# A Lifestyle Choice? Mental Capacity & Multiple Exclusion Homelessness


LIZZIE FURBER – SOCIAL WORKER

ROUGH SLEEPERS MENTAL HEALTH PROJECT – EAST LONDON NHS FOUNDATION TRUST

ELIZABETH.FURBER@NHS.NET

# Session Outline

- 1.5 hour session. Opportunities for questions throughout – type in the chat.
- The realities of life on the street.
- The specific needs of people experiencing Multiple Exclusion Homelessness.
- The Mental Capacity Act 2005: A brief recap.
- Executive Capacity.
- Autonomy vs. Protection.
- Is service refusal the end of the story?
- Common dilemmas and engagement tips.

# Why does this matter?

July 2019: MS died on the streets of Hackney, aged 63.

MS was open to Adult Social Care and Mental Health “front door” services at the time of his death.

June 2019: Safeguarding referral declined as MS “of no fixed abode”.

MS SAR published November 2020.

Analysis of SARs: self-neglect the most prominent type of abuse/neglect reviewed (Preston-Shoot 2021).

# SAR Recommendations:

- **Legal literacy**: Mental Capacity Act 2005, Care Act 2014, Mental Health Act 1983, as amended 2007, Homelessness Reduction Act 2017.

- **Executive capacity.**

- **Trauma – informed practice.** Seeing the person behind the "problem".

- **Collaborative and coordinated working between agencies.** Multi-agency meetings.

- **Stereotypical assumptions / unconscious bias.** Anti-oppressive practice.

- **Concerned curiosity.** Why is the person making these decisions?

- **Think family.**

# On (not) learning from self-neglect SARs

- First national SAR analysis (Preston-Shoot et. al, 2020) covering a two-year period, April 2017–March 2019, 45% of published and unpublished SARs featured self-neglect (n = 104/231).
- Most recent SAR analysis (Preston-Shoot, 2021): 77 more SARs relating to self-neglect. Multiple Exclusion Homelessness, alcohol dependence and service refusal featured highly.
- Safeguarding Adults Boards are not learning from or building upon the evidence base for best practice when working with people who self-neglect.
- The same themes recur: lack of legal literacy, lack of or poor quality MCA assessments, lack of knowledge about executive capacity, lack of relationship-based practice, lack of concerned curiosity, failure to acknowledge the legal, policy and financial context safeguarding occurs in, inappropriate notions of “lifestyle choice”.

# A Lifestyle Choice?

# Street Life

The average age at death for men who are sleeping rough is 45 years and for women it is 43 years (ONS, 2018).

In 2017 over half of deaths on the street were due to three causes: accidents (predominantly drug overdoses), suicide and liver disease (PHE, 2020).

People who are street homeless are more likely than the general population to have mental health, physical health and substance use related needs (PHE, 2020).

# Street Life

Sanders & Albanese (2016):

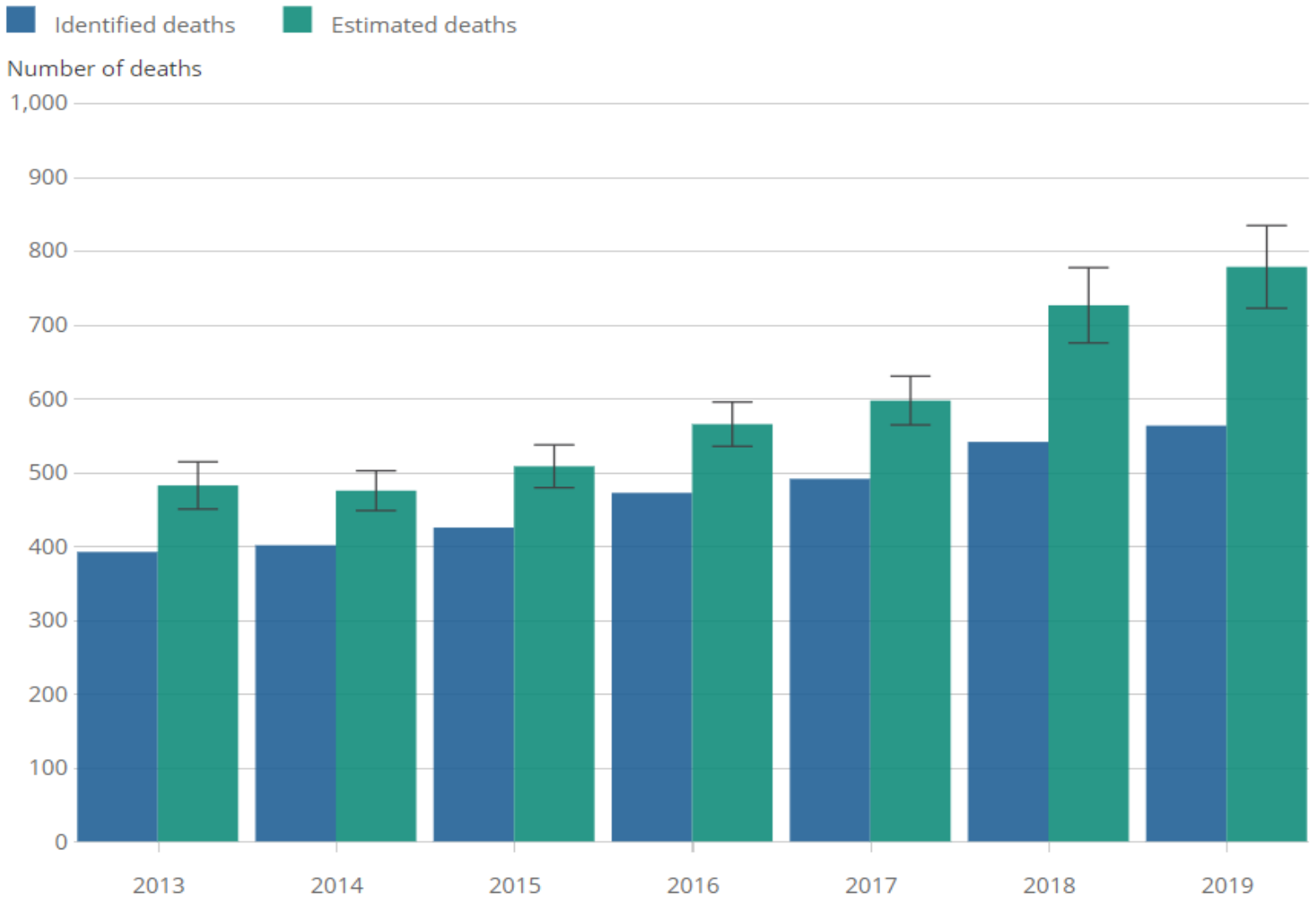
- Three in ten rough sleepers report being deliberately hit or kicked or experiencing another form of violence in the past 12 months (women proportionally more).

- Six per cent of respondents had been sexually assaulted.

- Almost half surveyed said they had been intimidated, or threatened with violence or force, had things thrown at them, been urinated on, experienced verbal abuse rough and harassment. Damage to, and theft of, their personal property was also commonly experienced.

- The report highlighted that rough sleepers live in fear and have to navigate constant risk and uncertainty about their safety. Higher risks for women and the LGBTQ+ community.

## Deaths of homeless people (identified and estimated deaths), deaths registered between 2013 and 2019, England and Wales




**Source: Office for National Statistics – Death registrations**

# Multiple Exclusion Homelessness

Street homelessness is not just a housing issue.

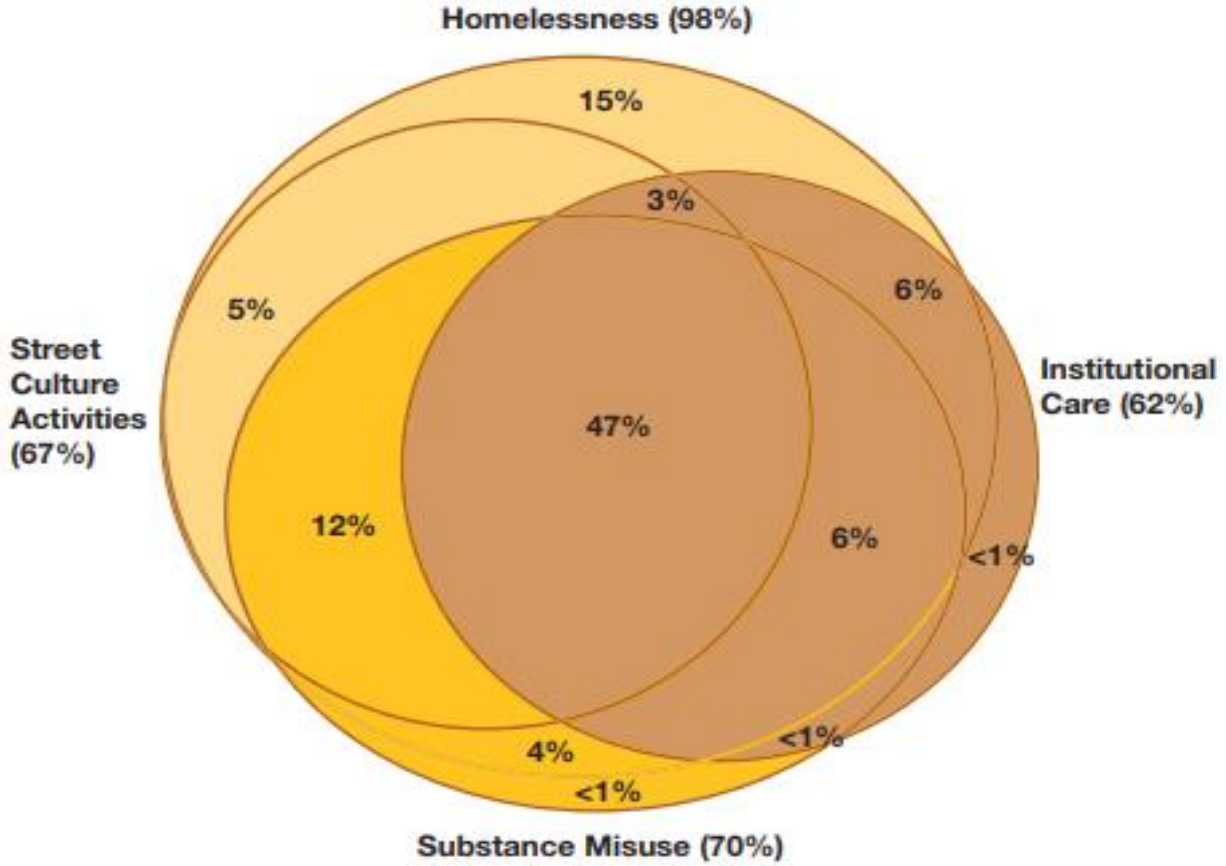
“People have experienced MEH if they have been ‘homeless’ (including experience of temporary/unsuitable accommodation as well as sleeping rough) and have also experienced one or more of the following other domains of ‘deep social exclusion’: ‘institutional care’ (prison, local authority care, mental health hospitals or wards); ‘substance misuse’ (drug, alcohol, solvent or gas misuse); or participation in 'street culture activities’ (begging, street drinking, 'survival' shoplifting or sex work).”

Fitzpatrick et. al, 2011.

“People with complex needs are at serious risk of falling through the cracks in service provision. There needs to be an integrated response across health, housing and social care.”

McDonagh, 2011.

# Figure 1 Overlap between experiences of homelessness and other social issues




(Base: 1,286)
Source: Fitzpatrick et al. Census Questionnaire Survey, 2010

# MEH Research Programme Round-up McDonagh, 2011

- Strong overlap between experiences of more extreme forms of homelessness and other support needs.
- Traumatic childhood experiences such as abuse, neglect and homelessness are part of most street homeless people's life histories.
- High instance of self-harm and suicide in adulthood.
- 'Visible' forms of homelessness – including the use of services like hostels or applying to the council as homeless – commonly happen after contact with non-housing agencies, for example mental health services, drug agencies, the criminal justice system and social services.
- Where homelessness and housing support agencies take on primary responsibility for supporting people with multiple and complex needs, workers can often feel isolated and out of their depth. **Suggestion that housing support workers are now filling the gap left by the retreat of social workers from direct work with adults.**

*The extreme nature of Severe and Multiple Disadvantage was often said to lie in the* ***multiplicity and interlocking nature of these issues and their cumulative impact****, rather than necessarily in the severity of any one of them.*

HARD EDGES, MAPPING SEVERE AND MULTIPLE DISADVANTAGE
BY BRAMLEY & FITZPATRICK ET AL. 2015

# Multiple & interlocking issues?

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# Traumatic Brain Injury

Traumatic brain injury (TBI) is more common in street homeless people than in the general population.

Leeds Study (Oddy, 2012):

48% of street homeless people reported a TBI compared to 21% of the non-homeless control group.

90% sustained first TBI before becoming homeless.

# Traumatic Brain Injury

## CAUSES

- Physical assault (as child or adult)

- Long-term alcohol use (Wernicke-Korsakoff syndrome, alcohol-related dementia)

- Domestic violence (hitting, strangling)

- Road traffic accident

- Seizure

- Brain tumour

-Stroke

## IMPACT

**Cognition & Executive Function**

Difficulty following through with plans. problem solving, imagining consequences of actions, following instructions, impaired memory, confabulation.

**Mood & Behaviour**

Disinhibition, emotional dysregulation, poor tolerance of frustration.

**Physical**

Sensory issues: sound, light.

Mortality: Glasgow Study – homeless people with TBI more than twice as likely to die than general population.

# Mental Distress

- Public Health England 2019 – 50% of people sleeping rough had self-reported mental health needs.

- Prevalence of psychotic illnesses in street homeless people is 50 – 100 times higher than in the general population (Timms, 2016).

- In 2018 the number of street homeless people who died by suicide increased by 30%, compared to 5% increase in the general population (ONS, 2019).

# Psychosis & Homelessness

- Negative symptoms and executive function.

- Hospital admission under the MHA is beneficial for people with a psychotic illness who are street homeless as a result of this and are refusing assistance (Timms 2016, Graham et. Al 1999).

- Challenges ensuring a useful hospital admission for people who are “quietly psychotic”.

# Physical Health

Rough sleeping has a cumulative impact on the person's physical health.

Rough sleepers are likely to present late to healthcare services.

Rough sleepers are more likely to experience strokes and heart disease.

UCL study by Aldridge (2019): A third of deaths in rough sleepers were due to conditions that could have been treated if identified earlier e.g. TB, gastric ulcers.

A group of people living in a hostel for long-term rough sleepers were surveyed re. physical health. The average age of the group was 56. Frailty scores were similar to housed people in their 70s and 80s (Rogans-Watson et. al, 2020).

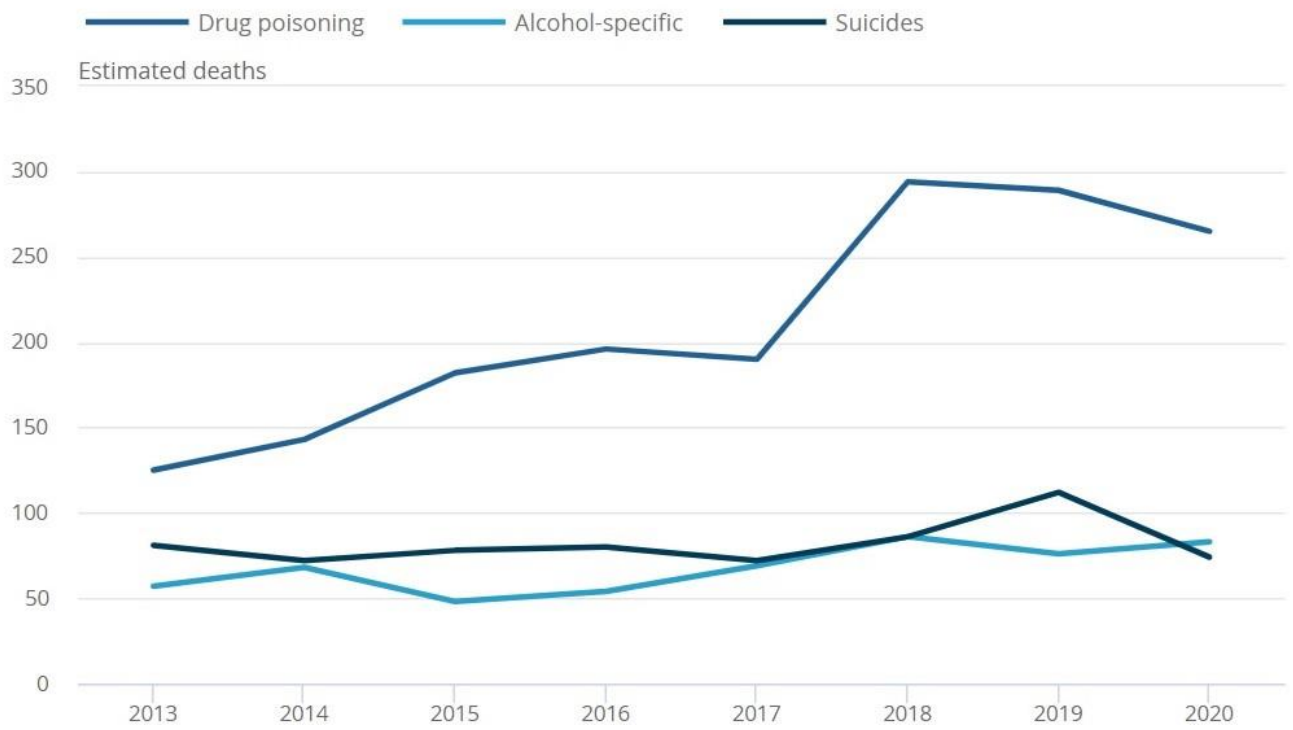
# Substance Use

In 2020:

- 38.5% of deaths of homeless people were due to drug poisoning. This remains the most common cause of death for homeless people.
- Alcohol specific causes were the second most common cause of death at 12.1%.
- Suicide is the third most common cause of death at 10.8%.

(ONS 2021)

**Deaths of homeless people (estimated) by selected causes of death, deaths registered between 2013 and 2020, England and Wales**



# St. Mungo's Report, 2020


- Six in 10 people sleeping rough in London in 2018-19 had a recorded drug or alcohol problem, an extra person in every ten compared to four years previously.
- 65% rise in street homeless women reporting drug and alcohol problems since 2014-2015.
- An estimated 12,000 people sleeping rough or at risk of doing so went without drug and alcohol treatment in England in 2019.
- Drug and alcohol services are often challenging for street homeless people to access, e.g. half of services surveyed required a local connection in order to access treatment, half of services required a person to wait over a week to access OST.
- Drug and alcohol use often precedes homelessness and starts due to adverse life circumstances, therefore making it more difficult to leave the street.
- Street homelessness compounds previous trauma, which can lead to riskier behaviour.

# Alcohol Dependence

*Chronic dependent drinkers may not have a diagnosed mental illness such as schizophrenia; but they are functionally mentally disordered at a level where choice is largely removed from the equation.* (Mike Ward & Michael Preston-Shoot, 2020)

Executive capacity and alcohol dependence.

TB v KB and LH (Capacity to Conduct Proceedings) [2019] EWCOP 14 – man with chronic alcohol dependence found to lack capacity to conduct proceedings as a litigant in person due to executive dysfunction impairing ability to use/weigh relevant information.

- Physical dependence – acute & cumulative impact on physical health.
- Alcohol related brain damage – affects at least 35-40% of this population group (Wilson, 2011).
- Depressant effect of alcohol.
- Physical health problems which impair judgement e.g. low energy levels due to liver disease or confusional states due to pancreatitis and UTIs (Ward & Preston Shoot, 2020).
- Glasgow study: 21% of homeless hostel residents surveyed had alcohol related brain damage (Gilchrist & Morrison, 2005).

# Learning & Literacy Difficulties


Higher prevalence of learning difficulties in the street homeless population compared to the general population. (Thames Reach, 2010)

51% of homeless people lack the basic English skills needed for everyday life, compared to 15% of the general population. (St. Mungo's, 2014)

# Autism Spectrum Disorder

Autism is more prevalent in the street homeless population than in the general population (Churchard et. al, 2017).

- Understanding and adapting to new rules can be a challenge.

- Executive function / following through with plans can be difficult even if the person is highly intelligent.

- Periods of transition (e.g. move on) are particularly stressful.

# Complex Trauma

- Adverse experiences in childhood.

- Trauma that occurs over a long period rather than one specific event.

- Emotional dysregulation.

- Difficulties with interpersonal relationships.

- Feelings of persecution and worthlessness.

- Low tolerance for frustration.

- Self-harm, suicide attempts, substance use.

- Difficulties with executive function.

**Capacity & complex trauma**

People exposed to complex trauma in childhood have higher levels of psychopathology and cognitive impairment at age 18 than both people who have not experienced trauma and people who have experienced non-complex trauma.

(Lewis et. al, 2021)

*What is clear from the literature is that many of those who find themselves engulfed within a life on the streets, do so* ***as a result of early exposure to significant trauma****/ adverse experiences in early childhood*

EVIDENCE REVIEW:

ADULTS WITH COMPLEX NEEDS, PUBLIC HEALTH ENGLAND 2018

# Questions?

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# Mental Capacity Act 2005

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# MCA Principles

Image from Lambeth Safeguarding Adults Board

# Presumption of capacity?

*The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult.*

(House of Lords Select Committee post-legislative scrutiny of MCA 2005, para 105, 2014)

# Unwise Decisions

“A person is not to be treated as unable to make a decision merely because he makes an unwise decision.” MCA 2005, s1(4)

Not the same as the “right” to make unwise decisions.

As well as duties to preserve right to liberty and to private life, state also has duties to act - common law duty of care, duty to preserve right to life.

# MCA s2 “The Diagnostic Test”

**Diagnostic test:**

“Impairment of, or disturbance in the functioning of, the mind or brain.”

Pennine Acute Hospitals NHS Trust v TM [2021] EWCOP 8

“It is a misunderstanding of section 3 MCA 2005 to read it as requiring the identification of a precise causal link when there are various, entirely viable causes.”

**Higher instance in rough sleeping population than general population of:**

Brain injury

Substance use

Childhood trauma

Learning disability

Autism

Mental disorder

# MCA s3 “The Functional Test”

Person lacks capacity to make a decision if they are unable to:

**understand** OR

**retain** OR

**use / weigh** OR

**communicate**

the information relevant to the decision as a result of the impairment identified in the diagnostic test.

*Capacity is decision and time specific.

*Remember principle of taking all practical steps to enable to person to make the decision.

*Consider the information relevant to the decision.

*Relevant information includes information about the consequences of the decision and of not making a decision at all.

# The Causative Nexus

Assessor must demonstrate how the “impairment or disturbance” causes the inability to understand / retain / use or weigh / communicate.

Re. C (adult: refusal of medical treatment) [1994] 1 All ER 819 (QBD)

Man with schizophrenia refusing leg amputation for gangrene despite risk of death if untreated. Court found that despite mental disorder, man had capacity to refuse amputation.

# Executive Capacity

# Put simply:

DECISIONAL CAPACITY

"Talk the talk"

EXECUTIVE CAPACITY

"Walk the walk"

# What is executive capacity?

*"For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain." (MCA s2(1))*

What is "the material time"?

Cameron and Codling (2020) – professionals have created a false rule that the "material time" is during an interview with the professional. This has led to real world evidence and observation being overlooked.

MCA does not state that capacity assessments should take place in interview setting nor that "material time" is for the length of the conversation.

Decision-making usually involves implementing information at a later date.

# What is executive capacity?

For decisions that require the person to apply information at a later date, outside of the interview / capacity assessment, there is a performative as well as decisional element.

**Decisional** – can the person make that decision in that moment, e.g. ability to consent to personal care there and then.

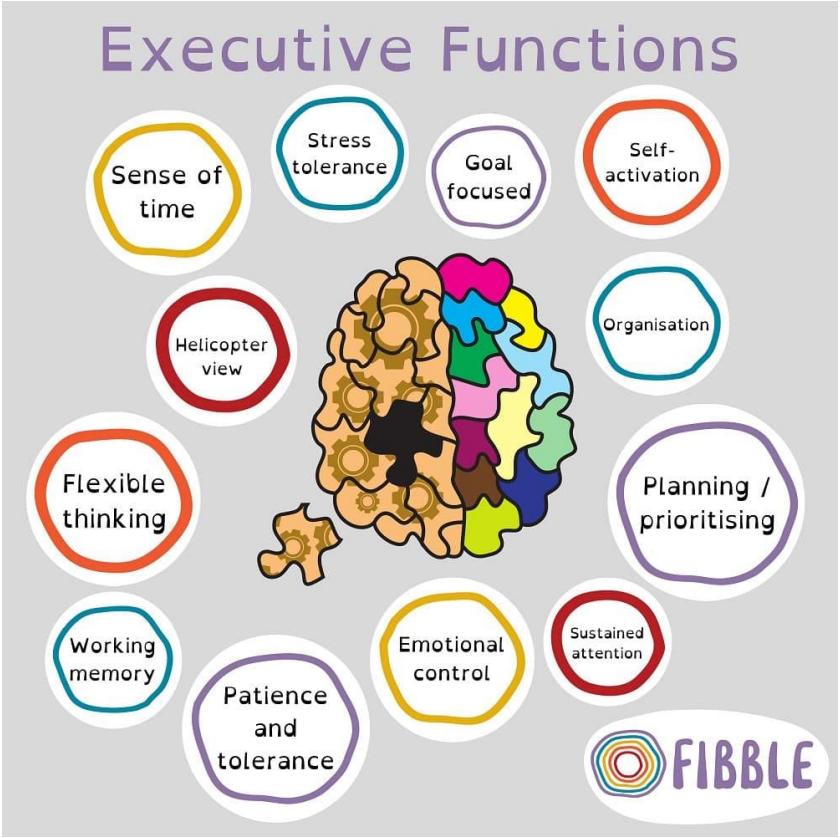
**Performative** – the need to apply information at a later date, e.g. ability to manage finances once benefits payment has been received in the future.

# What is executive capacity?

**Executive function**: "*the ability to think, act, and solve problems, including the functions of the brain which help us learn new information, remember and retrieve the information we've learned in the past, and use this information to solve problems of everyday life*." Cobb J (A Local Authority v AW [2020] EWCOP 24)

Executive dysfunction can be caused by brain injury, psychosis, substance use, complex trauma, epilepsy, autism, etc.

Executive capacity is the ability to follow through with plans and use the information when the "material time" is outside of the assessment.



# MCA & Executive Capacity

The terms “decisional” and “executive” capacity are not mentioned in the MCA or MCA Code of Practice.

Keeping to the language of the MCA is advised when recording capacity assessments.

Executive dysfunction and executive functioning are recognised clinical terms. Psychologists, Occupational Therapists and Psychiatrists can provide clinical evidence to demonstrate executive dysfunction.

Developing body of case law e.g. A Local Authority v AW [2020] EWCOP 24, TB v KB and LH (Capacity to Conduct Proceedings) [2019] EWCOP 14

# MCA & Executive Capacity

39 Essex Chambers (Mental Health Law Specialists, see final slide for link to capacity assessment guide) suggest the following in practice:

You can assess a person as lacking capacity due to inability to use / weigh information if they can't use the information when necessary despite stating that they can.

BUT

Need to support this with evidence of a repeated mismatch of what the person says and what the person does.

AND

Need to explain how the executive dysfunction relates to the functional test. E.g. causes inability to weigh and use information. Causative nexus.

# Executive Capacity, Safeguarding & Homelessness (Preston-Shoot, 2020)

"Mental capacity assessments should explore rather than simply accept notions of lifestyle choice. This means applying understanding of executive capacity and how adverse childhood experiences, trauma, brain injury, and 'enmeshed' situations can affect decision making. Repeating patterns may be one clue here, especially when someone does not follow through on expressed intentions."

# Capacity Assessment Common Dilemmas

Refusal to engage in assessment: Is the person unable or unwilling? Is there someone the person trusts more who could do the assessment? Does the person know why the assessment is taking place? Is the person being coerced into non-engagement? What is the person saying with their behaviour? Consider collateral information and observation.

Professional disagreement: It's usual to have professional differences of opinion. Part of the remit of the Court of Protection is to resolve these differences. Are you the person who knows the person best? Have shown your working and recorded clearly? Is there anyone else who could assess and take a view?

# Capacity Assessment Common Dilemmas

Fluctuating capacity: If the decision is urgent then the person's capacity will need to be assessed based on their presentation in that moment, e.g. intoxicated person is refusing an ambulance for serious injury. If the decision can wait then visit the person at different times to find out when they are most likely to have capacity, e.g. deciding whether the person has capacity to decide where to reside. For people with fluctuating capacity it is important that their capacity is regularly re-assessed. Capacity assessments are time specific. RB Greenwich v CDM [2018] EWCOP 15 "micro & macro capacity".

Executive capacity: Collateral information and real world observation is key in evidencing executive dysfunction. Look for patterns of "disengagement". Request cognitive assessment or OT assessment if possible. Provide a longitudinal picture that brings together one-off or snap shot assessments.

***"These assessments are marathons not sprints."*** (Ward and Preston-Shoot, 2020)

# Questions?

ELIZABETH.FURBER@NHS.NET

# Autonomy vs. Protection

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# To intervene or not?

“What good is it making someone safer if it merely makes them miserable?”

Lord Justice Munby, 2007.

"I record that I have found it deeply shocking to hear how it is possible, in modern Britain, for a relatively young man, living on the streets of a major city, in the enhanced visibility of our present public health crisis, to have suffered in the way that he obviously has.“

Justice Hayden, 2021.

# Autonomy vs. Protection

- Care Act 2014: Making Safeguarding Personal, focus on the person's wishes, move away from disempowering, paternalistic "vulnerability" discourse.
- Care Act 2014: Wellbeing Principle – the individual is best-placed to judge their own wellbeing.
- MCA Principles: presumption of capacity, unwise decisions.
- MCA Best Interests: less restrictive option.
- Human Rights: Art. 5, Art. 8
- Resist the "protection imperative" - Ryder J in Oldham MBC v GW and PW [2007] EWHC 136 (Fam) and many following after.

# Autonomy vs. Protection

- Common Law Duty of Care – duty to maintain the health, safety & wellbeing of others. Manthorpe & Martineau (2019) – SARs show this is not understood by professionals.
- Human Rights: Art. 2 – positive obligation of the state to safeguard the lives of those within its jurisdiction.
- Inaccurate use of law is not empowering: "assuming capacity", not considering CoP, not considering inherent jurisdiction. Consistent SAR themes (Preston-Shoot, 2021).
- Research and analysis: professionals give more weight to autonomy than protection (Braye, Orr, Preston-Shoot 2017).
- Political and policy context: Neoliberalism, individualism, chronic cuts to public services.

*[There is a]* ***danger of collectively prioritising an illusion of autonomy*** *over pragmatic, humane intervention to secure an individual's wellbeing, dignity and right to life. Faced with such ethical and legal complexities, practitioners fall back on service user choice and self-determination as a means of managing dissonance arising from ambiguities in public policy and law* ***with the result that some people are essentially abandoned****.*

AUTONOMY & PROTECTION IN SELF-NEGLECT WORK:

THE ETHICAL COMPLEXITY OF DECISION MAKING

(BRAYE, ORR, PRESTON-SHOOT 2017)

# Is service refusal the end of the story?

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You come up and say, "I'm your social worker," and I'm gonna think, "Well fuck off then!" I had social worker when I was a kid and people still didn't believe what was going on at home. I had a social worker in prison and was still released to the street. A social worker took my kids away. A social worker locked me up in the nuthouse. No social worker has ever helped me so why am I going to listen to you?

I remember you. You came to see me when I was on the street. But I didn't know if you were real. I was being followed, or I thought I was. It was frightening so I kept running away.

I know I was rude, but you came just as I was waking up and I was rattling. I needed to get some money and get sorted. I'd got myself in a terrible state really. It was embarrassing to admit. Why would you be offering me help? I didn't think you'd care enough to come back.


Phone appointments
Opt in letters
Waiting lists
Silo'd services
"That's a housing issue"
"Take responsibility"
"CHALLENGING TO ENGAGE"

# Engagement tips

- Be compassionate, be patient, be human.

- Engagement is a two way street. What can you offer them?

- Organise to meet the person when / where is best for **them.**

- Acknowledge that the person will have had negative experiences with statutory services, potentially dating back to early childhood. How is your service different? Sewell 2021, Toxic Interactions Theory.

- Model secure attachment: Consistency, compassion, reliability, tolerance of extremes of emotion, advocacy. Williamson 2012, “The Dependency Paradox”.

- An assertive outreach model has been shown to work best for engaging long-term rough sleepers (Philips & Parsell, 2012). If your service doesn’t allow this, visit the person with a worker they trust.

# I've had a referral for a rough sleeper, what do I do?

- **Go to see the person**. Could be at sleep site, at begging site, in a café, in a park. Do a joint visit with the outreach team. Outdoor visits are low risk for COVID transmission.

- **Assess** needs, risk and capacity to decide to sleep rough.

- If refusing assistance **consider use of legislation**: MCA & CoP, MHA.

- **Advocate** – supporting letter for benefits application, supporting letter for housing application ("more vulnerable than ordinarily vulnerable"), challenge intentionality decisions.

- **Relationship building**. Research shows that people value consistency – seeing the same worker, the worker following through with agreed actions, the worker responding to attempts to make contact (Wilberforce et. al. 2020).

- **Multi-agency meetings**. Outreach workers are skilled and knowledgeable but need support from statutory services. High risk panels.

- **Concerned curiosity** & **respectful challenge** of service refusal and concerning decisions.

# Questions?

ELIZABETH.FURBER@NHS.NET

# Resources

Pathway, Mental Health Service Interventions for People Sleeping Rough
https://www.pathway.org.uk/publication/mental-health-service-interventions-for-people-sleeping-rough/

Mike Ward and Michael Preston-Shoot (2020), Safeguarding Vulnerable Dependent Drinkers
https://proceduresonline.com/trixcms2/media/14068/safeguarding-vulnerable-dependent-drinkers.pdf

Michael Preston-Shoot (2020) Safeguarding and homelessness: a briefing on positive practice
https://www.local.gov.uk/publications/adult-safeguarding-and-homelessness-briefing-positive-practice

Dr Emma Cameron and James Codling (2020), *When mental capacity assessments must delve beneath what people say to what people do*, Community Care https://www.communitycare.co.uk/2020/10/28/mental-capacity-assessments-must-delve-beneath-people-say/

39 Essex Chambers Mental Capacity Guidance Note: Carrying out and Recording Capacity Assessments – May 2021
https://1f2ca7mxjow42e65q49871m1-wpengine.netdna-ssl.com/wp-content/uploads/2021/05/Mental-Capacity-Guidance-Note-Capacity-Assessment-May-2021.pdf