Working together to support people with self-neglect and/or hoarding needs

An event presented by:

NSAB self-neglect and hoarding subgroup

Thursday 24th October 09.15 – 15.20

Rachel Omori

Chair of the Norfolk Safeguarding Adults Board self-neglect and/or hoarding subgroup

Independent Living Manager, Community Services, Norwich City Council

Welcome!

An opportunity to focus on some key themes when working with people who may self-neglect and/or hoard. A chance to network across your areas and the county, as well as:

- Learn more about innovations in service delivery in some of our Norfolk localities
- Meet providers of services which support those with self-neglect and hoarding needs
- Hear about recent research that Norfolk partners supported into multi-agency working
- Work together to understand more about safeguarding pathways and the challenges for professional partnerships

Plan for today - morning:

09.15	**Arrive** / networking time	
09.45	**Introduction**	**Rachel Omori** (Independent Living Manager, Community Services, Norwich City Council)
10.00	**Safe & Habitable homes** (Norwich City Council) + Q&A	**Jaya Merryweather and Joe Sampson** (SHH Team)
10.25	**Research perspective** including Q&A, then intro to **group work**	**Dr David Orr** - (Senior Lecturer in Social Work University of Sussex)
11.10	**Group work** pathways in working with self-neglect and/or hoarding issues (time includes tea, coffee & comfort breaks as people require)	
11.55	**Group feedback**	
12.10	**Overview of NCC provider framework**	**Izzy Shaw and Jenna Bardwell** (Norfolk County Council)
12.35	**Lunch**	

Plan for today - afternoon:

1.15	**Animation and recording of lived experience**	**Becky Booth** (Deputy manager Norfolk Safeguarding Adults Board) and **Rachel**
1.25	**Hoarding Support** service (Great Yarmouth Borough Council project) + Q&A	(Introduced by Becky) **Dave Olding** (Lofty Heights)
1.55	**Group work** What challenges for interprofessional working? (time includes comfort breaks as people require)	**Dr David Orr**
2.55	**Group feedback**	**Dr David Orr**
3.10	**Round up, feedback request and close 3.20pm**	**Becky**

Safe and Habitable Homes

SHHS

Supporting Better Living

Who are we?

SHHS
Supporting Better Living

We are a tenure neutral self-neglect and hoarding service, developed in collaboration by Norwich City Council and St Martins with wider support from Norfolk County Council (Adult Services and Norfolk and Waveney Fire Service) as well as wider voluntary partners including social prescribing teams, NIHCSS and Mind. We support people who live in Norwich. We operate on a long-term person centred and trauma informed model, to engage residents in a supportive, holistic and effective way.

Our goals:

- Reduce the risks around hoarding and self-neglect behaviours
- Improving wellbeing, engagement and confidence
- Involve support from unpaid carers and families
- Reduce the need for formal housing procedures

Joe

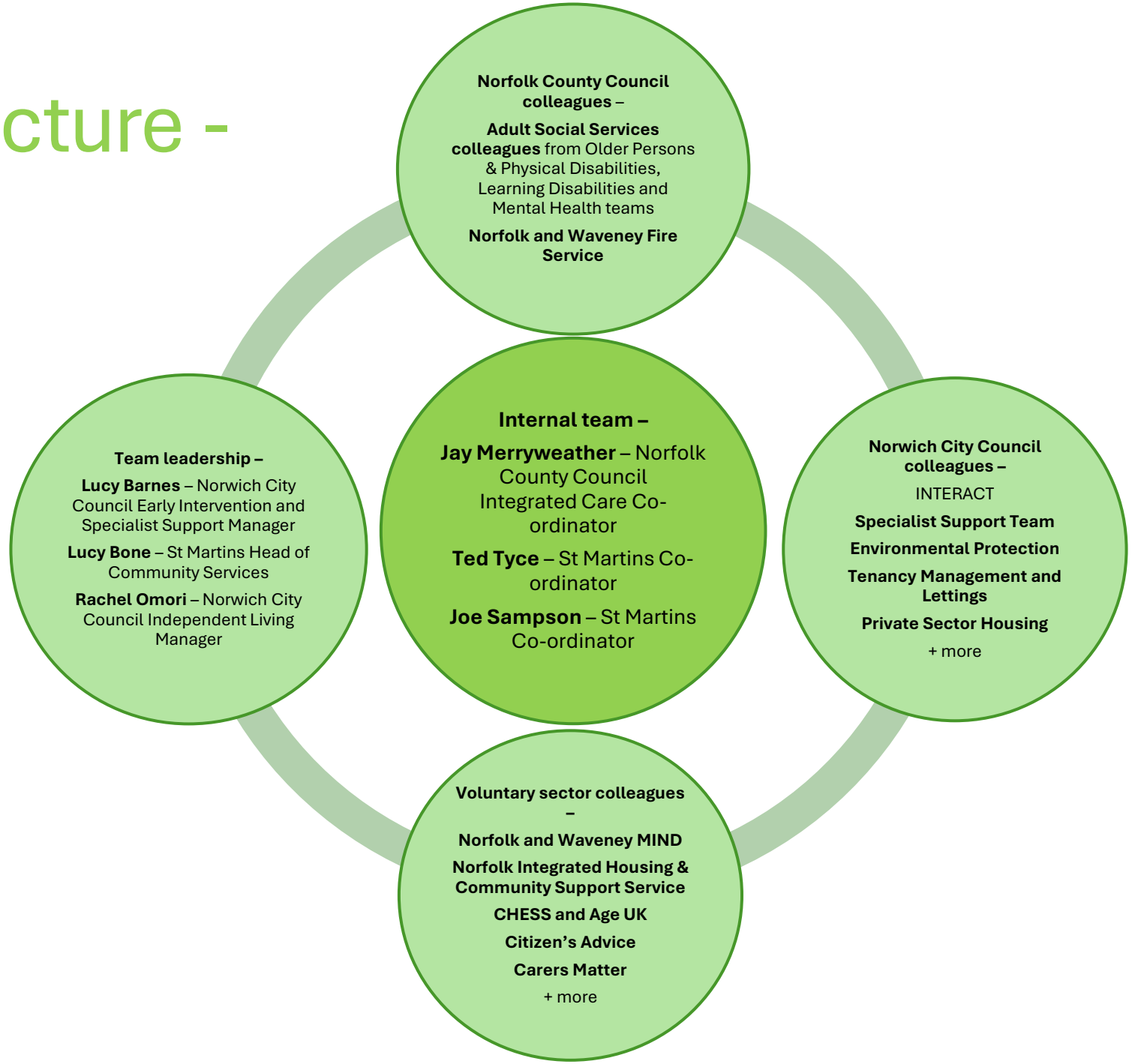
Why is our service needed?

SHHS
Supporting Better Living

- We all know that self-neglect and hoarding is a high risk and growing issue faced by significant number of people and many organisations.
- There is a lack of long-term wrap around support for people facing this complex issue. The work is often time-consuming and challenging.
- We know that a trauma-informed approach is key. The majority of residents facing these issues have experienced significant trauma in their lives. Clearances and enforced action re-traumatise people and do not resolve self-neglect and hoarding behaviours.
- We know that multi-agency teams are the way forward, where different skillsets, knowledge and areas of expertise are present.

Alison

Team structure -



Jay

Our values –

SHHS
Supporting Better Living

- **Choice** – Clarifying individual goals with no assumptions; using professional curiosity.
- **Adaptive** – The coordinator with the best rapport with the resident leads support.
- **Team compassion and challenge** – supporting one another and valuing all perspectives.
- **Safety** - safe practice in managing risk, ensuring residents feel safe and we feel safe.
- **Non-judgemental and empathetic** – Positivity and keeping belief in someone meeting their goals. Recognising difficulty in change.
- **Trauma-informed** – implementing trauma-informed practice. Recognising the pillars of safety, transparency, collaboration, empowerment, and cultural and historical context.
- **Solution-focused** – Being clear on shared risks and goals. ‘How can we?’, not ‘you can’t’.
- **Collaborative and person centred** – Involving client in everything possible – ‘nothing about me, without me’.

Joe

Our reach

SHHS
Supporting Better Living

Since the service started, 21 months ago we have **received 138 referrals** to Safe Habitable Homes Service.

We **accepted 87 referrals** and we are **currently actively working with 36 residents**. Our original business case bid was to support 40 people in 18 months, which we have greatly exceeded.

32 residents have already **met all their goals** we set out together to achieve.

We currently have **19 residents waiting** for our support.

Overall, of the residents we offered direct support to we have an **87% engagement rate.**

We provided **advice, guidance and signposting** regarding **51 residents** to help those professionals who already had a **positive on-going relationship** with the resident to help them to **take action and make change. The support we provide around this can be ongoing –** with coordination of MDM's. Our team has a 'never a closed door' policy.

We also run a peer support group on Wednesdays at 1pm at St Martins' Under 1 Roof for people experiencing self-neglect and hoarding behaviours regardless of whether they're directly open to us.

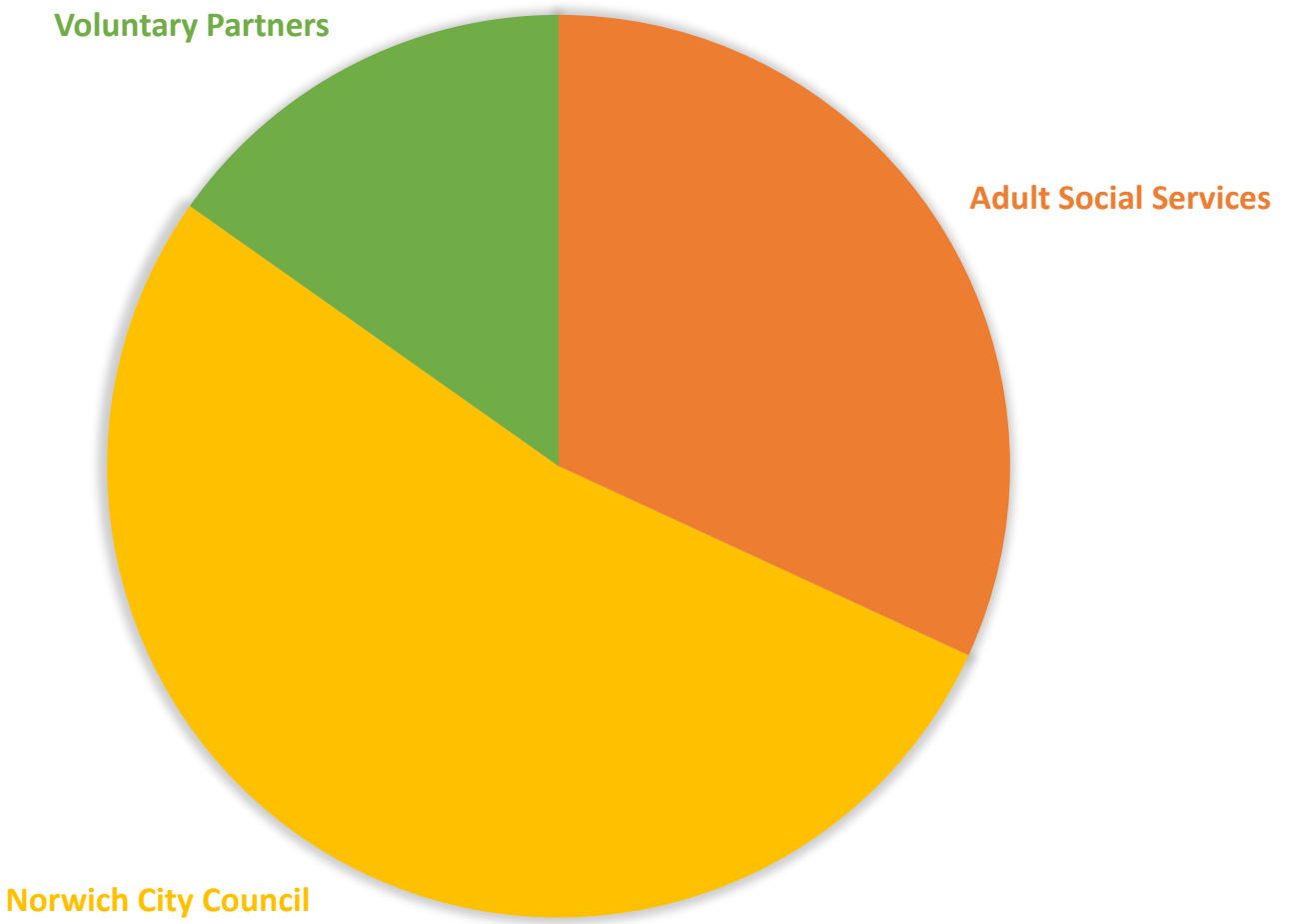
We know through our research that there are around 200 *known* Norwich residents experiencing self-neglect and hoarding. We do feel this presents a capacity issue as we are only able to support a fraction of this cohort at a time.

Lucy

Referrer trends -

- Our highest referrer is Norwich City Council, followed by Adult Services and then voluntary sector partners.

- Housing – 73 referrals
- ASSD – 44 referrals
- Voluntary – 21 referrals

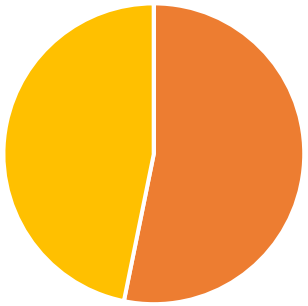


Jay

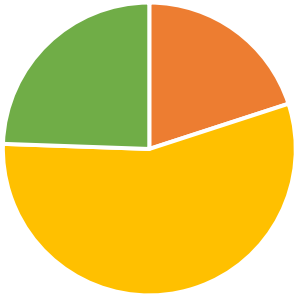
Reducing risks around self-neglect and hoarding behaviours, and improving health & wellbeing

SHHS
Supporting Better Living

Initial fire risk



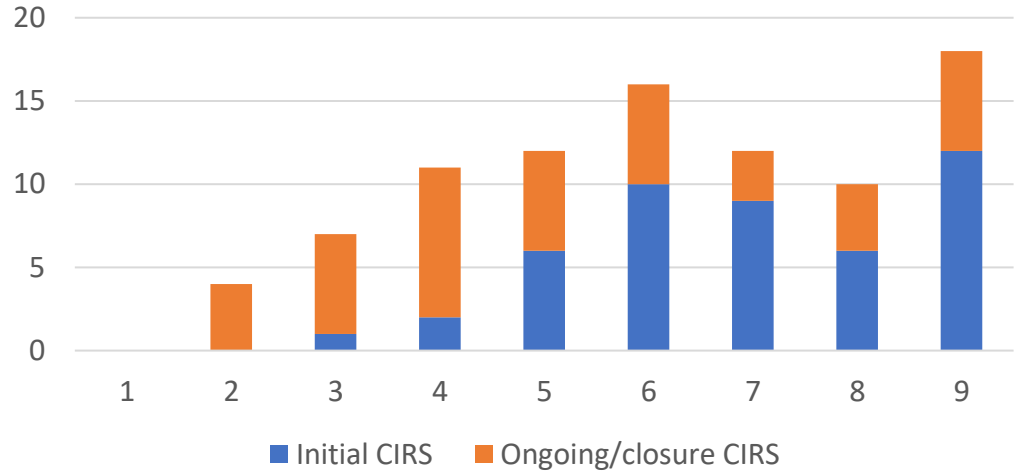
Ongoing and closure fire risk



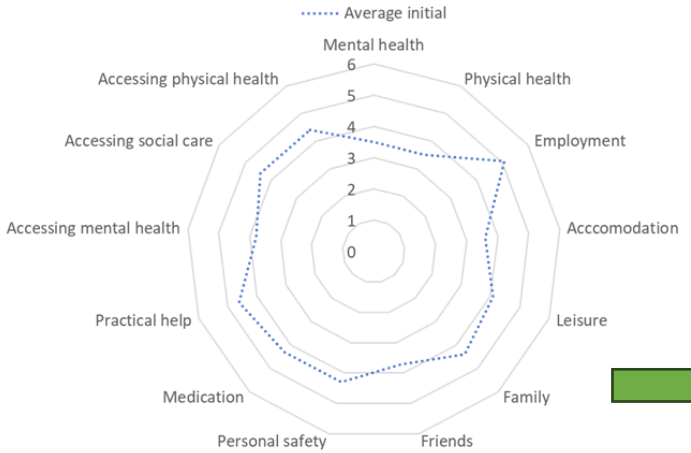
■ High (red) ■ Medium (amber) ■ Low (green)

■ High (red) ■ Medium (amber) ■ Low (green)

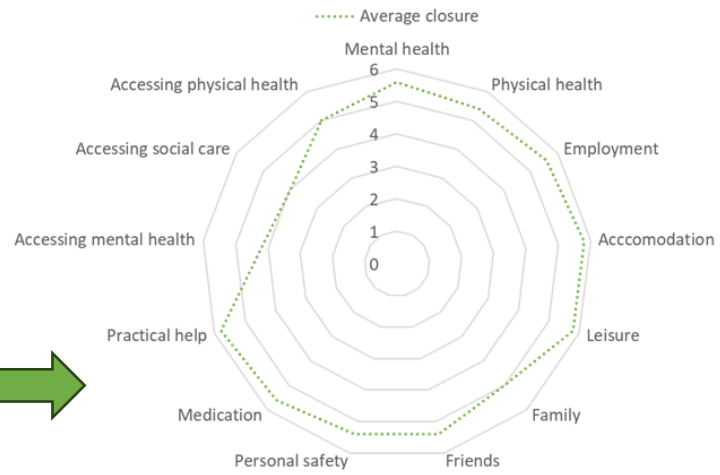
Clutter ratings



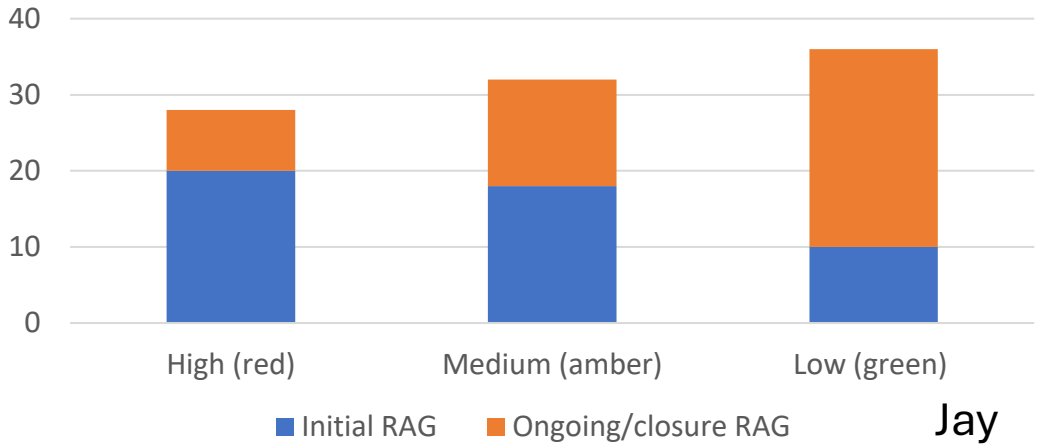
AVERAGE INITIAL DIALOG+ SCORES



AVERAGE CLOSURE DIALOG+ SCORES



Infestation risk



Jay

Involving support from unpaid carers and families, and reducing the need for formal housing procedures

SHHS
Supporting Better Living

- Of the 68 residents we have worked with, **we have supported the engagement and education of the unpaid carers and families of 26 residents.** We have also signposted/referred 3 clients to Carers Matter Norfolk.
- **26 residents** have been supported to increase their engagement for essential housing safety checks and **reduce their need for major repairs.**
- **36 residents** have been supported to **prevent or end formal housing procedures** against them.

Joe

SHHS
Supporting Better Living

Thank you. Any questions?

Working together to support people with self-neglect and hoarding issues:

What research tells us

Wymondham, 24th October 2024

Dr David Orr

UNIVERSITY OF SUSSEX

brighton and sussex medical school

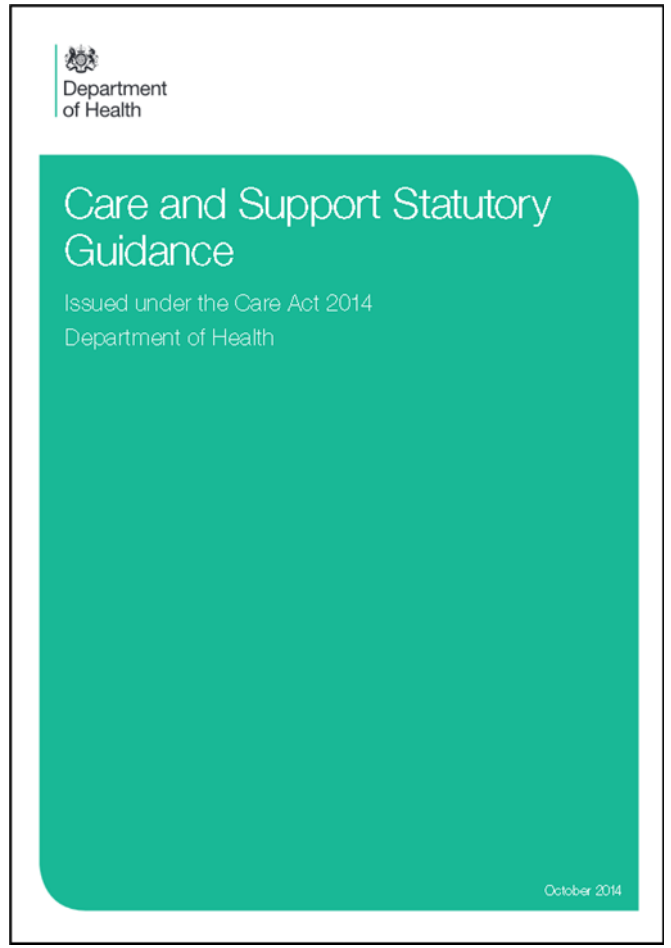
FUNDED BY NIHR | National Institute for Health and Care Research

What are we talking about when we talk about self-neglect?

"covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding."

(DHSC, 2023, s. 14.17)

- neglect of health conditions
- hoarding and home conditions
- fire, nutrition risks
- multiple-exclusion homelessness
- self-care and substance use



What does self-neglect mean for people experiencing it?

"I just accepted the way I was and I didn't care. I didn't see myself as something valuable enough to be worth the effort of trying to fix."

"You know, to be a hoarder, you might as well say whore – it has the same connotations. You don't want anybody to know. … It's very shameful, very shameful"

"I was still grieving that because nobody had ever really explored grief with me and enabled me to fully process the grief. And then it was grief about other things that had happened. Grief about not having any money, grief about not having any choices. And then grief of, well, if I'd had that help back then, maybe I'd be in a better position now."

"Well, I don't know to be honest. Suddenly one day you think, 'What am I doing here?'"

"When you say neglect is to do with self and neglecting, but I don't see it that way. I see it both ways."

What makes working together with self-neglect challenging?

- Self-neglect can be a slippery label, so hard to reach a common understanding
- Factors contributing to self-neglect can be complex and subtle
- Takes time to engage and understand, in the face of limited resources and often reluctance
- Services often not set up in ways that respond to situations of self-neglect
- High stakes: pressure to act on risk, but no clear way forward

How to respond to self-neglect …?
The dilemma

Self-neglect: a widespread challenge …

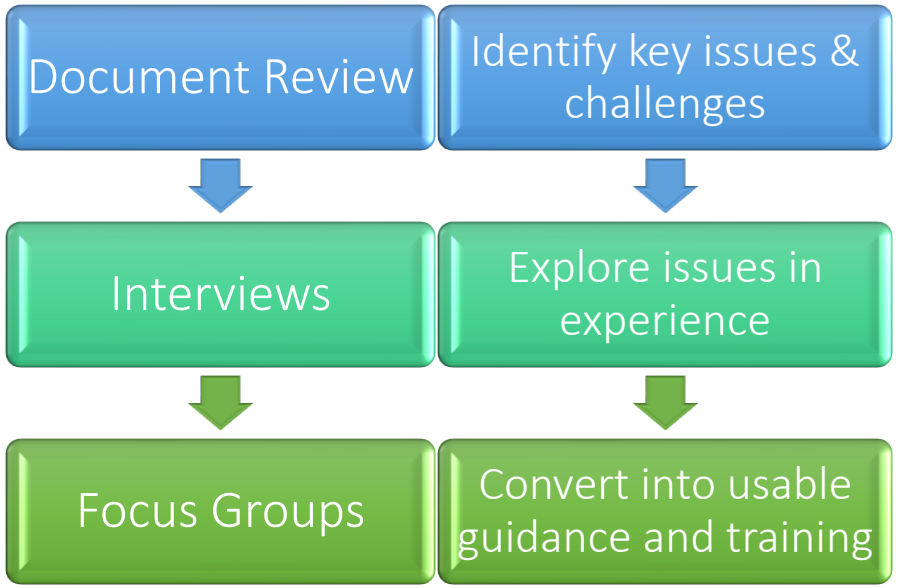
- Self-Neglect featured in 60% of all Safeguarding Adults Reviews in a Local Government Association study – the single biggest category of abuse / neglect

(Preston-Shoot et al. 2023)

- More than 500 Safeguarding Adults Reviews featuring self-neglect conducted by mid-2023

(Preston-Shoot et al. 2023)

Study methods



- literature-based synthesis: SAB policies + procedures, 273 SARs, 41 research studies
- Interviews with 69 practitioners and 16 people with lived experience (2 carers) at five sites
- co-production of findings and resources
- survey- and interview-based assessment of resources, guidance and recommendations.

Self-Neglect and Challenges of Inter-agency Working
(or, What do that lot over there think they're doing?)

- Uncertainties over each other's roles, esp. legal powers

  Patterns of over- and under-referral: 'jumping hurdles'

  Distrust that other services will be trauma-aware in their approach

  Shared language (false friends)
- Multiprofessional perspectives: clashing not complementing, or 'drift'

  Practitioners feeling 'isolated' with risk

  'Wrangling' rather than 'no wrong door'

  Keeping collective focus on the person

  Mental capacity not handled well between professionals

  Gaps in information sharing
- Learning that manages anxiety, not increases it

  Working across the borders: organisations and place

  Where do people with lived experience sit?

Inter-professional curiosity

Policies and procedures providing shared reference points

Bringing practitioners together:

Integration, ‘bridging’, communities of practice

Learning from each other:

Joint visits, ‘tea and toast’

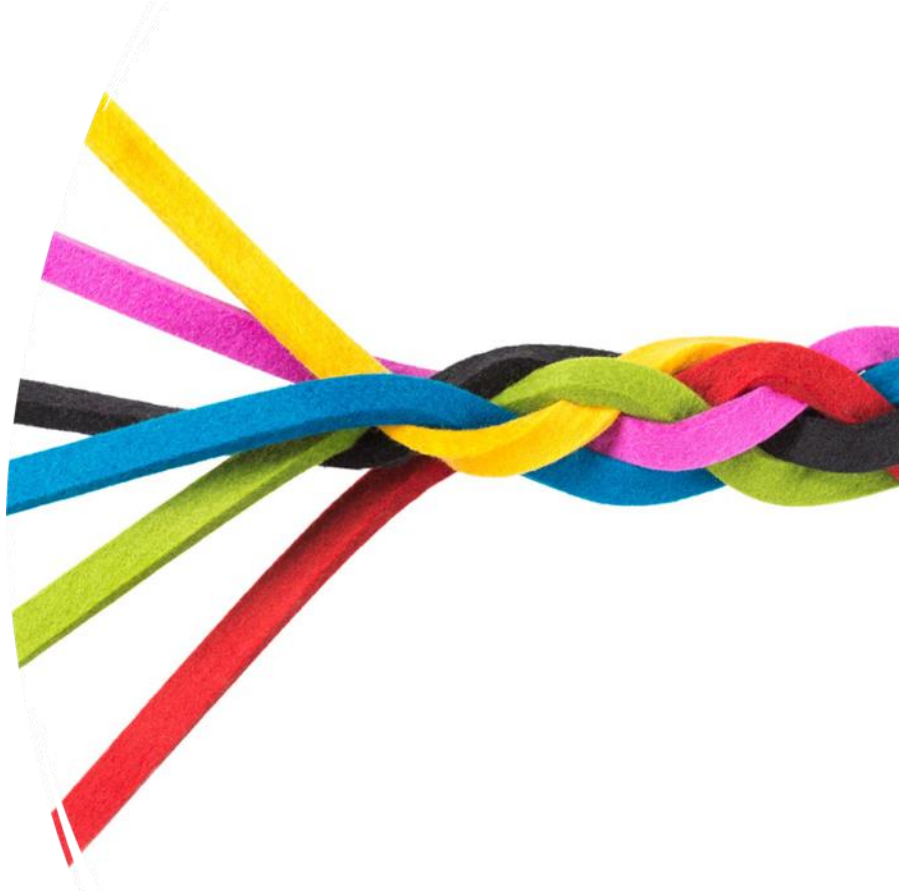
Guidance materials that are truly inter-agency

De-escalating the referral ‘hurdles’:

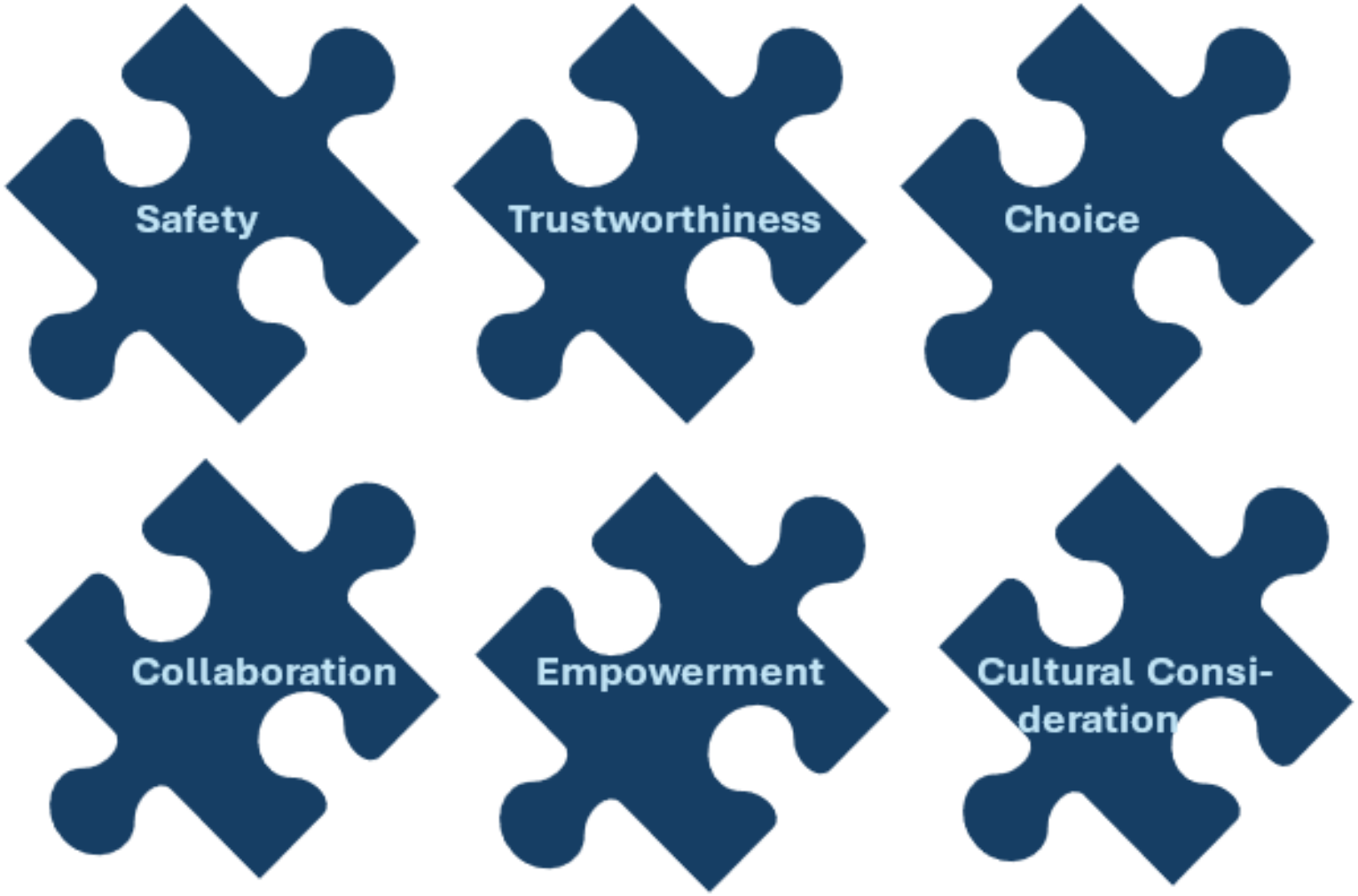
Knowing the right route, perceived barriers to acceptance, feeling confident in referring

Seeing the person and situation ‘in the round’

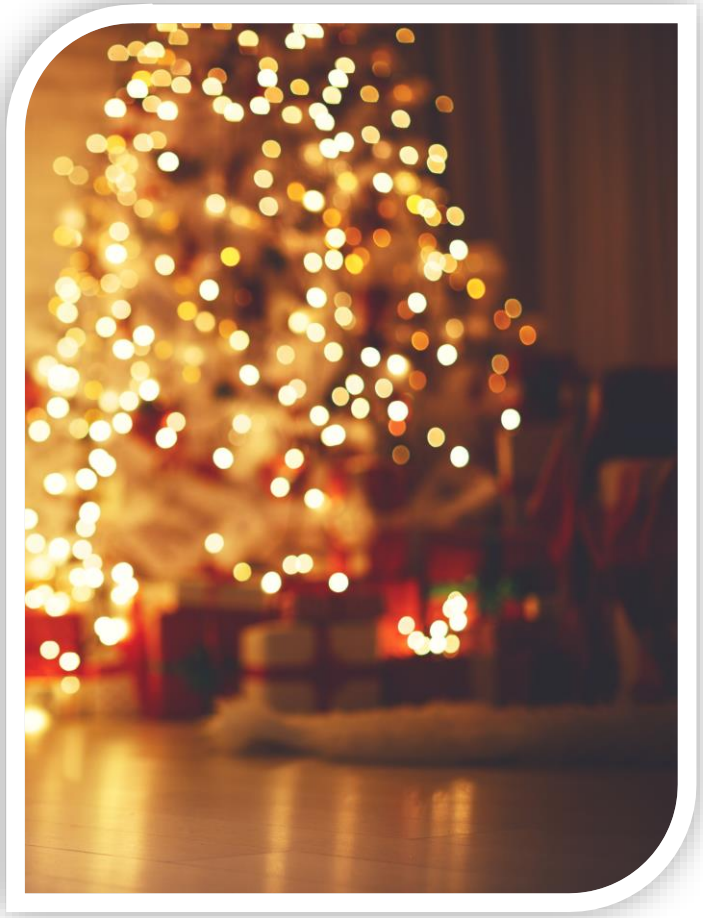
- Trauma-awareness as a golden thread
- More inclusive language
- Building in ‘devils’ advocacy’ as a feature, not a glitch
- Making people with lived experience more prominent
- Positive learning



Trauma-aware practice



Some images of self-neglect



Engaging people experiencing self-neglect: Things to consider

- Concerned curiosity
- What is the focus – motivation to change or reducing harm?
- The person's aspirations – identifying discrepancy

  "They had no hot water. I would just take, I was literally taking a flask with me at the time of hot water just to fill up a hot water bottle and things like that."
- Making connections through care for others

  "One service chipped away with a service user, reminding him of the effect he is having on other people. He is very empathetic and affected by the impact on other people, but he doesn't care about the effects on himself – it has got him through two years, when no-one thought he would."
- Neurodiversity awareness

  "I remember a willingness to work at my pace with things because I react very negatively to pressure. I, every time I feel like things are being expected of me, my brain shuts down and I can't make myself do it. Even if I want to, I can't make myself cooperate and they seemed sensitive to that."

Mental capacity

- SARs regularly finding mental capacity could be handled better
- E.g. practitioners assuming mental capacity without further consideration, even when decisions are causing harm to self
- Clarity over who should assess mental capacity, and the judgement
- The role of executive functioning in mental capacity includes:
  - Impulse control
  - Planning and prioritising
  - Flexible thinking
  - Self-monitoring (see Atkins, 2023)

Atkins, A. (2023) *The Capacity to Act …?* https://www.kcl.ac.uk/hscwru/assets/research-projects/homelessness/peer-network/internship-executive-function-by-ellie-atkins-2023.pdf

What have people experiencing self-neglect said about that involvement from services?

"Yes, through her input and, you know, the way she approached me. She didn't say your ivy was growing up to the ceiling 'cause I'd've just said, 'Yeah? And what's it to do with you?' know what I mean. She set off brilliantly, soft, listening, and that's what people like me need. They don't need to be dripping on for hours and hours, but they need – at the end of the day, you get to the root of the problem and a lot of the problem with hoarding is bereavement, mental health, depression and loneliness."

But I think part of it was I was allowed to literally help myself and I've I feel I've got control back of this. I've got help. It's just now I've got help. But it's the fact it's help that allows me to be in control of my own…. My own thing it's, you know, it's sort of like they're helping me help myself."

"I hadn't realised that there are quite a lot of people in the world who are like me, with piles of stuff and floundering."

"This is a turning point, I have to make, make the best of this and use it as a start for myself. For the future."

What can help people experiencing self-neglect

Trauma-informed approach

Neurodiversity awareness

Person-centred support from care agencies, declutterers

Multi-agency approach

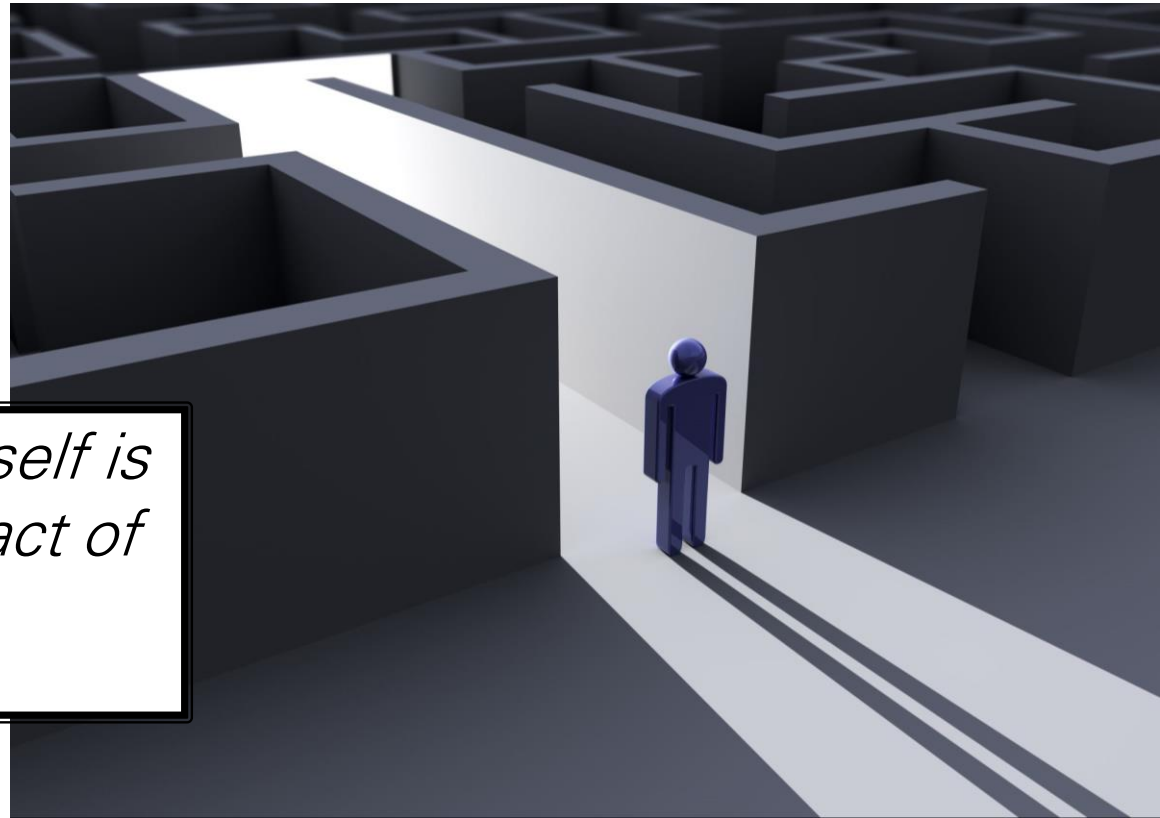
Clutter clubs; community involvement

Small steps with long-term view

Understanding over confrontation; roll with resistance

Summary

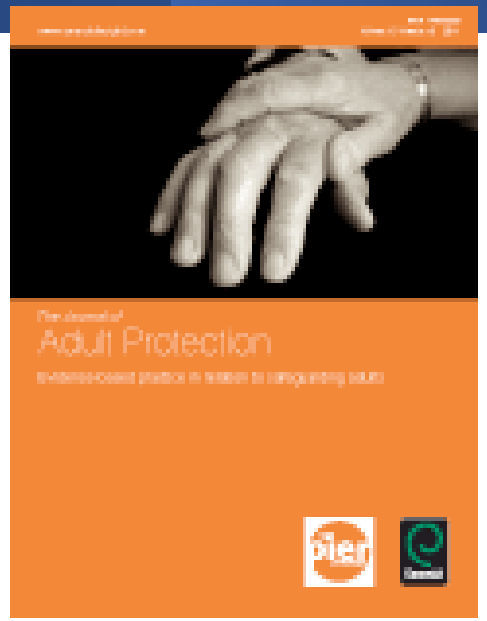
- Self-neglect can result from the interaction between capabilities, feelings and environment – need to explore all the possibilities and be informed by trauma-awareness
- Services are encountering self-neglect more and more – and we have a responsibility to respond
- 'Concerned curiosity' and identifying openings key to supporting people experiencing self-neglect

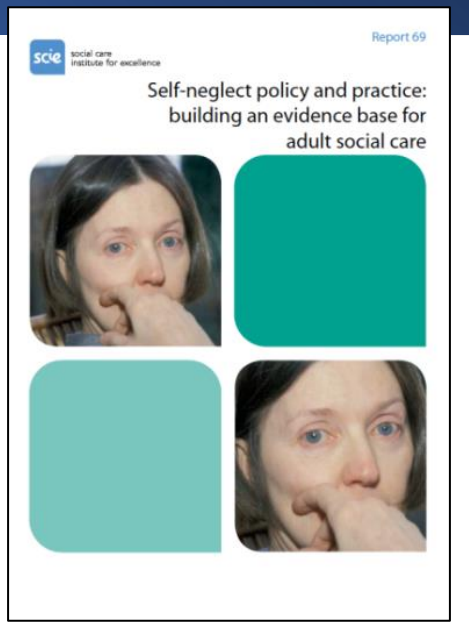


" I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival." – Lorde, A

Further Information

- Preston-Shoot, M: series of articles in Journal of Adult Protection analysing Safeguarding Adult Reviews featuring self-neglect
- Braye, S, Orr, D & Preston-Shoot, M (2014) Self-neglect policy and practice: building an evidence-base. Social Care Institute for Excellence. https://www.scie.org.uk/self-neglect/policy-practice/evidence-base
- Cornes, M et al. (2023) Opening the “too difficult box”: strengthening adult safeguarding responses to homelessness and self-neglect
- Orr, D et al. (in preparation) Improving collaborative inter-agency systems and practice in self-neglect. http://www.sussex.ac.uk/socialwork/cswir/research/researchhighlights/self-neglect





Group work – part 1

Scan QR for case studies

Self-Neglect & Hoarding Event

Wymondham Rugby Club 24th October 2024

Izzy Shaw & Jenna Bardwell, Norfolk County Council

How we work with the Self Neglect & Hoarding Subgroup

Norfolk County Council sees the partnership as an opportunity to:

- ✓ **Work together-** With partners across the integrated care system who are interested & involved in supporting & understanding self-neglect in Norfolk.
- ✓ **As experts & partners-** We share ideas, good practice & current expert thinking & training.
- ✓ **Develop joined up opportunities-** Highlight how we can effectively support individuals & gather evidence to make this happen consistently.
- ✓ **Prevention-** Identify those people who are at risk of SN&H
- ✓ **Understand** the direct experiences of people with self-neglect & hoarding.
- ✓ **Reflect** on the people we support, gather evidence & stories to ensure we can show the value of our services.
- ✓ **Set out expectations, future direction & next steps** for the provider framework, keeping it up to date, monitor the type of support we access & utilise
- ✓ **Listen & discuss** better ways of doing things with our partners, providers & clients – by being proactive & responsive

What is the

Self-Neglect & Hoarding

Provider Framework?

Jenna Bardwell –Senior category Manager Procurement NCC

Why did we need a framework?

- The framework came into place to support practitioners such as social workers, case workers who needed to access professional support & services quickly.
- Previously when services such as this needed to be purchased there could be delay & confusion re purchasing this type of specialist clearing / cleaning/ support service.
- Deciding who & how the service would be commissioned & paid for meant people we wanted to support weren't getting that help quickly enough.
- It took away the need for practitioners to purchase services ad hoc , ensuring quality approach & reassurance that people needing the services got the right support & what was purchased wasn't detrimental to their needs.
- It also ensured the Norwich City Council 'Safe & Habitable Homes Service' can access the most appropriate service across the city, by responding proactively to the needs of people they are working with.

Background

- With our partners we developed the Self-Neglect & Hoarding Provider Framework, which went ‘live’ in October 2023.

- Essentially it is a collation of providers who signed up to work with us to deliver professional support services for those who are experiencing self-neglect / hoarding issues.

- The framework was established collaboratively between
  - Norfolk County Council
  - Norwich City Council
  - Integrated Care Board.

- We produced a comprehensive list of providers which can be accessed & used by practitioners to identify organisations able to provide the right type of support or service needed to help an individual.

- What is the benefit of having a framework?

  It enables the Council to place orders* speedily & directly award work as its needed.

  (Also known as a Call Off Contract)

- Providers who apply & sign up to the framework have confirmed that they want to work with us on the terms stated in the agreement. Which makes this transparent & gives clarity.

Framework expectations: Norfolk County Council & Norwich City Council

- All our framework providers are set up on our internal systems, using the information that was provided as part of their providers applications.

- The provider list is then shared with operational colleagues who work in the Norwich area. Examples of these might be:

✓Social Workers

✓Assistant Practitioners

✓Case/development workers

- When someone requires support & the worker identifies a service is needed, they can utilise the list to identify providers or services that are most suitable to that person, it becomes bespoke & not generalised. It is important that the worker also takes account of the needs & wishes of the person they are purchasing the service for.

- The worker then contact & organise the work sharing the specific needs of the person they are purchasing the service for. This can be a one-off request or part of an ongoing care plan. There is flexibility in the use of the framework & the purchase of services, communication is always the key.

- Being set up on the system means that invoicing and payment arrangements will be faster and more streamlined.

- The Provider framework **does not guarantee work.**

Benefits of being on the Framework

Coordinated information and points of contact within commissioning organisations

Support of a wider multidisciplinary team of professionals from different organisations, with the opportunity to book a meeting slot to discuss someone you are working with as needed

Clear objectives and a good response timeframe for the work to be carried out

Background information about the person, including risks

Standardised terms and conditions - Helps to resolve issues if they arise btw provider & case

Interested in joining the framework?

- Although the framework is currently closed to new providers, we will be in touch with the whole market when we reopen the framework in 2025.

- We would be very interested to hear from District Councils who would like to discuss the potential for using the framework, like Norwich City Council currently do

- If you would like to know more about the framework in general terms & the impact, it's already had.

  In the first instance please contact :

- **Commissioning Manager Central Team Communities, Prevention & Partnerships, Norfolk CC**
  izzy.shaw@norfolk.gov.uk

Thank you

Jenna Bardwell Senior Category Manager – Procurement

Norfolk County Council

Izzy Shaw Commissioning Manager - CPP

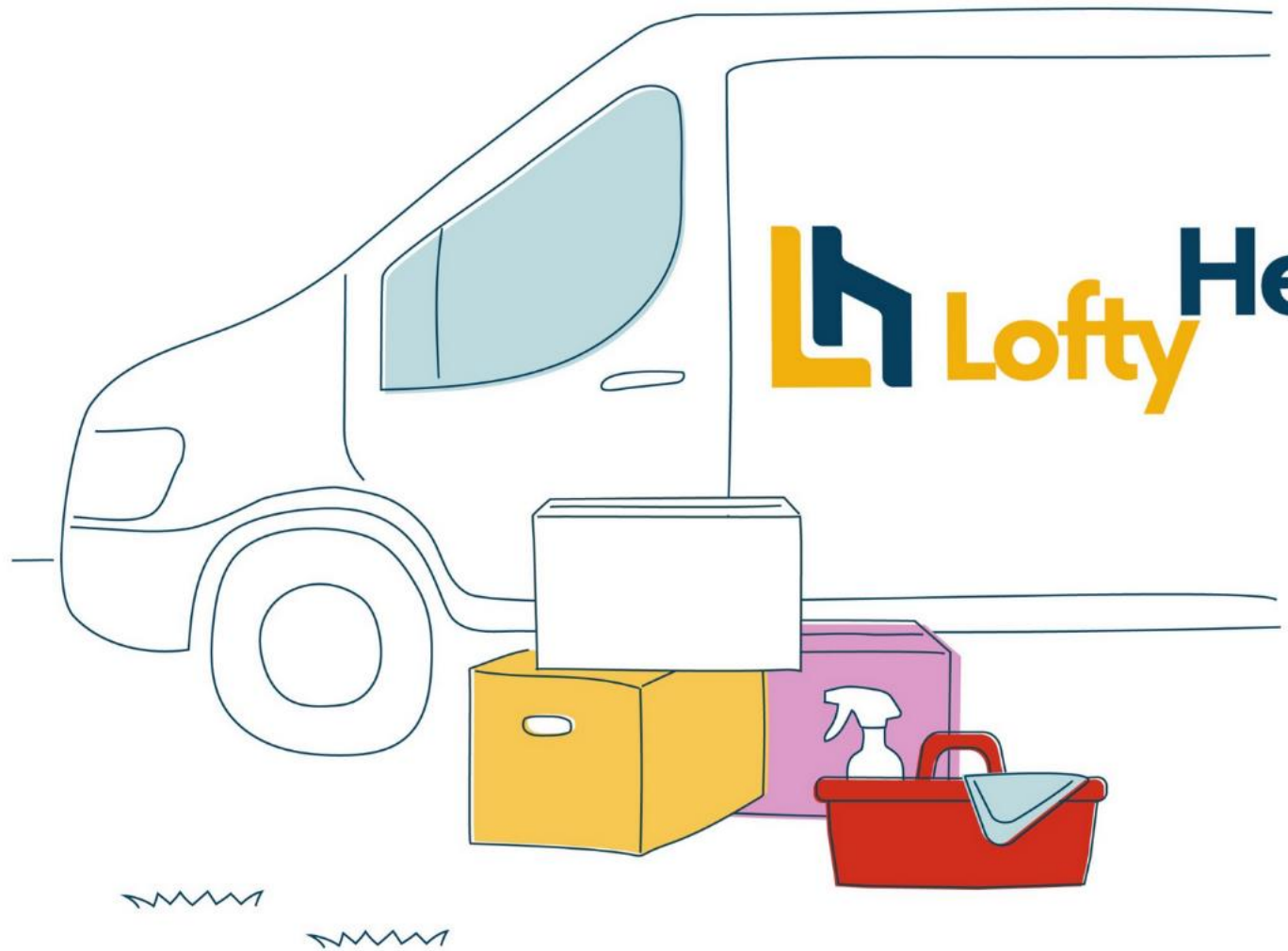
Norfolk County Council

Animation

Our self-neglect and hoarding animation can be viewed here

Services

by Lofty Heights



About us

Lofty Heights CIC is a not-for-profit social enterprise. With our decluttering, homeward-bound and house clearance services, we support vulnerable people throughout East Anglia to live safely at home.

We help people live safely at home by sensitively decluttering, deep cleaning and organising their belongings and living space.

Reliability
We believe how we do things is as important as what we do. We follow a tried and tested process and carefully protect any important items during our work.

Honesty
We appreciate that home is a safe space, but it can become disorganised & dangerous. We believe involving our customers throughout the process is integral to a successful outcome, we always seek to understand the situation and manage expectations.

Trustworthy
we are guests in people's homes (safe spaces). We never take that for granted, We want our customers to feel comfortable and confident in us. all staff have valid advanced DBS Checks

.

Lofty Heights

Our services

As a Not Profit Social Enterprise, Lofty Heights CIC supports vulnerable people throughout East Anglia to live safely at home with our decluttering, homeward bound and house clearance services.

We also help relatives, close family members, and carers at a time of change or bereavement when they need a little help to either clear or reorganise a space.

We always deliver our services with dignity and respect and never shy away from what can seem like an overwhelming task.

- Decluttering
- House clearance
- Hospital Discharge Service
- Garden clearance
- Help with hoarding
- End of tenancy cleaning

Lofty Heights

Case study 1

Mr. H was at a high risk of experiencing a long-lie fall, which could have led to hospital readmission. This was primarily due to excessive clutter throughout his home, particularly in his bedroom, living room, and kitchen. As a result, Mr. H had been living and sleeping in a recliner chair in the living room.

Local authorities had attempted to arrange care for him, but no agency was willing to take on Mr. H due to the state of the property. After discussions with the housing provider, we decided to carry out one of the five scheduled sessions before the bank holiday to mitigate the risk of readmission. After the break, we completed the remaining four sessions.

As a result of this intervention, Mr. H was able to get out of the recliner chair and walk around with confidence, and care agencies were willing to provide the support he needed to remain at home.

Please see the images to the left for reference.

Lofty Heights

Case study 2

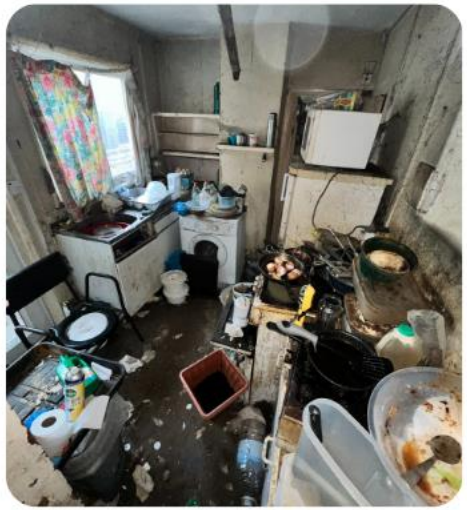
Ms. D had been struggling with severe depression for a long time and had lost hope of ever getting her life back on track. When we first met Ms. D during the assessment, she was disengaged and unmotivated. However, by the time the work was completed, her outlook and attitude toward life had completely transformed. Seeing her go from being withdrawn during the initial visit to giving hugs, smiling, and laughing was incredible.

These photos show just one part of the property, but in total, the work involved the entire home and was completed within six days. This not only ensured a safer living environment but also provided Ms. D with a fresh start, free from clutter, as she began the next chapter of her life.

From the assessment on March 27th to completing the work on May 3rd, this transformation was made possible through close collaboration with Great Yarmouth Borough Council and Social Services.

Lofty Heights

Case study 3



Mr. G had become reclusive and, as a result, was uncomfortable reaching out for help when issues arose in his home. This led to a vicious cycle, as no one knew that Mr. G's toilet had stopped working several years earlier. He resorted to using plastic bottles and buckets to store his waste, which he then disposed of in a shared manhole in his rear garden. This caused friction with his neighbours, further isolating Mr. G and making him withdraw even more.

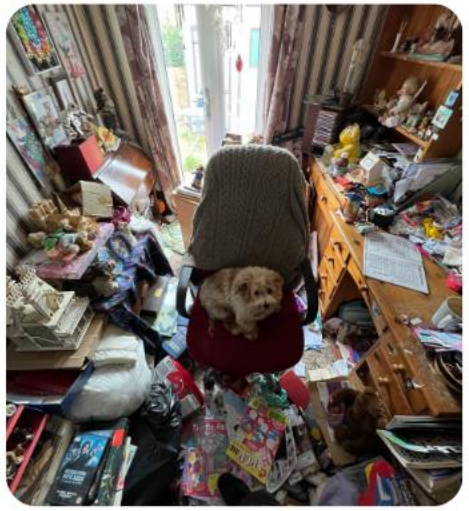
Concerned neighbours reported the situation to the local council, who had worked with us on a few previous cases and asked for our help. It took several attempts to reach Mr. G by phone, and multiple scheduled assessments were cancelled. Finally, we made a breakthrough when Mr. G agreed to meet with us and allow an assessment of the property.

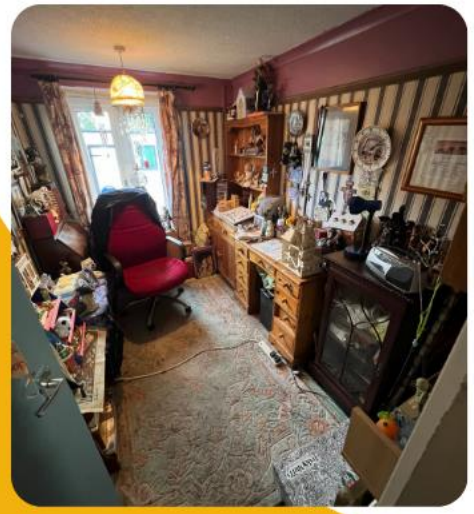
The work, funded jointly by Great Yarmouth Borough Council and Social Services, took six days to complete. On the first day, we discovered the toilet was non-functional, and this was immediately reported to the council. After our work was completed, the council arranged for a new toilet to be installed, ensuring that Mr. G wouldn't have to rely on plastic bottles and buckets to manage his waste anymore.

The key to this successful outcome was maintaining open lines of communication. Without this, Mr. G likely would have felt abandoned and returned to his previous coping methods. Afterwards, Mr. G was able to have a much-needed hip operation and recover safely at home.

Lofty Heights

Case study 4





For many years, Ms. M had not engaged with her housing provider or accepted help to ensure her property met the conditions of her tenancy agreement. As an elderly person, she was at risk of falling. Initially, we faced resistance from Ms. M, but over time, we were able to make gradual progress.

The images show the area where Ms. M felt most comfortable allowing us to work. This gave us a valuable opportunity to build trust and establish common ground, which allowed us to move forward into other areas of her home. The work in this room took about three hours, during which we built enough rapport to address the parts of the home that were of greatest concern to the housing provider.

Being flexible with the original plan was crucial to achieving a successful outcome. Breaking the work down into stages and spreading it out over several months often increases the likelihood of success, as it did in this case.

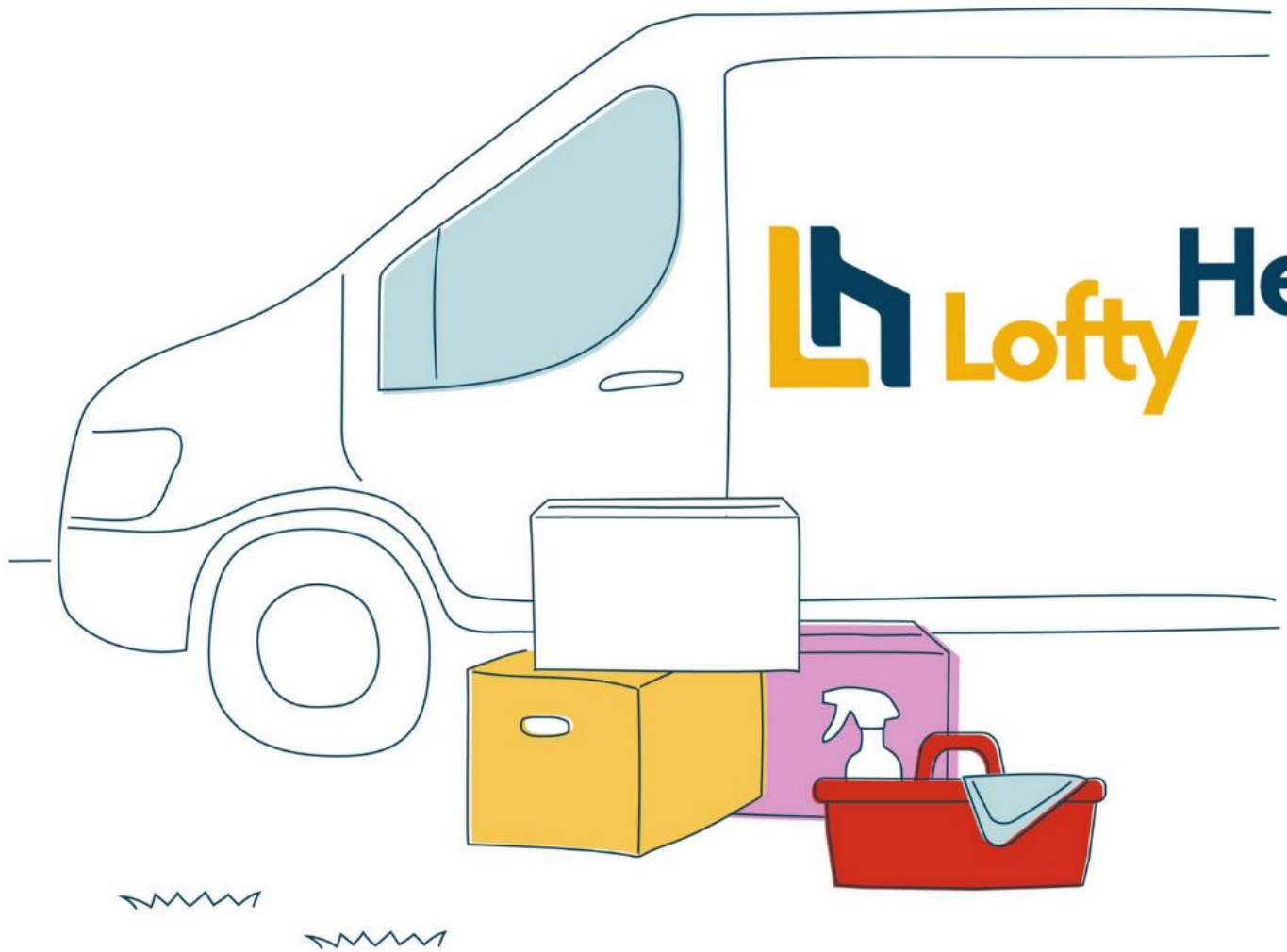
Lofty Heights

How to make a referral

www.lofty-heights.org
David@lofty-heights.org
01473 345301

Please feel free to come and ask questions.

Lofty Heights



Group work – part 2

Case studies and presentation

Case Study 1, Part A

A gentleman is referred for assessment due to concerns that he is not coping. Most rooms – other than the kitchen – are cluttered with items of little apparent value. This makes cleaning, maintenance and movement through the flat difficult, raising worries about hygiene, fire risk and self-care. But the biggest concern is that he is now in his 60s and becoming unsteady, with reduced mobility. He lives in a self-contained flat, one of four in a family house conversion. The entrance to his flat has steep stairs with doors at the bottom and top, and the risk of falls there is considered high – and worsened by the risk of piles falling on top of him.

Housing have discussed the situation with him and he acknowledges that there are risks which could cause him harm. They have explored more suitable accommodation options and been able to offer him options. But he seems oddly passive. Though he hasn't objected, he always finds an excuse or is out when they try to move forward with a decision. One officer is querying whether there may be mental capacity issues: that although he understands the risks, he may not be weighing them to reach a decision.

- What are your thoughts on the information offered to this point and what approaches might be helpful?

Case Study 1, Part B

In this particular case, a supervisor questioned how staff could be sure that a move was what he really wanted, rather than what they thought was in his best interests. With time, and discussion that focused more on what was important to him than on what action needed to be taken, they learned more about his past. He confided that he had been abused when young, and it became clear that the doors and stairs – and perhaps even clutter – were an important barrier that helped him feel safe from the outside world. Workers realised that he rarely objected directly to suggested plans about anything, but his body language indicated he felt threatened by the idea of moving to somewhere new.

Questions to Consider:

- When and how do you inquire this closely? What makes it difficult?
- How do you build the trust to get to that point?
- How do you explore solutions given what we now know?
- How do you ensure the services involved work together with a shared understanding, from their different remits? What complicates this?

[There is a Safeguarding Adults Review that can be paired with this, where hoarding concerns were not responded to. Would this be useful?]

Case Study 2, Part A

Mr G neglects his health, putting him at risk of diabetic complications, and is often found sleeping rough alongside friends of his, though he has his own flat. At these times, he tends to drink significant amounts of alcohol; he used to get into fights when drinking that led to at least three hospital admissions for head injury. The flat itself is deteriorating and he is at risk of losing his tenancy. Professionals have assessed his mental capacity to make the relevant decisions, and he seems able to understand and talk through the risks he is running. Each time he says that he understands the consequences of his actions and assures them – apparently earnestly – that he will stop sleeping on the street, not invite people in, address fire risks, and engage in self-care. Each time he does not follow through. Professionals are puzzled and growing increasingly concerned and frustrated about the likelihood he will come to harm.

Questions to Consider:

- What different explanations might there be for the discrepancy between what Mr G says and what he does?
- How might you work together to explore each of them?

Case Study 2, Part B

In this particular case, one practitioner argued that there might be more going on than telling professionals what he thought they wanted to hear, or making 'unwise decisions.' Mr G's history of head injury, persistence of discrepancy over time, and inability to account for why he had not carried out his decisions made her wonder about his executive functioning. Mr G agreed to a brain scan on the same visit as a diabetes check-up, which confirmed that there was possible brain damage. Mr G seemed able to weigh up a decision when the options were set out in a structured way in the mental capacity assessment, but then proved unable to do so 'at the appropriate time' when placed in an unstructured situation, and 'went along' with what was easiest. Professionals then felt able to be more proactive in offering support, which Mr G accepted in a way he had not when it was offered as one of several options.

Questions for Consideration:

- What indicators might lead professionals to consider executive functioning in relation to mental capacity?
- If someone is found to have likely executive impairment, how should services respond ethically?

[Safeguarding Adults Reviews show how failure to take account of brain damage can leave practitioners assuming that the person has meaningful mental capacity to make self-care decisions, when in fact they do not. This leaves them addressing only parts of the problem rather than tackling it holistically.]

Atkins, E. (2024) *Why You Need To Know About Executive Functioning*. www.youtube.com/watch?v=4dc-gknSxd0

Case Study 3, Part A

Mr H is a man in his early twenties, living alone in an apartment since he left his mother's house three years ago. Neighbours, who had moved in some months before, raised concerns about the state of the property. When the council contacted him about his obligations, it was observed that the flat was dirty and highly cluttered. Mr H looked underweight and exhausted, and avoided eye contact, yet appeared emotionally flat. He repeated himself several times during the conversation but did not give a clear explanation for the situation. The worker tried to explore with him what options there were and asked if he needed support, but he grew more and more tense, muttered 'I don't know,' then broke off the conversation abruptly. Follow-up attempts to contact him were unsuccessful, and he rarely seemed to be at the flat.

Questions to Consider:

- How many possible factors can you think of that might be contributing to this situation, and how might you explore them?
- What do you think services would be most likely to do next?

Case Study 3, Part B

There might be many reasons why someone prefers to avoid a conversation with services about self-neglect. In cases in our study, we heard how undiagnosed autism can play a role in self-neglect. Mr H struggled to cope independently but found it difficult to access a diagnosis or get recognition of his needs from the Work Capability Assessment. He noted that "it's just my nature is I try to get into a comfortable routine and I just sort of put in roots in that lifestyle and I accept it, so I didn't understand how bad things were for me," and was questioning if it was worth living. He was already in debt, poor health, and deteriorated living conditions when new neighbours moved in who were noisier than the old ones. It disrupted familiar routine and the noises stressed him. Trying to raise it with them did not go well as they found his manner hostile and he had difficulty reading their reactions, leading to an argument. Intimidated, Mr H started spending as little time in his flat as he could, making things even more difficult.

Fortunately Mr H's mother realised he was struggling and involved social services. His social worker was able to work with him to understand what approaches helped:

- working at Mr H's pace to manage the demands placed on him and find "a good balance of obligations I had to meet as well as, you know, support and and patience in getting to them";
- showing understanding rather than judging, or putting on pressure to rush to make changes;
- offering options to choose from rather than presenting too many unstructured choices, which increased Mr H's anxiety: "Eventually I think we just sort of settled into having a conversation about me and them being able to then suggest things they could do for me and that made the most sense."

This resulted in a suitable care package which he found worked for him.

> "Every time I feel like things are being expected of me, my brain shuts down and I can't make myself do it. [...] If I can get away from any kind of obligation, I, I will. I'll seek the shortest path to not having to do it"

See Westminster HHCP (2020*) Autism and Homelessness Toolkit*. https://2020health.org/wp-content/uploads/2020/11/Autism_Homelessness_Toolkit.pdf

Case Study 4, Part A

Ms B, recently retired, has lived with Mr A since he moved in with her a few years ago. She has an adult son nearby, but they are not in contact; this upsets her and she attributes it to tensions between him and Mr A. The community nursing team have now visited Ms B at home, due to concerns that she is showing signs of slight cognitive impairment. They were startled by the levels of clutter in the house which have appeared in the last few years – they reach 7 on the Clutter Rating Scale and leave little space to move around in. The objects include several old typewriters, newspapers and jottings, broken tools, DIY scraps, and even an old lawnmower. Ms B is vague about when they got these items, what they are and why they are being kept. The nurses offer to refer for a fire safety assessment, which Ms B accepts. The officers discuss the significant risks with her and she seems to accept the risks, but says, “Oh, I couldn’t get rid of these things! She does not seem to know what many of them are and admits she has never used most of them.”

- What are your thoughts on the information so far, and what would be your next steps?

Case Study 4, Part B

In this particular case, practitioners took time to discuss with Ms B why it was important to her to keep the items. Though they were open with her about their concerns over the risks, they were careful to make clear things would not be removed without her permission. They explained the risks slowly and carefully so she could understand and remember them, involving Mr A to help her understand. During these discussions, it became clear that Ms B was willing to consider removing the items; however, Mr A was not, and refused even to acknowledge the risks. In the end safeguarding concerns were raised – not because of hoarding / self-neglect, but because of Mr A's controlling behaviour and placing Ms B at risk. Her son later confirmed that Mr A had brought the hoard with him when he moved in.

Questions to Consider:

- How do we sensitively explore the role others may be playing in apparent self-neglect under the surface?
- How do we respond when the person self-neglecting is in a caring role?

[Several Safeguarding Adults Reviews consider how complex caring relationships are often not explored in self-neglect cases. There may be particular concerns when the self-neglecting person themselves has caring responsibilities (these are touched on in policies when they are caring for children, but less often for adults.]

Responding to trauma caused by services

Some interviewees told us about how they had been affected by professionals not believing them about health conditions or a disability. That experience could lead to distrust or hopelessness.

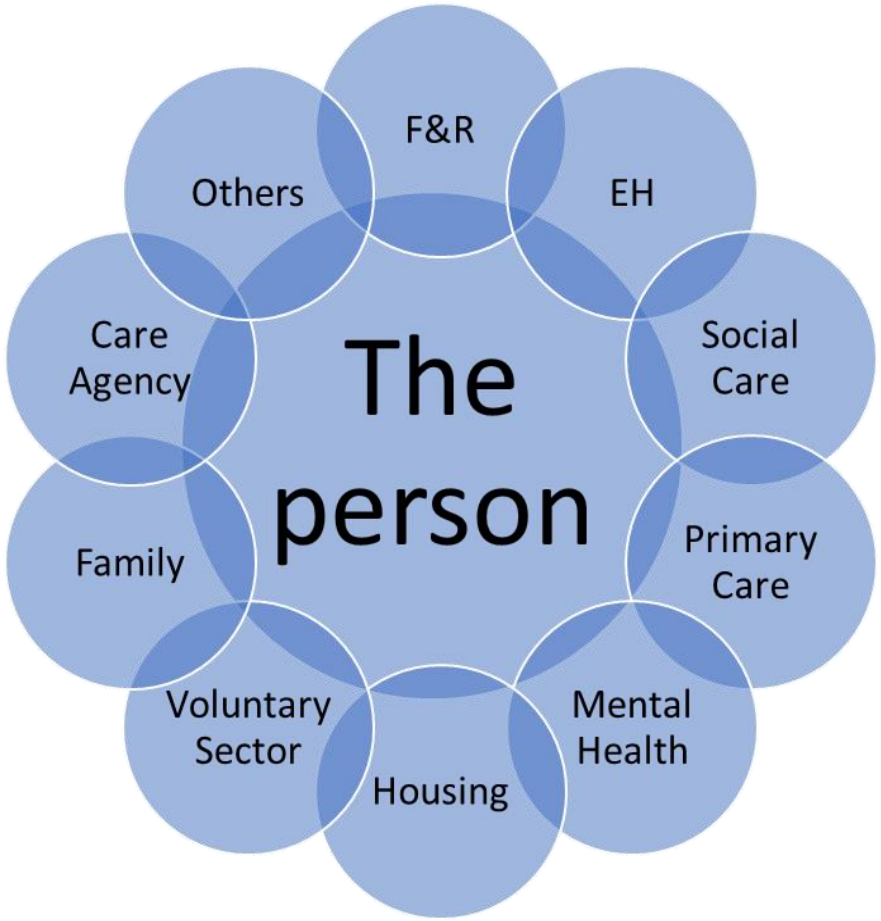
Questions for consideration:

- How do you consider and address that, whether you are from the same service or a different one?

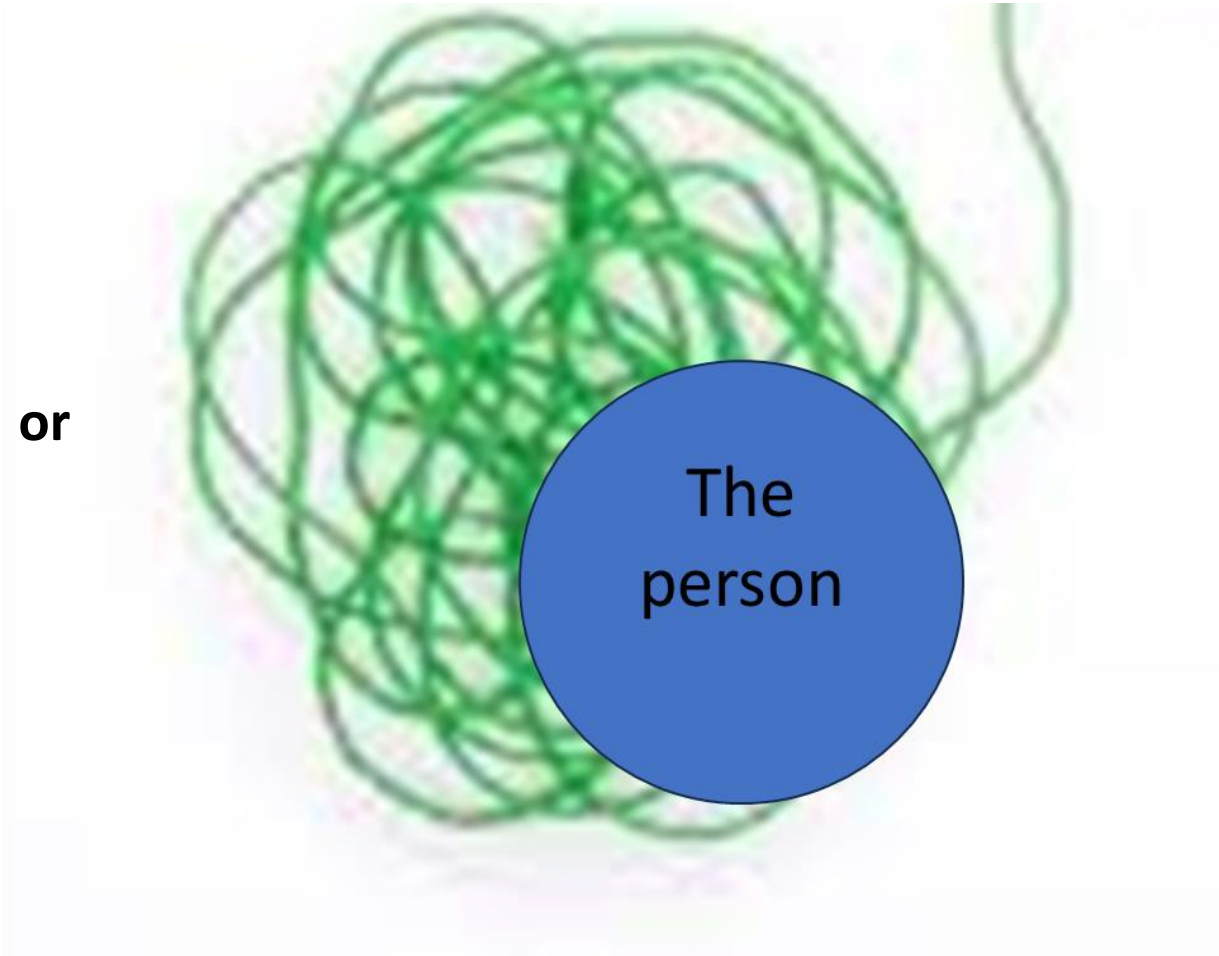
> **“*Listen*. *Listen*. You know when somebody's telling you they're not well, it's not pissed off or having a bad day. They're not well. You know when somebody opens their heart and say well, I don't feel right.”**

So how can we work together better to support people experiencing self-neglect?

Inter-agency collaboration: keeping the person at the centre



or



Shared Understanding? The Example of Referral

> “It can be quite a long process of getting someone that appointment in the first place and so after two months of trying to get them that appointment and they go and then they're discharged. That's a lot of work and a lot of effort, and that's just gonna put them off ever engaging again. And we're sort of no further forward and we're sort of further back.” (Homelessness Nurse)

- Do we always speak the same language?
- Do we always see risks in the same light?
- Are we desperately hoping someone else can solve it?

Shared understanding? The example of referral

Is self-neglect safeguarding?

Safeguarding applies when an adult:

- (a) has needs for care and support (whether or not the authority is meeting any of those needs),
- (b) is experiencing, or is at risk of, abuse or neglect, and
- (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

"Self-neglect may not always prompt a section 42 enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support."

Result: different practice in different places

Shared understanding: the example of referral

TRIGGERING REFERRAL

- Noticing
- Recognising as a cause for concern
- Recognition as self-neglect

PERCEPTIONS OF REFERRING

- Knowing the right route
  - When is it safeguarding / not safeguarding?
  - What's the local process?
  - Who should I involve?
- Perceived barriers to acceptance
  - 'They're hardened over there – or overloaded'
  - 'They don't take referrals from us seriously'
  - 'They're not engaging' means nothing happens
  - 'Did they read it?'
- Feeling able to refer
  - Lack of confidence in what happens after
  - Navigating the forms
  - Fear of reprimand or legal consequences

PROBLEMATIC CONSEQUENCES

1. NOT REFERRING
2. INDISCRIMINATE REFERRING

WHAT HELPS

- Encouragement
- Communication
- Triage and Systems

SMOOTHER REFERRALS & INTER-AGENCY WORKING

Inter-professional curiosity

- In SAB self-neglect policies + procedures, we found checklists can have 6-21 indicators of self-neglect, including:
  - ‘portraying alternative lifestyles which some may view as eccentric behaviour’
  - ‘poor hair care’
  - ‘we agreed to expand the definition of self-neglect to include unwise ‘choices’ made by a young adult who had been sexually exploited as a child’
- Are there indicators or risk factors that are red flags for you?
- In your groups, which ones are similar and different? What do you make of others’ choices?

Inter-professional curiosity

"I think they think we have more powers than we do."

Who said this?

- Adult Social Care
- Environmental Health
- Fire & Rescue
- Housing
- Mental Health
- Multi-Agency Safeguarding Hub
- Police

For discussion

- What relevant powers / duties do you have?
- What limits are there on them?

And as a follow-on:

- It can be a useful reflective exercise to reflect from an outside perspective. How do you think your organisation / profession is seen by others, in relation to self-neglect? Is there something you would like everyone to know?

> “If people understood, you know – you hear this thing, ‘oh, they won’t help them. […] No one’s saying they won’t. It’s about whether they’re legally able to.”

“You know, it's a terribly frightening situation dealing with patients like this because you want to do the best by people and you're respecting their wishes and their rights as human beings. And then they're telling you that they don't want any help. But it's very clear that everything that is being presented at you, nonverbal communication and the presentation of the house, everything is telling you that this person needs and probably wants help, but is unable to access it. And how do you, how do you breakdown that that barrier?” (District Nurse)

- Different professions can have different levels of training and support of managing the dilemmas and feelings of watching someone suffering, while refusing help. What support is available to you with this?

Final reflections

- Is there something useful you have learned today, either about self-neglect or about how local services work?
- Is there something you want to find out after today, either about self-neglect or about how local services work?

Our research continues …

We need *your* input

- As well as the standard learning event evaluation, you are invited to complete some further questions to help us understand how best to use and communicate the learning from the study.
- This will inform further development of training and materials.
- It is entirely up to you whether you participate, but it will help us if you do.

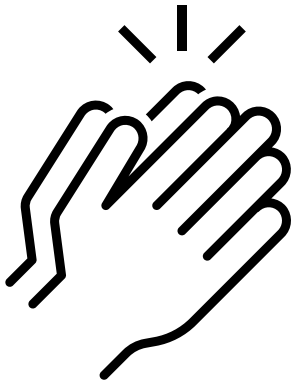
We are also looking to carry out a small number of further interviews with practitioners to help finalise our study.

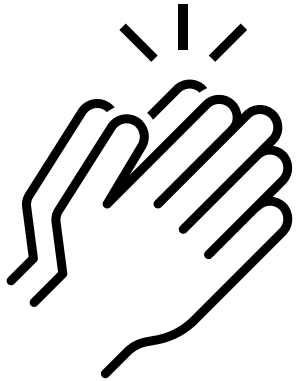
We are interested in talking with a few practitioners from each agency.

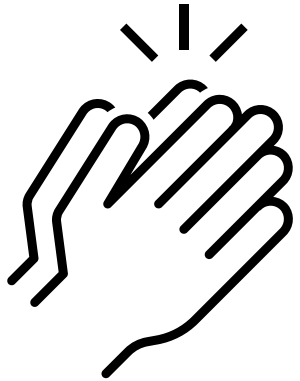
It would take about 30 minutes and can be done online at a mutually convenient time.

See the printed information sheets for more information or contact me at d.orr@sussex.ac.uk

Thank you for listening







Becky Booth

Deputy Manager
Norfolk Safeguarding Adults Board

becky.booth@norfolk.gov.uk

www.norfolksafeguardingadultsboard.info

@norfolksab

Summing up….

…and a huge thank you!