UNDERSTANDING AND RESPONDING TO SELF-NEGLECT: WHAT GOES WRONG AND WHAT GOES RIGHT?

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9th December 2016

The research

- Literature review
- SAB survey
- Practitioner focus groups
- Analysis of SCRs and SARs
- Interviews with service users, practitioners and managers
What do we mean by self-neglect?

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

Neglect of the living environment
- Hoarding (hoarding disorder)
- Squalor
- Infestation

Risk to safety and wellbeing
Refusal of services that would mitigate harm

“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)

Bringing self-neglect in from the cold…

SAB oversight of measures to help and protect

Safeguarding
Adult social care
Multiagency process
The key challenges of self-neglect

1. 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: 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 wouldn’t say I let my standards slip; I didn’t have much standards to start with.”

  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

- **Influence of the past:** childhood, loss
- **Positive value of hoarding:** a sense of connection, utility
- **Beyond control:** voices, obsessions

  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.
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 duty to protect from foreseeable harm
- Human dignity compromised
- ECHR articles 2 and 3
- Risk to others

A more nuanced approach

- Respect for autonomy may entail
  - Questioning 'lifestyle choice'
  - Respectful challenge
- Protection does not mean
  - Denial of wishes and feelings
  - Removal of all risk

Autonomy does not mean abandonment
Protection entails proportionate risk reduction

"Respecting lifestyle choice isn’t the problem; it’s where people don’t think they’re worth anything different, or they don’t know what the options are."
3. Mental capacity: affects perception of risk and intervention focus

Understanding mental capacity

- Mental capacity involves
  - The ability to understand and reason through a decision AND the ability to enact it in the moment

- Impaired *executive* function (frontal lobe impairment) affects
  - Understanding, retaining, using and weighing relevant information in real-time problem-solving

- ‘Articulate and demonstrate’ models of assessment
  - GW v A Local Authority [2014]
    EWCOP20
4. Legal literacy: who has what powers & duties

- Care Act 2014
- Mental Health Act 1983
- Mental Capacity Act 2005
- Children Act 1989
- Powers of entry
- Beyond adult social care
- Inherent jurisdiction

5. The organisational context: a perfect storm

Reluctance to engage
Organisational pressures

"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'".
Creating a supportive organisational environment

**Supervision and support**
- Recognition of the personal impact
- Support and challenge

**Time for a ‘slow burn’ approach**
- Workflow that permits repeat visits and longer-term engagement

**Shared risk management & decision-making**
- Places & spaces to discuss: panels/forums

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6. Interagency cooperation: SAR findings

- **Lack of leadership and coordination**
- **Service standards**
- **Relationship dynamics**
- **Legal literacy: Mental capacity**
- **Failures of communication**
- **Collective omission of ‘the mundane and the obvious’**

**Learning about working together**

- Work on uncoordinated parallel lines
What makes for robust interagency working?

Shared strategic ownership and understandings

Interagency governance

Clarity on roles and responsibilities

Referral pathways

Commissioning

Forum for shared risk management

Turning strategy into operational reality

Training, supervision, support

Space for relationship-based work

Case coordination and leadership

Multi-agency governance

Organisational infrastructure

Legal literacy

Relationship-based practice

Moral reasoning

The person

Whole system alignment
Service user views: the importance of relationship

Intervention delivered through relationship: emotional connection/trust

Support that fits with the individual’s own perception of need/utility: practical input

Respectful engagement

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

“He has been human, that’s the word I can use; he has been human.”

“He’s down to earth, he doesn’t beat around the bush. If there is something wrong he will tell you.”

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.

Practitioners say …

Sound knowledge base

Effective practice involves

Qualities brought to the relationship

Working to contain not eradicate risk

Finding the latitude

Recognition

Hands-on/ hands-off balance
Knowing, Doing and Being

Integrating negotiated and imposed interventions
### In summary: practitioner approaches

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<th>Practice with people who self-neglect is more effective where practitioners</th>
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<tr>
<td>Build rapport and trust, showing respect, empathy, persistence, and continuity</td>
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<td>Seek to understand the meaning and significance of the self-neglect, taking account of the individual’s life experience</td>
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<td>Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes</td>
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<td>Keep constantly in view the question of the individual’s mental capacity to make self-care decisions</td>
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<td>Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility</td>
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<td>Ensure that options for intervention are rooted in sound understanding of legal powers and duties</td>
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<td>Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks</td>
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<td>Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals</td>
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### In summary: organisational approaches

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<th>Effective practice is best supported organisationally when</th>
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<td>Strategic responsibility for self-neglect is clearly located within a shared interagency governance arrangement such as the SAB</td>
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<td>Agencies share definitions and understandings of self-neglect</td>
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<td>Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems</td>
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<td>Longer-term supportive, relationship-based involvement is accepted as a pattern of work</td>
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<td>Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice</td>
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Research reports

  - (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.

Journal articles


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