

Institution: University of Sheffield		
Unit of Assessment: D-27 English Language and Literature		
Title of case study: Narrative and voice in health and social care		
Period when the underpinning research was undertaken: 2004–2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Brendan Stone	Professor of Social Engagement and the Humanities	2004–now
Period when the claimed impact occurred: August 2013–July 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact (indicative maximum 100 words)

Stone's application and embedding of narrative approaches impacted positively on health and well-being. He influenced, at regional, national, and international levels, the development of mental health policy which integrates patient voice and maximises service-user engagement. He devised workshops and award-winning resources training doctors and social-care workers how to listen to and more effectively support patients/clients, and – through founding the charity Flourish – enabled sufferers of mental ill-health and their carers to articulate experience, navigate support services, build a sense of community, and discover self-worth. Communicating the experience of mental illness has increased public understanding, combating social stigma, including in health-care settings.

2. Underpinning research (indicative maximum 500 words)

Stone's research is grounded on using narrative methodologies to understand and engage with marginalised groups and individuals, especially those living with mental health difficulties. Stories allow people to organise information about, and make sense of, events or actions. Analysing the shape and form of a narrative (as well as its content) reveals the often-tacit beliefs and values of its authors and the culture that created it, and shows how narrative constructs and moulds a sense of identity. Interpreting narrative – including autobiographical accounts – requires attending to how things are said, as well as what is said.

Stone's research has investigated the relationship between narrative and identity in the context of narrative representations of mental illness (R1-2). Through readings of autobiographical and fictional texts, it considers how identity is textually figured, and how the disruptive effects of 'madness' shape these figurations, for example, by using literary techniques – such as bricolage, metanarrative, metaphor, and disrupted chronologies – which are often associated with post-modernism and/or poetry. It explores the ethics and dangers of narrating distress, which may require re-experiencing the roots of distress and disorder, and argues that traditional forms of narrative – which depend on closure, linearity, unity, and coherence – do not adequately represent the experience of mental illness. As a consequence, it suggests that theoretical conceptions of 'narrative identity' should be reworked to account for the experience of vulnerable, marginalised subjects.

Stone subsequently applied the techniques developed for understanding the experience of mental ill-health as expressed in literary texts to analysing the oral and written accounts of actual

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people, using methods of co-production and research-through-practice (e.g. R3). This work not only shows the importance of listening to lived experience for the insights it gives into the realities of living with mental illness; it also demonstrates the therapeutic value of storytelling, and strives to find ways of influencing policy and practice (R4).

Since 2014, the focus of Stone's research has widened to explore the experience of other medical conditions, notably non-epileptic attack disorder (R5-6). Frequently, there is no biologically effective test to determine what is causing seizures, which are usually triggered by stress/trauma. Narrative tools are therefore needed to understand the texture and nature of patients' experience in order to determine what intervention best suits their needs. This research demonstrates, in a different health context, the therapeutic value of listening to patient experience, explored elsewhere in Stone's research in relation to mental health.

3. References to the research (indicative maximum of six references)

- **R1.** Stone, B. (2004). Towards a Writing without Power: Notes on the Narration of Madness. *Auto/Biography*, 12(1), 16–33. https://doi.org/10.1191/0967550704ab0020a
- **R2.** Stone, B. (2006). Diaries, Self-talk, and Psychosis: Writing as a Place to Live. *Auto/Biography*, *14*(1), 41–58. https://doi.org/10.1191/0967550706ab030oa
- **R3.** Stone, B. (2012). A'rt, Autoethnography and use of self in Stickley, T. (ed.), *Qualitative Research in Arts and Mental Health*. PCCS. Available on request.
- **R4.** Stone, B. (2010). 'An anti-discriminatory approach to therapy with seriously distressed clients' in Lago, C. & Smith, B. (eds.) *Anti-Discriminatory Counselling and Psychotherapy* Practice (2nd ed). Sage. Available on request.
- **R5.** Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2017). Written accounts of living with psychogenic nonepileptic seizures: A thematic analysis. *Seizure*, *50*, 83–91. https://doi.org/10.1016/j.seizure.2017.06.006
- **R6.** Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2018). A pilot randomised controlled trial of a home-based writing intervention for individuals with seizures. *Psychology & Health*, 33(9), 1151–1171. https://doi.org/10.1080/08870446.2018.1478974

4. Details of the impact (indicative maximum 750 words)

Influencing health policy and practice

Stone acted as consultant for Sheffield Health and Social Care [SHSC] NHS Trust (104 days, 2015-17). Drawing on his research into the importance of hearing patients' voices, he developed a 5-year strategy (2016-21) for engaging patients with conditions including mental illness, learning disabilities, substance abuse, and neurological disorders; this involves service-users in staff-training and all levels of decision-making [S1]. The strategy instigated a cultural shift that destigmatised health professionals 'coming out' as mental-health service-users and was instrumental in SHSC developing a Lived Experience Network that was 'inconceivable a few years ago' [S2]. It also led to the establishment of Sheffield's Quality Improvement Unit, which uses patients' narratives about their treatment to drive service improvement. This was recognised as 'highly innovative work' that other trusts are 'now emulating' [S4]. Stone received

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the 2016 Excellence in Patient Experience Award (Yorkshire and Humber NHS Leadership Academy) for his work in ensuring service-users have a voice.

The positive impact of these developments is reflected in the Care Quality Commission identifying SHSC as one of the country's most improved mental-health trusts in 2018: 'involving patients and people who use services' was a key factor noted [S3, p.8]. 'Before it was them and us – staff and service-users. Now we feel at the heart of care' [S3, p.36]. In Healthwatch Sheffield's 2018 survey, 69% of respondents agreed that community mental-health support helped with what was important to them, bucking downward national trends in satisfaction [S2]. SHSC's ability to demonstrate expertise in soliciting robust feedback – including from traditionally hard-to-reach groups (e.g. the Afro-Caribbean community) – is also a 'significant advantage' when tendering for services (e.g. in Drug and Alcohol, and Gender Services) [S2].

Stone's impact on NHS practice and policy extends beyond Sheffield. As co-chair of NHS England's Reducing Restraint Strategic Oversight Group [RRSOG] (2018-20), Stone promoted user-voice and experience [S4]. Pilot studies in 38 psychiatric wards, implementing changes designed by staff and service-users, showed a 60+% drop in the use of restraint, with a reduction as high as 88% in some wards [S5]. RRSOG also undertook a critical path analysis of the care and treatment of 'SA', a young person in NHS-commissioned care. Stone ensured that a person with learning disabilities sat on the panel to voice service-user experience. 'SA' has subsequently been moved out of seclusion [S4].

Stone presented RRSOG's work in Finland (2019 [S5]) and was an invited participant at the 2018 Global Ministerial Mental Health Summit: the first meeting of government ministers and clinical leaders from across the world to develop policy and practice [S6, S4]. Stone's inputs to the subsequent declaration (signed by all 61 countries present) concerned the need to involve people with experience of mental illness and the importance of interventions being locally appropriate.

Training professionals

In 2014, Stone developed masterclasses for medical professionals and students in SHSC, working with service-users and using narrative to deepen understanding of living with mental illness. Representative feedback: 'I have learned more about "handling" mental health problems here than anywhere else'; 'I have rediscovered what it means to be a good doctor who listens to his patients' [S7]. Service-users involved also benefited: 'it helped me process what has happened with my mental health and experience of health care'; 'it's given me faith in medicine' [S7]. A film of these masterclasses was runner-up in the UK's 2018 Haelo Film Awards for public sector films [S7].

Stone's work with SHSC led Health Education England to commission *Fairhealth* (2018): narrative resources to help health professionals 'better understand their patients' lives, improve their outcomes, and reduce the health gap [between rich and poor]', which won a 2019 Training Journal Gold award for the best Inclusivity and Diversity Programme [S8]. These on-line resources are used for training doctors internationally (e.g. University of Western Sydney) and in the UK (e.g. Sheffield's 'Deep End' programme, providing professional development for nine GP practices caring for 63K+ patients in areas of significant multiple deprivation) [S8].



Helping marginalised groups and individuals

Stone is Founding Director of the award-winning mental-health charity Sheffield Flourish (founded 2016; 2017 UK Digital Charity Leader of the Year). Stone's research underpins the charity's ethos and activities. Flourish shares information about mental illness and available support, and tackles the isolation often accompanying mental illness by building a sense of community on- and off-line. There are currently 18,000+ website users annually, 520,000+ Twitter impressions, and 122 newsletter sign-ups [S9]. 60% of users have diagnosed mental-health conditions; 40% have been hospitalised by mental ill-health. 81% said their emotional well-being/mental health had improved through involvement with Flourish; the remaining 19% stated no change, indicating mental-health stability. 90% said they had better understanding of, or felt more informed about, issues impacting on mental health.

Stone's work has facilitated new expressions of people's experience of mental ill-health. Flourish uses methods of co-production piloted by Stone on 'Storying Sheffield' (impact case study, REF2014) to provide creative space for people to tell their stories, visually, verbally, or musically, impacting positively on participants' self-worth and sense of belonging. As one participant wrote: 'Together they are learning to have confidence in their abilities... that there are compassionate, understanding people right here in our own community. They are flourishing one little miracle at a time' [S10].

Flourish showcases work on-line, through printed anthologies, and annual exhibitions, giving visibility to the experience of mental ill-health, **improving public understanding of mental illness** and **combatting social stigma**. In 2018, HSBC commissioned Flourish to provide 36 pieces of artwork for their Sheffield headquarters [S10].

- **5. Sources to corroborate the impact** (indicative maximum of 10 references)
- **S1.** SHSC Service-user strategy.
- **S2.** Evidence of improvements to SHSC (email from Deputy Medical Director at Sheffield Health and Social Care Foundation Trust; Healthwatch Sheffield 2018 survey).
- **S3.** Care Quality Commission 2018 report.
- **S4.** Testimonial from National Clinical Director for Mental Health (NHS England).
- **S5.** Strategic Oversight Group: presentation.
- **S6.** Evidence about Global Ministerial Health Summit.
- **S7.** Evidence about narrative masterclasses (feedback; press-release about award).
- **S8.** Evidence about *Fairhealth*.
- **S9.** Flourish annual report (2019).
- **\$10.** Evidence about Flourish (feedback; HSBC commission; award).