Keeping Adults Safe in Shropshire Board

Telford & Wrekin Safeguarding Adults Board

Safeguarding Adults Event 2018 – Preventing Abuse in Shropshire and Telford & Wrekin

with

Professor Michael Preston-Shoot

Working with adults who self-neglect: best practice evidence from research and reviews

Shropshire Partners in Care
The Care Workforce Development Partnership

Event Objectives

- Identify best practice evidence from research and reviews when working with adults who self-neglect

- Identify what learning from SARs tells us for best mental capacity practice

We want you to use the reflective workshops to:

- Explain what you will do as a result of your learning from the event

Event Resources

Professor Michael Preston-Shoot was filmed talking about working with adults who self-neglect: best practice evidence from research and reviews this is now available on YouTube via a link from the SAB websites:

Shropshire

www.keepingadultssafeinshropshire.org.uk/

Telford and & Wrekin

www.telfordsafeguardingadultsboard.org/sab/about

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Working with adults who self-neglect: best practice evidence from research and reviews

Michael Preston-Shoot (researcher with Suzy Braye and David Orr)

Shropshire KASiSB & Telford and Wrekin SAB

14th June 2018

What do we mean by self-neglect?

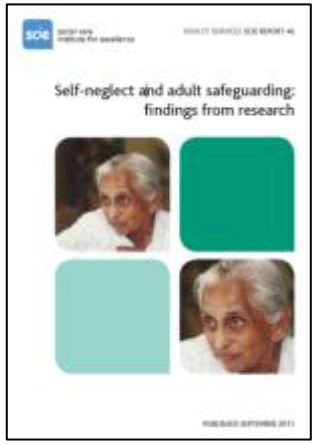
Neglect of self-care	Neglect of the domestic environment
❖ Personal hygiene ❖ Nutrition/hydration ❖ Health	❖ Hoarding: ("persistent difficulty discarding or parting with possessions, regardless of value" DSM V) ❖ Squalor ❖ Infestation

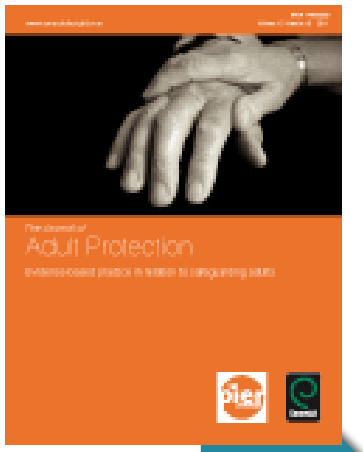
To such an extent as to endanger health, safety and/or wellbeing

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" (DH 2017)

Self-neglect: the research evidence





SAB governance

Scoping the evidence on self-neglect

Workforce development needs

2013

Review of serious case reviews

2014-18

Exploring self-neglect practice

2013-15

Summary of research findings: 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

Summary of research findings: organisational approaches

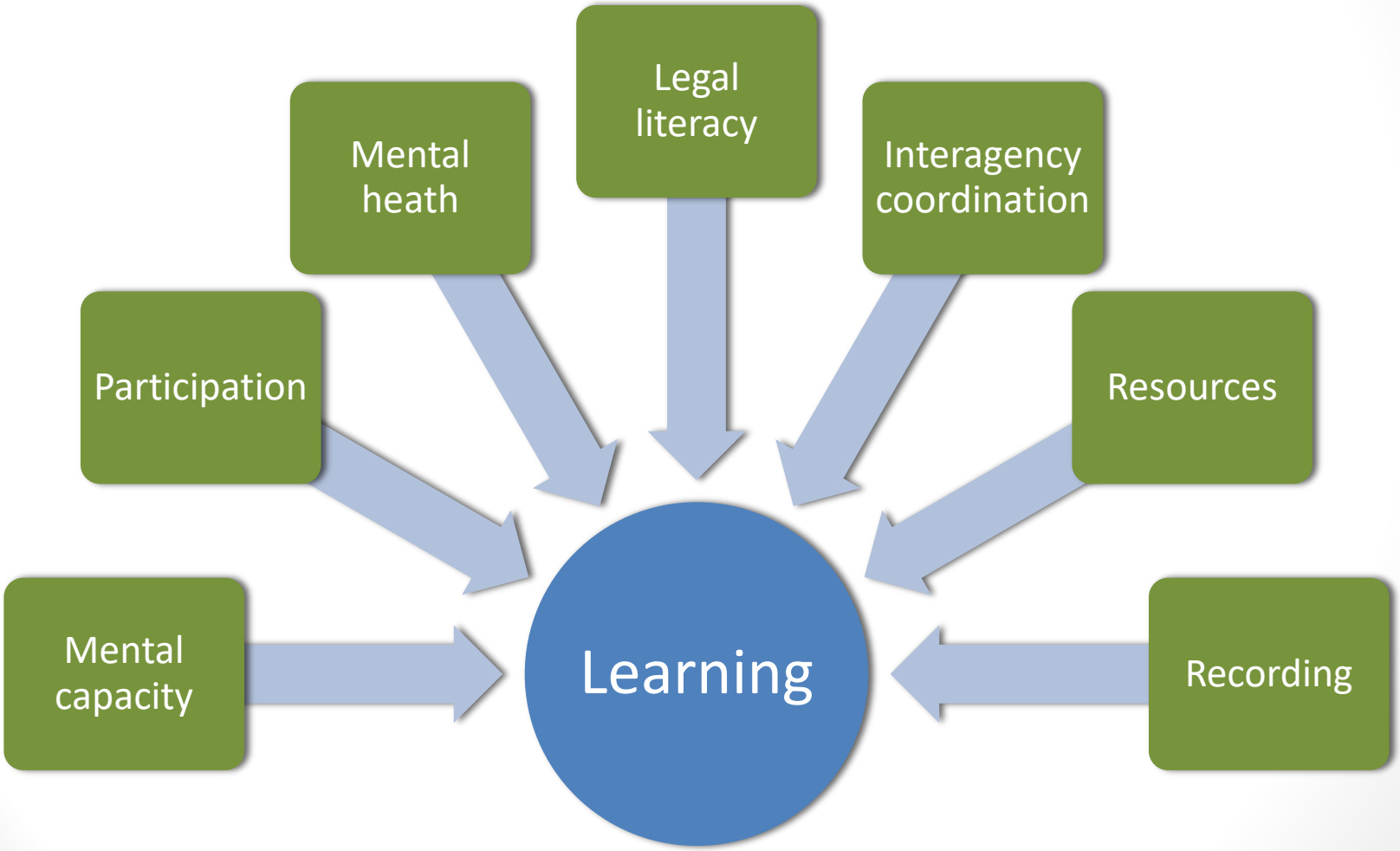
Effective practice is best supported organisationally when
Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB
Agencies share definitions and understandings of self-neglect
Interagency coordination and shared risk-management 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

Case reviews find shortcomings across the system

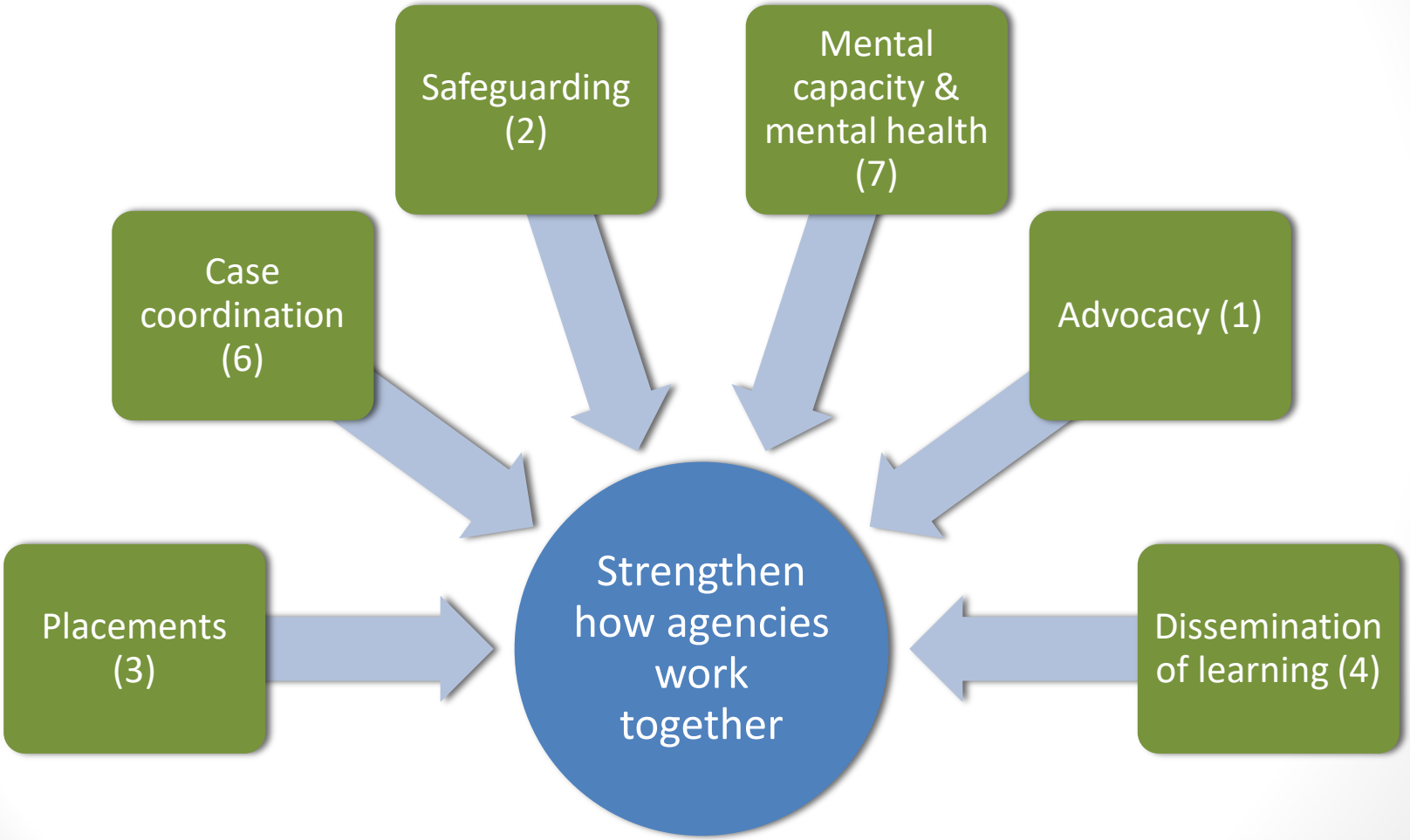
East Sussex SAB: Mr A - a pen picture

- Died 24th July 2016, aged 64, Kent resident, no family contact
- Medical history: Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis & ulceration
- Placed in nursing care in East Sussex Sept 2015, commissioned by West Kent CCG: no suitable local placement, placement search ongoing, no suitable alternative
- Placement (and DoL) in best interests as deemed to lack capacity to decide where to live
- Supported in decision-making by a former colleague with LPA
- Self-neglect: refusal of care and treatment
- Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, idiopathic hepatic cirrhosis

Mr A: Key findings



Mr A: Recommendations



Example SCRs/SARs

- Gemma Hayter – Warwickshire – no agency took responsibility for young disabled adult
- WD – Waltham Forest – what is a lifestyle choice when living in squalor?
- Ellen Ash – Glasgow – a complex mother/son relationship, repeating pattern not addressed
- ZZ – Camden – changing behaviour not challenged by home care staff
- Mr C – Bristol (2016) – capacity assumed, impact of organisational capacity, inconsistent multi-agency working, interface between mental health and drug use, anti-social behaviour, legal literacy on section 117 MHS 1983, non-punitive approach and tenacious work by housing professionals
- YY – Camden – delays in raising concerns and commencing safeguarding enquiries; lack of contingency planning; no high level risk management meeting; procedures not well publicised or known
- Ms F - West Berkshire (2014) – complex family with co-dependent needs, tenacious and non-punitive approach by housing staff
- Adult D – Newcastle – son preventing agencies from addressing his father's needs
- Adult A - North Tyneside – failure to collect repeat prescriptions for type 2 diabetes not noticed by the health centre; utility company did not raise an alert
- A1 – Birmingham – failure to liaise with psychiatrist over a capacity assessment and with Ambulance Trust over hospital admission

Example SARs

- Mr V – Isle of Wight (2015) – discharge planning should involve all agencies and carers, capacity assessments to be recorded, use expertise of specific healthcare professionals
- Mr W – Isle of Wight (2015) – importance of liaison between GPs and District Nurses, and sharing of safeguarding concerns across agencies; demanding workloads
- KH – Gloucestershire – importance of precise referrals, and of community nurses reporting concerns; demanding workloads; disguised compliance; lack of knowledge of adult safeguarding amongst housing providers
- Ted – Gloucestershire (2016) – district nursing service in "turmoil", understaffed and being reorganised, importance of full information in hospital discharge letters, review repeat prescriptions, involve sheltered housing staff
- BB and CC – Islington – multi-agency meetings must share information, analysis and agree action plans; importance of liaison between GPs, OTs and care agency
- Importance of liaison, multi-agency meetings and information-exchange; medication reviews; training in mental capacity and mental health law, thorough risk and capacity assessments, supervision (South Tyneside, East Sussex, Surrey, Newcastle, Tower Hamlets, Kent and Medway, Slough)

Thematic analysis – the adult

- History – explore questions why; curiosity
- Person-centred approach – be proactive, address patterns
- Hard to reach – try different approaches, use advocates and concerned others, raise concerns, discuss risks, maintain contact, avoid case closure
- Mental capacity – ongoing assessment & review, guidance for staff regarding people with capacity who refuse services and are at risk
- Autonomy & life style choice an increasing focus (Adult A North Tyneside, B & C South Tyneside, Mr I West Berkshire, W Isle of Wight, and several Gloucestershire cases – OO, R, AT and KH)
- Carers – offer assessments, concerned curiosity & challenge, explore family dynamics and repeating patterns, engage neighbours and non-resident family members

Thematic analysis – team around the adult

- Recording – clarity & thoroughness of work done, agreed plans, outcomes achieved, discussions held
- Legal literacy – know and consider available law
- Safeguarding literacy – awareness of guidance & procedures, of risks and vulnerabilities, of safeguarding systems; adequate exploration of apparent choices
- Working together – silo working, threshold bouncing, inflexible agency responses, shared assessments & plans, liaison & challenge, follow-through
- Information sharing
- Advocacy – consider use with hard to engage people
- Use of procedures – DNAs, safeguarding alerts, risk assessments
- Standards of good practice – thoroughness of assessments, challenge professional optimism, lack of assertiveness & curiosity, authoritative practice

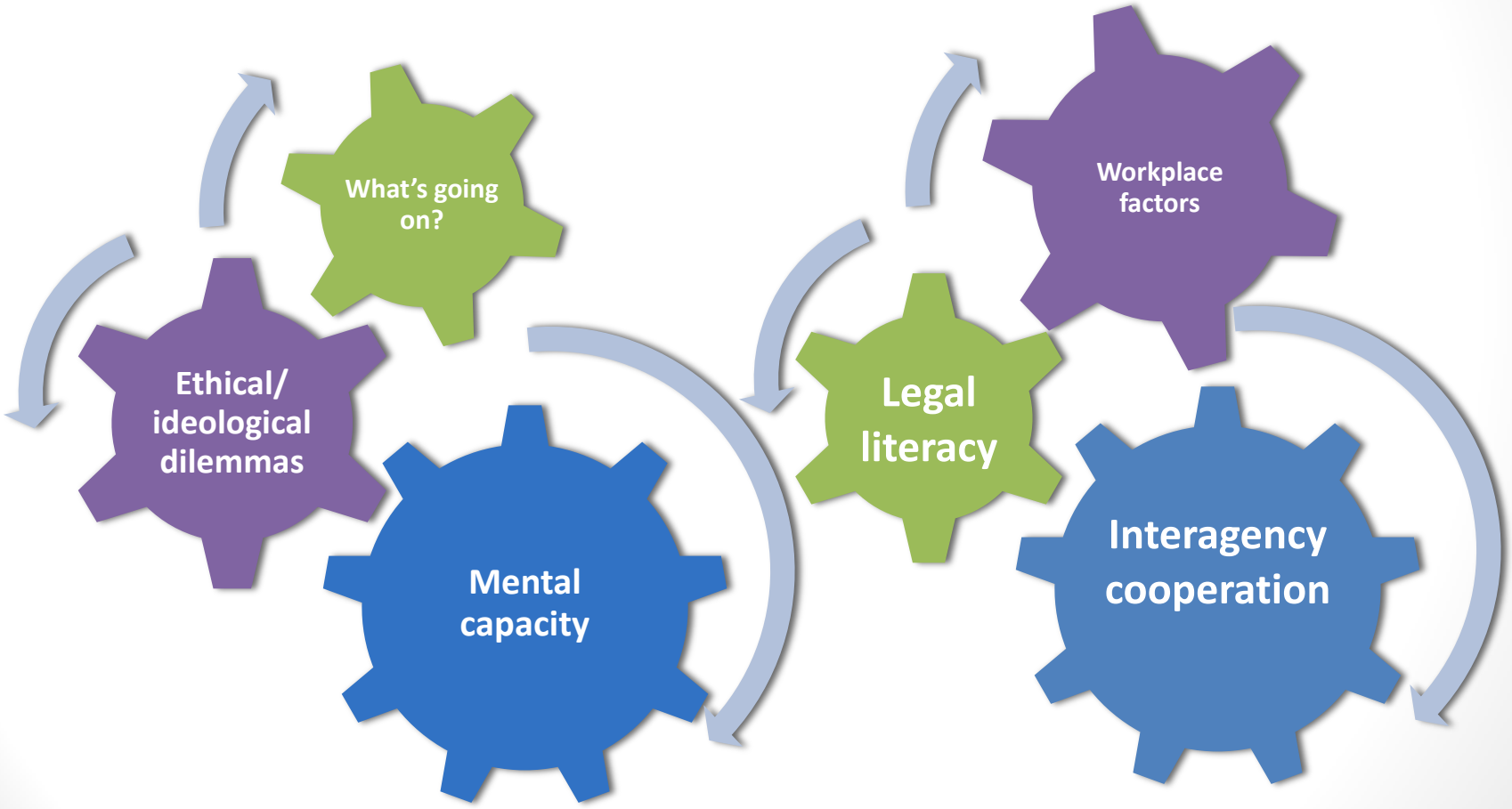
Thematic analysis – organisations around the team

- Support – cases are complex, high risk, stressful & demanding, so support systems essential; review scope and adequacy of policies
- Culture – encourage challenge & escalation of concerns; balance personalisation with duty of care; review case management approach
- Supervision & managerial oversight – senior managers should take responsibility for overseeing complex cases; effective supervision; use risk panels; audit cases
- Staffing – practitioners must have appropriate experience & resilience; review allocation of work; mindful of health & safety

Thematic analysis – LSAB around the organisations

- Conducting SARs – involve family & carers, avoid delay
- Monitoring & action planning – robust action plans and audits of impact needed
- Procedures & guidance – develop protocols on risk & capacity assessments, follow up of service refusal, cases where adults have capacity but at risk of harm
- Use of SAR – across SABs, in training, with government departments, for procedural development
- Training – on mental capacity, law, procedures, writing IMRs, on person-centred approach & strategies to engage people; evidence outcomes

Key challenges of self-neglect: how can research and reviews help?



What's going on?

- No one overarching explanatory model
- Complex interplay of physical, mental, social, personal and environmental factors, and of (un)willingness and (in)ability
- Need for understanding the meaning of self-neglect in the context of each individual's life experience

Understanding 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 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

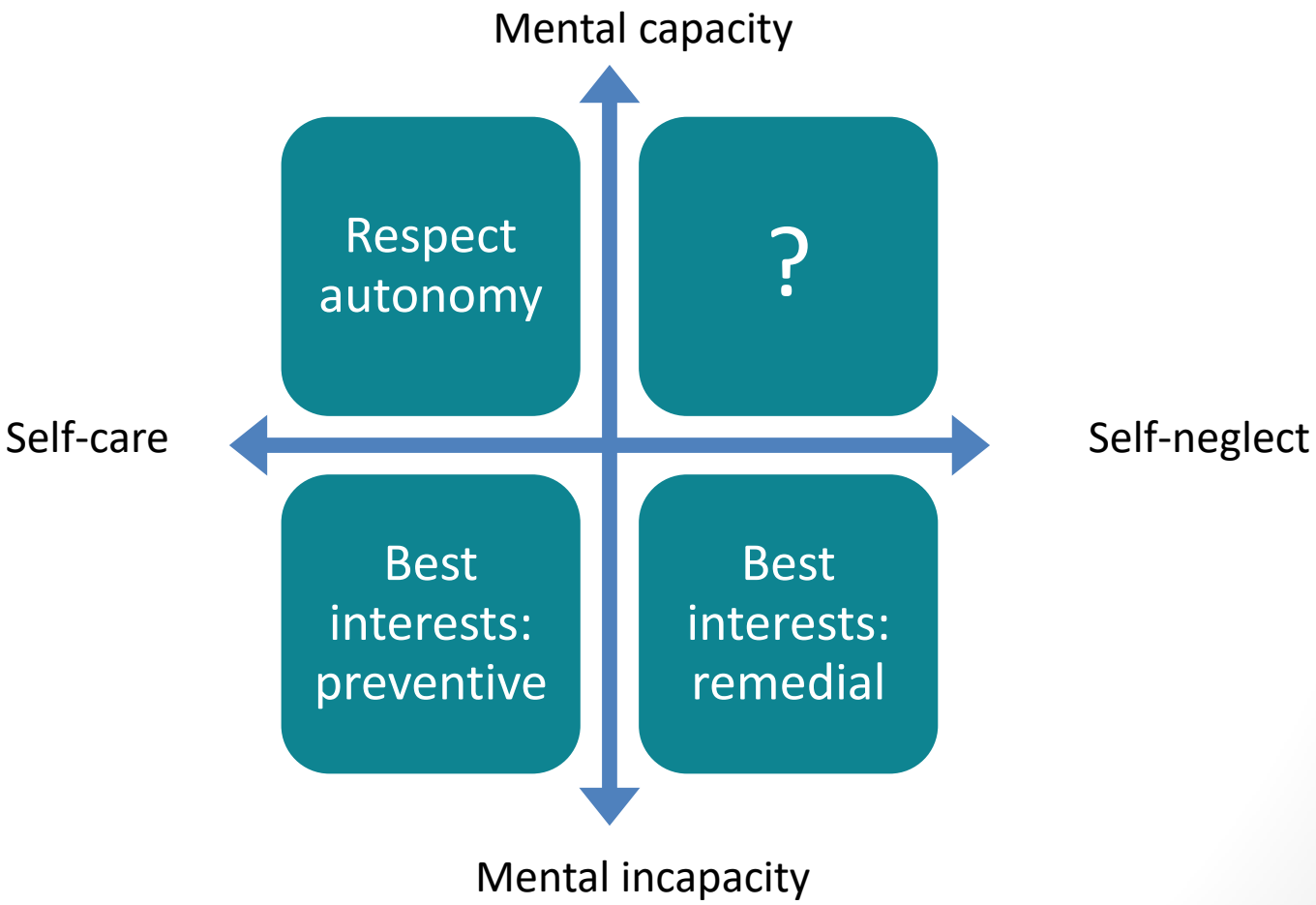
I want things that belonged to people so that they have a connection to me.

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.

Mental capacity: affects perception of risk and intervention focus



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:

"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."

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

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

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 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."

Challenging the dichotomy between autonomy and protection

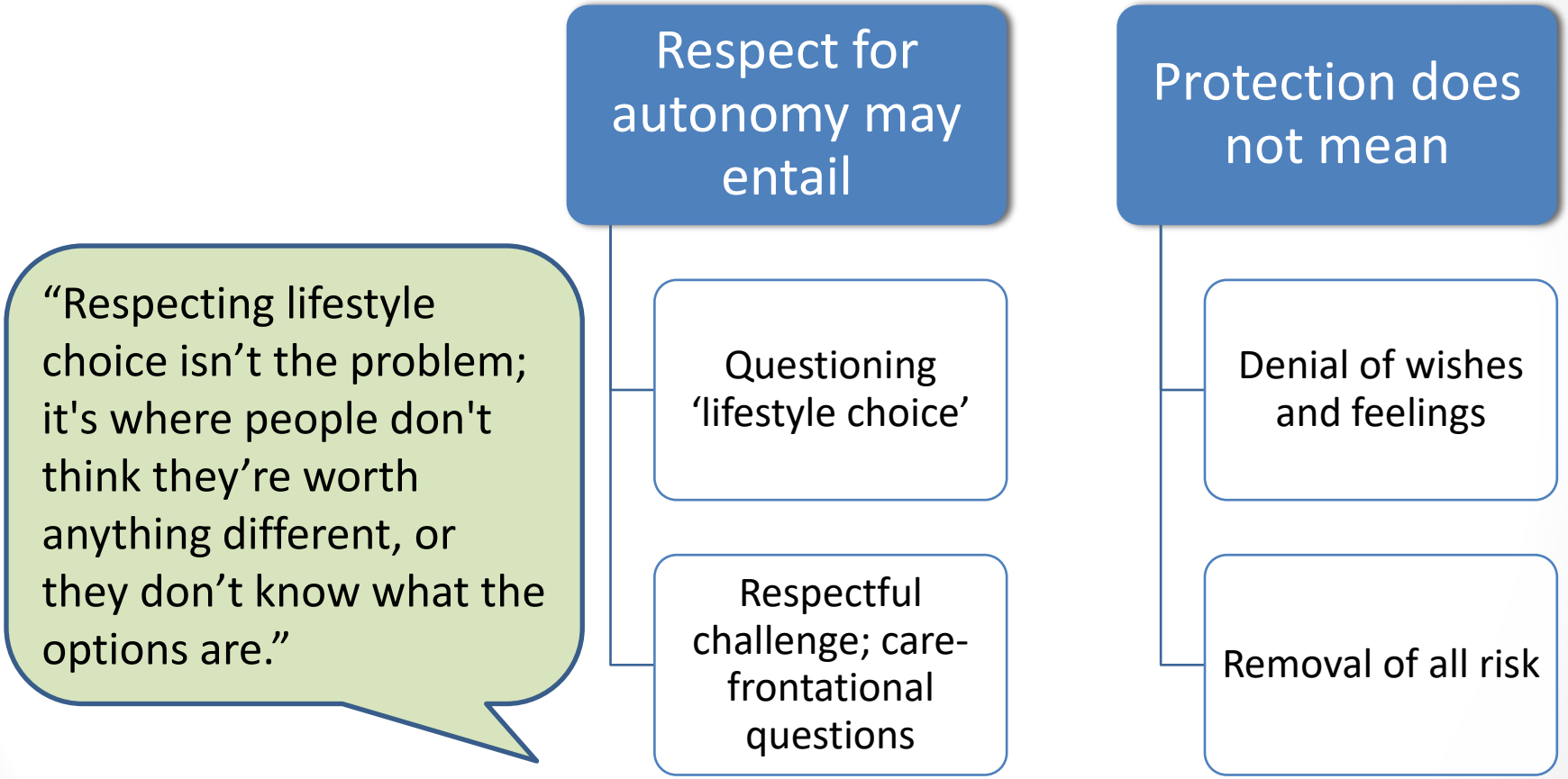
Is it really autonomy when …

- 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 circumstances
- Your mental ill-health makes self-motivation difficult
- You have impairment of executive 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

A more nuanced approach

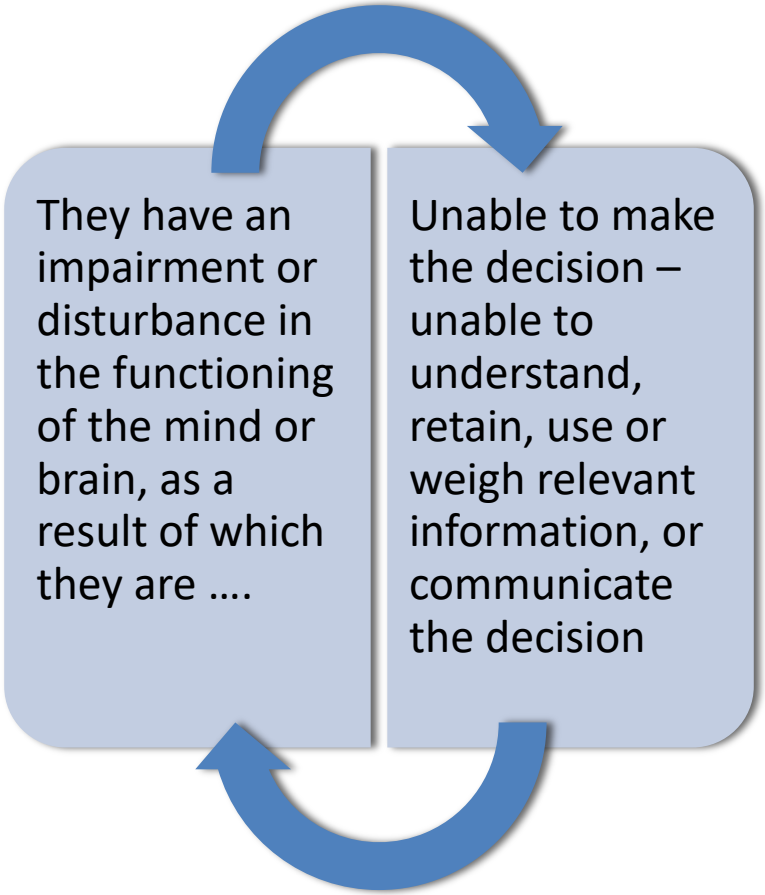


Autonomy does not mean abandonment

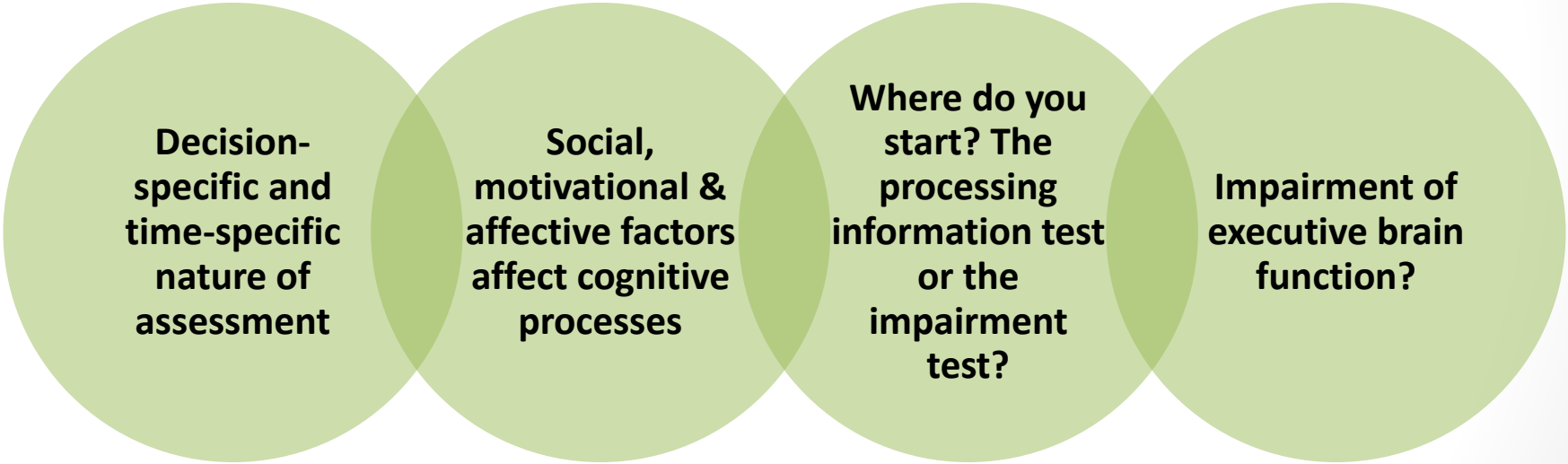
Protection entails proportionate risk reduction

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

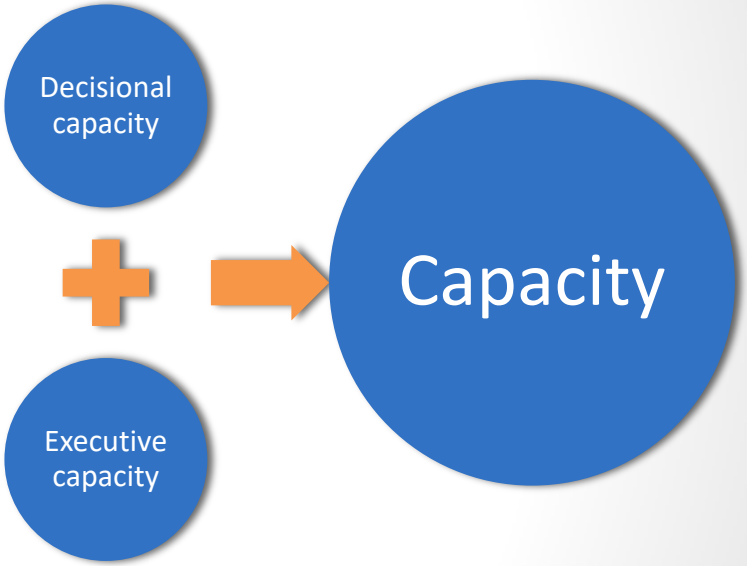


Mental capacity in the self-neglect literature

- Involves

  Not only
  - the ability to understand and reason through the elements of a decision in the abstract

  But also
  - the ability to realise when a decision needs to be put into practice and execute it at the appropriate moment – the 'knowing/doing association'
- 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, enacting a decision at the appropriate point



A more nuanced understanding

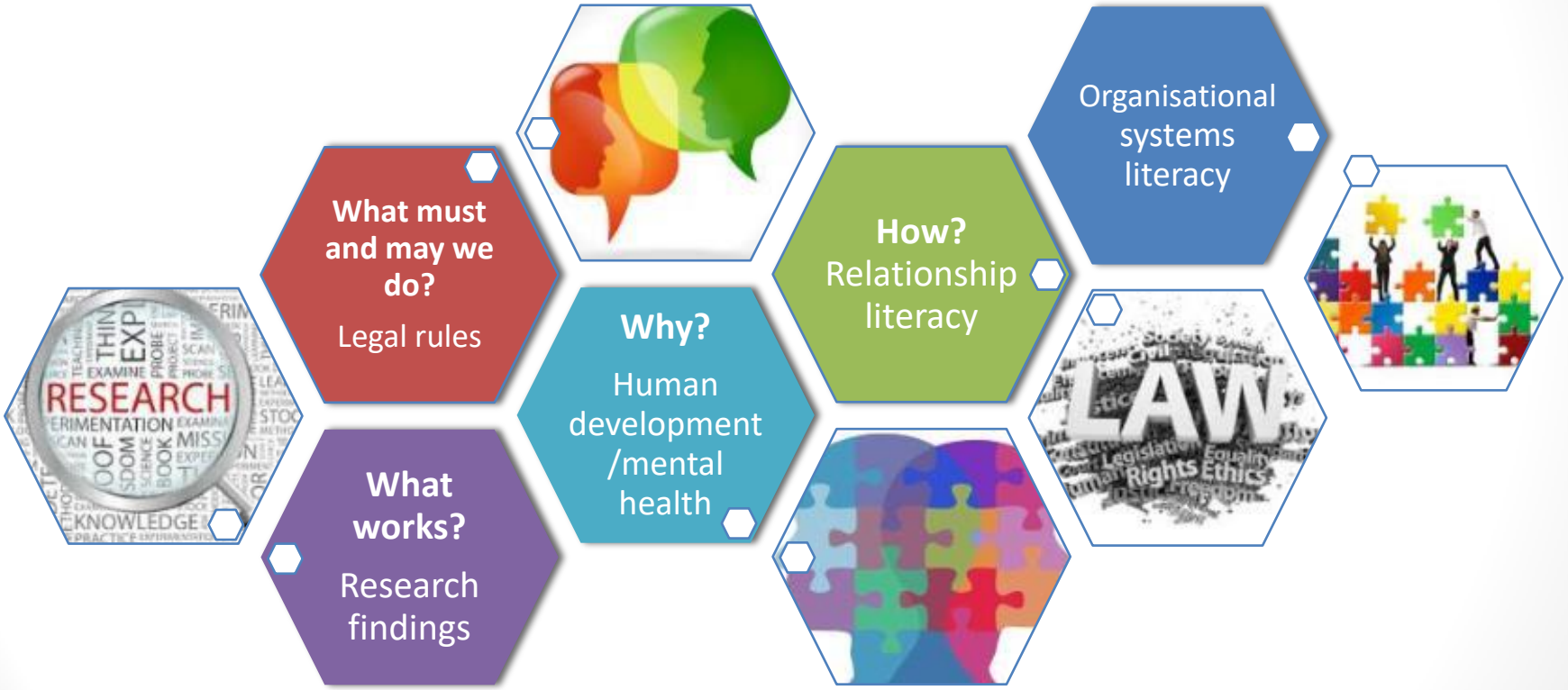
Decision-making difficulties may be masked by

- Articulate use of language; verbal reasoning skills; high perceived self-efficacy
- Decision-making "good in theory, poor in practice"

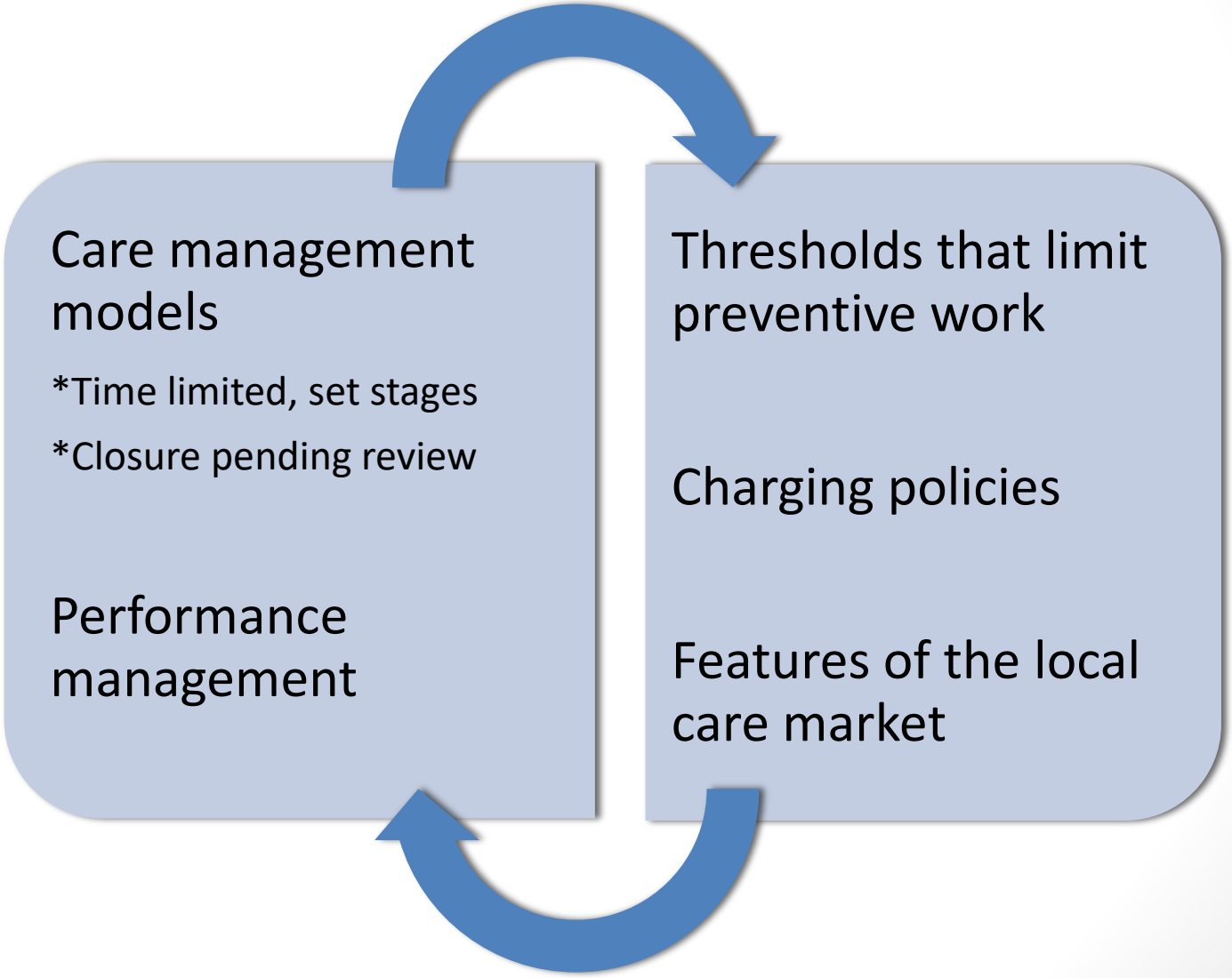
Capacity assessment to take account of

- Articulate and demonstrate models; the person in context; real world behaviour
- *GW v A Local Authority [2014]* EWCOP20

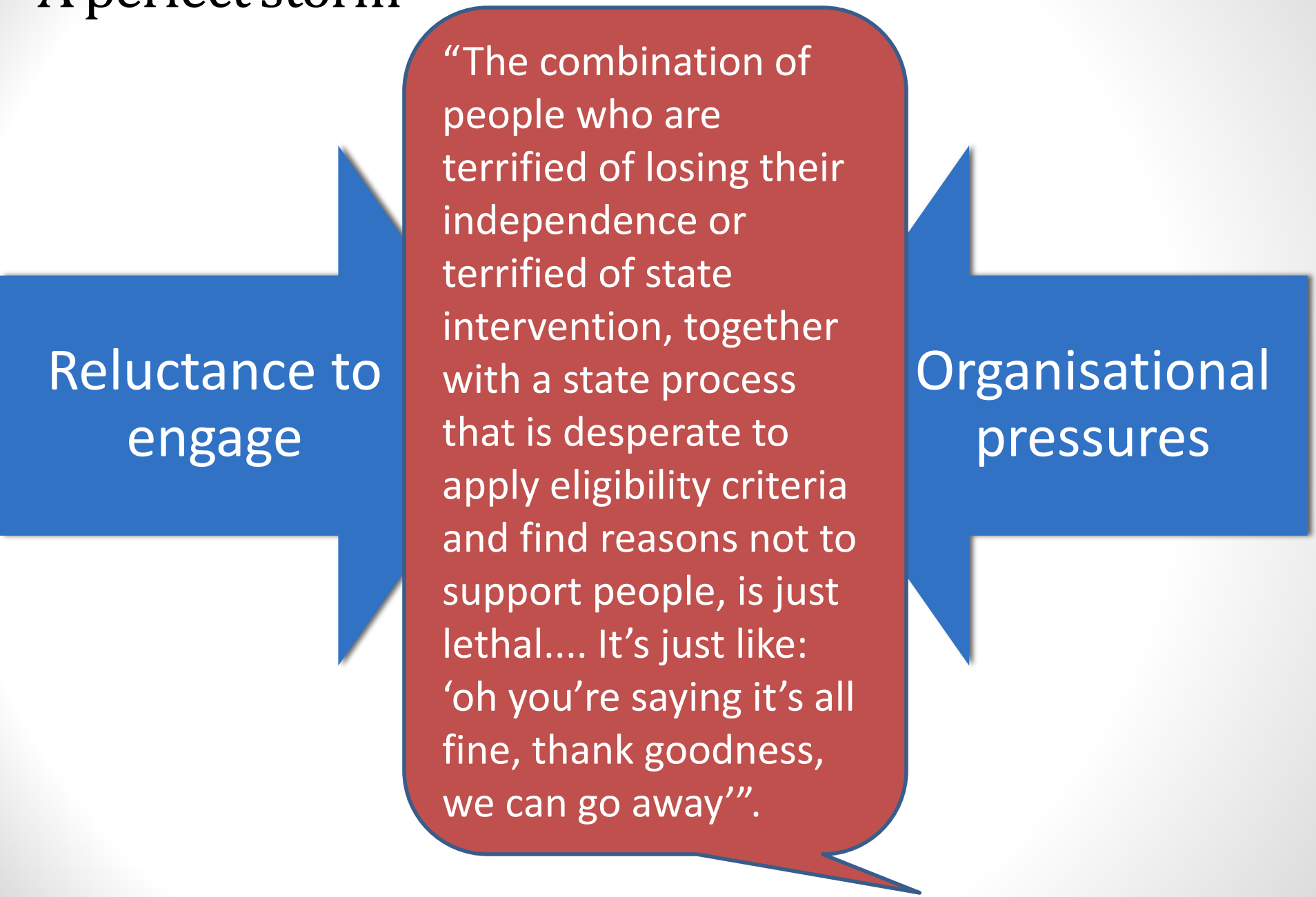
Effective self-neglect work: interlocking literacies



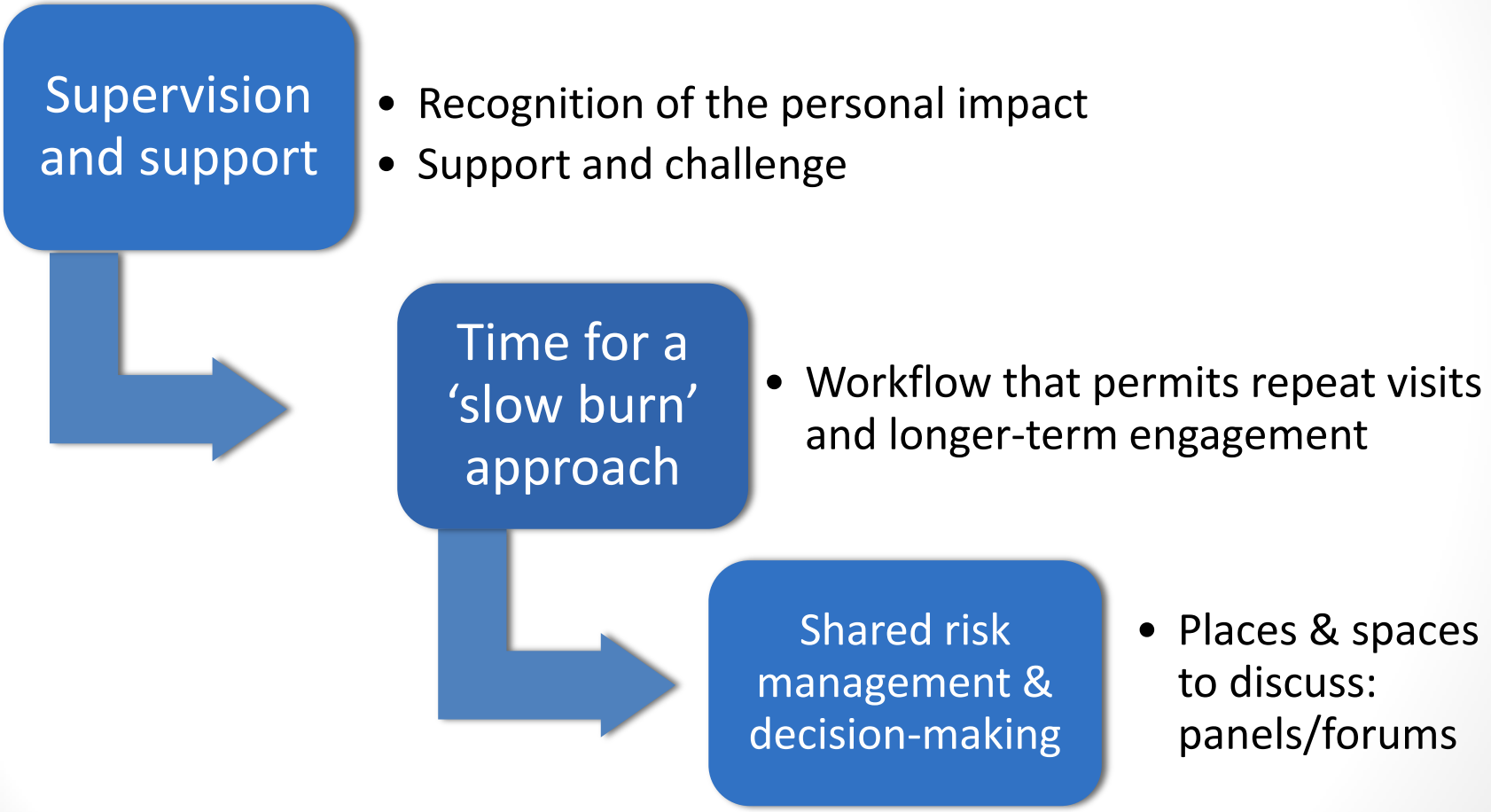
The organisational context



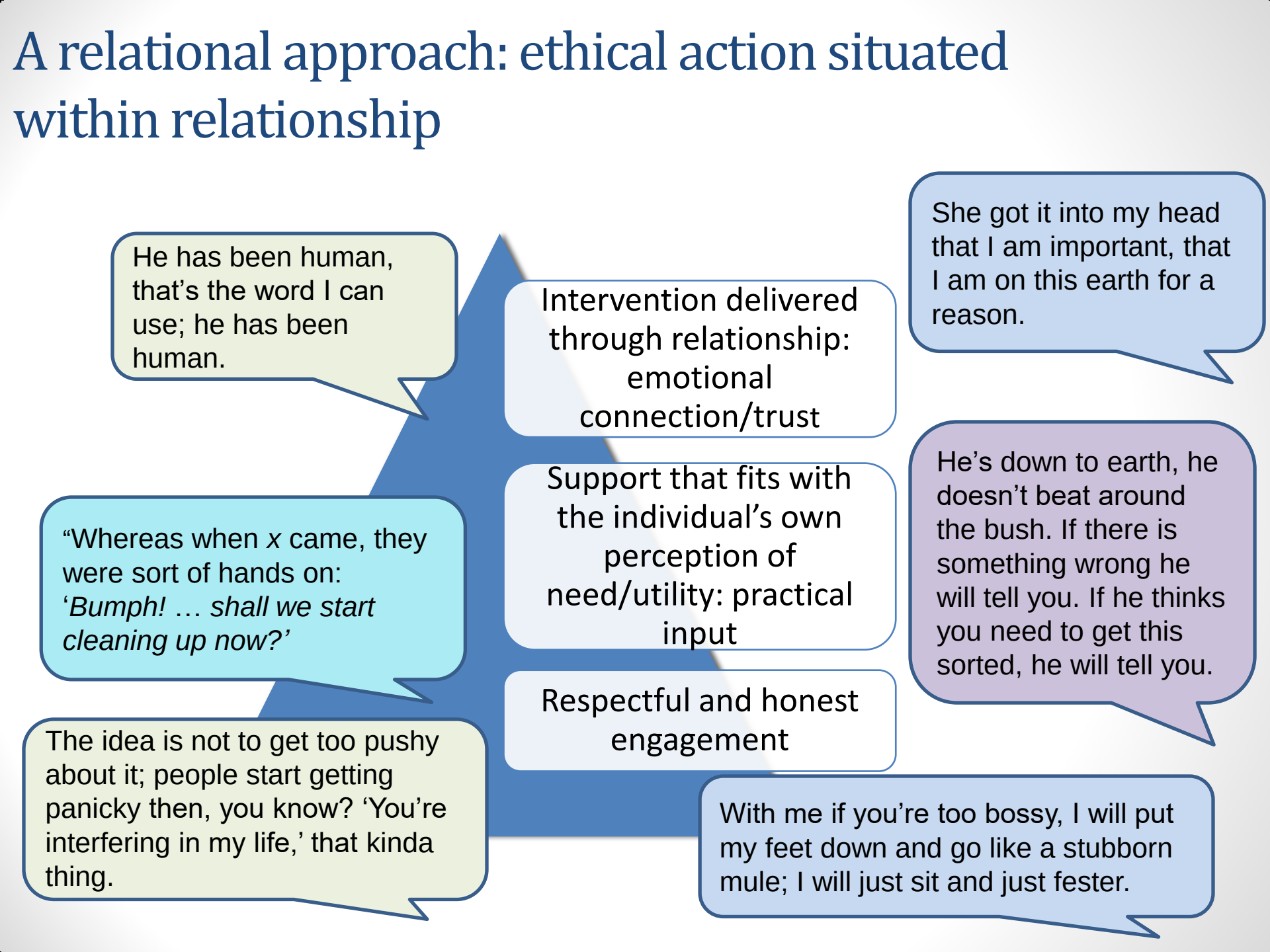
A perfect storm



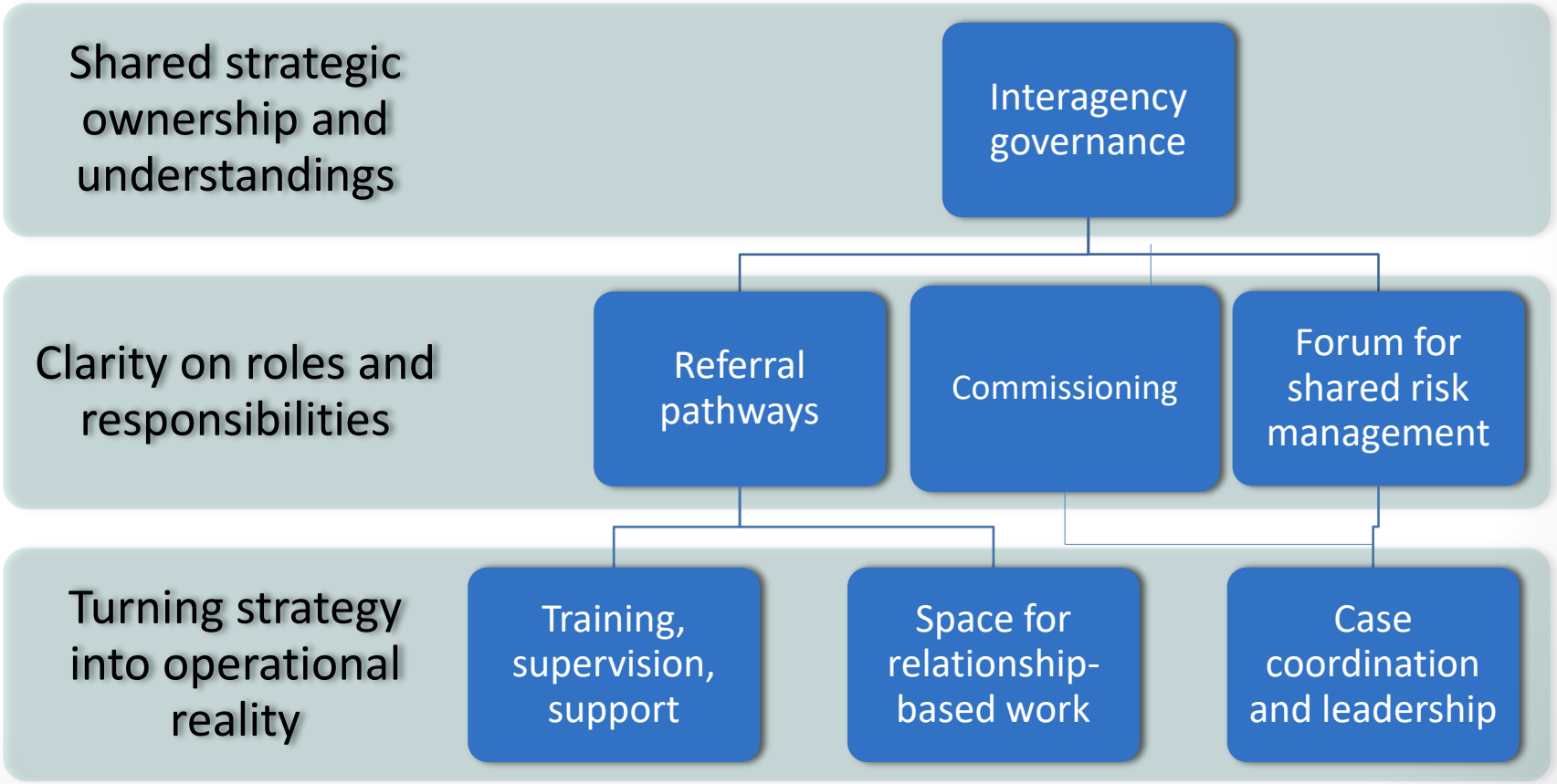
Creating a supportive organisational environment



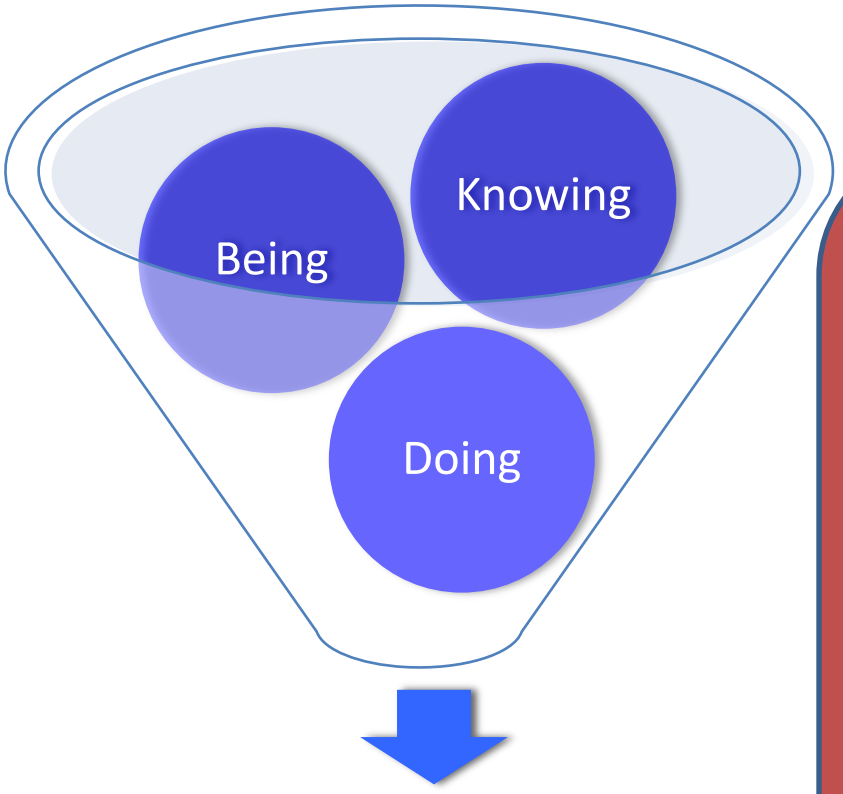
A relational approach: ethical action situated within relationship



What makes for robust interagency working?



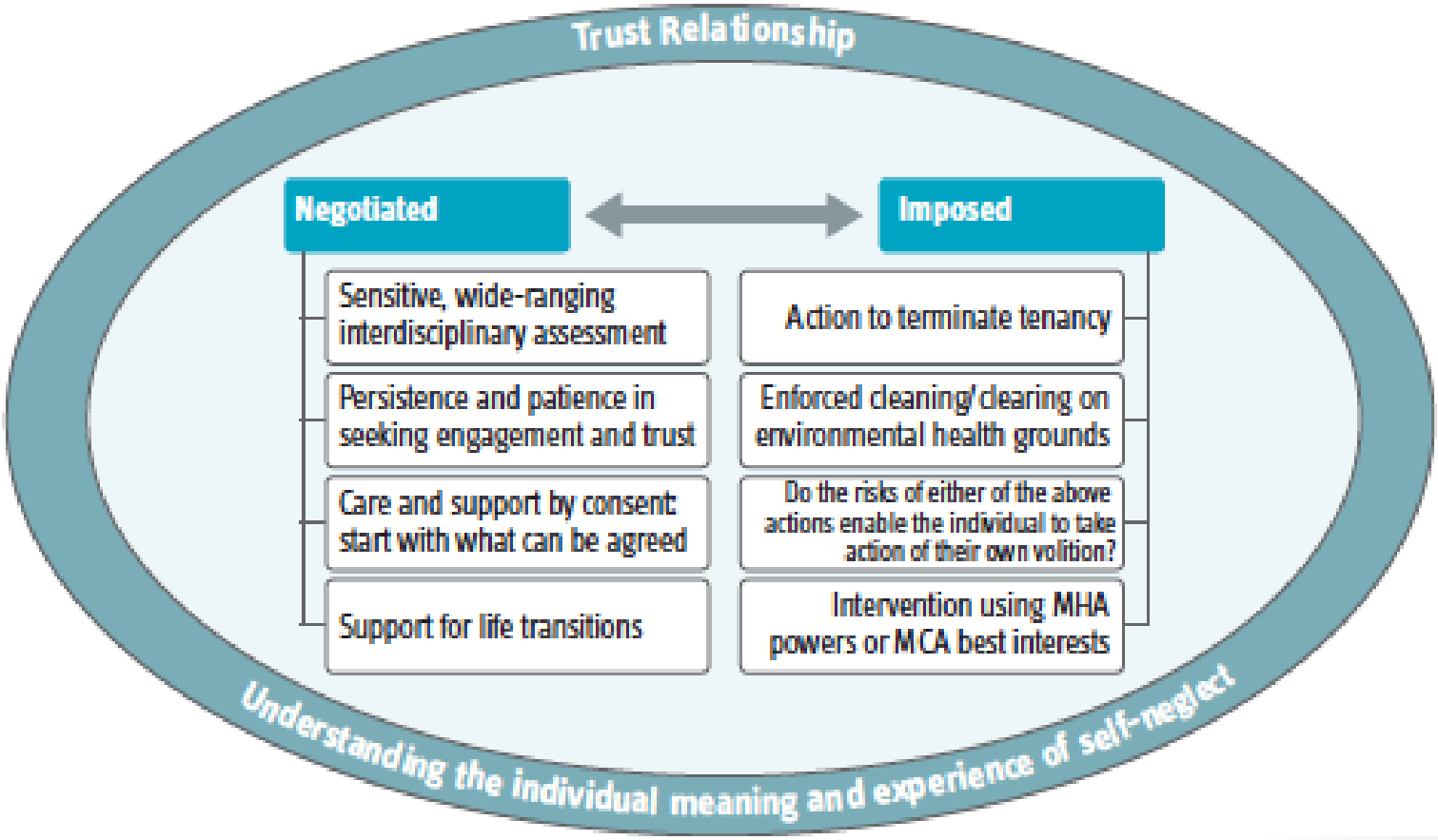
Knowing, Doing and Being



Relationship

I think the only thing that will help that is concern, another human being connecting with you that's got a little bit more strength than you, that pulls you through those forms of depression, that's what keeps you alive.

Integrating negotiated and imposed interventions



Effective practice requires whole system alignment

What next for you? When you leave the workshop …

- Reflection: what have been the key points from today?
- Read the SAB's self-neglect and hoarding strategy document
- What needs to come next? Identify how you will develop your own practice.

Action steps could be related to

- Strategy and governance
- Interagency communication and decision-making
- Work patterns in your team
- Your own knowledge or skills in 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/ Also available are 3 shorter summary reports: for managers, for practitioners and for a general audience.

Journal articles

- **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., 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).
- **Orr, D., Preston-Shoot, M. and Braye, S. (2017) '**Meaning in hoarding: perspectives of people who hoard on clutter, culture, and agency', Anthropology & Medicine, http://dx.doi.org/10.1080/13648470.2017.1391171
- **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.
- **Preston-Shoot, M. (2018)** 'Learning from Safeguarding Adult Reviews on self-neglect: addressing the challenge of change.' *Journal of Adult Protection*, 20 (2), 78-92.

Additional resources

- Self neglect
  - Braye S, Orr D and Preston-Shoot M (2016) *Working with People Who Self-neglect: A Practice Tool (2nd edition)*. Dartington: Research in Practice for Adults.
  - Braye S and Preston-Shoot M (2016) *Legal Literacy in Adult Social Care*. Strategic Briefing. Dartington: Research in Practice for Adults.
  - Braye, S., Orr, D. and Preston-Shoot, M. (2017) 'Self-neglect and hoarding,' in Cooper, A. and White, E. (eds) *Safeguarding Adults under the Care Act 2014: Understanding Good Practice*. London: Jessica Kingsley. (pp 180-198)
  - Orr, D., Braye, S. and Preston-Shoot, M. (2017) *Working With People Who Hoard: A Frontline Briefing.* Dartington: Research in Practice for Adults.
- Legal literacy
  - Braye S and Preston-Shoot M (2016) *Legal Literacy: A Practice Tool*. Dartington: Research in Practice for Adults.
  - Braye, S. and Preston-Shoot, M. (2016) *Practising Social Work Law, 4th edition*. Basingstoke: Palgrave.
- Executive capacity
  - Hildebrand C, Taylor M and Bradway C (2014) 'Elder self-neglect: the failure of coping because of cognitive and functional impairments'. *Journal of the American Association of Nurse Practitioners* 26 452-462.
  - Naik A, Lai J, Kunik M and Dyer C (2008) 'Assessing capacity in suspected cases of self-neglect'. *Geriatrics* 63 (2) 24–31.

Derby and Derbyshire CCG Podcasts

Suzy Braye, Emerita Professor of Social Work at the University of Sussex and Michael Preston-Shoot, Emeritus Professor of Social Work at the University of Bedfordshire talk with Ed Ronanyne, Safeguarding Adults Manager at NHS Derby and Derbyshire Clinical Commissioning Groups, about their research findings in relation to self-neglect and safeguarding.

Access here

Key contacts

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