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justice issues. In September 2018 she was awarded the John Nisbet Fellowship by the British Educational Research Association for an outstanding contribution to educational research over a career. Since originally writing this piece the majority of Pat's publications have been associated with the *Perceptions and Experiences of Children and Young People Who Have a Parent With Dementia* study. Other relatively recent publications include Sikes, P. & Novacovik,

Y. (Eds) (2020) *Storying the public intellectual: commentaries on the impact and influence of the work of Ivor Goodson* London, Routledge; Goodson, I., Sikes, P. Andrews, M. & Antikainen, A. (Eds) (2017) *The Routledge International Handbook of Narrative and Life History* London, Routledge; Sikes, P. and Piper, H. (2010) *Researching Sex and Lies in the Classroom: Allegations of Sexual Misconduct in Schools* London, Routledge/Falmer.

Hijacked by the project?

Research which demands to be done.

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ABSTRACT

This paper discusses how a commitment to follow C. Wright Mills's (1959) imperative to engage the sociological imagination ethically and critically and in such a way that 'the personal uneasiness of individuals is focused upon explicit troubles and the indifference of publics is transformed into involvement with public issues' (1970: 11–12) can have the effect of shaping research agendas. I tell two stories from my career about research that I didn't so much choose to do but which, rather, seemed to choose me to do it.

DEVELOPING A RESEARCH STANCE

Every June, the little bookshop at Doncaster College of Education, which I attended from 1974 to 1978, held a stock clearance, getting rid of the titles that weren't moving. I remember the 1977 sale vividly because by that time I'd realised that my long-term ambition to become a schoolteacher was a mistaken disaster. I wanted to be a sociologist instead and here, on the cut-price table, were books that I thought might help me on my journey.

Over the past three years I'd done the standard sociology of education course that most teacher trainees at that time experienced. I'd been lucky in that my lecturers were inspiring, up to date in their reading, and comprehensive and critical in the content of their syllabus. I'd been made aware of foundational

authors and schools of thought and of contemporary substantive, theoretical and methodological issues and debates, but I needed more depth. So from the pile of blue Pelicans that were on sale I chose two titles by Erving Goffman, *Stigma* (1963) and *Asylums* (1968), and C. Wright Mills's (1959/1970) *The sociological imagination*. There were also a few black University Penguins from which I selected Peter Berger and Thomas Luckmann's (1966/1971) *The social construction of reality*. I decided to splash out, too, on a still relatively expensive hardback copy of Howard Becker et al.'s (1961) *Boys in white*.

Without descending (or rising?) to hyperbole, reading these texts changed my career and life trajectory: I specialised in sociology (and drama) during my BEd year, became Lawrence Stenhouse's research assistant in September 1978, started an Economic

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and Social Research Council-sponsored PhD at the University of Leeds in 1979, worked on various research projects and evaluations at the Open University after that, became a lecturer in the social aspects of education at the University of Warwick in 1988, and now am Professor of Qualitative Inquiry in the School of Education at the University of Sheffield (see also Sikes & Goodson 2003; Sikes 2009).

I bought those books almost 40 years ago, but throughout my career the perspectives, theories and approaches they introduced me to have been constant influences (see Bochner, 2014, for a similar account). In particular I have been entirely persuaded by C. Wright Mills's imperative/exhortation to sociologists to use the sociological imagination ethically and critically and in such a way that 'the personal uneasiness of individuals is

focused upon explicit troubles and the indifference of publics is transformed into involvement with public issues' (1970: 11–12). Personal uneasiness arises out of things that touch us: either because we are moved by what we hear or because of things happening in our own lives. Mills, like Goodson (2013), Oakley (1979) and many others, recognises that those of us in settings and positions where we can, and indeed are expected to, do research, have the opportunity to exploit the enormous potential that auto/biographical approaches (Stanley 1993) offer for connecting private and public in ways that could lead to transformative action at individual and wider levels.

On this view it sometimes feels as if we have no choice but to research a particular area if we are to be true to the commitment to be ethical researchers who strive to make things better. That's how it has been for me anyway and I have over the years, and inter alia, undertaken studies with roots in personal experience or interest, or because of personal uneasiness/anger/indignation arising out of what I see as social injustice. This research has included work exploring the perceptions and experiences of: parents who teach (1997); RE teachers (Sikes & Everington 2001, 2003, 2004); those engaged in consensual romantic pupil–teacher relationships (Sikes 2006a); teachers accused of sexual misconduct which they deny (Sikes & Piper, 2010); and, currently, children and young people who have a parent with dementia. Here I want to tell two stories about research projects which I didn't so much choose to do but which, rather, seemed to choose me.

ACCUSATIONS OF SEXUAL MISCONDUCT

This tale begins in 2008 at a party when a woman who knew I had done some work focusing on teachers and sex (Sikes, 2006a) told me about what had happened when her husband, a secondary school teacher in his 40s, was accused of the sexual assault of a female pupil, which

he said he didn't commit. The account she gave was of a Kafkaesque nightmare involving suspension from work, lengthy periods of silence on the part of the investigators and the authorities, police interrogations and community ostracism. The whole family's physical, mental and emotional health suffered and relationships were strained as they coped with uncertainty and suspicion. After ten months of living under the shadow of an identity as a paedophile, the teacher was informed that he could return to school because the girl had admitted lying in order to 'get her own back' for having been given a detention. However, the man's sensitivity to the possibility that people were thinking 'there is no smoke without fire' had affected his professional self-confidence as well as his relationships with colleagues and students. Mud had stuck, and working as a teacher was no longer possible for him, so, in addition to everything else, the family income was dramatically reduced since he couldn't get a job that paid at the same level.

I was shocked and did some research to find out if this had been an isolated incident. I found that: the events I'd heard about were not unusual; figures for unproven allegations against teachers were rising dramatically; teachers' unions were campaigning against how they were investigated; and the official line was that, 'fortunately, cases of malicious allegations or false allegations that are wholly invented are very rare' (DfES 2004: 2.9). It began to seem to me that this was a topic warranting serious research because it appeared that significant injustices were being perpetrated against accused teachers and also against their families. I shared my thoughts with Heather Piper, who had researched the associated topic of teachers and touch (Piper & Stronach 2008). Heather was equally concerned, so we designed a research project that used a narrative, auto/biographical approach to investigate the perceptions and experiences of male school teachers, and those of members of their families, their friends and colleagues, who had

been accused of sexual misconduct with female students which they said they had not committed and of which they were eventually cleared (Sikes & Piper 2010).

In getting this project underway we faced a number of difficulties coalescing around: contemporary moral panic and fear of the paedophile (cf. Webster 2005; Bauman 2006); and the strength and pervasiveness of what has come to be a master narrative 'that children are innocent and asexual' (Cavanagh 2007: 12–13) and are therefore unlikely to lie about abuse. So strong is this narrative, which treats all those under 18 as a homogeneous group, attributing the same understandings and motivations to toddlers and teenagers alike, that when we sought ethics clearance we were told there was no research project to be cleared because there was nothing to investigate. Children do not lie about abuse, ergo there are no false accusations and in proposing to do this research we could 'be seen as trying to protect abusers' (CSFC 2009: 8). We argued that a concern to investigate miscarriages of justice against teachers could coexist alongside a commitment to protecting children and young people from abuse. We found that 'at a time when there is so much concern about child protection, it is difficult to write about adult vulnerabilities' (McWilliam & Jones 2005: 119) and were told that it was preferable that an innocent teacher go to jail than for a child to think their accusation might not be believed. Our position was that such a view constituted yet further injustice that did nothing to help to create a safe environment for either teachers or students.

Although obtaining ethical clearance was challenging (Sikes & Piper 2008, 2010), this study clearly raised serious ethical dilemmas. For instance:

- questioning narratives that have worked to protect young people from danger could weaken that protective effect if they came to be regarded as mistaken (cf. Sikes 2010a)

- inviting those accused of sexual misconduct to tell their stories could provide opportunities for guilty persons to construct identities as wronged innocents, potentially making it easier for them to go on to commit further offences (cf. Ricoeur 1980; Plummer 1995; Sikes 2000; Goode 2009); and
- telling painful personal stories could occasion considerable distress (Sikes, 2010b).

Recognising the ethical minefield we were in, we did what we could to minimise harm and provide support if required. The major safeguard was to include only those cases where, after formal investigations that for some people continued after a guilty verdict and imprisonment, the allegations were eventually declared unproven on the burden of available evidence or were disconfirmed or were recanted by the accuser. Of course, this does not necessarily mean that the allegations were false, but it probably reduces the possibility that they were untrue or mistaken.

We sought personal stories, believing that they offered the only, as well as the most ethically and methodologically acceptable, means of obtaining the sort of personal sense of the lived experiences we were interested in (Sikes & Piper 2010: 39–42). This decision inevitably raised more questions around ethics and truth: were we being given ‘true’ accounts and were we ‘truthfully’ analysing and re-presenting what we were told? That we constructed composite fictions primarily in order to protect the identities of the people we spoke with, but also for analytical and re-presentational reasons, added further layers of complexity (Sikes & Piper 2010a: 42–7).

Stories have the potential to connect with readers, to make imaginative contact, evoke emotions, ‘encourage compassion and promote dialogue’ (Ellis & Bochner 2000), all of which are necessary if the Millsian imperative is to be met. When

we were invited to make a submission, based on our research, to a House of Commons Select Committee Inquiry into Allegations against school staff (CSF 2009) we felt that we had demonstrated this potential. The stories our informants and others who gave evidence to the inquiry had to tell about their experiences of being accused of sexual misconduct made real the consequences of policies and practices employed to investigate allegations, showed the damage that could be done to individuals in a way that no statistics ever could, and led to some changes in investigative procedures (Sikes & Piper 2011). Thus a project that raised a myriad of ethical concerns and which had its genesis in anger did, perhaps, make a very small difference.

The perceptions and experiences of children and young people who have a parent with dementia

When my daughter was in the lower sixth and her brother was in Year 8 they began to complain that they didn’t feel safe when their father did the school run. He had been made redundant the previous year, aged 55, and was therefore usually available to ferry them around. As time went on his driving got more erratic and other changes in his behaviour and attitude began to manifest. For instance, he began to take an inordinately long time to complete decorating and other DIY jobs; he often appeared to be unable to see things that were directly in his line of vision; he made surprisingly illogical and financially unfortunate decisions and purchases; he reacted in what seemed to the rest of us to be a completely inappropriate, over-the-top and aggressive manner to insignificant events; and he began to continually mislay keys and other things.

He had always been a collector of various arts-and-crafts artefacts and first edition books and had planned, on retirement, to start trading on a serious level. However, his collecting suddenly became totally obsessive and the house, loft, garage and garden buildings were filling up at an

alarming rate to the extent that the kids felt that it was too embarrassing to have friends round. It didn’t matter what we said: he seemed to have no concern for our feelings.

Time passed. My daughter went to university while her father’s behavior got more and more disturbing. She, away from home much of the time on a high-pressured course at an Oxbridge college, was anxious. Her brother, who was still in the house and by now in the sixth form and aiming for a three/four A-level A grades course, was having to cope with a total lack of consideration for his need to study.

Eventually a routine visit to the optician led to a diagnosis of young-onset dementia (involving characteristics of vascular, fronto-temporal and Alzheimer’s variants). This diagnosis provided an explanation but little in the way of remedy since dementia is an incurable terminal disease. It is also a disease that wreaks havoc with ‘normality’, whatever form that takes in any family. For us, the events of the past ten years would previously have been unimaginable, even though my mother lived with Alzheimer’s from the age of 82 until her death, from a stroke three days short of her 90th birthday.

Observing the effect of their father’s condition on my children, and particularly, given their ages and what they were doing, on their educational careers, led me to wonder what it was like for other young people in similar positions. I did a bit of searching and found that there was very little available in the form of supportive resources of any kind. Nor was there anything in the academic literature about the experiences of members of this group. Seeing this gap led me to put a proposal to the Alzheimer’s Society for a narrative, auto/biographical project to investigate the perceptions and experiences of children and young people who have a parent with dementia, with a particular emphasis on how it impacts their educational careers. The proposal was successful and the project

started in October 2014. Early interviews, undertaken by Research Associate Mel Hall, confirm my suspicions that youngsters in this position are usually having to cope, at the least, with emotional issues around coming to terms with the effective loss of the parent they had alongside their changed feelings for them. In addition, difficult home conditions may involve them having to undertake caring roles, making concentration and study hard. They feel both marginalised and isolated, and that their experiences aren't acknowledged or known about. Even with recent literary and media re-presentation of young-onset dementia (such as the film *Still Alice* and the Richard and Judy Book Club read *The Memory Book* (Coleman, 2014)), within the public perception dementia = Alzheimer's = old people. And this is not surprising because this is the most common manifestation of dementia. Our intention, with the full support of the young folk who have volunteered to take part, is that our project will raise awareness of their situation and provide at least some support for those who are in it. We have begun to do this by putting those who have asked if this would be possible in touch with others who know what they are going through. For Mel and I that, in itself, is enough, but we hope to do more over the next 18 months of the project's life.

FINAL THOUGHTS

Both of the projects described above challenge master narratives that have attained hegemonic status. It seems likely that taking up Mills's imperative usually will involve such a challenge because the sort of research that follows from that stance tends to reveal other narratives, other storylines, that can both have explanatory value and provide scripted resources for those to whom it matters (Downs 2013; Goodson 2013).

It is, perhaps, important to note that making private troubles and uneasiness public can mean taking risks that can have various negative consequences for researchers, including attracting

unpleasant and negative media attention and possibly affecting their career development (see Sikes 2006b, 2008). In deciding to go ahead with the study of allegations of sexual misconduct, I and Heather were well aware of the sort of public opprobrium and professional censure we might face, because we both had experience of researching topics linking sex and children and of the sort of media coverage such work can provoke. We took an informed decision. With respect to the dementia work there are potential difficulties about calling into question such notions as that children should love (and not hate) their parents and that people living with dementia are 'still' the same person that they were before they became ill. At this stage, at the start of the project, we have yet to see a response other than from those who have an up-close and intimate view and who wish that view to be more widely known and recognised to enable them to begin to get the support they need. ■

I would have come to Mills, auto/biographical approaches, symbolic interactionism and social constructivism eventually, but that sale day in the bookshop was undoubtedly epiphanic. From those books and from subsequent reading I have felt justified in allowing anger and uneasiness (admittedly coupled with my privileged position as a senior academic) to shape my research agenda and maybe to enable my work to have some, however small, impact in the quest for social justice.

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May 2021 Postscript

My commitment to making private troubles public concerns through narrative auto/biographical research is one thing that hasn't changed during the six years since I wrote this piece. Much else has, both professionally and personally.

In so many ways, the *Perceptions and Experiences of Children and Young People Who Have a Parent With Dementia* study that started in November 2014 turned out to be something of a life changer, as well as a great success. Over 18 months, Mel Hall met with 23 6–31 year olds, in most cases at least twice. The stories they told gave rich, privileged insights into what having a parent with a young onset dementia meant for them, its impact on their personal lives, and on their educational and professional careers. The longitudinal aspect of the study also showed how they experienced the progressive and terminal nature of parental dementia. To date, we have published nine journal articles and a couple of chapters and there is likely more to come. That the work has been unique within what is a neglected field is clear from the number of people from across the world who, having come across reports and papers, have contacted us to tell their stories, usually saying they thought they were the only person who was going through what they were. I still get at least one of those emails every week. Then, there are the systematic reviews, which are starting to appear in dementia and health journals, which demonstrate that 'our' study is the most extensive and detailed there has been to date. There is great satisfaction in getting these young people's voices heard – and not just in academia but, and more importantly, through organisations involving those living with dementia, professionals and practitioners, who can do something to help meet their needs. Moving on, there is to be an international study in collaboration with colleagues in New York looking at how young people at risk of inherited dementias make decisions

about genetic testing. All this has meant that my identity has expanded from being Pat Sikes whose key substantive interests lay in education and teachers' lives and careers to Pat Sikes who is concerned with young onset dementia.

In personal terms and over the years, my husband, David, whose young onset dementia was the catalyst for that identity development, went into care.

As his condition developed, he and our family had to come to terms with myriad changes, few, if any, good, echoing the experience of the participants in the study and posing a serious challenge to the dominant narrative of living well with dementia. Positively, however, our children began to establish careers. They missed their dad at their graduations, weddings, and when their children were born, and he missed sharing in these significant, as well

as in quotidian, events. I became grandma – a wonderful new identity that brings enormous pleasure. David died as a result of dementia in May 2020 (see <https://www.solidarityandcare.org/stories/essays/death-in-the-absence-of-hugs>) and being a widow is something else again. I retired on my 65th birthday in September 2020 and was honoured with emeritus status. It's been a busy 10 years. ■

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