

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

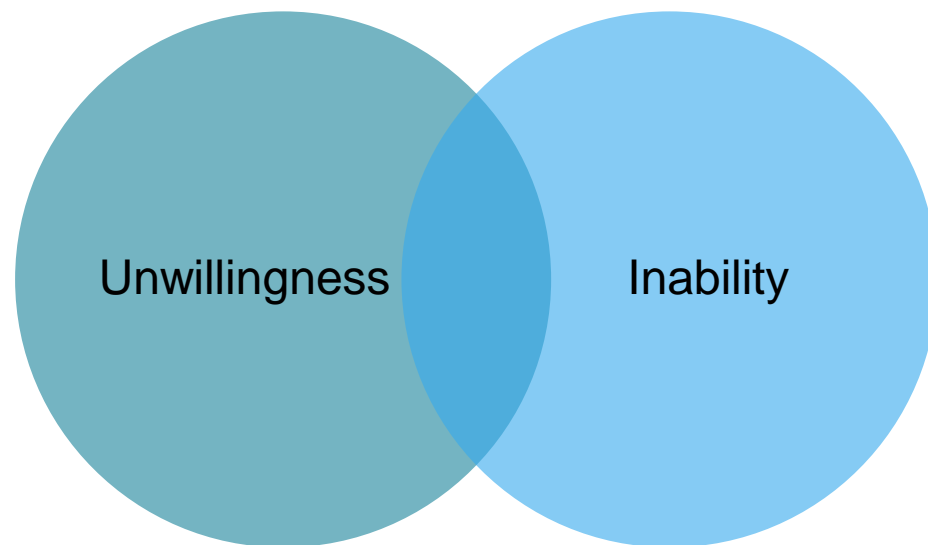
Definitions

“A wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding” (DH 2017)

Where individuals – wilfully or otherwise – do not attend to their hygiene, health or home surroundings to an extent that poses a danger to their health, safety or well-being

Definitional complexity

- A wide range of manifestations
- Arising from unwillingness or inability to care for oneself, or both
- Interlinked where apparent unwillingness arises from the care and support needs of the individual
- Requires assumptions of 'lifestyle choice' to be questioned



The changing legal and policy context for self-neglect work

No
Secrets



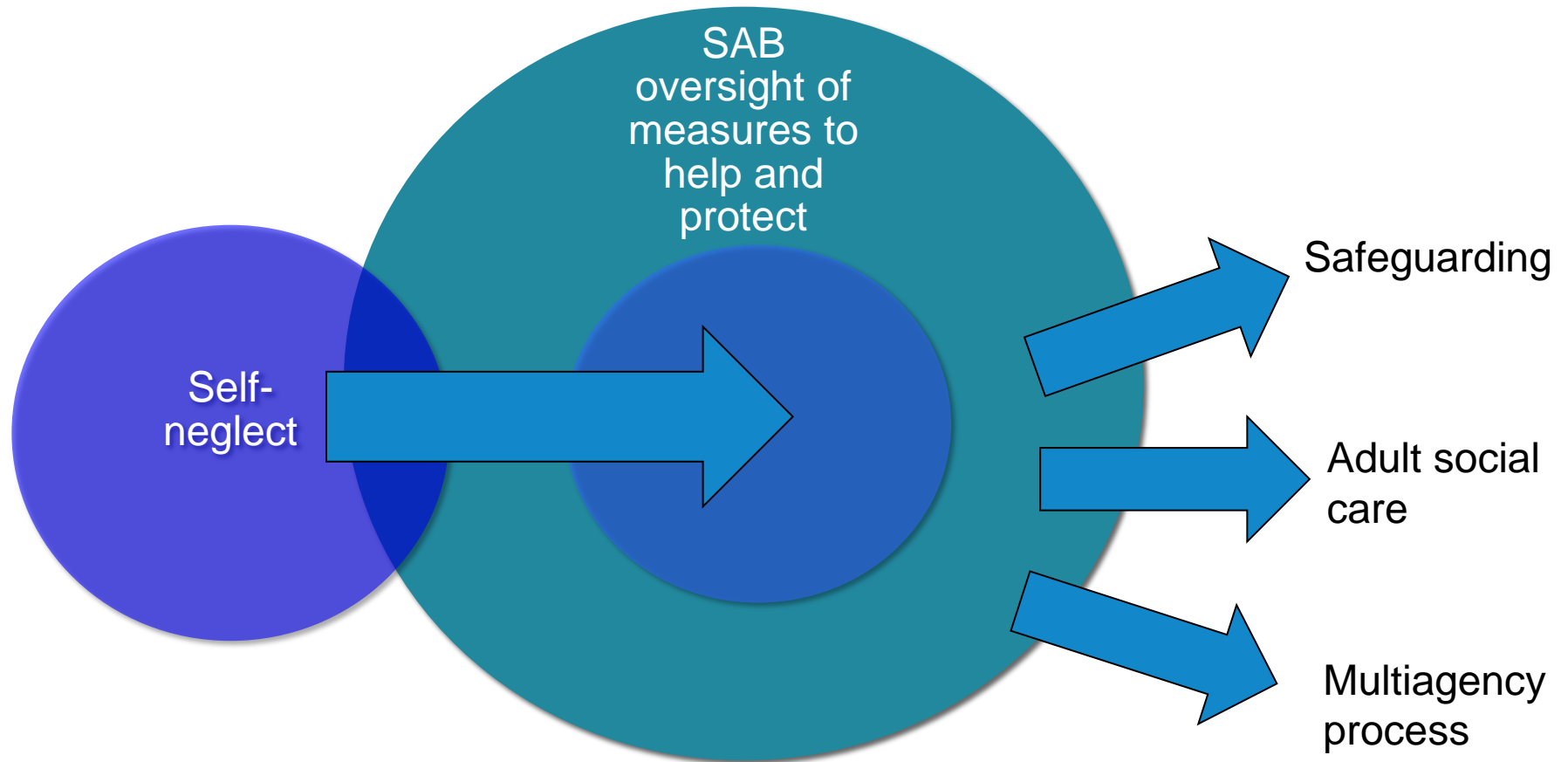
- Self-neglect outside 'vulnerable adult' definition – third party risk only
- Does not figure in eligibility criteria
- Rarely mentioned in SAB documentation
- No formalised interagency mechanisms
- Uncertainty about lead responsibility

Care
Act
2014



- Broader concept of 'adults in need of care and support'
- SAB statutory function: to help and protect adults with care & support needs experiencing abuse & neglect
- Self-neglect listed (DH 2014, 2016) within the circumstances that constitute abuse and neglect

Bringing self-neglect in from the cold...



The research evidence



**SAB
governance**

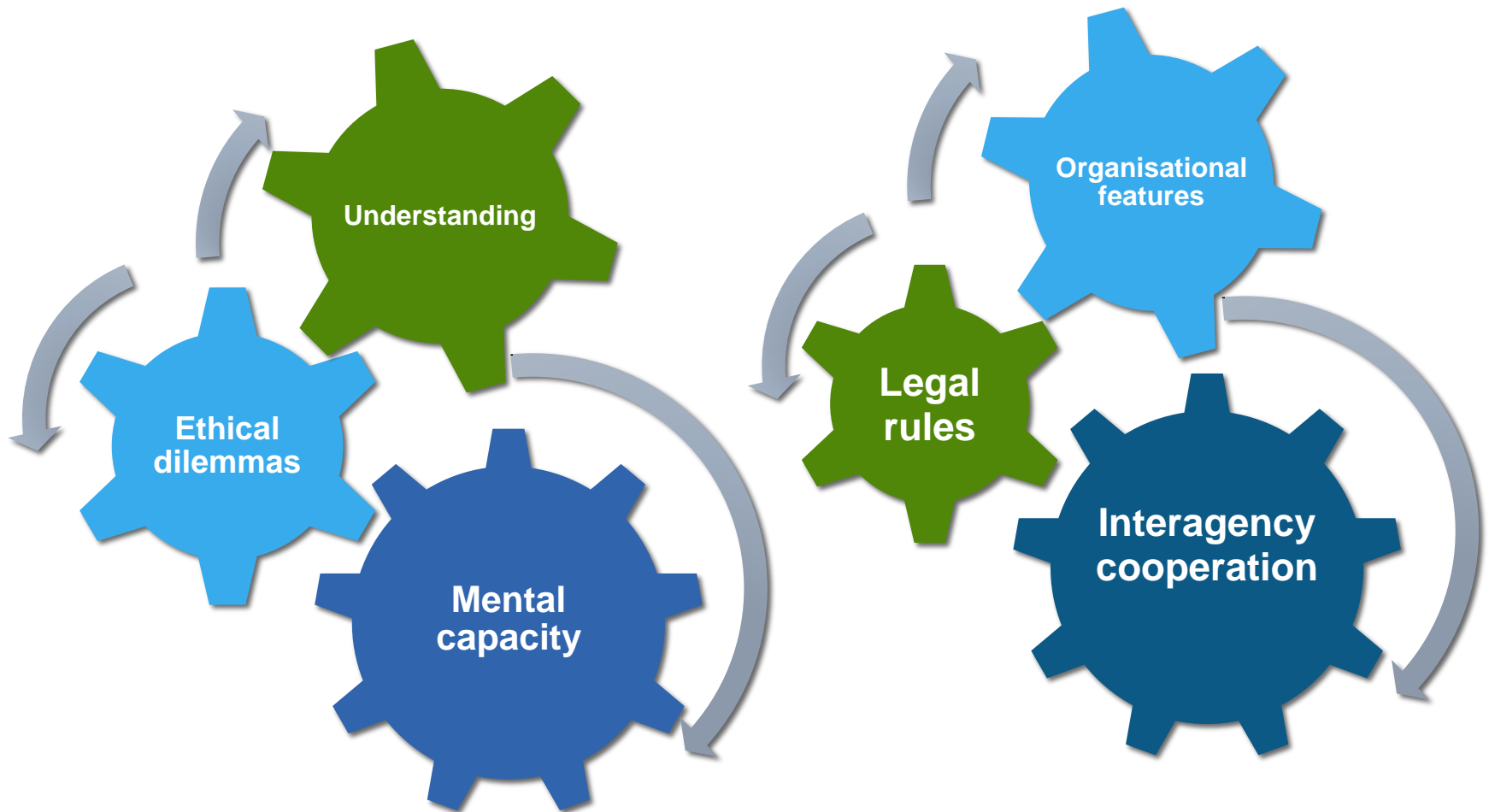
**Scoping the
evidence on
self-neglect**

**Workforce
development
needs
2013**

**Review of
serious case
reviews
2014-16**

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

The key challenges of self-neglect: how does the research evidence help?



1. Understanding causation: association with

Physical health issues

Impaired physical functioning

Chronic pain

Nutritional deficiency

Mental health issues

Depression; negative symptoms

Frontal lobe dysfunction

Impaired cognitive functioning

Substance misuse

Alcohol

Other drugs


Psycho-social factors

Diminished social networks

Poor access to services

Traumatic histories / life-changing events; high perceived self-efficacy

But ...

- 
- No one overarching explanatory model
 - Complex interplay of physical, mental, social, personal and environmental factors
 - Unwillingness and inability difficult to distinguish
 - Shifting levels of engagement
 - Need for understanding the meaning of self-neglect in the context of each individual's life experience

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
- ❖ Limitations to state power
- ❖ Policy context of personalisation
- ❖ 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 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 the dichotomy

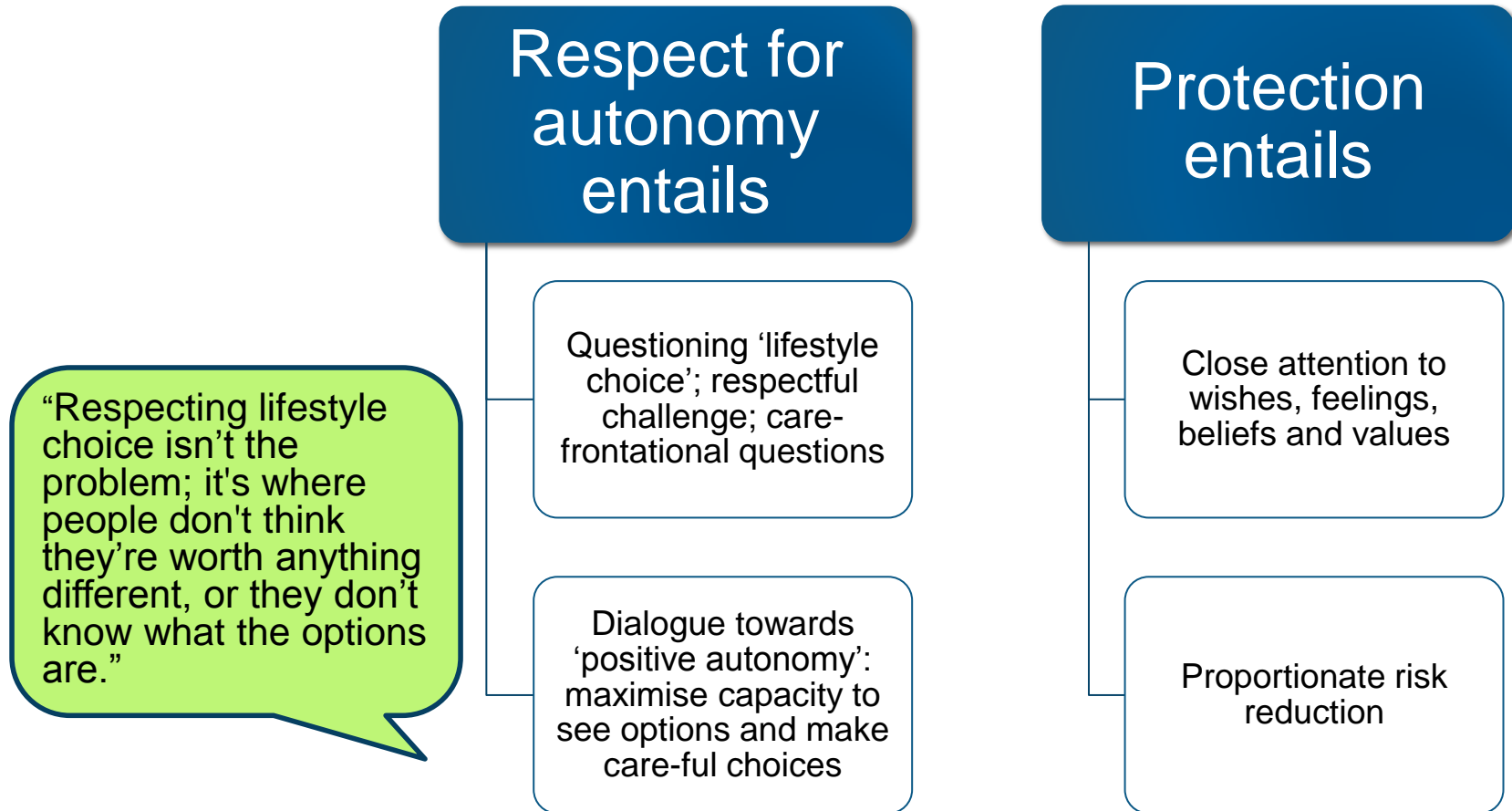
Is it really autonomy when ...

- 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
- Impairment of executive brain function makes real-time problem solving difficult

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 ethical literacy



Autonomy does not mean abandonment
Protection does not mean denial of wishes...

A situated, relational approach to determining the ethics of intervention

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.

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

"When x came, they were sort of hands on: '*Bumph! We've got to do this*' ... *shall we start cleaning up now?*'

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

The idea is not to get too pushy about it ... people start getting panicky ... if you're too bossy, I will put my feet down and go like a stubborn mule; I will just sit and just fester.

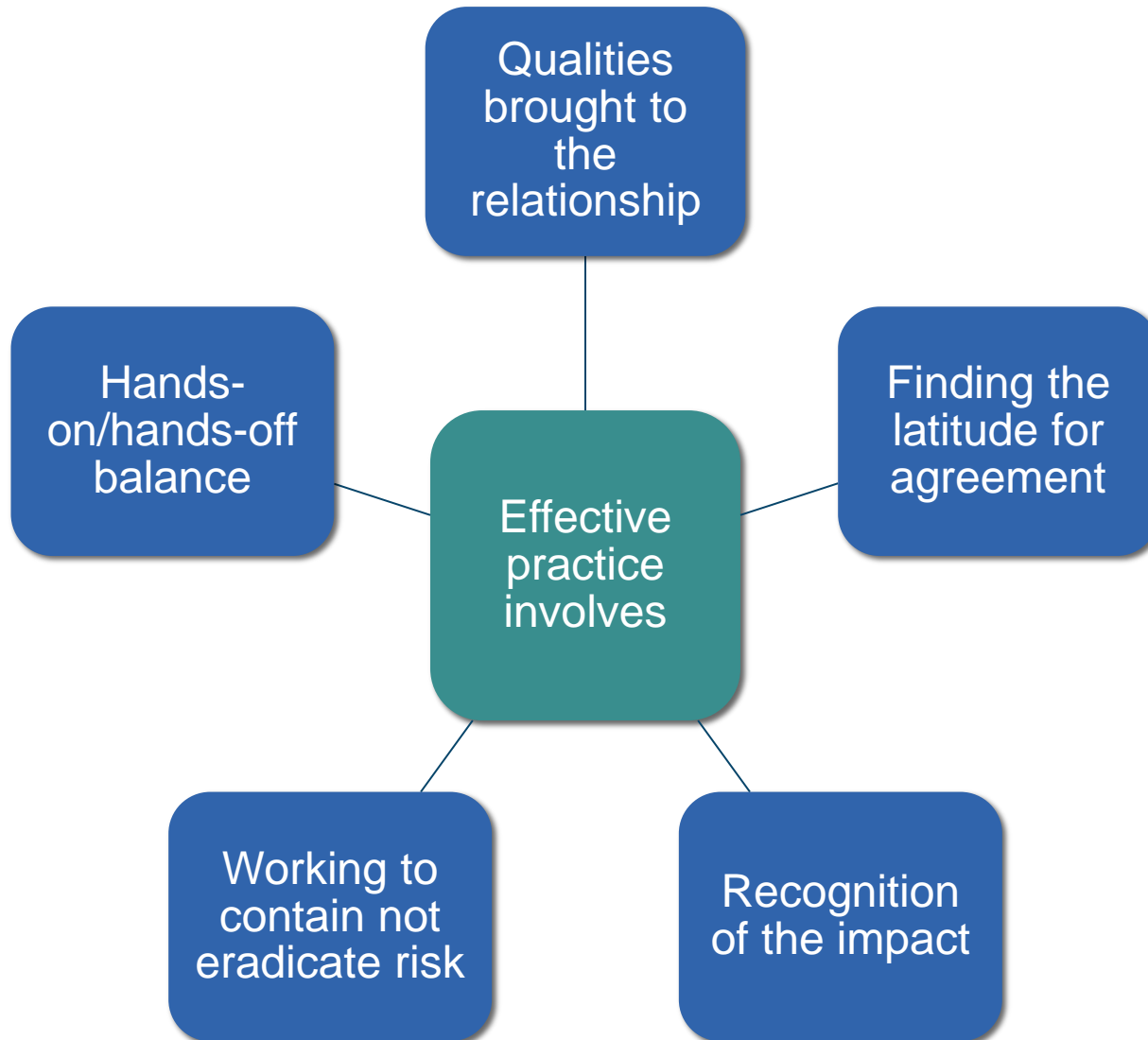
He has been human, that's the word I can use; he has been human.

Intervention delivered through relationship: emotional connection/trust

Support that fits with the individual's own perception; find latitude: practical input

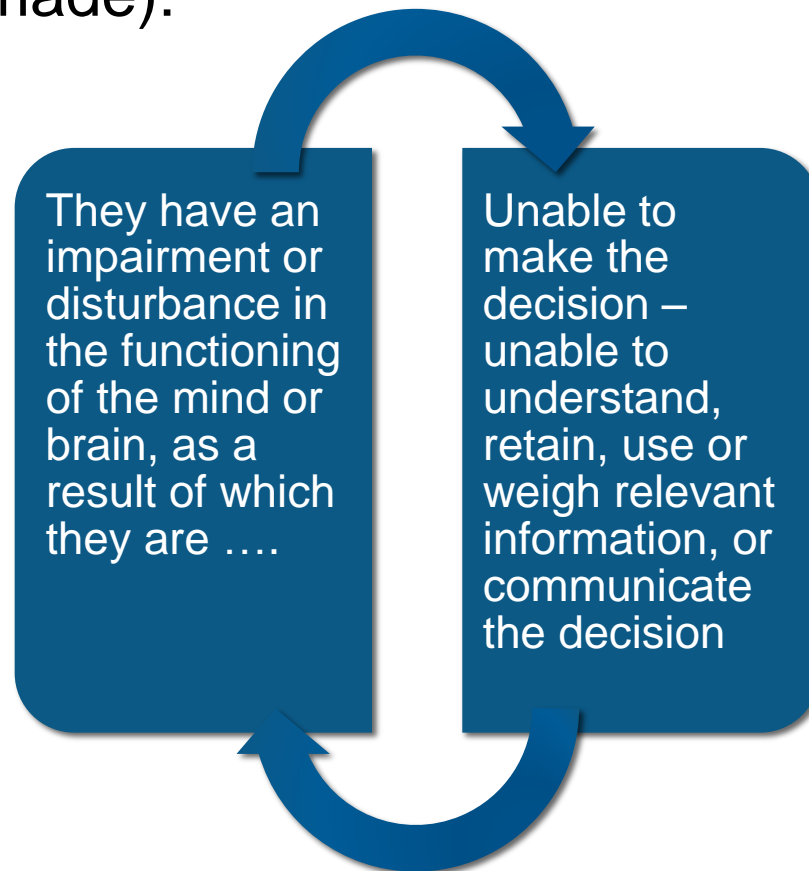
Respectful and honest engagement; recognition of the individual's journey

Practitioners say ...

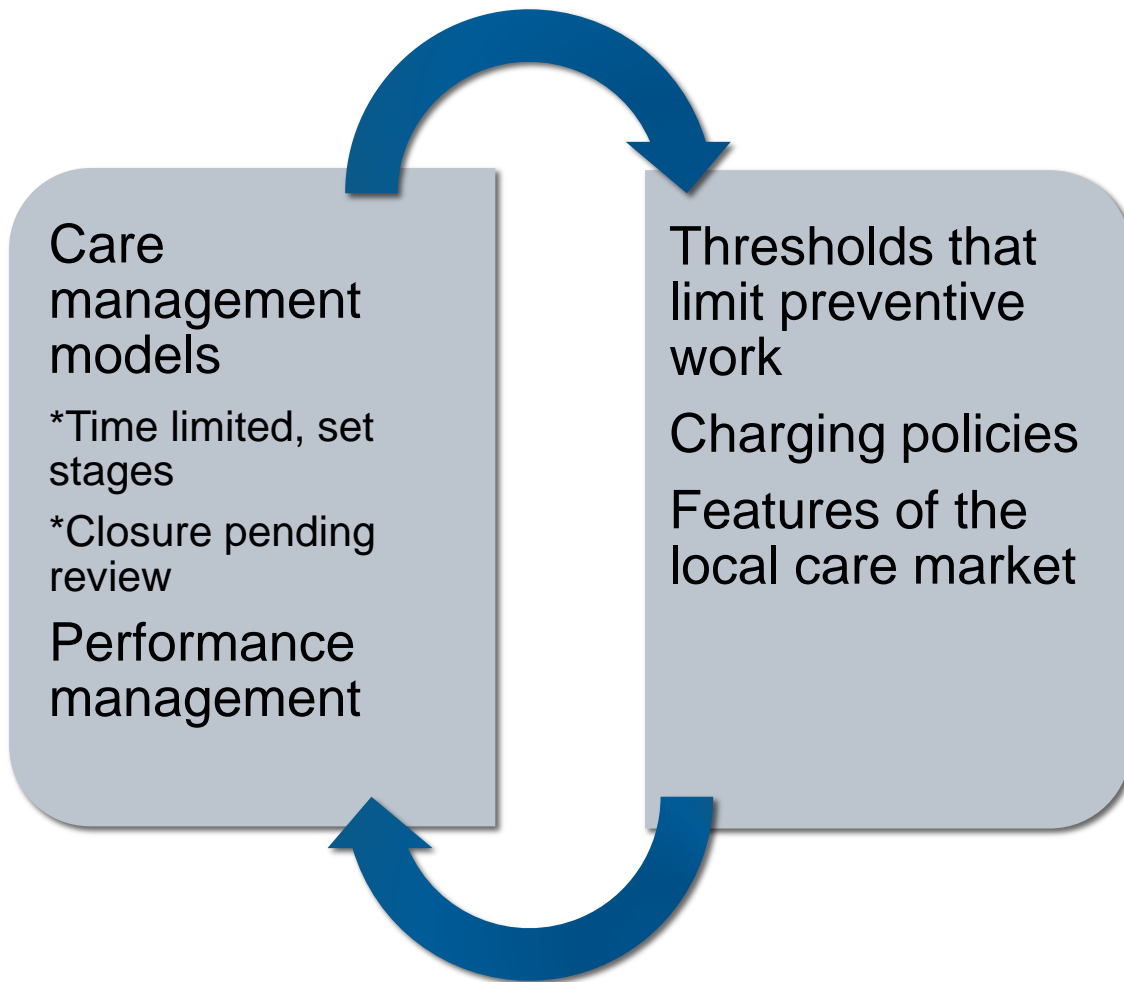


Mental capacity: a reminder

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



4. The organisational context



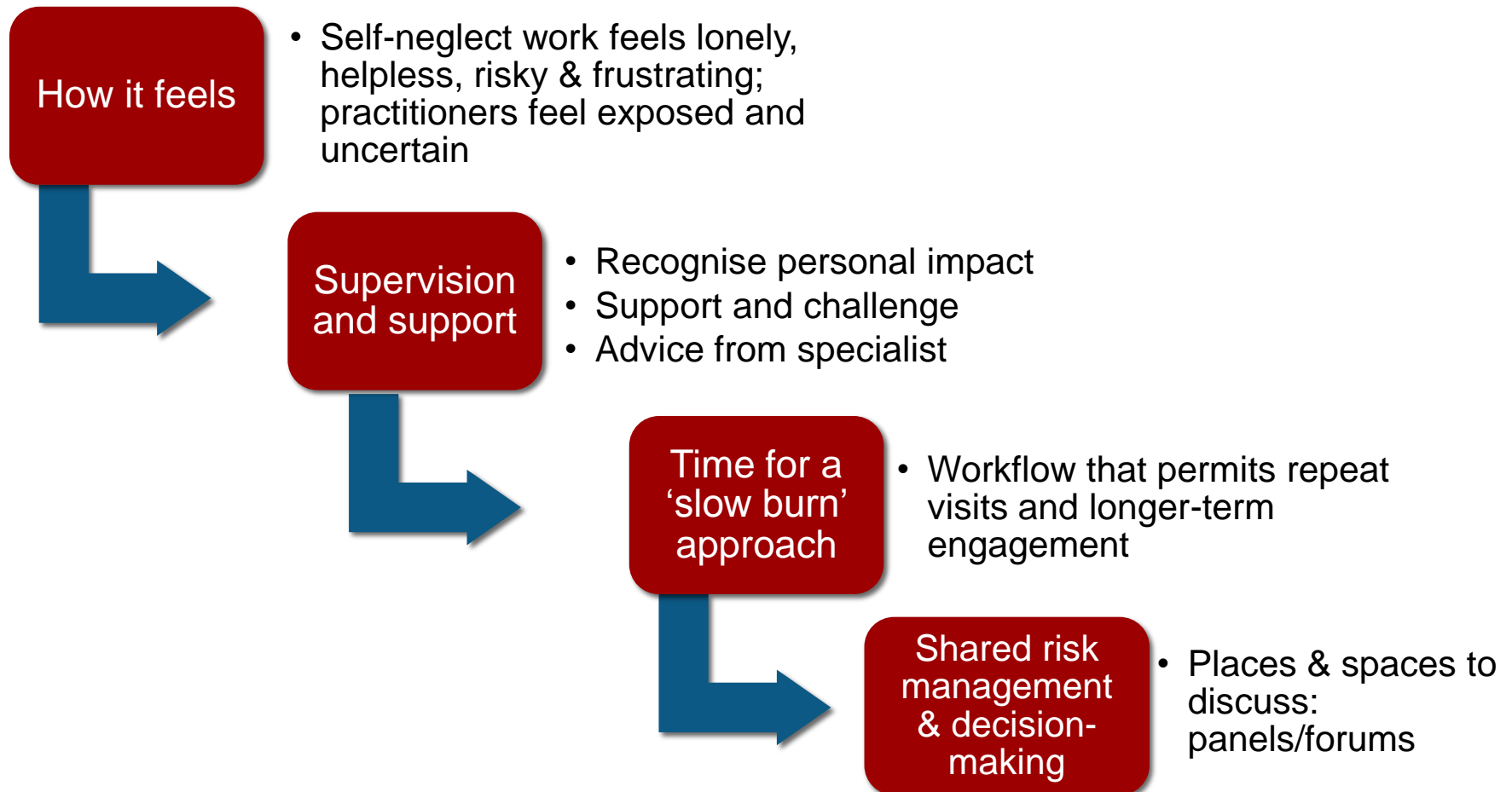
A perfect storm

Reluctance to engage

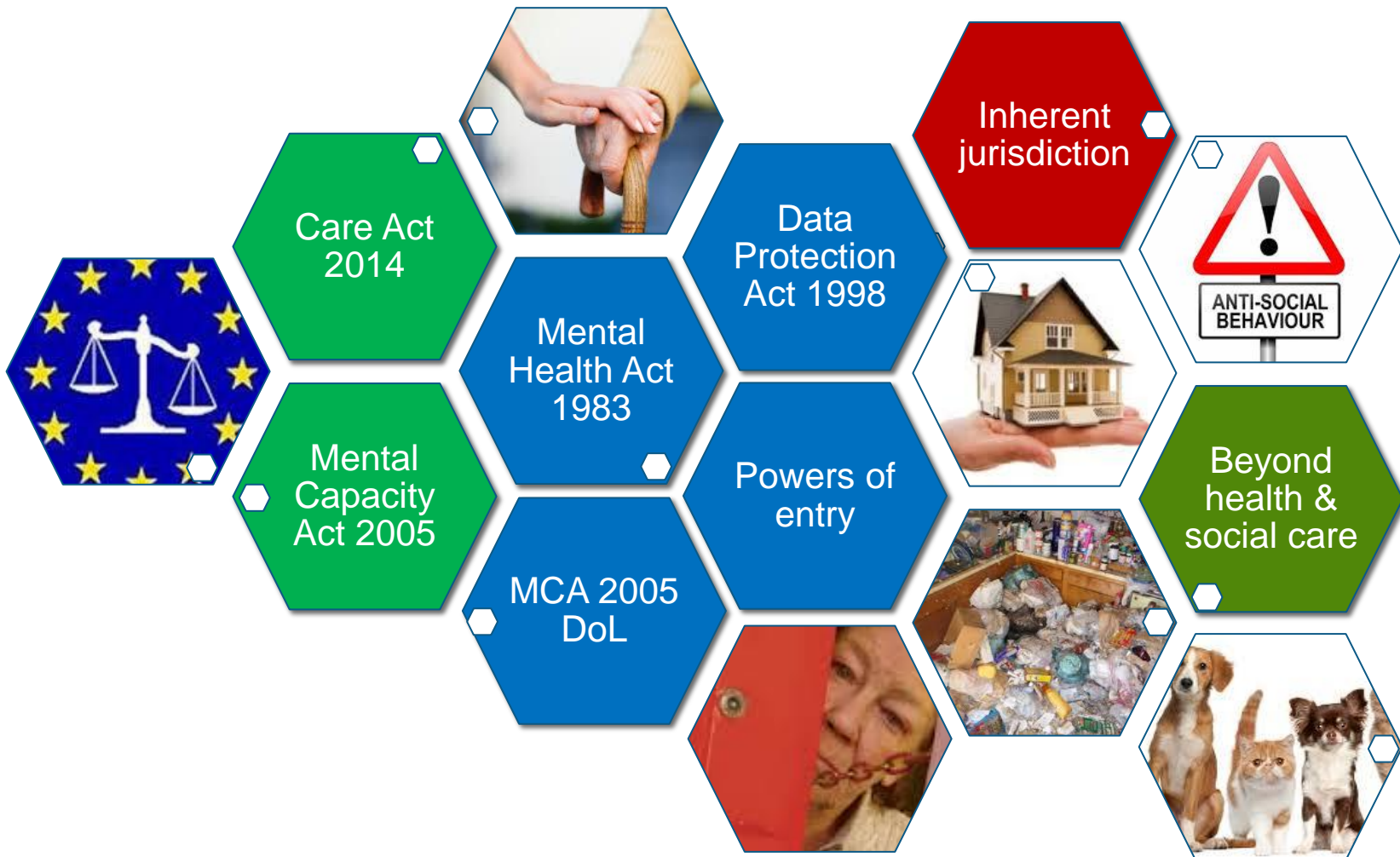
“The combination of people who are terrified of losing their independence or terrified of state intervention, together with a state process that is desperate to apply eligibility criteria and find reasons not to support people, is just lethal.... It's just like: 'oh you're saying it's all fine, thank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

Organisational pressures

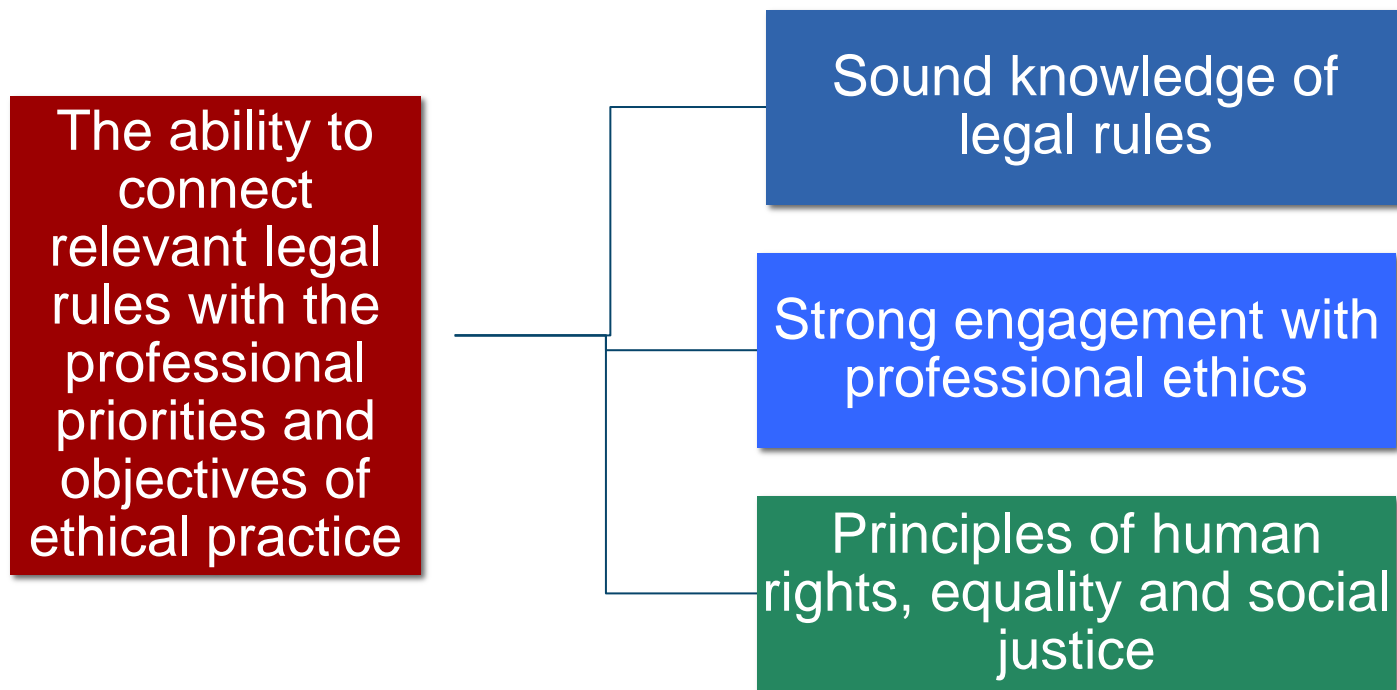
Organisational support for practice



5. The complexity of the legal framework

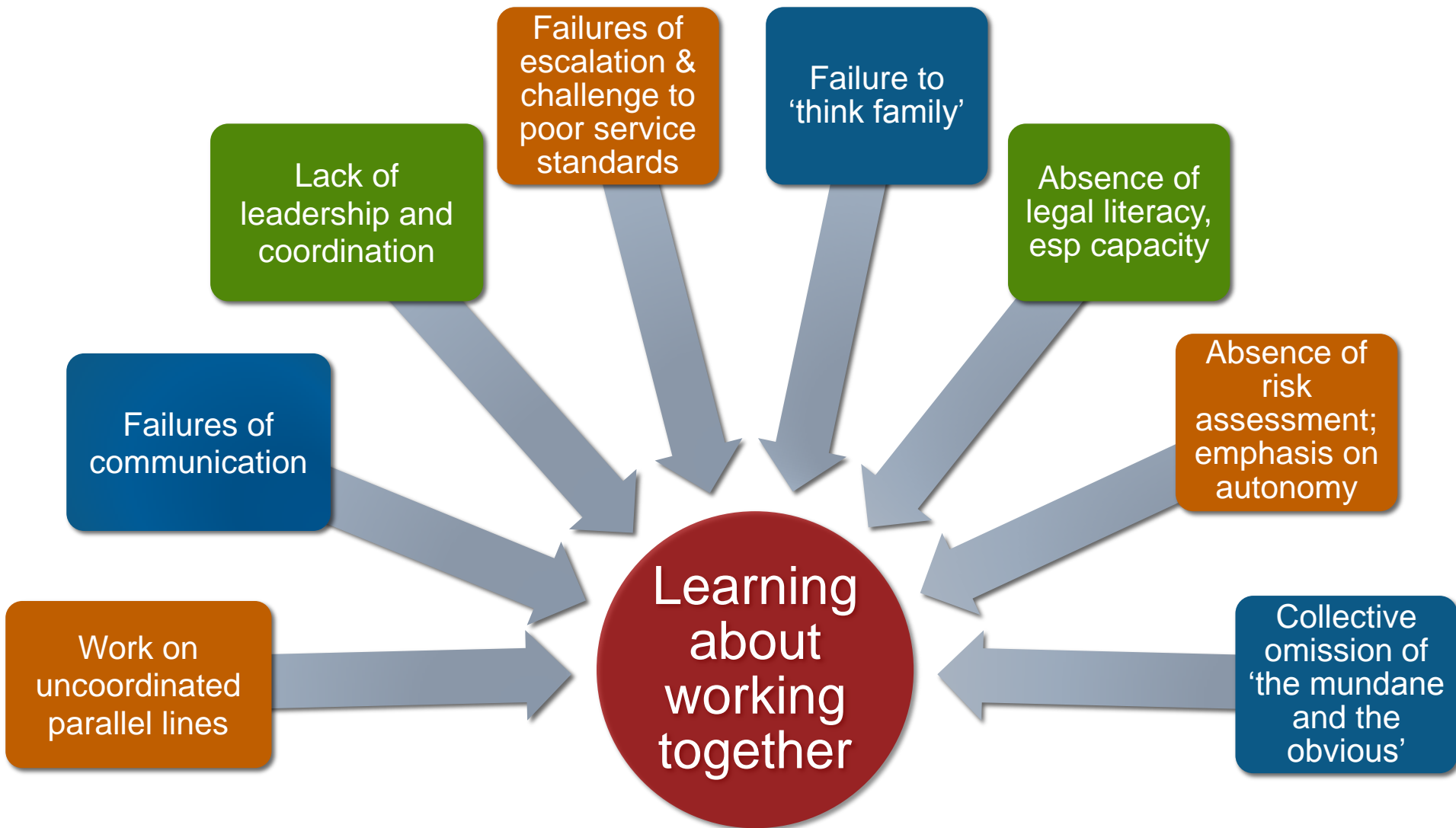


Legal literacy



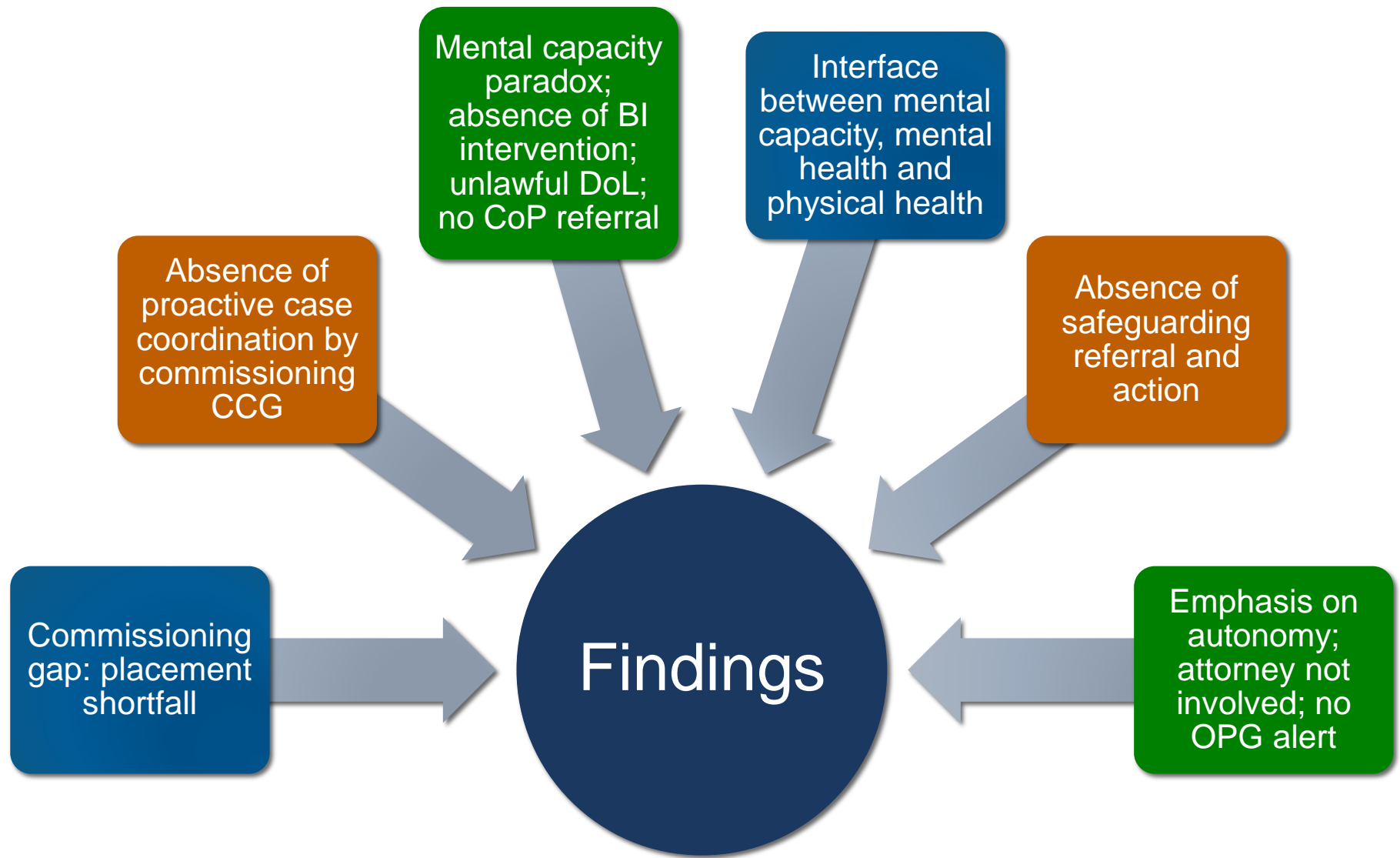
Joined-up consideration of which agencies have duties and powers, and how they might be applied in any given situation

6. Interagency cooperation: SAR findings

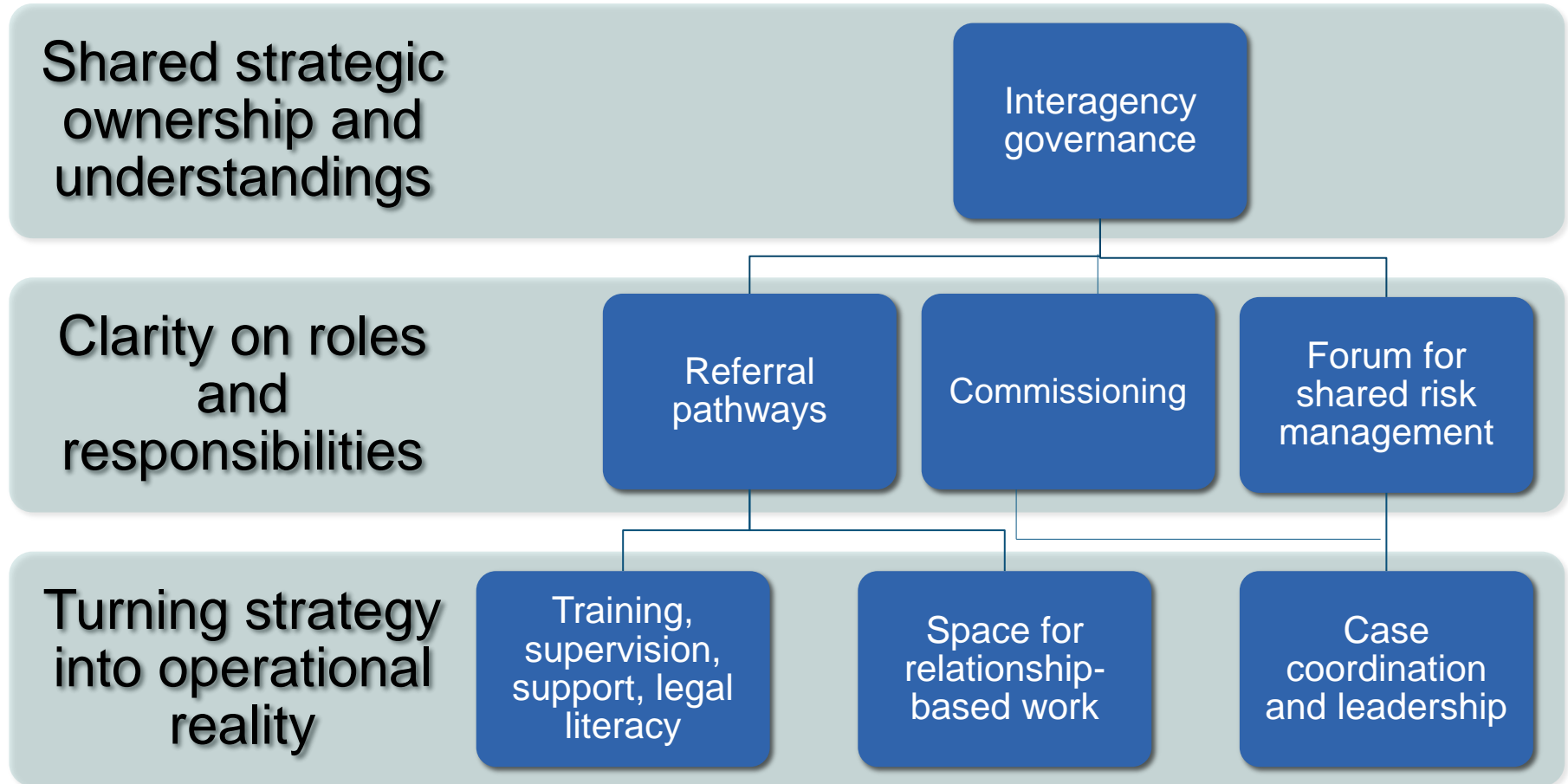


Mr A: a pen picture

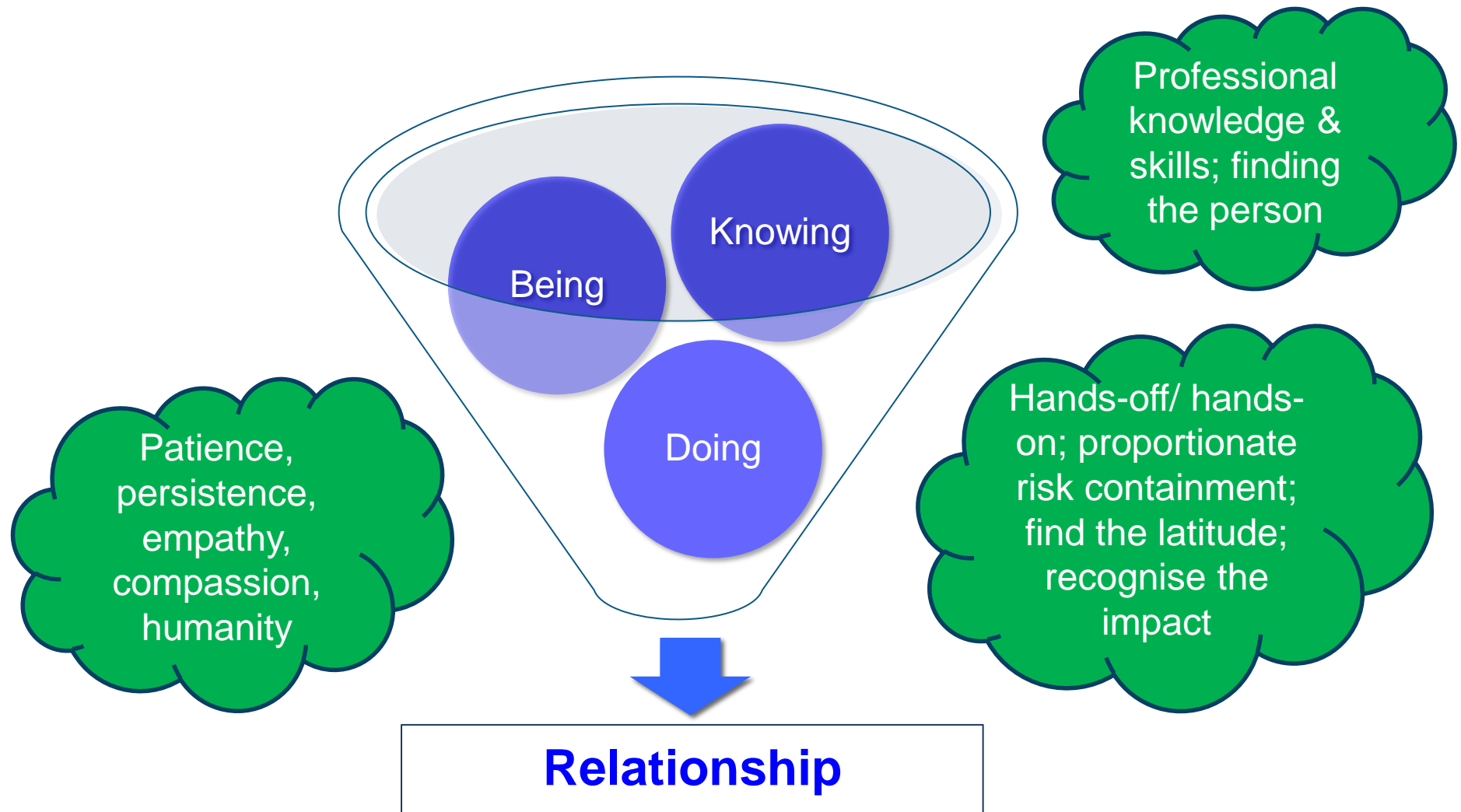
- Aged 64, no family contact, former colleague with LPA
- Medical history: Korsakoff Syndrome, arteriovenous malformation, epilepsy, encephalopathy, type 2 diabetes, and bilateral leg cellulitis & ulceration
- Hospital discharge: no suitable local placement, CCG commissioned 'temporary' nursing care placement in neighbouring county
- He (and his attorney) opposed the placement, but it (and DoL) was made in his best interests as deemed to lack capacity to decide where to live
- Self-neglect: persistent refusal of care and treatment; extreme compromise to his health
- Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes and hepatic cirrhosis



What makes for robust interagency working?



Knowing, Doing and Being



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