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# Three early papers on self-neglect

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## Abstract

**Purpose** – The paper examines three English research papers on self-neglect, from 1957, 1966 and 1975, discussing them in the context of more recent thinking and the statutory framework in England.

**Design/methodology/approach** – In reviewing the three research papers, developments and points of continuity in the field of self-neglect were identified and are discussed in this paper.

**Findings** – In light of the findings of the three articles, the present paper traces some of the classificatory refinements in this field that have taken place since the papers were published, notably in respect of hoarding and severe domestic squalor. Some of the difficulties in making judgements about behaviour thought to breach societal norms are described, and the challenges practitioners face in intervening in cases, particularly where the person concerned is refusing assistance, are examined.

**Originality/value** – By drawing on the historical research context, the paper contributes to our current understanding of the field of self-neglect.

**Keywords** Safeguarding, Legal, Care Act 2014, Hoarding, Self-neglect, Severe domestic squalor

**Paper type** General review

## Introduction

When, around a decade ago, Suzy Braye, David Orr and Michael Preston-Shoot (2011) conducted their review of self-neglect research for the Social Care Institute for Excellence (SCIE), some three-quarters of the literature they included was from North America. It is often remarked, though, that the pioneering work in this field was conducted in England. This paper revisits this research—by Shaw and Macmillan in Nottingham in 1957 and 1966, and a decade later, the article by Clark, Mankikar and Gray (1975) that coined the term “Diogenes Syndrome”—placing it in the context of some more recent thinking on the topic and the statutory framework provided by the Care Act 2014.

The need for further research in this topic was indicated by the James Lind Alliance (2018), which ranked effective adult social worker responses to people who self-neglect among its top ten research priority areas, following a survey of the views of service users, carers and practitioners. Prompted by this, but also by a recent study which raised doubt as to the degree to which self-neglect was recognized by practitioners working with people who are homeless (Martineau and Manthorpe, 2020), this paper aims to contribute to current thinking by returning to early work on the topic by clinicians who both recognized a problem and sought to name a syndrome. Although not grounded in a formal literature review, the paper derives from a close reading of the articles and draws on the questions this provoked to direct a selective gaze at more recent literature along with the present statutory context in England. It aims for a discursive engagement with this early research, prompted by observed points of continuity and change. The paper starts out with definition (*What is self-neglect?*) and then moves to a brief consideration of social context and social norms in this topic (*“a completely uncivilized state of affairs”*). The paper ends by focusing on some

of the challenges practitioners face in providing care and support to those who self-neglect (*Refusals and interventions*).

### What is self-neglect?

Since the SCIE report of 2011 mentioned above (Braye *et al.*), the Care Act 2014, read with its accompanying guidance (Department of Health and Social Care, 2020), has provided self-neglect with a definition of sorts and a statutory framework for those tasked with responding to it in England. Just as local authorities are given a broad mandate to promote individual well-being in Part 1 of the Act, so, in the statutory guidance, self-neglect is presented in broad terms as referring to a person's neglect of their health, hygiene, or surroundings (this last including hoarding). The definition is left at that, although an entry in the guidance's glossary indicates that refusal of assistance by the person is also part of the picture (Department of Health and Social Care, 2020).

Local authority obligations and powers deriving from the 2014 Act include, where statutory conditions are met, duties to assess people's needs and to follow adult safeguarding protocols. Self-neglect's formal inclusion within the practice of adult safeguarding in the guidance to the Act was new and marked a significant conceptual as well as a policy shift. Prior to this, the ambit of adult protection (as the field had been called) only extended to abuse and neglect by a third party (Department of Health and Home Office, 2000). This is in contrast to the United States (U.S.) where self-neglect has fallen within the remit of Adult Protective Services for some years (Jackson, 2016). In England, it only became mandatory for local authorities to report case numbers three years ago; there were 7,790 concluded safeguarding enquiries into self-neglect in 2018-19. In terms of annual count, this puts self-neglect at number six of the eleven forms of abuse and neglect within adult safeguarding practice in England (NHS Digital, 2019).

#### *Breakdown in Nottingham, Diogenes in Brighton*

The pioneering paper here, from Nottingham in 1957 (Shaw and Macmillan), did not actually use the term *self-neglect*, rather "social breakdown in the elderly"—suggesting a failure or inability on the part of the person to meet certain core social obligations—"a state resulting from prolonged neglect of the physical and mental health of the individual and of his environment, rendering the sufferer offensive to society" (p. 823). In a selective study focusing only on those aged 60 and over, practitioner-researchers Patricia Shaw and Duncan Macmillan (both doctors) reported on 139 people drawn from 987 health visitors' records, examining symptoms and signs, causes, remedies and prevention [1]. Later, in what is often described as the seminal paper in this field, published in the *British Medical Journal* (*BMJ*; Macmillan and Shaw, 1966), the same researchers sought to crystallise the symptoms into a syndrome, which they saw as being characterised by "severe self-neglect", as they put it (p. 1032). They referred to it as "senile breakdown" because, except for one 48-year-old, they only found it in the "senile epoch" (again, 60 and over) in their group of 72 cases (*ibid.*). It was marked by a lack of "personal and environmental cleanliness" (*ibid.*), and Macmillan and Shaw developed scales to grade the person (a five-item assessment of: "skin, hair, hands, clothes and method of disposing of excreta") and premises (distilled into ten items: "floor, walls, ceiling, windows, bed, table, cooker, coal, dirt, and smell"). Each facet was subject to a five-tier severity grading. In the case of the person's hair, for example, these were: 1. clean, cared for; 2. clean, untidy; 3. rather dirty and untidy; 4. very dirty; 5. filthy, infested (p. 1033).

Writing in *The Lancet* in 1975, Clark *et al.*, based at the Department of Geriatric Medicine at Brighton Hospital, discussed a group of 30 people (aged 66-92) who had been admitted with acute illness and self-neglect: "All had dirty, untidy homes and a filthy personal appearance about which they showed no shame" (p. 366). There was considerable definitional overlap with the Nottingham work—

“domestic squalor, disorder, and extreme self-neglect” (*ibid.*)—but the *Lancet* study gives much greater prominence to hoarding, which was absent from the 1957 paper and worthy of only passing mention in 1966, where “hoarder” was presented as a personality trait sometimes observed (Macmillan and Shaw, 1966, p. 1033). In Brighton, the researchers reported that “hoarding” of “rubbish” was seen in several of the cases: “newspapers, tins, bottles, and rags, often in bundles and stacks—and in six instances the size of the collection seriously reduced living space” (Clark *et al.*, 1975, p. 366). The authors also used the word *sylllogomania*—from the Greek, “collecting madness”—for this behaviour, but the term they introduced for the whole constellation of behaviours and circumstances was “Diogenes Syndrome” (we return to Diogenes, and the reference to shame, in the third section of this paper).

### *Neglect of surroundings, neglect of self*

Since these three early studies, there have been refinements in classification in some quarters of the medical literature—a disaggregating shift away from the seeming catch-all of Diogenes Syndrome. By giving hoarding a discrete classification in its diagnostic manual (*DSM-5*), the American Psychiatric Association (APA) (2013) was no longer presenting it as a symptom of obsessive-compulsive disorder (OCD), rather as a related disorder in its own right. Hoarding, “the persistent difficulty discarding or parting with possessions, regardless of their actual value” (APA, 2013), was now to be distinguished from comparable behaviours ascribable to other health conditions. The manual entry notes, for example, that where hoarding-type behaviour does show up in people with OCD it is more likely to feature the accumulation of bizarre items, such as “trash, feces, urine, nails, hair, used diapers, or rotten food”, adding, “[a]ccumulation of such items is very unusual in hoarding disorder” (APA, 2013). It is now possible, then, to be diagnosed with both hoarding disorder and OCD where the two discrete sets of symptoms are present (*ibid.*). The World Health Organization (WHO) followed the *DSM-5*’s lead in the 11<sup>th</sup> revision of its International Classification of Diseases (ICD) in 2018. The ICD is the formal source for standards for disease classification in the National Health Service, though WHO Member States are not scheduled to start reporting using *ICD-11* until 1 January 2022 (WHO, 2018; Pertusa *et al.*, 2019).

The drawing of distinctions does not stop with hoarding. Published in the run-up to the release of *DSM-5*, in a book reviewing research into what the editors (three psychiatrists) refer to as “severe domestic squalor”, this term is applied “when a person’s home is so unclean, messy and unhygienic that people of similar culture and background would consider extensive clearing and cleaning to be essential” (Snowdon *et al.*, 2012, p. 11). Within severe domestic squalor, the editors propose six sub-types and, like the authors of the 1966 paper, refer to a scale for degrees of severity. Note the conceptual difference from hoarding disorder: severe domestic squalor is a report on living conditions; it does not describe the people and is not a medical diagnosis (though it may emanate from a medical condition). And the editors report that: “Hoarding is common in those who live in squalor, but most people who hoard do not live in squalor” (p. 183). That said, a significant minority of people who hoard, perhaps as high as 25 per cent, do live in varying degrees of squalor, according to psychologist David Mataix-Cols in a chapter on hoarding in the book (Mataix-Cols, 2012).

And what of the divisions between surroundings and self? According to Snowdon *et al.* (2012), the degree of personal cleanliness does not appear to correlate well with degrees of domestic uncleanliness. There was some support for this in the *BMJ* study: Macmillan and Shaw (1966) reported that in a few cases the person cared for her person but not her environment. Snowdon *et al.* (2012) report that some individuals have been observed to live in filthy homes but need to be acceptably clean in order to go out to work. The converse can also be the case: “Personal uncleanliness may not go hand-in-hand with environmental squalor” (Snowdon *et al.*, 2012, p. 182).

The net result of these reports from research as it stood in 2012 is that these researchers prefer to place a tight definitional cordon around the term *self-neglect*, having it refer to a lack of care of self (whether nutrition, health and/or personal hygiene), and distinguishing it from people's relation to their surroundings, which they put in different terms (whether under *squalor* or *hoarding* or a mixture of the two). And within these discriminations, it is interesting to note that Snowdon *et al.* (2012) comment that the literature on hoarding has evolved separately from that on squalor and that "there would be value in seeing what might be learned from each other and what happens when there is overlap" (p. 183).

It is in the light of distinction making of this order that Braye *et al.* (2011, p. 8) comment on the "almost bewildering" array of manifestations that may call for the designation of self-neglect. Given this, it is worth stressing that the policy environment in England is now governed by the use of *self-neglect* as the formal umbrella term for lack of care for both environment and self, whatever dissonance this sets off within the wider scholarly and clinical context. In this, it is harking back to the broad confines of Diogenes Syndrome, though that term is not used in the guidance and self-neglect under the Care Act 2014 is not restricted to a particular age category (see further below).

It may be useful to close this discussion of definition by touching on three other aspects which are highlighted to varying degrees by the papers under review: alcohol, age, and service refusal. The 1957 and 1966 papers both fastened on alcohol use as a prominent causal factor in the development of self-neglect (or social/senile breakdown as it was named). Recent analysis of Safeguarding Adults Reviews (SARs) where homelessness had been a factor identified an ambiguity in this area, where substance misuse and alcohol dependency were often prominent (Martineau and Manthorpe, 2020). One SAR, for example, described practitioners manifesting 'a universal sense of professional frustration that was caught up in the confusion of not having a universal understanding of chronic alcohol use being self-neglect' (Waltham Forest Safeguarding Adults Board, 2017, p. 17). Similarly, Alcohol Change UK (2019), in its examination of alcohol-related SARs, seemed to open the door to alcohol misuse being seen as self-neglect. Substance misuse and alcohol dependency might theoretically fit within the description of "self-neglect" in the Care Act 2014 statutory guidance (via its health component: Department of Health and Social Care, 2020), but they have not been part of the conventional understanding of the phenomenon. Indeed, though Lauder *et al.* (2009) have argued for a sub-category of self-neglect associated with substance abuse, this is still presented by them as either a co-morbidity or in terms of aetiology (or both), rather than a widening of the definition of self-neglect itself. In line with this approach, in a study by Paudyal *et al.* (2020) of people experiencing homelessness, substance misuse is classified as a failure of risk avoidance or mitigation through engagement in risky behaviour, but not as self-neglect (which, along with adult safeguarding, is not mentioned in the paper).

As regards age, *DSM-5* (APA, 2013) and Snowdon and his colleagues (2012) report that neither hoarding disorder nor severe domestic squalor respectively is the sole province of older people (in this regard, Snowdon *et al.* argue that research has been hampered to a significant extent by selection bias). One might surmise that these things only become a problem, or a problem that is noticed by others, with the passage of time (and note that in England a local authority's duty to assess is only triggered when "it appears" to it that an adult might have need for care and support: section 9 Care Act 2014). In 1975, Clark *et al.* speculated that the syndrome they described might speak of a "lifelong proclivity" (p. 368). Braye *et al.* (2011) reported as a theme in the literature the transformation of a behaviour, such as collecting, from something functional to something dysfunctional over time for the individual, as consequences became more difficult to manage (the proclivity may also become stronger). Shaw conceded that "social breakdown" was found in younger

age groups—but she was not looking there (Shaw and Macmillan, 1957). More recently, hoarding symptoms, the *DSM-5* suggests, may first emerge around ages 11-15 years, with “clinically significant impairment” by the person’s mid-30s (APA, 2013; see also, Zaloski *et al.*, 2019).

Finally, while under the Care Act 2014 age no longer occupies the place it once did in thinking about self-neglect, it is a peculiarity of the Act’s guidance that it indicates in its glossary of terms that refusal of assistance is a necessary component of self-neglect (in this, the guidance’s definition is awkwardly split across the main body of the document and its annexes: Department of Health and Social Care, 2020)[2]. While this is how a proposed definition of self-neglect was presented in the research cited in the guidance (Braye *et al.*, 2014, p. 191), subsequent work by the same authors has allowed for self-neglect to be found where no such refusal is manifest (e.g. Braye *et al.*, 2015; Preston-Shoot, 2020). Service refusal is returned to later in this paper, but as an aspect of self-neglect it is perhaps best seen as a secondary feature compared to the first order elements, neglect of self and/or environment. Further, it might be apt to follow William Lauder and colleagues who suggest that service refusal is “almost pathognomic of severe self-neglect” (Lauder *et al.*, 2009, p. 453, emphasis added).

### “a completely uncivilized state of affairs”

Putting definitional questions aside, one observes in these early papers hints of the social matrix out of which self-neglect may emerge and the relevance of social norms. We see this particularly in Shaw in 1957 as she attempts to anatomise causation. As already noted, Shaw described what she was seeing in her role as Senior Medical Officer for Prevention, Care and After Care in Nottingham, as “social breakdown in the elderly” (Shaw and Macmillan, 1957, p. 823). This “social ill-health” (*ibid.*) could be attributed to an array of factors that “so react upon one another that it is difficult to apportion the share of blame to any given one” (p. 826). These included physical ill health, poor mental health, alcohol dependency, bereavement, retirement, and finally old or too-large housing that was difficult to manage for the individual concerned. In relation to mental ill health, she remarked:

“Minor degrees of psychosis, limited intelligence and even eccentricities all can play a part in social failure, mainly by alienating the sympathy and interest of those neighbours who might help. There is nothing that frightens neighbours more than a suggestion of mental lack of balance” (p. 826)

This depiction lifts us out of an atomised picture of the individual, as does the description of a single self-neglecting retiree who had moved from a busy job at age 67 to “no company at all. She lived in a mean, little, comfortless house in a row, with quite repellent neighbours” (p. 827). In bereavement (highlighted as a prominent cause in all three of the papers under review) there may be failure to adjust to a life alone; in the case of the “natural isolate” there may be “a gradual failure of standards, simply because there is no one to care and to live up to.” (p. 827).

If this is a sociology of self-neglect, then it is barely nascent. It leads naturally, though, to a consideration of the role of community norms in this field. Talk of “a gradual failure of standards” or of “disordered” lives (we have already seen the word “disorder” in the 1975 Diogenes study) is surely contingent on the standards brought to bear in each case. Focusing on “Incontinence and Dirty Habits” (p. 825) as symptomatic of the “social breakdown” she was discussing in 1957, Shaw remarks:

“The main evil is that neighbours and home helpers shun such a case and it becomes almost impossible to provide means of keeping the house clean. A few older people develop filthy

habits and without constant supervision a completely uncivilized state of affairs will eventually occur.” (Shaw and Macmillan, 1957, p. 826)

Reference to the breaching of community norms in some descriptions of self-neglect (for Shaw, the markers of a civilized state of affairs; for Snowden *et al.* 2012, p. 11, in their reference to people of “similar culture and background”) begs the question: who makes the determination? Alive to this, Shaw wrote of the diagnosis of social breakdown in the elderly as being “arbitrary; some borderline cases may indeed be classified one way or the other according to the interpretation of different observers” (Shaw and Macmillan, 1957, p. 823). Along similar lines, and with reference to the classification of hoarding disorder, one might tritely observe that a person deviating from social norms (being eccentric, say: see Lauder *et al.*, 2005) is not necessarily to be seen as diseased. And certainly, in the run-up to *DSM-5*, there were considerations of the dangers of over-pathologizing (see, for example, the Nordsletten and Mataix-Cols 2012 paper, “Hoarding versus collecting: Where does pathology diverge from play?”). There is an analogy to be made here with the “unwise decisions” principle of section 1(4) Mental Capacity Act 2005.

There are many other examples of corrective approaches aimed at enhancing individual agency in this context. Staying with hoarding, David Orr *et al.* (2019, p. 274) have reported the views of people who have been described as hoarders, generating a “counter-narrative”. At the same time, some of the study participants recount the benefits of diagnosis—the opening up to them of a collective identity with fellow sufferers and a potential remedial course of action (Orr *et al.*, 2019). Coming from a different perspective, Scott Herring (2014) has written in the U.S. context of the restive public curiosity around hoarding. He suggests this is symptomatic of wider societal panics (after Stanley Cohen), focusing on instances of self-neglect which have been the subject of extraordinary and prolonged interest to make his point—the Collyer brothers in 1940s New York, for example, and the Beales of Grey Gardens in the 1970s.

The Care Act 2014, building as it did on principles in the Mental Capacity Act 2005, is a potential resource for these kinds of critique—section 1(3)(a) of the 2014 Act, for example, stressing “the importance of beginning with the assumption that the individual is best-placed to judge the individual’s well-being”; and section 1(3)(b) highlighting “the individual’s views, wishes, feelings and beliefs”. It may be the case that the individual’s conduct constitutes a nuisance to neighbours, breaches public health laws or amounts to a failure to meet other obligations (as a tenant, for example). But in any case, the approaches and principles touched on in this section weigh against reductionist labelling, the foreclosing of engagement, and flight into inappropriate interventions by professionals. It is to some of the difficulties around engagement and intervention in self-neglect work, evidenced both in the three articles under review but also more recently, that the last section in this paper turns.

### Refusals and interventions

Under the sub-head “Refusers” in their 1966 paper, Macmillan and Shaw discuss 22 of the 72 cases under review who were reluctant to engage with services: “These people gave the impression that they could not bear any disturbance of their isolation” (p. 1036). Such observations echo references to “the natural isolate” in Shaw’s earlier study (Shaw and Macmillan, 1957, p. 827), or the “Hermits of Harlem” (Homer and Langley Collyer) or the “reclusive” Beales of Grey Gardens in Herring’s recent study of American hoarders (Herring, 2014, pp. 28; 14). The two Nottingham studies and the Brighton study also alighted on certain personality types that appeared to the researchers both prevalent and relevant. In the Diogenes paper, in which a third of the patients under review had persistently refused offers of help, researchers found subjects to be “more aloof, detached, shrewd,

suspicious, and less well integrated” (Clark *et al.*, 1975, p. 367). In Nottingham: “Typical of the adjectives applied to them were independent, unfriendly, stubborn, obstinate, aloof, aggressive, suspicious, secretive, and quarrelsome” (Macmillan and Shaw, 1966, p. 1034). The authors reflected:

“As a result of our observations we have come to the conclusion that the rejection of the usual standards of personal and environmental hygiene, which is the cardinal feature of this condition, is in many cases an active and positive reaction, and is not simply a passive deterioration. It is an expression of a hostile attitude to and a rejection of the outside community.” (Macmillan and Shaw, 1966, p. 1036)

The aptness of referring to Diogenes of Sinope in this field is often questioned (he was no hoarder, for example) and reference in the literature to Diogenes Syndrome appears to have faded. However, refusal is one area where his example does seem to resonate. At two and a half pages, the 1975 Diogenes paper is frustratingly thin in some respects. We are left to speculate, for example, about the place of shame in the syndrome (“they showed no shame”: Clark *et al.*, 1975, p. 366). (There is a link here with Diogenes who was known as Diogenes the Dog because of dogs’ association with shamelessness in ancient Greek culture.) For the Brighton authors, their linkage of the syndrome with a lack of shame may perhaps have been borne of their observations of typical personality traits (see above), the fact that only two of the sample apologised for their personal or domestic state, and the presence of a significant minority who refused help. Whatever the significance of shame (and shamelessness) here, Diogenes’ refusal of an offer of assistance from Alexander the Great was described as a paradigmatic case of refusal of support by Scanlon and Adlam in their 2008 consideration of the psychosocial aspects of the social exclusion of certain groups (see also Fuller, 2017). And, as they point out, this particular snub was in keeping with his general refusal to abide by community norms, which was integral to his active protest against them. There is a continuity to be observed here with the way in which Scanlon and Adlam’s interpretation is embedded in their own highly critical commentary on the social and political circumstances in which the socially excluded find themselves. It is a commentary suggestive of a more profound social breakdown than the one to which Shaw and Macmillan (1957) referred.

Recent work examining Safeguarding Adults Reviews of the care and support of people who were homeless (and Diogenes did present as street homeless) took a step back from simple refusal and suggested there were reasons on both sides of the encounter for poor engagement (Martineau and Manthorpe, 2020). Reviews evidenced a reluctance to engage on the part of individuals who were homeless—sometimes this appeared to be the result of mental health problems or bound up with the itinerant nature of individual lives. On the other hand, practitioner approaches sometimes seemed to be at fault—review authors criticized failures of professional curiosity, for example, or stigmatising attitudes, or insufficiently nuanced approaches to mental capacity, not least in relation to the ability of individuals to see decisions through. It may be that in such cases service refusal is a feature less of self-neglect than of “a mismatch between needs of the self-neglecting person, and the ways in which services are structured and offered” (Lauder *et al.*, 2009, p. 453).

Among the legal rules relevant here are those in section 11 Care Act 2014, dedicated to *Refusal of assessment*. In short, the local authority’s obligation to carry out a needs assessment falls away if the person refuses (though pre-Care Act case-law would suggest that such refusal should be “persistent and unequivocal”: *R v Kensington & Chelsea RLBC, ex p Kujtim*, 1999, para 32; quoted in Clements, 2017). The local authority’s duty to assess remains, though, if the person is a safeguarding concern or if they lack capacity to refuse the assessment. This paper ends with a brief discussion of some of the challenges in intervening in self-neglect cases, including in the face of an apparent reluctance to be helped on the part of the person concerned, addressing also questions of mental capacity.



## *Interventions*

One of the many changes to the practice of adult safeguarding brought in by the Care Act 2014 was the dropping of the word *investigation* in favour of *enquiry*. The then lead civil servant on adult safeguarding at the Department of Health stressed that while “investigation” may be suited to criminal, disciplinary or clinical fields, “enquiry” emphasised the need for discussion, reflection and a process that gives importance to “the subjective experience of the individual as well as the views of the professional”—going on to say, “the enquiry, the discussion itself, is part of the intervention” (Crawley, 2015, p. 152).

As was mentioned above, there were 7,790 such safeguarding enquiries concluded in 2018-19 related to self-neglect in England (NHS Digital, 2019)—that is, where conditions set out in section 42 Care Act 2014 were met in the case. Section 42 should be read alongside the guidance, which counsels that whether or not a safeguarding enquiry is called for is to be assessed on a case-by-case basis, with consideration being given to whether or not the person is able to control their behaviour without external support (Department of Health and Social Care, 2020).

The factors judged to be in play in any given instance, though, will obviously have a bearing on the nature of professionals’ enquiry and intervention, and on which agencies take the lead. In the earliest of the papers under review here, there was a recognition that the challenges of this kind of work could be intractable:

“as each case of social breakdown comes to light one is faced with a problem which may, and indeed usually does, take hours of many people’s work before it is even partially solved; often it is solved only by death.” (Shaw and Macmillan, 1957, p. 830)

Where reluctance on the part of the person concerned was encountered, what was required was “time and patience” and “frequent visiting” so that “good relations are established” (p. 829). Such rapport building might also serve a preventative purpose, enabling incipient cases to be flagged: to that end a general practitioner acquaintance of Shaw “visits all her elderly patients regularly once a month and pays a semi-social visit” (p. 829). The same author also favoured what she called “integrated working” between the Health and the Welfare Services Departments which, in Nottingham, had showed “the fixed determination that a little overlapping is better than one old person being deprived of help” (p. 828). Both Shaw and the Diogenes study authors saw little value in compulsory removal (a power itself removed by section 46 Care Act 2014), Shaw noting this was “a drastic measure and usually leads to great distress... any sudden upheaval in an old person’s life often ends in a speedy death” (p. 829).

The general drift of these approaches (stressing the importance of time, continuity, relationship, and of joint working) finds resonance in the growing contemporary literature, both that reporting research (e.g. Braye *et al.*, 2014) and that targeted at practitioners (e.g. Barnett, 2018). Unsurprisingly, such recent work is of a different order of sophistication compared to the three papers under review. For example, under the rubric of adult safeguarding, Braye *et al.* (2017) have isolated a seven-component skill set for practitioners working on self-neglect; Mason and Evans (2020) have discussed the dynamics involved in joint working in this field; and, Preston-Shoot (e.g. 2020) has analysed Safeguarding Adults Reviews to examine failings in such collaboration.

Aside from the development of adult safeguarding and the Care Act 2014’s critical impact on this practice, arguably the most significant innovation since the publication of these three early papers has been the Mental Capacity Act 2005. Both the 1966 and the 1975 studies reported that, in terms of mental health, around half of the sample were reported to exhibit a psychiatric disorder. In the

earlier of the two this was mostly “senile psychosis” and it was, for the authors, an outstanding research question as to why the syndrome they sought to name was in some cases found coupled with psychiatric illness, but not in others (Macmillan and Shaw, 1966, p. 1037). Today, mental capacity assessments under the 2005 Act are integral to self-neglect practice and arguments as to the legitimacy of intervention have been well rehearsed in recent years. This is chiefly thanks to the evolving case-law from the Court of Protection (the well-known Sykes case, for example, below); and in developments of the inherent jurisdiction of the High Court, the recent contentious case of *Southend-on-Sea Borough Council v Meyers* (2019) being an instance where, arguably, self-neglect by Mr Meyers ran alongside the undue influence of his son with whom he lived, in dreadful conditions. Connected debates focusing on the social-model approach of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) have also become increasingly prominent.

It may be fitting to close this paper by recounting a single case of self-neglect where the inability of the person to make decisions about their care and support placed them within the jurisdiction created by the Mental Capacity Act 2005. The case of Manuela Sykes is illustrative of how judges working in the jurisdiction may render the individual’s best interests in such a way that the person’s wishes are prioritised, indeed followed, notwithstanding their inability to make decisions germane to the matter at hand. As Peter Jackson J put it in another case:

“once incapacity is established so that a best interests decision must be made, there is no theoretical limit to the weight or lack of weight that should be given to the person’s wishes and feelings, beliefs and values.

[...]

“a conclusion that a person lacks decision-making capacity is not an ‘off-switch’ for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view.” (*Wye Valley NHS Trust v Mr B*, 2015, paras 10-11)

Manuela Sykes was, among other things, a political activist and campaigner. She had stood unsuccessfully seven times for Parliament; on the other hand, she was successful in her campaign to be named in the 2014 Court of Protection judgment of which she was the subject—not the norm in such cases. Diagnosed with dementia, she was found by the Court of Protection to lack capacity to make decisions about her care and support (*Westminster City Council v Manuela Sykes*, 2014). She expressed a strong desire, though, to reside in her own home, a wish expressed both in her Lasting Power of Attorney *and* to the Court. She objected to living at the care home where she had been placed by the local authority. Her flat was said to be in a chaotic state, so unhygienic and cluttered as to be hazardous, and there were concerns about poor personal care including malnourishment and poor medication compliance. She was also reported to have used verbal, physical and threatening behaviour towards carers coming into her flat in an earlier phase. It fell to District Judge Anselm Eldergill to determine her best interests and, in ordering a trial period at home despite the risks involved, he remarked:

“The law requires objective analysis of a subject not an object. [Manuela Sykes] is the subject. Therefore, it is her welfare in the context of her wishes, feelings, beliefs and values that is important. This is the principle of beneficence which asserts an obligation to help others further their important and legitimate interests. In this important sense, the judge no

less than the local authority is her servant, not her master.” (*Westminster City Council v Manuela Sykes*, 2014, pp. 21-22)

Sykes died some three years after this judgment, aged 92. The precise character of the trial period is unreported—though Sykes’ obituary (Canneti, 2017) records that the return home proved unsustainable and she was back in the care home in a few weeks.

### Concluding remarks

These three early papers, in their different ways, attempt to isolate a syndrome, “an entity in its own right [...rather than...] merely a collection of incidental accompaniments of a variety of conditions” (Macmillan and Shaw, 1966, p. 1036). It is hoped that, while it draws on neither a comprehensive review of the literature nor an historical analysis of the topic, the reading presented here puts current thinking on self-neglect and the English legislative framework into some relief. The three papers give a vivid depiction of self-neglect’s clinical presentation. While hoarding disorder has since been accorded formal diagnostic criteria—within the biomedical approach, at least, it is an entity in its own right—there remain those behaviours and circumstances, which are not in themselves amenable to diagnosis. We have seen some of the challenges in understanding the way that all of these elements manifest and the ambivalence that can arise in making judgements about them.

Today, under the Mental Capacity Act 2005, an individual’s ability to make decisions is a central concern for practitioners engaged with those who may be exhibiting self-neglect. This altered legislative and conceptual context is an obvious point of distinction where the three early papers are concerned, and there is little to draw from them here. An individual’s mental capacity has a bearing on whether the person is viewed as being unwilling or unable to look after themselves and their immediate environment. Perhaps unsurprisingly, the survey of service users, carers and practitioners mentioned in this paper’s introduction found that addressing this question was one of the most problematic facets of self-neglect practice (James Lind Alliance, 2018).

For practitioners today, to these complexities is added the question of whether safeguarding protocols should be invoked in instances of self-neglect. This paper is not the place to interrogate what self-neglect’s inclusion in adult safeguarding practice contributes in terms of outcomes. But it is worth noting that the insertion of self-neglect by the Care Act 2014 statutory guidance among the pre-existing safeguarding categories carried with it an historical irony. For, before the recognition of elder abuse in the community in the 1970s and the slow ensuing development of elder abuse policy in England, welfare intervention into the lives of older people had historically been *limited* to cases of self-neglect (whether or not it was named as such)—for which there was legislative provision for the compulsory removal of the individual concerned (Biggs, 1995). The three early papers under review are notable for advising against strong interventions of this kind. Indeed, as we have seen, perhaps the most striking point of continuity between research then and now is to be found in the earliest of these papers, in the work of Shaw, with its focus on the importance of relationship building and integrated working in professional approaches to self-neglect (Shaw and Macmillan, 1957).

### Notes

1. The 1957 paper was joint authored by Shaw and Macmillan, but each writing discrete parts. This paper focuses on the part written by Shaw. Hence, while the reference remains Shaw and Macmillan (1957), in the text the paper refers to Shaw alone.

2. The Care Act 2014 statutory guidance entry in Annex J (glossary) for self-neglect reads: “Where someone demonstrates lack of care for themselves and or their environment and refuses assistance or services. It can be long-standing or recent.” (Department of Health and Social Care, 2020).

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### References

- Alcohol Change UK (2019), *Learning from tragedies. An analysis of alcohol-related Safeguarding Adult Reviews published in 2017*, Alcohol Change UK, London.  
<https://alcoholchange.org.uk/publication/learning-from-tragedies-an-analysis-of-alcohol-related-safeguarding-adult-reviews-published-in-2017>
- American Psychiatric Association (2013), *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.), APA, Arlington, USA.
- Barnett, D. (2018), *Self-neglect and hoarding: a guide to safeguarding and support*, Jessica Kingsley Publishers, London.
- Biggs, S. (1995), “The development of an elder abuse policy in Britain: patterns and prospects”, *Social Work in Europe*, Vol. 2 No. 3, pp. 30-33.
- Braye, S., Orr, D. and Preston-Shoot, M. (2011), *Self-neglect and adult safeguarding: findings from research*, Social Care Institute for Excellence, London.  
<https://www.scie.org.uk/publications/reports/report46.pdf>
- Braye, S., Orr, D. and Preston-Shoot, M. (2014), *Self-neglect policy and practice: building an evidence base for adult social care*, Social Care Institute for Excellence, London.  
<https://www.scie.org.uk/files/self-neglect/policy-practice/report69.pdf>
- Braye, S., Orr, D. and Preston-Shoot, M. (2015), *Self-neglect policy and practice: key research messages*, Social Care Institute for Excellence, London. [https://www.scie.org.uk/files/self-neglect/policy-practice/self-neglect\\_general\\_briefing.pdf](https://www.scie.org.uk/files/self-neglect/policy-practice/self-neglect_general_briefing.pdf)
- Braye, S., Orr, D. and Preston-Shoot, M. (2017), “Self-Neglect and Hoarding” in Cooper, A. and White, E. (Eds.), *Safeguarding Adults Under the Care Act 2014. Understanding Good Practice*, pp. 180-198, Jessica Kingsley Publishers, London.
- Canneti, R. (2017), “Manuela Sykes obituary”, *The Guardian*, 28 November.  
<https://www.theguardian.com/politics/2017/nov/28/manuela-sykes-obituary>
- Clark, A. N. G., Mankikar, G. D. and Gray, I. (1975), “Diogenes syndrome: a clinical study of gross neglect in old age”, *The Lancet*, Vol. 305 No. 7903, pp. 366-368. [https://doi.org/10.1016/S0140-6736\(75\)91280-5](https://doi.org/10.1016/S0140-6736(75)91280-5)
- Clements, L. (2017), *Community Care and the Law* (6<sup>th</sup> ed.), Legal Action Group, London.
- Crawley, C. (2015), “A view from the Department of Health”, *The Journal of Adult Protection*, Vol. 17 No. 3, pp. 151-152. <https://doi.org/10.1108/JAP-04-2015-0011>

Department of Health and Home Office (2000), *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, Department of Health; Home Office, London. <https://www.gov.uk/government/publications/no-secrets-guidance-on-protecting-vulnerable-adults-in-care>

Department of Health and Social Care (2020), *Care and support statutory guidance*, (updated 24 June 2020), Department of Health and Social Care, London. <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

Fuller, J. (2017), "Safeguarding Diogenes", *Health & Social Care Workforce blog*, 17 August. <https://blogs.kcl.ac.uk/socialcareworkforce/2017/08/17/safeguarding-diogenes/>

Herring, S. (2014), *The Hoarders. Material deviance in modern American culture*, University of Chicago Press, Chicago.

Jackson, S. L. (2016), "The shifting conceptualization of elder abuse in the United States: From social services, to criminal justice, and beyond", *International Psychogeriatrics*, Vol. 28 No. 1, pp. 1-8. <https://doi.org/10.1017/S1041610215001271>

James Lind Alliance (2018), *Priority Setting Partnerships: Adult Social Work Top 10*, James Lind Alliance, Southampton. <https://www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/top-10-priorities.htm>

Lauder W., Davidson, G., Anderson, I. and Barclay, A. (2005), "Self-neglect: the role of judgements and applied ethics", *Nursing Standard*, Vol. 19 No. 18, pp. 45-51.

Lauder, W., Roxburgh, M., Harris, J., and Law, J. (2009), "Developing self-neglect theory: analysis of related and atypical cases of people identified as self-neglecting", *Journal of Psychiatric and Mental Health Nursing*, Vol. 16 No. 5, pp. 447-454. <https://doi.org/10.1111/j.1365-2850.2009.01397.x>

Macmillan, D. and Shaw, P. (1966), "Senile breakdown in standards of personal and environmental cleanliness", *British Medical Journal*, Vol. 2 No. 5521, pp. 1032-1037. <https://doi.org/10.1136/bmj.2.5521.1032>

Martineau, S. and Manthorpe, J. (2020), "Safeguarding Adults Reviews and homelessness: making the connections", *The Journal of Adult Protection*, Vol. 22 No. 4, pp. 181-197. <https://doi.org/10.1108/JAP-02-2020-0004>

Mason, K., and Evans, T. (2020), "Social work, inter-disciplinary cooperation and self-neglect: exploring logics of appropriateness", *British Journal of Social Work*, Vol. 50 No. 3, pp. 664-681. <https://doi.org/10.1093/bjsw/bcz031>

Mataix-Cols, D. (2012), "Hoarding and severe domestic squalor", in Snowdon, J., Halliday, G. and Banerjee, S. (Eds) *Severe Domestic Squalor*, Cambridge University Press, Cambridge, pp. 65-80.

NHS Digital (2019), *Safeguarding Adults, England, 2018-19. Experimental statistics*. <https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/annual-report-2018-19-england>

Nordsletten, A. E., and Mataix-Cols, D. (2012), "Hoarding versus collecting: Where does pathology diverge from play?" *Clinical Psychology Review*, Vol. 32 No. 3, pp. 165-176. <https://doi.org/10.1016/j.cpr.2011.12.003>

Orr, D., Preston-Shoot, M., and Braye, S. (2019), "Meaning in hoarding: perspectives of people who hoard on clutter, culture and agency", *Anthropology & Medicine*, Vol. 26 No. 3, pp. 263-279. <https://doi.org/10.1080/13648470.2017.1391171>

Paudyal, V., MacLure, K., Forbes-McKay, K., McKenzie, M., MacLeod, J., Smith, A., and Stewart, D. (2020), "'If I die, I die, I don't care about my health': Perspectives on self-care of people experiencing homelessness", *Health & Social Care in the Community*, Vol. 28 No. 1, pp. 160-172. <https://doi.org/10.1111/hsc.12850>

Pertusa, A., Lopez Gaston, R. and Choudry, A. (2019), "Hoarding revisited: there is light at the end of the living room", *BJPsych Advances*, Vol. 25 No. 1, pp. 26-36. <https://doi.org/10.1192/bja.2018.39>

Preston-Shoot, M. (2020), "Safeguarding adult reviews: informing and enriching policy and practice on self-neglect", *The Journal of Adult Protection*, Vol. 22 No. 4, pp. 199-215. <https://doi.org/10.1108/JAP-02-2020-0003>

*R v Kensington and Chelsea RLBC, ex p Kujtim*, (1999) 2 CCLR 340, CA

Scanlon, C. and Adlam, J. (2008), "Refusal, social exclusion and the cycle of rejection: A cynical analysis?" *Critical Social Policy*, Vol. 28 No. 4, pp. 529-549. <https://doi.org/10.1177/0261018308095301>

Shaw, P. H. S. and Macmillan, D. (1957), "The Evidence of Social Breakdown in the Elderly: (a) Social Breakdown in the Elderly; (b) Psychiatric Aspects of Social Breakdown in the Elderly", *Journal (Royal Society of Health)*, Vol. 77 No. 11, pp. 823-836. <https://doi.org/10.1177/146642405707701118>

Snowdon, J., Halliday, G. and Banerjee, S. (Eds.) (2012), *Severe Domestic Squalor*, Cambridge University Press, Cambridge.

*Southend-on-Sea Borough Council v Meyers* [2019] EWHC 399 (Fam) <https://www.bailii.org/ew/cases/EWHC/Fam/2019/399.html>

United Nations (2006), *Convention on the Rights of Persons with Disabilities*, United Nations, New York. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Waltham Forest Safeguarding Adults Board (2017), *Safeguarding Adults Review on Andrew*, Waltham Forest Safeguarding Adults Board, London.

*Westminster City Council v Manuela Sykes* [2014] EWHC B9 (COP) <http://www.bailii.org/ew/cases/EWHC/COP/2014/B9.html>

World Health Organization (2018), *International Classification of Diseases* (11<sup>th</sup> ed.), WHO, Geneva. <https://www.who.int/classifications/icd/en/>

*Wye Valley NHS Trust v Mr B* [2015] EWCOP 60 <https://www.bailii.org/ew/cases/EWCOP/2015/60.html>

Zaboski, B. A., Merritt, O. A., Schrack, A. P., Gayle, C., Gonzalez, M., Guerrero, L. A., Dueñas, J. A., Soreni, N. and Mathews, C. A. (2019), "Hoarding: A Meta-Analysis of Age of Onset", *Depression and Anxiety* Vol. 36 No. 6, pp. 552-64. <https://doi.org/10.1002/da.22896>