

SAFEGUARDING PEOPLE WHO SELF-NEGLECT: WHAT WORKS?

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What do we mean by self-neglect?

“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 Care Act 2014 Statutory Guidance)

Neglect of self-care

- ❖ Personal hygiene
- ❖ Nutrition/hydration
- ❖ Health

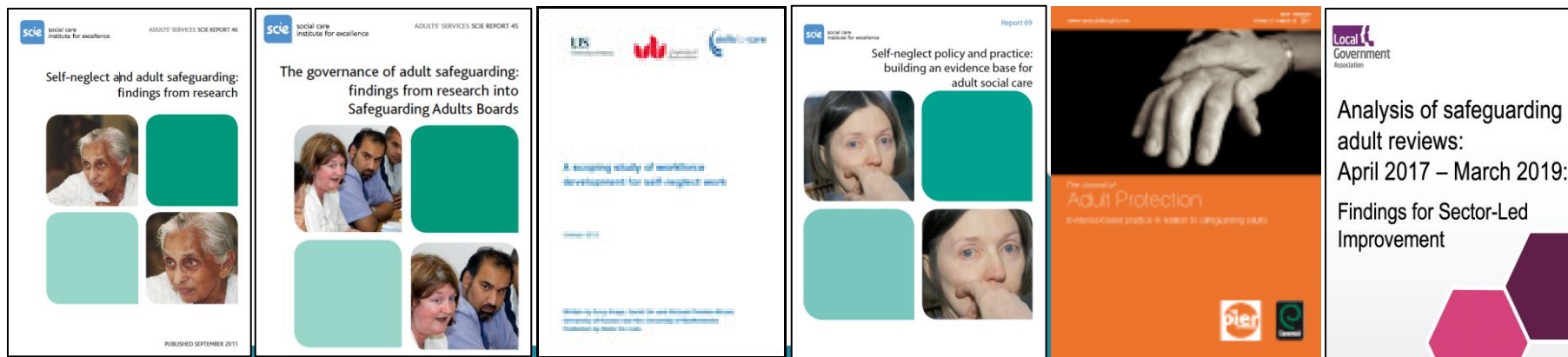
Neglect of the domestic environment

- ❖ Squalor
- ❖ Infestation
- ❖ Hoarding: (“persistent difficulty discarding or parting with possessions, regardless of value”)

To such an extent as to endanger health, safety and/or wellbeing

Refusal of services that would mitigate risk of harm

Research evidence and SAR learning



Scoping the
concept of
self-neglect
2011

SAB
governance
2011

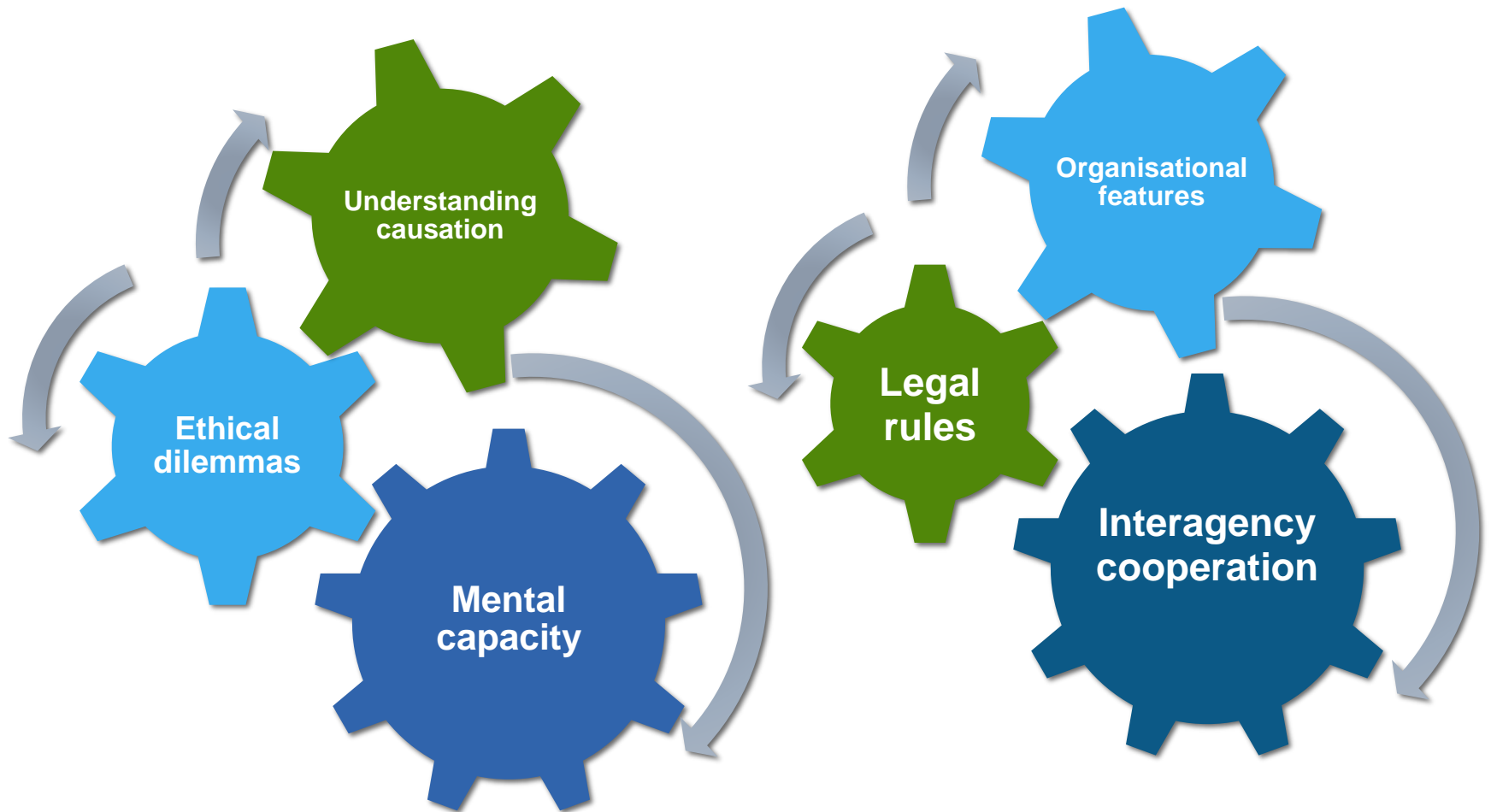
Workforce
development
needs
2013

Positive
outcomes in
self-neglect
2014

Reviews of
serious
cases
2014
ongoing

National
analysis of
SARs

Six key challenges of self-neglect: how does the evidence base help?



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 meaning of the self-neglect in the individual's life context

Keith's story

- As you watch the video:
 - Think about the multiple influences on Keith's behaviour, and how they have affected his self-neglect journey
 - Reflect on how it felt for him, and what helped
 - Consider how his account helps us in understanding self-neglect
- <https://www.youtube.com/watch?v=fhmfptpwNZc>



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. Ethical dilemmas



- ❖ Professional codes of ethics
- ❖ MCA 2005
- ❖ ECHR articles 8 and 5
- ❖ Policy context of personalization & making safeguarding personal
- ❖ Longstanding limitations to state power

- ❖ 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 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.”

Challenging our assumptions

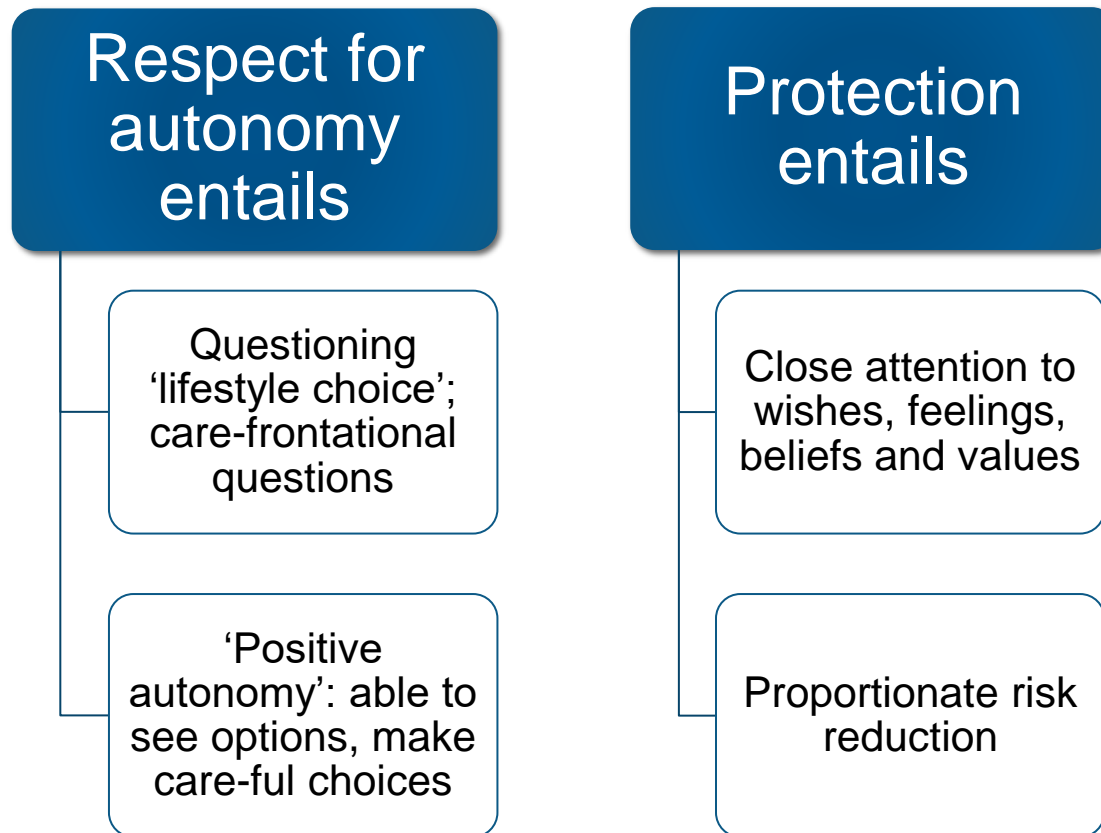
Is it really autonomy when ...

- You don't see how things could be different
- You don't think you're worth anything different
- You didn't choose this, but adapted gradually to worsening circumstances
- Your mental ill-health makes self-motivation difficult

Is it really protection when ...

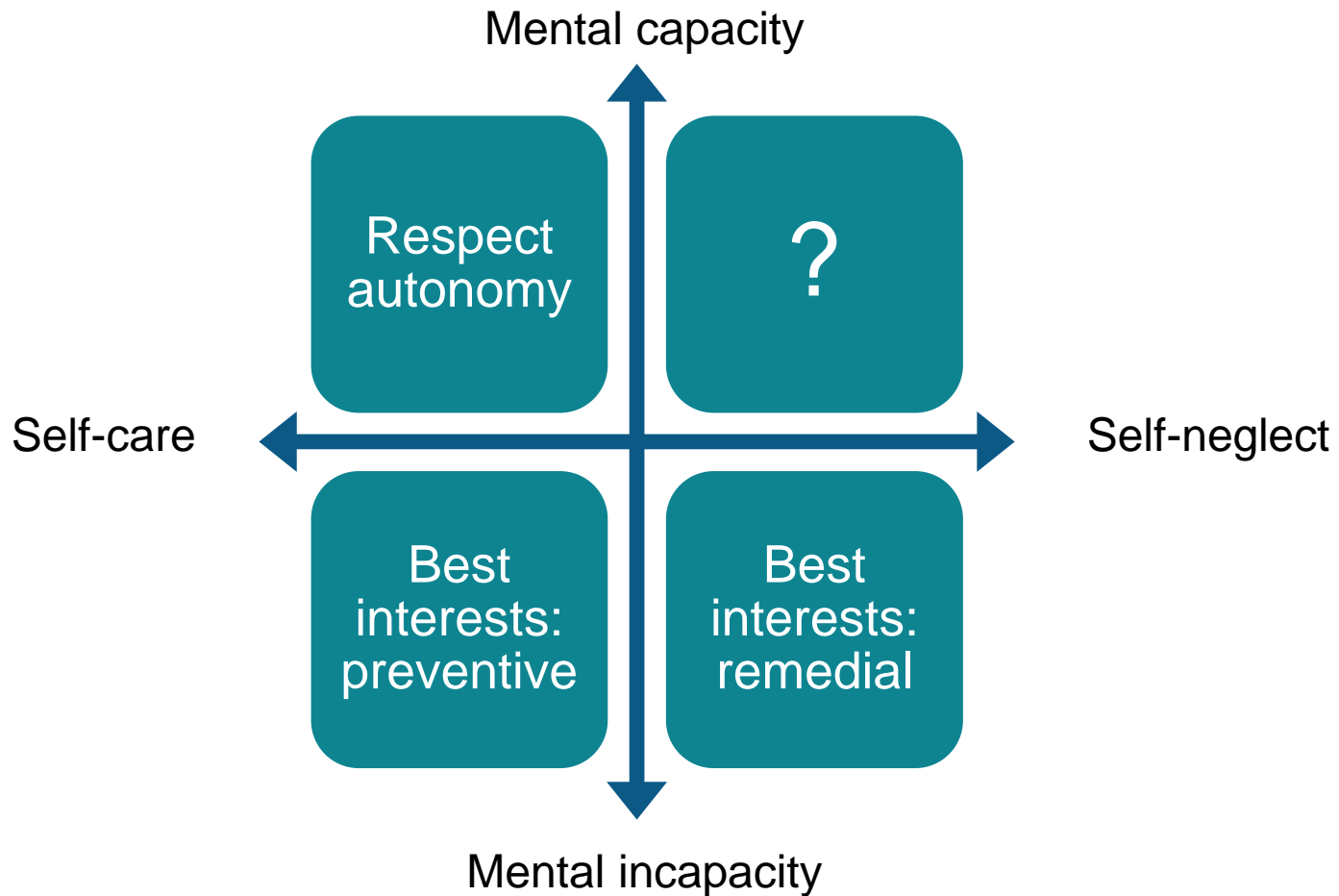
- Imposed solutions don't recognise the 'meaning of the mess'
- Your 'sense of self' is taken: "*hoarding is my mind*"
- You have no control and no ownership
- Your safety comes at the cost of being miserable

A more nuanced ethical literacy



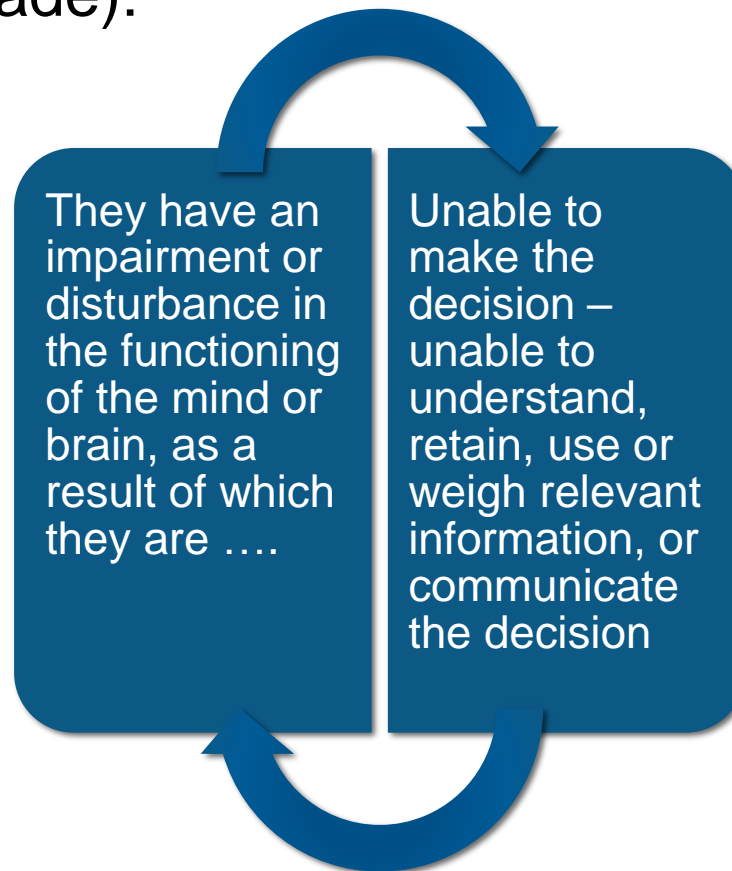
Autonomy does not mean abandonment
Protection does not mean removal of all risk

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

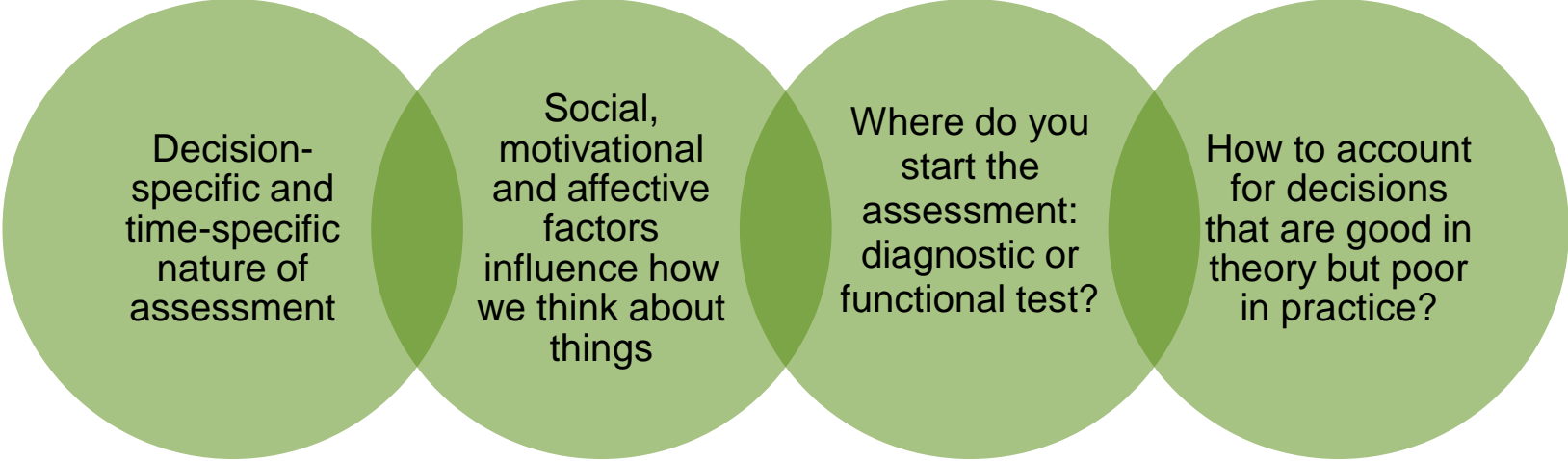


Mental capacity: a reminder

- 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



Decision-specific and time-specific nature of assessment

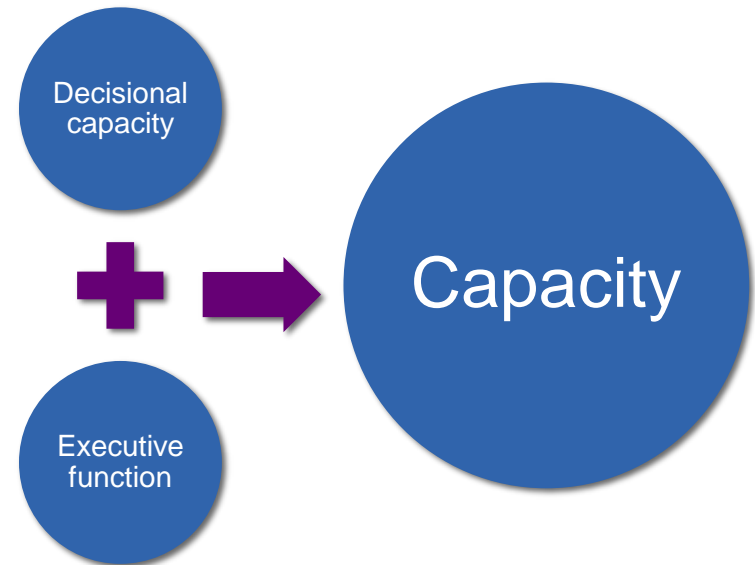
Social, motivational and affective factors influence how we think about things

Where do you start the assessment: diagnostic or functional test?

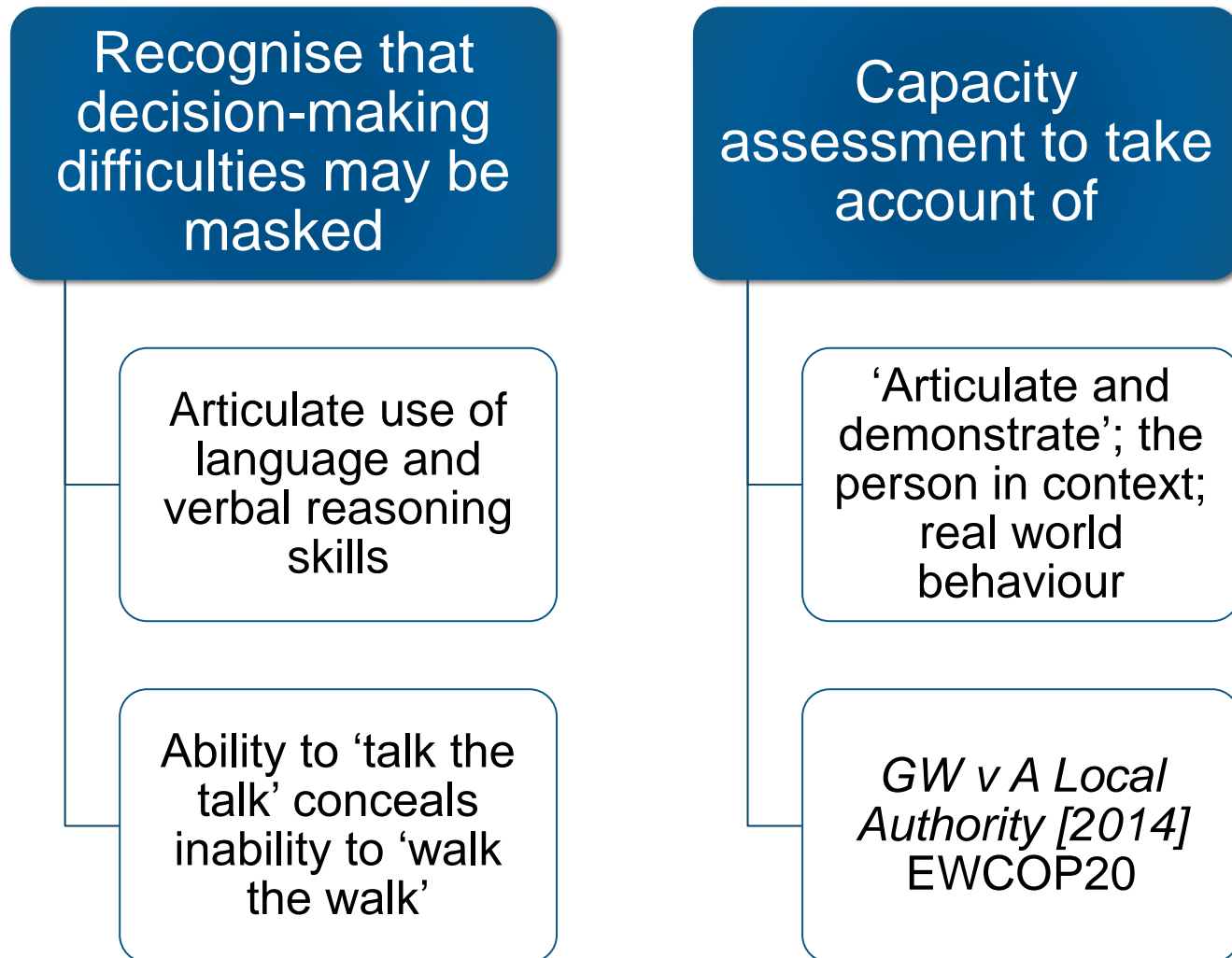
How to account for decisions that are good in theory but poor in practice?

Mental capacity...

- Involves not only
 - the ability to talk about a decision in the abstract
- But also
 - the ability to execute it at the appropriate moment – the ‘knowing/doing association’ – which requires executive brain function
- Frontal lobe damage may cause loss of executive brain function, resulting in difficulties:
 - understanding, retaining, using and weighing information in the moment, thus affecting
 - problem-solving and enacting a decision at the appropriate point



A more nuanced understanding



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

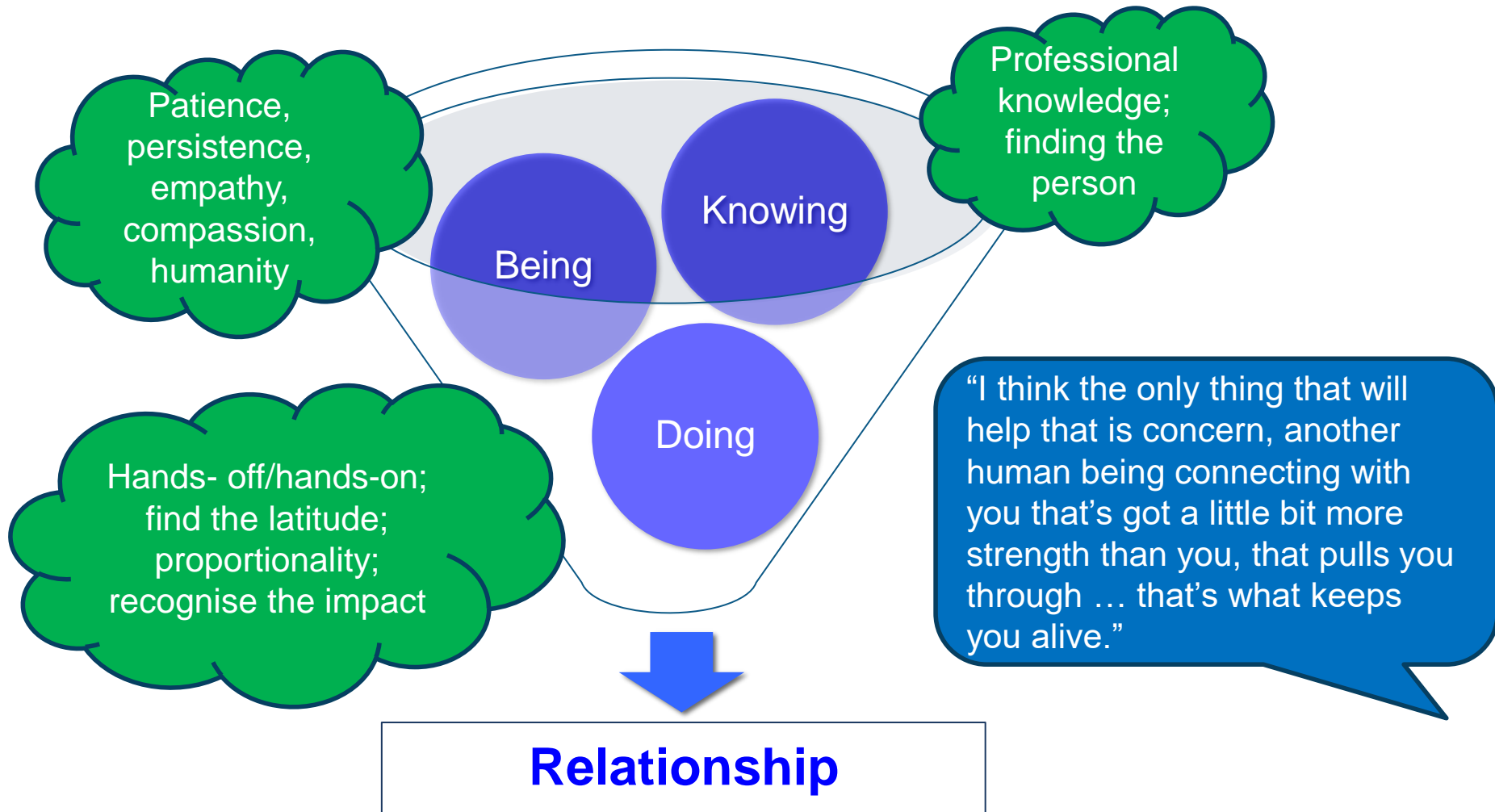
She got it into my head that I am important, that I am on this earth for a reason.

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.

Direct practice: Knowing, Being, Doing

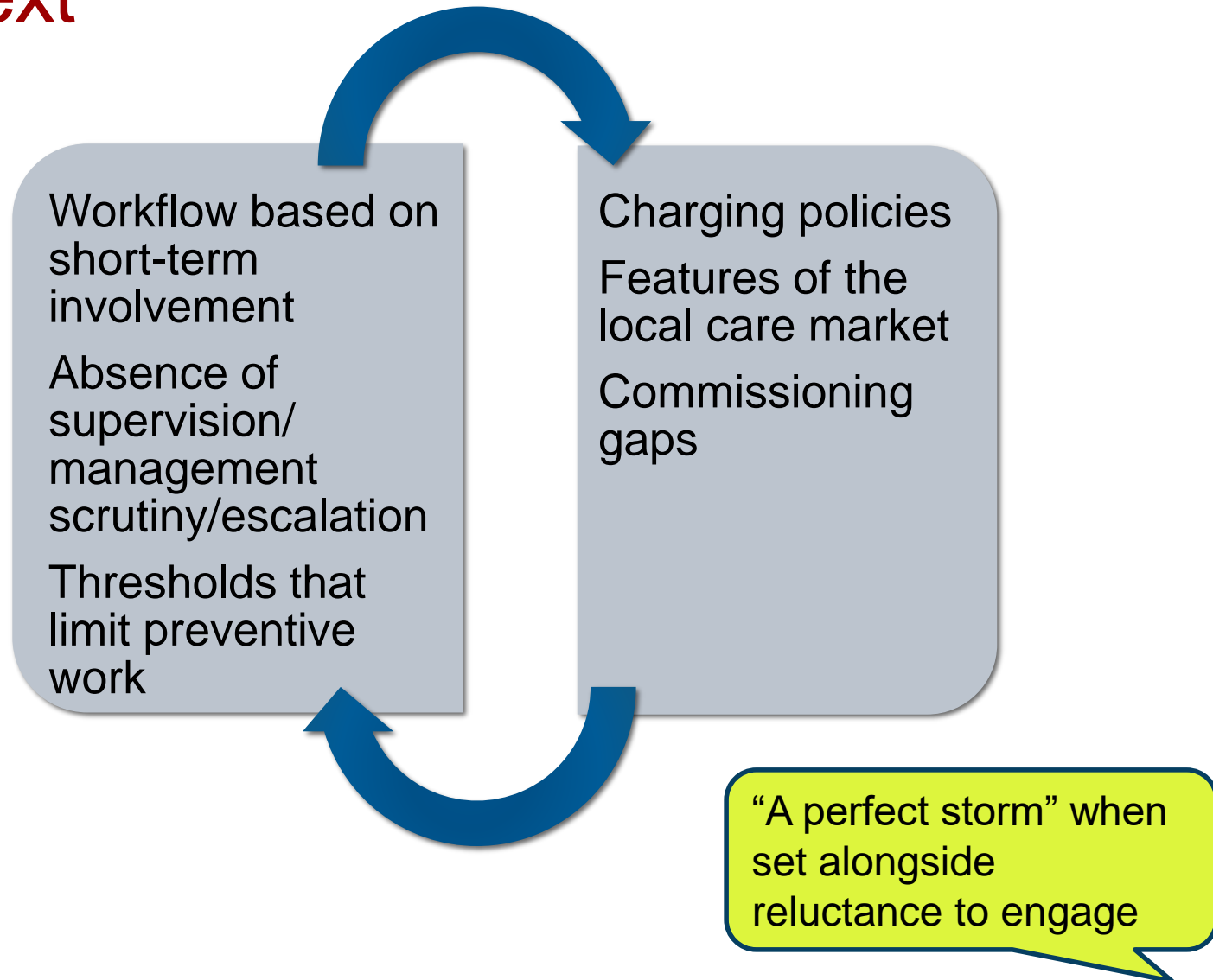


But is it possible to practise in this way?

- There are factors that influence whether and how practitioners are able to implement best practice



4. Challenges in the organisational context



Key features of organisational support for effective practice

Supervision
and support

- Recognition of the personal impact
- Provision of support and challenge
- Access to advice from specialists



Time for a
'slow burn'
approach

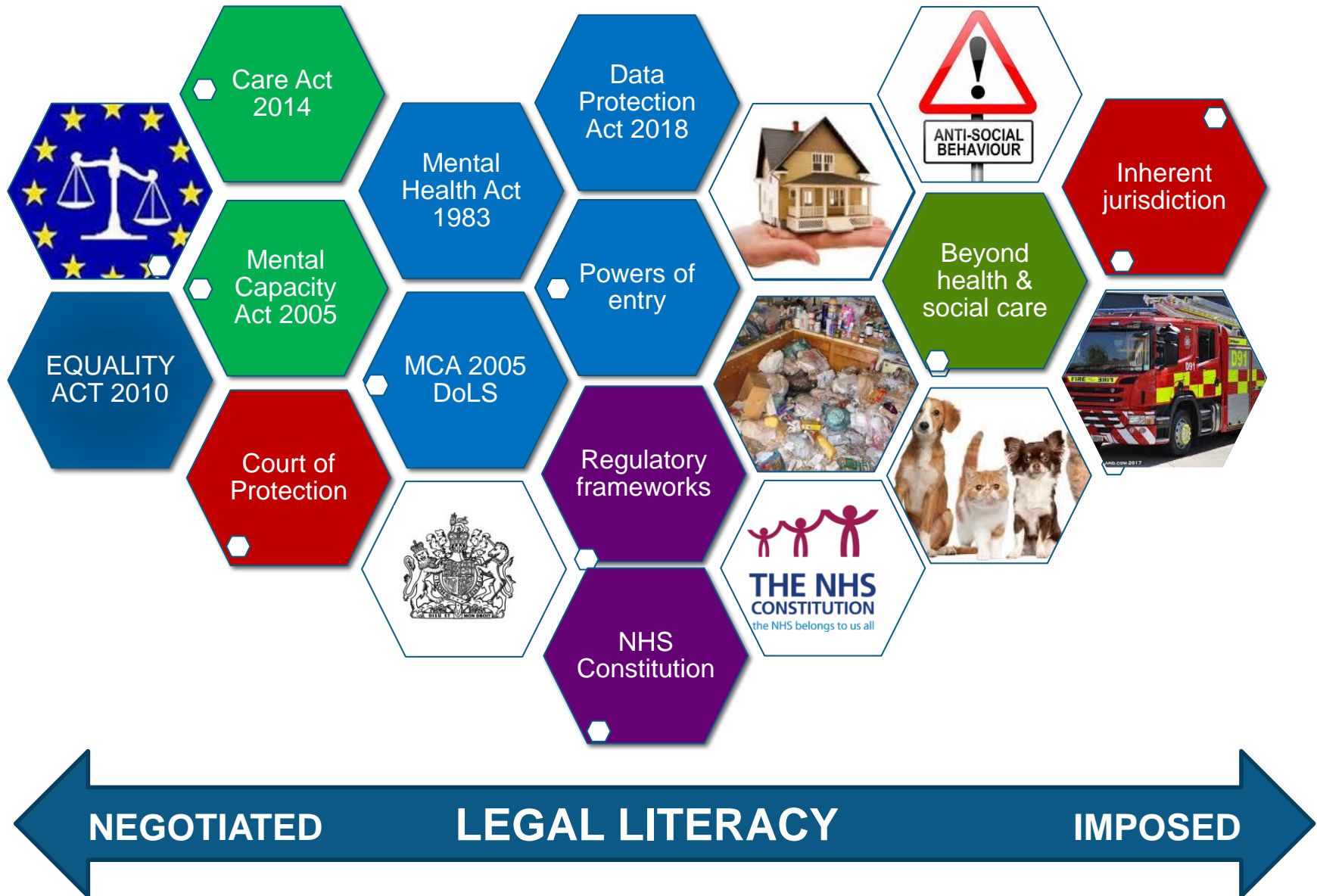
- Workflow that permits repeat visits and longer-term engagement



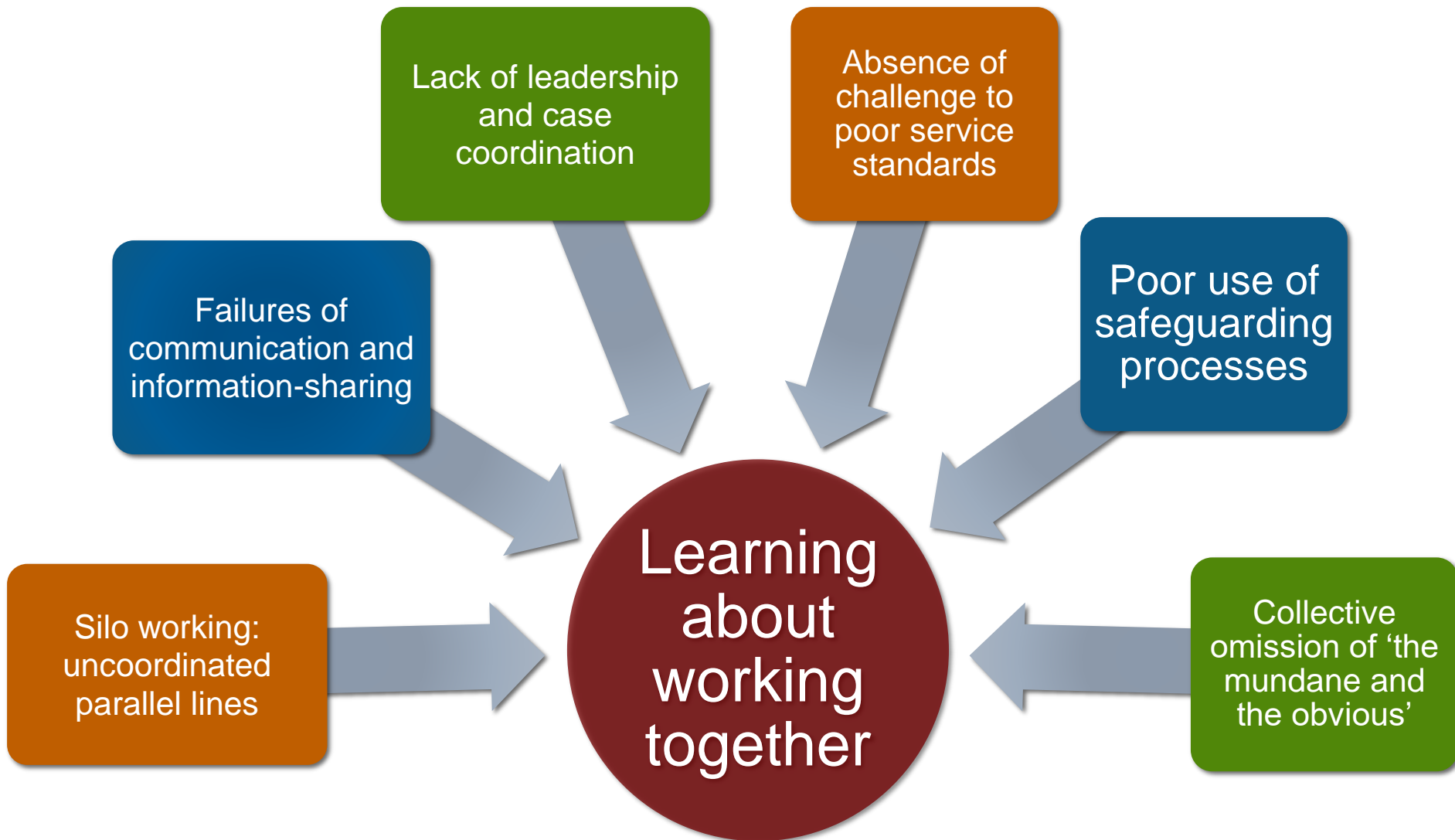
Shared risk
management
& decision-
making

- Places & spaces to discuss; escalation routes

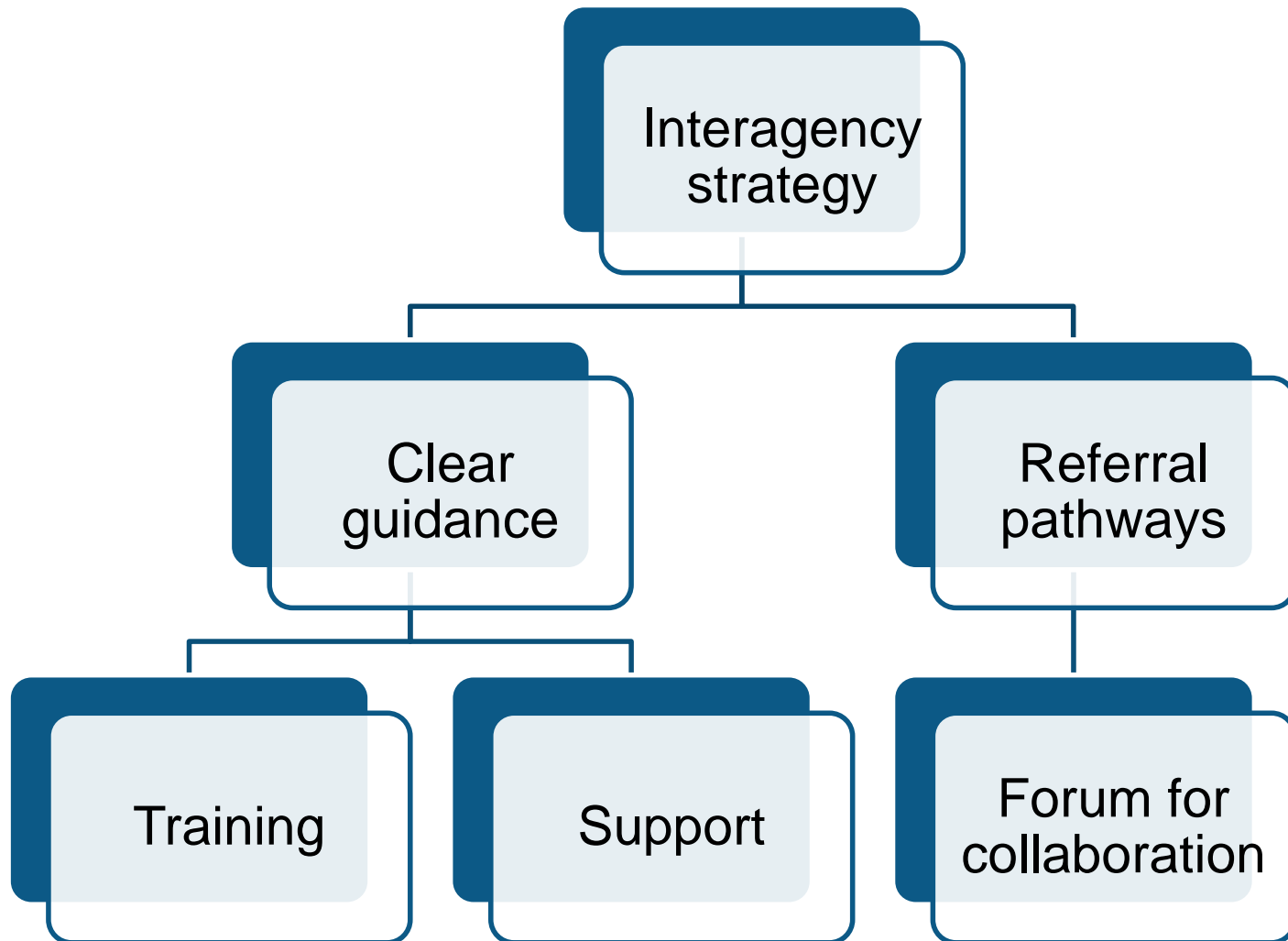
5. Legal literacy: complex legal rules



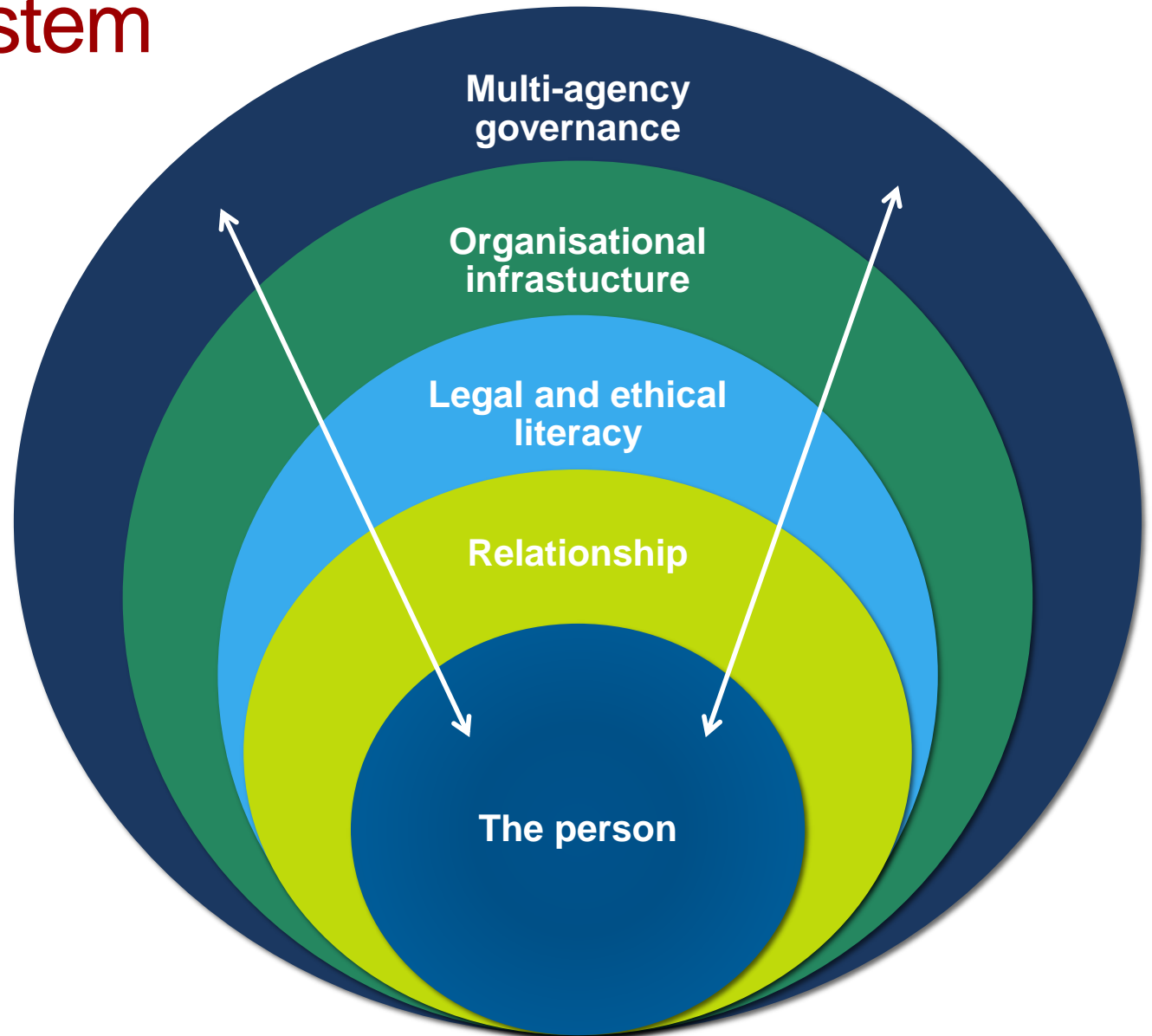
6. Interagency coordination



Key features of a robust interagency system



Whole system alignment



The last word ...

A short video made by Lambeth Safeguarding Adults Board, drawing on the key messages from the research



<https://www.youtube.com/watch?v=ZEXrczADeKo&feature=youtu.be&medium=email&source=GovDelivery>

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 are facilitated by clear referral routes, communication and decision-making systems

Longer-term supportive, relationship-based involvement is accepted as a pattern of work in complex, high-risk cases

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

Research reports

- **Braye, S., Orr, D. and Preston-Shoot, M. (2011)** *Self-Neglect and Adult Safeguarding: Findings from Research*. London: SCIE.
<http://www.scie.org.uk/publications/reports/report46.pdf>
- **Braye, S., Orr, D. and Preston-Shoot, M. (2013)** *A Scoping Study of Workforce Development for Self-Neglect*. London: Skills for Care.
<http://www.skillsforcare.org.uk/NMDS-SC-intelligence-research-and-innovation/evidence-impact/Research-reports/Workforce-development-for-self-neglect.aspx>
- **Braye, S., Orr, D. and Preston-Shoot, M. (2014)** *Self-Neglect Policy & Practice: Building an Evidence Base for Adult Social Care*. London: SCIE. (Summary reports also available)
<http://www.scie.org.uk/publications/reports/69-self-neglect-policy-practice-building-an-evidence-base-for-adult-social-care/>
- **Preston-Shoot, M., Braye, S., Preston, O., Allen, K. and Spreadbury, K. (2020)** *Analysis of Safeguarding Adult Reviews April 2017 – March 2019: Findings for Sector-Led Improvement*. London: LGA and ADASS. (Full report and executive summary available)
<https://www.local.gov.uk/analysis-safeguarding-adult-reviews-april-2017-march-2019>

Journal articles and book chapters

- **Braye, S., Orr, D. and Preston-Shoot, M. (2011)** 'Conceptualising and responding to self-neglect: challenges for adult safeguarding', *Journal of Adult Protection*, 13, 4, 182-193.
- **Braye, S., Preston-Shoot, M. and Orr, D (2012)** The governance of adult safeguarding: findings from research', *Journal of Adult Protection*, 14, 2, 55-72.
- **Braye, S., Orr, D. and Preston-Shoot, M. (2015)** 'Learning lessons about self-neglect? An analysis of serious case reviews', *Journal of Adult Protection*, 17, 1, 3-18.
- **Braye, S., Orr, D. and Preston-Shoot, M. (2015)** 'Serious case review findings on the challenges of self-neglect: indicators for good practice', *Journal of Adult Protection* (17, 2, 75-87).
- **Braye, S., Orr, D. and Preston-Shoot, M. (2017)** 'Autonomy and protection in self-neglect work: the ethical complexity of decision-making', *Ethics & Social Welfare*, <http://dx.doi.org/10.1080/17496535.2017.1290814>

- **Preston-Shoot, M. (2016)** 'Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work,' *Journal of Adult Protection*, 18(3), 131-148.
- **Preston-Shoot, M. (2017)** 'On self-neglect and safeguarding adult reviews: diminishing returns or adding value?' *Journal of Adult Protection*, 19, 2, 53-66.
- **Braye, S., Orr, D. and Preston-Shoot, M. (2017)** 'Self-Neglect and Hoarding', in A. Cooper & E. White (eds) *Good Practice in Safeguarding Adults*, London: Jessica Kingsley.
- **Braye, S. Orr, D. & Preston-Shoot, M. (2018)** Adult safeguarding and self-neglect: emergent lessons from England', In M.R. Day, G. McCarthy & J.J. Fitzpatrick, (Eds), *Self-Neglect in Older Adults a Global, Evidence-Based Resource for Nurses and Other Healthcare Providers* (175-192).
- **Orr, D., Braye, S. and Preston-Shoot, M. (2019)** 'Meaning in hoarding: perspectives of people who hoard on clutter, culture, and agency', *Anthropology & Medicine*, 26(3):1-17.
- **Preston-Shoot, M. (2020)** 'Safeguarding adult reviews: informing and enriching policy and practice on self-neglect', *Journal of Adult Protection*, 22, 4, 199-215.

Key contacts

Please contact me if you have any queries:

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