SELF-NEGLECT:
EVIDENCE BASE AND IMPLICATIONS FOR PRACTICE

• Professor Suzy Braye & Dr. David Orr, University of Sussex
• Professor Michael Preston-Shoot, University of Bedfordshire

Presented by David Orr
Adult Safeguarding: Changes, Challenges and Opportunities
Conference, 12th June 2015
Plymouth
SELF-NEGLECT: EVIDENCE BASE AND IMPLICATIONS FOR PRACTICE

- What’s new in working with self-neglect?
- What’s so difficult about it anyway?
- What do people with experience of being in situations of self-neglect have to say about it?
- How can we achieve better outcomes?

“I have come to believe that caring for myself is not self-indulgent. Caring for myself is an act of survival.” – Audre Lorde
**The Care Act: bringing self-neglect in from the cold...?**

**No Secrets**
- Self-neglect outside ‘vulnerable adult’ definition – third party risk only
- Does 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
- s.42 duty to ‘make enquiries’
“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 2014, p234)
FORMS OF SELF-NEGLIGENCE:

Lack of self-care

- Personal hygiene
- Care of daily needs (e.g., nutrition)
- Non-compliance with services (especially medical)
- ‘Risky’ behaviour

Lack of care for environment

- Living in squalor
- Hoarding
- Animal collecting
- ‘Diogenes syndrome’
WHAT IS SELF-NEGLECT?
SHADES OF COMPLEXITY

- Self-neglect can arise from unwillingness or inability to care for oneself, or both:

[Diagram: Venn diagram with two overlapping circles labeled 'UNWILLINGNESS' and 'INABILITY']
SELF-NEGLIGENCE PRESENTS CHALLENGES ON MANY LEVELS:

- Legal and policy environment
- Organisational context
- Individual approaches to practice
- The person
Engaging with the individual
Understanding underlying causes
Uncertainty about legal frameworks
Thresholds for intervention
Frustration, anxiety, not knowing ‘what works’
A duty of care, to secure dignity, even where mental capacity is present, is valued and in some cases prioritised over autonomy.

Communities are also seen as having rights that counterbalance those of individuals.
“Where services are more focused on encouraging choice and independence, it becomes more of a battle against the ethos of their organisation – we commission someone because they’re very good at promoting independence, and then we tell them they have to curtail that independence in certain circumstances. It's easy in safeguarding where they’re putting themselves obviously at risk with a perpetrator ... there is a degree of social judgement in self-neglect, and it causes anxiety.”
Mental capacity is a key challenge

- The right to make unwise decisions ...

- ... but some concerns about how this may be applied:

  “There can be a feeling of ‘It’s not my job. It’s not a duty of care. If they have capacity and they don’t want to engage, then that’s my duty of care fulfilled.’”

  “How far do you go with that case, when they’re inflicting it on themselves? [...] And there can be quite a judgemental attitude…”

  “Because to me it’s too easy to walk away from situations by saying, ‘Well, they’ve got capacity’ [...] They may have capacity to actually understand and process that information, but they haven’t got the wherewithal to actually deal with the situation and rectify it in any way.”
CHALLENGES FOR ORGANISATIONS

- Finding a ‘home’ for self-neglect
- Workflow patterns based on time-limited care management
- Diverse agency cultures, practices and priorities
- Establishing clarity around information and decision sharing
Sources of Research Evidence

- Scoping the concept of self-neglect 2011
- Addressing workforce development needs 2013
- Review of serious case reviews 2015
- Exploring self-neglect practice 2014
The research design of the most recent study

What policy/practice approaches are associated with perceived positive outcomes in self-neglect intervention?

National survey (34.9% response)

In-depth interviews (10 authorities)

Managers (20)

Practitioners (42)

Service users (29)

National Social Care Research Ethics approval: Reference 13/IEC08/0013
## WHAT DO WE KNOW ABOUT SELF-NEGLECT?

SELECTED SURVEY RESPONSES

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you routinely collect data about self-neglect?</td>
<td>Yes</td>
<td>9.1%</td>
</tr>
<tr>
<td>How confident are you in your answer about the volume of self-neglect cases?</td>
<td>Very confident</td>
<td>9.1%</td>
</tr>
<tr>
<td>Is self-neglect explicitly defined, or are examples given, in any of your guidance?</td>
<td>Yes</td>
<td>52.7%</td>
</tr>
<tr>
<td>What has been most challenging about working with self-neglect?</td>
<td>Challenges around capacity and refusal to accept help</td>
<td>80%</td>
</tr>
</tbody>
</table>
Often a complex interplay between some of:

- **Physical health issues**
  - Impaired physical functioning; pain; nutritional deficiency

- **Mental health issues**
  - Depression; mental health problems; frontal lobe dysfunction; impaired cognitive functioning

- **Substance misuse**
  - Alcohol; substance misuse

- **Psychological and social factors**
  - Diminished social networks; limited economic resources; lack of access to social or health services; personality traits; traumatic histories and life-changing events; high perceived self-efficacy; personal philosophy

- **No one overarching explanatory model for understanding**

- **Need for understanding of the meaning of self-neglect in the context of each individual’s life experience**
But this can be difficult...

Shifting responses

- Refusal or withdrawal of permission for access
- Avoidance or deflection of involvement
- Permission for access and discussion, but outright rejection of support
- Partial acceptance of input
- Full acceptance of input
“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.”

“Well I don’t know to be honest. Suddenly one day you think, ‘What am I doing here?’”

“My possessions are my family ... I’m very fearful of throwing something away.”

“I got it in my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.”

“I’ve noticed over the years that I didn’t give two monkeys ... I seemed to have plenty of time to do everything but I don’t seem to have the time now.”

“I can’t physically bend down and pick things up.”

“I put everyone else first – and that’s how the self-neglect started.”
Service users’ perspectives

Neglect of self-care

- Demotivation: homelessness, health, loss, isolation – self-image, negative cognitions
- Different standards: indifference to social appearance or ‘other priorities’
- Inability to self-care: mental distress, physical ill-health, homelessness

Neglect of environment

- Influence of the past: childhood, loss, abuse, bereavement
- Positive value of hoarding: emotional comfort, connection to something, “my family”, hobby, to be appreciated by others
- Beyond their control: voices, obsessions, physical ill-health, lack of space
WHAT HELPS TO GET ENGAGEMENT IN SELF-NEGLECT?

Recognising openness to involvement, even if ambiguous
A sense of timing
Keeping the door open
Ensuring there is awareness and access to available help
Honest recognition with service users of when they may have little or no choice in the matter
Working with service users to provide the right kind of input: not intrusive, cost considerations, encouraging, hands-on, person-centred, going the extra mile, reliable, compassionate, understanding
What works?

- Early intervention to prevent entrenched patterns
- Combined approaches: MI, CBT, sorting, tasks
- Assistance with routine daily living
- Psychotropic medication in some cases
- Cleaning as a short term solution only
- Harm reduction, not symptom reduction
Learning from SCRs

- Nature and timeliness of capacity assessments
- Training on working in the context of service refusal
- Support for the professionals involved
- Clarification of relationship with safeguarding
- Communication and information sharing, and follow up of referrals
- Multi-agency arrangements for shared/single assessment processes
- Lead/coordinating manager for real-time management of risk
**WHAT HELPS ACHIEVE POSITIVE OUTCOMES? SERVICE USERS’ VIEWS**

**Respectful, timely engagement**
- Spotting motivation and being there at the right time
- Encouraging, person-centred, not intrusive, directive, pushy
- Someone who goes the extra mile, is reliable and understanding

**Intervention delivered through relationship**
- ‘Being with’ the person when they are making changes, promoting choice where possible

**Support that is relevant to the service user’s own perception of needs**
- Practical input, equipment, benefits, advocacy, housing
- Access to mental health services
- Links with others
WHAT HELPS ACHIEVE POSITIVE OUTCOMES?
Practitioners’ views

- Self-neglect work is often challenging, so practitioners may need spaces for discussion and management support for a ‘slow burn’ approach.
- Collaborative work with other agencies and neighbours / family networks.
- Understanding of motivational approaches, mental capacity and legal powers.
- Qualities of persistence, patience, resilience, respectful curiosity, respect and honesty.
- Balance of hands-off and hands-on approaches, knowing which when.
- The ability to take baby steps, value small achievements, recognise what is being given up and what can take its place.
WORKING THROUGH NEGOTIATED AND IMPOSED APPROACHES

Trust Relationship

Negotiated
- Sensitive, wide-ranging interdisciplinary assessment
- Persistence and patience in seeking engagement and trust
- Care and support by consent: start with what can be agreed
- Support for life transitions

Imposed
- Action to terminate tenancy
- Enforced cleaning/clearing on environmental health grounds
- Do the risks of either of the above actions enable the individual to take action of their own volition?
- Intervention using MHA powers or MCA best interests

Understanding the individual meaning and experience of self-neglect
**Implications for 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 and skills involved in self-neglect practice
FURTHER INFORMATION


