

Ursula SAR

Safeguarding Adult Review

January 2025

Ursula

Ursula lived alone in a privately owned detached property. Ursula was in her early 70s. Her property was heavily hoarded with items preventing her from using or accessing most areas of her home. There were also items including food collected and stored within her car on the driveway. Ursula was reported to be a very private person who had very limited contact with most of her neighbours who said she was rarely seen, more often at night. In August 2022 concerns about Ursula and her property were raised from Anti Social Behaviour Team to Adult Social Care, there followed an extended period where multiple organisations including police, health, adult social care and fire service made attempts to make contact with and engage with Ursula with limited success. Ursula sometimes answered text messages and sometimes spoke through the door. In December 2023 she was found deceased inside her property.

Ursula – Summary from Professional information

2022 - Concern about rubble outside her front door causing “infestation of rats and foxes” and “bad smell”. Evidence of hoarding in home and car. Garden overgrown “like a forest”.

- Ursula only comes out of the house at night
- No rubbish ever comes out
- Perishable food is kept in the car and some is out of date
- Evidence of high level of hoarding
- Cars on drive full of items and food
- House smells of rotten food
- No one has entered the house in 20 years
- Garden overgrown
- Woodwork on house rotting

Who had contact with Ursula ?

Police

Adult Social
Care

GP

Fire Service

WICN

Anti Social
Behaviour
Team

Environmental
Health

CMHT

Approaching a SAR a little bit differently



LEAD BY PEOPLE WITH LIVED EXPERIENCE



FINDING OUT WHAT PEOPLE WORKING IN THE SYSTEM THINK WILL MAKE A DIFFERENCE?



AN EVENT WAS HELD WITH FAMILY, NEIGHBOUR AND PROFESSIONALS



THOUGHTS AND FEEDBACK WAS SOUGHT FROM ATTENDING PROFESSIONALS AFTER THE EVENT

Family member and Neighbour Perspective



Ursula – What we learnt about her from her family

- Ursula was highly intelligent and had worked in a high level government job in IT until her 60's, took voluntary retirement
- Family suspected that she may be autistic
- Ursula could be funny and always spoke her mind
- She was close to family and attended events and functions and visited for Christmas
- Until recently she was well presented
- Ursula did not allow anyone into her home
- Ursula would cease contact with family members if they tried to talk to her about her home and hoarding behaviour
- Ursula had plans for the future, she would talk about renovation of bathrooms or kitchen. She would talk about plans for travel.
- Ursula had breast cancer in 2002 and sought treatment, she did not tell her family about it, they only knew when she attended an event wearing a wig.

Ursula – What we learnt about Ursula from her neighbour

- In the first conversation I had with Ursula she told me she had every Argos catalogue since 1972, that she kept strange hours and I would never see her in the morning! Since discovered that she used to alphabetically file all junk mail. She came across as intelligent and articulate.
- Ursula was always very chatty if you happened to meet on the driveway, 1-2 hours conversations but only occasionally accepted invite inside for a drink. She talked about family a lot, no one was allowed to call but I know she visited her parents and family. She always smelt of shampoo and washing powder and was clean and tidy except for the teeth.
- Ursula became more reclusive after her mum died, she found it very hard. She also had a bout of illness which we were only aware of when I threatened to call the police if she didn't answer the door or my notes. It was then she (reluctantly) gave me her mobile number.
- During covid the online ordering increased, ordered lots of plants and soil for the garden but never did anything with them and refused any help to pot up saying she was going to plant in the back garden. Even at that time it was a jungle. We had offered many times to cut the grass but were refused. It was a fight to keep the brambles out and there were problems with wasp nests.
- Started online food shopping, large amounts of food. Started storing food outside front door which meant problems with rats, flies and smell.
- The only time Ursula asked for or accepted help was when she needed help with the car. She was so desperate to go to the family at Christmas. When her new car developed a fault (probably due to all the food etc in there) things really started to deteriorate.

Areas initially identified by author

Application of Mental Capacity Act, indicators of potential concern about executive capacity.

Repeating behaviours that have been shown not to work, telephone calls and unannounced visits

Unannounced visits repeated which allowed people to check Ursula still alive but did not impact the risk.

Assessment of Mental Health declined by CPE – Hoarding Disorder as potential diagnosis.

Lack of consideration of Inherent Jurisdiction of High Court

Seeking order to allow access to assess capacity - Indicators of possible lack of executive capacity

Not using appropriate Multi Agency Meetings

Lack of Multiagency risk assessment

Safeguarding enquiry could have provided framework for multiagency working.

Self Neglect and Hoarding SG Pathway Toolkit

MARM

Not informed in writing that she had been assessed as having eligible care and support needs and how the LA suggested meeting these

What Ursula's family and neighbour told us

That she was loved, that she had a family who she was really close to

There may be family involved that nobody is aware of

She admitted in the early days that she struggled to accept help from anyone

That professional intervention may not have made any difference to her

Any intervention needs to be at the early stages, noticing things like no bins being collected

Need to be better at treating the underlining issues that caused the hoarding behaviours

There needs to be a greater understanding of hoarding behaviour

There is a lack of support for those who are worried about people and their hoarding behaviour

What Ursula's family and neighbour told us

We need support for families and friends to know where to get information to help without alienating the person.

Taking legal action to clear the house or remove her “would have killed her”

Can anything be done to support people living near hoarder who owns own home?

The ability to treat root cause would be beneficial but how to treat someone who does not know they have a problem until it's gone too far, I don't know. I think it is a cruel illness.

What Ursula's family and neighbour told us

I found professionals kind and concerned, felt their frustration at Ursula's unwillingness to even speak them.

Police were very supportive, sensitive and helpful in their contact with family after Ursula died.

We had no idea she had a relationship with her neighbour

We had no idea she had a loving and supportive family

Maybe we could have joined forces



What could make a difference to family

- Knowing where to get support without breaking trust and relationships
 - Bereavement support
 - Support for family after a loved one's death
 - Information and guidance from Environmental Health
 - Navigation more difficult if family are out of borough, eg not allowed access to recycling centres
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Professionals Reflection having heard from Ursula's family and neighbour

- Having heard from Ursula's family member and neighbour, one of my main reflections was that it was clear that in the view of her family and neighbour all agencies did everything that they could have done whilst Ursula was still alive to support and assist and that nothing more could have been done in their opinion
 - Although all agencies done everything they could whilst Ursula was still with us, upon reflection agencies could do more to support the family members, in this case Ursula's Niece could have received more support after Ursula had passed away with dealing with the property
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Professionals Reflection having heard from Ursula's family and neighbour

- Who else may be able to identify significant hoarders e.g. bin men.
When even those closest to the individual do not know how to gain engagement the challenge for safeguarding is even more difficult.
- I felt quite disheartened when the niece repeatedly said there was 'nothing that could have been done' and that there is 'no cure for hoarding'. I would not have challenged this in that environment but my professional experience is that there is lots we can do to support people with hoarding and self neglect behaviours, its about the professional curiosity of the worker and the persistence too, which unfortunately social workers don't have the time to get underneath what's actually causing the behaviours. Hoarding is a symptom of something else, something we can usually help with.

Professionals Reflection having heard from Ursula's family and neighbour

- Ursula was clearly a very clever woman who was fiercely independent, however there are moments when she would accept support showing that the way support was provided was vital. It was saddening to hear that the family received a lack of support after Ursula died. It shows a lack of empathy from services. I feel the smallest amount of support such as an information and advice line or connecting them to a service to help clear the property would have provided them with a better experience.

Professionals Reflection having heard from Ursula's family and neighbour

- Early intervention and support is crucial with hoarding. supporting people to understand their own possible diagnosis early is important.
- Family and neighbour/friendship support for those supporting people with hoarding is crucial.
- Support/ training research about bereavement and hoarding and increase in risk needs further work.
- After death support is essential for those left behind in terms of environmental health and cleaning up. Coroner service and support with families following death need improvement.
- Risk indicators by other bodies and organisations need further exploration and work i.e. dustmen/postman. Knowing when to flag a risk with the LA.
- Discussions with legal at an early stage if someone is not engaging and there are concerns about hoarding.
- A very difficult situation where the family felt everyone tried to engage her.

Professionals Reflection having heard from Ursula's family and neighbour

- The learning from records, practitioners and family are very different. Without starting from the voice of experts we miss the practical changes to practice that make a difference to people receiving supporting people subject to SARs. They were not annoyed or angry they were looking for hope, change and not conflict with services
- Encourage all to ask families about people's history and wishes in any assessments
- Maybe if we had known the extent of the situation earlier
- Valuable insight into the family members experience dealing with the aftermath after Ursula's death

Professionals Reflection having heard from Ursula's family and neighbour

- Questions on how services could have better supported the individual to reduce the risks. was her executive functioning impaired, given that she displayed the ability to clear the porch when she was approach by environmental health and was able to clear car for MOT, along with organise the purchase of a new car. This displays a level of understanding around problem solving.
- How could we have supported the family better post death to clear the property as there was human matter throughout the property.
- How can we as services support others in the community with similar hoarding issues as it is not a case of just clearing the house, there is a psychological aspect to be considered.
- This requires support from a specialised team, not a community team. due to lack of skill and the time it takes to work with the individual.

Areas discussed with professionals at event and feedback requested afterwards

After S11 2(b), What next?

Communication between agencies,

Recognition of escalating risk

Use of guidance from Sandra SAR

MCA, Executive Capacity / Functioning and Self Neglect

The impact of affluence and eloquence on response of services

Engagement – Trying something different

Treatment pathways for hoarding – Well understood?

Comments and Feedback

Contributions were made by the 18 attendees at the learning event.

Written responses were received from representatives of different Local Authorities, Health and Fire and Rescue Services.

Written responses were received from 50% of attendees.

Care Act section 11

S11 Refusal of assessment

- 1 Where an adult **refuses a needs assessment**, the local authority concerned is not required to carry out the assessment

- 2 But the local authority may not rely on subsection (1) (and so **must carry out a needs assessment**) if
 - a) the adult **lacks capacity to refuse** the assessment and the authority is satisfied that carrying out the assessment would be in the adult's best interests, **or**

 - b) **the adult is experiencing, or is at risk of, abuse or neglect.**

Section 12

(Assessments under sections 9 and 10: further provision)

(3)

The local authority must give a written record of a needs assessment to—

- (a) the adult to whom the assessment relates,
- (b) any carer that the adult has, if the adult asks the authority to do so, and
- (c) any other person to whom the adult asks the authority to give a copy.

What changes (if any) in practice are needed, when applying s11 and s12 of the Care Act, to support a positive outcome for someone, where there are concerns about self neglect?

- “We are working wider within the LA to ensure S11 and 12 assessments are undertaken. More resource, time and MH intervention.”
- “We need to give the staff the message that its OK to be curious and its OK to work with people longer term if we have any chance of supporting these people. Applying helps ensure we have met our statutory duties, but doing an assessment without someone’s consent means that they are very unlikely to agree to support. I believe its much better to allow staff to use their social work skills and to take time to 'get their foot in the door'. I think working closely with our other local agencies also helps, eg RBFRS”

What is changes (if any) in practice is needed, when applying s11 and s12 of the Care Act, to support a positive outcome for someone, where there are concerns about self neglect?

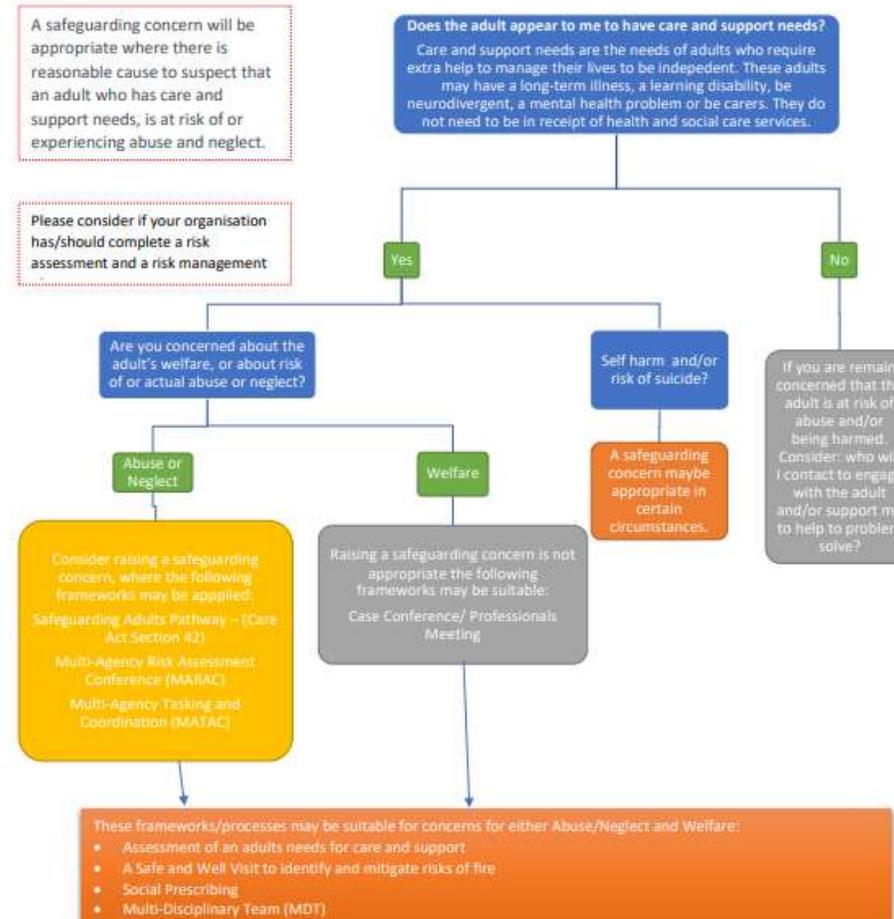
- “We need to be confident in applying S.11 and gather information from other agencies if we are unable to communicate with the person directly. We also need to obtain legal advice promptly if we are unable to move forward with an assessment or service where there are safeguarding concerns.”
- “Risk flags for all organisations re hoarding.”
- “Offering help earlier”
- “A more lateral approach may be required when one service is unable to make contact/assess and a focus on a person centred approach rather than process driven.”

What is changes (if any) in practice is needed, when applying s11 and s12 of the Care Act, to support a positive outcome for someone, where there are concerns about self neglect?

- “Evidencing s11 and s12 is essential and limitation this may have and perhaps more support from legal teams to say enough has been achieved or direction as to why court may be an option. Decision maker with the MDT (multi disciplinary) teams to consider impact on the person. Seek legal advice and ask is there more we could do or explore or is this a court decision. Maybe a legal clinic drop in ?”
- “Confidence of staff and teams to complete the assessment even when it is being refused rather than not completing it. Using the legal system appropriately to support the completion of the assessment if barriers remain.”

Pathways for multi-agency planning

Across the West of Berkshire there are several pathways available to use in order to support adults with care and support needs where there are concerns about their welfare and/or Abuse or Neglect. This document has been produced to support practitioners in their understanding of these frameworks.



Pathways for multi-agency planning

Thinking about multi-agency communication and the tools that are in place.

What are the barriers in applying these tools? What (if any) are the gaps in the tools available?

- “I believe that the tools are in place for multi-agency communication but better effort could be taken to apply them, for example using the right routes to request multi-agency meetings to discuss a case”
- “Consideration of those with neuro diversities.”

Thinking about multi-agency communication and the tools that are in place.

What are the barriers in applying these tools? What (if any) are the gaps in the tools available?

- “Everyone works on a different system and this has long been a problem for sharing information and communicating. A strategy meeting is the best tool we have re comms when safeguarding people.”
- “Staff need to be clear where all the tools are kept and what tools are available. I am currently aware of the self-neglect tool and MARM however as I am relatively new to post there is likely to be tools I am not aware of. A central list of what is available may be helpful so people can then explore these in their own time. A contact list for safeguarding/MCA leads for different services may also be beneficial for staff so they can quickly identify the best email/telephone line to discuss concerns with.”

Thinking about multi-agency communication and the tools that are in place.

What are the barriers in applying these tools? What (if any) are the gaps in the tools available?

“Regular joined up training involving all organisations and the voice of the family/ neighbour. Coming together to share current situations , what has been tried, linking everyone involved using a map and a flag system.”

“The tool are in place to MDT and escalate. The time to use these is a factor we cannot ignore in current practice . Attendance and getting key people is an issue for very practical reason teams assists but is a challenge as they conflict with other appointment increase pressure for people to make decision without all the key people being available.”

Thinking about multi-agency communication and the tools that are in place.

What are the barriers in applying these tools? What (if any) are the gaps in the tools available?

- “Better in communicating with each other.”
- “Services do not always alert the other when they believe there is a problem, they are not taking a holistic approach to the individual. they are only seeing what is in front of them at the time. It quite often only comes to the attention of social services when there is a complaint or concern from the community that LAs are made aware of the situation. MARMs are in place but it is generally ASC that organise them. Does there need to be broader understanding about risk and how to alert other professionals. Safeguarding referrals are not always used appropriately and in a timely fashion.”

Thinking about multi-agency communication and the tools that are in place.

What are the barriers in applying these tools? What (if any) are the gaps in the tools available?

- “From experience each agency is stretched with their resources and are reluctant to take responsibility for work that does not strictly fall within their remit, especially with complex cases. I've found that in regards to self neglect and hoarding, as this is not a priority and often put down to "lifestyle choice" there is not the same level of response for these situations as there would be for something like Domestic Abuse. It could be that there are similar challenges and barriers when looking into Domestic Abuse, however Self-neglect does not always receive the same level of response. It could however be argued there is a similar level of risk to the individual.”

MCA, Executive Capacity / Functioning and Self Neglect

Are we and our colleagues confident in this area?

What are the barriers?

What do we need?

MCA, Executive
Capacity / Functioning
and Self Neglect.

Consider the
following:

Are we and our
colleagues confident
in this area?

What are the barriers?

What do we need?

- “RBFRS (Royal Berkshire Fire and Rescue Service) staff have an understanding of MCA and are able to recognise signs of self-neglect and will raise Safeguarding referrals and concerns when they do so. However, RBFRS staff are not trained or required to assess someone's capacity.”
- “This is an area where I feel more training is needed, case examples etc is required.”
- “I don’t think staff are confident in this area. I think staff have some of the legal knowledge but don’t always know how to undertake in practice.”

MCA, Executive Capacity / Functioning and Self Neglect.

Are we and our colleagues confident in this area?

What are the barriers?

What do we need?

- “I feel it can be difficult to be confident in assessing executive capacity if there is limited communication with the person. These assessments can be complex and are not frequent therefore staff's confidence can vary. It would be useful if staff had the opportunity to attend an MCA surgery to help plan an assessment prior to completing if it's complex circumstances.”
- “It would be great to have some legal / hoarding training. When to approach court etc.”

MCA, Executive Capacity / Functioning and Self Neglect.
Are we and our colleagues confident in this area? What are the barriers? What do we need?

- “Confidence is growing, it is a challenging areas and again requires time. Perhaps legal clinic drop in across services for people to explore cases fortnightly to learn from each other and use the experts in the system.”
- “Not confident , need more insight and the help that is available”

MCA, Executive Capacity / Functioning and Self Neglect.

Consider the following: Are we and our colleagues confident in this area? What are the barriers? What do we need?

- “In cases like this it needs a specialised team to support that has received additional training around executive functioning, psychology of hoarding, understanding around completing a MCA linking to self neglect to ensure they know how to ask the deeper, in depth, questions to gain a true understanding of the individual’s level of understanding into the risks.”
- “Social work teams are too stretched to have in depth skills in all areas, which is difficult if you only work with these sort of cases once in a while.”
- “They also require time to work with the individual, more than that of a normal case, this can span years rather than months.”

MCA, Executive Capacity / Functioning and Self Neglect.

Are we and our colleagues confident in this area? What are the barriers? What do we need?

- “I feel that often MCA is overlooked as it can appear that people who are self-neglecting can appear to have capacity generally and are often closed quite early. Self-neglect is not always overtly obvious which can lead to enquiries/interventions being closed early on, and there being a lack of persistence when individuals decline to engage. It may be that a designated lead/person/team may be required to assess and oversee cases of self-neglect.”

The impact of affluence and eloquence on response of services



Do you think this is a factor?



How can we be mindful of this?

The impact of affluence and eloquence on response of services

Do you think this is a
factor? How can we
be mindful of this?

- “Those in social housing are tied into tenancies with conditions attached. Those who own their own property can effectively decide to maintain this as they wish. Ursula's known intelligence is likely to have influenced those around her and possibly hidden the extent of the issue.”
- “People in social housing get more focus on them just because the social landlord will go to eviction in many cases. They can effectively enter the property unlike privately owned homes.”
- “Adult Social Care has no “Power of Entry” if they cannot see, they cannot risk assess.”

The impact of affluence and eloquence on response of services

Do you think this is a factor? How can we be mindful of this?

- “This is an issue alongside social bias and part of our social culture and hence is a really difficult to identify and to reduce.”
- “It requires MDT managers and individuals to have this prompted periodically on supervision to get feedback on how are people considering their decision making in context to the above.”
- “If it is a prompt all the time it could risk becoming "tokenistic" .”
- “Deep dive audits over a longer period or celebration of good practice considering diversity and culture awareness.”
- “Providing evidence to allow people to describe cultural awareness and challenge our own social bias, Using this to inform and support workforce.”

The impact of
affluence and
eloquence on
response of services

Do you think this is
a factor?

How can we be
mindful of this?

- “The results would have been different if she had lived in local authority housing, she would have been subject to the tenancy agreement and services would have responded differently to ensure the risk was removed.”
- “If the property was a semi detached or terrace property and represented risk to others.”
- “Due to the property being detached and the individual being highly educated then she was able to mask the risk for so long.”

The impact of affluence and eloquence on response of services

Do you think this is a factor? How can we be mindful of this?

“I feel Ursula was not supported as she would have been if she were renting or living in social housing. There appears to be a lack of support from some services as Ursula was a self-funder therefore could have paid for services to clear the property. Risk to her own health and neighbours did not appear to be considered in detail. Ensuring different departments in the council are linked up could support with this, for example regular meetings with Environmental Health, Community Safety and Adult Social Care. This would provide oversight from different areas and address what support could be provided from each department. The gaps could also be recognised and Ursula/her neighbour could have been connected to services that would help fill these gaps.”

The impact of affluence and eloquence on response of services

Do you think this is a factor? How can we be mindful of this?

“In Ursula's case it was evident that she was highly intelligent and affluent. There is a social stigma with involvement from Social Services and often not seen as something that people with from affluent socio-economic backgrounds will engage with, especially at the first point of contact. Often the individual's own legal literacy and knowledge of rights can be a barrier to professionals pursuing enquiries. There is not the same stigma with other public services such as the NHS and potentially better cross agency working is required in such situations. From my experience working as a Community Nurse, I often had privileged access and automatic trust that is not often afforded to agencies such as the Police and Social Services. If support had been offered through an NHS service initially, it may have been able to bridge a gap and build trust with other services.”

Engagement

How do we reflect on how effective our engagement is with people who display self neglect and hoarding behaviours? How could this be improved?

- “RBFRS (Royal Berkshire Fire and Rescue Service) engage with members of the community on a daily basis that display signs of self-neglect and hoarding. Safe and Well Visits are person centered and tailored to individual needs and circumstances. Fire Safety advice and supporting technologies can be provided to reduce risk and Safeguarding referrals are completed when further assistance is required or requested
- There is more time and resource required for this area of safeguarding. Supervision regularly takes place but a longer term approach is required.”
- “The successes I have had working with people who display self neglect and hoarding behaviours has been dependent on having the time to invest in that relationship building. Time is currently a precious resource in ASC.”
- “Needs a multidisciplinary approach.”

How do we reflect on how effective our engagement is with people who display self neglect and hoarding behaviours? How could this be improved?

- “Audits is our main measure of how effective interventions have been. Gov metrics is also used for safeguarding concerns therefore if anyone was being supported under this framework they would have the opportunity to feedback after the involvement. A hoarding workstream is due to be set up in Wokingham. This could be improved further by asking the SAB to complete a group audit where several agencies have been involved.”
- “Promoting tools for GP's. safe and well checks and consider MCA executive capacity alongside people past wishes and beliefs. I think following the event I would consider more about their own safety and happiness.”

How do we reflect on how effective our engagement is with people who display self neglect and hoarding behaviours? How could this be improved?

- “Having more insight into the person, family, work situation, changes the way we think about them.”
- “Currently the majority of LA's manage hoarding cases with the community teams, there is a push to close cases. This is not an appropriate method of working with someone that is displaying self neglect and hoarding. Time is the factor that needs to be considered, developing a rapport with the individual, ensuring they feel comfortable with the worker rather than being criticised or forced to do something that they don't want to do. Having the mental health skills to work with the individual. work in a solution focused manner with the individual by setting small goals for them to work towards. Not making them feel that they don't have any control over their life.”
- “Engagement is limited as they are generally people that require long term work where trust is built over months rather than days, and can be easily missed, or fall through the net through their own non-engagement.”

Treatment Pathways for Hoarding

How well are they understood by the system and the public?

At what point are interventions effective?



Treatment pathways for hoarding.

- “Although hoarding is discussed widely among agencies/services and I would like to believe is well understood, I don't know how well understood it is to the general public. RBFRS continuously try to provide education, advice and offer our service provisions to assist with hoarding to reduce risks. ARP (At Risk Programme) is delivered to a number of agencies to increase awareness and advice guidance can be found on our website. I do believe more could be done by all agencies to try and increase public knowledge of support available for hoarding.”
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Treatment pathways for hoarding.

- “Interventions such as deep cleans are effective but only in the short term. We do not have a long term support system. Hoarding as a recognised mental health condition does not have the same support and recognition as other MH diagnosis.”
- “I dont think there is very much in depth knowledge in the system or in public. Interventions are most effective the earlier they are made.”
- “Not understood very well. More work needed. As soon as possible.”

Treatment pathways for hoarding.

- “Hoarding is misunderstood by people's own biases and assumptions. People don't realise hoarding is often related to trauma or an underlying mental health issue. There is no clear resource for the public/community to report their concerns for hoarding if they are concerned for a neighbour or information easily available on how they could help. Interventions are mostly effective if we can understand a person's trigger, we can then support them in the early stages to organise the clutter, identify that they may have a problem and this may become unmanageable unless they receive support.”

Treatment pathways for hoarding.

- “This is not a quick fix it requires long term interventions and preventative support services including working with people at their pace with experience.
More commissioning jointly needs to take place with a long term funded options, volunteers, families and use of our community. In some ways this is a community safety areas with the right people being supported funded and use to help people in their community.”
- “Not well understood.”
- “Hoarding is misunderstood and can be ignored until it becomes a problem to others such as smell or infestations. Otherwise people look the other way. It is considered a way of life and a life choice, rather than a psychological condition.
Ideally intervention should take place earlier, however it is difficult to spot the signs unless families and communities are upskilled with the knowledge to spot earlier and how to report it.”

Treatment pathways for hoarding.

“I feel that they are poorly understood as most people's logical step would be to declutter and deep clean, however as seen from the family and friend of Ursula this approach could have done more harm than good. I feel that this is also a common idea amongst professionals and the deep rooted psychological causes are not generally well understood.”



Learning reflections for your organisation from participants

- “Following learning taken away from the discussion with Ursula's Niece and Neighbour, learning we believe we can take back to our organisation is to still offer a Safe & Well Visit to family members entering a hoarded property if the person the referral is for has passed away. Listening to Ursula's Niece we recognised that she felt unsupported and was left to deal with a dangerous environment.”
 - “To look at engaging wider family/friend networks in the engagement of hoarding cases.”
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Learning reflections for your organisation from participants

- "Specialist Hoarding services in ASC who undertake this long term work"
 - "Hoarding sessions about what practitioners have in their tool box that could make a difference - ie MHA, MCA. Improve legal literacy."
 - "Consideration of any recovery support that could be provided to family/friends in the event of a person's death before closing our involvement."
 - "MCA surgery's to help with preparation of completing an MCA for complex circumstances."
 - "Wider learning for services who may have regular contact about signs of hoarding i.e bin collection service, tree surgeons/gardeners, utility providers etc."
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Learning reflections for your organisation from participants

- “Training - legal-when to involve court?”
 - “Understanding interventions in relation to hoarding and how to involve everyone.”
 - “Understanding risk flags and when to act.”
 - “For the ICB (Integrated Care Board) place based directors to consider work with the CSP (Community Safety Partnership) on programmes for support for psychological interventions and public health campaigning.”
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Learning reflections for your organisation from participants

- “Reading BC has set up a separate service to support with hoarding and neglect within the mental health team. For services to be up skilled around hoarding and self neglect online training is not always enough.”
 - “A dedicated/specialist Self-neglect worker/team who has the ability to either oversee/consult or work alongside other teams to act as an advocate. They would be able to build the therapeutic relationship required and bring in other teams as required at the appropriate time in a coordinated approach.”
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Learning reflections for your organisation from participants

- “A resource "pack" that can be given to families would be helpful. From experience as a District Nurse, it was part of my role to carry out "bereavement visits" that supported family especially after they had End of Life support from the DN service. From a statutory point of view, duty ends when the person dies which can leave people in limbo and resulted in the situation that Ursula's family found themselves in. Something similar from the Local Authority maybe useful and beneficial for families”
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- “Increase awareness of Hoarding support available to the public.”
 - “To look at resources for families of those known to hoard and self neglect.”
 - “SAB could undertake a media programme in West of Berks asking informing everyone of what hoarding is and where to go for advice and support.”
 - “An annual group audit of self-neglect/hoarding cases to ensure tools are implemented and there's cohesive partnership working in situ. This will also identify any gaps in support.”
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- “More information about hoarding and autism to be shared in hospitals and GP surgeries etc.”
 - “To consider displaying a family guide to hoarding help including services Environmental health and support group for families.”
 - “To work with the appropriate services to minimise the risk of hoarding and self neglect in a more timely fashion, rather than when the risks have reached points similar to this.”
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Learning reflections for the West of Berkshire Safeguarding Adults Partnership from participants

- “Information for public and people with hoarding behaviour about when there are duties for Local Authority to be involved.”
 - “Does there need to be a separate hoarding and self neglect forum for critical cases to be heard, to ensure that all services are working in a cohesive manner to minimise risk to the individuals.”
 - “More multiagency working is needed as a single agency approach is often not successful, however, due to strain on resources, agencies are reluctant to pick up "extra work".”
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Suggestions for National Government from participants

- “To provide wider support for funding when it comes to private home owners and hoarding.”
- “I think the Care Act needs updating. Although self neglect/hoarding is in S42 as a type of abuse, sometimes it is hard to identify the care and support needs the people have, under S9 and therefore they don't get support early on in their journey. S11 is a net to catch these people, but how do you engage and relationship build with someone you have already enforced an assessment on?”

Suggestions for National Government from participants

- “As items become more accessible to buy the clutter in people's home will increase. Providing further resource to Local Authorities and fire services to manage hoarding and the risks associated with it will help with early identification of triggers.”
- “More research in to hoarding and the links with different diagnosis and interventions. More awareness around hoarding and the impact on families and where to get help.”

Suggestions for National Government from participants

- “To empower both communities and NGO to undertaken long term work and directly fund this via the national hoarding groups from a centrally protected fund including links to families advice and on line chat groups.”
- “National Policy in place for people with hoarding issue.”
- “A model such as is implemented for Domestic Abuse could be useful in such situations. It could be argued there are similar levels of risk. Something similar to the MARAC model could be useful to engage different agencies and decide on responsibilities for individual agencies on a case by case basis, but hosted by the Local Authority rather than Police.”

Suggestions for National Government from participants

- “To widen the knowledge and remove the shame/stigma linked to hoarding and self neglect, so that families and communities can report concerns earlier rather than when the person is at significant risk.”
- “To provide appropriate support for individuals who are experiencing hoarding and self neglect, such as long term psychological and mental health treatment.”

Reflections at Safeguarding Adult Review Panel

Discussion highlighted that the areas raised through Ursula SAR were prevalent across West of Berkshire and that a similar situation could happen again.

Themes that arose from the SAR were having time, skills and knowledge when working with people with hoarding behaviour.



Areas identified as training needs by professionals

- Self Neglect and hoarding behaviour – root and causes and effective interventions.
- Mental Capacity, Executive Capacity and Self Neglect and hoarding behaviour.
- Self Neglect and Hoarding – Legal Framework.
- Impact of affluence and eloquence on intervention.

Recommendations

Communication / Awareness

- West of Berkshire SAB to raise public awareness and seek to destigmatise hoarding behaviour and hoarding disorder and provide information about where to get help or advice, including exploration of community support available for people and their family and friends through groups of people with lived experience. Signposting to existing resources.
- West of Berkshire SAB to produce information to provide to people with hoarding behaviour explaining legal duties of Local Authorities and others, including when those organisations have to be involved and how they can work with them.
- West of Berkshire SAB to work with stakeholders to produce information for families about specific bereavement support after someone dies related to self neglect and hoarding.
- For learning to be shared with key stakeholders to aid consideration of how refuse collection (or lack of) could provide early indication of hoarding behaviour and how families can be signposted to resources.

Recommendations

Practice

- Agencies to review their existing hoarding protocol to consider whether any amendments are needed to be made based on reflections in this SAR. Protocols to include guidance on recognising escalating risk or risk not changing and when to seek legal advice and how.
- Health and Social Care to work together to establish hoarding pathways and more in depth understanding of root causes of hoarding behaviour.
- Multiagency review of existing Multiagency risk management forums for hoarding and self neglect - SG Strategy Meetings, Case Conferences, MARM, Best Interest Meetings - explore why not working in hoarding and self neglect cases and consider the alternatives.
- Stakeholders to explore commissioning of specialist providers to work with people with hoarding behaviour.
- Agencies to review their training plans against training needs identified by the workforce in this SAR to assure themselves and the board.