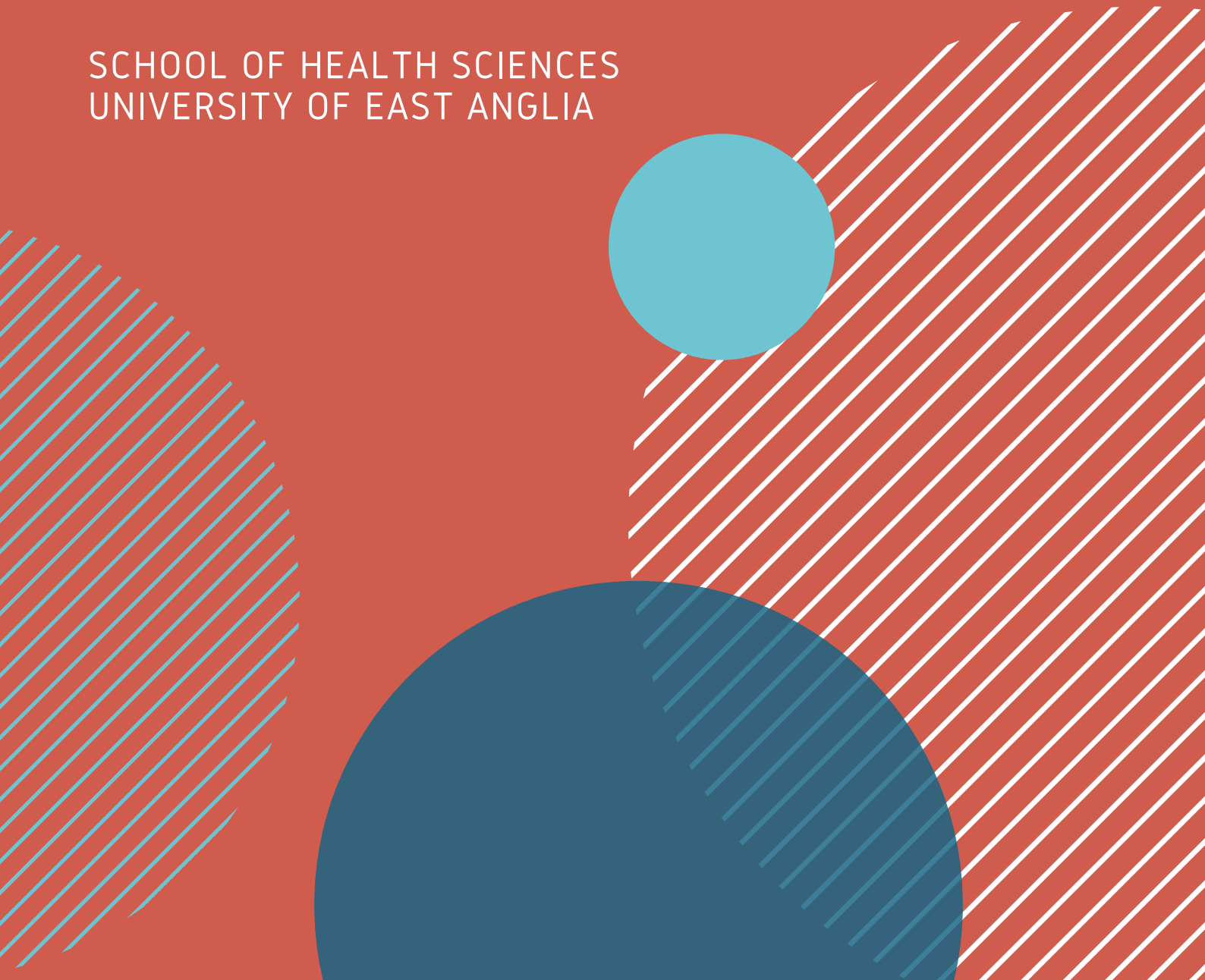


A REPORT ON HOARDING BEHAVIOURS IN NORWICH CITY COUNCIL MANAGED HOMES

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EXECUTIVE SUMMARY

Background

Hoarding disorder is defined as the persistent difficulty in discarding possessions, resulting in an accumulation of belongings causing severe clutter and the obstruction and congestion of living areas which creates significant distress and impairment in functioning. Hoarding behaviours are associated with a higher rate of healthcare utilization, chronic and severe medical concerns, higher rate of mental health service use and housing insecurity due to threat or concern of eviction due to hoarding.

Hoarded homes can present a significant fire and environmental health risk and significant economic burden to housing providers and emergency services. Working with people with hoarding behaviours presents many challenges to housing providers, balancing the care of their properties with the care of their tenants.

What we did

In total, 11 NCC staff from different teams were interviewed in summer 2021. Typically interviews took 60 minutes and were conducted using Microsoft Teams. During the interview a case was described, in terms of what worked well, what presented challenges, agencies involved and key learnings.

We developed a trial database which was populated by Housing Officers from May – August (2021). This included Clutter Rating Index, vulnerability of the tenant, safeguarding and referrals, duration of tenancy, environmental health and fire risk and a short description of the case.

MAIN FINDINGS

- Preliminary data from the trial Norwich City Council Hoarding Report (May-August 2021) reported 38 active and known cases of people with indicative hoarding behaviours, although given the interviews, the actual number of hoarding cases is expected to be much higher.
- 47% of cases had a known vulnerability or disability, around 60% of cases were resident in flats and 34% of cases had a reported environmental health or fire risk. The majority lived alone.
- The preliminary data from the trial database indicates underreporting as each of our 11 interviewees had approximately 6-10 people with problematic hoarding.
- Staff felt very conflicted about how to best protect the property, whilst acting in the best interests of the tenant and their mental health issues and vulnerabilities.
- This is a frontline job dealing with a highly complex issue. There is a training need around hoarding behaviours, that is trauma informed but this also needs to be solution focused. Staff expressed a need to better understand best practice approaches but that they are not mental- health trained and that this goes beyond the boundaries of their role.
- Building relationships and finding solutions to manage hoarding to levels that are safe and acceptable to the tenant, the property and neighbours are vastly time-consuming. The long term, ongoing support that is needed to manage hoarding cases is challenged by other demands of the job, which are often emergency situations.
- Staff were very committed to finding person-centered solutions and were helped in this by being able to problem solve in their team and because they were not micro-managed.
- The professional meetings and access to the hoarding fund enables team problem solving and quicker solutions.

RECOMMENDATIONS


- Review induction for tenants at the beginning of their tenancy. Offer training and greater support (particularly for those who have previously been without a home or young adults) at the start of the tenancy.
- Much stronger links to mental health providers and referral pathways.
- Education and training for staff about trauma informed practice
- Education or training for staff in evidence-based, best practice ways to support and involve the individual, relatives or friends or other support services as part of the process and package of support.
- Consider developing staff expertise in the management of hoarding cases. This could take the form of a dedicated hoarding team or dedicated 'hoarding champions'
- Managing hoarding (and complex) cases is emotionally demanding for staff, and staff may require additional support and opportunities to share experiences.
- Training or guidance for staff on how to use the online reporting system, including risk rating, to improve consistency in reported information and better risk stratification.
- Reporting system to be used across teams in the Council, given that our interviews suggested that there are many more known tenants with hoarding behaviours than those initially captured in the trial database.
- Record referrals and relationships with other services. Given the interviews with staff and previous discussions, we expect the reporting around referrals is limited and not reflective of the true extent of involvement with other teams or services.

BACKGROUND INFORMATION ABOUT HOARDING

Hoarding disorder (HD) is defined in the DSM-5 as a persistent difficulty discarding possessions, resulting in an accumulation of belongings causing severe clutter and the obstruction and congestion of living areas which creates significant distress and impairment in functioning (American Psychiatric Association, 2013). Difficulties with hoarding often have an early onset, starting at around age 10-13 years of age. However, help-seeking is less common before the age for 40 years, when people with hoarding difficulties come to the attention of services (Mackin et al., 2011). The severity and impact of hoarding is also likely to increase over time and there is evidence to suggest that hoarding difficulties disproportionately impact people over 55 years of age (Eckfield and Wallhagen, 2013).


Prevalence estimates of hoarding are limited and difficult to estimate as it is highly stigmatised and is associated with embarrassment and shame. A recent systematic review estimated that approximately 2% of working adults in the general population meet HD criteria (Postlethwaite et al., 2019).

A study to examine the economic and social burden of self-reported hoarders found that they were more likely to have a higher rate of healthcare utilization, reporting a broad range of chronic and severe medical concerns and a five times higher rate of mental health service use. Hoarding behaviours (HB) affects those in work. A study (albeit over 10 years ago) estimated that an average of seven working days were affected over the previous month, equivalent to that reported by individuals with psychotic disorders (Tolin et al., 2008). Our background work with a local professional organiser (a 'de-clutterer' brought in by social housing providers to make houses safe and functional again) gave us insights into professional people whose working lives have been profoundly affected by hoarding, affecting their ability to perform effectively at work.



As well as affecting the individual's health, wellbeing and normal functioning, hoarding often affects (family) relationships and family life with reported negative feelings towards the person who hoards and also a sense of loss (Sampson, 2013). Isolation therefore becomes a key issue for people with hoarding difficulties as people with hoarding difficulties report distancing themselves from relatives and social support (Sampson, 2013; Tompkins, 2011; Wilbram et al., 2008). This isolation means that people with hoarding difficulties may not be known, or may not access professional health care, and protective support from family and friends may be absent causing much distress to all involved. A qualitative study of people with hoarding behaviours and their families found that carers struggled to cope with both the environmental and interpersonal impacts of hoarding and that there is a lack of both formal and informal support and information and carers need treatment options for themselves and their families (Wilbram et al., 2008). This was highly apparent in a recent event for those affected by hoarding run by Hoarding Disorders UK with multiple case studies of distress and isolation and being rejected by their families and friends. Our background work with two local GPs has also given us insight into patients seeking help, for example, a need for a pathway to seek early intervention and patients being unable to transition into social care environments in older age due to the hoarding that needs to be dealt with in their home environment.

A small study in the North East of England with Housing Association providers and Tyne & Wear Fire and Rescue Service found that although hoarders comprise a relatively small sample of the population, they nevertheless present a significant economic burden to housing providers and emergency services (Neave et al., 2017). The estimated cost per hoarder per year to the Housing Association providing the individual their home was £15,589. There are then the additional costs to other public services. In the same study, the Fire and Rescue service conducted 30,000 home safety checks across the region and identified 2,108 properties that presented significant safety issues in the form of the hoarding of materials constituting a fire hazard. They identified 51 properties as posing a significant danger to fire officers in case of a fire. For this one Fire and Rescue service, the estimated average cost of dealing with hoarders per year in terms of extra staffing costs, staff hours, equipment etc. was £107,784.



When cases of hoarding arise in local communities and they come to the attention of local authorities, such as NCC (e.g., building or fire inspectors, contractors attempting to complete mandatory gas checks, community health care providers) there is an obligation to intervene due to health and safety issues. However, unsolicited intervention and removal of clutter is vastly distressing and traumatic for the individual, often leading to more severe hoarding (Muroff et al., 2011). Hoarding affects the individual's housing security as hoarding behaviour has been associated with the threat or experience of eviction from a home. It has been estimated that between 8- 12% of people who hoard have been evicted or threatened with eviction due to their hoarding (Tolin et al., 2008). Our background work with NCC brought our attention to one of their cases where the property was visited every two weeks by a housing officer, a fire officer and a support worker to enable NCC to assess risk and avoid eviction. This is unlikely to be perceived as a satisfactory 'intervention' to the tenants or to staff involved. NCC also suggest that complaints about hoarding have increased during lockdown due to Covid-19. This is possibly due to more awareness by neighbours working from home and due to hoarding increasing due to the protective factors that supported mental health issues being removed during 'lockdown'.

Purpose of project

The purpose of our research was to conduct a small exploratory study to better understand the nature and extent of hoarding within Norwich City Council housing stock by:

1. Estimating the number of known people with hoarding behaviours and associated characteristics, using their recently generated (anonymous) data.
2. Exploring hoarding from the perspective of NCC staff to understand current working practices, staff training and support needs, and suggestions from them on suitable and workable approaches.

METHODS

1. Norwich City Council Hoarding Report

In May 2021, Norwich City Council started to compile data on hoarding as part of a trial database. Data was collated until August 2021 for this project. The data was collected by housing officers who identify (flag) if an individual has hoarding behaviours. The data set included the housing officer's perception of the clutter (if seen) on the Clutter Rating Scale as well as free text description. Please see the link to the validated Clutter Rating Scale here: <https://hoardingdisordersuk.org/wp-content/uploads/2014/01/clutter-image-ratings.pdf>

The data also included, age, gender, length of tenancy, information about the property (type, occupancy, floor level) whether living alone and the presence of children, disability, fire risk, safeguarding referrals and current support in place. We used this data to draw out preliminary estimates of the number of people with identified hoarding behaviours, describing the demographics, associated characteristics and contact with other services. The findings were grouped together to create exemplar case studies.

Note:

This a trial database and reporting system and provides some early indications of the type of cases in NCC managed homes. Given the early introduction of this system, we do not expect that the current reporting of hoarding cases reflects the true extent of hoarding in NCC managed homes. However, we do expect the system to be useful moving forward in the reporting and management of hoarding.

2. Norwich City Council Staff Views

We interviewed Norwich City Council staff who have experience working with people with hoarding behaviours. We aimed to purposively sample staff from across multiple teams, including housing management team, specialist support teams, public protection, anti-social behaviour team, property maintenance, health and safety and social services. We also asked interviewees to suggest other people to contact (snowball sampling).

All staff were contacted via Rachel Omori (Independent Living Manager), who sent an email to staff teams asking them to directly contact UEA if they wanted to take part. No individual staff who took part in the project were identified to NCC by the researchers. The property maintenance team were unable to be involved due to demands on time.

All interviews took place online, using Microsoft Teams and were digitally recorded, transcribed and stored on password protected University of East Anglia OneDrive. Interviews were conducted by experienced post-doctoral researchers, Dr Sarah Hanson or Dr Bryony Porter. All identifying names and information were removed from the transcripts and audio recordings were destroyed. Quotes were used to illustrate findings and further measures taken to ensure de-identification.

Data storage, sharing and management

All information provided during the study was stored in accordance with the Data Protection Act 2018 and the General Data Protection Regulation (GDPR) and the UEA Research Degrees' Code of Practice 2012. At the end of the research period data will be passed into central file storage within the Faculty of Medical Health and destroyed after 10 years.

The data in the Norwich City Council hoarding report was accessed by the two UEA staff working on this project, using a OneDrive document that was password protected. The data was de-identified when it was shared with UEA (including removal of names or locations). A Collaboration Agreement was put in place between UEA and NCC, including a Data Processing Agreement. As per UEA policy all information processed and collected as part of this research was considered privileged information. The project was approved by the Faculty of Medicine and Health Ethics Committee (2020/21-144).

FINDINGS

1. Norwich City Council Hoarding Report

The Norwich City Council Hoarding Report (May-August 2021) reported 38 known active cases of people with indicative hoarding behaviours (Table 1). Of these, 24 (63%) were male and the average age was 60 years, ranging from 27 to 79 years old and 33 (87%) of people lived alone. The report suggested that 18 (47%) have a known disability or vulnerability, with nearly twice as many males who were reported to have a disability (14, 58%) than female residents (4, 29%).

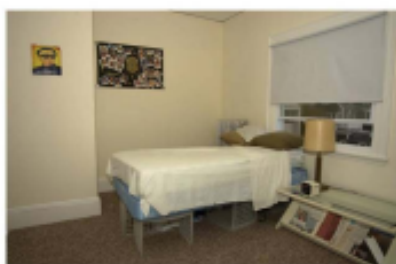
The average duration of occupancy was 24 years and ranged from 6 to 43 years. Three properties were Sheltered housing. Most commonly, people with hoarding behaviours were resident in flats (22 properties, 58%, plus 2 or 5% residing in tower block flat accommodation) or a house or bungalow (14 properties 37%). There were some discrepancies in the reporting of property type, so this should be viewed with some caution and further checks or feedback to reporting housing officers may be required. The majority of properties were occupied by one person (33 properties, 87%). There were children present in 2 (5%) of the properties and pets in 4 (11%).

According to the Clutter Rating Scale (pictured), most of the properties were rated 4-6 (18 properties, 47%), or 7-9 (15 properties, 39%) on the scale. There were more male residents with Clutter Rating Scale scores of 7-9 (11 properties, 46%) than female residents (4 properties, 29%). Our interviews also suggested that staff tended to slightly down-rate the scoring on the Clutter Image Rating.

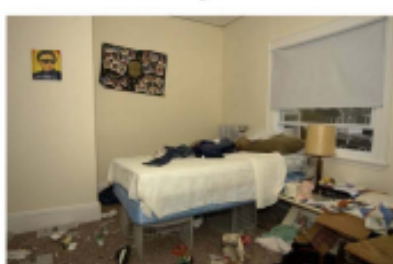
There was an Environmental Health and Fire Risk identified in 13 (34%) properties (34% for both Environmental Health and Fire Risk). There was a lack of clarity about the risk rating (RAG rating) that NCC uses. The overall risk rating was not reported for 14 (37%) properties.

Clutter Image Rating: Bedroom

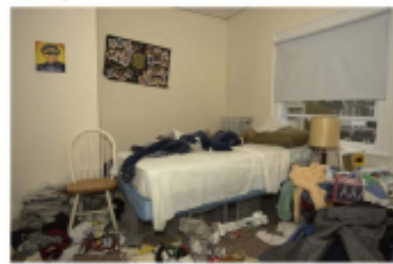
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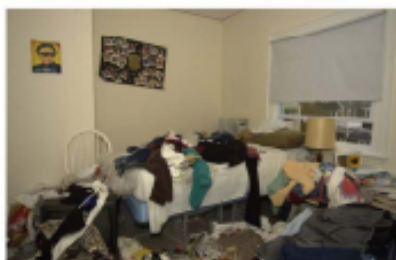
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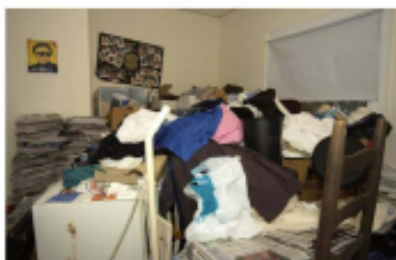
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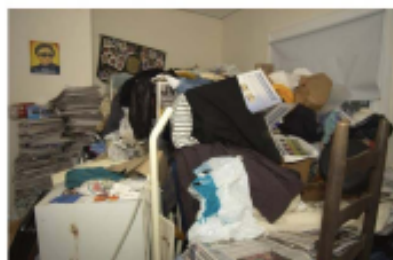
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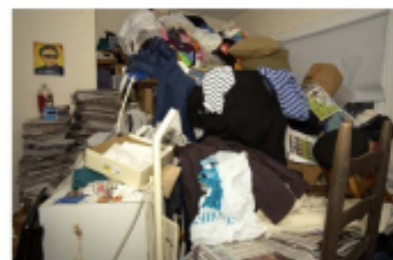
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Image: Clutter Image Rating Scale: Bedroom

<https://hoardingdisordersuk.org/wp-content/uploads/2014/01/clutter-image-ratings.pdf>

Table 1: Characteristics of tenants with hoarding behaviours
Norwich City Council Hoarding Report May-August 2021

		Total n=38	Female n=14 (37%)	Male n=24 (63%)
Characteristics (n,%)				
Age (mean, range) (years)		60 (27-79)	58 (36-71)	62 (27-79)
Disability or vulnerability reported		18 (47%)	4 (29%)	14 (58%)
Housing Information				
Occupancy duration (mean, range) (years)		24 (6-43)	25 (6-43)	24 (7-43)
Sheltered accommodation		3 (8%)	2 (14%)	1 (4%)
Property type				
	House or Bungalow	14 (37%)	8 (57%)	6 (25%)
	Flat	22 (58%)	6 (43%)	16 (67%)
	Flat (Tower)	2 (5%)	0	2 (8%)
Single occupancy		33 (87%)	10 (71%)	23 (96%)
Child present		2 (5%)	1 (7%)	1 (4%)
Pets (1 or more)		4 (11%)	2 (14%)	2 (14%)
Hoarding and Risk				
Clutter Scale Rating				
	1-3	5 (13%)	54 (29%)	1 (4%)
	4-6	18 (47%)	6 (43%)	12 (50%)
	7-9	15 (39%)	4 (29%)	11 (46%)
Environmental Health Risk		13 (34%)	4 (29%)	9 (37%)
Fire Risk		13 (34%)	4 (29%)	9 (38%)
Overall risk rating				
	Not reported	14 (37%)	8 (57%)	6 (25%)
	Green	2 (5%)	1 (7%)	1 (4%)
	Amber	14 (37%)	4 (29%)	10 (42%)
	Red	8 (21%)	1 (7%)	7 (29%)
Referrals				
Total number of reported referrals p/case				
	0	29 (76%)	11 (79%)	18 (75%)
	1	6 (16%)	2 (14%)	4 (17%)
	2	2 (5%)	1 (7%)	1 (4%)
	3	1 (3%)	0	1 (4%)

FINDINGS

2. Norwich City Council Staff Views

We interviewed 11 staff from Private Sector Housing / Environmental Health, Tenancy Management, and the Specialist Support Team. The interviews highlighted six key areas, barriers and facilitators, training and support needs, working with others, enforcement and feeling conflicted in their role.

The staff also reported a wide range of experiences and expertise in working with people with hoarding behaviours, including sharing case studies of their work that have been collated (and anonymised) for this report. Quotes from participants (p) are used to illustrate the findings.


Barriers and facilitators

There were a number of barriers raised by staff, starting with their roles that involved competing demands, other complex cases and large caseloads. Hoarding often presented alongside other support needs e.g., substance misuse, trauma, depression, where staff were working beyond the limits of their expertise.

With hoarding cases, simply because they require such a huge amount of work, often the work with hoarders tends to be left at the kind of frontline support worker level who are already inundated with other cases. (p8)

Although some teams enabled scope for creative approaches, some felt that processes for enabling creative approaches could be made much more accessible.

So, I think there is a lack of consciousness from management around how challenging it is to get an idea to them. And I often hear them saying, you know, we really want ideas and they genuinely do, but I don't think they realize how many hoops there are. (p8)



All staff reported that clients required long-term support to build relationships with them and other agencies, especially as many tenants had a history of previous negative experiences with the council or other statutory agencies. Additionally, cases required a long-term approach that took account of the individual client's needs, including potential trauma.

It's all very well doing all of that, getting that done, but they need aftercare. A lot of these people you can't leave because you know their hoarding is a mental health issue at the end of the day, you can take away and try and sort the visible part of it, but the hidden part is the hoarder themselves and what made them do that in the first place. And so, you might be tidying up the bit that everyone can see, but the actual root of the problem that caused it isn't necessarily being dealt with, is it? So, it will come back. (p10)

In addition, staff gave many examples of how they worked to engage with clients in an individualistic and compassionate way.

You have to be so patient, it's a drip feed, build up that relationship... my first instinct is to build up a relationship, I ignore the condition of the property. I concentrate on the tenant first of all. (p9)

Staff were all aware of the potential for underlying trauma and mental health conditions. This appeared to motivate their compassionate approach, but they also recognised the limits of their role.

She opened up to me a lot and talked to me but I'm not a professional mental health worker. That's what she really needs. (p6)

Staff recognised the importance of developing a good relationship with their client, being non-judgmental and consistent.

a few of my hoarders have said this, it's so nice for somebody to come around and not judge me and not have a go at me. I was so frightened to let you in because I thought I was gonna lose my tenancy (p10)


Some staff used tools like taking photographs to help the client to visualise progress in clearance of items, although it was important that there was a trusting and non-judgemental relationship established first. Use of this approach was not consistent across staff. Some reported that they would not take photographs but would use the Clutter Imaging Rating scale instead when working with external agencies or professionals.

I like to take photographs, I always ask their permission and I say something like you're gonna work with me and you know maybe we can take a bag a week away it won't be that painful, would it be alright for me to take a photograph now so that in a few weeks' time we can have a look at that photograph and see how well we're doing. And you know, try and encourage them that way. (p9)

Staff training and support needs

Managing hoarding cases was challenging for staff, particularly alongside existing large and complex caseloads. All staff talked through a case study and the handling of these was found difficult by all, on many different levels. Staff described managing these cases as tiring, with susceptibility to fatigue and burnout and impacting staff resilience. There were clearly identified support needs for staff, where there may have been missed opportunities to help staff process their experiences of challenging cases, many of which stuck in the minds of staff for years.

*I guess being cut a bit of slack sometimes instead of being hammered all the time, just realizing that sometimes you come away from a case and you do feel a bit s**t like you know, and then you've got internal and external parties, putting pressure on you constantly. Sometimes when you come away from an upsetting case and you are feeling a little bit down and vulnerable from it, to then be thrown straight back into the next, like little bomb that's exploding. It's really, really tiring. (p11)*



We're not managing burnout particularly well. [Hoarding cases] take a lot of time to achieve, you're going into properties where you're seeing clients really struggling there at the kind of worse end of self-neglect and you then have the additional impacts of having to change your clothes.... smelling their property for a very long time and it remains on your skin, in your hair and then going into other complex appointments, that can be quite wearing over time because these cases also take a long time. And movement can be micro level, or they can go right back, there's a big impact on the professional psychological resource and their resilience. And we don't manage that well. (p8)

Alongside a clearly identified need for supporting staff, staff also articulated the mental health needs of their clients. Some expressed a training need in working with people living with past trauma and psychological needs but were also clear that they were not mental health professionals or trained and that the role required professional boundaries. Staff highlighted that previous training had helped inform an understanding of 'what' hoarding is and 'why' hoarding may happen, but that the training lacked practical insight into 'how' to work with or help a person with hoarding difficulties.

We don't know enough about what helps. I think that's why it's such a hot potato because nobody really feels confident in knowing what's the best approach. So we've all got some ideas that we try and use and do. But I think everybody needs to understand, you know, have a better understanding of what is helpful. (p2)

You might have been the only person that's gone into that person's life for a long time as a frontline member of staff, but then you've walked away 'cause you don't have the skills or the training or the help or the tools or support to deal with it. I'm scared of re-traumatizing her by going back and talking through this stuff and actually dealing with this stuff. I have at times felt frightened of the extent to what I'm working with. (p1)

The mental health awareness of what it involves dealing with it, how to best to [deal with it] or things to do not do. That mental health awareness for officers to understand, and I've built mine up over years of experience but never really knowing whether it's the right strategy or not to play with certain people. I'd kind of like play it by ear with who I meet and whether you can be you, whether you can befriend them first and just, you know, talk to him. But again, there might be, more scientific ways wow to deal with it. (p3)

I'm really conflicted 'cause I feel like my empathy and my empathetic path would take me on a journey through right, come on, we can fix everything, but then I also think because of how emotional I can be, it would be very taxing and draining on me and almost a little bit too much because I don't tend to shut off from these people. (p4)

Working with others

Managing hoarding cases involved multiple agencies, collaboration and partnership working with other services, health professionals, other council teams, working with individuals and their families and friends. There were acknowledged challenges when it came to working together and a need for a more collective approach:

I think it's like a scrambled brain. We've got no synapses going to each other. That's what it feels like to me. We need to get some really good, clear pathways, set up some networking of similar officers.... That's a key thing to do now to give us that feeling of empowerment again, like we can do it all together, but we need to do it in a kind of like a programmed way. (p3)

Hoarding was considered a 'hot-potato' issue and could be bounced between services who may not consider the client was their responsibility or met the criteria for need.

As workers, you could shy away from really engaging with somebody because that creates more work for you to do so if a housing officer went "Oh well, I referred it to social services" and then they [social services] could bounce back and do the opposite with us. (p2)

developing a closer relationship with the well being service with NSFT (Norfolk and Suffolk Foundation Trust). So that we actually start looking at when we're going out to see hoarders. We don't just go with a fire safety person, we actually go with a therapist and do ... maybe a brief assessment. (p1)

There was an awareness that involving friends and families alongside the client could be either positive or problematic and required careful consideration. Staff recognised that having supportive relationships may help the client in the long term.

Sometimes they could be really helpful and can say things and get, you know, things moving in a way that that no professional never could. And they're going to be alongside them forever, whereas we're not... But other times, it can be really destructive and actually we're looking for them to develop other more healthy, supportive relationships elsewhere that may not be their family members or their friends. (p2)

Some staff also asked for training in ways to better integrate working with friends and families in the processes, as potential sources of support for their clients.

I think it [training in support for family and friends] would definitely be useful. Yeah, because if we are looking at serving a notice it would be good to inform any kind of support party that might be present as well just to let them know that this is going to happen. And to make sure that they're there to offer their support and be there for the person really so it probably would be a good thing for us to be aware of. (p11)

There were cases where integrating families into processes may help to avoid additional trauma (e.g., throwing away personal / familial items during decluttering process).

The integration of family when it comes to planning out decluttering doesn't happen at all. So, for example, I think we miss out on really treasured items that are then thrown away in the decluttering process, going to family members, that might support clients to feel like they're holding onto their key bits. (p8)

Enforcement

It was apparent that approaches to managing hoarding had changed over time. There was a recognition from all staff of the potential harm that an ‘enforcement’ approach could take and that using a holistic, person-centered approach would have benefit.

We're getting a better grasp of knowing who our hoarders are and taking a deliberate approach with them in a quite holistic way, which I think is really important. And not just doing enforcement action, which I think, used to be the format of what we'd fall back on. It would get to such a bad situation where we had very little choice but to do enforcement action. (p2)

Although, it was argued by some interviewees that an ‘enforcement’ approach may be helpful to apply “leverage” (p4), if needed.

Il think there is a bit of a responsibility to try and encourage people in all properties to make sure that their actions aren't having a detrimental effect on people who live above, below or beside them. So, I do just wonder if there's a way that something that can be done through that group [NCC as a 'landlord'] to reinforce the tenancy agreement structure to help persuade people to be a bit more compliant when they're asked to do certain things. (p11)

Feeling conflicted in their role

Staff often reported a sense of conflict in what they were required to do as part of their role and a tenant's rights for self-determination and autonomy.

I would I hate it if someone came into my home and said, you know, why are you doing that? ... that would upset me more than anything else, so I think I just don't ever see an end but I also think that I get a bit conflicted about whether I should really be telling people how to live their lives and that bit upsets me sometimes because sometimes I just want to leave them alone and let them get on with it and just think there's nothing, nothing really, but they're not hurting anyone, maybe themselves. (p4)

Sometimes, this led to some experiences that 'stuck' in their mind and 'stayed with them,' often for years after the case.

Yeah, it's you know there's certain aspects of the job that kind of stick with, you know you get quite good at leaving certain elements at work when you go home. You don't really worry about it, but things like that, they stick in your mind. So you don't really forget about them. It's just pretty horrible to have to be that bearer of bad news, and you know, it's one of those things where you kind of think, what if I turned eye, then you know they never would have been torn apart, and that sort of thing (p11) [experience of social services removing children from hoarded property]

Staff were also concerned about the potential damage that decluttering process can do, when they are enforced and cases where the client had been removed from the home and not told that decluttering was going to happen.

And the problem is every time they enforce the clearing, his hoarding gets more embedded and he is much more resistant to the decluttering process because that feels to them like they're being ripped apart because the way, I have to say, the way local authorities and social services declutter, it's pretty brutal. There's not a lot of control. They're often put in another property, often not told when the decluttering is going to happen, and this stuff is gone. it's a very uncomfortable process. (p8)

There was also a recognition that many of their tenants had additional needs, for example due to previous head injuries, accidents and learning disabilities.

I do tend to find that a lot of people who are in you know in these situations do have learning difficulties, they've got mental health issues. They have, you know, really complex sets of needs. (p4)

Personal conflicts also arose when working with other agencies and feeling a sense of responsibility for the advocacy of their clients and not feeling listened to.

This is what's happening so often. Hoarding cases rely on the professional on the ground to really push through and battle. [As an] advocate [who] scream, shout, kick their toes, and often sometimes walk away from [multi-team] meetings having a good old cry 'cause you're like, what's wrong with you people? Why can't you help this person? And then trying again the next day. (p8)

STAFF SUGGESTIONS

Training for tenants at the beginning of their tenancy

Staff suggested that tenants be offered more support and even a training programme when they start their tenancy, particularly for people who have previously been without a home or young adults (for example, previously looked after children).

"I really would like to see a dedicated team at the Council for new tenants. That really gives intensive support for the first three months or something."


The feeling was that this prevention-approach may help to support better support tenants who may be inexperienced in managing a home on their own.

"It's the Golden Chalice, isn't it? I've got my flat, but then all these new problems start and they're real problems. You know that it's not easy and it's not a great gift to be given a council flat. It's a lot of work and responsibility, and it's quite isolating for lot of people."

Dedicated Hoarding Team

Many staff raised the idea that a dedicated team of people with expertise in managing hoarding cases would be of great benefit in addressing many of the challenges identified in the interviews. Ideally this would be a multidisciplinary team, including mental health. Or even, 'hoarding champions' of staff within the existing team structures who have expertise and are trained.

"I think I'm not the only one who suggested a dedicated hoarding team because I think we really need somebody who's psychologically trained. I think we really need a qualified therapist to be going out to these people and actually understanding from an individual perspective what they actually need and working with them to try and engage them and motivate some to get help."



“To have, I mean then what would be really nice if we could have a small team of people who have those skills to work directly. And I mean our team do it, but that's not the only thing we're there to do, and but to have some officers who focus on hoarding cases. And build those relationships with all those relevant services.”

However, it was acknowledged that this may be a challenging and emotionally demanding role that would require enhanced staff support.

“if we had a more manageable workload or even a dedicated team who just did hoarding, which I don't think anyone could do that job for very long because it is so difficult and complicated”

“I think if all the clients I worked with were hoarding cases, then I think it would be really difficult because all of our cases are different and they have different issues that variety, yeah.”


Stronger links with mental health support

The role of mental health was raised by many staff, including a clear awareness of the potential to be working with individuals with severe trauma and mental health conditions. There was a call for stronger links with NSFT or mental health support alongside the teams.

“I think it's more having access to people with knowledge around mental health to then have those discussions around those cases would be the most useful thing.”

Providing ongoing ‘light-touch’ support

It was felt that it would be an advantage to be able to offer on-going support. Some teams (e.g., Specialist Support Team) already offer longer-term, on-going support with cases, enabling time to develop good relationships with tenants, understand their previous experience (and potential trauma behind the hoarding behaviours) and work towards a resolution. With the large number of properties being managed, it may be that sometimes difficult to reach tenants or more complex cases can ‘slip through the net’.



"I've had quite a few hoarding disordered tenants who I've tried to visit multiple times and they turn me away or they'll call me the day before, say no, I can't do it. And then I lose track of it, and I get side-tracked by other emergency issues that are going on. So, I then I forget for a while and then you know a month will go by and I'll remember. Oh God, I haven't seen so and so. So yeah, it would be good if, when it's identified it is pushed through to a dedicated team. You have the time to actually do that work, but I think it needs to be therapeutically led and not just about clearing the property and not just by the clearing, you know, I think it needs to be very sensitive and I think with somebody who's trained."


Managing complex cases

Staff reported that strategy meetings / multidisciplinary team meetings are helpful as a means of discussing complex cases and identifying the best approaches. It was suggested that it may be useful to develop a hoarding strategy across the council, to explain the approaches that can be taken. It was suggested by a staff member that this ought to be tenure neutral, therefore also covering private sector housing and bring expertise from environmental health. Moreover, it was suggested that part of the approach should also include ways to 'face-lift' the outside of a property, as there were concerns that dilapidated buildings can attract unwanted attention and vandalism.

Culture

The relationship with other support services that the staff were working with (e.g., social services) was described by some staff as fraught. Staff reported feeling that each service had its own agenda and that cases could be closed by other support services when there were still outstanding issues.

"What am I looking for? Just to be able to understand what our roles and responsibilities are versus what the services are, because I think sometimes the services feel like we can do a lot more than we can. "



Some staff felt they could ask more experienced colleagues about complex cases and appreciated the autonomy and freedom in their role to deal with properties in the way they saw best fit, suiting a person-centred approach. However, others felt that this sometimes left them in a 'sink or swim' situation. The support from colleagues to manage dealing with complex cases is limited when working from home, some staff reported that they missed being in a team and having a laugh, being light-hearted about the challenges of the job.

“That was a lot easier to be with people who we all have the same sort of cases, and it's easier to bounce ideas around and also you know put it into perspective a bit more. I wouldn't be sitting at home dealing with it in isolation. The cases are still the same, but that seems more overwhelming.”

Self-care

It was apparent that working with complex hoarding behaviour cases was emotionally demanding and challenging. When there was progress in a case it was incredibly rewarding but it may take a long time to get to that point, with plenty of setbacks on the way. The Council may need greater recognition of the challenge and impact that dealing with people that hoard has on staff and their workloads, and how this affects their mental health, and do more to proactively support staff who are working with hoarding cases.

CASE STUDIES

These case studies are based upon the Norwich City Council Hoarding Report and our interviews with Council staff who have experience working with hoarding cases in Norwich. Names are pseudonyms and aspects of the cases altered to ensure that is not possible for the person to be identified.

Hilary

Hilary is a council tenant (aged 39) who lives on her own and has been a tenant for 15 years and lives in a flat. Hilary's son died 4 years ago in traumatic circumstances and it was Hilary who had to identify the body. Hilary's husband left her after the death of their son. Hilary had collected lots of toys and they are filling up the room. Hilary has been very frightened, and this has at times arose as anger.

It took many attempts before a housing officer was allowed into the house and it was over a tea that Hilary disclosed her previous traumas. To enable checks and a safety inspection, it was agreed that the hallway would be cleared. This has been completed and the safety checks carried out.

The housing officer has not been back to the house because they are fearful that this may re-traumatize Hilary by going back and having to address the issues.

Lionel

Lionel is a single tenant, aged 70 years who lives in a house in Norwich. The case was first reported due to complaints from a neighbour because the garden is full of timber and waste. On the first visit, the property looked like there was no-one living inside, the outside of the house is in a poor condition and the housing officer does not get an answer.

After another visit, the housing officer meets Lionel who lives in the house. From an initial view, inside the house is also filled with plastic and rubbish, which Lionel explains he wants to have recycled 'properly'. Lionel also explains that other people dump rubbish, timber etc. into the bottom of his garden, contributing to the build-up of waste.

There is a concern from environmental protection that Lionel is also at risk of vandalism or damage to the property and that the hoarding is making him vulnerable.

The housing officer is due to contact social services but is wary that they may not be keen to be involved. The officer will be visiting with Norfolk Fire to discuss how to manage the fire risk and aim to clear the property, with Lionel.



Kishan

Kishan is a tenant in a flat, aged 36 and has been a tenant for 6 years. Kishan is semi-skilled but lost his job during Covid lockdown. He has some issues with alcohol. He had found the body of a parent after they had committed suicide.

The housing officer visited as the electricity checks were overdue and found some rooms in the property filled with rubbish. Initially the housing officer found Kishan difficult to engage but after a couple visits, they were able to go into the house with Norfolk Fire and talk to Kishan about the fire risk and options for support.

Having returned after 1 month, the tenant had cleared a lot of the rubbish from his flat (explained that he'd had help from a friend). There is still some work to do but it is much improved. The housing officer cannot quite believe it but it's really pleased he has. The officer will revisit in 3 months to see if it has been refilled.

Erica

Erica is a 70-year-old tenant, who has been a tenant for 28 years. Erica lives with her 3 cats in a flat. There have been complaints from the neighbours about the shared access areas (hall and stairs), where items have begun to spill out.

Erica has begun to clear the living room, but there are still a large number of items (some financially valuable) in the property. The windows and doors are in urgent need of replacing as they are rotten and both the kitchen and bathroom upgrades have been missed.

Erica was visibly quite upset when the visit was made. Previously, Erica's property had been cleared (due to Environmental Health warrant) and this left Erica distressed and is struggling to re-establish trust with housing officers.

There remains a serious concern about Fire Risk and the housing officer will visit with Norfolk Fire soon.

Cyril

Cyril is 71 and lives in a one bedroom flat. Cyril has previously been diagnosed with a head injury and has generally poor physical and mental health but still gets out and about around the city. Cyril sleeps on the floor, by the front door of his flat and has no heating or hot water (the boiler has been condemned). There are four ovens inside the kitchen that do not work and Cyril uses a hotplate to heat his food. The upgrade to the kitchen and bathroom is overdue, plus the flat needs re-wiring, new doors and windows. Cyril attends a place in the city for homeless people to shower.

The council have been working with Cyril for over 7 years. A previous clearance removed 6.5 tonnes of material, including newspapers dating back 15 years. The flat has now returned to its previous state.

Social Worker is now involved and there are now discussions about his mental capacity, currently the way he lives is considered his choice, however this may mean that the decisions need to be taken in his best interest.

Ameillia

Ameillia is 63 and living in a flat, she has very poor mobility and no heating because of the hoarding (the gas had to be capped off). Ameillia had an awful winter, the council provided radiators and blankets and she was sleeping on the sofa. During this time Ameillia was not eating properly because she could not access the kitchen and there was food in the living room.

Ameillia was happy to move and a move to sheltered housing helped her choose items to take. It took six months for a place to become available and there were weekly visits before the move to enable this (phone calls each week during lockdown). Mentally, she was ready to move.

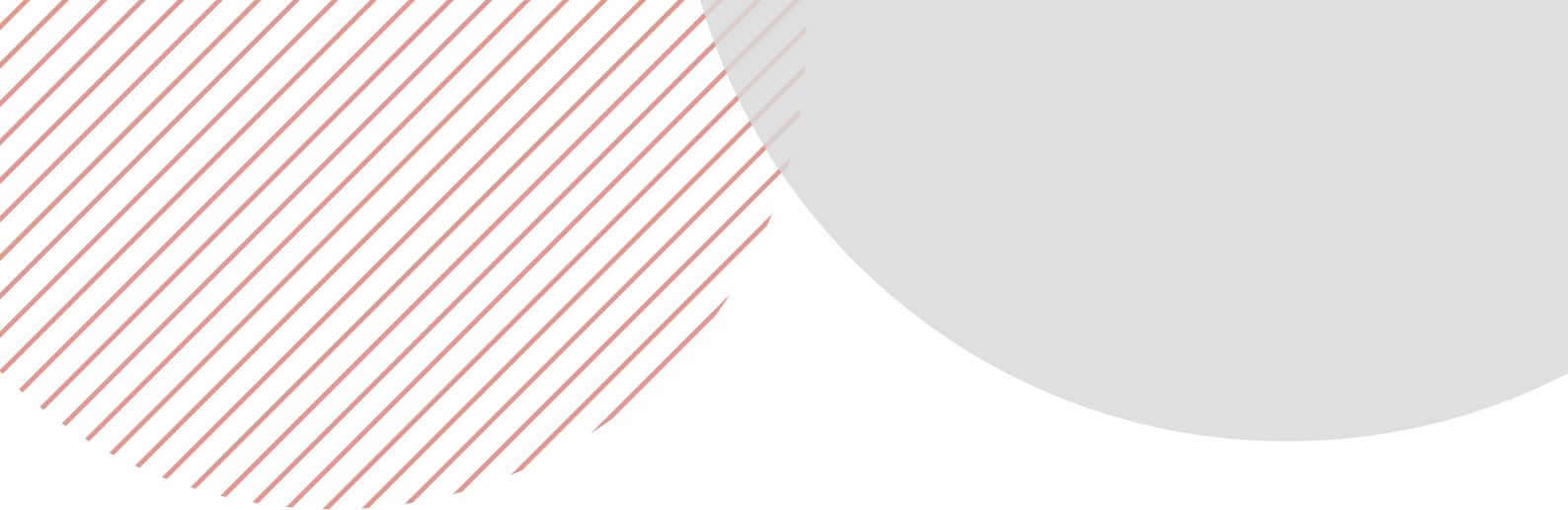
Ameillia said that her collecting started when her daughter left home and she was alone, feeling abandoned and she bought little trinkets to fill the void. She has also had a difficult relationship with ex-husband and her father. She has agreed to go to OCD support group with the Housing Support officer with her for support.

In ongoing visits to the property, there is still a lot of hoarding, but the walkways are clear and kitchen clean. She now has contact with daughter and grandchild who visits on their way home from school (previously it was unsafe in the flat). She looks better and the move has had a really positive impact on her physical and mental health.

SUMMARY OF FINDINGS

There are no established national guidance for managing hoarding behaviours. This report highlights challenging and complex nature of managing properties with people with hoarding behaviours in NCC Managed Homes. The preliminary data from the trial database identified 38 active, known cases, although we expect that this is an under-estimate of cases based on the caseload discussed in our 11 interviews, where each had approximately 6-10 tenants with problematic hoarding. Of those cases identified in the report, 47% of cases had a known vulnerability or disability, around 60% of cases were resident in flats and 34% of cases had a reported environmental health or fire risk and the majority lived alone. People with hoarding behaviours were often also living with additional support needs, including substance misuse, trauma, physical disabilities, comorbidities and mental health conditions. These were complex and long-standing cases that staff worked with.

NCC staff were motivated, knowledgeable and compassionate in their approaches. With what was often described as limited (or no) formal training, staff applied person-centered approaches to supporting people with hoarding behaviours. Many of these cases were complex and longstanding and required the development of good and supportive relationships with the individual. Staff were very committed to finding person-centered solutions and were helped in this by being able to problem solve in their team and because they were not micro-managed. However, staff felt very conflicted about how to best protect the property, whilst acting in the best interests of the tenant and their mental health issues. This was clearly a frontline job dealing with a highly complex issue. There were many training needs around hoarding behaviours, including trauma informed approaches and practical, solution-focused support for the people they work with. Staff were creative and individualistic in their approaches but also expressed a need to better understand best practice and evidence-based approaches. Mental health was often raised as a missing link for support for the people with hoarding behaviours and staff highlighted that the mental health needs go beyond the scope and abilities of their roles.



Importantly, staff highlighted the challenging and demanding nature of working with hoarding cases. Staff reported concerns of fatigue and burnout. Finding solutions to manage hoarding to levels that are safe and acceptable to the tenant and the property are vastly time-consuming whilst staff build relationships with the tenant. Some mentioned a lack of appreciation or recognition of the relentless nature of the demands of the role, managing hoarding cases alongside a large and complex caseload, which are often emergency situations. The British Psychological society in its Division of Clinical Psychology Good Practice Guidelines on Hoarding (2015) recommends that everybody working with people who hoard should have access to training and information about good practice to ensure competence in the assessment of and interventions for hoarding. There is limited research understanding the impact working with people with hoarding behaviours has on staff or volunteers (Brown and Pain, 2014, Holden et al., 2019, Ryninks et al., 2019).

RECOMMENDATIONS

There are a number of observations and recommendations within the body of this report that may assist NCC in strategic planning to move forward on redesigning approaches to managing hoarded homes, including opportunities for early intervention, developing expertise, working collaboratively and supporting staff in their roles. We would suggest that the development of any new strategy is underpinned by behaviour change strategies that are known to work, such as the COM-B model, which would focus on the capability, opportunity and motivation of tenants and staff. A summary of our recommendations is below.

- Review induction for tenants at the beginning of their tenancy. Offer training and greater support (particularly for those who have previously been without a home or young adults) at the start of the tenancy.
- Much stronger links to mental health providers and referral pathways.
- Education and training for staff about trauma informed practice
- Education or training for staff in evidence-based, best practice ways to support and involve the individual, relatives or friends or other support services as part of the process and package of support.
- Consider developing staff expertise in the management of hoarding cases. This could take the form of a dedicated hoarding team or dedicated 'hoarding champions'
- Managing hoarding (and complex) cases is emotionally demanding for staff, and staff may require additional support and opportunities to share experiences.
- Training or guidance for staff on how to use the online reporting system, including risk rating, to improve consistency in reported information and better risk stratification.
- Reporting system to be used across teams in the Council, given that our interviews suggested that there are many more known tenants with hoarding behaviours than those initially captured in the trial database.
- Record referrals and relationships with other services. Given the interviews with staff and previous discussions, we expect the reporting around referrals is limited and not reflective of the true extent of involvement with other teams or services.

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