

# Effective work with adults who self-neglect: the evidence-base from research and reviews

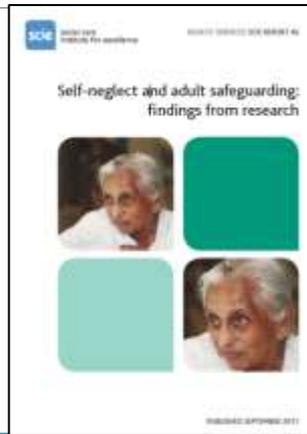
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MICHAEL PRESTON-SHOOT (RESEARCHER WITH SUZY BRAYE AND DAVID ORR)

BEXLEY

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# Self-neglect: the research evidence



**SAB  
governance**

**Scoping the  
evidence on  
self-neglect**

**Workforce  
development  
needs  
2013**

**Review of  
serious case  
reviews  
2014-17**

**Exploring  
self-neglect  
practice  
2013-14**

# What do we mean by self-neglect?

## NEGLECT OF SELF-CARE

- Personal hygiene
- Nutrition/hydration
- Health

## NEGLECT OF THE DOMESTIC ENVIRONMENT

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

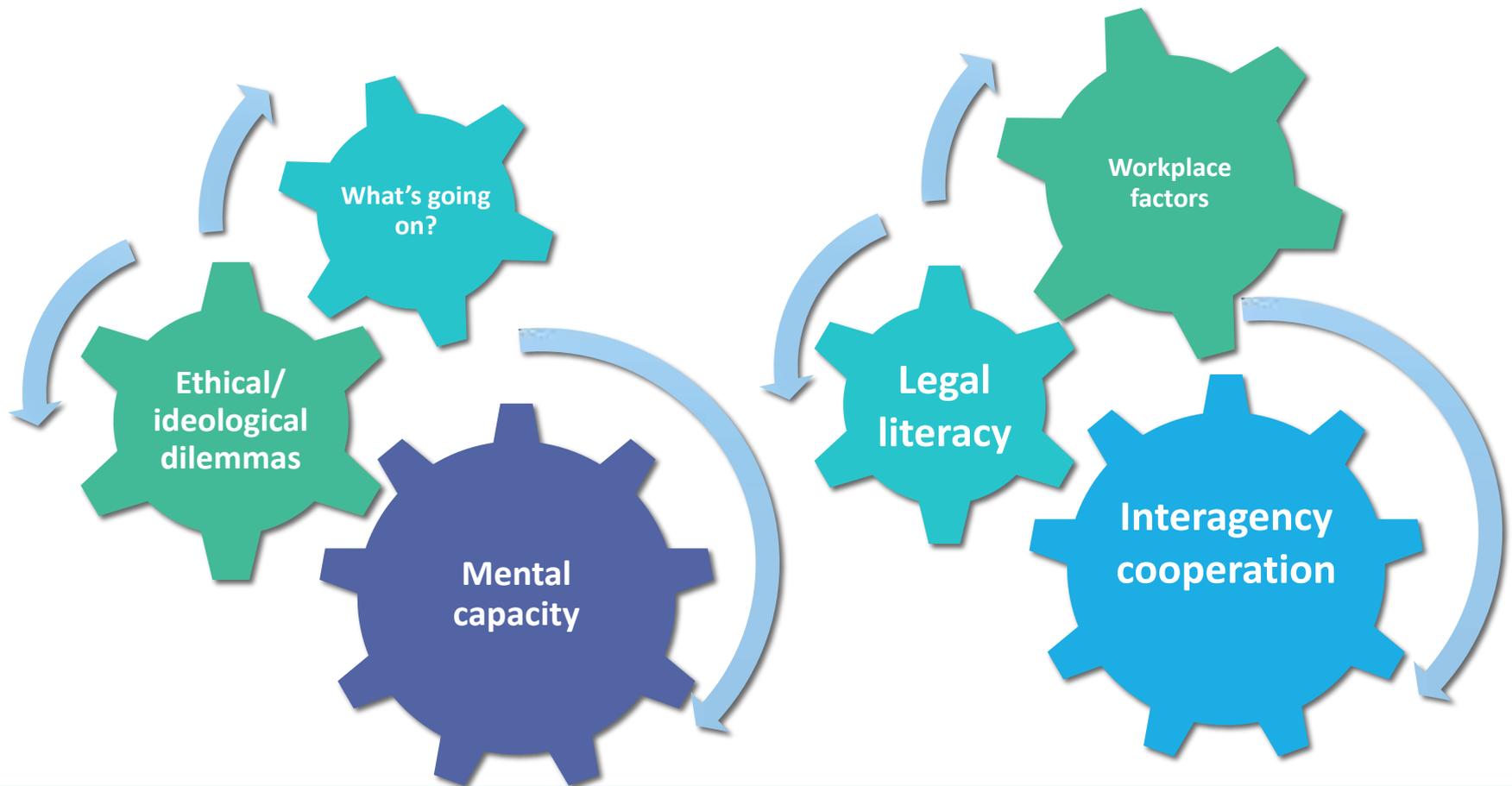
To such an extent as to endanger health, safety and/or wellbeing

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 2016)

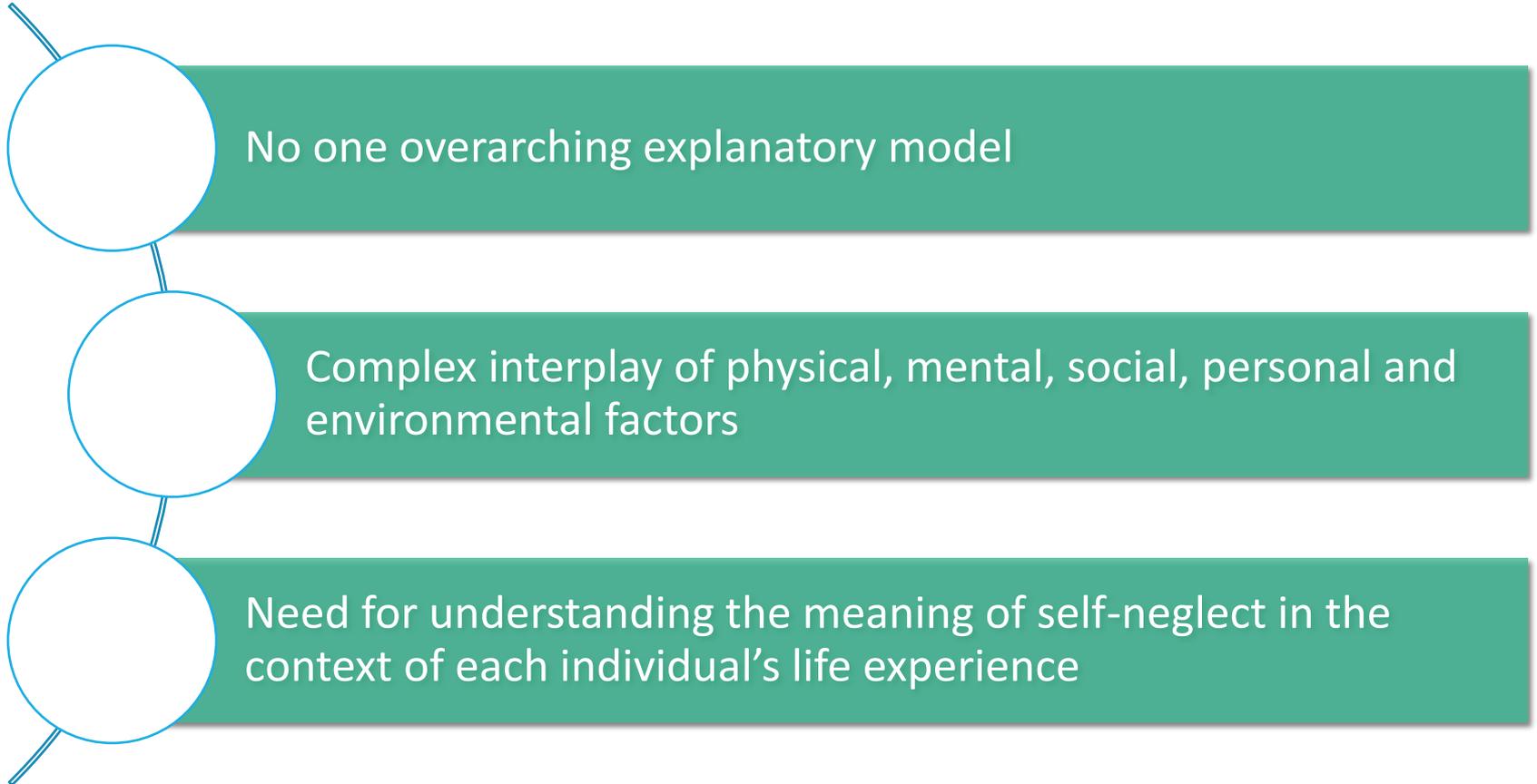
# The key challenges of self-neglect: how can the research help?

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# 1. What's going on?

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# Understanding lived experience: neglect of self-care

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

**Negative self-image:**  
demotivation

**Different standards:** indifference to social appearance

**Inability to self-care:**

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

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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.

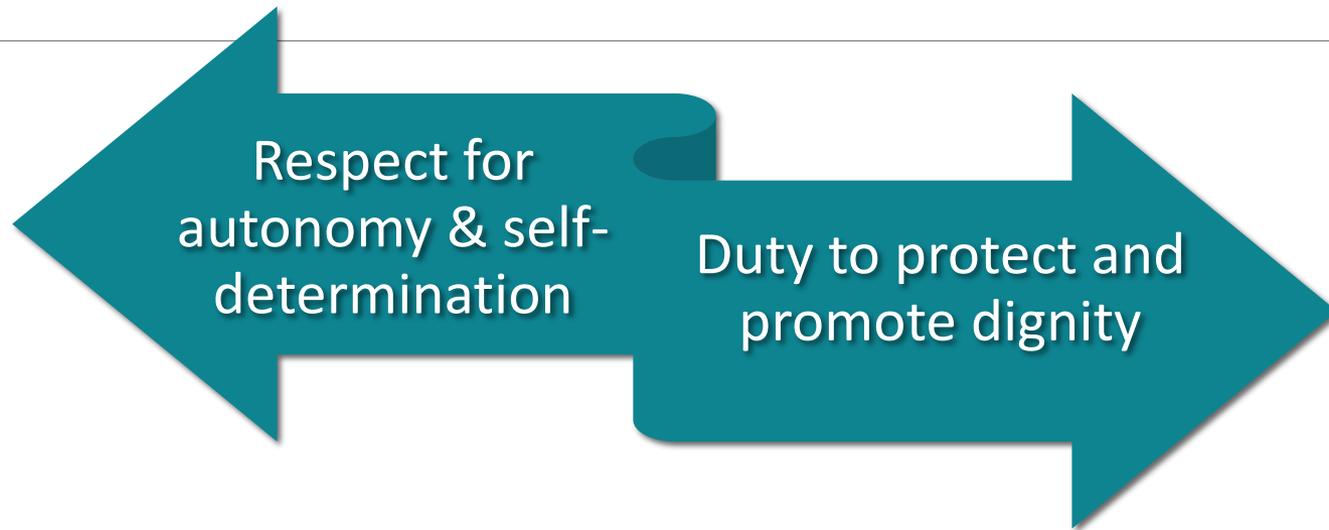
**Influence of the past:** childhood, loss

**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 arise from competing imperatives



- Professional codes of ethics
- Human rights principles
- Legislation (MCA)
- Limitations to state power
- Policy context of 'personalisation' and making safeguarding personal

- The duty to protect from foreseeable harm
- Human dignity compromised
- Human rights principles
- Risk to others

# The core dilemma

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“The fact is that all life involves risk, and the young, the elderly and the vulnerable are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and welfare can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person’s happiness. **What good it is making someone safer if it merely makes them miserable?**” MM (An Adult)[2007]

# Why 'choice' and 'control' are not synonymous in self-neglect

"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."

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

"I can't physically bend down and pick things up."

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

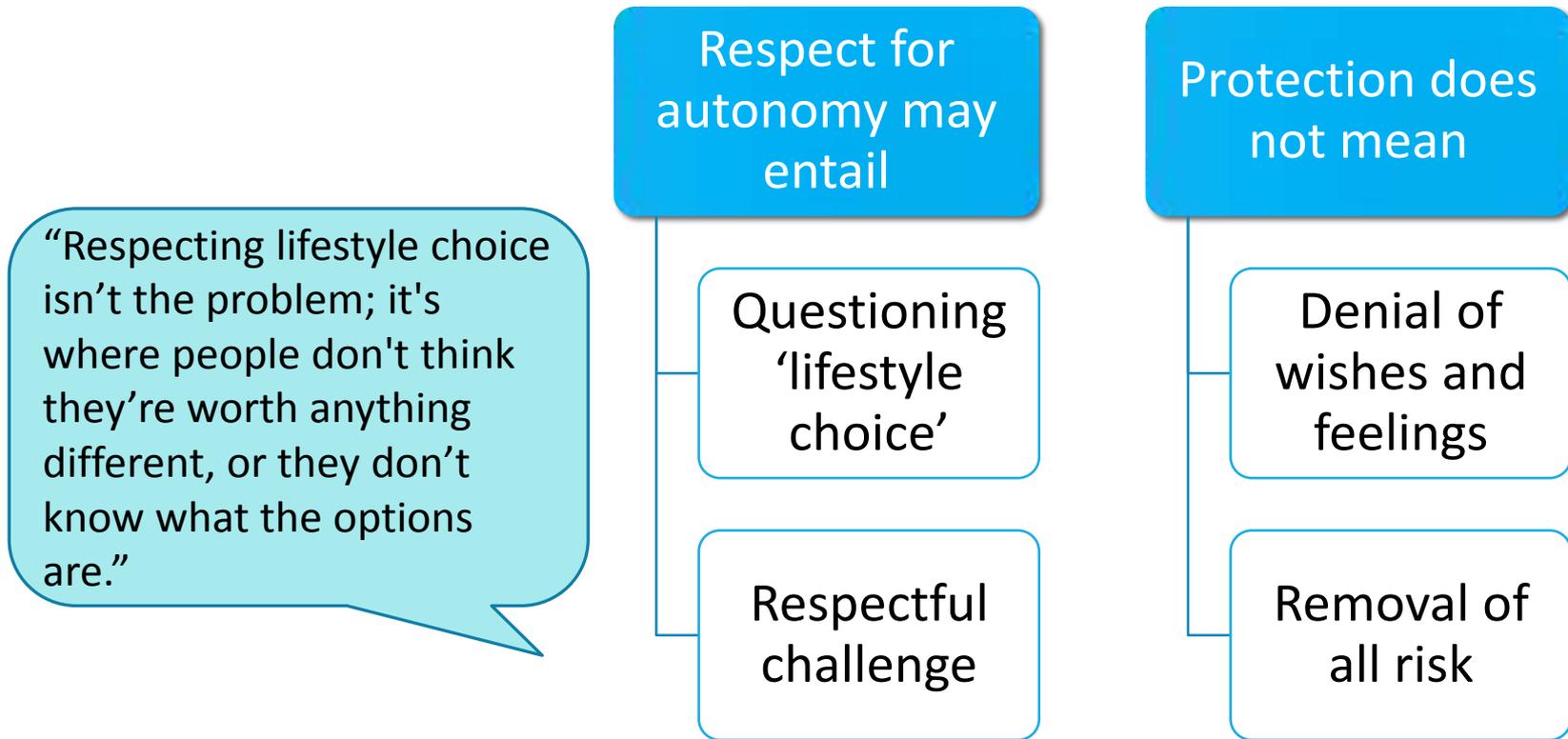
"I used to wake up in the morning and cry when I saw the sheer overwhelming state... My war experience in Eastern Europe was scary, but nothing compared to what I was experiencing here."

"I put everyone else first – and that's how the self-neglect started."

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

"I always neglected my own feelings, for instance, and I didn't address them ... I thought, 'no, no, my feelings don't come into it, she's more important.'"

# A more nuanced approach



Autonomy does not mean abandonment  
Protection entails proportionate risk reduction

# 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.

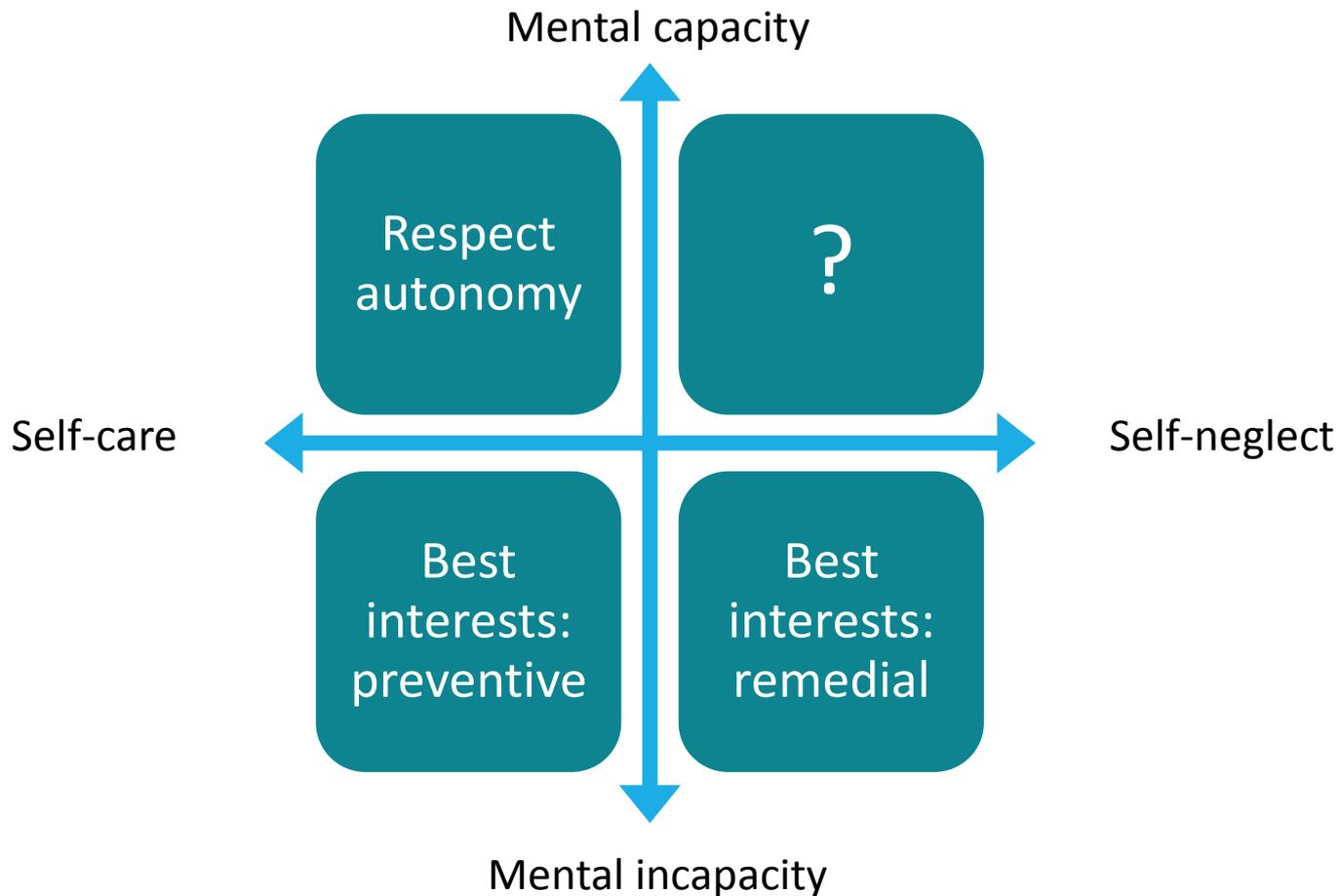
He has been human, that's the word I can use; he has been human.

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.

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

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# An enhanced understanding of mental capacity

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## Mental capacity involves

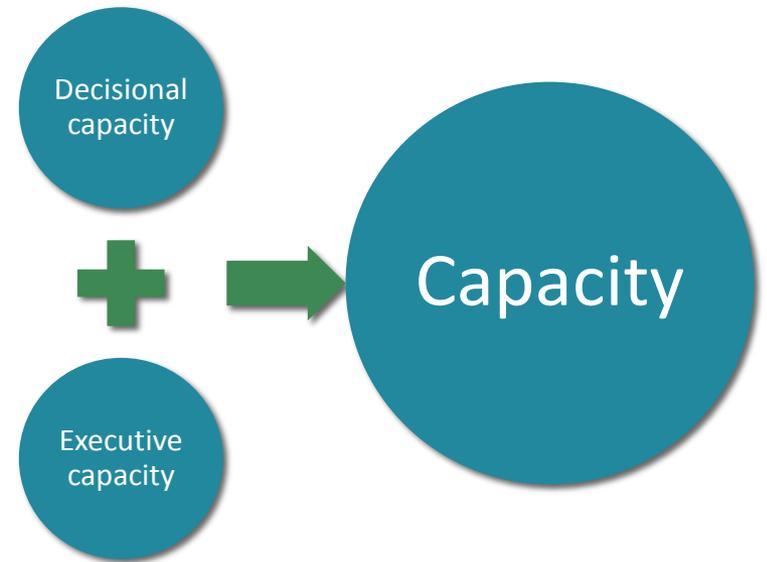
- The ability to understand and reason through a decision AND the ability to enact it in the moment

## Impaired *executive* function (frontal lobe impairment) affects

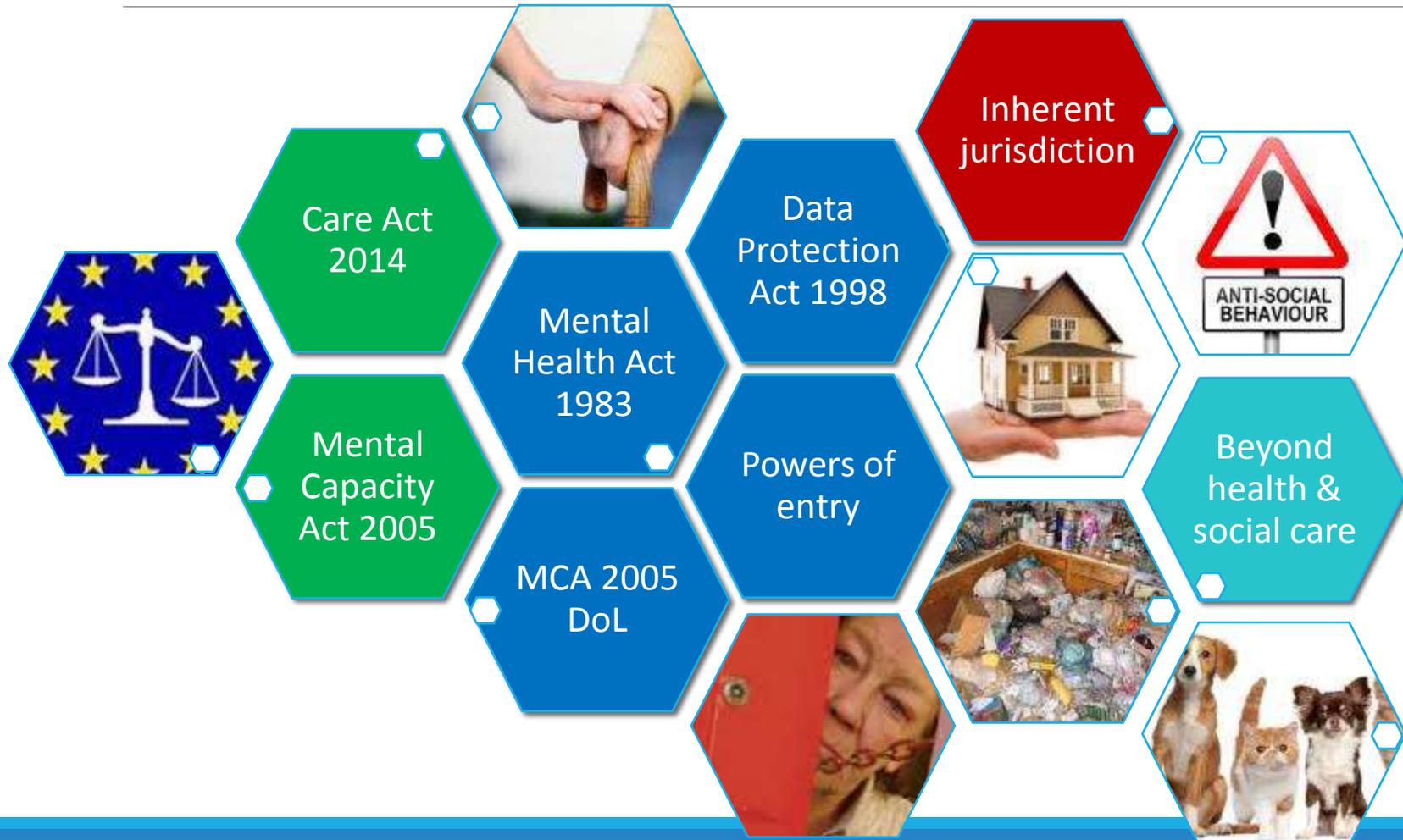
- Understanding, retaining, using and weighing relevant information in real-time problem-solving

## 'Articulate and demonstrate' models of assessment

- *GW v A Local Authority* [2014] EWCOP20



# 4. Legal literacy



# Practitioners and managers need to:

Have sound knowledge of the legal rules in adult social care:  
Powers and duties for intervention + Principles of administrative law

Be able to identify how real world circumstances fit those legal rules

Abide by a professional code of ethics

Ensure that human rights are observed

Be confident in identifying options, weighing their respective merits, and justifying the choices made

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The ability to connect relevant legal rules with the professional priorities and objectives of ethical practice

Sound knowledge of legal rules

Strong engagement with professional ethics

Principles of human rights, equality and social justice

Consideration of which agencies have duties and powers, and how they might be applied in any given situation

# Reflected in administrative law requirements on decision-making

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## Public authorities must act lawfully

- Not exceed their powers
- Respect human rights
- Promote equalities

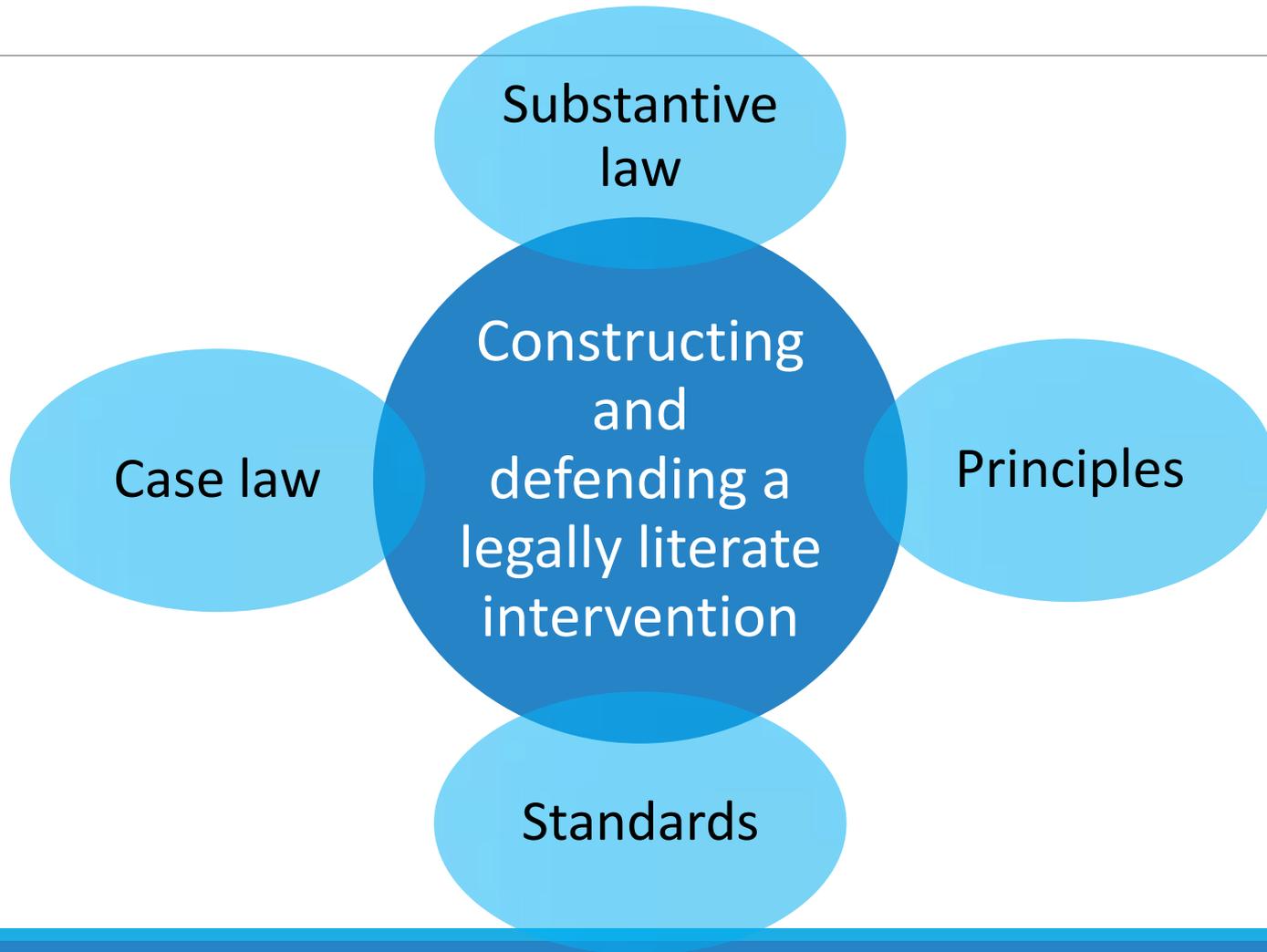
## They must observe standards in the use of statutory authority

- Make timely decisions
- Take account of all relevant considerations
- Avoid bias
- Share information and consult
- Provide a rationale for the exercise of discretion

## Professional codes of conduct include acting lawfully

# The legal literacy map

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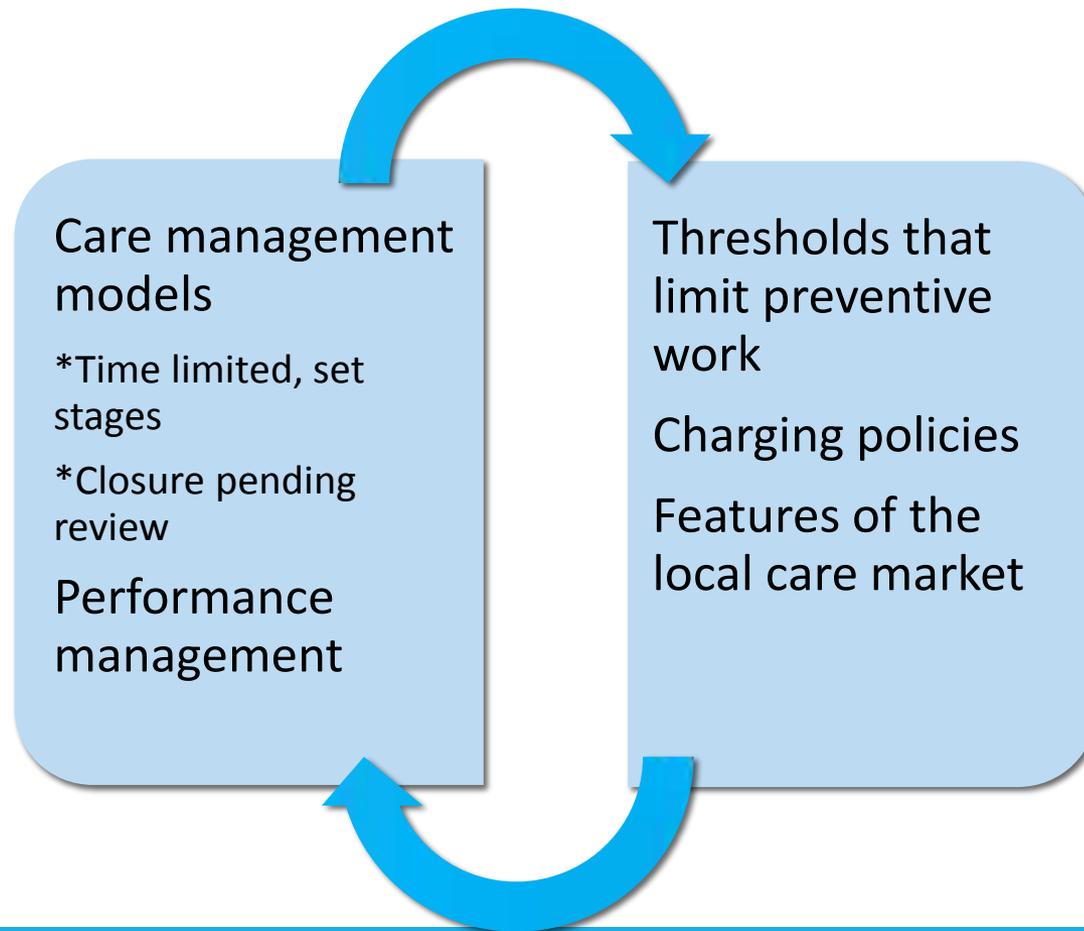
# And of course legal literacy has to connect with other literacies

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# 5. The organisational context

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# A perfect storm

Reluctance to  
engage

“The combination of people who are terrified of losing their independence or terrified of state intervention, together with a state process that is desperate to apply eligibility criteria and find reasons not to support people, is just lethal.... It’s just like: ‘oh you’re saying it’s all fine, thank goodness, we can go away’”.

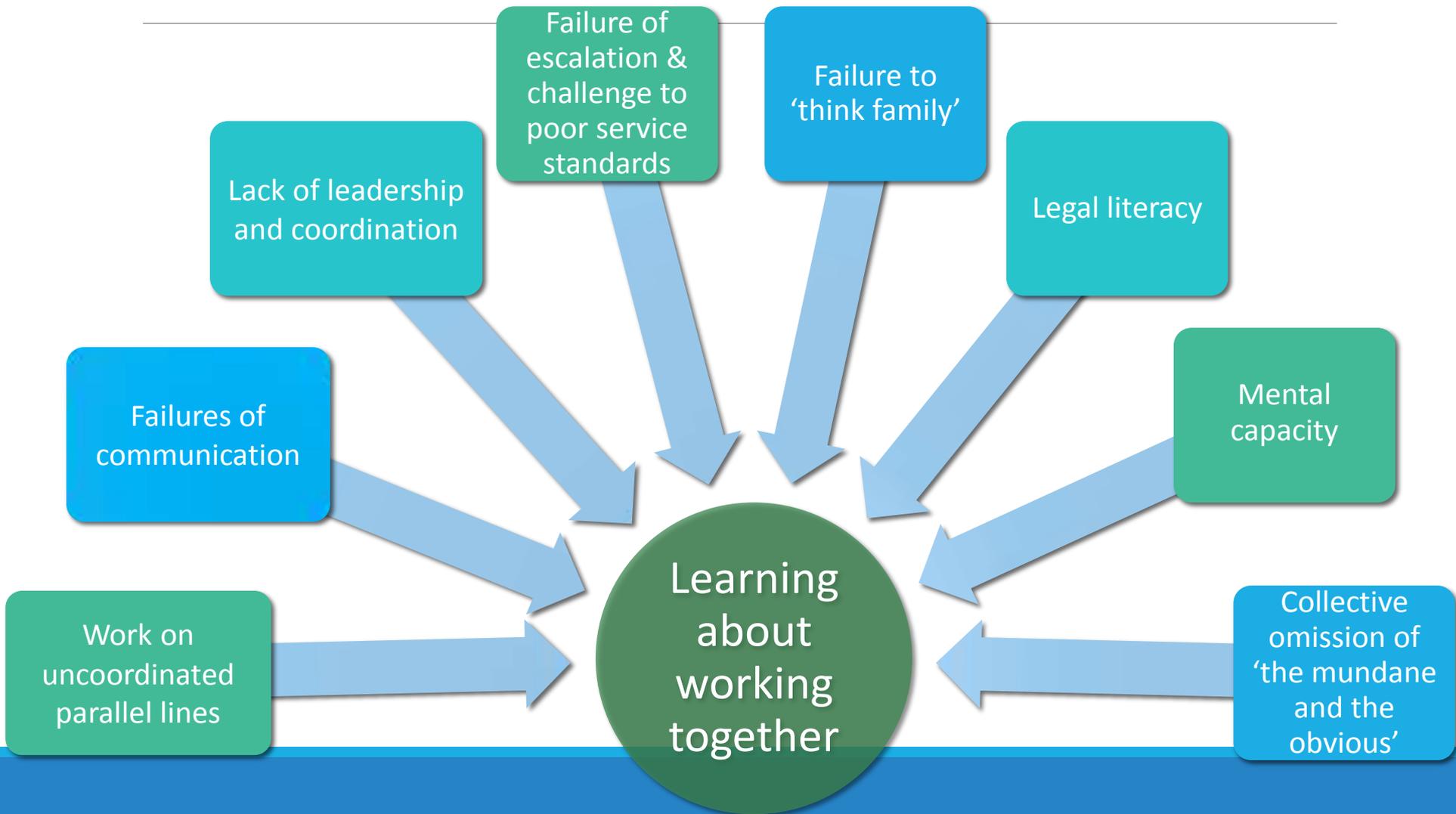
Organisational  
pressures

# Creating a supportive organisational environment

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# 6. Interagency cooperation: case review findings



# Example SCRs/SARs

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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

Anon - Barnsley (2010) – inflexible agency responses

Ms F - West Berkshire – complex family with co-dependent needs

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

# SARs focusing on primary care

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Mr V – Isle of Wight – discharge planning should involve all agencies and carers, capacity assessments to be recorded, use expertise of specific healthcare professionals

Mr W – Isle of Wight – 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

Ted – Gloucestershire – district nursing service in “turmoil”, understaffed and being reorganised, importance of full information in hospital discharge letters, review repeat prescriptions

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 and information-exchange, medication and repeat prescription reviews, training in mental capacity and mental health law (SARs by SABs in Surrey, Newcastle, Tower Hamlets, Kent and Medway, Slough, Mental Welfare Commission Scotland)

# Thematic Analysis – Adult

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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

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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

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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

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Conducting SCRs – involve family & carers, avoid delay

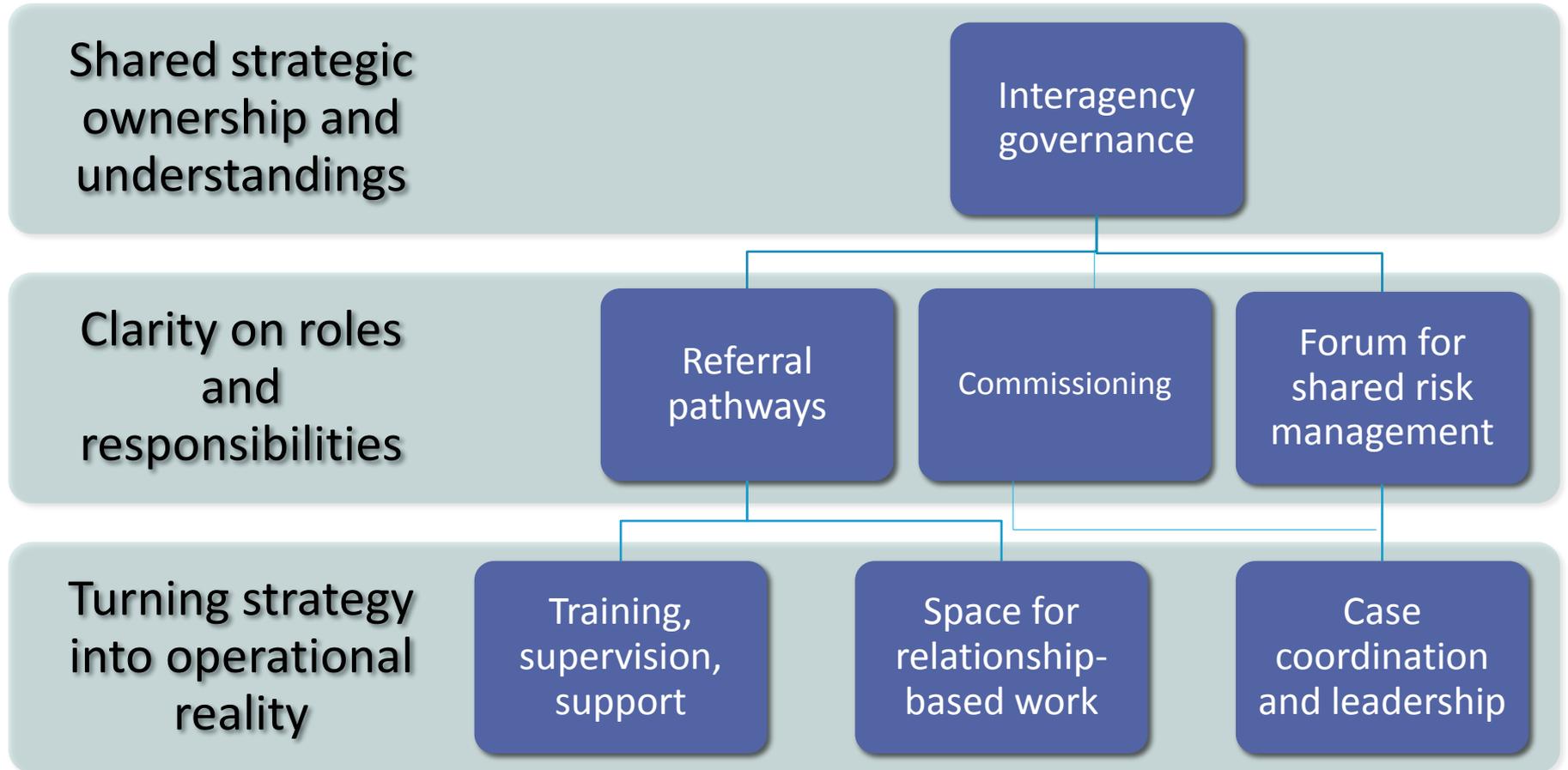
Monitoring & action planning – robust action plans and audits of impact needed

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 SCR – across LSABs, 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

# What makes for robust interagency working?



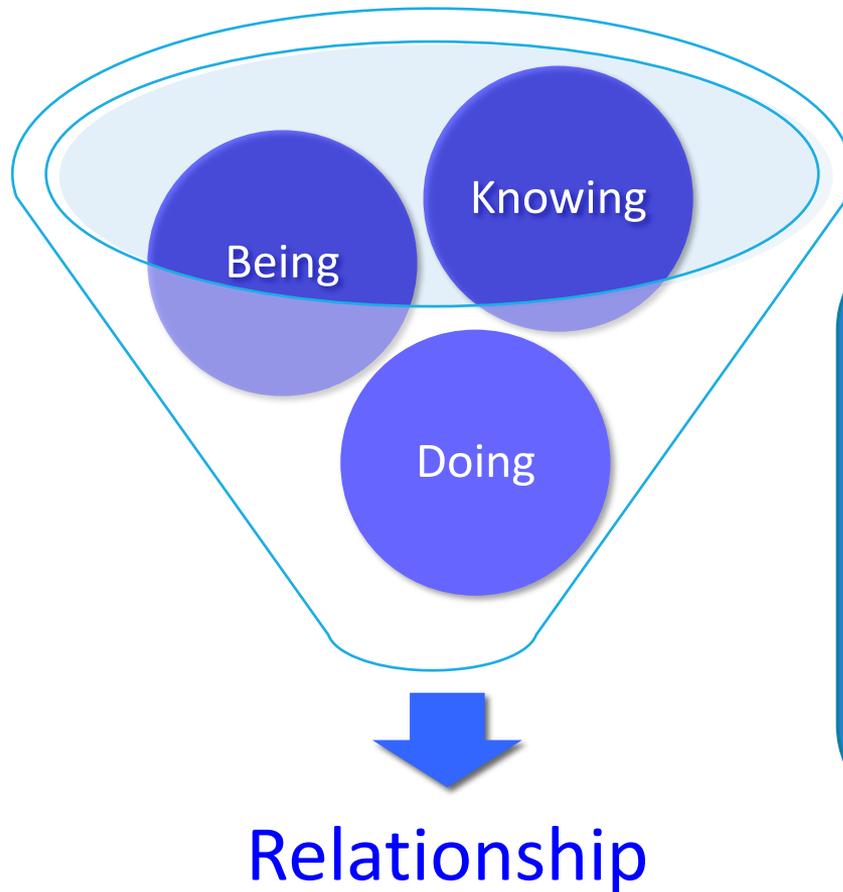
# Whole system alignment

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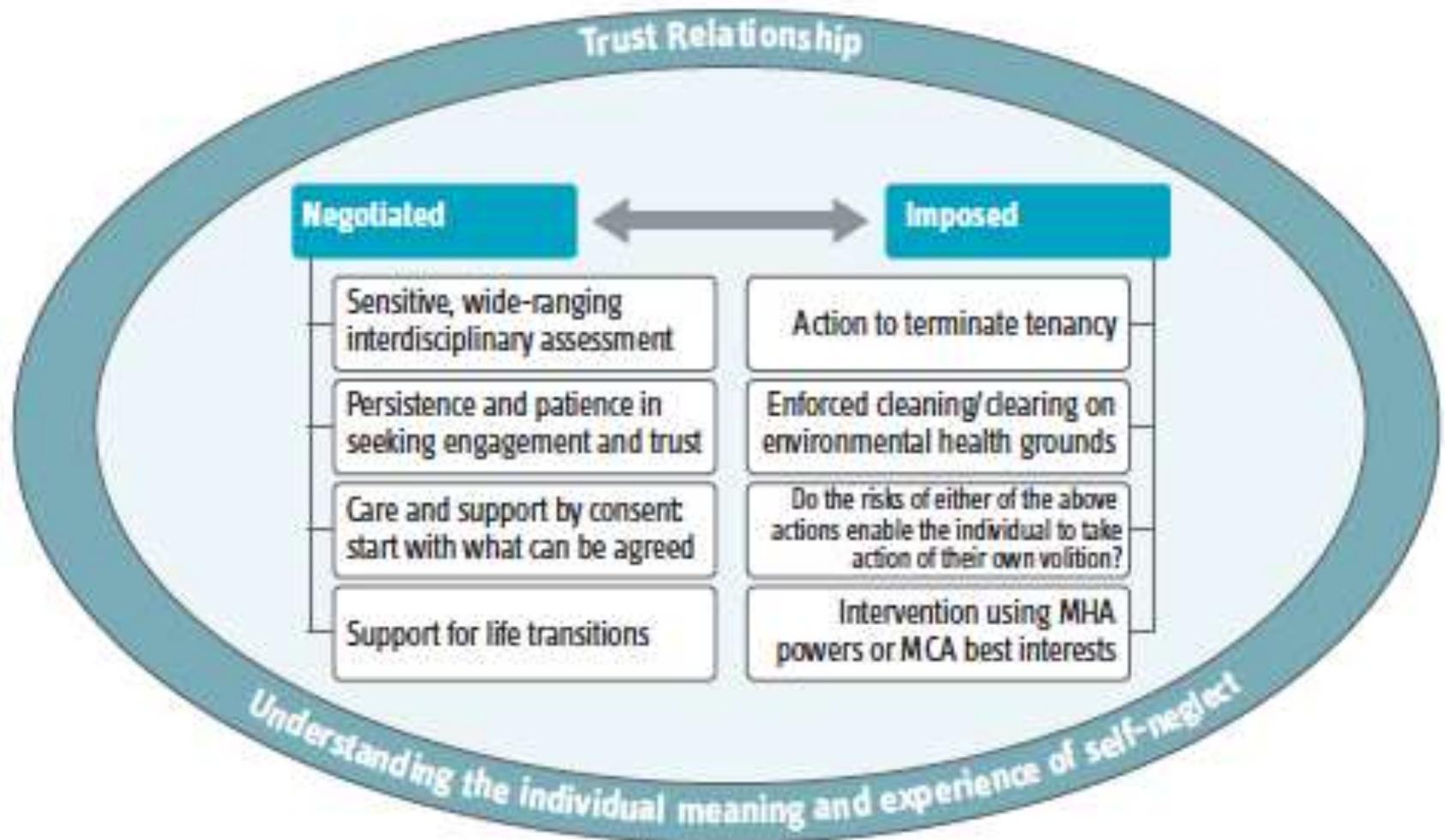
# Knowing, Doing and Being

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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



## 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

# Research reports

**Braye, S., Orr, D. and Preston-Shoot, M. (2011)** *Self-Neglect and Adult Safeguarding: Findings from Research*. London: SCIE.

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<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.

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**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).

**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.

# Key contacts

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Please contact us if you have any queries:



Professor Suzy Braye, [s.braye@sussex.ac.uk](mailto:s.braye@sussex.ac.uk)

David Orr, [d.orr@sussex.ac.uk](mailto:d.orr@sussex.ac.uk)

Professor Michael Preston-Shoot, [michael.preston-shoot@beds.ac.uk](mailto:michael.preston-shoot@beds.ac.uk)