BEHIND THE CLUTTER

A CLIENT'S PERSPECTIVE OF HOARDING

MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

July 2021

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MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

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Outer East Primary Care Partnership

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I'M A COLLECTOR NOT A HOARDER!

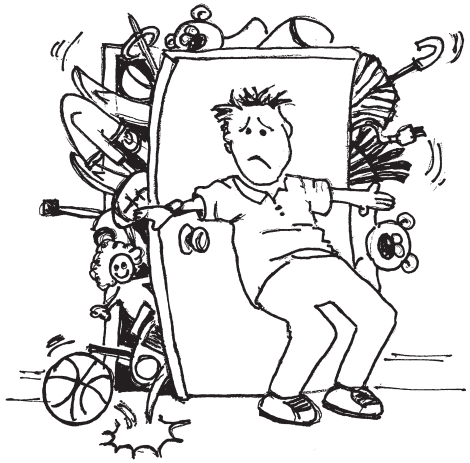
IN THE EARLY DAYS IT WAS HARD, SO MANY PEOPLE WERE JUDGEMENTAL AND WANTED TO GIVE ADVICE EVEN IF THEY WERE NOT QUALIFIED TO DO SO.

I WAS TOO EMBARRASSED TO ASK THEM IN.

I JUST WANT TO BE LEFT ALONE!

INTRODUCTION

AUSTRALIAN RESEARCH ESTIMATES THAT MORE THAN 600, 000 PEOPLE (2.6% OF THE POPULATION) MAY EXPERIENCE HOARDING DISORDER.



Hoarding behaviors can lead to significant distress and risks to the person who is hoarding as well as to others living in the home. People affected will often feel overwhelmed, relationships may break down and attempts to discard causes emotional stress. The risk of fire is significantly increased as well as other risks such as falls, an inability to access bathrooms and kitchens, electrocution, eviction, homelessness, mental health issues and structural damage to buildings and squalor.[1]

Every 4-6 days Fire Rescue Victoria firefighters respond to a fire or emergency where there is hoarding and/or squalor.[2]

An estimated 46% of people with hoarding challenges live with someone else. This increases the risk of health issues listed above to other household members, including the risk of family breakdown.

Hoarding is defined by difficulty discarding material possessions, accompanied by frequent accumulation of possessions and cluttered, disorganised living spaces.[3]

While hoarding is a diagnosable mental health condition it is rarely treated as one. Unfortunately, a stigma exists that people with hoarding behaviours are disorganised, neglectful and unsanitary. On the contrary people who hoard are often highly intelligent, hardworking and resourceful. In some cases, hoarding behaviour is only first identified once it becomes a compliance issue.

Hoarding is associated with broad impairment across multiple domains of functioning, including family and home management as well as leisure activities and work. Comorbidity is common, especially major depression, other anxiety-based disorders, attention-deficit/hyperactivity disorder, and acquisition-related impulse control disorders. Hoarding clients are also more likely than the general population to report a broad range of chronic and serious medical concerns, such as autoimmune diseases, obesity, rheumatism, stroke, or diabetes.[4]

In Australia, hoarding and squalor is estimated as a $1.8 billion issue, with minimal intervention costing around $3,000 per case. This cost can quickly escalate without coordinated and effective response and intervention.[1] In the City of Maroondah, the average cost of a single hoarding case when enforcement action is required is $47,887. Persistent hoarding takes on average 100 + hours of council staff time per property. The reported number of incidents of hoarding are rising and will continue to do so.

DEFINING HOARDING DISORDER

The DSM-5 prescribes four criteria for a diagnosis of hoarding disorder:

a) persistent difficulty discarding or parting with possessions, regardless of their actual value;

b) this difficulty being due to a perceived need to save the items, and to the distress associated with discarding them; and

c) the difficulty discarding possessions results in the accumulation of possession that congest and clutter active living areas, substantially compromising their internal use.

d) the hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment safe for oneself or others).

1. Catholic Community Services (2018) *About Hoarding and Squalor*
2. Fire Rescue Victoria website https://www.frv.vic.gov.au/hoarding-and-squalor
3. Collett, J, *Unpacking hoarding disorder*
4. Woody et al (2020) *How well do hoarding research samples represent cases that rise to community attention?*

BACKGROUND

IN OUTER EASTERN MELBOURNE THE MAROONDAH HOARDING AND SQUALOR NETWORK (MHSN) HAS BEEN ESTABLISHED.

It is a forum for local agencies and community groups confronted with hoarding and squalor issues, to come together, develop and share skills and knowledge. The network has developed a website to improve community and sector knowledge around hoarding and squalor, to build awareness of support options and to improve referral pathways.

The MSHN have identified several significant barriers when working with hoarding behaviours:

Understanding
There is a societal misunderstanding about hoarding as a mental health condition. Stigma and shame prevents people seeking help. Services are unclear of their responsibilities and duty of care. Workers in the sector may be apprehensive or even fearful about getting involved in hoarding cases. Intolerance and judgment in the community can exacerbate issues of isolation often experienced by people experiencing hoarding.

Complexity
Most situations include complex social and psychological issues requiring more complex tailored responses.

Reporting
Often occurs by a relative or neighbour when the situation is critical, resulting in lack of opportunity for early intervention and therefore increased cost of health management and clean up.

Service Coordination
Hoarding management requires an inter-agency program however no one government department oversees or funds a coordinated approach.

Funding
Services who come across clients with hoarding, often do not have capacity, skills, knowledge or funding to deal with the issue. Cost of management; ongoing counselling and clean up are significant. The introduction of My Aged care and the National Disability Insurance Scheme (NDIS) have further impacted on referral pathways.

This Project

In 2020, The Outer East Primary Care Partnership (OEPCP) and the Maroondah Hoarding and Squalor Network (MHSN) developed a set of four personas to represent the MHSN community; 2 clients with hoarding challenges, a family member and a worker from the sector. Personas are fictional, yet believable prototypes that are developed to represent a group in the community. They have individual names and stories that reflect personal attributes and behavioural characteristics such as needs, goals, attitudes and fears and frustrations.

The purpose of developing these personas was to:

- raise awareness of the issue of hoarding and its complexities
- Build empathy for clients with hoarding behaviours
- Better understand the challenges faced by those supporting people with hoarding behaviour (family members and workers).

THE MAROONDAH COUNCIL AGED & DISABILITY TEAM ALONE, RECEIVES ON AVERAGE **EIGHT** HOARDING SUPPORT ENQUIRIES PER MONTH.

Project Objectives

Use the personas as a basis to tell a story of:

- The lived experience of people experiencing hoarding – people with the condition, their carers and people working in the sector.
- The experience of people with hoarding or their family/carers accessing and using services in the sector.
- The experience of staff working in the sector trying to find/deliver services to support people experiencing hoarding.
- The key themes/challenges/gaps for all stakeholders experiencing hoarding.
- Provide considerations for Service Providers based on research findings.

METHODOLOGY

TWO CORE GROUPS WERE CONSULTED AS PART OF THE PROJECT:

LIVED EXPERIENCE
individuals and family members with hoarding challenges

Clients were invited to participate in an interview to share their experiences. A flyer was distributed via contacts of the MHSN and the project was promoted on the MHSN website. A member of the project team attended a local Buried in Treasures monthly peer support group to discuss the project. Interviews were 45-60 minutes long and held in a location that the client nominated as most comfortable for them such as their home or a local café.

While population prevalence estimates for hoarding do not differ by gender, women appear to volunteer for research in greater numbers.[5] The sample of clients in our consultation reflected this with most of our participants being female and demonstrating good to fair insight of their hoarding severity and its consequences. For people to volunteer to take part in this project, they needed to be able to identify their own hoarding problems. Poor insight about the extent or consequences of the hoarding behaviour is an obvious barrier to volunteering for our project.

PROFESSIONAL EXPERIENCE
professionals working in the sector

Staff from organisations in the region participated in a facilitated small group discussion. The purpose of these sessions was to gather insights and understand the experience of professionals who assist clients with hoarding difficulties in order to identify what is working well, what challenges exist and where there are service gaps.

Organisations represented included:

- Eastern Health
- Fire Services Victoria
- Knox City Council
- Maroondah City Council
- Mind
- My Inclusion
- Salvo Care Eastern
- Victoria Police

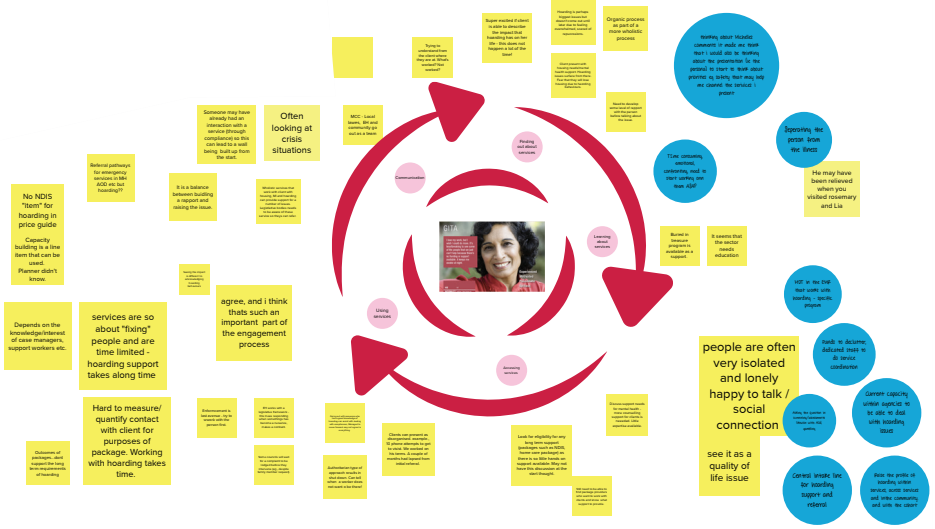
Professionals from these organisations represented a variety of programs and roles. This highlighted the breadth of services working with people with hoarding challenges and these included aged and disability, local laws, environmental health, HARP, emergency services, first responders, mental health and housing.

5. Woody et al (2020) *How well do hoarding research samples represent cases that rise to community attention?*

These images are provided as a reference to demonstrate the development process of the project. For confidentiality purposes, the content is intentionally unreadable.

SECTOR CHALLENGES

- Lack of skills and training.
- Lack of funding to support.
- No / unclear referral pathways.
- Lack of services to deal with the condition.



Output from sector consults conducted over Zoom using collaboration platform Mural.co.

USER RESEARCH – OEPCP – Hoarding Network client research output

Client consult data synthesis shown on Mural.co.

MEET OUR PERSONAS

JACK – CLIENT

EXPERIENCING SEVERE HOARDING CHALLENGES AND HAS NO INSIGHT INTO HIS SITUATION.

JACK

Loner
Rigid
Avoidant
Indignant
Thrifty

CLIENT

I PREFER TO DO THIS MYSELF AS IT'S VERY PERSONAL. I DON'T WANT ANY HELP. I DON'T NEED ANY HELP.
I JUST WANT TO BE LEFT ALONE!

AGE 74

OCCUPATION
Retired TAFE carpentry teacher

EDUCATION
Tertiary degree

FAMILY
Widower – wife Patricia passed away suddenly 9 years ago. No children

HEALTH
ABI – after an accident 9 years ago.
Back injury – ongoing pain.
Anxiety & bouts of depression.
Deteriorating health – poor eating and sleeping.
Heart issues.

BIO

Yeah hi, the name's Jack. If you're here to tell me to clean up my house you can bugger off. I'm sick of people coming around sticking their noses in and telling me what to do in my own home. People have no respect.

Sure, when Pat passed after the accident things went a bit haywire, but I'm fine now. I know I've got a fair bit of stuff, but I've built a high fence to cover it up from the street. I've got my shed and my tools and lots of things I want to do. It keeps me busy. I started collecting my books when I was in my 20s. My collection means the world to me and I am very proud of it. I'm not going to just get rid of it all! My stuff isn't rubbish, it's worth money.

I've got a bad back and I don't sleep at all. I live off canned food because I can't cook, but that's my choice. I'm not complaining. I don't have anyone and I don't care. I like to be on my own, minding my own business. Unlike everyone else around me!

INTERESTS
- Avid reader
- Tinkering in the shed and fixing things
- Scouring the Trading Post

SERVICE NEEDS
- Don't label me a 'hoarder'
- If they really want me to get rid of stuff – they could pay for a skip
- Leave me alone to do this in my own time

GOALS
- I just want to get these people off my back
- Leave me alone to tidy up. It's personal

FEARS & FRUSTRATIONS
- Everyone is hassling me – they're calling me a 'hoarder'
- Neighbours making complaints
- Council keep appearing at my door – they want to take away all my things

PERSONALITY
introvert – extrovert
analytical – creative
changeable – loyal
passive – resourceful

TECH USAGE
low – high
internet
(Accessed at the local library)
email
social media
mobile apps

PREFERRED CHANNELS
online
social media
word of mouth
media (TV, radio, print)
(Believes everything he hears on talk back radio)

INCOME LEVEL
low – high
(Asset rich, cash poor)

PAGE 10

Refer to page 10 for Jack's detailed persona and experience

SARAH – CLIENT

EXPERIENCING MID-RANGE HOARDING CHALLENGES AND SOME INSIGHT INTO HER HOARDING.

SARAH

Family focused
Overwhelmed
Alone & Scared

CLIENT

I'M SO OVERWHELMED.
I NEED HELP, BUT I'M SO ASHAMED TO TELL ANYONE ABOUT WHAT'S GOING ON. IT'S BAD. I COULD LOSE MY FAMILY.

AGE 42

OCCUPATION
Stopped working when her youngest child was 3.
Previously worked as an executive assistant.

EDUCATION
Business degree

FAMILY
Separated from husband 12 months ago.
Lives with her two children aged 10 & 7 – youngest has high functioning autism.

HEALTH
Depression & anxiety – a history trauma.
Obsessive compulsive personality.
Low energy levels.
Following a vitamin regime.
Minimal exercise.

BIO

Hello, Sarah is my name. I'm a mother of two children and three fur babies. I was married to Matthew for 13 years, but we separated 12 months ago and he moved out. I stopped work about five years ago when my daughter was diagnosed with autism. I look after her, and do my best to manage the house and all the kids stuff – school, sports, activities, play dates.

It's a struggle to get out of bed in the morning and no matter how many vitamins I take and 'good things' I do for myself, I'm constantly lacking energy. I usually pull myself together to get the kids off to school, but then get home and collapse in a heap. I find myself sitting on the couch with the dog ordering things online and buying stuff on Facebook Marketplace that I know I don't need.

INTERESTS
- Animals – has a much loved dog and two cats
- All sorts of craft – a keen sewer and knitter
- Volunteers at her kids' basketball

SERVICE NEEDS
- Someone to listen to me without judgement
- Help to get my house back in order and create a better life for me and my kids

GOALS
- I want to tidy up! I need to get back in control of my life
- I want to be closer to my kids and husband
- I want a room where my kids' friends can come over and play

FEARS & FRUSTRATIONS
- I don't know how to say no when friends offer me things
- I'm losing my connection with my family
- I don't feel like anyone understands me
- I can't get anything done – I have no energy and my surroundings are overwhelming

PERSONALITY
introvert – extrovert
analytical – creative
changeable – loyal
passive – resourceful

TECH USAGE
low – high
internet
email
social media
mobile apps

PREFERRED CHANNELS
online
social media
word of mouth
media (TV, radio, print)

INCOME LEVEL
low – high

PAGE 12

Refer to page 12 for Sarah's detailed persona and experience

MEET OUR PERSONAS

DOUG – CARER

IS THE HUSBAND OF SOMEONE WHO HAS MID-RANGE HOARDING CHALLENGES WITH LIMITED INSIGHT INTO HER HOARDING.

DOUG

Defeated
Burdened
Resentful
Pessimistic
Detached

I GIVE UP. IT'S A DISGRACE. I'VE TRIED, BUT I DON'T KNOW HOW TO HELP ANYMORE. WHAT CAN I DO?

FAMILY

AGE 52

OCCUPATION
Factory Foreman

EDUCATION
Trade school /apprentice

FAMILY
Married for 19 years
Two children 19 & 16

HEALTH
Low mood.
Just started seeking psychological support.
Issues with anxiety and depression.
Felling defeated and burdened, worn down and feeling helpless.

BIO

Hello, Doug here. There was a time when Cath and I had a lovely life. We built this house, had our two gorgeous girls, went on lots of holidays and would do things together. But about seven years ago, it all changed.

Our oldest daughter Zoe, had problems starting high school and Cath didn't cope. She got really down and fell into a state of depression. That's when all the secretive stuff started – she was buying things on the sly, saving everything, stashing stuff in cupboards, under beds. The girls and I thought it was a bit amusing to start with, but then it got out of control.

I've got her all the help I can. She's seen psychs' and counsellors, but then she just stops going. I don't think she has ever spoken to them about her 'collecting'. I can't do it anymore. I can barely move in my own bedroom, can't get to the computer or dining room. We can't invite anyone to visit. I escape to my shed, it's the only place there isn't clutter. Her stuff is all just rubbish! I just want to get a skip and throw everything out! There's no chance of that though – Cath won't admit there's a problem – and I'm done with getting abused for saying anything.

INTERESTS
- Limited interest / Socially isolated
- Uses the computer / online for social interaction

SERVICE NEEDS
- How do I get Cath to admit there's a problem?
- How do I even start to clean up this mess?

GOALS
- Find help for Cath – psychological and practical support
- Get some sense of structure and order into my home life.
- Get my life back & reconnect with my kids

FEARS & FRUSTRATIONS
- I can't even have a conversation with Cath about this. It always turns into a full blown argument
- I just don't know how to get help, or who I can even contact to talk about this
- I'm stuck in this mess and I can't see a way out except for leaving her – but the kids might never forgive me

PERSONALITY
introvert – extrovert
analytical – creative
changeable – loyal
passive – resourceful

TECH USAGE
low – high
internet
email
social media
mobile apps

PREFERRED CHANNELS
online
social media
word of mouth
media (TV, radio, print)

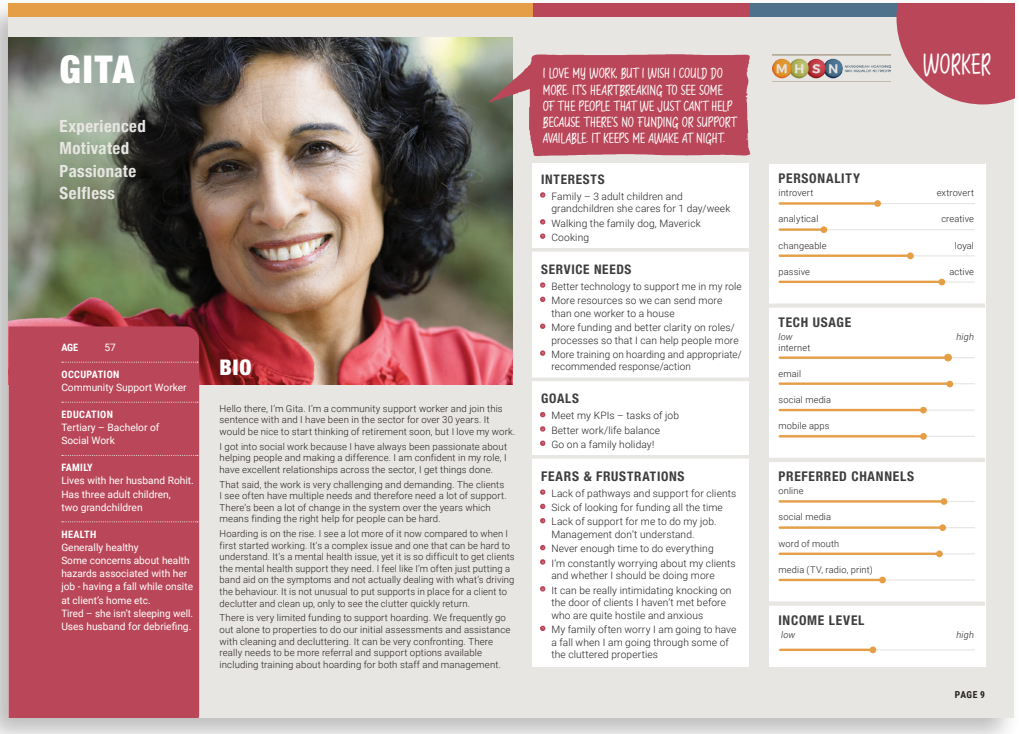
INCOME LEVEL
low – high

PAGE 14

Refer to page 14 for Doug's detailed persona and experience

GITA – WORKER

A COMMUNITY SUPPORT WORKER WORKING WITH PEOPLE WITH HOARDING CHALLENGES.



GITA

Experienced
Motivated
Passionate
Selfless

I LOVE MY WORK. BUT I WISH I COULD DO MORE. IT'S HEARTBREAKING TO SEE SOME OF THE PEOPLE THAT WE JUST CAN'T HELP BECAUSE THERE'S NO FUNDING OR SUPPORT AVAILABLE. IT KEEPS ME AWAKE AT NIGHT.

WORKER

AGE 57

OCCUPATION
Community Support Worker

EDUCATION
Tertiary – Bachelor of Social Work

FAMILY
Lives with her husband Rohit.
Has three adult children, two grandchildren

HEALTH
Generally healthy
Some concerns about health hazards associated with her job - having a fall while onsite at client's home etc.
Tired – she isn't sleeping well.
Uses husband for debriefing.

BIO

Hello there, I'm Gita. I'm a community support worker and join this sentence with and I have been in the sector for over 30 years. It would be nice to start thinking of retirement soon, but I love my work.

I got into social work because I have always been passionate about helping people and making a difference. I am confident in my role, I have excellent relationships across the sector, I get things done.

That said, the work is very challenging and demanding. The clients I see often have multiple needs and therefore need a lot of support. There's been a lot of change in the system over the years which means finding the right help for people can be hard.

Hoarding is on the rise. I see a lot more of it now compared to when I first started working. It's a complex issue and one that can be hard to understand. It's a mental health issue, yet it is so difficult to get clients the mental health support they need. I feel like I'm often just putting a band aid on the symptoms and not actually dealing with what's driving the behaviour. It is not unusual to put supports in place for a client to declutter and clean up, only to see the clutter quickly return.

There is very limited funding to support hoarding. We frequently go out alone to properties to do our initial assessments and assistance with cleaning and decluttering. It can be very confronting. There really needs to be more referral and support options available including training about hoarding for both staff and management.

INTERESTS
- Family – 3 adult children and grandchildren she cares for 1 day/week
- Walking the family dog, Maverick
- Cooking

SERVICE NEEDS
- Better technology to support me in my role
- More resources so we can send more than one worker to a house
- More funding and better clarity on roles/ processes so that I can help people more
- More training on hoarding and appropriate/ recommended response/action

GOALS
- Meet my KPIs – tasks of job
- Better work/life balance
- Go on a family holiday!

FEARS & FRUSTRATIONS
- Lack of pathways and support for clients
- Sick of looking for funding all the time
- Lack of support for me to do my job. Management don't understand.
- Never enough time to do everything
- I'm constantly worrying about my clients and whether I should be doing more
- It can be really intimidating knocking on the door of clients I haven't met before who are quite hostile and anxious
- My family often worry I am going to have a fall when I am going through some of the cluttered properties

PERSONALITY
introvert – extrovert
analytical – creative
changeable – loyal
passive – active

TECH USAGE
low – high
internet
email
social media
mobile apps

PREFERRED CHANNELS
online
social media
word of mouth
media (TV, radio, print)

INCOME LEVEL
low – high

PAGE 9

Refer to page 9 for Gita's detailed persona

WHAT'S IMPORTANT TO PEOPLE EXPERIENCING HOARDING
CORE THEMES

IN SPEAKING TO THOSE WITH LIVED EXPERIENCE, THREE CORE THEMES WERE IDENTIFIED AS CRITICAL FOR PEOPLE TO ENGAGE WITH SERVICES AND ACCEPT HELP WITH THEIR HOARDING BEHAVIOUR.

NON-JUDGEMENTAL APPROACH

Participants articulated a significant level of shame and stigma associated with their hoarding behaviours. The research findings clearly demonstrate that successful engagement occurs when people feel service providers can see and engage with them as a person first and as someone who experiences hoarding challenges second.

Participants spoke positively about service providers who showed:

Empathy
> The first time he came out I felt really ashamed and embarrassed. But he said, 'Believe me, I've seen a lot worse than this. Don't feel bad.'

Motivation
> He was lovely. He said to me, 'I'll make a deal with you, you clean up one room and we'll paint it.'

Perseverance
> I had no will to move. I was very depressed. She understood. She said we'll just move the appointment to the next fortnight. Even though she could have charged me for it, she didn't.

Flexibility
> We managed to move forward but may not have agreed to everything.

Empowerment
> So, you can't sit there and go, 'I'm imposing my priorities on you, this is what you need to do.'

PRACTICAL SUPPORT

In addition to an empathic and non-judgemental approach, the most successful outcomes are achieved when practical supports are offered and well-utilised. People experiencing hoarding challenges usually have physical or mental barriers that will prevent them from taking the steps required to 'clean up' on their own. Supporting people in this situation typically requires several coordinated service options. Participants spoke about the following practical supports as being beneficial:

- Hands on support with the decluttering process. This typically involves someone to help with the process of sorting items into categories eg., keeping, selling, discarding.
- Booking skips for the removal of items from the home once the individual is ready to discard items.
- Utilising council hard waste collections including the negotiation of additional bookings in the instance where booking caps have been exceeded.
- Industrial cleaning services.
- Referral to counselling services and self-help groups such as the Buried in Treasures program.

COLLABORATIVE SERVICES

In the current environment where awareness of the condition and funding to support hoarding is fragmented, coordinated support across multiple providers is critical.

The participants who had experienced positive outcomes had all received support from several services. These services appeared to work collaboratively with each other. In the most successful scenarios, the individuals described feeling like they had a team of people on their side, wanting to support them to deal with their hoarding challenges.

In these instances, a collaborative model was described as:

- A team providing motivation and inspiration to continue on the decluttering path. e.g. clear out this room and we'll paint it.
- Facilitated referrals between service providers to coordinate a program of practical and emotional support. For example:
  - Council – environmental health, local laws, community support – aged and disability
  - Social and Community support
  - Housing – government and community services
  - Buried In Treasures self-help support group
  - Decluttering and industrial cleaning services
  - Counsellors and psychologists

MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

GITA

Experienced
Motivated
Passionate
Selfless

I LOVE MY WORK, BUT I WISH I COULD DO MORE. IT'S HEARTBREAKING TO SEE SOME OF THE PEOPLE THAT WE JUST CAN'T HELP BECAUSE THERE'S NO FUNDING OR SUPPORT AVAILABLE. IT KEEPS ME AWAKE AT NIGHT.

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Lives with her husband Rohit. Has three adult children, two grandchildren

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Tired – she isn't sleeping well.
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There is very limited funding to support hoarding. We frequently go out alone to properties and it can be very confronting. There really needs to be more referral and support options available including training about hoarding for both staff and management.

INTERESTS

- Family
- Walking the family dog, Maverick
- Cooking

SERVICE NEEDS

- Better technology to support me in my role
- More resources so we can send more than one worker to a house
- More funding and clarity on processes so I can help people more
- More training on hoarding

GOALS

- Meet my KPIs – tasks of job
- Better work/life balance
- Go on a family holiday!

FEARS & FRUSTRATIONS

- Lack of pathways and support for clients
- Sick of looking for funding all the time
- Lack of support for me to do my job. Management don't understand.
- I'm constantly worrying about my clients and whether I should be doing more
- It can be intimidating knocking on the door of clients I haven't met before
- My family worry about me doing this work

PERSONALITY

introvert — extrovert
analytical — creative
changeable — loyal
passive — active

TECH USAGE

low — *high*
internet
email
social media
mobile apps

PREFERRED CHANNELS

online
social media
word of mouth
media (TV, radio, print)

INCOME LEVEL

low — *high*

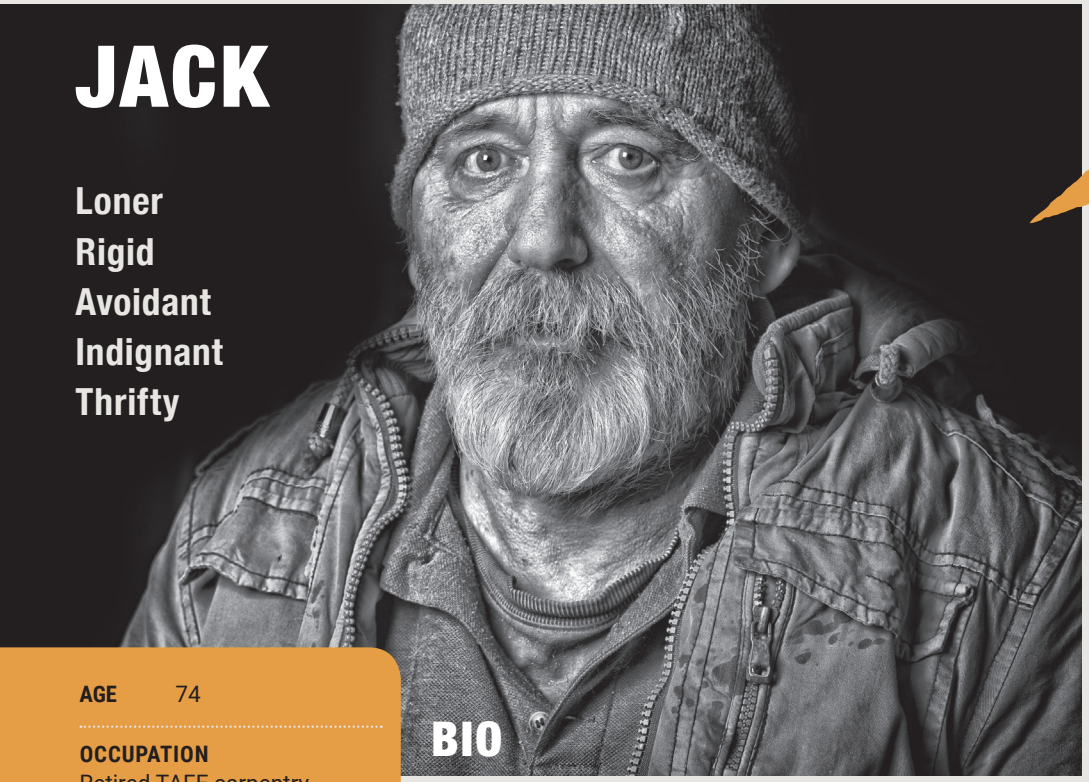
The Experience of the Personas

The following pages detail the personas and their lived experience with hoarding challenges.

Jack, Sarah and Doug are presented individually, while Gita's experience as a sector worker is reflected in response to supporting each of the personas.

JACK

Loner
Rigid
Avoidant
Indignant
Thrifty



AGE 74

OCCUPATION
Retired TAFE carpentry teacher

EDUCATION
Tertiary degree

FAMILY
Widower – wife Patricia passed away suddenly 9 years ago. No children

HEALTH
ABI – after an accident 9 years ago.
Back injury – ongoing pain.
Anxiety & bouts of depression.
Deteriorating health – poor eating and sleeping.
Heart issues.

BIO

Yeah hi, the name's Jack. If you're here to tell me to clean up my house you can bugger off. I'm sick of people coming around sticking their noses in and telling me what to do in my own home. People have no respect.

Sure, when Pat passed after the accident things went a bit haywire, but I'm fine now. I know I've got a fair bit of stuff, but I've built a high fence to cover it up from the street. I've got my shed and my tools and lots of things I want to do. It keeps me busy. I started collecting my books when I was in my 20s. My collection means the world to me and I am very proud of it. I'm not going to just get rid of it all! My stuff isn't rubbish, it's worth money.

I've got a bad back and I don't sleep at all. I live off canned food because I can't cook, but that's my choice. I'm not complaining. I don't have anyone and I don't care. I like to be on my own, minding my own business. Unlike everyone else around me!

I PREFER TO DO THIS MYSELF AS IT'S VERY PERSONAL. I DON'T WANT ANY HELP. I DON'T NEED ANY HELP.

I JUST WANT TO BE LEFT ALONE!

INTERESTS

- Avid reader
- Tinkering in the shed and fixing things
- Scouring the Trading Post

SERVICE NEEDS

- Don't label me a 'hoarder'
- If they really want me to get rid of stuff – they could pay for a skip
- Leave me alone to do this in my own time

GOALS

- I just want to get these people off my back
- Leave me alone to tidy up. It's personal

FEARS & FRUSTRATIONS

- Everyone is hassling me – they're calling me a 'hoarder'
- Neighbours making complaints
- Council keep appearing at my door – they want to take away all my things

MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

CLIENT

PERSONALITY

introvert — extrovert
analytical — creative
changeable — loyal
passive — resourceful

TECH USAGE

low — *high*
internet
(Accessed at the local library)
email
social media
mobile apps

PREFERRED CHANNELS

online
social media
word of mouth
media (TV, radio, print)
(Believes everything he hears on talk back radio)

INCOME LEVEL

low — *high*
(Asset rich, cash poor)

JACK'S EXPERIENCE

SCENARIO

The council is sending me letters and coming around telling me I have to clean the place up or they'll fine me. They say my property is a risk to others and apparently neighbours have been complaining.

Yeah ok, the house isn't in great nick. I don't have heating and the rain causes some issues at times, but I'm fine. I just don't see what the problem is. I wish people would mind their own business and leave me the bloody-hell alone.

NON-JUDGEMENTAL APPROACH

HOW HAS MY DODGY FENCE LED TO PEOPLE COMING TO MY HOUSE AND TELLING ME TO CLEAN UP?

DON'T LABEL ME. I AM A COLLECTOR... NOT A HOARDER.

SHE HATED BEING HERE... KEPT SAYING 'PEOPLE LIKE YOU' AND LOOKING AROUND MY PLACE WITH SUCH DISGUST.

SHE WAS A NICE LADY. SHE JUST WANTED TO CHAT ABOUT THE FENCE AND WHAT WE CAN DO TO GET IT FIXED. SHE DIDN'T CALL ME UNTIDY LIKE OTHERS HAVE..

- We've got to acknowledge Jack and separate out the environment from the person. We need to be patient, and take time to build his trust.
- Going out with someone who has a good knowledge of hoarding can assist with dealing with compliances.

PRACTICAL SUPPORT

THEY DID SAY I COULD GET A FEW EXTRA HARD RUBBISH COLLECTIONS, AND SOMEONE FROM THE FIRE BRIGADE CAME OVER AND SAID THEY'D CHECK MY SMOKE ALARMS.

I'LL SORT THINGS OUT ON MY OWN. I'LL ASK FOR HELP IF I NEED IT.

THEY'RE SENDING ME LEGAL LETTERS, THE COPS ARE COMING AROUND, THEY'RE TELLING ME THEY'LL COME AROUND AND TAKE ALL MY STUFF.

- Focusing on safety with Jack is a good lead in to making change. Smoke detectors or clearing a corner of the yard are sometimes achievable first steps.

COLLABORATIVE SERVICES

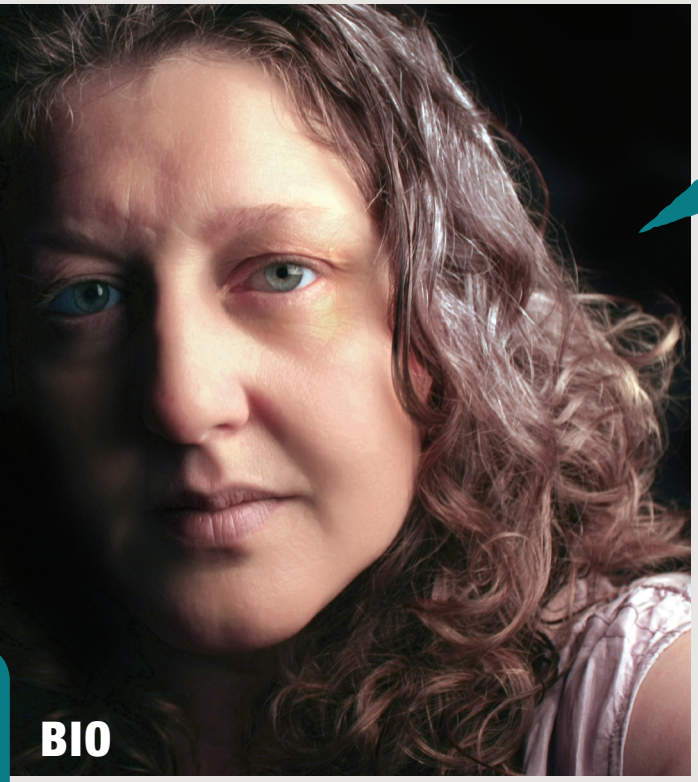
STOP ALL THESE DIFFERENT GROUPS COMING AT ME. EVERY WEEK SOME NEW PERSON WTH A FANCY TITLE HASSLING ME.

AT LEAST THEY'VE STOPPED SENDING ROUND A DIFFERENT PERSON EVERY OTHER WEEK. IT'S JUST THAT NICE LADY FROM COUNCIL THAT DROPS BY NOW.

THEY'RE TELLING ME ALL THESE THINGS THEY CAN HELP WITH. BUT I DON'T NEED ANY HELP.

- Clear communication with sector peers is vital. It's important we don't overwhelm the client with multiple contacts. We need to work together in a coordinated way to ensure they get the support they need without being hassled.

SARAH



Family focused
Overwhelmed
Alone & Scared

AGE 42

OCCUPATION
Stopped working when her youngest child was 3.
Previously worked as an executive assistant.

EDUCATION
Business degree

FAMILY
Separated from husband 12 months ago.
Lives with her two children aged 10 & 7 – youngest has high functioning autism.

HEALTH
Depression & anxiety – a history trauma.
Obsessive compulsive personality.
Low energy levels.
Following a vitamin regime.
Minimal exercise.

BIO

Hello, Sarah is my name. I'm a mother of two children and three fur babies. I was married to Matthew for 13 years, but we separated 12 months ago and he moved out. I stopped work about five years ago when my daughter was diagnosed with autism. I look after her, and do my best to manage the house and all the kids stuff – school, sports, activities, play dates.

It's a struggle to get out of bed in the morning and no matter how many vitamins I take and 'good things' I do for myself, I'm constantly lacking energy. I usually pull myself together to get the kids off to school, but then get home and collapse in a heap. I find myself sitting on the couch with the dog ordering things online and buying stuff on Facebook Marketplace that I know I don't need.

MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

CLIENT

I'M SO OVERWHELMED.

I NEED HELP, BUT I'M SO ASHAMED TO TELL ANYONE ABOUT WHAT'S GOING ON. IT'S BAD, I COULD LOSE MY FAMILY.

INTERESTS

- Animals – has a much loved dog and two cats
- All sorts of craft – a keen sewer and knitter
- Volunteers at her kids' basketball

SERVICE NEEDS

- Someone to listen to me without judgement
- Help to get my house back in order and create a better life for me and my kids

GOALS

- I want to tidy up! I need to get back in control of my life
- I want to be closer to my kids and husband
- I want a room where my kids' friends can come over and play

FEARS & FRUSTRATIONS

- I don't know how to say no when friends offer me things
- I'm losing my connection with my family
- I don't feel like anyone understands me
- I can't get anything done – I have no energy and my surroundings are overwhelming

PERSONALITY

introvert — extrovert
analytical — creative
changeable — loyal
passive — resourceful

TECH USAGE

low — *high*
internet
email
social media
mobile apps

PREFERRED CHANNELS

online
social media
word of mouth
media (TV, radio, print)

INCOME LEVEL

low — *high*

SARAH'S EXPERIENCE

SCENARIO

About 3 years ago I started to realise things were getting out of hand. Matt was travelling more for work and I was left home with the girls. Life was like groundhog day. I was doing nothing, achieving nothing, just stuck at home looking after everyone. It started with my craft room. It slowly became jam packed. Everything was perfectly organised and colour coordinated but you could barely move. Now it's taking over the house.

It's a mess. It's really cluttered and I can't find anything anymore. Friends have offered to help me sort through things but I'm so embarrassed. I don't let anyone come into the house anymore. The kids can't even have friends over. I was once a really efficient personal assistant – super organised and on top of things. But now look at me, I'm not coping.

NON-JUDGEMENTAL APPROACH

YOU NEED TO TAKE TIME TO GET TO KNOW MY STORY. TRY TO UNDERSTAND WHAT MY FAMILY AND LIFE IS LIKE.

I'VE SPENT YEARS KEEPING PEOPLE AT BAY. SO MUCH SHAME – CAN I REALLY LET SOMEONE SEE THIS?

GITA WAS SO UNDERSTANDING AND KIND, AND NEVER PUT ME DOWN. SHE WAS ALWAYS POSITIVE.

- Spending time with Sarah to get to know her and understand her life builds trust.
- I try to establish what will motivate Sarah. Her kids being able to have friends over is a big incentive.
- It's important to set realistic expectations with Sarah. Let her know we understand this is difficult and we don't expect her to fix things overnight.

PRACTICAL SUPPORT

IT FEELS IMPOSSIBLE. WHERE DO I EVEN START? I NEED TO WORK OUT WHY I DO THIS AND HOW TO GET BACK IN CONTROL.

I NEED HELP TO SORT THROUGH MY STUFF. I CAN'T GET ANY EXTRA HARD-RUBBISH COLLECTIONS OR HELP TO GET THINGS OUT TO THE NATURE-STRIP. I CAN'T DO IT ALONE!

GITA EXPLAINED THE STEPS / ROLES AND PROCESS REALLY CLEARLY. I FELT IN CONTROL BUT SUPPORTED.

GOING TO THE BURIED IN TREASURES GROUP HAS BEEN GOOD. I DIDN'T REALISE THERE WAS SO MANY PEOPLE LIKE ME.

- I explain my role and the focus of our services. We discuss our way of working with a focus on empowering Sarah and not taking over.
- I explore different options with Sarah. I will refer her for support with decluttering. This may be tricky as Sarah is not eligible for funding and it is expensive.
- Sarah needs emotional support. There are limited options for counsellors with hoarding expertise.

COLLABORATIVE SERVICES

THEY ARE TALKING ABOUT A SERVICE WHO MAY BE ABLE TO GET ME A SKIP. THAT WOULD MAKE A BIG DIFFERENCE.

APPARENTLY I'VE BEEN REGISTERED WITH THE FIRE BRIGADE AS A HOARDERS HOUSE. NO ONE TOLD ME THEY WERE DOING THIS!

GITA HAS INTRODUCED ME TO A FEW PEOPLE. THEY ALL SEEM TO WORK TOGETHER AND HAVE THE SAME GOAL OF CREATING A GOOD ENVIRONMENT FOR MY FAMILY AND ME.

- Sarah is not eligible for any funding – I'm going to have to get creative.
- It's so frustrating. For a client with hoarding, especially one with no funding, services are scarce. I'm constantly calling on favours to scrape together support for people.
- It shouldn't have gotten his bad, but hoarding can be very confronting. Some services might put in the 'too hard basket.'

MHSN MAROONDAH HOARDING AND SQUALOR NETWORK

DOUG

Defeated
Burdened
Resentful
Pessimistic
Detached

I GIVE UP. IT'S A DISGRACE. I'VE TRIED, BUT I DON'T KNOW HOW TO HELP ANYMORE.
WHAT CAN I DO?

AGE 52

OCCUPATION
Factory Foreman

EDUCATION
Trade school /apprentice

FAMILY
Married for 19 years
Two children 19 & 16

HEALTH
Low mood.
Just started seeking psychological support.
Issues with anxiety and depression.
Felling defeated and burdened, worn down and feeling helpless.

BIO

Hello, Doug here. There was a time when Cath and I had a lovely life. We built this house, had our two gorgeous girls, went on lots of holidays and would do things together. But about seven years ago, it all changed.

Our oldest daughter Zoe, had problems starting high school and Cath didn't cope. She got really down and fell into a state of depression. That's when all the secretive stuff started – she was buying things on the sly, saving everything, stashing stuff in cupboards, under beds. The girls and I thought it was a bit amusing to start with, but then it got out of control.

I've got her all the help I can. She's seen psychs' and counsellors, but then she just stops going. I don't think she has ever spoken to them about her 'collecting'. I can't do it anymore. I can barely move in my own bedroom, can't get to the computer or dining room. We can't invite anyone to visit. I escape to my shed, it's the only place there isn't clutter. Her stuff is all just rubbish! I just want to get a skip and throw everything out! There's no chance of that though – Cath won't admit there's a problem – and I'm done with getting abused for saying anything.

INTERESTS

- Limited interest / Socially isolated
- Uses the computer / online for social interaction

SERVICE NEEDS

- How do I get Cath to admit there's a problem?
- How do I even start to clean up this mess?

GOALS

- Find help for Cath – psychological and practical support
- Get some sense of structure and order into my home life.
- Get my life back & reconnect with my kids

FEARS & FRUSTRATIONS

- I can't even have a conversation with Cath about this. It always turns into a full blown argument
- I just don't know how to get help, or who I can even contact to talk about this
- I'm stuck in this mess and I can't see a way out except for leaving her – but the kids might never forgive me

PERSONALITY

introvert — extrovert
analytical — creative
changeable — loyal
passive — resourceful

TECH USAGE

low — *high*
internet
email
social media
mobile apps

PREFERRED CHANNELS

online
social media
word of mouth
media (TV, radio, print)

INCOME LEVEL

low — *high*

DOUG'S EXPERIENCE

SCENARIO

I wish when we first had services knocking on our door saying there was a problem, I hadn't been so defensive and told them that everything was fine. Maybe if I hadn't made so many excuses for her behaviour we could have got the help we needed. It's destroyed my family. Zoe moved away as soon as she could and my youngest, Claire is never here. Neither of them really talk to us anymore. I guess they're embarrassed of both of us – we've both given up.

I decided to have a look online to see if I could find anything about hoarding. It seems the council has some stuff on offer and a woman gave me call to discuss.

NON-JUDGEMENTAL APPROACH

I'M REALLY UNSURE ABOUT GETTING SERVICES INVOLVED. WHAT WILL IT DO TO MY FAMILY, MY WIFE?

DON'T JUDGE ME OR MY FAMILY... WE ONCE HAD A BEAUTIFUL HOUSE. AND PLEASE DON'T GIVE ADVICE WHEN YOU ARE NOT QUALIFIED TO DO SO.

PRACTICAL SUPPORT

I JUST WANT TO KNOW HOW TO TALK TO CATH ABOUT THIS WITHOUT THE ARGUMENTS.

CAN I GET HELP IN THE BACKGROUND WITHOUT HER KNOWING?

I WENT TO A COUPLE OF THE BURIED IN TREASURES GROUPS WHICH WAS OK. I UNDERSTAND IT A BIT BETTER NOW BUT I WISH THERE WAS A GROUP FOCUSED ON HOW TO HELP AS A FAMILY MEMBER.

COLLABORATIVE SERVICES

I RECKON TALKING TO A COUNSELLOR MIGHT BE GOOD FOR ME, BUT I WANT TO SPEAK TO SOMEONE WHO UNDERSTANDS HOARDING.

GITA HAS INTRODUCED ME TO A LADY WHO DOES DECLUTTERING. IT'S EXPENSIVE AND I'M NOT SURE IT WILL WORK, BUT I'M GOING TO TRY AND GET CATH TO MEET WITH HER.

- Families are often the first ones to raise a concern. I will need to have lots of conversations with Doug prior to any engagement with Cath. He needs to trust me.
- Family involvement can be tricky. Some do not necessarily have the clients best interests at heart.

- I wish we had a more resources to help families. Info sessions and specific groups for them would be ideal.
- Doug, so what do we need to do to support YOU in all of this?

- To help Doug I need a network of people who understand mental health and hoarding. He needs skills to support his wife. This is tough, because there's not a lot available.

OBSERVATIONS FOR SERVICE PROVIDERS

CORE THEMES

NON-JUDGEMENTAL APPROACH

THEY CAME IN AND THEY SAID, "YOU'VE GOT TO DO SOMETHING ABOUT THIS. IF YOU DON'T DO ANYTHING ABOUT IT, YOU WILL BE OUT." THIS MADE FEEL HORRIBLE, TERRIBLE.

YOU CAN'T GO TO THE FIRST VISIT WITH A MOP AND BUCKET EXPECTING TO BE CLEANING UP.

Establishing trust is a critical first step to gaining traction with anyone experiencing hoarding. While it is not yet widely recognised, hoarding disorder is a mental illness. Therefore, people experiencing hoarding should be treated with the same respect and care as those with other mental illnesses.

Most hoarding clients do not actively seek help and may resist intervention. Clients who have previously had interactions with services (because of risk of eviction; complaints from neighbours etc) may have increased resistance and uncertainty, particularly if these experiences were negative. With this is mind it is imperative that services allow time to engage with clients and build rapport and trust.

Trust is established with a non-judgemental, empathetic and curious approach. Over time conversations can be directed towards understanding the person's hoarding behaviour. This includes, how the hoarding first started; identifying other services in place; what support has worked in the past; exploring new options and clarifying worker and client roles. It is also necessary to identify how committed the person is to reducing clutter. This evolves over a number of visits – not just one.

In many cases hoarding behaviours remain private until the situation becomes extreme. Most of the participants we spoke to did not actively seek assistance for their hoarding. Support came as a result of either contact with a service provider for other support needs (e.g., assessment for home maintenance) or when multiple service professionals became involved as a result of a fire hazard, neighbour complaint or squalor. This highlights the importance of having a workforce who are aware of the challenges around hoarding and are trained to identify and sensitively respond to signs of hoarding. Many clients also fear the consequences of the discovery of their hoarding behaviour. These consequences can range from social (e.g., stigma, ostracism, judgment) to deeply practical (being evicted, family services getting involved etc.).

In some instances, it can take months from the time of the initial referral, just to make an appointment to visit the home. Multiple phone calls and persistence may be required to get past a person's willingness to engage and/or the disorganisation in some people's lives. Sometimes the state of the home is at a point where workers cannot enter to do an assessment. However, regardless of the severity services must persist to ensure access to supports.

Understanding why people acquire and save possessions can be insightful. Many of the participants we spoke to described the emotional attachment and sentimental value they had with many of their items. Avoidance of waste was also a frequent motivator for acquiring and saving possessions. It is important to acknowledge that working with hoarding can be confronting and emotional particularly when family members, children or animals are living in the home. Services need to ensure they are appropriately training and supporting staff and their management to deal with the complexities of hoarding.

I'M WORRIED THAT HE MIGHT TRY AND TAKE THE KIDS OFF ME, USE MY HOUSE AGAINST ME.

EARLY INTERVENTION IS LACKING WHICH IS MOST LIKELY DUE TO THE LACK OF AWARENESS AND EDUCATION. SERVICES ARE NOT COMING IN UNTIL IT HITS CRISIS POINT.

I HAVE A PROBLEM OF SAYING NO.... I TAKE IT EVEN THOUGH I KNOW I DON'T NEED IT.

WE HAVE SAT WITH CLIENTS IN THE DRIVEWAY ON CAMP CHAIRS IF WE CANNOT ENTER THE HOME FOR SAFETY REASONS.

I HATE WASTE. I HATE THINGS GOING TO LANDFILL.

CORE THEMES

PRACTICAL SUPPORT

THE COUNCIL SAID I COULD HAVE AS MANY PICK-UPS FOR A YEAR AS I WANTED TO GET RID OF STUFF.

THEY WANT YOU TO DRAG IT OUT ON THE WEEKEND. IT WOULD TAKE ME WEEKS AND WEEKS TO DRAG STUFF OUT THE FRONT.

The participants we spoke to had previously or were currently receiving some sort of practical support. Hoarding support options are limited and expensive. In most cases financial assistance was provided by community service providers to fund this.

Hands-on Support

The most common support offered is the sourcing of a skip and additional hard rubbish collections. Most participants had utilised their allocated hard rubbish pick-ups and were hugely appreciative when services were able to negotiate an extra collection.

However, this was not an option for everyone. Some councils in the region would not deviate from their hard rubbish process. For example, some councils provide only two collections per year, while others require that materials are only placed curbside on the weekend prior to pick up. This is not always feasible for people with hoarding behaviour who have lots of items to dispose of, often have physical limitations and may live alone.

IT'S THE PHYSICAL PART THAT REALLY KNOCKS ME AROUND. I JUST DO A BIT, AND THEN I'M LATHERED IN PERSPIRATION AND GASPING FOR AIR.

Assistance with decluttering was the other primary support that participants spoke of highly. However, decluttering services are extremely limited, especially those which are publicly funded. A limited number of local councils provide this type of support for low-level hoarding behaviour, but it is only focused on achieving short term goals. For example, to get domestic assistance in place or decrease risk of fire, eviction etc. Private decluttering services offer long-term support, but the costs are a significant barrier for most people.

For most people the process of sorting items is both emotionally and physically draining. While working with a decluttering service may give them strategies, their physical and personal circumstance often hinders their ability to continue with the decluttering process independently. This can include a lack of family support, motivation and health issues.

SHE'S FANTASTIC. SHE SETS UP HER TABLE, WE HANDLE THE OBJECTS. SHE TALKS ME THROUGH THE THINKING AROUND EACH OBJECT AND HELPS ME DECIDE WHAT TO DO WITH IT.

BURIED IN TREASURES

The Buried in Treasures program is a self-help group that is internationally recognised. It is based on the book *Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding*, by Dr Randy Frost, Dr David Tolin and Dr Gail Steketee who are among the world's leading experts in the study and treatment of hoarding challenges.

The group runs for 16 weeks. Each week specific challenges and topics are covered. The course looks at increasing participants understanding about why they collect; explores thought processes and practical steps and strategies to help participants make decisions about which items to save and how to resist collecting more.

CORE THEMES

PRACTICAL SUPPORT

ONCE A PACKAGE IS IN PLACE, FINDING A PACKAGE PROVIDER WHO WANTS TO AND KNOWS HOW TO WORK WITH CLIENTS WITH HOARDING BEHAVIOURS, IS A CHALLENGE.

IF I DIDN'T HAVE NDIS FUNDING, WE WOULDN'T BE ABLE TO AFFORD IT.

Funding

If the individual is eligible, long-term decluttering support can be achieved through funding such as NDIS and Home Care Packages. However access and pathways to these funding options can be complex and lengthy and staff may lack confidence to deal with the issue of hoarding.

In the case of the NDIS this requires some creativity as the NDIS does not have a specific item for hoarding support. Capacity building is a line item that has been used for this purpose. However, not all NDIS planners are aware of this and in general the NDIS struggles to understand how hoarding behaviour fits into mental health support.

OH, I DIDN'T REALISE THERE WERE SO MANY PEOPLE THAT DID THIS.

Emotional/Psychological Support

An important foundation for receiving practical support is the person having some level of insight about their hoarding. Everyone who took part in the research had some level of insight, yet very few participants had ever received formal counselling or psychological therapy specific to their hoarding behaviour.

For some people this insight came from participating in the Buried in Treasures program. These clients spoke about the valuable insights and strategies the program provided. It also offered a sense of belonging and understanding achieved by connecting to other people with similar challenges.

In response to participant feedback for ongoing support a monthly peer support group known as BITS has been established to support those who are dealing with hoarding challenges. BITS is facilitated by people with lived experience and offers ongoing support, information and connection. Some of the group members spoke about helping out with the decluttering process in each other's homes.

IT EXPLAINED EVERYTHING, WHY WE WERE LIKE THAT AND WHAT TO DO ABOUT IT. EACH WEEK WE HAD SOMETHING WE HAD TO DO AT HOME.

MORE COUNSELLING SUPPORT FOR CLIENTS IS NEEDED. LITTLE EXPERTISE AVAILABLE.

IF ANYBODY WANTS HELP TO CLEANUP, WE WILL HELP. ONE OF THE GROUP WAS HAVING AN INSPECTION. SO THREE OF US WENT DOWN TO HELP HER.

CORE THEMES

COLLABORATIVE SERVICES

Collaboration in Action

Some of the research participants had several services involved in their care. In these instances, each service had a specific area of focus related either directly, or indirectly to hoarding support. By joining forces with other service providers a holistic support model was delivered. Such services included:

- Council and local laws
- Community services
- Health providers
- Housing services
- Cleaning and decluttering

When multiple services were involved the clients were not always clear on the 'who's who' or 'who was doing what.' However, this service model was always a positive experience. The clients' perception was services worked collaboratively to assist with their hoarding and health challenges.

MY NEIGHBOUR WOULD ALWAYS ASK ME OVER FOR COFFEE. SHE'D SAY, "I'VE NEVER BEEN TO YOUR PLACE" AND I THOUGHT, "OH WELL, I'LL ASK YOU ONE DAY." I NEVER GOT ROUND TO IT. BUT NOW SHE COMES ALL THE TIME.

Case Study 1

A woman in her 70's living in public housing had a department property inspection. Hoarding issues were identified. After an initial negative experience with a housing representative, she was paired with an empathetic and non-judgemental person who helped her get the support she needed. This included:

- Incentivising her clean up with the property improvements – painting and window furnishings – Public Housing
- Sourcing and paying for a skip – Community Service organisation
- Council:
  - Coordinating extra hard rubbish
  - Referral to Buried in Treasures program

With the collaborative support of these organisations, the woman made great progress. She now proudly has guests in her home and feels secure in her long-term housing. She spoke about the challenges of keeping on top of things. For example, the isolation impacts of Covid affected her and she noticed herself slipping back into her old ways. Thankfully, the awareness she had picked up from the Buried in Treasures program enabled her to identify the behaviour and make changes early.

I HAD STUFF IN EVERY ROOM AND ONLY NARROW PATHWAYS THROUGHOUT THE HOUSE. YOU HAD TO LEAP-FROG TO GET INTO BED.

CORE THEMES

COLLABORATIVE SERVICES

THE KIDS AT LEAST ARE IN A CLEAN HOUSE AND THERE'S NOT MICE AROUND EVERYWHERE.

THEY THREW OUT ALL MY LOUNGE SUITS AND EVERYTHING.

THEY WORKED TOGETHER AND SEEMED TO ALL GET ALONG WELL. THEY ALL WANTED THE SAME GOAL WHICH WAS TO HAVE A GOOD ENVIRONMENT FOR ME AND MY FAMILY.

Case Study 2

A woman who spoke of living a minimalist lifestyle in her 20's, experienced a series of traumatic personal events that kick started her hoarding behaviour. Now in her 40's, she found herself living in a squalor environment with her children. Her hoarding had become so severe that an infestation of mice required her to engage a pest control service. Six months later, when the mice returned, she realised she was financially unable to cover another round of pest control. At this point she reached out for help.

Through the involvement of several services an industrial scale clean was coordinated. This clean up was organised once all other attempts had been exhausted. It was put into action quickly and over a couple of days almost everything removed from the home. The clean-up was traumatic for the client. She had no say in what was discarded and she lost many sentimental items.

While the grief of losing everything has been painful, she is now able to reflect on this as a necessary and life-changing experience. She appreciates that her family is now living in a clean home and her kids can have friends visit.

In relation to the collaboration between services, the woman spoke of everyone working together towards a common goal – to support her to clean up and most importantly, keep her family together. The services who collaborated to make this happen were:

- Community Service organisations:
  - Outreach mentor for decluttering
  - Carer support
  - Funding for industrial cleaners and skips
  - Counselling and family violence support through
- Council:
  - Buried in Treasures 16 week program.

The challenges of collaborative services

In the current environment, successful hoarding support relies on the determination, perseverance and personal connections of workers in the sector to cobble together service supports as required.

There is a significant gap in care coordination, management and support for hoarding. While most health and social issues, such as substance abuse or family violence, have centralised intake and defined referral pathways, these do not exist for hoarding. Resources dedicated to hoarding such as the DHHS Hoarding and Squalor manual are now outdated and there is no dedicated funding for hoarding support. This means service providers who are presented with hoarding often manage cases without the appropriate support or understanding to do so effectively.

Hoarding cases are highly complex, they take time and resources. Specialist services for hoarding such as support coordination and specific multidisciplinary mental health programs do not exist.

Individual organisations are developing their own strategies and processes for how to deal with hoarding, but the inter-agency model required for collaborative service support has not been developed. In the absence of these dedicated services, this role often falls to the person who identifies the case.

Hoarding is a challenging and at times, confronting social issue. During the sector consults, it was suggested that hoarding intervention was often left much later than it should be. In the absence of clear referral pathways and/or an awareness of hoarding as a mental health challenge, people who identify a hoarding case may be inclined to 'put it in the too hard basket'. The results of this are a delay in service access and the worsening of an individual's hoarding situation.

A LEVEL OF CREATIVITY IS NEEDED TO PULL THINGS TOGETHER.

SUMMARY – WHAT WORKS

SERVICE PROVIDER CONSIDERATIONS

NON-JUDGEMENTAL APPROACH

1. Empathetic and non-judgmental staff who have an awareness and understanding of hoarding.
2. Taking time to build trust and establish relationships – ensuring the client feels informed and in control in the process.
3. Taking a holistic approach to understand the client and their life experience - not just focusing on the clutter.

PRACTICAL SUPPORT

4. Focus on identifying client priorities and working to support immediate needs and reduction of risk – e.g. installing smoke detectors, clear access and egress to property, material aid.
5. Working with the client to determine support options, providing information and appropriate service referrals.
6. Flexible hard-rubbish collection options once the individual is ready to discard items.
7. Affordable decluttering support.
8. Buried in Treasures 16 week program and Peer Support Programs.

COLLABORATIVE SERVICES

9. Services working together with a common goal. Leveraging their service strengths to deliver holistic support to the client. This could span:
   - **Practical support**
     hard rubbish, skips, decluttering support, meals
   - **Physical and mental health**
     counselling, Buried in Treasures
   - **Relationship management**
     communication and care coordination
10. Dedicated resources – e.g. care coordination/case management.*

** some organisations have managed to creatively create this within their current operating model without dedicated funding.*

MAROONDAH HOARDING AND SQUALOR NETWORK