# Self-neglect: learning from safeguarding adult reviews, research and people with lived experience

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# The evidence-base for working with adults who self-neglect

- Learning from individual safeguarding adult reviews
- Analysis of 400+ reviews in England
- Much smaller numbers in Wales and Scotland
- Research studies (SCIE, Journal of Adult Protection)
- National SAR Analysis April 2017 – March 2019
- 98% response rate from SABs
- 231 SARs in the sample
- 45% focus on self-neglect
- Self-neglect the most frequent type of abuse or neglect reviewed

# Self-Neglect Definition

- lack of self-care – neglect of personal hygiene, nutrition, hydration, and health, thereby endangering safety and well-being, and/or
- lack of care of one's environment – squalor and hoarding, and/or
- refusal of services that would mitigate risk of harm.

- A variety of key episodes – fire deaths, drugs and alcohol abuse, infections from poor tissue viability, impact of mental distress or learning disability, multiple exclusion homelessness, untreated diabetes …

# 1. Understanding self-neglect: what do we know about prevalence?

- Scotland: 0.2% of the population (200 in 100,000)
- Ireland: 0.14% of the population (142 in 100,000)
- Australia: 0.1% of people over 65 (100 in 100,000)
- South Korea: 23%
- US: 29% of Chinese older adults; 22% of African-American older adults; 5% of white older adults
- UK: 20% of high-risk situations involving mental ill-health
- Hoarding: between 1.5%/6% of the population, pooled estimated prevalence of 2.5% (2,500 in 100,000)
- All ages, more common in older adults, severity increases
- Similar prevalence in men and women
- All socio-economic groups, more common in areas of deprivation
- Race: US - 58% white non-Hispanic, 20% Black/African-American, 18% Hispanic-Latino

# Self-neglect and safeguarding

- US: 61% of referrals to adult protection services
- Ireland: 20/25% of elder abuse service referrals
- England: 4.2% of s.42 enquiries; 45% of SARs

# Voices of Experts by Experience

- When asked what he needed, Terence replied: “Some love, man. Family environment. Support.” He wanted to be part of something real, part of real society and not just “the system”. (reported in a thematic review on people who sleep rough, Worcestershire SAB (2020)).

- Adult N (Kirklees SAB) – a poem about alcohol dependence that challenges the narrative of lifestyle choice. Periodically homeless, he died in temporary accommodation.

- From the Leeds Thematic Review (2020):
  - “I lost everything all at once: my job, my family, my hope.”
  - “Without [this help in Leeds], I’d already be dead. I’ve no doubts about that. If the elements hadn’t got me, I would have got me. Sometimes I have rolled up to this van in a real mess and they have offered help and support and got my head straight.”

# Learning from the voices of lived experience

- Seeing the whole person in their situation
- A trauma-informed, whole system response to the person in context
- Being careful and care-ful when thinking about removing a coping strategy
- In the context of people's experiences, the notion of lifestyle choice is erroneous but too often an assumption or stereotype
- Tackling symptoms is less effective than addressing causes.
  - Attempting to change someone's behaviour without understanding its survival function will prove unsuccessful. The presenting problem is a way of coping, however dysfunctional it may appear. Put another way, individuals experiencing multiple exclusion homelessness are in a "life threatening double bind, driven addictively to avoid suffering through ways that only deepen their suffering."

# What people with lived experience say about working with them

- *Engagement* – recognise that people may be wary of professionals and services, possibly due to past experiences of institutions and the care system; appreciate that individuals may feel alone, fearful, helpless, confused, excluded, suicidal and depressed, unable to see a way out.
- *Professional curiosity* – "I was not asked 'why?'" There is always more to know. Experiences (traumas) had a "lasting effect on me." "Appreciate the beginning of the journey."
- *Partnership* – "work with me, involve me, and support me." "Keep in touch so that we know what is going on." Help with form filling, bank accounts and other practicalities.
- *Person-centred* – see the person and, where necessary, adapt our approach; "people did not see beyond the sleeping bag"; challenge misconceptions of people who are homeless and any evidence of assumptions (unconscious bias) that someone may be undeserving; there are multiple reasons behind why a person may become homeless.
- *Assessment* – what does this individual need? Do not assume or stereotype.
- *Language* – be careful and respectful about the language we use; words and phrases can betray assumptions. For example, who is not engaging? What does substance misuse imply?

# What people with lived experience says about how services work together

- *Collaboration* – widen the multi-agency, partnership and colocation approach; a breadth of expertise is needed to respond to individuals' complex needs involving physical and mental health, substance use and homelessness.
- *Safeguarding* – do not assume that people know what adult safeguarding actually is; for some it may be understood as the removal of children and as practitioners "working against, not with me."

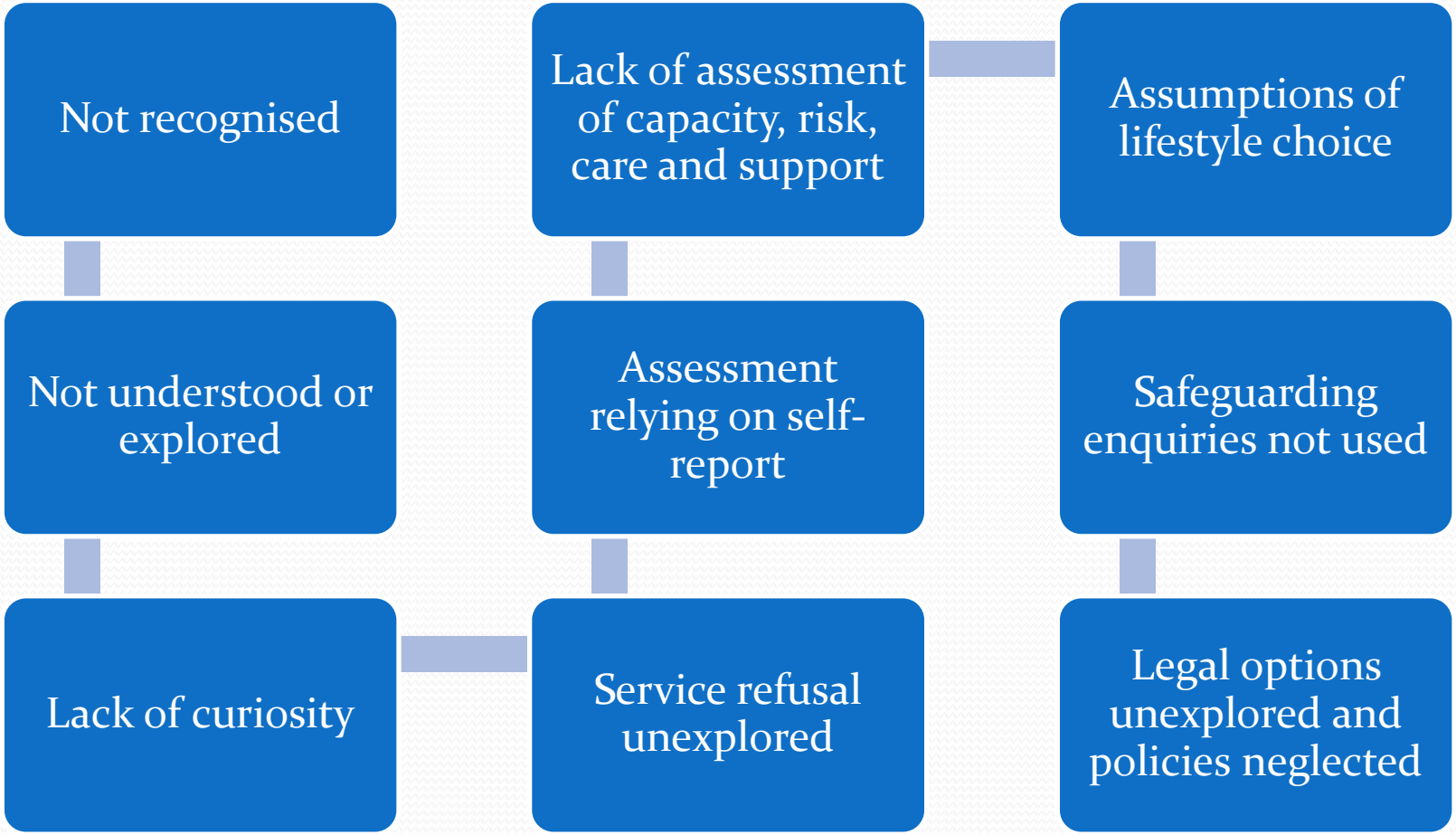
# What people with lived experience advise organisations

- *Commissioning* – focus on evidence-based practice and what works. Hostels and night shelters are not suitable for everyone and can be more frightening than the streets. Wrap-around support is often crucial – "I would not have coped otherwise."
- *Managerial oversight* – understand the barriers to effective practice and learn from positive outcomes.
- *Supervision and staff support* – support a culture of reflective practice across teams to enhance practitioner wellbeing and resilience.
- *Service development with commissioners and providers* – use our expertise and experience to promote improvement and enhancement.

# Comments from people with lived experience about governance

- *Review* – learn from failures.
- *Training* – education is essential so that practitioners and managers understand the multiple routes into homelessness and the pathways for prevention, intervention and recovery.
- *Involvement* – use our expertise.
- *Audit* – not just tick boxes but outcomes that matter to people.

# National Analysis Findings



## Risk

- Assessments absent or inadequate
- Failure to recognise and act on persistent and escalating risks

## Mental capacity

- Assessments missing, poorly performed or not reviewed
- Absence of detail about best interest decision-making

## MSP

- Insufficient contact with the individual
- Unclear focus on individual's wishes, needs and desired outcomes
- Focus on autonomy excludes consideration of risks to others and duty of care

- Absence of attention to complex family dynamics; failure to involve carers
- Lack of curiosity about meaning of behaviour & key features in a biography
- Lack of time & agency encouragement of relationship & trust building; absence of continuity

# SAR findings

| | | |
|---|---|---|
| Too accepting of "lifestyle choice & insufficient professional curiosity | Mental capacity and risk assessments insufficiently robust | Delays in raising safeguarding concerns or commencing Section42 enquiries |
| Failure to escalate concerns to senior managers | No agreed strategies to continue to engage | Poor record keeping of decision-making |

# Recommendations

- Multi-agency risk management meetings (what do we mean by autonomy, risk etc)
- Legal literacy – consider all legal options
- Record of decision-making, having evaluated options
- Persistent offers of support & respectful challenge (caution about case closure)
- Updated risk & executive capacity assessments (including how beliefs & experiences shape wishes)
- Consider mental health, risk to others and dignity

# Direct practice – best practice

| | | |
|---|---|---|
| Person-centred, relationship-based practice | Professional curiosity (history) | Assessment of care & support, and mental health |
| Transitions – opportunities not cliff edges | Assessment & review of risk and capacity | Family involvement (think family) |
| Availability of specialist advice | Legal literacy | Balancing autonomy with a duty of care |

# Inter-organisational environment – best practice

| | | |
|---|---|---|
| Guidance on balancing autonomy with a duty of care | Information-sharing & communication | Working together on complex, stuck and stalled cases |
| Use of multi-agency meetings and safeguarding enquiries | Clear roles and responsibilities (lead agencies and key workers) | Shared record-keeping |

# Organisational environment – best practice

| | | |
|---|---|---|
| Development, dissemination & review of guidance | Clarifying management responsibilities and oversight | Staffing, supervision, support & training |
| Recording standards | Commissioning & contract monitoring | Culture of openness, challenge and escalation |

# SAB governance – best practice

| | | |
|---|---|---|
| Audit & quality assurance of what good looks like | Multi-agency training | Review of management of SARs |
| Workplace as well as workforce development | Continual review of outcome of recommendations | Use of SARs to inform policy development, practice audits and training |

# Discussion Point One

- Where do we align or get close to the evidence-base?
- What has helped us to do this?
- What obstacles and barriers have hindered getting close to the evidence-base?
- What further changes in systems, policy or practice could enhance the enablers of effective practice and address barriers to improvement?

# East Sussex SAB: Mr A

- Died July 2016, aged 64, 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 opposed by Mr A and the LPA
- Placement (and DoL) in best interests as deemed to lack capacity to decide where to live (but should have been referred to Court of Protection)
- LPA withdrew after the placement was made (no follow up with Office of the Public Guardian)
- Self-neglect: refusal of care and treatment; practitioners uncertain what to do when acting in his best interests proved very challenging
- No adult safeguarding concerns referred until the final weekend; no multi-agency meeting with all services and practitioners present
- Cause of death: systemic sepsis, cutaneous & soft tissue infection of legs, diabetes mellitus, idiopathic hepatic cirrhosis

# Using the voice of lived experience (SAR - Ms H and Ms I – Tower Hamlets SAB)

- In the context of people's experiences of multiple exclusion homelessness and self-neglect, the notion of lifestyle choice is erroneous.
- Tackling symptoms is less effective than addressing causes.
  - Attempting to change someone's behaviour without understanding its survival function will prove unsuccessful. The problem is a way of coping, however dysfunctional it may appear. Too often we are responding to symptoms and not causes. Put another way, individuals experiencing multiple exclusion homelessness are in a "life threatening double bind, driven addictively to avoid suffering through ways that only deepen their suffering."
  - At times "she could not help herself" because of the feelings that were resurfacing; access to non-judgemental services was vital and helpful, and that support is especially important when individuals are striving to be alcohol and drug free. It was during these times that stress, anxiety and painful feelings could "bubble up", prompting a return to substance misuse to suppress what it was very hard to acknowledge and work through.
- Making Safeguarding Personal is not just about respecting the wishes and feelings that an individual expresses.
  - He reflected on the challenge of knowing when to allow a person freedom of movement and when, for their own benefit, to curtail or supervise this. He described this as a "moral question." It is indeed a question that, in a multi-agency and multi-disciplinary forum, needs to be answered in each unique situation, drawing on an analysis of risks and mental capacity.

# Salford SAB: Andy

- Andy died aged 32 at home.
- He required treatment for throat swelling, diabetes and renal failure; he did not always comply with his insulin regime or attend dialysis appointments.
- His living conditions in private rented accommodation were poor but his engagement with efforts to improve his housing situation was intermittent.
- He was living in poverty but his engagement with efforts to improve his financial situation was intermittent.
- He was known to self-neglect and to be hard to consistently engage. There was a pattern of rejecting assessments and treatment, followed by case closure.
- There are references to concerns about low mood and depression.
- Was he unwilling or unable to engage in the way services expected?
- There was some support/contact with a friend and family members but they were not consulted by the services involved.

# Salford SAB: SAR Eric

- Eric, aged 81, died in hospital in October 2019. Since mid-September he had consistently refused food, water, personal care and treatment
- Coroner ruled that the medical cause of death was starvation and noted that Eric lacked mental capacity over a period of time but this was not picked up.
- Three years previously Eric had experienced a period of depression, anxiety and weight loss. More recently in August 2019 he had refused to eat and drink, and to take prescribed medication.
- His wife and daughter have described Eric as happy but a private family man. He perhaps struggled with getting older.

# SAR Eric: Conclusions

- The influence of the lens through which cases are viewed
- The case raises the dilemma of autonomy versus a duty of care, and the challenge of differentiating between decisional and executive capacity, and of assessing (fluctuating) capacity when the person does not easily engage
- Consider legal options explicitly throughout management of high risk cases
- Develop a culture where escalation and challenge is seen as central to best practice
- Insufficient familiarity and/or use of self-neglect policy
- Insufficient use of whole system meetings
- Take time to ensure care-givers understand the support that can be offered and acknowledge the stress and anxiety they carry
- Debrief staff and offer support when cases of high risk result in a person's death

# Isle of Wight – Howard (2018)

- Homeless single adult without local family support
- Impact of adverse life events
- Longstanding alcohol misuse (seen as lifestyle choice rather than impulse control disorder) and physical ill-health
- Hospital and prison discharges to no fixed abode
- Police and ambulance crews concerned about risks of financial and physical abuse, and his self-neglect; he declines support (undue influence on decision-making?)
- Refused housing as not regarded as in priority need
- No wet hostel available
- Referrals to adult safeguarding do not prompt multi-agency meetings or investigation; no completed Care Act 2014 care and support assessment
- No lead agency or key worker; no risk assessment or mitigation plan

# Carol (2017) Teeswide SAB

- Attacked and murdered by two teenage girls
- Lack of understanding of coercive and controlling behaviour, of risk from others
- Long history of chronic alcohol use, mental health problems and vulnerability and had been identified as having multiple care and support needs
- Multiple agencies involved
- Diagnosed with a personality disorder - primarily Emotionally Unstable Borderline Personality Disorder (EUPD). Carol was therefore considered to have a dual diagnosis.
- Identified the need to develop existing treatments to better meet the needs of personality disordered substance abusers with therapeutic attention to reduce the severity of the substance abuse and other associated psychiatric problems such as depression, anxiety, paranoia
- Identified the need to consider executive functioning when assessing capacity

# MS: City of London & Hackney SAB (2021)

- MS died, aged 63. Cause of death was acute myocardial infarction, coronary artery atherosclerosis and aspiration pneumonia. He died at a bus stop where he had been living and sleeping for several weeks.
- MS was Turkish (Kurdish ethnicity) with limited understanding of English and a history of homelessness, self-neglect and substance abuse. He had returned to the bus stop where he eventually died at the end of May 2019, having spent the previous five months in a nursing home. When that placement came to an end he was offered a hotel room but declined. He is reported as having said that "something brings [me] back to the bus stop."
- There were discussions on whether and how to use anti-social behaviour powers, and mental capacity and mental health legislation, in order to safeguard his health and wellbeing, and to address expressed concerns from local residents. No effective means of resolving the situation was found before he died.
- When practitioners could not agree on whether he had capacity, they walked away, unable to reach a decision.
- Referred adult safeguarding concerns did not lead to a section 42 enquiry

# Discussion Point Two

- How involved have you been in reviews?
- How often do you read reviews commissioned locally or elsewhere?
- How often would you discuss reviews with your team/service colleagues?
- Where would you go to for advice and support when working with challenging and complex cases of self-neglect?

# Alcohol-related SARs

- 57 cases (25%) where the principal focus was on a person with alcohol-related concerns
- Correlations with self-neglect and/or homelessness
- Examples of fire deaths involving alcohol abuse
- Impact of loss and trauma
- Additional 5 cases where someone in the person's environment was alcohol-dependent
- Highlights the importance of thinking family (domestic abuse, impact on children, understanding family and relational dynamics)
- One case of a paid carer being alcohol-dependent

## Good practice in alcohol-related reviews

- Thorough and robust care and support, risk and/or mental capacity assessments
- Routine monitoring of, and treatment for, physical health issues
- Liaison with drug and alcohol teams
- Information-sharing

# 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 abuse not seen as self-neglect

## Partnership 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

## Service response

- 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

# Findings on multiple exclusion homelessness

- 14 references to good practice
  - Rapport building, expression of humanity, provision of care and support and emergency accommodation, health services outreach, colocation of practitioners, clear referrals
- 42 references to practice shortfalls
  - Delayed or missing risk, mental health and mental capacity assessments, unclear referral pathways, discharges to no fixed abode, lack of use of available legal rules, absence of consideration of vulnerability
- 18 recommendations
  - Wrap-around support (health and care and support as well as housing), coordination of response, legal literacy, commissioning for health and social care as well as housing, governance oversight

# Findings on mental health

Good practice

- Timely and thorough assessments
- Understanding and use of law
- Referral practice
- Effective collaboration and communication
- Use of adult safeguarding
- Assertive outreach and follow-up

Practice shortfalls

- Failure to differentiate between mental health and MHA 1983 assessments
- Poor (risk) assessments and reviews
- Failure to think family and assess dynamics
- Lack of outreach
- Case bouncing/revolving door
- Referral pathways into mental health – who can refer?
- Lack of secondary mental health services for people not in immediate crisis
- Lack of understanding of MHA 1983
- Failure to use safeguarding procedures
- CPA guidance not followed

# Findings from the National SAR Analysis – Mental Capacity

## Good Practice

- Robust capacity assessments and best interest decisions
- Outcomes clearly recorded
- Assessment clearly mapped against MCA requirements

## Practice Shortfalls

- Failure to assess or review
- Poor assessments
- Misunderstanding of MCA principles
- Misunderstanding of diagnostic test
- Neglect of executive capacity
- Neglect of advocacy
- Assumptions about lifestyle choice
- Poor recording
- Lack of confidence

# Example: Amy

- Amy was found deceased on a mattress in a bedroom. The house was strewn with litter and rubbish, and rooms were piled high with possessions, with little room to walk. There was evidence of alcohol cans in both downstairs rooms. She was 50 years old.

- Of more concern is the acceptance by some professionals of the condition of the house, and the presentation and lifestyle of Amy.

Adult D SAR Lancashire 2018

# The tricky concept of lifestyle choice

- SARs tell us we are quick to assume capacity, respect autonomy (and walk away) – "it's a lifestyle choice"
- 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?'

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

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

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

# Challenging the dichotomy

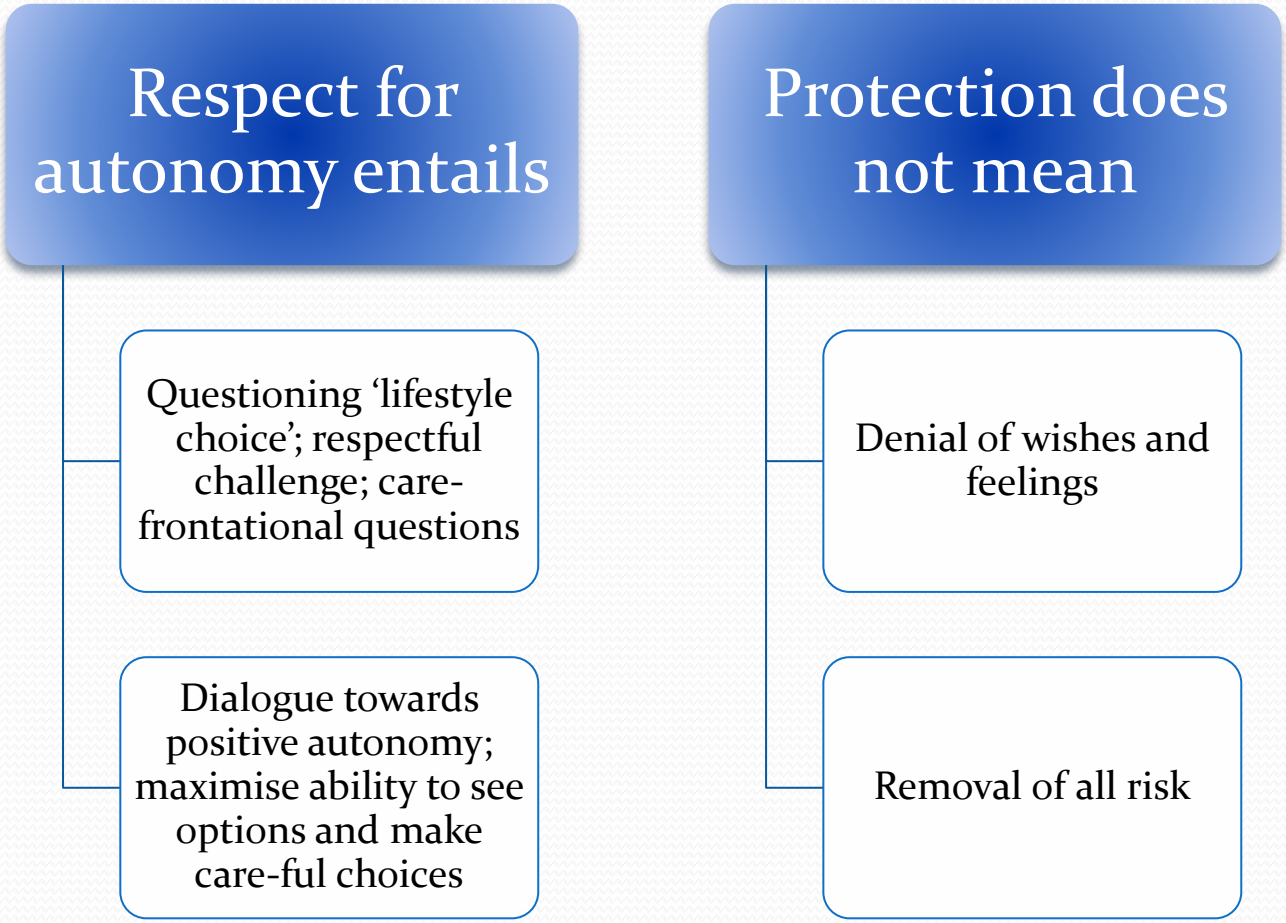
**Is it really autonomy when …**

- 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
- 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 ethical literacy




Autonomy does not mean abandonment

Protection entails proportionate risk reduction

# Mental capacity: a reminder

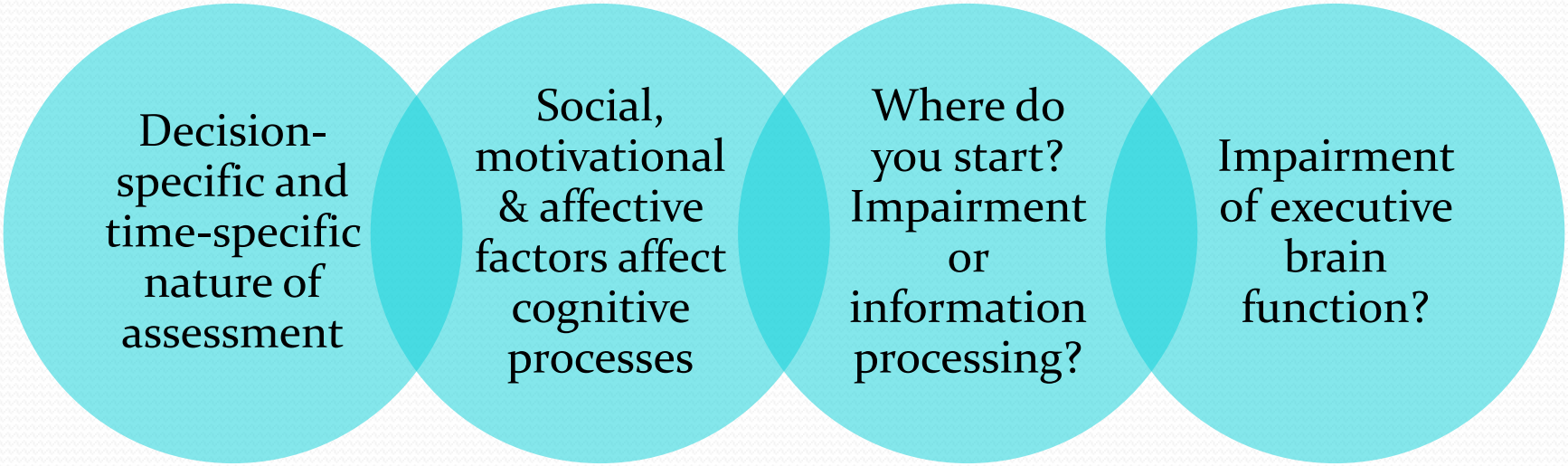
- Capacity is decision specific and time specific
- s.2, MCA 2005: A person lacks capacity if (at the time the specific decision has to be made):
  - They are unable to make the decision in question because of
  - An impairment of, or disturbance in the functioning of, the mind or brain
- s.3, MCA 2005: A person is unable to make a decision if they are unable to:
    - understand the information relevant to the decision, or
    - retain that information, or
    - use or weigh that information as part of the process of making the decision, or
    - communicate their decision

# Mental Capacity Act 2005: a reminder

## Five key principles

- Assume a person has capacity unless proven otherwise = presumption of capacity: adult has right to make decisions, unless incapacity proven
- Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them = right to support to maximise capacity to make own decisions
- A person should not be treated as incapable of making a decision because their decision might seem unwise = not exactly a right to make eccentric or unwise decisions
- Best interests duty for decisions taken on behalf of people lacking capacity
- Least restrictive intervention to preserve basic rights and freedoms

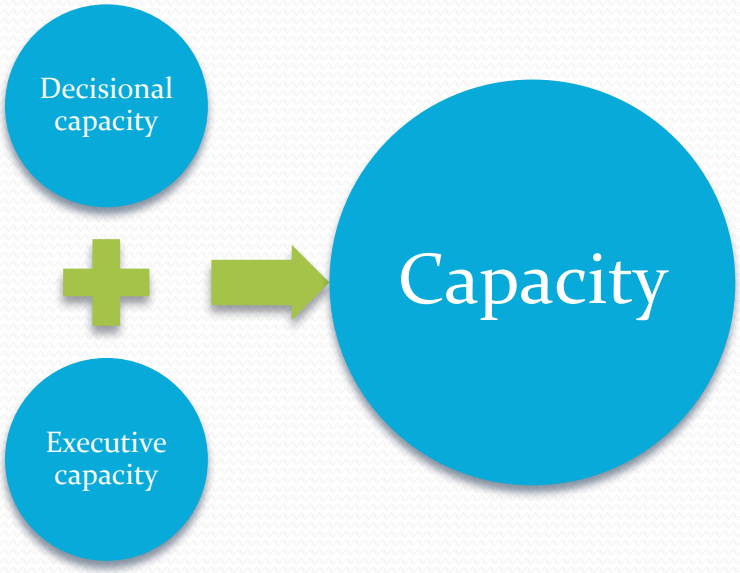
# Challenges of mental capacity in self-neglect



- Mental capacity in the 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:
  - Selecting relevant information and using or weighing it in the right context, in the moment
  - And therefore in planning, problem-solving, enacting a decision in situ



# 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)

# Case Law: Executive Functioning

- Sunderland City Council v AS and Others [2020] EWCOP 13
  - Importance of real world observation to obtain a full picture.
- A Local Authority v AW [2020] EWCOP 24
  - Ability to think, act and solve problems include the functions of the brain which help us to learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life.

# Signposts to best practice

- In cases of fluctuating capacity, the courts and NICE have advised taking a long-term perspective on someone's capacity rather than simply assessing the capacity at one point in time..
- Carol SAR (Teeswide SAB): *the concept of "executive capacity" is relevant where the individual has addictive or compulsive behaviours. This highlights the importance of considering the individual's ability to put a decision into effect (executive capacity) in addition to their ability to make a decision (decisional capacity).*
- Howard SAR (Isle of Wight SAB) and the Ms H and Ms I SAR (Tower Hamlets SAB) highlight people who are driven by compulsions that are too strong for them to ignore. Their actions often contradicted their stated intention to control their alcohol use: i.e. they were unable to execute decisions that they had taken.
- Ruth Mitchell SAR (Plymouth SAB): *To assess Ruth as having the mental capacity to make specific decisions on the basis of what she said only, could produce a false picture of her actual capacity. She needed an assessment based both on her verbal explanations and on observation of her capabilities, i.e. "show me, as well as tell me". An assessment of Ruth's mental capacity would need to consider her ability to implement and manage the consequences of her specific decisions, as well as her ability to weigh up information and communicate*

# Discussion Point Three

- There are repetitive findings of shortfalls across different types of abuse/neglect and across the different needs and risks that practitioners encounter. Common shortfalls include:
  - Absence of (robust) mental capacity assessments
  - Lack of person-centred, relationship-based practice
  - Failure to work together and to use multi-agency (risk management) meetings
  - Lack of management oversight of challenging and complex cases
  - Absence of supervision and failure to seek specialist (legal) advice early

- Why do you think these are repetitive findings?
- Reflecting on common occurring scenarios in your lived experience of work, where do you think there is good practice and what facilitates or enables this?
- Where are there obstacles or barriers that result in practice shortfalls?
- What recommendations would you offer for tackling the barriers?

# How? Why?

- Research pinpoints:
  - Client characteristics leading to neutralisation of moral concerns
  - Unconscious bias
  - Lack of wrap-around integrated provision to respond to trauma and adverse life experiences
  - Desensitisation
  - Complexity of work exacerbated by constraints
  - Policy overload, time and workload pressures
  - Complexity of legal mandates
  - Multi-agency working grafted onto single agency structures

# Final Observations

- We have an evidence-base; we know what positive, good practice looks like.
- We need to focus on what facilitates and what blocks necessary change to “get to good” across the four domains of the evidence-base.

- How embedded is guidance, for example in supervision and decision-making?
- Provide training but consider also the need for workplace development so that what is learned can be applied.

- Develop strategies for local learning , organisational reflection and service development.
- Search and use the SAR library: https://nationalnetwork.org.uk

# Comments & questions

Please contact me if you have any queries:

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# Some references


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