Self-Neglect Thematic Review

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1. Introduction

1.1 Covid-19 and the associated restrictions are felt to have impacted upon the increasing number and the complexity of safeguarding concerns involving self-neglect that are being reported in Newcastle.

1.2 As well as safeguarding concerns there have been a high number of referrals into the Safeguarding Adults Review (SAR) Committee (in Newcastle and across the North East Region) involving self-neglect[1].

1.3 As a result, The Newcastle Safeguarding Adults Board (NSAB) wanted to try and further understand practitioner experiences of self-neglect in order to make improvements to policy, guidance and training in this area.

1.4 The NSAB's SAR Committee gathered practitioner views in two ways: via an online survey and a workshop. This report summarises the findings from both and makes a number of recommendations to support front-line practice.

2. Summary

2.1 The key points from this report are:

- Practitioners report a relatively high degree of confidence in responding to self-neglect cases.
- Positive, person-centred engagement with the person at risk of, or experiencing, self-neglect is crucial.
- Trying to understand the cause of self-neglect is an important part of being able to deal with the symptoms.
- Self-neglect cases will require long-term, consistent, multi-agency involvement.
- Understanding and applying the Mental Capacity Act is fundamental to self-neglect cases but this can be complex and challenging.
- Early identification, intervention and prevention are desired but sometimes the reality is that cases are only picked up and dealt with at crisis point.
- There was limited awareness and familiarity with local self-neglect practice guidance.
- Very few practitioners had received recent self-neglect training that met their needs.

2.2 The following actions are recommended:

Things that will be done **now**
• This report is published and widely shared so that it can be used to prompt discussion, reflection and professional development. • The findings from this report are used in the review of self-neglect practice guidance and single and multi-agency training. • Regional self-neglect 7-minute guides are widely shared across practitioner groups and networks.

[1] Cases are referred to the SAR Committee where an adult has died or suffered serious harm as a result of abuse or neglect and there is a concern about how professionals and agencies have worked together.

• All agencies to include or disseminate key messages and links to resources about self-neglect on intranet sites or via internal communication methods.
Things that could be done **sooner**
• Establishment of a local self-neglect practitioner forum. • Increasing practitioner confidence in application of the Mental Capacity Act.
Things that we will explore **later**
• Agencies to explore self-neglect risks/prompts being added to core assessment forms/documentation. • Find out more about dedicated services that support people who self-neglect and the potential of these being funded/commissioned locally.

3. Online survey responses

3.1 There were 78 responses to the self-neglect practitioner survey, from a wide range of professions and sectors.

3.2 Respondents identified a relatively high degree of confidence in responding to self-neglect cases. The average response was 7.34 (with 1 being the least confident and 10 being the most confident). Responses ranged from 3 through to 10.

3.3 When asked **what worked well,** responses focussed on:

3.3.1 **Empathy and compassion**. Many respondents talked about the need to listen to the adult and ensure responses are non-judgemental.

"Make it quite clear you are not there to judge, but provide help and referrals". (Police Constable)

3.3.2 **Understanding the cause**. There were numerous references to getting a clearer understanding of what might have led to the self-neglect, with practitioners talking about the need to be professionally curious and trauma-informed.

"Understanding the driving force behind the self neglect, it might be severe and enduring due to schizophrenia illness, an indication of abuse, historical or current abuse…Be curious, persistent and collaborative." (Social Worker)

3.3.3 **Person-centred interventions.** Practitioners referred to the need to understand what the adult wants to happen; what their short-term and long-term goals might be. Respondents talked about strengths-based approaches. Respondents also talked about matching practitioners who the adult at risk would be most likely to engage with positively.

"Taking a individualised/personalised approach; if you know the person, then you should play to their strengths, interests and capabilities. I find that you must always preserve a person's dignity and ensure the staff work in this manner too." (Day Centre Manager)

3.3.4 **Risk assessment.** A number of respondents talked about the need to be clear about what the risks were as a result of the self-neglect and then what steps could be taken to manage those risks.

"Understanding the level of problem by good risk assessment. Consideration of capacity and an outcome focused and multi-disciplinary plan to address the matter matters causing or contributing to the identified self-neglect" (Care Director)

3.3.5 **Multi-agency working.** Many respondents talked about the need to work collaboratively across agencies, communicating well and sharing information. There were references to working using MDT (Multi-Disciplinary Team) approaches or safeguarding adults procedures.

"Having a team; finding someone who is able and willing to advocate for the patient - be it relative, friend, carer, social worker, CPN etc" (GP)

3.3.6 **Time and resource.** Another repeated response was about practitioners being afforded the time and resources to work with an adult who was self-neglecting. People talked about the need to take small steps with the individual and to work at the pace of the adult at risk.

"Empathy, patience, and most importantly time and resources. Self-neglect doesn't happen overnight and it can't be reversed overnight. If a social worker hasn't got time and resources to work with the person at their pace then the work won't be effective" (Social Worker)

3.4 When asked **what was challenging**, responses were grouped around:

3.4.1 **Mental capacity.** Practitioners talked about the challenges of undertaking mental capacity assessments or presumptions that adults were making choices without capacity assessments being completed/evidenced. There were also references to the difficulties of taking action when someone is assessed as having mental capacity to take a particular decision.

"There is a lack of understanding between capacity to make informed decisions and capacity to plan, implement and respond to daily self-care needs. Particularly those with complex co-morbidities. I have worked overseas with people with cognitive impairment due to trauma/abuse/foetal alcohol syndrome/substance misuse. They often had capacity to make decisions but required support with daily care. The only way to access support was through neuropsychological assessment. " (Specialist Nurse)

"If a client has mental capacity (when not under the influence) to understand the consequences of their actions on their physical and mental health, chooses to continue to take drugs/alcohol and understands the associated risks - what can a professional do? It is a vicious cycle of Adults Concerns/Safeguarding and no positive

outcome. A high-risk client with a repeated pattern of self neglect. It is disheartening, frustrating, disempowering." (Social Worker)

"Assessing capacity is really hard and time consuming. Because it is situation dependent, it has to be done repeatedly for each decision. I've struggled to get support in making a mental health diagnosis which would help quantify a patient's vulnerability." (GP)

"It can be quite easy to choose the viewpoint that self-neglect is the product of an informed and chosen way to behave / live. To the contrary of this we have a duty to evidentially decide if it is choice or a lacking capacity to make the choice. (Care Manager)

3.4.2 **Identification.** Another recurring response was how hidden self-neglect can be. Respondents talked about the embarrassment and shame that is often associated with self-neglect which might mean the person wouldn't ask for help or let professionals into the home environment. A reduction in face-to-face contact has increased these risks. The subjectivity of self-neglect was also referenced.

"Identifying self neglect isn't always easy - someone can present in the community as being okay, but only when you see their home situation do you see concrete evidence of self neglect". (Voluntary and Community Sector worker)

3.4.3 **Positive engagement.** Practitioners repeatedly talked about the difficulties in engaging with an adult who was self-neglecting. Where engagement was limited or non-existent, this made assessments (e.g. MCA, risk, care or health needs) difficult. Having the adult at risk positively engaged was felt to be crucial to achieving positive outcomes.

"Engagement with services - not answering the door, phone calls or letters. When the person has no support networks and does not consent to formal support, it is extremely difficult to gauge how well or how at risk they are. Assessing capacity regarding self-neglect can be difficult when the person does not wish to engage with any part of the process and may present less confused or more understanding of their situation than their cognition allows." (Social Worker)

3.4.4 **Time and resources.** A number of respondents talked about services not being set up to support people on a long-term basis.

"We find identifying self-neglect with a degree of ease, as we spend a lot of time with the people we support. Responding is more challenging as it takes time, especially working in a person-centred way." (Registered Manager)

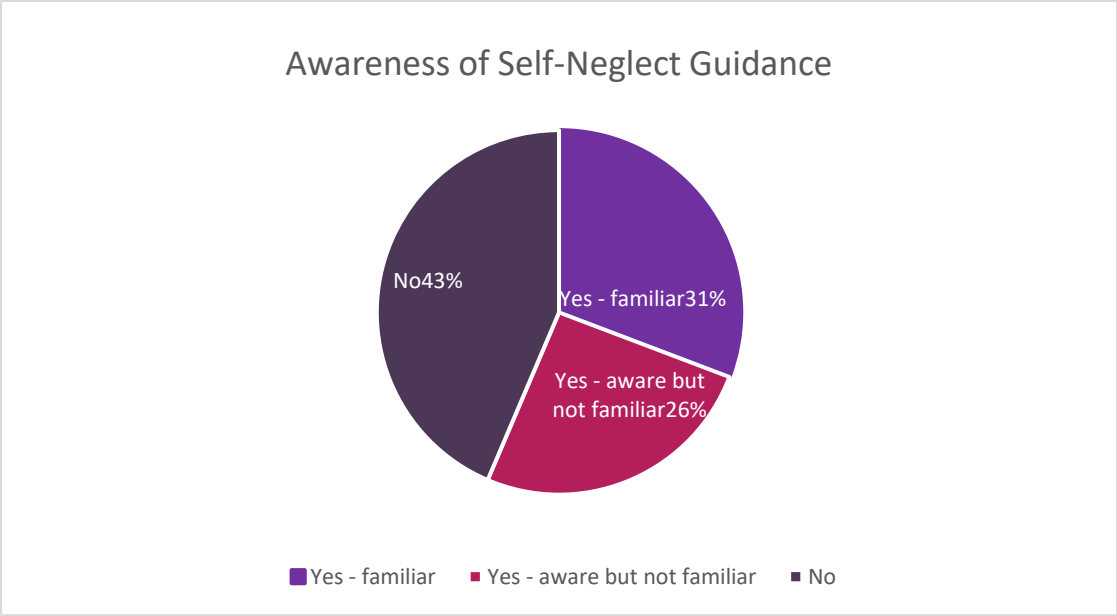
3.4.5 **Multi-agency working.** There was an underlying commentary (in response to a number of the questions) of professionals thinking that other agencies could do more to respond to self-neglect.

"Getting other professionals to take it seriously." (GP)

"Lack of response from partner agencies". (Police Constable)

"Reluctance from other agencies to get involved". (Social Worker)

3.5 We asked respondents whether they were **familiar with the Self-Neglect Practice Guidance** and what they liked about it if they were familiar with it. 43% were not aware of the guidance, and only 31% were aware and familiar with it.



3.6 For those who were familiar with it, the **sections they liked the best** were:

- Information on what self-neglect is (22 responses)
- Information about mental capacity and self-neglect (21 responses)
- Clutter rating tool (19 responses)
- Suggested responses based on the level of risk/harm (18 responses)
- Summary flow-chart (18 responses)

3.7 We asked people what we could do to **raise awareness of the guidance**. Suggested responses included:

- Sharing the guidance with all agencies/services (including commissioned services).
- Having it available online (rather than as a pdf).
- Compressing it into factsheets
- Highlighting it/using it on training which should be available across all partner agencies.
- Promoting the guidance at meetings e.g. team meetings, provider networks
- A mobile phone app would be useful.
- Adding to intranet sites/internal document storage/apps (System one and Phablets mentioned).
- Credit-card sized information which could be stored with ID card or Warrant Card.

- Encouraging practitioners to have short-cut to the resources for practice webpage from the Safeguarding Adults Board website on their desktop.

3.8 Respondents told us how they thought we could **share learning and best practice**. Responses included:

- Sharing Safeguarding Adults Reviews or case studies
- Training and webinars (and in particular multi-agency sessions)
- Practitioner forum/working group
- Newsletters
- Surveys
- Supervision
- Feedback when safeguarding adults referrals are made

3.9 We asked respondents to tell us **what they hoped would be different in a year's time**:

- Better multi-agency working. Open and honest dialogue between professionals.
- More continuity in care/workers
- More training and increased visibility of the self-neglect practice guidance
- Lower caseloads/more time to work with the person
- Quicker access to mental health support
- A commissioned service to work with adults who self-neglect who specialise in mental health/hoarding.
- Agreed partnership working between drug/alcohol and mental health services.
- Standardised involvement of safeguarding adults leads/specialists in high-risk/complex cases.

4. Practitioner workshop feedback

4.1 The practitioner workshop agenda was based around similar questions to the online survey but gave more opportunity for conversation around the issues. There were 21 attendees from a range of professions and agencies.

4.2 The workshop began with some learning from SARs and research around self-neglect. Five local cases were also summarised[2], three were cases which had been referred to the NSAB SAR Committee but which did not meet the criteria for a SAR.

4.3 Participants were divided into smaller groups to talk through the key lines of enquiry.

4.4 When discussing **what worked well,** responses focussed on:

4.4.1 **Engagement with the person**. Discussions about what worked well primarily focussed around positively engaging with the adult at risk. This included building up a good relationship with the adult that started from a

[2] See appendix for case summaries

point of being non-judgemental. Attendees talked about taking a “let’s work together” approach with the person and trying to positively encourage personal responsibility. A step-by-step approach was also felt to work well, with activity being broken up into realistic and achievable actions. In their experience, practitioners felt they’d come across scenarios where the person had disengaged because they’d felt overwhelmed.

4.4.2 **Language**. The language that professionals used with person was felt to be important – speaking in a language that the person would understand and not using jargon. The term “self-neglect” has the potential to be perceived as victim-blaming - how professionals frame the concern and describe the situation to the person at risk needs careful consideration.

4.4.3 **Persistence and tenacity**. Concerns related to self-neglect were unlikely to be resolved quickly. Persistence and tenacity were important aspects of good engagement in self-neglect cases, particularly where the adult was deemed to have mental capacity in relation to decisions about their care or treatment and they were refusing offers of help or support.

4.4.4 **Understanding different legal options.** Attendees talked about the importance of having a good knowledge of the legal options available, particularly where the person was not engaging. This included being confident in applying the Mental Capacity Act, as well as knowing about other potential powers to intervene e.g. around environmental health, housing, animal welfare and fire.

4.4.5 **Knowing who to call for advice.** Practitioners valued being able to call their safeguarding adults teams for support – this might be when they felt stuck with a challenging case or if they wanted support with escalation if they weren’t happy with a response from another agency. Safeguarding Teams are unlikely to be directly involved in the case so can provide a “helicopter perspective”, as well as being able to draw on similar cases they might have been involved with.

4.5 When asked **what was challenging**, responses were grouped around:

4.5.1 **Prevention.** There was an acknowledgement that ideally, we would intervene in cases of self-neglect much earlier and outside of safeguarding adults procedures, but this was challenging. Attendees talked about difficulties in working on a multi-agency basis outside of the safeguarding adults framework, for example that it wasn’t easy to convene an MDT meeting about a self-neglect case. It was reflected that assessment documents don’t always identify self-neglect as a possible risk so there were potentially missed opportunities for things to be picked up and addressed at an earlier stage. Resource pressures within services often meant that lower-level self-neglect cases weren’t seen as a priority until it got to a crisis point.

4.5.2 **Resources**. Attendees talked about a lack of services and support (in particular community-based resources) being available that would directly support the adult at risk. One particular gap that was highlighted was support for people in privately-rented or owner-occupied properties. A point that was raised in the workshop and also via the survey was that often people would be reluctant to accept help if this meant that they had to pay for it. There was a comment that the pandemic had an impact on the services available.

4.5.3 **Substance misuse cases.** Practitioners felt that cases where drugs and/alcohol were a factor were particularly challenging. Understanding the person's mental capacity to make decisions was more complex. There was a worry that there was more of an acceptance of self-neglect where a person used drugs or alcohol problematically and interventions might be different and/or delayed.

4.5.4 **Helplessness when a person doesn't want help or support.** Practitioners talked about feeling helpless and trapped with some cases – where they were really worried about someone who had mental capacity to make decisions about accommodation, care and/or treatment. Practitioners reflected the conflict of duty of care versus respecting the person's wishes or choices. A case example was discussed of a man who had been in hospital that day, where it was felt there were limited opportunities for change because of the capacitated choices he appeared to be making.

4.6 There was very limited **awareness of the self-neglect practice guidance**, with most people only being aware of it as a result of being at the workshop.

4.6.1 Attendees felt that generally written guidance wasn't helpful as there was so much of it – practitioners can be overwhelmed and it can get lost amongst everything else. Instead, people would prefer quick guides on the bare basics to get them started and interested to find out more.

4.6.2 There was a query as to whether the guidance could be embedded within electronic recording systems (an example from Adult Social Care).

4.7 In terms of **training**, attendees described either not having received any training in this area or that it was some time ago and therefore not reflective of some of the current issues. Some people who had received training (not via the NSAB) felt that it was focussed too heavily on hoarding and not covering some of the broader issues or challenges.

4.7.1 Bite-size training was felt to be more impactful, rather than longer sessions. An example was given of the Community Mental Health Team having guest speakers coming along to team meetings and slide-decks being shared for future reference.

4.8 Attendees told us how they thought we could **share learning and best practice:**

- Sharing case examples where there has been a positive outcome (sometimes it feels like there is too much of a focus on times when things have gone wrong).
- Including information about self-neglect on agencies' intranet sites or via banners/screensavers.
- Talking about self-neglect in Team Meetings.
- A multi-agency self-neglect practitioner forum/networking group would be welcomed. Practitioners reflected that it was useful to hear different agency perspectives at the workshop – it helped understand what different services could offer and what was and wasn't possible.
- Learning from elsewhere. Sometimes it was difficult to learn from cases that had happened locally – it was easier to be objective in cases that had happened out of the Newcastle area.
- Multi-agency supervision could give an opportunity to reflect and learn from cases.

4.9 We asked attendees to tell us **what they hoped would be different in a year's time**:

- All agencies being more receptive to responding to lower-level self-neglect cases at an earlier stage rather than dealing with something at crisis point.
- An acknowledgement and awareness that self-neglect was not just about hoarding. This needed to be a key message through practice guidance and training and hopefully this would change attitudes on the front-line. One person talked about a case they'd been dealing with where there was evidence of self-neglect but they were only able to get access to services when hoarding became a feature
- Getting feedback on safeguarding adults referrals about self-neglect so practitioners know what is happening with a case.

5. Conclusion and recommendations

5.1 Practitioner views and experiences have given a valuable insight into self-neglect. There are some clear recurring themes identified which can help inform practice improvement in this area.

5.2 The NSAB already has a number of relevant actions included within their Strategic Annual Plan and Sub-Committee work plans for 2022-23 including:

- Contribution to regional (ADASS-led) communications activity around self-neglect (7 minute guides and short animation).
- Review and re-launch self-neglect guidance.
- Partner agencies to produce a position statement to the NSAB in relation to their MCA practice which will allow Board members to promote good practice and address any challenges highlighted.
- Training programme for 2022-23 to offer multi-agency training around self-neglect.
- NSAB to undertake work with public health on training and other available resources to upskill the workforce who may work with adults who use alcohol problematically. This should include the complexity of Mental Capacity Assessment in those adults.

A number of these actions have already been progressed as can be seen when accessing the weblinks above.

5.3 Further to the above actions, the following recommendations are proposed from this Thematic Review:

Things that will be done **now**
• This report is published and widely shared so that it can be used to prompt discussion, reflection and professional development. • The findings from this report are used in the review of self-neglect practice guidance and single and multi-agency training. • Regional self-neglect 7-minute guides are widely shared across practitioner groups and networks. • All agencies to include or disseminate key messages and links to resources about self-neglect on intranet sites or via internal communication methods.
Things that could be done **sooner**
• Establishment of a local self-neglect practitioner forum. • Increasing practitioner confidence in application of the Mental Capacity Act.
Things that we will explore **later**
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Appendices

Online Survey Questions

1. On a scale of 1-10 how confident do you feel in responding to cases involving self-neglect? With 1 being the least confident and 10 being the most confident.
2. In your experience, what works well when responding to people who self-neglect?
3. What are the challenges in identifying and responding to self-neglect cases? Please tell us anything you have learnt from overcoming these challenges
4. Are you familiar with the NSAB's self-neglect practice guidance?
5. If you are familiar with the guidance, what do you like about it?
6. How can we make sure self-neglect guidance is at the "finger-tips" of practitioners when they need it?
7. What are the best ways for us to learn about and share best practice related to self-neglect?
8. Imagine we are meeting in 12 months' time to review the practice around self-neglect - what would you hope would be different and how have we resolved the challenges you have raised?
9. Are there any actions that you or your organisation could take to improve practice around self-neglect?
10. Any other comments or reflections that you would like to share?

Practitioner Workshop Agenda

9 May 2022, 2-4pm

Introduction and background

Key definitions, covid impact, learning from national research

Case studies and reviews

Local case studies and reviews

Discovery

1. In your experience, what works well when responding to people who self-neglect? *Think of a time when you've helped the most vulnerable person who was self-neglecting, what worked well? Can you think of someone in your team who is most confident in responding to self-neglect cases, how could we learn from them?*
2. We've talked about some of the challenges that have been identified through reviews – thinking about your personal experiences what have you found most challenging when identifying and responding to self-neglect cases and what has been the most important learning to emerge?
3. What is good about the NSAB's self-neglect practice guidance?
4. How has existing training provision supported good practice?

Dream

5. How can we make sure self-neglect guidance is at the “finger-tips” of practitioners when they need it?
6. What are the best ways for us to learn and share best practice related to self-neglect?
   Our people are our greatest assets, how can we learn from them? How can we learn from national developments? Who could help us to increase understanding and knowledge?
7. We are meeting in 12 months’ time to review the practice around self-neglect - what is different and how have we resolved the challenges and raised?

Delivery

8. What would the most practical and realistic steps we could do to improve identification of, and responses to, self-neglect?
9. Thinking about actions that the NSAB (and it’s partner agencies) could take:
   9.1 What do we need to do now?
   9.2 What do we need to do sooner?
   9.3 What could we leave until later?

Case summaries used at the Practitioner Workshop

Adult L

- Died aged 75, concerns about domestic abuse and self-neglect (refusal of care and hoarding/clutter). Complex health and care needs.
- Known to drink alcohol problematically.
- Husband Main Carer. Six calls per day from home care service as well as community nursing input.
- Mental capacity fluctuated.

Learning

- Recognising and supporting people who are alcohol dependent.
- Deeper understanding and use of MCA.
- Support for carers
- Use of self-neglect guidance
- Team-around-the-person approach
- Use of safeguarding leads/specialists
- Clarity on communication

Read the full SAR Report and associated documents here:
https://www.newcastlesafeguarding.org.uk/safeguarding-adults/safeguarding-adults-reviews/

Adult M

- Died aged 72, very little contact with services.
- Some recent contact with GP and District Nurses to help care for wounds on her legs.
- Viewed to have mental capacity to make decisions about her care and treatment.
- Found unresponsive at home – son had been concerned for four days – died in hospital.
- Fire Service reported significant clutter in property.

Learning

- Limited opportunities for professionals to identify self-neglect.
- Covid-19 messaging (stay home, save lives, protect the NHS) may have deterred Adult M and family seeking help.
- Family did not view themselves as carers.

Read the 7 minute-briefing here:
https://www.newcastlesafeguarding.org.uk/safeguarding-adults/safeguarding-adults-reviews/

Adult P

- Died at home aged 68, lived with adult son. YHN tenant.
- Police officers described home as a “health hazard”.
- Son reported mum had become unwell following a fall two weeks prior and had refused to seek medical attention.
- Previous safeguarding involvement in 2017 around hoarding and clutter.
- Limited professional contact other than gas safety checks and repairs and maintenance.
- Began accumulating rent arrears one year before her death.

Learning

- Impact of Covid-19 on face-to-face contact.
- Capacitated adults – what powers are available to professionals to intervene?
- Raising awareness of self-neglect and safeguarding with those who don’t work directly with adults with care and support needs e.g. repairs and maintenance staff, refuse collectors.
- Role that families/neighbours can play in identifying and reporting significant self-neglect.

Adult Q

- Died at home aged 67, husband died two months prior.
- Low IQ
- Concerns raised by family and professionals about condition of property, personal hygiene and general presentation.
- Repeated offers of an assessment from Adult Social Care were declined.
- Viewed to have mental capacity in relation to making decisions about care and support.
- Died as a result of metastatic breast cancer which was undiagnosed/ unknown.

Learning

- Capacitated adults – what powers are available to professionals to intervene?
- Escalation of cases where risks are high and remain unmanaged.
- Significant deterioration in health and recent loss of husband possible causal factors.
- Relationship building is difficult during Covid-19.

Adult R

- Young female who was bed-bound.
- Agencies experiencing difficulties seeing her, carers only seeing her through a window.
- Partner did not let individuals come into the house, raising cause for concern about domestic abuse.
- Disclosed skin impairment and pain.
- GP, Social Workers, District Nurses, Mental Health Services, Fire Services and CCG all involved in safeguarding adults process.

Learning

- Looking beyond the obvious/simplest solution.
- Revisiting the same issues/questions is important – robust reflection and risk assessment prevents becoming de-sensitised or lost in complex situations.
- The importance of MCA assessment.
- The voice of the adult at risk is crucial - sometimes a professional's desired outcome is not the one the adult at risk would want.
- Maximising opportunities for assessment of needs and risks – e.g. during a hospital admission.
- The value of investing time in multi-agency working to hold and manage risk.