma-informed care and responses, services are at risk of inflicting further harm.

A gap identified in the evaluation is the lack of available services to provide long term case management once the HASS trial has completed or has done what it can in the specific context. In the current environment, there is rarely funding allocated for long term intensive case management. There is evidence available that even with highly intensive therapeutic services, 'boosters' may be needed - that is, clients may need assistance again (Moran et al., 2004). This is not necessarily a program failure.

Due to the nature of people who experience hoarding and/or squalor lives (e.g. anxiety, histories of loss or trauma, long-term social isolation) a lengthy period of rapport and trust-building between staff and clients is essential to be built into the model. Further, the model should allow for higher intensity and lower intensity service without clients having to disengage and reengage with different people. It is therefore important that any new model of HASS be not too prescriptive as to the length of service provision and respond according to individual client needs.

A new program or service must explicitly work informed by a trauma-informed framework recognising that many people who have hoarding and squalor issues have experienced trauma.

Strategies for building capacity across the service system

There has been some recognition of the need to provide a broad range of services for people and families affected by hoarding and squalor. The Buried in Treasures course and Families as Motivators program is planned for later in 2021, dependent on lockdown limitations and funding.

The HC has also begun to provide training to community groups/services to increase their knowledge and skills to recognise and respond to circumstances of hoarding and squalor with very positive feedback. In any new iteration of HASS, consideration of a broader role needs to include a stronger consultation role[5], training and consistent funding for programs such as BIT and FAM.

---

[5] Consultation models could include discrete one-off 'case based' discussions (secondary consultation) or to work directly with clients (primary consultations)

Facilitation of reflective practice sessions (e.g., clinical supervision and supervision of supervision) where there are circumstances of hoarding or squalor

The new HASS could also be responsible for developing a set of resources for service providers along the lines of a Victorian resource [6].

There was mention in the minutes of HCMG of developing Communities of Practice (CoPs) for services to build expertise and problem solve. This is yet to occur but could be an important strategy to build the capacity of the service system to identify and respond to hoarding and squalor situations more effectively. CoPs are groups of people who work together on an ongoing basis and share knowledge and expertise. While CoPs can form without external support/facilitation, the evidence is that support is required to facilitate CoPs to promote knowledge generation, stimulate innovation, provide practical guidance, share knowledge, or address system change (McKellar, Saint-Charles, Berta, et al., 2020). The new HASS could support the development of CoPs and facilitate its activities.

CONCLUSION

Despite the small size of the project, the HASS trial showcases a potentially effective model for working with people living in severe hoarding and squalor. The trial highlights a gap in service delivery for a highly vulnerable client group with complex and unmet needs as well as the necessity for an earlier intervention response. Stakeholders agreed that the HASS trial model used important features to be included in a future service for people living in severe hoarding and domestic squalor. With further enhancements, based on what has been learned from this trial, a new program will play an important role in working with people who live with hoarding and squalor.

It is essential that further funding is found to support an enhanced HASS to fill the evident service gap with ongoing evaluative reflection to continue to improve on service design. Clients who hoard, especially those who are already at risk of serious consequences, need a respectful coordinated response, with strong advocacy to support their rights and to support them to respond to any legal requirements. More broadly, the service system will benefit from a workforce with an increased understanding of hoarding and squalor to enable them to recognise issues earlier and to have confidence in either providing or finding appropriate responses.

Professional advice about 'working with hoarding clients' capacity within teams, programs or organisations.

[6] https://www2.health.vic.gov.au/about/publications/policiesandguidelines/hoarding-and-squalor-practical-resource

REFERENCES

Bratiotis C, Schmalisch CS and Steketee G (2011) The hoarding handbook: A guide for human service professionals. Oxford University Press.

Bratiotis C, Woody S and Lauster N (2018) Coordinated Community-Based Hoarding Interventions: Evidence of Case Management Practices. Families in Society 100(1): 93-105.

Bratiotis C and Woody SR (2020) What's so complicated about hoarding? A view from the nexus of psychology and social work. Journal of Obsessive-Compulsive and Related Disorders 24: 100496.

Cave L, Lazarus G and O'Hare S (2016) Mission Australia's room to grow pilot program: Implementation and evaluation of a hoarding and squalor intervention in greater metropolitan Sydney. Parity 29(10): 60-62.

Dozier ME, Ayers CR. (2017) The etiology of hoarding disorder: a review. Psychopathology;50:291-6. https://doi.org/ 10.1159/000479235

Frost, R. O., Steketee, G., Williams, L. (2000). Hoarding: A community health problem. Health and Social Care in the Community, 8, 229-234.

Gleason A, Perkes D and Wand AP (2021) Managing hoarding and squalor. Australian Prescriber 44(3).

Hudon C, Chouinard MC, Pluye P, et al. (2019) Characteristics of case management in primary care associated with positive outcomes for frequent users of health care: a systematic review. The Annals of Family Medicine 17(5): 448-458.

Kwok, N., Bratiotis, C., Luu, M., Lauster, N., Kysow, K., & Woody, S. R. (2018). Examining the role of fire prevention on hoarding response teams: Vancouver Fire and Rescue Services as a case study. Fire Technology, 54, 57–73.

Layton, M and McArthur, M (2011), Healthy Home: Healthy Me. Evaluation Report for Northside Community Services, Canberra. Institute of Child Protection Studies

Maruthappu M, Hasan A and Zeltner T (2015) Enablers and Barriers in Implementing Integrated Care. Health Systems & Reform 1(4): 250-256.

McKellar KA, Saint-Charles J, Berta W, et al. (2020) Application of an evaluation framework for extra-organizational communities of practice: assessment and refinement. Canadian Journal of Program Evaluation 35(2).

Mission Australia, (2016) Room to Grow, Final Evaluation Report, Sydney

Nordsletten AE, Reichenberg A, Hatch SL, Fernández de la Cruz L, Pertusa A, Hotopf M, et al. (2013) Epidemiology of hoarding disorder. Br J Psychiatry;203:445-52. https://doi.org/10.1192/bjp.bp.113.130195

Postlethwaite, A., Kellett, S., & Mataix-Cols, D. (2019). Prevalence of hoarding disorder: A systematic review and meta-analysis. Journal of affective disorders, 256, 309-316.

Roane DM, Landers A, Sherratt J, Wilson GS. (2017) Hoarding in the elderly: a critical review of the recent literature. Int Psychogeriatr;29:1077-84. https://doi.org/10.1017/ S1041610216002465

Rogers, P. J. (2008). Using Programme Theory to Evaluate Complicated and Complex Aspects of Interventions. *Evaluation, 14*(1), 29-48.

Slatter M (2012) Law and mess. In: J. Snowdon, G. Halliday and Banerjee S (eds) Severe domestic squalor. Cambridge Cambridge University Press, pp.123-149.

Snowdon J, Shah A, Halliday G. (2007) Severe domestic squalor: a review. Int Psychogeriatr;19:37-51. https://doi.org/ 10.1017/S1041610206004236

Steketee, G., Frost, R. O. (2014). Treatment for hoarding disorder: Therapist guide. New York, NY: Oxford University Press

Tolin DF, Frost RO, Steketee G, Fitch KE. (2016) Family burden of compulsive hoarding: results of an internet survey. BehavRes Ther 2008;46:334-44. https://doi.org/10.1016/ j.brat.2007.12.008

Tolin DF, Meunier SA, Frost RO, Steketee G. (2010) Course of compulsive hoarding and its relationship to life events. Depress Anxiety 27:829-38. https://doi.org/10.1002/ da.20684

Vic Health, (2013) Hoarding and squalor: A practical resource for service providers. https://www2.health.vic.gov.au/about/publications/policiesandguidelines/hoarding-and-squalor-practical-resource

Winkworth G and White M (2010) May do, should do, can do: Collaboration between Commonwealth and State services for vulnerable children. Communities, Children and Families Australia 5(1): 5-20.