

EFFECTIVE PRACTICE IN SELF-NEGLECT: MESSAGES FROM RESEARCH

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Presented by Suzy Braye
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The focus of the presentation

- The challenges of self-neglect work
- What goes wrong? Findings from SCRs/SARs
- What goes right? Promoting positive outcomes
- Building an effective infrastructure for interagency communication, decision-making and risk management

What do we mean by self-neglect?

Neglect of self-care	Neglect of domestic environment
<ul style="list-style-type: none"> ■ Personal hygiene ■ Nutrition/hydration ■ Health 	<ul style="list-style-type: none"> • Hoarding • Squalor • Infestation
<p>To such an extent as to endanger health, safety and/or well-being Refusal of services that would mitigate risk of harm</p>	

'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, 14.17)

'Where someone demonstrates lack of care for themselves and/or their environment and refuses assistance or services. It can be long-standing or recent.' (DH 2016, Annex J: Glossary)

Self-neglect: a new domain of adult safeguarding

No Secrets 2000

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Care Act 2014

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

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

Bringing self-neglect in from the cold...

The research

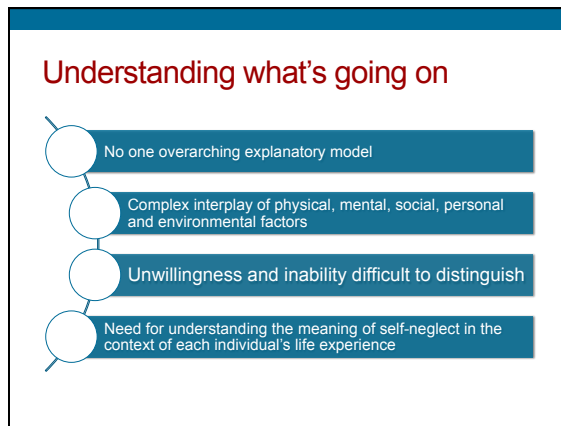
Scoping the concept of self-neglect 2011

SAB governance 2011

Workforce development needs 2013

Review of SCRs and SARs 2013-14

Exploring self-neglect practice 2013-14



Understanding the lived experience: self-care

- Demotivation:** self-image, negative cognitions
- Different standards:** indifference to social appearance
- Inability to self-care:** physical and practical challenges

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'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, very tired, and people who don't have it don't understand ... 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: environment

- Influence of the past:** childhood, loss, abuse, bereavement
- Positive value of hoarding:** emotional comfort, a sense of connection, utility
- Beyond control:** voices, obsessions, physical ill-health, lack of space

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.
 The distress of not collecting is more than the distress of doing it.

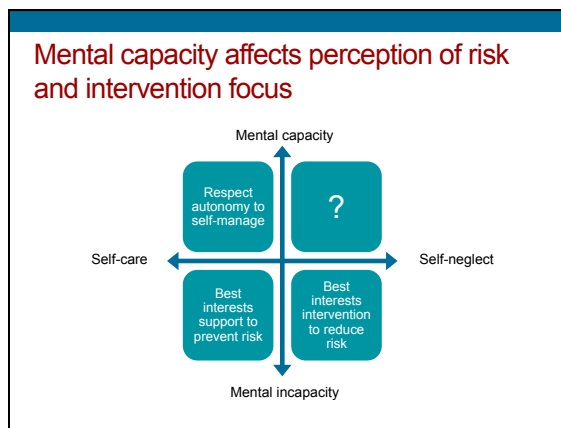
Competing moral imperatives: challenges to professional values

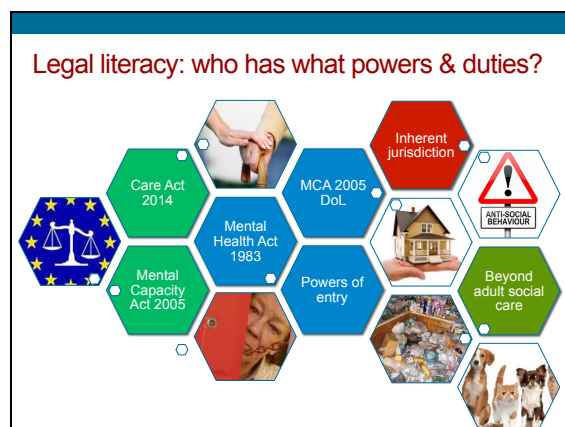
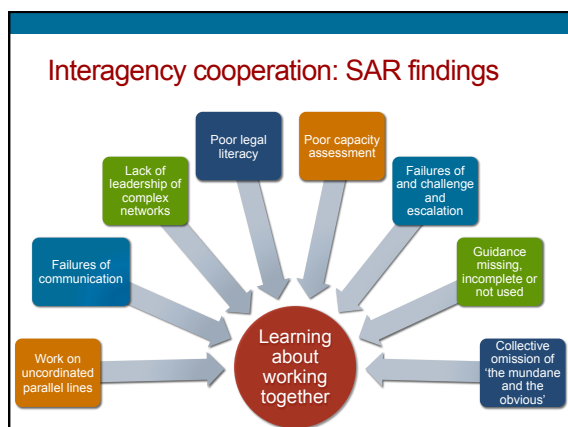
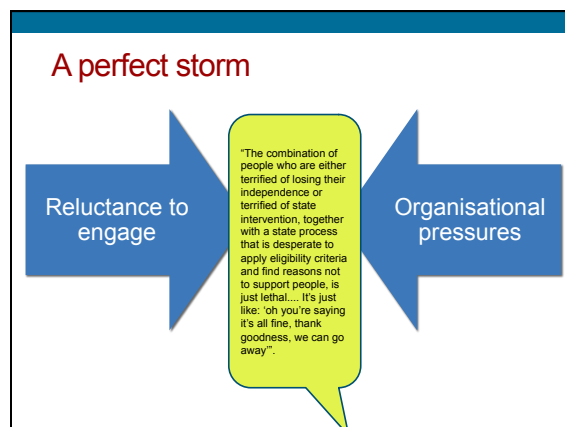
Respect for autonomy & self-determination

- Professional codes of ethics
- Right to make decisions others think unwise (MCA 2005)
- Limits to the power of the state (800 years of 'unwritten constitution')
- ECHR articles 8 and 5
- Personalisation: making safeguarding personal

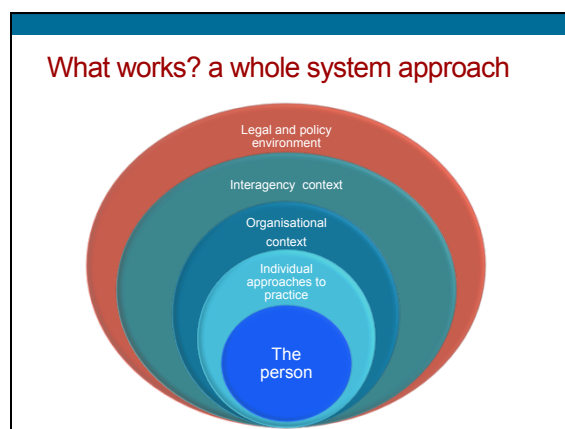
Duty to protect and promote dignity

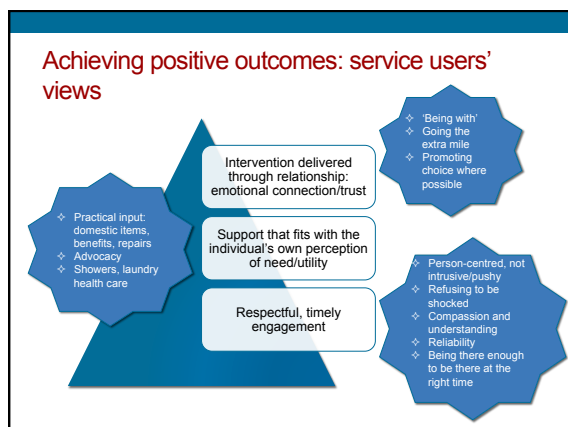
- The state's duty to protect citizens from foreseeable harm
- Extreme self-neglect compromises human dignity – "surely someone could/should have done something"
- ECHR articles 2 and 3
- Risk to others





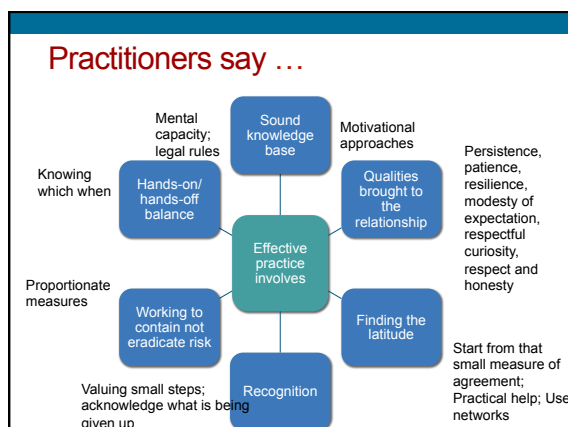
- ### What works? Limited previous evidence
- No 'gold standard' evidence in the literature
 - Cleaning may help, but by itself is not likely to be effective in the longer term
 - Assistance with routine daily living tasks can be effective in building trust, ensuring basic standards and mediating risks
 - Combined approaches: MI, CBT, sorting tasks
 - Debate over effectiveness of SRI medication for hoarding – not consistently effective





People who self-neglect say ...

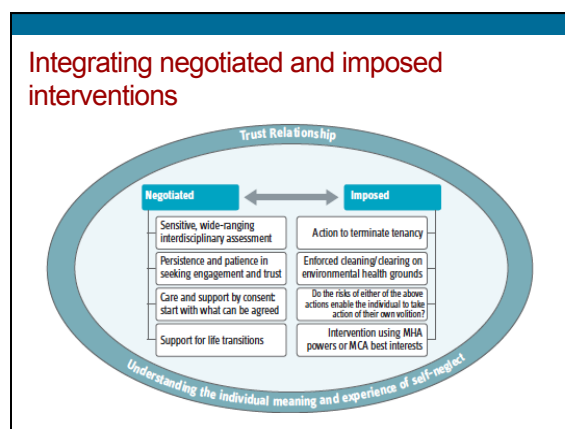
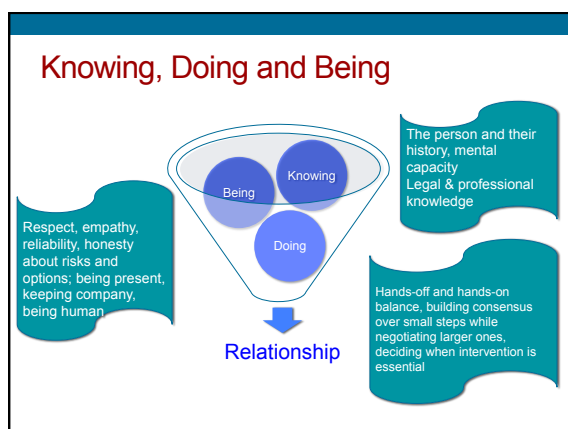
"Recognising self-neglect earlier I think is important ... Then, like I say, the idea is not to get too pushy about it, people start getting panicky then, you know? 'You're interfering in my life', that kinda thing."
 "He's down to earth, he doesn't beat around the bush. If there is something wrong he will tell you. If he thinks you need to get this sorted, he will tell you."
 "She got it into my head that I am important, that I am on this earth for a reason."
 "... He sees the needs ... goes that extra mile."
 "Tenancy support started coming up but they weren't helping, they were just leaving it for me to do. Whereas when x and his colleagues came, they were sort of hands on: 'Bump! We've got to do this' ... 'shall we start cleaning up now?'"
 "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."
 "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."
 "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."
 "He has been human, that's the word I can use; he has been human."

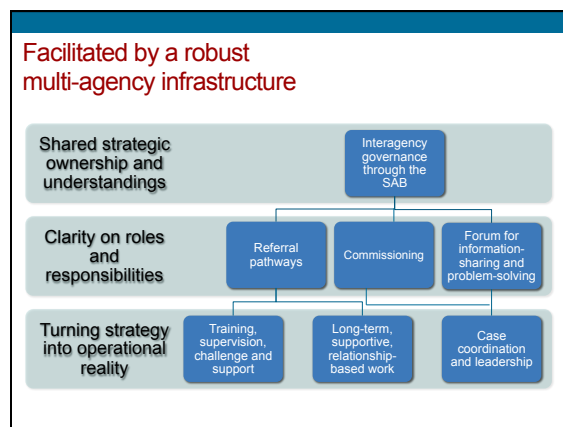
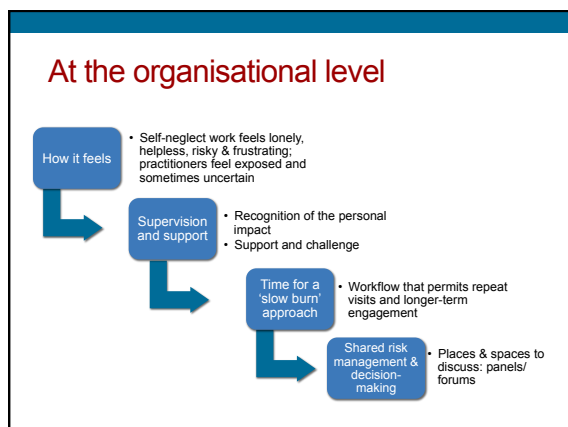


Engaging with the complexity of capacity

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- Mental capacity involves
 - The ability to understand and reason through the elements of a decision
 - And
 - The ability to realise when that decision needs to be put into practice and execute it at the appropriate moment
- Impaired **executive** function (frontal lobe impairment) may impair
 - Understanding, retaining, using and weighing relevant information
 - And
 - Planning, problem-solving, enacting a decision in the moment
- 'Articulate and demonstrate' models of assessment
 - GW v A Local Authority [2014] EWCOP20





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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

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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

References: Research reports

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- 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.

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