

GOOD PRACTICE IN SELF-NEGLECT: USING SAR LEARNING AND RESEARCH EVIDENCE TO INFORM PRACTICE

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Hampshire: 23rd March 2023

Our focus today

The essentials of good practice with self-neglect: what goes wrong and what goes right?

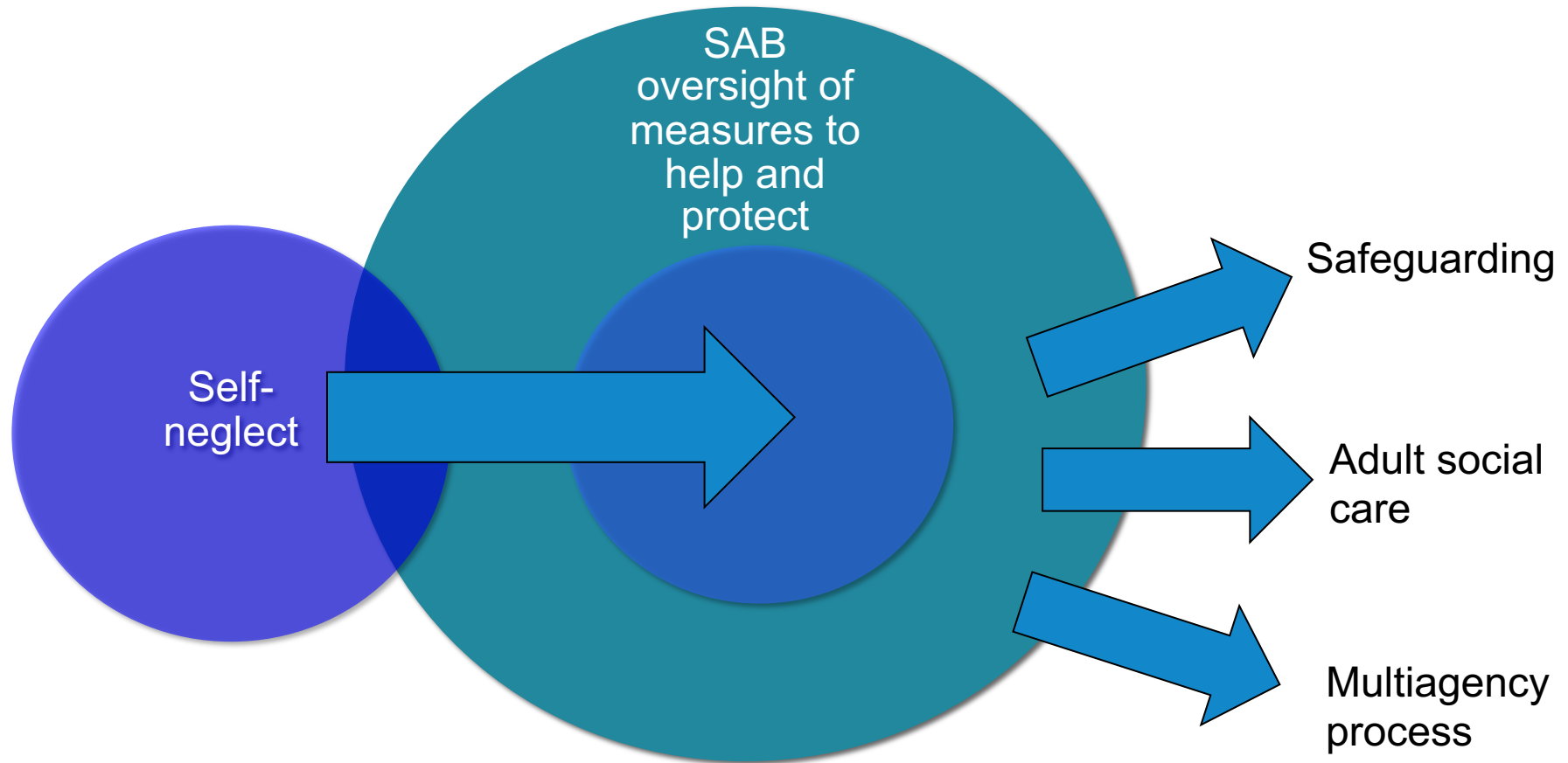
1. Understanding what lies behind self-neglect
2. Working out the right thing to do about it
3. Recognising the significance of mental capacity
4. How organisations can support their staff
5. Using legal powers and duties
6. Interagency collaboration and coordination

What do we mean by self-neglect?

Neglect of self-care	Neglect of the domestic environment
<ul style="list-style-type: none">❖ Personal hygiene❖ Nutrition/hydration❖ Health	<ul style="list-style-type: none">❖ Squalor❖ Infestation❖ Hoarding:<ul style="list-style-type: none">❖ “persistent difficulty discarding or parting with possessions, regardless of value” (DSM V)❖ “accumulation of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value” (ICD 11)
To such an extent as to endanger health, safety and/or wellbeing	
Refusal of services that would mitigate risk of harm	

“Self-neglect: this covers a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding” (DHSC CareAct Statutory G)

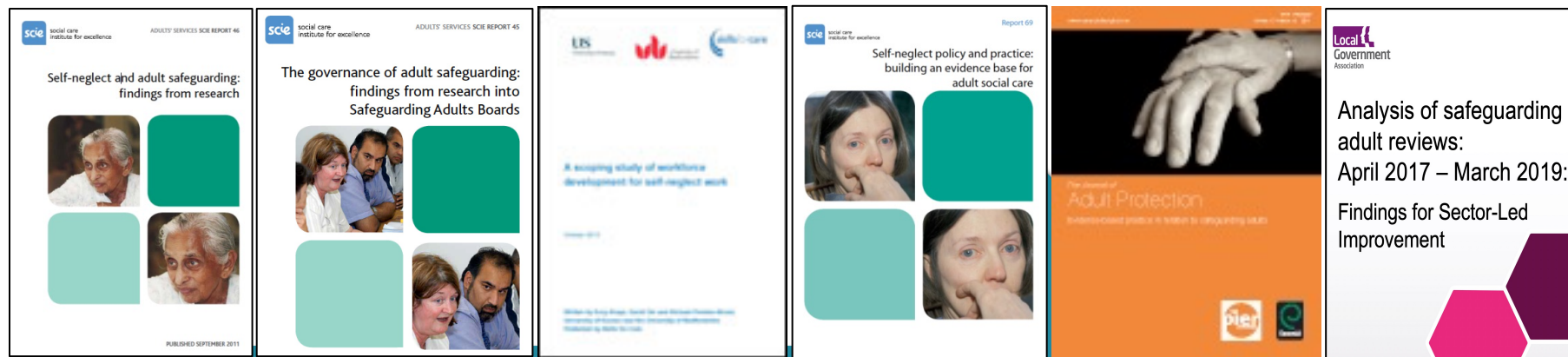
Care Act 2014: bringing self-neglect in from the cold...



Whole system understanding



What do we know about self-neglect?



**Scoping the
concept of
self-neglect
2011**

**SAB
governance
2011**

**Workforce
development
needs
2013**

**Positive
outcomes in
self-neglect
2014**

**Reviews of
serious
cases
2014
ongoing**

**National
analysis of
SARs**

Safeguarding Adult Reviews

Care Act 2014: SAB duty to conduct a SAR

- Where an adult with care and support needs has died, or has experienced serious abuse or neglect, and
- The Board knows or suspects that the death resulted from abuse or neglect, and
- There is reasonable case for concern about how the Board, its members or others worked together to safeguard the adult

Purpose:

- To identify lessons learnt and apply to future cases
- To improve how agencies work, singly and together, to safeguard adults



1. Understanding self-neglect

Association with

- Physical ill-health
- Mental ill-health
- Substance misuse
- Psychosocial factors

But ...

- No one overarching explanatory model
- Complex interplay of factors
- Unwillingness or inability?
- Need to understand the unique 'meaning of the mess'

Keith's story

- <https://www.youtube.com/watch?v=fhmfptpwNZc>
- As you watch the video, think about the multiple influences on Keith's behaviour, and how they have affected his self-neglect journey
- Please use the chat box to share your thoughts

Understanding the lived experience: neglect of self-care

- **Negative self-image:**
demotivation
- **Different standards:**
indifference to social
appearance
- **Inability to self-care:**

I got it into my head that I'm unimportant, so it doesn't matter what I look like or what I smell like.

I'm drinking, I'm not washing; I wouldn't say I'm losing the will to live, that's a bit strong, but I don't care, I just don't care.

"I wouldn't say I let my standards slip; I didn't have much standards to start with."

(It) makes me tired ... I get tired because daily routines are exhausting me, to do the simple things like get washed, put on clean clothes, wash my hair.

I always neglected my own feelings for instance, and I didn't address them, didn't look at them in fact, I thought 'no, no, my feelings don't come into it'.

Understanding the lived experience: neglect of domestic environment

The only way I kept toys was hiding them.

“When I was a little boy, the war had just started; everything had a value to me ... everything in my eyes then, and indeed now, has potential use

I want things that belonged to people so that they have a connection to me.

I don't have time to make a note of everything in the paper that has an interest to me and so I'm very fearful of throwing something away.

- **Influence of the past:** childhood, loss
- **Positive value of hoarding:** a sense of connection, utility
- **Beyond control:** voices, obsessions

The distress of not collecting is more than the distress of doing it.

2. What's the right thing to do? Ethical dilemmas



- ❖ Professional codes of ethics
- ❖ MCA 2005
- ❖ ECHR articles 8 and 5
- ❖ Limitations to state power
- ❖ Making safeguarding personal

- ❖ The state's duty to protect from foreseeable harm
- ❖ Human dignity compromised
- ❖ ECHR articles 2 and 3
- ❖ Risk to others

The tricky concept of lifestyle choice

- SARs tell us that we are quick to assume capacity, respect autonomy (and walk away)
- But life stories tell us otherwise:

“Well I don’t know to be honest. Suddenly one day you think, ‘What am I doing here?’ ”

I got it into my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.

“I used to wake up in the morning and cry when I saw the sheer overwhelming state... My war experience in Eastern Europe was scary, but nothing compared to what I was experiencing here.”

Your esteem, everything about you, you lose your way ... so now you’re demeaning yourself as the person you knew you were.

Challenging our assumptions

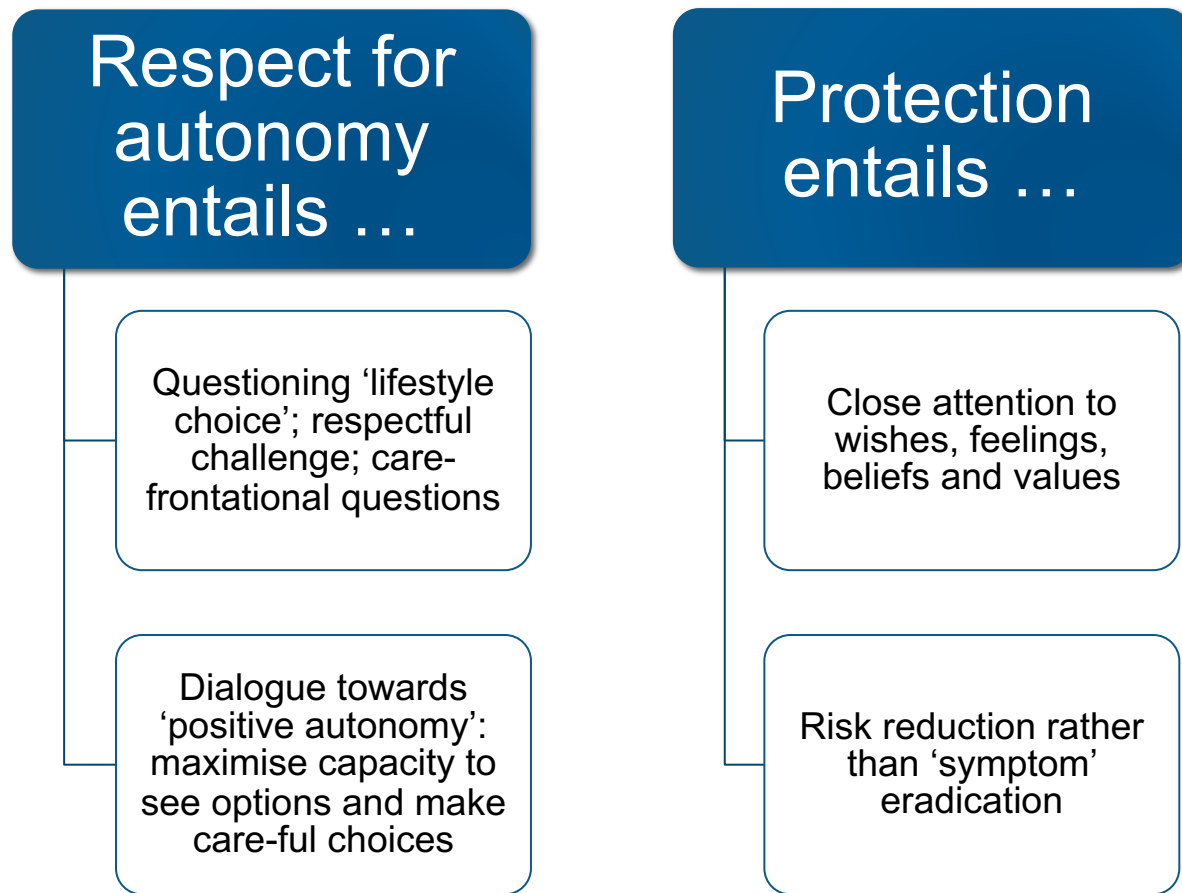
Is it really autonomy when ...

- You don't see how things could be different
- You don't think you're worth anything different
- You didn't *choose* to live this way, but adapted gradually to changing circumstances
- Your mental ill-health makes self-motivation difficult
- You have impaired brain function

Is it really protection when ...

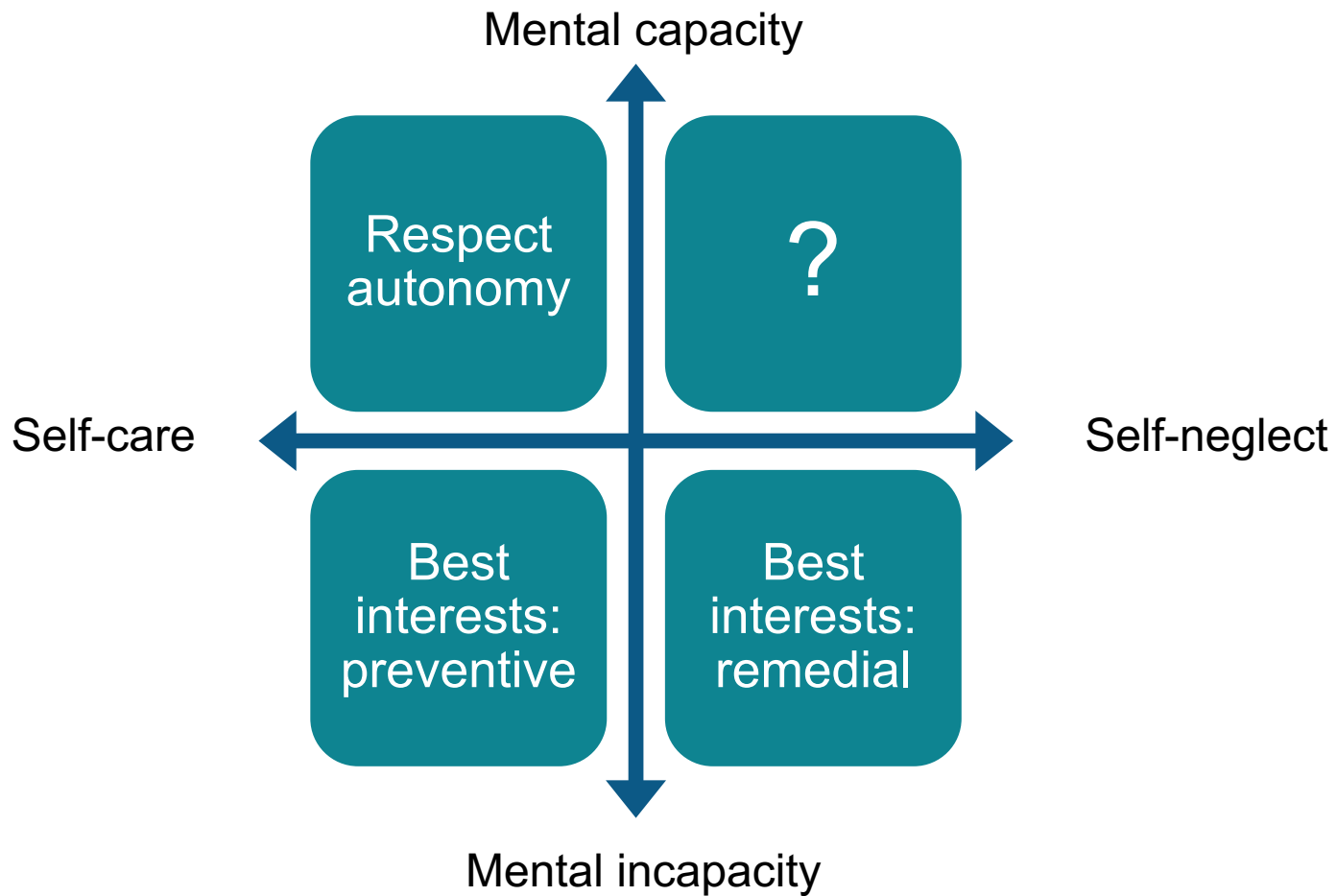
- Imposed solutions don't recognise the way you make sense of your behaviour
- Your 'sense of self' is removed along with the risks: "*hoarding is my mind*"
- You have no control and no ownership
- Your safety comes at the cost of making you miserable

What does this mean for practice?



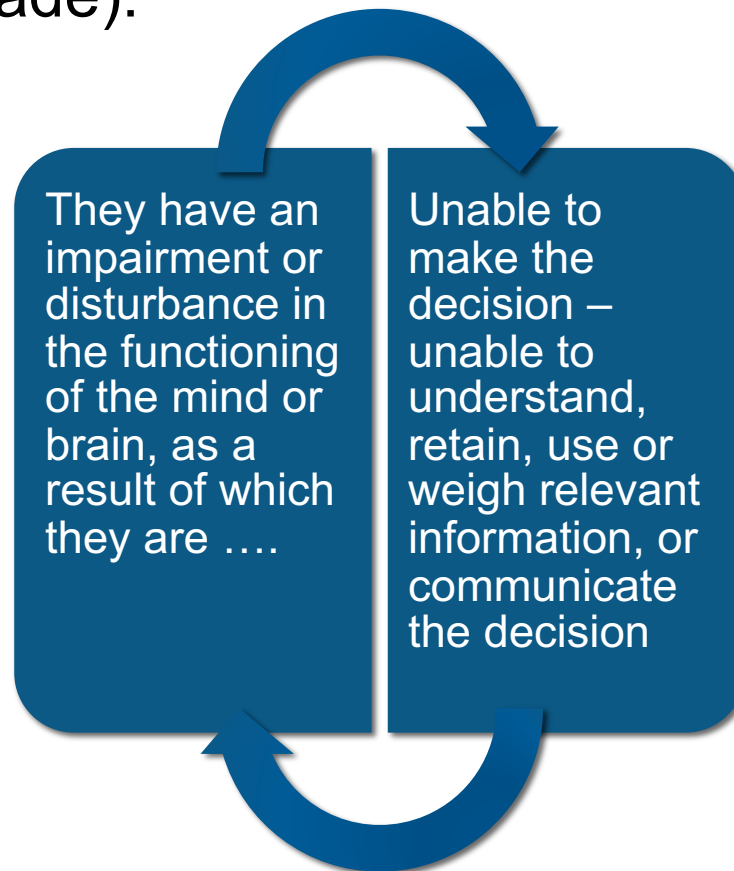
Autonomy does not mean abandonment
Protective responses must be proportionate

3. Mental capacity: affects perception of risk and intervention focus

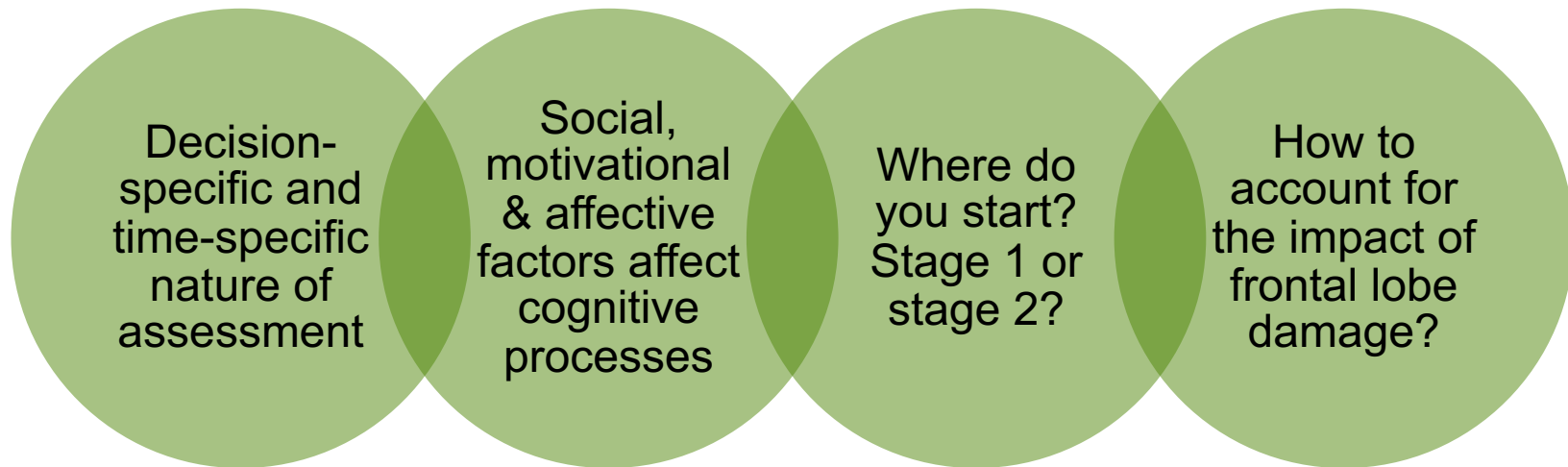


Mental capacity: a reminder

- Capacity is **decision specific** and **time specific**
- A person lacks capacity if (at the time the specific decision has to be made):



Challenges of mental capacity assessment in self-neglect



Mental capacity in SARs

Failure to undertake assessment

Reliance on

- The assumption principle
- The judgement of a third party
- 'Lifestyle choice'

Failure to recognise impact of deteriorating health or changing circumstances

Uncertainty about responsibility

Assessment undertaken but ...

- Inadequate evidence of 'understand, retain, use or weigh'
- Not repeated in changing circumstances
- Missing key information

- No 'real world observation'
- Failure to recognise implications for practice – the capacity paradox

"The record of the assessment provides no direct evidence to show how his ability to make this decision was assessed; it records only his continued assertion that he did not want to move and appears to use this as evidence of his capacity ... no mention of how the 4 key elements of decision-making were evaluated."

"In cases of self-neglect, physical deterioration and factors such as nutritional deficiency can impact upon mental capacity, which can then change very quickly, and John's capacity should have been kept under review."

"Viewing behaviours as lifestyle choice or anti-social resulted in underestimating the significance of underlying mental health issues."

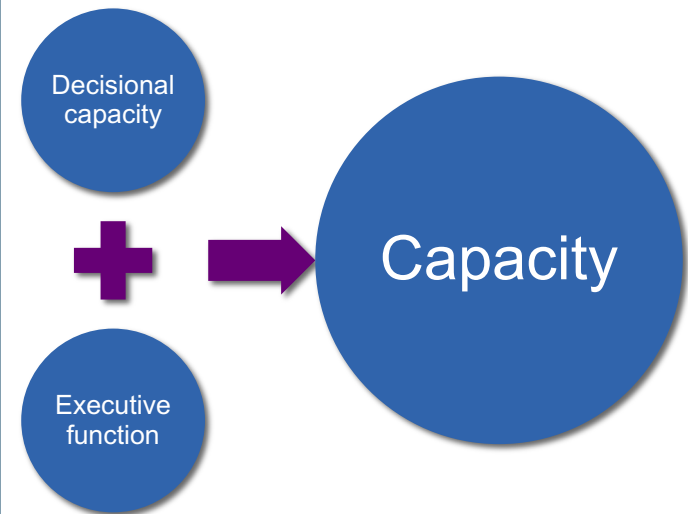
"The logic of his reasoning could cause him to present as if he had capacity to make decisions. In addition, he could at times be assertive, even aggressive, making it even more difficult for those caring for him to challenge his beliefs and to persuade him to accept treatment."

"It would appear that degree of agency and freedom of choice that Tom had after his brain injury was more severely compromised than professionals ... had appreciated."

"Tom was situationally incapacitated by exploitative and drug using peers - a fact that was known to many professionals who did not question the absence of mental capacity assessments."

Extending our understanding of capacity

- Mental capacity involves
 - Not only
 - the ability to make a decision in the abstract
 - But also
 - the ability to enact it at the appropriate moment – the ‘knowing/doing association’
- Frontal lobe damage may cause loss of *executive brain function*, resulting in difficulties:
 - Selecting relevant information and using or weighing it when we need to
 - And therefore in planning, problem-solving and enacting a decision in the moment



Putting this understanding into practice

Decision-making difficulties may be masked by

Articulate use of language; verbal reasoning skills; high perceived self-efficacy

Resulting in decision-making that is “good in theory, but poor in practice”

Capacity assessment to take account

Articulate and demonstrate models; the person in context; real world behaviour

GW v A Local Authority [2014]
EWCOP20

National guidance (NICE 2018)

Practitioners should be aware that it may be more difficult to assess capacity in people with executive dysfunction – for example people with traumatic brain injury. Structured assessments of capacity for individuals in this group (for example, by way of interview) may therefore need to be supplemented by real world observation of the person's functioning and decision-making ability in order to provide the assessor with a complete picture of an individual's decision-making ability.

Decision-making and mental capacity guidance (para 1.4.19)

SAR findings: direct practice



Case study: Barbara

What are you most worried about here?

- *Barbara, in her sixties: a heavy drinker and smoker*
- *Lives in a flat with her adult son*
- *Neglects her personal care and diet*
- *Living accommodation is dirty and bleak*
- *Spends her days and often nights too in an armchair, surrounded by magazines*
- *Complex health problems, including ulcerated legs*
- *Community nursing cancelled by her son: mother doesn't want their help, she can apply the emollient cream herself.*
- *When drinking she can be incontinent and often falls*
- *Has been hospitalised with fractures and burns*
- *Has told her doctor she drinks to blot out the past*
- *Has refused alcohol or smoking reduction strategies*
- *Daily care worker visit but will only agree to preparation of food*
- *Promises to eat the food but doesn't*
- *Agrees to change her clothes but doesn't*
- *Losing weight; skin deteriorating badly.*
- *Care workers have been told that she has mental capacity and her wishes must be respected They are very concerned, but don't know what to do.*

Practice shortfalls in alcohol-related reviews

DIRECT PRACTICE

- Superficial or missed assessments (impact of alcohol on capacity)
- Focus on single issues rather than holistic (risk) assessment
- Lack of think family approach
- Lack of curiosity (history)
- Reliance on self-report
- Labelling and prejudice, assumptions about life-style choice
- Alcohol use not seen as self-neglect

INTERAGENCY WORK

- Mental health and drug and alcohol services not working together
- Inflexible thresholds and referral bouncing
- Law seen as complex (mental capacity and alcohol-dependence; mental health and alcohol-dependence)
- Absence of safeguarding referrals

ORGANISATIONS

- Loss of services
- Lack of services (mental health support; supported accommodation; outreach)
- Lack of policies and protocols to guide staff
- Need for training
- Need for more robust, humane and flexible approach

Preston-Shoot, M. and Ward, M. (2021) *How to Use Legal Powers to Safeguard Highly Vulnerable Dependent Drinkers in England and Wales*. London: Alcohol Change UK.
<https://alcoholchange.org.uk/publication/how-to-use-legal-powers-to-safeguard-highly-vulnerable-dependent-drinkers>

Best practice: a relational approach

Ethical action situated within relationship

They all said, 'we're not here to condemn you, we're here to help you' and I couldn't believe it. I thought I was going to get an enormous bollocking.

"Tenancy support ... weren't helping ... just leaving it for me to do. Whereas when x came, they were sort of hands on: '*Bumph! We've got to do this*' ... *shall we start cleaning up now?*'

The idea is not to get too pushy about it; people start getting panicky then, you know? 'You're interfering in my life,' that kinda thing.

Intervention delivered through relationship: emotional connection/trust

Support that fits with the individual's own perception of need/utility: practical input

Respectful and honest engagement

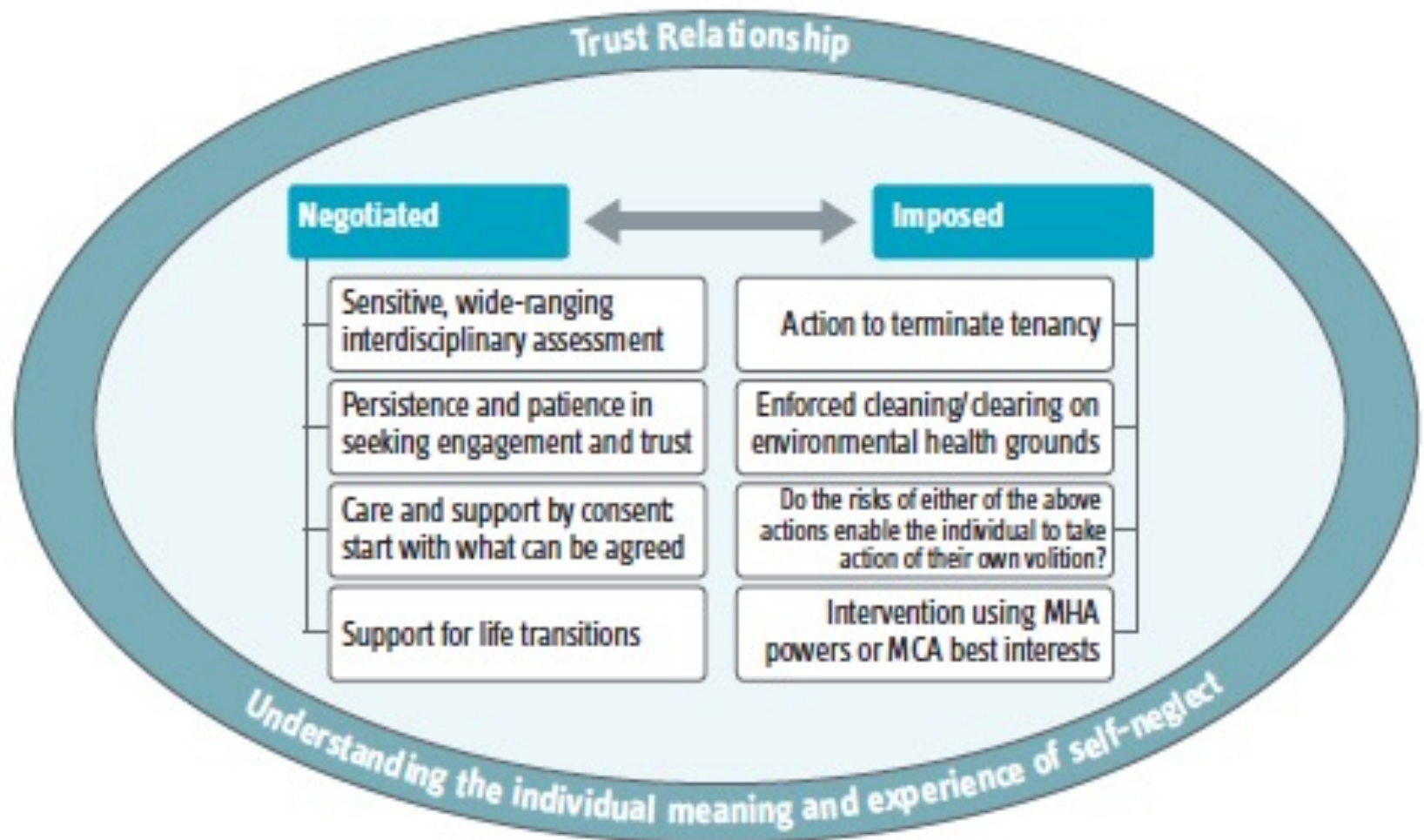
She got it into my head that I am important, that I am on this earth for a reason.

He has been human, that's the word I can use; he has been human.

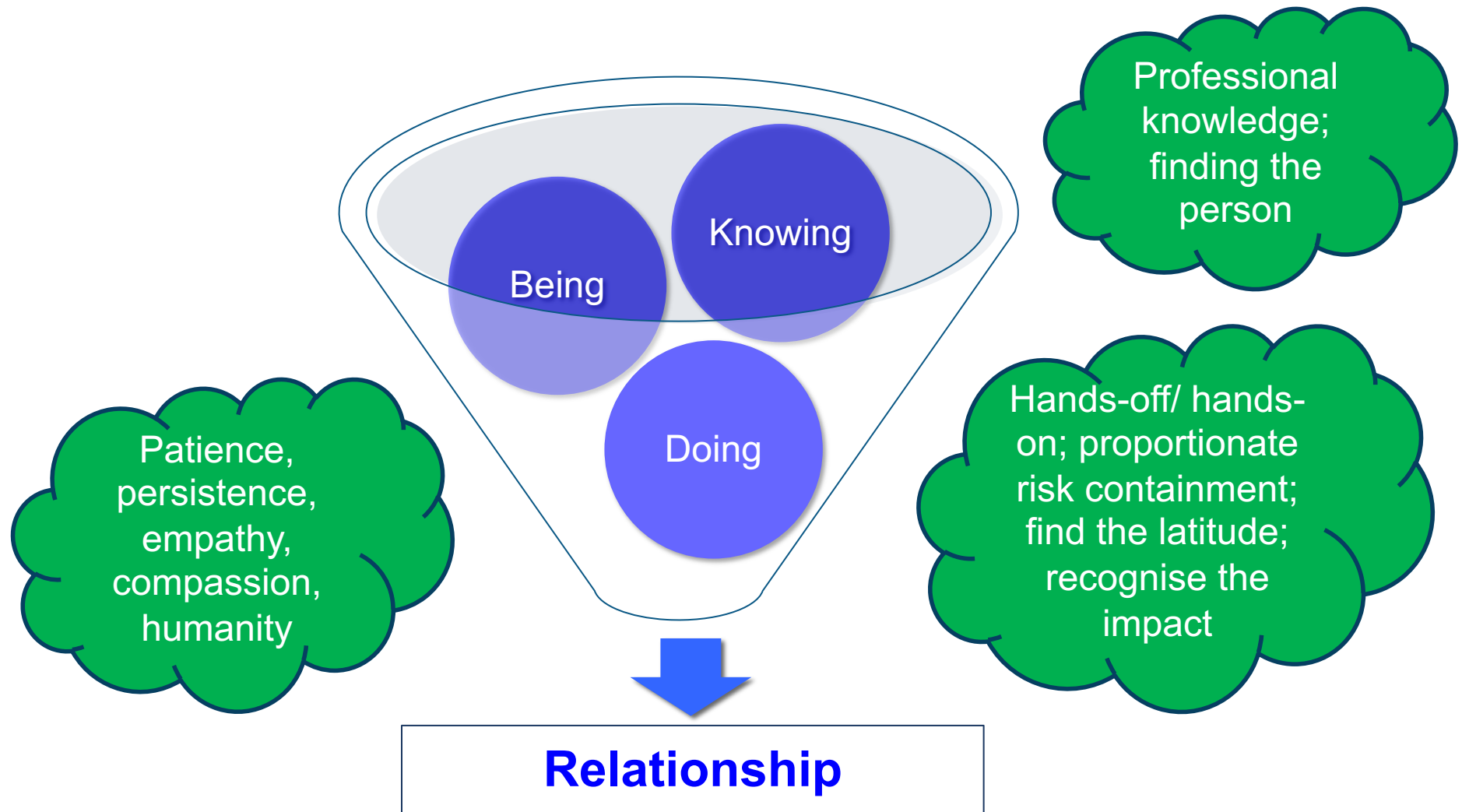
He's down to earth, he doesn't beat around the bush. If there is something wrong he will tell you. If he thinks you need to get this sorted, he will tell you.

With me if you're too bossy, I will put my feet down and go like a stubborn mule; I will just sit and just fester.

Integrating negotiated and imposed interventions



Knowing, Doing and Being

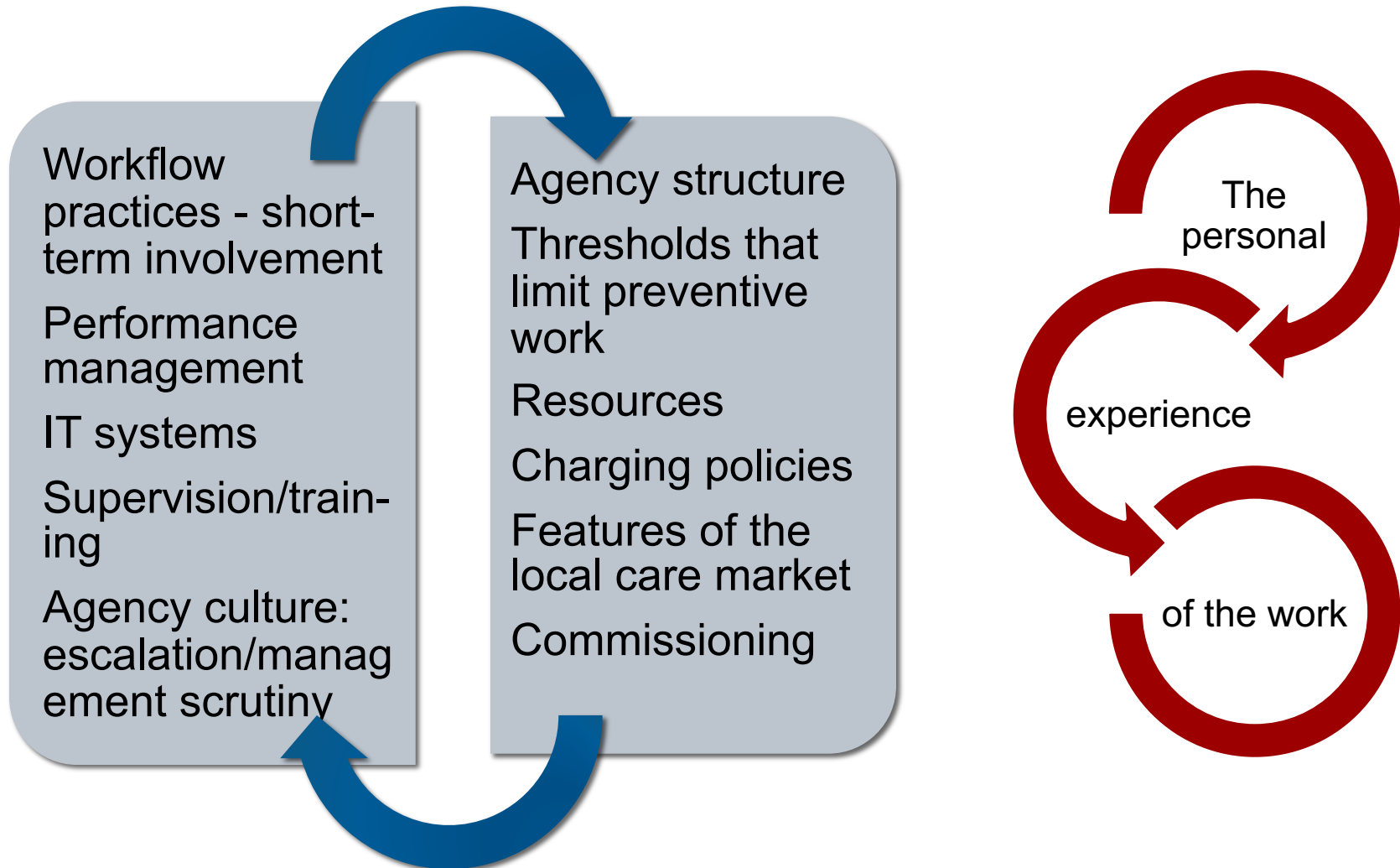


Is it possible to practise best practice?

- There are factors that influence whether and how we can implement best practice



4. Challenges in the organisational context: “a perfect storm”



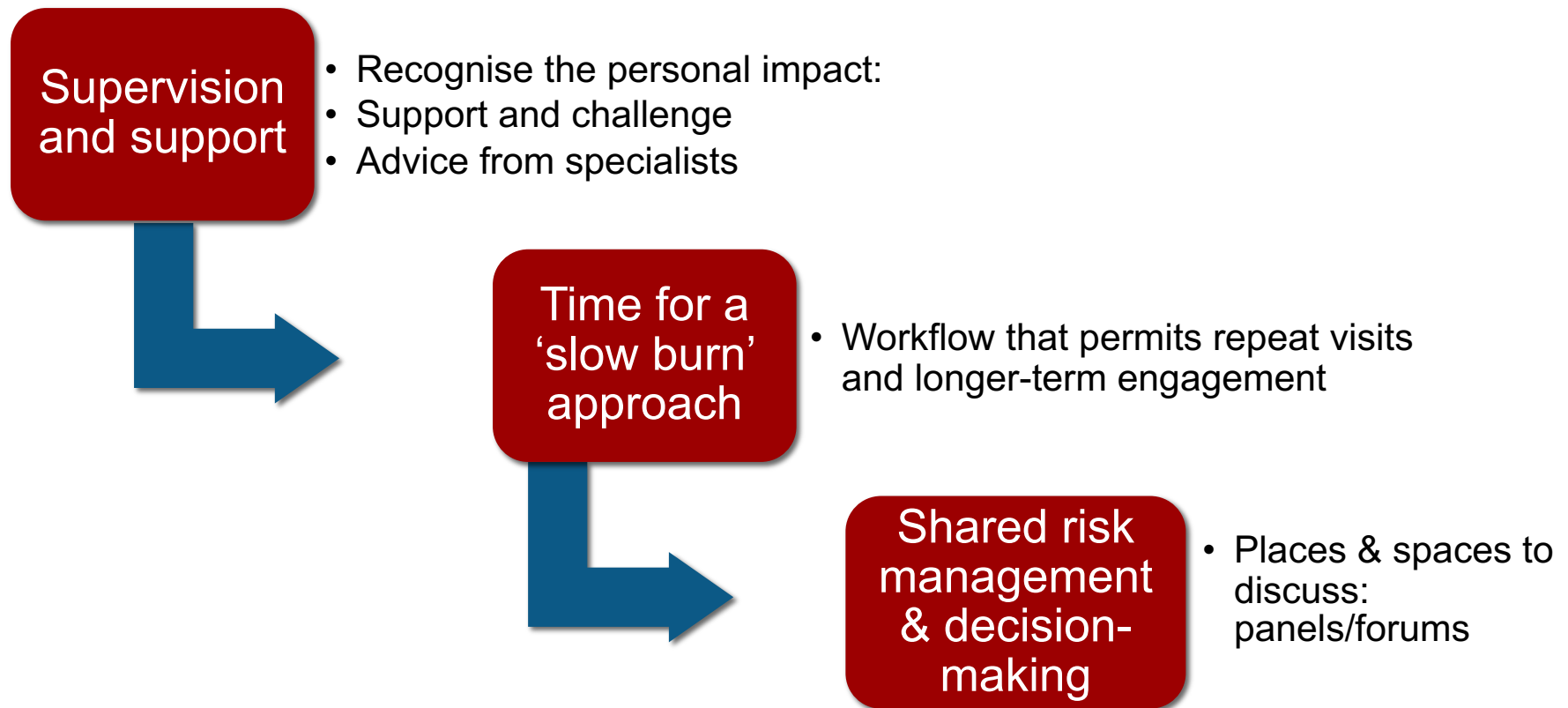
Reflecting on your own work environment

- Take a moment to consider your own workplace (poll)

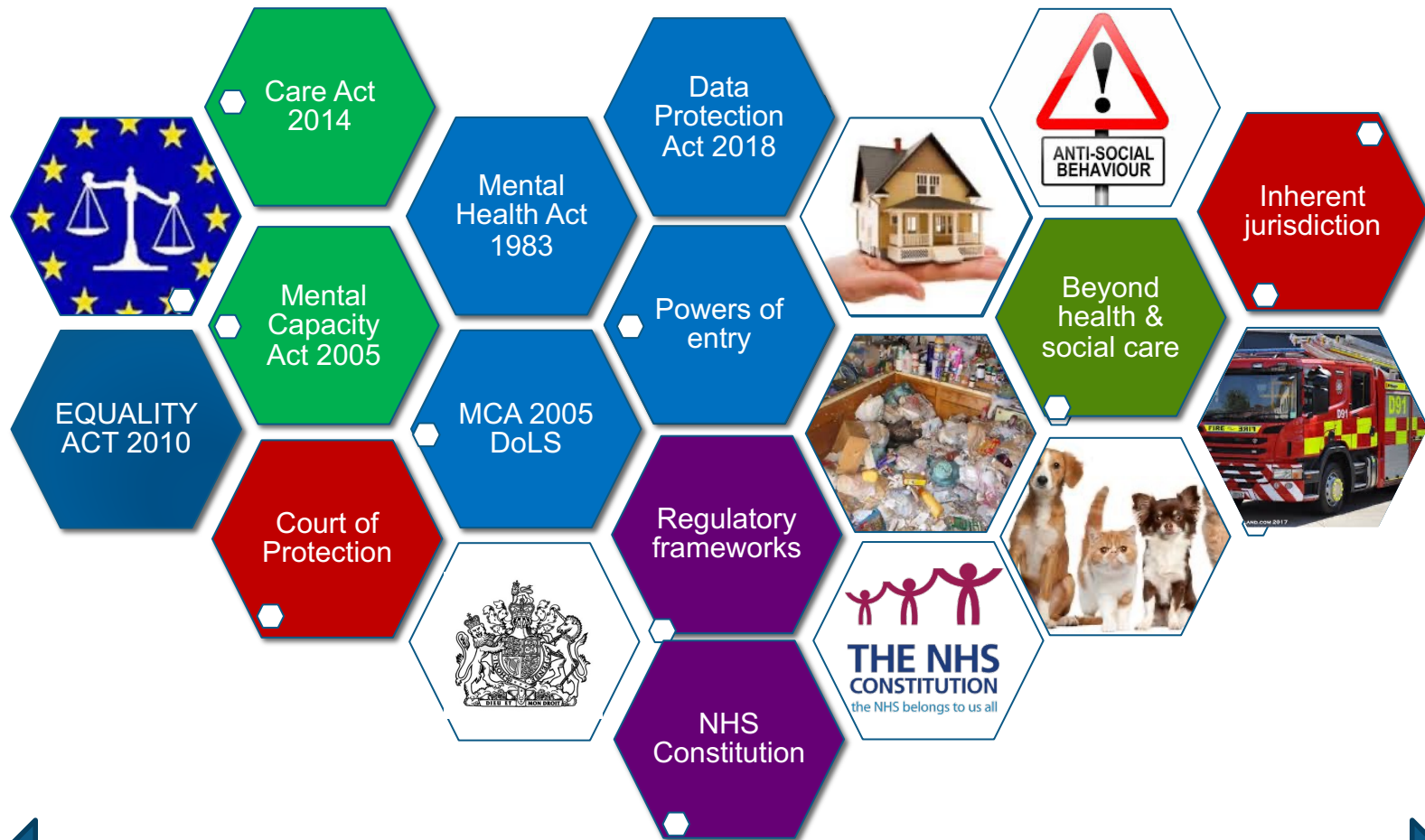


- Do you recognize any of these hindering features?
- Are there any features that support you in good practice? **If so, please put the details in the chat box.**

Organisational support for practice



5. The complexity of the legal framework



NEGOTIATED

LEGAL LITERACY

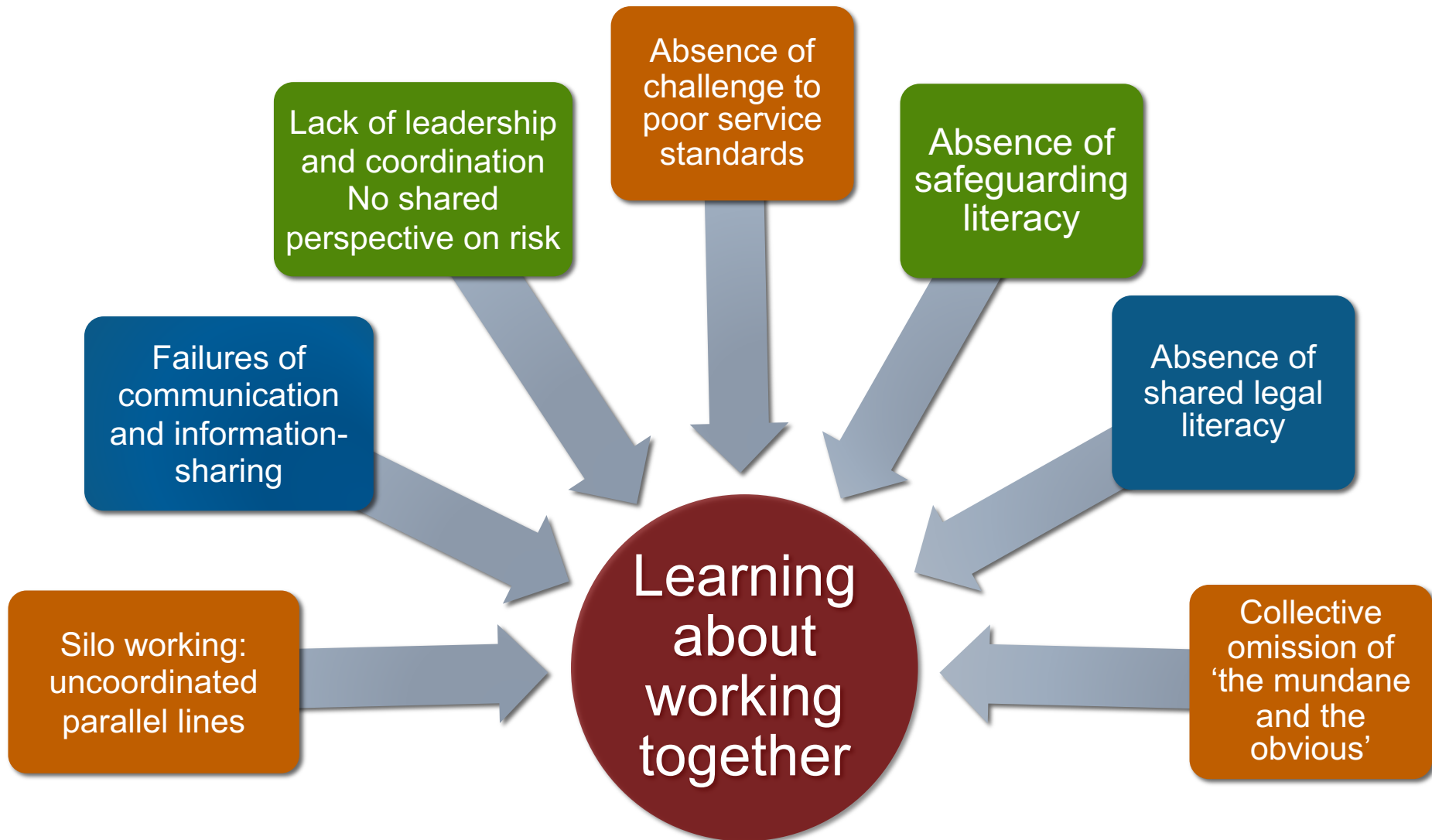
IMPOSED

Reflecting on your own legal literacy (poll)

- How confident are you that you understand:
 - The legal powers and duties of your own agency in relation to self-neglect
 - The legal powers and duties held by other agencies in relation to self-neglect



6. Interagency cooperation: SAR findings

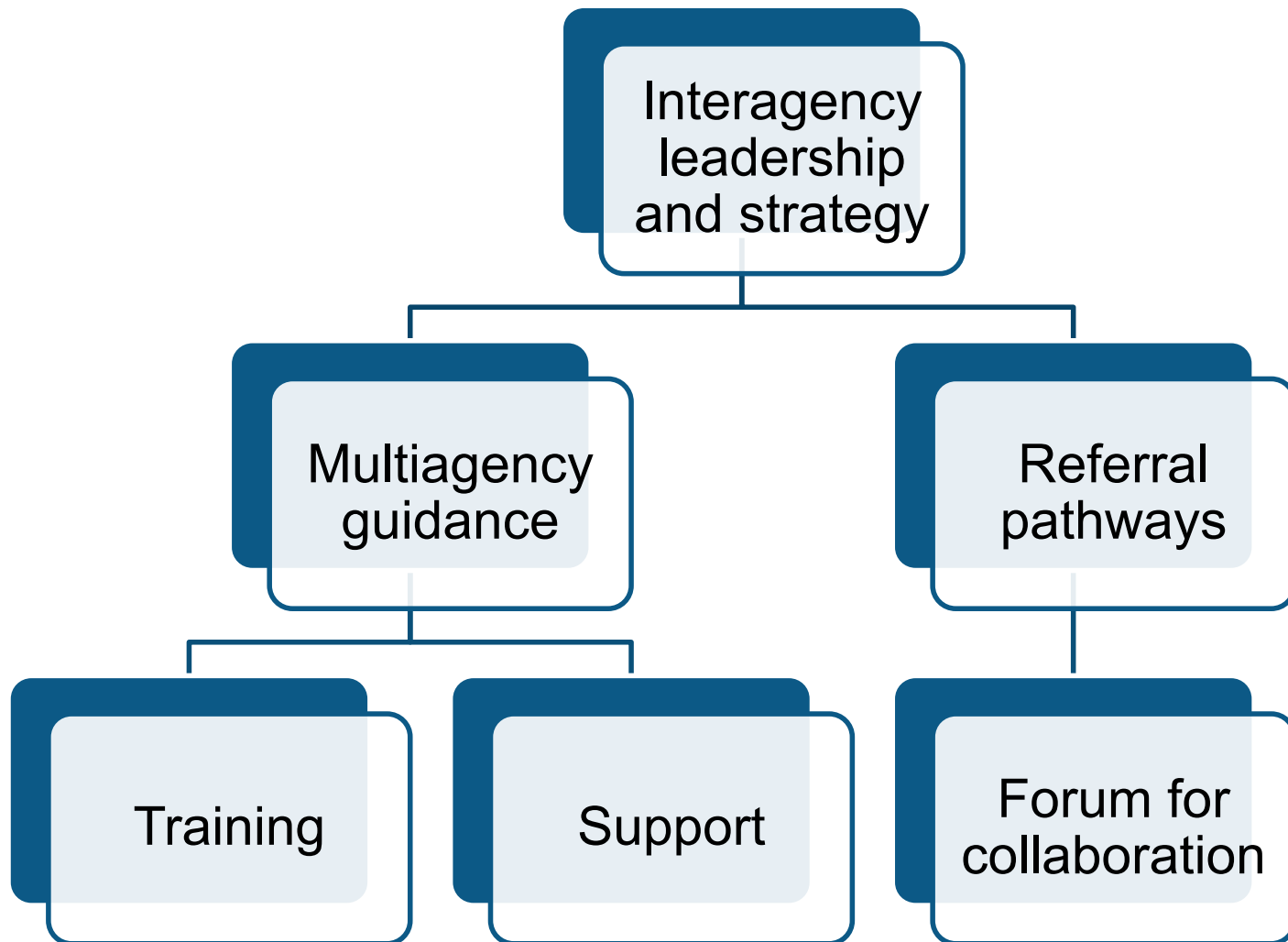


Does this happen here? (poll)

- Do you recognise any of these problems of interagency working in your own work environment?
- In your experience have you found any examples of particularly good interagency working? **If so, please put the details in the chat box.**



Key features of a good interagency system



What next in Hampshire?

Reflection:

- What have been the key take away points from today? Please use the chat box to tell us.
- What needs to come next? One key action you will take to put this learning into practice.
- Please use the chatbox to tell us.



A final word ...

A 3-minute video made by Lambeth Safeguarding Adults Board, drawing on the key messages from the research that is covered in this presentation:

<https://www.youtube.com/watch?v=ZEXrczADeKo>

In summary: practitioner approaches

Practice with people who self-neglect is more effective where practitioners

Build rapport and trust, showing respect, empathy, persistence, and continuity

Seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience

Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes

Keep constantly in view the question of the individual's mental capacity to make self-care decisions

Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility

Ensure that options for intervention are rooted in sound understanding of legal powers and duties

Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks

Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals

In summary: organisational approaches

Effective practice is best supported organisationally when

Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB

Agencies share definitions and understandings of self-neglect

Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems

Longer-term supportive, relationship-based involvement is accepted as a pattern of work

Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice

Further resources

- Braye S., Orr D. and Preston-Shoot M. (2011) *Self-Neglect and Adult Safeguarding: Findings from Research*. London: SCIE.
- Braye S, Orr D. and Preston-Shoot M. (2013) *A Scoping Study of Workforce Development for Self-Neglect*. London: Skills for Care.
- Braye S., Orr D. and Preston-Shoot M. (2014) *Self-Neglect Policy and Practice: Building an Evidence Base for Adult Social Care*. London: SCIE.
- Braye, S., Preston-Shoot, M., Preston, O., Allen, K. and Spreadbury, K. (2020) *Biennial Analysis of Safeguarding Adult Reviews April 2017-March 2019: Findings for sector-Led Improvement*. London: LGA.
- Preston-Shoot, M. (2019) 'Self-Neglect and Safeguarding Adult Reviews: Towards a Model of Understanding Facilitators and Barriers to Best Practice.' *Journal of Adult Protection*, 21 (4), 219-234.
- Preston-Shoot, M. (2021) 'On (not) learning from self-neglect safeguarding adult reviews', *Journal of Adult Protection*, 23, 4, 206-224.
- Preston-Shoot, M., O'Donoghue, F. and Binding, J. (2022) 'Hope springs: further learning on self-neglect from safeguarding adult reviews and practice.' *Journal of Adult Protection*, 24 (3/4), 161-178.
- Preston-Shoot, M. and Ward, M. (2021) *How to Use Legal Powers to Safeguard Highly Vulnerable Dependent Drinkers in England and Wales*. London: Alcohol Change UK

Key contacts

Please contact us if you have any queries:



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