

Hertfordshire

Safeguarding Adults Board

Working together to prevent abuse

Lived Experience of the Adult Practice Guidance

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Introduction

Hertfordshire Safeguarding Adults Board (HSAB) regularly undertake Multi-Agency Audits and Safeguarding Adults Reviews. These audits and reviews emphasise the importance of exploring the lived experience of the adult; what life is like for the adult should be recorded and factored in when trying to support the adult. In cases where the lived experience of the adult is missing, it may not be prioritised, or may be drowned out by louder voices of family, friends, or other professionals, to the detriment of attempts to safeguard the individual.

This document has been developed by partners to enable practitioners to take into account the adult's experience and ensure that the adult's lived experience remains central to any action taken to safeguard the adult at risk.

This guidance is for use by all professionals (the term includes managers, staff, and volunteers) who have direct and indirect (i.e. may work with families/carers) contact with adults at risk; and who therefore have responsibilities for safeguarding and promoting their welfare.

1. Definition

'What an adult at risk sees, hears, thinks and experiences on a daily basis that impacts on their personal development and welfare, whether that be physically or emotionally. As practitioners we need to; actively hear what the adult has to say or communicate, observe what they do in different contexts, hear what family members, significant adults/carers and professionals have said about the adult at risk, and to think about history and context. Ultimately, we need to put ourselves in that adult's shoes and think 'what is life like for this person right now?'

(Adapted with kind permission from **Definition of 'lived experience' task and finish group 2018**)

2. Making Safeguarding Personal

Statutory requirements regarding the Safeguarding of Adults at Risk are set out in the Care Act 2014 and explained in the [Care and Support Statutory Guidance](#). The statutory guidance sets out the concept of *Making Safeguarding Personal*.

Making Safeguarding Personal (MSP) is the necessary approach to Safeguarding Adults as agreed by the Local Government Association (LGA), the Association of Directors of Adult Social Care (ADASS), and other national partners.

Making Safeguarding Personal requires practitioners to find out about the **lived experience of the adult**.

As worded in the Care and Support Statutory Guidance (14.15):

Making safeguarding personal means it should be person-led and outcome-focused. It engages the person in a conversation about how best to respond to their safeguarding situation in a way that enhances involvement, choice and control as well as improving quality of life, wellbeing and safety.

Case studies demonstrating effective practice regarding Making Safeguarding Personal are published online by the LGA and are available here: <https://www.local.gov.uk/making-safeguarding-personal-201819-case-studies>. These MSP case studies provide examples of practitioners taking into account the lived experience of the adult at risk.

3. Necessary Skills for Safeguarding Practice

SARs, both local and national, highlight the importance of a set of skills and techniques necessary for professionals working with adults at risk; without which there will be a lack of information regarding the adult's lived experience. This in turn may lead to missed opportunities to work with that individual effectively.

These include, but are not limited to:

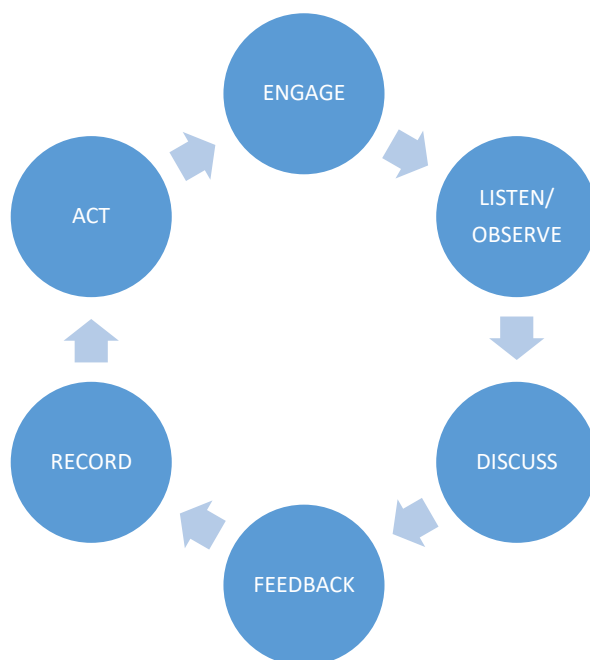
- Professional Curiosity
- Respectful Uncertainty
- Flexible Thinking
- Cultural Competence

These skills all require an understanding of the importance of asking questions, a full and thorough approach to communication, a willingness to challenge assumptions, and a reluctance to take things at face value.

Also relevant to understanding the lived experience of the adult:

- Awareness of Disguised Compliance
- Not letting the voice of the adult be drowned out by family/friends/carers
- 'Carefrontational Approach'; in which discrepancies between what adults say they will do and what they can actually do are respectfully, but directly, challenged.

4. Cycles of Engagement



An understanding of the lived experience of the adult, and consequently effective and supportive safeguarding, requires regular engagement with the adult that is relationship based and long term.

5.1 Tips for engagement:

- **Be prepared** - Check out the adult at risk's history before you go (i.e. Risk / Vulnerability) / Think about what appropriate tools (to help you engage and communicate) you need to take with you for the task in hand
- **Joint working** – Home visits may need two professionals present (health and safety/joined up working to save duplication and multiple professional visits) – think about who will be communicating and what things each needs to say and do (e.g. one could ask questions regarding the adult at risk whilst the other observes the interactions and environment)
- **Planning your assessment**- If you only ever go to the house at the same time and see an adult at risk in front of the TV, how do you know if this is part of their appropriate daily routine, or are they there all the time? Be clear from the start of your involvement that you will need to see the adult at risk, and that might be alone or not in the home
- **Consider who is best placed/able to establish a productive relationship**— Relationships may be complicated; it is important to recognise where a relationship is proving to be counterproductive, and consider whether a change in approach, or a change in professional may be necessary.

5. Practical Tips for Effective Communication

- a. Explore creative ways of engaging with the adult with regards to their communication skills, mental capacity, and personal history, to enable them to share their history
 - Can you use art, music or other media to encourage conversation or to better understand the adults circumstances
- b. Remember the importance of non-verbal communication. Be observant and consider:
 - Personal appearance
 - Environment- What can you see, smell and hear? What do you need to ask?
 - Familial/carer interactions

6. Concerns About the Adult's Ability to Share

There are specific conditions which may actively work to distort professionals' understanding of the lived experience of the adult, which professionals need to be aware of, including:

- Coercive and Controlling tactics by the abuser, which prevent the victim from engaging
- The adult at risk lacking the mental capacity to decide if they need to be safeguarded or lacking the capacity to participate in the safeguarding process.

Coercive controlling behaviour has been described by many experts as the most damaging and risky form of abuse. This type of abuse is less likely to be reported to the police as victims often feel they won't be believed. This is often **not** reported due to fear of what will happen if reported or could be out of loyalty to the abuser, it could be because the abuser is their partner, spouse, child or carer.

Behaviour that is controlling and coercive may be

- Isolation
- Taking control over aspects of the adult's everyday life, where they can go, who they can see, who they can talk to
- Depriving them of access to support services
- Repeatedly putting them down, telling them that they are a nuisance/burden etc.
- "Gas lighting" which is psychological manipulation where seeds of doubt are sown making an individual question their memory or perception. Using consistent contradiction, misdirecting, lying and denial can destabilise the individual and cause them to disbelieve themselves.

Incident of gas lighting may range from denial by an abuser that any previous abusive incidents have occurred or an abuser flatly denying that they have ever been violent or unkind so much so that the victim begins to doubt themselves and may question their own mental health, making them even more dependent on the abuser.

This is discreet emotional abuse where the abuser seeks to have full control of feelings, wishes and thoughts of the victim. It degrades the individual's self-esteem and makes them wholly reliant on the abuser.

Warning signs of Coercive and controlling behaviour could include

- Withholding information from the victim
- Countering information to fit the abuser's agenda
- Trivialising, ignoring, or distorting the individuals wishes
- Discounting the individual's needs, not relaying/identifying them to support services
- Blocking or diverting attention away from the individual
- Gradually weakening the individual's worth and their freedom to express themselves
- All of this allows for absolute control, making the individual totally vulnerable, isolated, and reliant on the abuser.

Mental Capacity-

Whenever possible, Adults at Risk should be asked if they want to be Safeguarded and should be part of the safeguarding process. However, some adults at risk will lack the mental capacity to make decisions regarding safeguarding.

- It is the duty of the professionals working with the individual to demonstrate that the individual lacks capacity.
- When an adult is determined to lack capacity to make decisions regarding safeguarding, decisions must be made in their best interest, as set out in the Mental Capacity Act (2005), and described in the Mental Capacity Act Code of Practice.
- A Care Act Advocate should be provided for the adult at risk, when the adult does not have suitable representation from a family or friend.
- Best Interest decision making requires the professional responsible for the decision to consider what the adult would have decided if they had capacity.

7. How do care needs impact communication?

- a. Adults with care needs may be unwilling or unable to acknowledge that they have care needs, and attempt to disguise difficulties they may be facing
- b. Some adults at risk may face difficulty communicating related to the condition resulting in care needs.
 - There are many tools available to help people communicate
 - A trained advocate may be necessary to communicate on behalf of the adult
- c. Be aware of how some health conditions may affect behaviour.
 - This may require research into the specific conditions, or input from another professional
 - Professionals need to unpick whether changes in behaviour are a result of the adult's care needs, or indicative of another need not being met, or of abuse
- d. Adults with care needs may have complicated relationships with the family/friends or other informal carers meeting those needs
 - Unwillingness to discuss abusive behaviour perpetrated by an informal carer, either to protect the carer or out of concerns about how care needs might be met
 - Perception of self as a 'burden'

- The carers may have valuable information to share, to help understand the lived experience of the adult. However, this information should not be given undue weight, particularly where it contradicts what you hear or observe from the adult.

8. Recording lived experience

Case notes should reflect what is known about the lived experience of the adult, how this is considered during assessment, and the impact it has on decisions made. Always remember to update case records for others to see what work has been completed with the service user. Remember:

- Use direct quotes where possible
- Notes should focus on facts relevant to the case
- Where professional opinion is required, it should be identified as such and justified.

9. Helpful tools for finding out more about and recording the lived experience of the adult

Listed below are a range of tools available to help practitioners find out about the lived experience of the adult they work with. Many of these tools are specific to a condition or set of needs, so they won't be applicable to all adults. A key aspect of exploring lived experience is to determine how best to communicate with the individual effectively.

Guidance

1. Guidance related to Self-Neglect and Hoarding can be found in the HSAB Self Neglect Policy and Guidance, available here: [Hertfordshire safeguarding adults BOARD self Neglect policy and GUIDANCE](#)

To help with communication impairment

2. Communication profiles completed by Speech and Language Therapy - It is important to use these when the ways that people communicate with their behaviour are clearer than the words that they use, or when what people say and what they mean are different. The Communication Assessment Profile (CASP) is a method of assessing the communicative abilities of adults with severe to mild learning disabilities. It makes use of photographs of functional adult-oriented objects.
3. Lightwriters - A Lightwriter is a switch and keyboard communication device whereby the user types out messages which are then relayed through the speakers by an automated voice. As a keyboard-based communication aid, users must have mobility in their hand. Most models on the market today have a dual screen display, one that the user can see and one that is outward facing for the person who is being communicated with to read.
4. A new communication resource is an app called picTTalk (facilitate stories and conversations) - picTTalk (pictorial Tools for Talking) was developed by professionals,

children and adults with a learning disability. picTTalk can help people to have a voice in what's happening to them in their lives.

5. Talking mats - Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen.
6. Communication boards, charts & books (Included are letter, word and picture charts, folders or books; eye pointer (or eye gaze) boards; and powered rotary pointer boards)
7. Picture Exchange Communication System (PECS), where the person hands over a picture to request or express something.
8. Sign language, e.g. British Sign Language (BSL), Makaton, Sign Supported English, or as part of a total communication approach (where a combination of methods is used, e.g. a person might receive information via speech and signs but express themselves using signs and symbols).
9. Communication boards and communication books, where the person can point to words, photos and/or symbols.
10. Communication cue cards, used primarily with people who are verbal, can be a reminder of what to say and provide an alternative means to communication in stressful situations.
11. Voice output communication aids, e.g. BIGmack, generate digitised speech when the person presses a symbol or button. The person will need an understanding of cause and effect to use these devices.
12. Alternative and augmentative communication (AAC) software

To understand condition-specific effects on behaviour

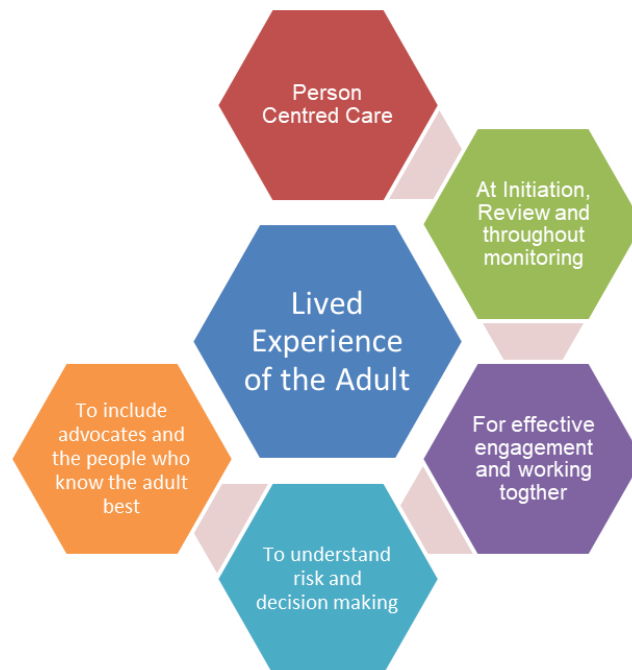
13. NHS Dementia Guide, see section 'Coping with Dementia Behaviour Changes', <https://www.nhs.uk/conditions/dementia/behaviour/>

Advocacy

When an adult at risk has substantial difficulty participating in the safeguarding process, they should be provided with an advocate. For more information and referral forms, see [POhWER](#).

Several areas of practice that improve and require an understanding of lived experience:

It is important to keep in mind the lived experience of the adult throughout the stages of your work with them. Attention to the lived experience of the adult is essential to person-centered care, and should be considered at initiation of services and throughout, is necessary for effective engagement, helps to understand risk and decision making, and should include conversations with the important people in the adult's life. Lived experience of the adult is not a one-off set of questions.



References:

Care and Support Statutory Guidance, updated 2 November, 2022, available at:

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

Controlling or Coercive Behaviour in an Intimate or Family Relationship; Statutory Guidance Framework, December 2015, available at:

<https://www.gov.uk/government/publications/statutory-guidance-framework-controlling-or-coercive-behaviour-in-an-intimate-or-family-relationship>

Making Safeguarding Personal Toolkit, Local Government Association, available at: [Making Safeguarding Personal toolkit | Local Government Association](#)

Mental Capacity Act (2005) Code of Practice, 2007, available at:

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

NHS Dementia Guide: [Dementia guide - NHS \(www.nhs.uk\)](#)

For further resources from the Hertfordshire Safeguarding Adults Partnership Board, please see: [Hertfordshire Safeguarding Adults Board](#) | [Hertfordshire County Council](#)