Institution: University of Sussex

Unit of Assessment: 20 – Social Work and Social Policy

Title of case study: Shaping policy and practice in self-neglect and adult safeguarding

Period when the underpinning research was undertaken: 2010 – 2015

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
David Orr	Lecturer / Senior Lecturer	2011 – present
Suzy Braye	Professor	2005 – 2014. Emeritus since 2015

Period when the claimed impact occurred: 2014 – 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Although self-neglect poses significant risks of harm, or even death, its place in policy was unclear and little was known about effective practice. Sussex research demonstrated the need for clear policy and pathways for interagency collaboration, and identified effective approaches to intervention based on enhanced understanding of self-neglect's causes. This directly contributed to legal and policy changes making Safeguarding Adults Boards (SABs) mandatory in England and naming self-neglect a statutory responsibility to be addressed through local health and social care safeguarding policies. The research helped shape those policies, set practice standards and directly influenced professionals' work with people who self-neglect.

2. Underpinning research

Self-neglect encompasses neglecting to care for personal hygiene, health and/or home surroundings, and may result in severe health issues, fire risks and death. Braye (Sussex), Orr (Sussex) and Preston-Shoot (University of Bedfordshire) worked closely together on a series of studies on policy and practice challenges in self-neglect and safeguarding, 2009-2014, across which all three researchers shared equal roles in research design, data collection, analysis and write-up. Three studies were particularly key:

Governance of Adult Safeguarding and Scoping Self-Neglect Policy & Practice: The Department of Health (England) (DH) funded research exploring (i) overall governance of adult safeguarding and (ii) conceptual and practice approaches to self-neglect (Dec 2009-May 2010). Through a rigorous review, policy analysis, and stakeholder workshops / interviews, the research:

- explored models of safeguarding governance, identified governance arrangements associated with strong performance, and recommended that government legislate to put adult safeguarding governance on a sounder footing; (R1)
- mapped the forms self-neglect can take and how it has been conceptualised and operationalised, assisting policy-makers, stakeholders and researchers to work towards definitions for policy and practice guidance;
- found that English local safeguarding policies rarely covered self-neglect and UK-based research literature was scant, highlighting the absence of clarity on service responsibilities for self-neglect and effective practice;
- identified multiple factors contributing to self-neglect, to inform assessment and aid professional recognition and awareness of the issue, and explored the complex, nuanced nature of mental capacity in self-neglect decisions;

- theorised the legal, ethical and practice dilemmas, exploring why people may apparently 'choose' to self-neglect and how professionals should respond in this situation, by addressing risks while respecting individual autonomy;
- explored the range of agencies that should be involved in self-neglect cases and the need for structures to underpin collaboration, enabling a coordinated and effective response to self-neglect. (R2, R6)

Identifying Good Practice in Self-Neglect: DH funded further research into effective practice, to inform major reforms to adult social care legislation (Mar 2013-Jan 2014). Based on a national survey and in-depth interviews with managers, practitioners, and the largest sample to date within qualitative research of people who self-neglect, the findings demonstrated how relationship-based practice, skilled legal literacy, creative interventions, and meaningful multi-agency working could lead to positive outcomes. They also evidenced how inter-agency governance, training and supervision, referral pathways, and meaningful data capture can support effective practice. (R3, R5)

Learning from Serious Case Reviews (SCRs) of Self-Neglect: SCRs, now renamed Safeguarding Adults Reviews (SARs), are inquiries required in law where there are concerns about agency effectiveness in working to protect individuals from serious abuse or neglect, in order to identify lessons learned. This research was the first to comprehensively collate and analyse SCR/SARs featuring self-neglect (Mar-Aug 2014). The study identified 32 such SCRs and extracted 19 recurring themes to inform service improvements. (R4)

3. References to the research

The research findings have been published in the form of four research reports, two book chapters and six journal articles. All journal articles were blind-reviewed by at least two peer reviewers; three won publisher awards for quality. Selected key references include:

R1. Braye, S., Orr, D. and Preston-Shoot, M. (2012), "The governance of adult safeguarding: findings from research", *The Journal of Adult Protection*,14 (2): 55-72.https://doi.org/10.1108/14668201211217512 [Outstanding Paper Award Winner, Emerald Literati Network Awards for Excellence 2013]

R2. Braye, S., Orr, D. & Preston-Shoot, M. (2011) *Self-neglect and Adult Safeguarding: Findings from research*. London: Social Care Institute for Excellence. http://www.scie.org.uk/publications/reports/report46.asp

R3. Braye, S., Orr, D. & Preston-Shoot, M. (2014) *Self-neglect policy and practice: Building an evidence base for adult social care.* London: Social Care Institute for Excellence. http://www.scie.org.uk/publications/reports/69-self-neglect-policy-practice-building-an-evidence-base-for-adult-social-care/files/report69.pdf

R4. Braye, S., Orr, D. & Preston-Shoot, M. (2015) 'Serious case review findings on the challenges of self-neglect: indicators for good practice,' *Journal of Adult Protection 17(2): 75-89.* http://dx.doi.org/10.1108/JAP-05-2014-0015 [Highly Commended Paper Award Winner, Emerald Literati Network Awards for Excellence 2016]

R5. Orr, D., Preston-Shoot, M. & Braye, S. (2019) 'Meaning in hoarding: perspectives of people who hoard on clutter, culture, and agency,' *Anthropology & Medicine 26(3): 263-279*. https://doi.org/10.1080/13648470.2017.1391171

R6. Braye, S., Orr, D. & Preston-Shoot, M. (2017) 'Autonomy and Protection in Self-neglect Work: the Ethical Complexity of Decision-making,' *Ethics & Social Welfare 11(4): 320-335* https://www.tandfonline.com/doi/full/10.1080/17496535.2017.1290814

Research Grants:

G1. Department of Health and Social Care. *A Guide to SafeGuarding Adults Boards*. Dec 2009 - Aug 2019. Amount: £60,649. PI: Braye

G2. Skills for Care (2011): £11,900: *Scoping workforce development needs around self-neglect in social care*. PI: Braye.

G3. Department of Health and Social Care: *Investigating practice in self-neglect*. P.I. Professor Suzy Braye (Sussex) Mar – Oct 2013. £35,618. Braye (50%) / Orr (50%)

G4. Sussex Social Science Impact Fund (ESRC Impact Acceleration Account, 2018): £16,167. *Organisational change for better outcomes in self-neglect*. PI: Orr.

4. Details of the impact

The research has permeated self-neglect policy and practice within England at all levels by:

- informing the government's decisions to make establishing a Safeguarding Adults Board (SAB) a statutory requirement for all local authorities in England and to impose a mandate to address self-neglect as a safeguarding matter;
- shaping the local policies of SABs across England;
- setting the standards against which Safeguarding Adults Reviews (SARs) have evaluated systems and practitioners' decisions, helping to define good practice;
- improving frontline practice by providing practitioners with an evidence base enabling effective, ethical safeguarding practice with people who self-neglect.

Beneficiaries include DH and SABs, relevant health and social care practitioners and people who self-neglect across England.

1. Impact on National Policy

The research, through three DH-commissioned research reports and direct consultation between DH and the researchers, shaped DH policy-making in two key ways:

A. Making SABs mandatory: The research showed the need for adult safeguarding governance to be underpinned by legislation, in order to strengthen inter-agency collaboration, accountability and commitment to safeguarding (R1). DH's then-Lead for Safeguarding states that the findings were "of use to DH in informing deliberations on what arrangements should be made for Local SABs" and were highlighted in the 2011 Statement of Government Policy. The research thereby informed awareness and understanding among stakeholders during the ensuing process of public consultation, which in 2014 finally resulted in the Care Act placing a statutory obligation on all localities to establish SABs (S1-2). The DH lead further notes that R1 "played a major part in our thinking" about the form SABs should take, guiding the final decision on how much flexibility the Care Act should allow beyond the core membership of the Local Authority, Clinical Commissioning Groups, and the police (S2). SAB responsibilities include safeguarding strategy, local policy development and quality assurance of practice, and their inclusion for the first time within legislation significantly strengthened the position of adult safeguarding.

B. Inclusion of self-neglect within adult safeguarding: R2 showed that practitioners and agencies were often uncertain of their mandate in self-neglect. Consequently, people who self-neglected could by default be left at significant risk. DH's then-Lead for Safeguarding notes that social care workers were "expect[ed] to resolve issues in the absence of any clear statutory or practice guidance" and that Sussex research (R2-3) was "invaluable in informing the Care and Support Statutory Guidance" (S2). This guidance, issued in October 2014, sets out how public bodies must comply with the Care Act. Sussex research "informed and clarified" the national policy definition of self-neglect that it set out and "informed" the decision that self-neglect could henceforth require a safeguarding response. This required SABs "to consider systematically how relevant agencies should respond" (S2) and raised awareness of self-neglect among practitioners. By alleviating the previous uncertainty over self-neglect, this made it less likely that people who self-neglected would be left to suffer significant harm due to lack of joined-up working by agencies. DH included within the statutory guidance two example case studies based directly on narratives gathered in R3, to support services and practitioners in recognising self-neglect and intervening through person-centred practice (S3).

2. Impact on Local Policies across England

Through research reports (R2-3), key messages briefings, and direct consultancy work with SABs, the studies also informed policy on a local level, helping SABs to interpret their new mandate. In response to self-neglect's new status, all SABs in England had to develop multi-agency policies and procedures to guide practice. The National SABs Chairs Network noted the value of the research for all members, stating that:

> "as SAB Chairs, we have promoted Braye, Orr and Preston-Shoot's research with partners of our Boards as it provided a framework for reviewing whether current policies, procedures and practice were fit for purpose, as well as evidence for ways of improving the effectiveness of safeguarding interventions in this area of practice" (S4).

For their Boards, the research (R2-6) "prompted and informed a different approach to working with people who self neglect" among SABs, "stimulating the development of longer term interventions and more supportive ways of working with people," "prompting the setting up of multiagency panels where complex issues and risks can be presented, discussed and shared," and "improving practitioners' organisational, legal and other literacies" (S4). Attesting to the extent of the research's impact is the fact that, while such local policies very rarely acknowledge academic work, 61 SABs' multi-agency policies explicitly state that they drew on the Sussex work in preparing the policy or direct practitioners to it for further guidance on good practice (S5); others have been implicitly or indirectly influenced.

3. Setting Practice Standards

SARs are a key learning mechanism for safeguarding, and feed back into practice and action planning by identifying 'lessons learned' from cases which have raised concerns. Although SARs rarely use research directly, 43 publicly available post-2013 SARs in 36 different authorities of England and Jersey have explicitly drawn on the research findings: as a benchmark against which to evaluate local structures; as the basis for recommendations aimed to improve practice; to frame the dilemmas which confronted practitioners in the case; to identify gaps in assessment; as evidence for the effectiveness of person-centred and rights-based approaches; to contextualise local challenges against the national backdrop; to argue for greater resourcing of safeguarding in future; and/or as resources recommended to the local SAB in responding to the SAR's conclusions (S6). In this way, the research drives forward the standards governing self-neglect work and informing SAR recommendations for service improvement. For example, a South Tyneside SAR described (S6) how 'Adult D' died of sepsis and multiple organ failure, having been living surrounded by faeces and without heating. It drew on the research findings to note the significance of traumatic life experiences in self-neglect (R3), missed by the practitioners. It further used the research to highlight practitioners' need for support and practice guidelines addressing the challenges of self-neglect (R2, R4) and prompt the development of an enhanced, research-based self-neglect toolkit. Through use in SARs, the research has contributed significantly to changing understanding, policies and practice within services where it is most needed.

4. Direct Impact on Practice

The researchers worked with multiple partners to influence awareness and practice in self-neglect across relevant professions, through: 115 half- or full-day workshops for individual SABs, the Royal College of GPs and Research in Practice for Adults (RiPfA) across 52 authorities; practice tools for RiPfA and Community Care Inform; webinars for the Local Government Association and RiPfA; and two research reports (R2-3). Unusually, the Care and Support Statutory Guidance itself signposted practitioners to R2 as evidence for "ways of working that can have positive outcomes for those who self-neglect" (S2, S3).

Each delivery partner evaluates training outcomes differently, making a full overview difficult. However, representative examples illustrate the significant impact on understanding and practice. RiPfA, a national registered charity promoting evidence-based practice with a partner network of over 50 organisations, reported that 89.6% (n=386) of respondents in a set of 16 multi-professional workshops, held in 2016-17, stated that the likelihood of the research impacting on their practice was high or very high (S7). [text removed for publication] (S8).

The research's insights into the complexities of mental capacity in self-neglect (R2, R6) have repeatedly been highlighted by practitioners. The Mental Health Professional Lead in Wakefield reports that the:

> "research looking at capacity and self-neglect is an important bridge between the legislation and social workers' experience in practice […] These new insights into the

> assessing of capacity […] allowed us to advise practitioners working through the complexities of confabulation" (S9).

The impact reaches beyond Adult Social Care. For example, the Adults Safeguarding Lead for an NHS Foundation Trust comments on increased awareness among hospital staff:

> "the research evidence embedded in the training has really made a difference […] it has just become pretty normal for staff to consider self-neglect/hoarding and the need for a multi-disciplinary approach" (S10).

Because of the changes described above that led self-neglect to be classified under safeguarding (S2), national data are now gathered that enable the scale of the issue to be estimated. NHS Digital figures report that 7790 safeguarding inquiries into self-neglect were completed under s. 42 of the Care Act in 2018-19; many more cases are dealt with through other referral routes. Sussex research has been pivotal at all levels – statute, policy and practice – to improving recognition, help and support for these thousands of people in situations of self-neglect.

5. Sources to corroborate the impact

S1. Care Act 2014, s.43. http://www.legislation.gov.uk/ukpga/2014/23/section/43/enacted
S2. Statement by the Former Lead for Adult Safeguarding at DH (now retired), 24 January 2020.
S3. Care and Support Statutory Guidance Care and Support Statutory Guidance, DH (October 2014). This evidences the mention of the self-neglect research (Section 14.112 and footnote, p. 261). The case studies are in Sections 14.14 (p. 233) and 14.112 (p. 261).
S4. Statement by the National Safeguarding Adults Boards Chairs Network, 18 July 2018.
S5. Record of Safeguarding Adults Board policies making explicit use of the self-neglect research.
S6. Index of Safeguarding Adults Reviews making explicit use of the research.
S7. Compilation of Evaluation Feedback from RiPfA Self-neglect Research Messages Workshops. These were gathered by RiPfA immediately following the workshops [available from HEI on request]
S8. Evaluation Report of Self-neglect Training Workshop Series for Local Authority.
S9. Statement by Mental Health Professional Lead, Wakefield, 2 October 2020.
S10. Statement by Adults Safeguarding Lead, James Paget University Hospitals NHS Foundation Trust, Norfolk, 1 October 2020.