Human stories about self-neglect: told, untold, untellable and unheard narratives in safeguarding adult reviews

Michael Preston-Shoot

Abstract

Purpose – *The purpose of this paper is to update the core data set of self-neglect safeguarding adult reviews (SARs) and accompanying thematic analysis. The initial data set was published in this journal in 2015 and has since been updated annually. The complete data set is available from the author. The second purpose is to reflect on the narratives about adult safeguarding and self-neglect by focusing on the stories that are told and untold in the reviews.*

Design/methodology/approach – *Further published reviews are added to the core data set, drawn from the national SAR library and the websites of Safeguarding Adults Boards (SABs). Thematic analysis is updated using the domains used previously, direct work, the team around the person, organisational support and governance. SAR findings and recommendations are also critiqued using three further domains: knowledge production, explanation and aesthetics.*

Findings – *Familiar findings emerge from the thematic analysis and reinforce the evidence-base of good practice with individuals who self-neglect and for policies and procedures with which to support those practitioners working with such cases. SAR findings emphasise the knowledge domain, namely, what is actually found, rather than the explanatory domain that seeks to answer the question "why?" Findings and recommendations appear to assume that learning can be implemented within the existing architecture of services rather than challenging taken-for-granted assumptions about the context within which adult safeguarding is situated.*

Research limitations/implications – *A national database of reviews completed by SABs has been established (www.nationalnetwork.org.uk), but this data set remains incomplete. Drawing together the findings from the reviews nonetheless reinforces what is known about the components of effective practice, and effective policy and organisational arrangements for practice. Although individual reviews might comment on good practice alongside shortfalls, there is little analysis that seeks to explain rather than just report findings.*

Practical implications – *Answering the question "why?" remains a significant challenge for SARs, where concerns about how agencies worked together prompted review but also where positive outcomes have been achieved. The findings confirm the relevance of the evidence-base for effective practice, but SARs are limited in their analysis of what enables and what obstructs the components of best practice. The challenge for SAR authors and for partners within SABs is to reflect on the stories that are told and those that remain untold or untellable. This is an exercise of power and of ethical and political decision-making.*

Originality/value – *The paper extends the thematic analysis of available reviews that focus on work with adults who self-neglect, further reinforcing the evidence base for practice. The paper analyses the degree to which SARs answer the question "why?" as opposed simply to answering the question "what?" It also explores the degree to which SARs appear to accept or challenge the context for adult safeguarding. The paper suggests that SABs and SAR authors should focus explicitly on what enables and what obstructs the realisation of best practice, and on the choices they make about the stories that are told.*

Keywords *Safeguarding adult reviews, Evidence, Self-neglect, Explanatory focus, Stories, Narratives*

Paper type *Research paper*

Michael Preston-Shoot is based at Faculty of Health and Social Sciences, University of Bedfordshire, Luton, UK.

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Introduction

During a webinar for practitioners focusing on the evidence-base for working with people who self-neglect, one training participant with lived experience of self-neglect shared her human story. This involved experiences of multiple trauma. She concluded by remarking that "no-one asked about my background" by which she meant that no professionals with whom she was in contact at the time expressed concerned curiosity about her backstory or about what lay behind the distress that she was experiencing and presenting. Until that webinar, her story had remained untold and unheard.

The author's discussion with those who have written safeguarding adult reviews (SARs) has elicited concerns about how to manage differences of opinion with service representatives about what should be included in reports. Similarly, debates occur between authors about how much to focus on the political context – law, social policy and budget allocations – within which adult safeguarding is situated and which profoundly influences what and how human needs are (not) met. This raises a question: what stories can be told and are being told through SARs, and what stories remain untellable?

The purpose of SARs [1] is to learn from human stories and to bring forth findings and recommendations for practice improvement and service development based on appreciative, critically reflective and co-produced inquiry [Department of Health and Social Care (DHSC), 2020]. However, given the repetitive nature of both findings and recommendations, are there stories to be told that are "not yet said" (Anderson, 1997)? Are there some stories that, in the analysis provided by SARs, have remained unknown, untold, unheard and untellable (Pearce and Pearce, 1998)?

This article, therefore, has two purposes. The first is to update earlier versions of the database of SARs in England that feature self-neglect. The complete database, which is available from the author, was first published in this journal in 2015 and has since been updated annually (Braye *et al.*, 2015; Preston-Shoot, 2016, 2017, 2018, 2019, 2020, 2021; Preston-Shoot *et al.*, 2022). The second is to reflect on how SAR authors tell the story – what they include and what they foreground, and what they backlight and what they omit – when analysing and editing what they read and hear. Two devices are used here. The first uses the mnemonic of told, untold and untellable stories (Pearce and Pearce, 1998), to which concepts of partially or lesser-told stories have been added. This mnemonic directs readers to reflect on what is (not) said. The second distinguishes between knowledge, explanatory and aesthetic domains (Lang *et al.*, 1990). To understand how services might have worked together more effectively to prevent or to protect individuals from abuse/neglect, SARs must seek to understand what did (not) happen – the knowledge domain. However, for recommendations to facilitate system change, they must also seek to understand why good practice flourished and/or shortfalls occurred – the explanatory domain. The aesthetic domain encourages those involved to critique current systems and to reflect on system design that captures our ambitions for effective adult safeguarding.

Each SAR tells a human story, which builds from the perspectives of the different people and services involved, ultimately concluding as one synthesis. The different perspectives and the final synthesis focus on what matters most to those involved. The purpose here is to mine these individual texts to reveal the stories told but also to uncover new possibilities for change from lesser-told, untold or untellable stories.

Told stories: the literature on self-neglect

The challenges of working with people who self-neglect and how best to navigate them are well covered in practice-based publications (Tolin *et al.*, 2014; Singh *et al.*, 2015; Barnett, 2018; Britten and Whitby, 2008, 2021). Barriers to effective practice, including Care Act 2014 assessment thresholds and lack of suitable care options, alongside recommendations for best practice, such as including executive functioning in mental capacity assessments,

ensuring legal literacy and assessing care needs "in context", have been identified both in relation to people experiencing homelessness and dependent drinkers (St Mungo's, 2022; Preston-Shoot and Ward, 2021; Ward *et al.*, 2023).

The evidence-base for practice has also been developed from research (Braye *et al.*, 2011, 2014) and from an analysis of learning from SARs (Preston-Shoot, 2019). Recent research studies (Martineau *et al.*, 2021; Harris *et al.*, 2022; Manthorpe *et al.*, 2022; Owen *et al.*, 2022) have also elaborated upon the challenges of working with people who self-neglect and reinforced the components of best practice. In terms of direct work with people experiencing self-neglect, research findings emphasise the importance of home visits to assess people "in context" and of earlier intervention. The research studies and practice-based evidence highlight the need for person-centred, relationship-based practice and sustained engagement to understand the causes of self-neglect as a prelude to preferably negotiated practical interventions and emotional support. In terms of the team around the person, the evidence highlights the centrality of a coordinated multi-agency response, including risk management meetings and information sharing. In terms of organisational support, the studies reference the importance of supporting staff to manage the emotional impact of this work.

Thus, the core components for working effectively with people who self-neglect represent the story told and are well known. Yet, the number of SARs that feature self-neglect, and the repetitive nature of the stories they tell, invite a focus on the stories that are either untold, unheard or untellable (Pearce and Pearce, 1998) in the analysis of findings and the shaping of recommendations. Put another way, as witnesses, editors and researchers of human stories, have SAR authors given greater prominence to the "productive domain", to naming individual findings, to the relative exclusion of the "explanation domain" (Lang *et al.*, 1990), to generating connections between separate findings and to hypothesising overarching themes?

Methodology

Reviews featuring self-neglect were identified through the SAR library [2] and by searching Safeguarding Adult Board (SAB) websites. Searches were undertaken and completed in December 2022. Numbering in the table of cases continues the database sequence. Cases containing references to one or more of the constituent elements of self-neglect (living in squalor, hoarding, significant neglect of health and wellbeing, rejection of care and support) [Department of Health and Social Care (DHSC), 2020] have been included.

Appendix contains the list of cases. The table gives basic demographic details. This enables analysis by gender and age. It also identifies the settings where self-neglect might occur. These characteristics are normally described to set the scene. Where the SAR is not in the public domain, only the region within which the SAB is located has been listed. This enables the numbers of completed reviews to be tracked by region (Preston-Shoot *et al.*, 2020). These SARs as human stories comprise the data for the ensuing analysis.

The ensuing analysis comprises two parts. The first concentrates on the background of the individuals whose lives are in focus and on the SARs themselves – the process by which they are commissioned, the methodological approaches adopted, the span of their analysis and the scope of their recommendations. The second part compares and contrasts the themes that emerge across the cases.

The same analytic focus has been adopted (Brandon *et al.*, 2011; Braye *et al.*, 2015), namely, to shine the lens on the four domains of direct practice with the individual, the professional team around the adult, the organisations around the professional team and SAB governance. A fifth domain, that of the legal, policy and financial context within which adult safeguarding is situated, has been added. However, the analysis that follows will

focus not just on the familiar stories told but will also explore how the reviews engage with and explain the repetitive shortcomings that are found.

Case and safeguarding adult review characteristics – told and untold stories

Gender

Where gender was specified in this sub-set, once again more men were represented in the reviews (59 SARs) than women (45). Where sufficient information about age was given to permit analysis, the age distribution was also familiar. In descending order, 37 individuals were aged between 40 and 59, 30 aged between 60 and 75, 22 aged over 76 and 18 aged between 21 and 39. There were a higher number of very young adults in this sample, 7 in total. The *untold story* is the omission of analysis of the impact of gender [3] and age, other than with respect to people experiencing homelessness, when some reference was made to premature mortality.

Race/ethnicity

Another protected characteristic is race/ethnicity. Few cases refer to the Equality Act 2010 explicitly [4]. Of the 100 cases, 44 cases in this sample reference the person's ethnicity. However, predominantly, SARs concentrate on description. There is virtually no analysis of the impact of ethnicity on how individuals experienced services and how services responded, although Case 502 is a notable exception. Case 456 found that ethnicity had no significant impact. This aspect of these human stories remains *untold* and, perhaps, is felt to be *untellable*. Another *untold* human story, or one that is again felt to be *untellable*, relates to the protected characteristic of sexuality. SARs are silent here.

Surviving significant harm. Almost all the individuals had died, so the question remains of how lessons are being learned with respect to multi-agency involvement in cases where people survive significant harm. That is another *untold story* about the commissioning of SARs and about the human stories where practitioners and managers believe useful learning can be heard. The voices of people with lived experience of self-neglect remain largely unheard through SARs.

Frequency of reviewing self-neglect cases. Sixty-two SABs are represented in this sample of SARs. Four SABs have not appeared in earlier iterations of this database. Of the SARs completed by the 58 SABs whose earlier reviews have been included in the database, only 23 (40%) referenced this. Some observed that their findings repeated prior learning. Occasionally, there were references to the impact of prior learning on policy, guidance and practice [5] or on how key lines of enquiry were shaped following a new referral. One review was explicit in seeking to build on learning from earlier SARs [6]. Another [7] bemoaned that there appeared amongst SAB partners to be a lack of awareness of other completed reviews. The impact of earlier learning and the difference that previous findings and recommendations have made to practice development and service improvement represent *an untold story* and a missed opportunity. In reflecting on the question "why?" a debate needs to be had on whether SARs are just an investigation into a single case, as the statutory guidance seems to imply, or whether SABs should use the opportunity of a new SAR to focus on what has (not changed) as a result of prior learning, both local and national.

Use of available safeguarding adult review learning

Within the sample, slightly more SARs (26) refer to learning published by other SABs. This includes 12 SARs that specifically refer to learning within the national analysis (Preston-Shoot *et al.*, 2020). Twenty-seven reviews referenced relevant research and/or guidance, such as alcohol dependence, diabetes, trauma or mental capacity, and 14 referred to the

evidence-base for working effectively with people who self-neglect (Braye *et al.*, 2014; Preston-Shoot, 2019). One SAR [8] commented that research was not used by agencies. There are *two untold stories* when reflecting on the extent to which SARs draw on available research. The first is that SAR authors are "starting again" rather than building on prior local but also national learning and reflecting on findings through the evidence-base for best practice. The second is that SABs and SAR authors are missing opportunities to question why this learning is not being used by the services involved – the explanatory domain.

Commissioning reviews

Only occasionally are readers given a glimpse into the processes involved in commissioning, undertaking and completing reviews. This is a *partially or lesser-told story*. Eight SARs refer to delays, which included the impact of the Covid-19 pandemic, the number of reviews being managed at any one time, the search for a reviewer, and the need to change authorship when the initially chosen reviewer was unable to complete the analysis. In individual cases, delays were the result of an inquest, disagreement about whether two Boards should undertake a review jointly, and failure by agencies to provide requested information. At least through the medium of reviews, *stories remain unheard* about the challenges involved in managing SARs, for example navigating parallel processes. Useful learning from experience could be collated and shared by SABs regionally and nationally, with concerns escalated to the Department of Health and Social Care where repetitive challenges are encountered, on which a future iteration of the statutory guidance could advise.

Safeguarding adult review methodologies

Where this information is given, most SARs adopted a hybrid approach of using chronologies and/or independent management reports, coupled with learning events, interviews and/or documentary analysis. Desktop information review was the method used in five cases [9]. One SAR [10] followed the Welsh model, whilst five [11] were reviews conducted in rapid time. Another five cases adopted the learning together approach [12]. One review [13] described a pathway to learn approach, whilst a panel took responsibility for identifying learning in another case [14]. The as yet *untold story* is a critical, appreciative and comparative analysis of the different methodologies in use.

Acknowledging national contexts

The mantra is that methodologies in use adopt a systemic approach, but is this claim justified? One way to answer that question is to explore the lens that SARs shine on the national legal, policy and financial context within which adult safeguarding is situated. The national analysis observed that this context was neglected in SARs (Preston-Shoot *et al.*, 2020), *an untold and/or untellable story*, and that remains true for this sample. Indeed, one review [15] is explicit in stating that the circumstances of the case could "*only* be understood in the context of individual agency working, thresholds and policies" (my italics). This approach appears to neglect one influential component in the systemic architecture surrounding adult safeguarding.

Only 14 SARs made any reference to the impact of austerity on service providers, most often highlighting the lack of resources to respond to substance misuse. Thus, one review commented on the "impact of years of restrictions on services" and another on government cuts that had resulted in the "loss of expertise, skills and capacity in the sector [16]." Others [17] observed the limited resources available to support people with complex needs and the limited options available for treatment. There were also references to the national shortage of social housing, to the North-South divide on social deprivation and to increasing demand challenging available resources [18]. Although the impact of austerity has been highlighted by inquiries into homelessness (McCulloch *et al.*, 2021) and substance misuse service provision (Black, 2021),

for SARs, austerity appears to be either *a partially or untellable story*. Useful learning about the impact of the cost of living crisis and austerity more broadly could be collated and shared by SABs regionally and nationally, with concerns escalated to the Department of Health and Social Care where deemed appropriate. Thus, as a matter of routine, those compiling chronologies and writing independent management reports for SARs should consider providing this contextual information.

Despite the frequency with which mental capacity appears amongst SAR findings and recommendations, the assumption appears to be that the Mental Capacity Act 2005 is fit for purpose as a framework for the complexities and challenges inherent in many self-neglect scenarios. Only three SARs [19] offer any critique of the legislation itself; for example, executive functioning, the capacity to act, is not explicit in the Act and yet is so fundamental in understanding situations encountered by practitioners. The assumption that available legislation is adequate to support adult safeguarding is not restricted only to mental capacity. Two reviews [20] highlight the gap in England of an adult safeguarding power of entry and of protection orders. Another refers to the limited view taken of eligible needs [21]. Otherwise, the Care Act 2014 escapes critique despite the narrowness with which it defines eligible needs, as highlighted when considering the circumstances of people who experience homelessness and/or alcohol dependence. One review [22] observes that changes to welfare benefit regulations can be "devastating." Another review [23] is critical of the Homelessness Reduction Act 2017 for not specifying that provided accommodation should match a person's needs, thereby exposing the individual to additional risks. One review [24] explicitly calls for national government to provide better guidance on how the Care Act 2014, Mental Capacity Act 2005 and Mental Health Act 1983 can better meet the needs of alcohol-dependent individuals. Otherwise, how legal rules and social policy shape adult safeguarding appears to be *an untellable story*.

Another way to explore the claim that reviews are systemic is to consider how they answer the question "why?" Given that much of the practice described in this sub-sample occurred during the Covid-19 pandemic, it is surprising that only 18 reviews reference its impact. Even fewer detail the precise effect it had on practice and services. Where the pandemic's impact is detailed, SARs refer to restrictions on face-to-face contact and nervousness due to the frequency with which guidance changed [25], increased workload pressures [26], complicated access to services [27] and impact on people's wellbeing [28]. This is as yet only *a partially told story*.

It is rare to find SARs that are forthright in their critique of the systems and context surrounding adult safeguarding. One SAR [29] observes that practitioners and managers often struggle to achieve best practice; feedback also given to this article's author when facilitating webinars on best practice for working with people who self-neglect. One review questions whether the person had been "failed by the system." This review, and another explicitly connect self-neglect with neglect and acts of omission [30]. This opens up *a lesser-told story* about the potential unhelpfulness of the term "self-neglect" since it risks blaming the individual for coping mechanisms developed in response to trauma and loss [31] and in a context of limited available provision to support someone through that experience of emotional distress.

As *told stories*, reviews tend to foreground what did (not) happen rather than, additionally, to seek explanations for findings from practitioners, operational managers and senior leaders. The focus is on the knowledge domain rather than the explanatory domain. There is even less focus on the aesthetic domain (Lang *et al.*, 1990) and on the values and aspirations for adult safeguarding.

Safeguarding adult review recommendations

The emphasis on the knowledge domain at the relative expense of the explanatory and aesthetic domains can also be traced in SAR recommendations. One category of

recommendations encompasses *the review process*. The trend of SARs making few recommendations in this area continues. Only four reviews [32] recommend that findings about shortcomings are escalated nationally, including concerns relating to funding for services, shortage of accommodation options for young adults and prevention of fire risks. None of these recommendations has yet led to a request to the national network for SAB chairs to escalate the concerns formally to government. Given the repetitive nature of the findings, it is perhaps surprising how seldom reviews recommend using SARs for learning, or encourage SABs to seek assurance on how prior learning has been used to enhance practice, service development and procedural change [33].

A second category of recommendations focuses on *staff support*. Here the main preoccupation is with training, for example on use of the Mental Capacity Act 2005, on legal literacy, on knowledge acquisition and skill development for trauma-informed practice or on working with people who self-neglect. The *unheard story* here is whether the organisational context enables practitioners to use the knowledge and skills acquired in training. There appears to be an unquestioned assumption that training will transfer into practice. Without a corresponding focus on workplace development (Braye *et al.*, 2013), workforce development might not achieve its objectives. There are fewer recommendations on supervision, caseload monitoring, access to specialists and management oversight, despite the complexities, dilemmas and ethical conundrums that working with self-neglect often involves.

A third category adopts *a procedural lens*. Here, the recommendations focus on either the development of guidance, procedures, protocols and toolkits, or their revision. The focus variously falls on transitional safeguarding, self-neglect, substance misuse, exploitation, mental capacity assessment, non-engagement, information-sharing, multi-agency working together and meetings, risk assessment, professional curiosity and/or escalation. Some SARs also recommend using audits to seek assurance about awareness and use of guidance, procedures and toolkits and adherence to expectations. Ideally, policies and procedures provide a framework of guidance for practitioners and operational managers. Once again, there appears to be an unquestioned assumption that guidance will be embedded in practice and that the architecture of the workplace will facilitate this. Given the repetitive reliance on procedures and the widespread evidence that they are not reflected in practice, how practitioners and managers experience the accessibility and utility of available guidance is an *unheard story*. Research has highlighted, for example, the importance of questioning policy overload in a context of time and workload pressures (Northway *et al.*, 2007).

The final grouping of recommendations covers *best practice*. One sub-set contains recommendations on direct work with individuals. This includes recommendations on mental capacity assessment, including executive functioning, trauma-informed practice, home visits, and the use of toolkits and templates to guide assessments and planning, especially in response to risk. There are also recommendations relating to provision of outreach and not closing cases without updated risk assessments and consultation with other services. Also emphasised are the importance of concerned curiosity, thinking family and carer assessments. Recommendations also address the perceived need to improve recording of referrals and decision-making and to enhance legal literacy, for example, of ordinary residence rules, the Homelessness Reduction Act 2017, and requirements concerned with review of (out of authority) placements.

A second sub-set contains recommendations for working together. Prominent here are recommendations to seek assurance on how services collaborate, for example with care-experienced young people and transition, or with people who experience both mental distress and substance misuse. Also prominent are recommendations to enhance the use of multi-agency meetings, including information-sharing, allocation of roles and responsibilities, and planning for discharge and transition. Recommendations also seek to promote referrals

of adult safeguarding concerns and to seek assurance regarding decision-making on safeguarding enquiries.

The *story being told* in these recommendations is that fundamental change in the architecture of adult safeguarding is unnecessary. The *subjugated, lesser-told story* is whether the legal, policy, organisational, practice and training architecture is fit for purpose. The recommendations rarely encourage review of the barriers encountered by people seeking accommodation, care and support or treatment, or exploration of the obstacles that have prevented the flourishing of what is known to be best practice [34].

Cross-case analysis – told and untold stories

Discussion here focuses on what explanations are offered for findings across the practice domains.

Direct work with individuals

The *stories told* are sadly repetitive and familiar. There are numerous examples of failing to speak with the person or allowing other voices to drown out a person's wishes and desired outcomes. Alongside shortcomings relating to person-centred assessment are missed opportunities to explore family relationships and assumptions about the ability and willingness of family members to provide care and support. Also reported are missed opportunities to offer and provide carer assessments.

There are repetitive findings of shortcomings in assessment and planning, of risk, care and support, mental health and mental capacity. Prominent is a lack of concerned curiosity, illustrated by assumptions regarding lifestyle choice, lack of recognition of a person's historical experiences, and closing down involvement rather than responding with outreach when a person appears to not be engaging.

What, however, are the explanations offered for these told, familiar stories? One theme that begins to emerge is that of balancing different duties. One SAR [35] identifies that balancing self-determination with safeguarding duties is a "difficult area." Several SARs [36] juxtapose the right to private and family life and the principle of autonomy with the right to life or self-determination and choice with the duties of prevention and the promotion of wellbeing. Two reviews [37] refer to a "false conflict" between freedom and protection, whilst another [38] suggests that adult services too readily default to adult autonomy, a presumption of capacity and a person's "right" to choose whether or not to engage.

Explanations are also occasionally offered in terms of practitioner understanding and use of available legal rules. One SAR [39] suggests that the law regarding mental capacity and alcohol dependence is unclear. Several reviews [40] identify misunderstandings and misuse of the principles within the Mental Capacity Act 2005 itself or uncertainty about how to weave the important focus on executive functioning into the functional assessment (section 3, Mental Capacity Act 2005). A few reviews look for explanations in terms of how the Care Act 2014 frames eligible needs for care and support, suggesting either that this narrows the vision of the support that can be offered to people with complex needs [41] or that the emphasis on eligibility results in a lost focus on wellbeing and prevention [42]. One SAR [43] suggests that adult social care has become process-led rather than principle-led.

Lack of concerned curiosity about self-neglect, coupled with evidence of normalisation or desensitisation, is a common critique of practice [44]. A few SARs begin to tell an *explanatory story* here, referring to lack of time and workload pressures that constrain relationship-based practice, or to unconscious bias and a failure to see the world from the service user's perspective, including previous experiences that might have resulted in reticence to engage with assessments, support and/or treatment [45]. In a link to the

domain of organisational support for practitioners, there are occasional criticisms of how services are unable to work flexibly because of the way they are commissioned [46].

Team around the person

The knowledge domain, answering the question "what?" is prominent here to the relative exclusion of the explanatory domain, answering the question "why?" The *stories told* are once again repetitive and familiar. SARs express concerns about missed opportunities for collaborative, joined-up working together, for example, between primary care and secondary acute or mental health services. Shortcomings are found in missed opportunities to convene the system around the person in the form of multi-agency (risk management) meetings or high risk and complex case panels and to share information so that all the agencies involved have a more complete picture of needs and risks.

Concerns are also expressed regarding the lack of legal literacy and safeguarding literacy, identified in omissions to consider specific powers and duties, such as section 11 Care Act 2014, and in the absence of referrals of adult safeguarding concerns and/or repetitive patterns of multiple referrals using the criteria in section 42(1) Care Act 2014 without any resulting in an enquiry under section 42(2). SARs also identify shortcomings in recording, noting significant gaps, for example, in what plans have been agreed in case discussions.

Venturing into the explanatory domain, occasional reviews acknowledge the complex context for multi-agency working, the need for an integrated care system, and the tendency to default to thresholds and eligibility criteria in response to workload demands [47]. The outcome then is referral bouncing. Occasionally, reviews also denote a lack of confidence in working together or the lack of clear pathways to manage need and risk between agencies [48]. One SAR [49] concludes that more work is needed to create a common multi-agency understanding of self-neglect. Specifically in relation to meeting together, two reviews [50] observed that there was misunderstanding and lack of clarity about which services could convene multi-agency meetings or conferences.

On legal literacy, there are occasional references to a lack of understanding of diverse powers and duties or a lack of confidence in their application [51]. One SAR [52] commented explicitly that there was a mistaken view that needs arising from substance misuse were excluded from Care Act 2014 eligibility criteria. On safeguarding literacy, an emerging explanation [53] was confusion about the interface between section 42 enquiries and multi-agency meetings or panels; in other words, which route should practitioners use when in response to adult safeguarding concerns and disquiet about how services are working together? Other explanations included a default to case management when a person was known to a service [54], the absence of a person's consent to a referral of a safeguarding concern, a misunderstanding about the principle of making safeguarding personal [55], or a mistaken belief that self-neglect was excluded from the provisions of section 42 [56].

Shortcomings in information-sharing were occasionally attributed to a fear of breaching confidentiality [57] or to the person refusing to give consent [58]. This reflects a lack of legal literacy regarding provisions in the Data Protection Act 2018. On findings relating to recording, the explanatory focus highlights the lack of access to different systems [59], which impedes information-sharing, rather than seeking to account for poor standards.

Organisational support

In this domain, references to the lack of awareness of and need for training on self-neglect are plentiful. There are also repetitive and familiar criticisms of the failure to use supervision and the absence of management oversight. There are some references to gaps in service provision and to staffing and workload issues. There is also some focus on the availability

and use of policies and procedures in respect of self-neglect, escalation and the resolution of professional disagreements.

Once again, however, *untold stories* emerge when occasionally SARs offer strident and/or reflective criticisms of organisational support. When focusing on the absence of managerial oversight, one review comments on the emotional impact of working with people who self-neglect and the importance of attending to feelings of helpless and being trapped with some cases [60]. Highly pressurised working environments are seen to result in "work arounds" and a focus on time-limited interventions, with workload management systems making it difficult to identify escalating risk [61].

The impact of constrained budgets is seen in how services are configured [62] and as an explanation for limited and declining resources, for example in mental health support or social housing [63]. Perhaps this picture might explain lack of awareness or use of policies and procedures, or perhaps even the absence of such protocols. Two reviews offer particularly forthright observations. One [64] observes that there were insufficient strategic organisational arrangements for collaborative assessments and case planning. Another [65] concludes that there was insufficient attention to system leadership across all partners and to ensuring that practitioners had the ability and systems that enabled them to work proactively together to share and manage risk.

Discussion

The preceding analysis has focused on the told, untold or lesser told stories in relation to shortcomings about practice and the management of practice. However, SARs do contain findings of good practice, especially in relation to direct practice and how the team around the person worked together. Nonetheless, once again the focus falls on the knowledge domain, answering the question "what?" The *untold story* is what enabled good practice to flourish.

To reinforce the point, one SAR [66] observes that few reviews compare actual practice with that recommended in guidance, and few explore the reasons why there is (or is not) a difference between the two. Thus, one reason why embedding change following reviews appears hard to achieve is the *untold story* of the reasons for a lack of alignment between work as recommended and work as done (Shorrock and Williams, 2016).

Research findings and practitioner and manager case studies on self-neglect fill the spaces in the explanatory domain left by SARs. Research findings on direct practice, for example, have highlighted attitudes towards people who self-neglect that can result in misrecognition, assumptions and loss of a person-centred approach (Harris *et al.*, 2022). By contrast, practitioners have described situations where human connection, persistence, continuity and a trauma-informed approach eventually released the potential for change. Research has identified the need to improve recognition and response to cognitive impairment and traumatic brain injury, especially in alcohol-dependent individuals (Ward *et al.*, 2023). Practitioners have expressed uncertainty about how to assess executive functioning, the capacity to act, for example, by using available screening and assessment tools.

Research findings on the team around the person have found that co-location changes attitudes and responses to self-neglect, helping to overcome a fragmented system and absence of a shared language (Martineau *et al.*, 2021). Practitioners have commented that recording in different systems does not support multi-agency working.

Despite a definition of self-neglect contained within statutory guidance [Department of Health and Social Care (DHSC), 2020], variability in how practitioners and managers respond to self-neglect has been attributed to uncertainty about how to define or conceptualise it (Harris *et al.*, 2022; Owen *et al.*, 2022). A review of SAB policies and

procedures on self-neglect (Orr, 2023) found that the statutory definition did not provide clarity about what threshold behaviour should be considered self-neglect or indicate when services should become involved. The statutory definition was not used consistently, and there were divergent views on whether section 42 or referrals into multi-agency (risk management) meetings should be used as the pathway response. The roles and responsibilities of panels were not always clearly laid out. Practitioners have sometimes reported that local authorities did not respond to self-neglect as an adult safeguarding concern or have expressed uncertainty about when to expect that an adult safeguarding enquiry would be opened.

Research findings on the organisational context unsurprisingly have found that time and resource constraints impact relationship-based, person-centred practice and the use of multi-agency pathways (Harris *et al.*, 2022; Owen *et al.*, 2022). Practitioners have commented that SARs do not reflect workload and workforce pressures or cuts in services, which negatively impact attempts to align practice with the evidence-base. Those providing information for SARs should include this contextual information. Equally, registered practitioners and managers have obligations attached to their registration to report to senior managers where there are issues significantly impacting their ability to deliver safe and effective services.

Practitioners also express concern about the emotional impact of witnessing self-neglect, about the wellbeing of staff, captured in the phrase "who looks after us?" Stories have been told of despondency and anxiety, even outrage, when system barriers block hope of change. Practitioners have questioned whether senior managers are sufficiently appraised of complex and challenging cases and of what has been described as "an epidemic of self-neglect."

Practitioners have also expressed uncertainty about how to balance a person's right to private and family life with a duty to promote wellbeing and to prevent an escalation of care and support needs. In his research, Orr (2023) found that not all SABs have policies or procedures on self-neglect, whilst others vary in the attention given to the tension between self-determination, the right to private and family life and the duty to prevent foreseeable harm. Policies and procedures also vary in guidance given on assessing executive functioning and on how to respond to refusals of assessment or support by a person with mental capacity.

When seen through these lenses and when these stories are told, it is unsurprising that practice and the (multi-agency) management of practice are found to be inconsistent with the evidence-base. Even exceptional practitioners can only get so far in a system that is not designed or resourced to consistently deliver the multi-agency practice, management and service response that is required. In SARs, these features and experiences remain, at best, a partially told story.

That observation raises several signposts for future SAR work. Firstly, SARs should be a collaborative endeavour between practitioners, operational managers, senior leaders, reviewers and people with lived experience of adult safeguarding, a search for meaning together, for example, in learning events and when findings are disseminated and action plans are put together.

Secondly, SARs should promote a vision or ambition for future adult safeguarding. This takes SAR work into the aesthetic domain. O'Reardon (2023) asserts that SARs have not lived up to their full potential to inform and transform practice. However, is transformation really possible if the fundamental architecture within which adult safeguarding is located remains unchallenged? Is the *untold story* that emerges from SAR findings one of neglect and acts of omission by all the agencies that contribute to the shaping of adult safeguarding? One SAR in the sub-set [67] openly asks this question. Another [68] question is the continual use of "sticking plasters." O'Reardon (2023) found that social workers were

hopeful about the impact of learning from SARs but fearful that they would be blamed for wider system failures.

Thirdly, SAR authors and SAB members are not neutral observers. Their own standpoints will influence the stories they choose to tell. In this sense, they exercise "narrative privilege" (Bolen and Adams, 2017), the power to shape and edit the story that is told about adult safeguarding. Is the story about shortcomings in concerned curiosity one of practitioner or service lack of interest, compassion fatigue, workload pressures and/or the impact of financial austerity on available resources? Is the story about shortcomings in working together a narrative about inappropriate execution of available processes and/or the result of lack of cohesion across services (O'Reardon, 2023)? How SAR authors and SAB members choose to engage with the explanatory and the aesthetic domains is an ethical and a political act. Where references are minimal to the legal, policy, financial and organisational context within which adult safeguarding is situated, structural and systemic issues might too easily slip into being depoliticised as stories only of practitioner and service shortcomings or service user resistance (Bozalek, 2014). The outcome in the recommendations that follow risks repetition compulsion, reinforcing rather than seeking to transform what is taken for granted.

Conclusion

The told stories of good safeguarding and practice shortcomings are familiar and repetitive. They refer to the knowledge domain – what has (not) happened. Lesser-told or untold stories, seeking to understand why good practice has been possible and why shortcomings have been found, point to an under-developed or emergent explanatory domain. There are stories yet to be told, referring to the aesthetic domain, about how to really improve adult safeguarding and the context within which it is located.

This article ends as it began, with a human story, this time from a senior local authority leader. After a meeting with policymakers in government and inspectorates, this author was thanked for voicing what they had felt unable to say because of their positional role. With now, over 500 SARs featuring self-neglect in England, those involved need the ethical courage to disrupt the frequently told stories and to reposition the lens of learning in the name of critical hope and transformational change.

Notes

1. Safeguarding Adults Boards (SABs) were established on a statutory footing by section 43 Care Act 2014. Amongst their responsibilities for ensuring the effectiveness of adult safeguarding in England is the commissioning of safeguarding adult reviews (section 44). Where an adult with care and support needs dies as a result of abuse or neglect, including self-neglect, or experiences significant harm, and there is concern that services could have worked more effectively together, SABs must commission a review. Where the criteria are not fully met but the SAB believes that useful learning could be obtained for practice and service improvement, it may exercise its discretion and commission a review.
2. https://nationalnetwork.org.uk
3. Cases 424 and 443 are exceptions, referencing preconceived notions about men and the challenges they face in accessing services.
4. Cases 476 and 487 are exceptions.
5. For example, Case 484.
6. Case 448.
7. Case 447.
8. Case 450.
9. Cases 426, 457, 461, 466 and 489.
10. Case 481.

11. Cases 405, 417, 432, 440 and 471.
12. Cases 429, 449, 451, 452 and 470.
13. Case 465.
14. Case 464.
15. Case 450, italics added for emphasis.
16. Cases 405 and 409.
17. Cases 439, 493 and 474.
18. Cases 444, 409 and 463.
19. Cases 441, 492 and 425.
20. Cases 406 and 480.
21. Case 450.
22. Case 403.
23. Case 432.
24. Case 430.
25. Cases 405, 416, 454, 456, 474 and 480.
26. Cases 405, 422, 431, 466, 474 and 494.
27. Cases 416 and 423.
28. Case 412.
29. Case 448.
30. Cases 487 and 446.
31. Case 442.
32. Cases 491, 412, 421 and 409.
33. Exceptions include cases 422, 432, 456 and 457.
34. Exceptions are cases 421 and 440.
35. Case 494.
36. Cases 424, 427, 443, 460, 471, 472, 488 and 493.
37. Cases 421 and 441.
38. Case 464.
39. Case 425.
40. Cases 441, 443, 472, 492 and 493.
41. Case 432, 450 and 493.
42. Case 501.
43. Case 500.
44. Cases 474 and 479 for example.
45. Cases 422, 427, 444 and 482.
46. Cases 432 and 466.
47. Cases 422, 423 and 492.
48. Cases 403 and 467.
49. Case 458.
50. Cases 428 and 485.
51. Cases 407, 432, 442 and 449.
52. Case 408.
53. Cases 405, 457 and 471.

54. Case 424.
55. Case 403.
56. Cases 409 and 453.
57. Case 492.
58. Cases 456 and 484.
59. Cases 417 and 482.
60. Case 468.
61. Cases 403, 422, 429, 448 and 470. Work arounds refers to how practice is adjusted to manage the lived experience of work and/or to secure a desired outcome.
62. Case 467.
63. Cases 405, 444, 463 and 474.
64. Case 412.
65. Case 441.
66. Case 502.
67. Case 411.
68. Case 442.

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Appendix

Table A1 Table of cases

Case	*SAB or region*	*Date; name*	*Gender; age*	*Living situation*
403	Gloucestershire	2021; Five women	Female; ages between 19 and 43. Experiences of homelessness and sustaining safe accommodation	
404	South Gloucestershire	2022; Mrs Y	Female; 50s	Moved into a care home
405	Hampshire	2022; Thematic	Deaths of three women and three men, all but one living alone. Age range 33–85	
406	North East Region	2021; Adult 14	Female; 69	Lived with extended family member and their partner
407	Merton	2021; Colin	Male; 73	Lived alone
408	Merton	2022; SK	Female; not given	Lived alone after daughters left
409	Rochdale	2022; Adult G	Male; 55	Lived alone
410	Herefordshire	2022; Thematic	Six people, four of whom were living in supported accommodation and one was homeless. One woman, aged 42. Five men aged between 24 and 54.	
411	Croydon	2022; Mr O1	Male; 87	Lived with his wife and daughter
412	Croydon	2021; Madeleine	Female; 18	Independent living placement
413	BANES	2022; Elley	Female; 93	Lived alone
414	BANES	2022; Mark	Male; 63	Supported accommodation
415	Stoke and Staffordshire	2022; Anne	Female; late 80s	Lived alone
416	Doncaster	2022; Adult V	Female; 22	Lived with baby and partner
417	Oldham	2022; Derek	Male; 69	Lived alone
418	North East Lincolnshire	No date; AC	Male; 77	Not specified
419	North East Lincolnshire	No date; AB	Male; 56	Homeless
420	North East Lincolnshire	No date; AD	Male; withheld	Lived with mother and step-father
421	Portsmouth	2022; G,H,I,J.	Thematic review of four men aged between 41 and 53 experiencing homelessness	
422	Cumbria	2022; Pauline and George	Male; late 60s Female; late 80s	Lived together
423	Essex	2022; Simon	Male; not given	Lived alone
424	Stoke and Staffordshire	2022; Andrew	Male; 38	Lived alone
425	Newcastle	2022; Adult L	Female; 75	Lived with her husband
426	Leicester	2022; Martin	Male; 30s	Hostel placement
427	Lewisham	2022; Amanda	Female; 57	Lived in a care home
428	Hertfordshire	2021; Hippy	Female; 48	Temporary accommodation
429	Havering	2022; Mr C	Male; early 60s	Own room in shared house after homelessness
430	Havering	2022; Simon	Male; mid 30s	Homeless/temporary accommodation
431	South Gloucestershire	2022; Mr D	Male; not given	Lived alone
432	Teeswide	2022; Molly	Female; 25	Homeless and a range of addresses
433	Torbay and Devon	2022; Thematic	Six people, all of whom lived alone. Three women, aged between 66 and 83. Three men, aged between 54 and 59	
434	Liverpool	2022; Hazel	Female; 55	Lived alone
435	Central Bedfordshire and Bedford Borough	2022; Max	Male; 18	Lived alone
436	Havering	2022; Adult Q and Adult Y	Male; 18 Male; 20	One young adult lived with a parent, the other was in semi-independent living accommodation
437	Sheffield	2021; E	Male; 41	Lived with his partner
438	Sheffield	2021; D	Male; 89	Lived with a family member
439	Newcastle	2022; Adult N	Female; 58	Supported accommodation
440	Manchester	2022; Gayle	Female; early fifties	Lived with younger adult brother
441	East Sussex	2022; Thematic	Four women aged between 19 and 51, all in permanent or temporary accommodation	
442	Dudley	2022; Thematic	Five people	All were living at home.
443	Somerset	2022; Robert	Male; 75	Lived alone
444	Salford	2021; Mathew	Male; not given	Homeless
445	Cornwall	2022; Anthony and Mary	Male; 47 Female; 78	Mother and son living together
446	North Somerset	2022; Thematic	Male; 54. Male; 74. Female; 71	Two men were living alone. A mother and son living together

(*continued*)

Table A1

Case	*SAB or region*	*Date; name*	*Gender; age*	*Living situation*
447	City of London and Hackney	2021; Mr EF	Male; 89	Lived alone
448	Leeds	2022; Thematic	Four cases involving five people living in their own homes. One man aged 74. Four women aged 54, 66, 78 and 81.	
449	Richmond and Wandsworth	2021; Daniel	Male; 36	Own tenancy
450	Kent and Medway	2022; Douglas	Male; 62	Homelessness and temporary accommodation
451	Wigan	2022; Diane	Female; 65	Lived alone
452	Wigan	2022; Colin	Male; not given	Lived with adult son
453	Tameside	2022; Cheryl	Female; 74	Lived with her husband
454	Cheshire East	2022; Jane	Female; 63	Lived with her husband
455	Slough	2022; Peter	Male; not given	Housed out of area following homelessness
456	Leicestershire and Rutland	2022; Person D	Male; not given	Lived with a friend
457	Kent and Medway	2022; Carl	Male: 57	Lived alone
458	Slough	2021; Mary	Female; 77	Lived with her husband
459	Leicestershire and Rutland	2020; Anna	Female; 50s	Tenancy after being of no fixed abode
460	West Berkshire	2022; Louise	Female; 40s	Lived at home, with a resident personal assistant
461	Leicester	2022; Martin	Male; 30s	Hostel placement
462	Bexley	2022; Elvis	Male; 50s	Lived with a friend
463	City of York	2021: Mr Z	Male; 48	Held a tenancy
464	Swindon	2022; Andrew	Male; 77	Lived alone
465	Worcestershire	2021; Joan, Kate and Laura	Female; not given, 23 and 20	Mother and daughters live together
466	Kent and Medway	2022; Lee	Male; 48	Lived alone in a caravan park
467	Enfield	2022; Mr K	Male; 70	Lived alone
468	Newcastle	2022; Thematic	Focus was not on specific cases but on learning from practitioner experiences	
469	Newcastle	2022; Adult M	Female; 72	Lived alone
470	Hillingdon	2022; Angela and Chris	Thematic review. Female, 64, living alone. Male, 65, living in a shared home	
471	Dudley	2022; Stanley	Male; 82	Lived alone
472	Calderdale	No date; Mr C	Male; 81	Lived alone
473	East Sussex	2022; Ben	Male; 64	Nursing home resident
474	Swindon	2022; Alison	Female; 49	Lived alone
475	Salford	2022; Irene	Female; 71	Lived with her husband
476	Salford	2022; Jayne	Female; 49	Lived with her mother
477	Barking and Dagenham	2021; JA	Female; 62	Lived with her son
478	Camden	2022; Mark	Male; 24	Lived alone
479	Buckinghamshire	2022; FF	Male; 94	Lived alone
480	Lancashire	2022: Adult T - Mary	Female; 74	Lived with her husband
481	Lancashire	2021; Adult P	Male; not given	Not specified
482	Lancashire	2021; Adult O	Female; not given	Lived alone
483	Lancashire	2020; Adult K	Male; 80	Lived with his wife
484	Kent and Medway	2022; Leon	Male; 31	Lived alone
485	Kent and Medway	2022; David	Male; 46	Lived with his brother
486	Kent and Medway	2022; Jodie	Female; not given	Lived with her partner
487	Kent and Medway	2022; Jack	Male; not given	Supported accommodation
488	Kent and Medway	2022; Caroline	Female; 38	Lived with her family
489	Suffolk	2022; Thematic	An analysis of learning from completed reviews, including a focus on self-neglect	
490	Essex	2022; John	Male; 50	Lived alone
491	Sutton	2022; Thematic	A thematic review of fire deaths.	
492	Rotherham	2021; Painter and son	Male; 91 Male; 61	Lived together
493	Rotherham	2021; David	Male; 60s	Lived alone
494	Waltham Forest	2022; Harry	Male; 68	Live-in landlord
495	Southampton	2022; Louise	Female; 87	Supported housing
496		2021; Ms Y	Female; not given	Lived in a low support care setting

(*continued*)

Table A1

Case	*SAB or region*	*Date; name*	*Gender; age*	*Living situation*
	Cambridgeshire and Peterborough			
497	Cambridgeshire and Peterborough	2022; Esther	Female; 51	Lived with her (ex)-partner
498	Cambridgeshire and Peterborough	2021; Carol	Female; 58	Lived with her husband and daughter
499	Oxfordshire	2021; Adult V	Male; not given	Lived alone
500	Oxfordshire	2022; Ian	Male; 36	Evicted from supported housing onto the street
501	Blackpool	2022; Adult Q	Male; 19	Lived with family members
502	Richmond and Wandsworth	2021; Evelyn	Female; 75	Died abroad in a care home

Source: By author

Corresponding author

Michael Preston-Shoot can be contacted at: michael.preston-shoot@beds.ac.uk

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