EFFECTIVE PRACTICE IN SELF-NEGLECT: MESSAGES FROM RESEARCH

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What do we mean by self-neglect?

Neglect of self-care
- Personal hygiene
- Nutrition/hydration
- Health

Neglect of domestic environment
- Hoarding
- Squalor
- Infestation

To such an extent as to endanger health, safety and/or well-being.

Self-neglect: this covers a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behavior 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
- 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

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 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

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

The research
What are the challenges of self-neglect?

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

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

Understanding the lived experience: environment
- Influence of the past: childhood, loss, abuse, bereavement
- Positive value of hoarding: emotional comfort, a sense of connection, utility

Competing moral imperatives: challenges to professional values
- 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

Mental capacity affects perception of risk and intervention focus
Organisational context

Workflow that assumes short term engagement

- Time-limited progression through stages
- No time for relationship-building

A perfect storm

Reluctance to engage
Organisational pressures

"The combination of people who are either 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 like: 'Oh you're saying it's all fine, thank goodness, we can go away'."

Interagency cooperation: SAR findings

Learning about working together

- Work on uncoordinated, parallel lines
- Failures of communication
- Lack of leadership of complex networks
- Poor legal literacy
- Poor capacity assessment
- Failures of escalation
- Guidance missing, incomplete or not used
- Collective omission of the mundane and the obvious

Legal literacy: who has what powers & duties?

- Care Act 2014
- Mental Health Act 1983
- MCA 2005
- DoL
- Inherent jurisdiction

Beyond adult social care

Legal and policy environment

Interagency context
Organisational context
Individual approaches to practice

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

What works? a whole system approach

Legal and policy environment
Interagency context
Organisational context
Individual approaches to practice
The person
Achieving positive outcomes: service users’ views

Intervention delivered through relationship:
emotional connection/trust
Support that fits with the individual’s own perception
of need/utility
Respectful, timely engagement

Practitioners say …

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Engaging with the complexity of capacity

Mental capacity involves
- The ability to understand and reason through the elements of a decision
- 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

Executive capacity

Knowing, Doing and Being

Knowing, Doing and Being

Integrating negotiated and imposed interventions

People who self-neglect say …

Practitioners say …

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At the organisational level

**How it feels**
- Self-neglect work feels lonely, helpless, risky & frustrating: practitioners feel exposed and sometimes uncertain
- Recognition of the personal impact
- Support and challenge

**Supervision and support**
- Workflow that permits repeat visits and longer-term engagement
- Time for a slower burn approach
- Shared risk management & decision making
- Phases & spaces to discuss: panels, forums

**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

**Facilitated by a robust multi-agency infrastructure**

**Shared strategic ownership and understandings**
- Shared 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

**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**

**References: Journal articles**

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