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HEALTH AND WELLBEING

The University of Essex Reader

foreword
Anthony Forster

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Foreword

Anthony Forster[*]

I am delighted to support the publication of the third volume in the University of Essex Inclusivity Reader series, which focuses on the important topics of health and wellbeing.

The University's mission is to deliver excellence in education and research, putting student success at the heart of everything we do – and supporting students to enable them to succeed irrespective of background. We know that creating a healthy and inclusive environment is key to enabling our students to fulfil their potential as individuals, to be active participants in their own educational experiences and to enjoy the transformational opportunities available to them at our University. This approach is equally important in supporting our staff, both directly and in enabling others to be the best they can be.

The focus of the Essex approach is to create an enabling environment: a healthy and supportive environment for all, that creates a sense of belonging, responsibility and a caring and sharing culture; the establishment of services based on partnership within the University and with the Students' Union and external agencies and organisations; diversity in the services we offer, ensuring services are tailored to individual need as far as possible; the development of services that are sustainable and scalable to safeguard quality and student benefit; and to manage risk effectively.

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We are keen to learn and what this volume underscores to me is the importance of understanding different evidence based perspectives and needs. This approach is vital to ensure that everyone is supported in their transformational journey of living, learning and working in our community.

Introduction

Ilaria Boncori and Tracey Loughran

We should be healthier and happier than any previous generation, according to some scholars. The Harvard psychologist Steven Pinker (2011: xxiii), for example, argues that violence has declined over time while human empathy has increased, and that "more peaceable societies also tend to be richer, healthier, better educated, better governed, more respectful of their women, and more likely to engage in trade". Meanwhile, for much of the western world, the decades after 1945 constituted a 'Golden Age' of health. Life expectancy soared, maternal and infant mortality declined, and scores of diseases were eradicated. The rise of welfare states improved the quality of life, not least through improved access to medical services. Yet, at least in the UK, we are not happier than previous generations. Research has found that people were happier in 1957 than at any point since – even though "in 1957 life expectancies were lower, Gross Domestic Product (GDP) was lower, more hours were worked in a typical week and few households had central heating and less than half owned a television, levels of public happiness were at a height never reached again in the British post-War period" (Mental Health Today, 2017).

Why are people less happy now? One view is that happiness is relative – if aspirations are higher, then people will be unhappy if those aspirations are not met, even if they have most of the things they need in life. But it is also true that recent political developments have made people less happy, and less healthy. As Professor Sir Simon Wessely, former president of the Royal College of Psychiatrists, points out "The job of government is not to make people happy – that is most determined by the quality of our interpersonal relationships. By promoting good health, making our streets safer, ensuring better quality of care and helping people into meaningful employment we can however create the conditions for a happier society. Finally, happiness is about fairness – In short; an unequal society is an unhappy society" (Mental Health Today, 2017). Since the Conservative-led UK Government launched austerity in 2010, introducing multiple policies that the UN rapporteur on extreme poverty and human rights has described as "punitive, mean-spirited, and often callous" (Booth and Butler, 2018), British society has become markedly less equal. Government spending on the police, road maintenance, libraries, courts, prisons, and housing has been slashed (Mueller, 2019). Over a million people a year are now using foodbanks, homelessness has more than doubled, and one-in-three children and around one-in-five pensioners have now dropped below the poverty line. As the Institute of Public Policy Research (2019), a progressive policy think-tank, points out, "these are real people, families and communities, who rely on government support to get by, and who have been devastated by austerity".

In theory, spending on education and health was protected from cuts made under austerity. In practice, miniscule increases to the National Health Service (NHS) budget over the past decade has left it in crisis – not least because the cumulative effect of all the spending cuts made in the name of austerity has made the most vulnerable people in society weaker, more ill, and less able to cope on their own, at the same time as the local government services that they rely upon have been slashed to the bone. In late 2018, the number of vacancies across the NHS in England hit a record high, and it was revealed that the service had an underlying deficit of £4.3 billion. The King's Fund (2019), an English health charity, has outlined how the NHS is "struggling to cope with record demand", while "social care services are stretched to the limit". Many people are not healthier, and therefore not happier, than previous generations because in recent years, their health and happiness has not mattered to the successive governments that have held power over their lives and deaths. This is not mere rhetoric: the *British Medical Journal* (2017) reported that cuts in health and social care were linked to 120,000 excess deaths in England alone. That figure has undoubtedly risen in the years since.

Austerity measures have had terrible effects on students and staff in the UK Higher Education sector too. The tripling of student fees and increase in means-tested repayable loans has left many students fearing crippling debt (Chalari and Sealey, 2017). It is impossible to isolate the effects of financial anxiety on students' mental health, but it is clear that there is a mental health crisis in the UK's universities. In September 2017 the Institute for Public Policy Research published a report on the need to improve mental health in universities (Thorley, 2017). It found that disclosure of mental health conditions among first-year students at UK HEIs had increased almost five-fold in the previous decade; that female first-year students are more likely than male first-year students to disclose a mental health condition; and, perhaps most worryingly, that just under half of the students who reported experiencing a mental health condition chose not to disclose it to their HEI. The report's recommendations included that the HE sector should "collectively adopt student mental health and wellbeing as a priority issue, with individual institutions developing their own 'whole-university' approaches, which are subject to audit and quality assurance, and underpinned by common principles which draw on best practice", that HEIs "should commit to increase the amount of funding dedicated to services which promote and support the mental health and wellbeing of students", and that "Government should facilitate the introduction of place-based coalitions which aim to improve the health of local student populations through greater integration across services" (Thorley, 2017: 3-5).

It's not just students who suffer. Across the UK, most universities are struggling to maintain excellent standards for more students with fewer resources. In February 2018, the *Times Higher Education* (THE) published the results of a major global survey of university staff views on work-life balance (Bothwell, 2018). The poll found that many staff believed "they are paid less and have a worse work-life balance than most of their friends"; that a "large majority of staff have considered leaving the higher education sector"; and that many staff "say that their job restricts their ability to see their friends and gets in the way of their ability to conduct a successful relationship". One professor cited in the article explained, "I feel very stressed. Work is never-ending, never good enough, lucrative enough [or] impactful enough, so there is always a lot of pressure to do more". Another said, "I don't have the time for friendships outside the academic world. Friendships at work are hard to maintain because of workload and also lack of staff common room facilities". It is not an easy time to study or work in a UK university – indeed, it is not an easy time to live in the UK.

Are there any glimmers of light in this gloom? The same THE survey offered the merest sliver of hope. Despite often reporting negative experiences, 65 per cent of academics and 75 per cent of professional staff said that they would recommend the job to their children, albeit, in the majority of cases "with reservations". As one respondent asserted, "I think about leaving HE but would have a hard time doing so because I love being surrounded by brilliant people and cutting-edge research. It is a vibrant and stimulating environment" (Bothwell, 2018). This volume on health and wellbeing, the third Essex Reader, speaks of the shadow but also the sunlight. The chapters unpick thorny problems in healthcare policy and practice across diverse organisations, systems, and sectors; but where they put forward an analysis of what is wrong, they also point towards ways in which these abuses could be put right. Our contributors have been searingly honest in their denunciations of certain aspects of policy, but equally truthful in sharing their own life stories, ways of coping, and reflections on the future. In doing so, they are helping to create the kind of environment that fosters the wellbeing of all its members – indeed, as Mental Health First Aid England (2019) states when describing its training course aimed at the higher education sector:

> Our courses won't teach you to be a therapist, but we will teach you to listen, reassure and respond, even in a crisis – and even potentially stop a crisis from happening.
>
> But more than that, our courses aim to give you the information and skills to look after your own mental health, promote positive wellbeing and raise awareness in the people around you. By giving you the tools to have these conversations, we hope to empower you to create a mentally healthy, supportive environment in your university.

Perhaps the main reason to be hopeful, however, is that, as in previous Essex Readers, these chapters have been penned by both students and staff; from those undertaking undergraduate degrees, right up to professors who have been at this institution for decades. We work together; we learn from each other; we support each other; and, together, we have the power to change the world we live in for the better.

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Part 1

1. What the practice of yoga can do for academic practice: personal reflections

Martyna Śliwa

Introduction

"This is the beauty of it: there is no point in thinking that you're great just because you can do a certain pose as there is always somewhere else to go, a more advanced option to work towards". It is Sunday morning and there are about 20 of us in the gymnasium of a primary school that makes its space available for fitness and yoga classes in the evenings and on the weekends. Our yoga teacher has been giving instructions for getting into *bakasana* – crow pose – and we are all trying to get into and to hold this seemingly gravity-defying pose, even if only for a second or two. One participant has actually mastered it and perhaps is ready for the next step now: jumping back, or – to use a more elegant, yoga-appropriate expression – floating, from crow to *chaturanga*, low plank. Indeed, there is always somewhere else to go.

Crow, sometimes also referred to as crane, is an arm-balancing posture which provides foundation for most other arm balances in yoga. It might be the first arm balance typically learned by those practising yoga but as far as I am concerned, it is certainly hard enough: one requires a good deal of core strength, balance and concentration to do it. The determination to overcome fear is also needed because of the quite realistic prospect of falling down, face-first. But it promises to be worth it: in addition to its physical benefits, such as strengthening and toning a variety of muscles, the crow pose is supposed to build confidence, relieve stress and anxiety, increase concentration and enable creativity in the practitioner. Precisely what I need! And therefore, just like everybody else in the room, I am giving this arm balance a go, hoping to get there without face-planting.

Over the years, participating in yoga classes has become essential to maintaining my health and wellbeing, and has been an activity that has accompanied and inspired me throughout my professional career. In fact, the first yoga session I ever attended took place on the premises of the sports centre of the university where I held my first lectureship position. These days, at the beginning of each teaching term, after I fill my diary with a schedule of meetings and lectures for the coming months, I make sure to add yoga classes to it as well, two to three times each week. Whenever I visit other cities for a certain period of time – for example, to collaborate with colleagues from other universities on a piece of research – I try to join a local yoga studio, even if only for a couple of weeks at a time. While I have not become either acrobatic or serene, over time, I have come to believe that yoga offers a form of exercise that is perfect for supporting me, in many different ways, in my professional and personal work and growth, and is essential to my sense of wellbeing. This essay provides an opportunity to share some of my experiences of practising yoga and benefiting from it in all aspects of my professional life. While my scholarly expertise is not directly related to yoga, throughout the text I refer to academic research as well as blogs that have addressed the effects of yoga practice on health and wellbeing.

Viewed holistically, yoga encompasses a broad philosophy known as the eight-fold path – or the eight limbs of yoga – outlined in Patanjali's Yoga Sutras and including: attitudes toward others/restraints (*yamas*), rituals/self-observances (*niyamas*), the physical practice of postures (*asana*), breathing practice (*pranayama*), withdrawal of the senses (*pratyahara*), concentration (*dharana*), meditation (*dhyana*), and state of enlightenment (*samadhi*) (Iyengar, 1979). The practice of yoga is expected to promote health in a holistic sense, through the balancing of physical, spiritual, psychological, and social aspects (Engebretson, 2002). In the Western context, the term 'yoga' is typically used with reference to physical exercise (*asana*), and to a lesser extent with regard to breathing techniques (*pranayama*) and meditation (*dyana*) (Garfinkel and Schumacher, 2000). While there is an emphasis on the physical exercise element, yoga is generally understood to be a mind-body practice, whereby the physiological state is considered to "affect the emotions, thoughts, and attitudes" and there is an underlying assumption that "the mental state has an effect on the body" (Cowen and Adams, 2005: 212).

Below I discuss five specific areas where yoga practice has proven to be of great help to me, supporting me in my development and in maintaining my physical and mental health: academic writing, relating to others, pedagogic practice, living and working without physical pain, and dealing with stress and anxiety.

Yoga and writing

The development of awareness of the inseparability of the body from the mind was one of the first lessons I gained from practising yoga. Surprisingly at first, reflections associated with this observation transferred into how I began to view and relate to the academic writing process. As anyone who has tried to practise yoga will have noted, the ability to do a particular yoga pose is about much more than a strong and supple body. In yoga classes, the teacher would point out countless times: "if your mind is distracted, you will struggle to hold a pose". Likewise, countless times I have been unable to ignore the fact that when the mind is "all over the place", this will be reflected in the body's struggle to get into and hold a particular *asana*, or to transition smoothly from one pose to another. From there, another observation followed, this time in relation to my academic writing practice: with a distracted mind, it is impossible for writing to flow. The practice of looking at the screen of the laptop, pressing keys in a particular order, reading words as they emerge – letter by letter – and become parts of sentences, then eventually form full sentences in front of my eyes, is an embodied practice that requires patience, time, skill, confidence and a great deal of concentration. In this regard, trying to write resembles trying to do yoga. Except, in the case of yoga, falling out of the pose when one loses concentration is immediately obvious. With writing, by contrast, one can spend a long time looking at the screen and even pressing the letter keys, before realising that not much has been happening because the mind has been distracted.

Perhaps this does not happen to everybody but is certainly true about me, since this has been, more than once, my experience of writing. It used to frustrate me greatly. Crafting a text takes me a long time. There are moments when I think I must be the slowest writer in the world. It seems like a drawn-out process even when I am able to maintain concentration quite well, let alone when the mind wanders in multiple directions, undermining the intention to reach whatever "writing objective" I set for myself on a given day. From frustration would come negative self-judgement, irritation, and overall, a feeling of wasted – and unpleasantly spent – time.

When one practises yoga in a class context, there is usually a teacher around who will say: "it's ok to wobble out of a pose. Approach this with lightness and a sense of fun. So what if you can't do it today? All you're doing is trying to stand on one leg, it's no biggy if you can't do it. Be joyful about it! Use your *bandhas* – energy locks, and *drishti* – a focused gaze, to support you. And try again". With the help of various yoga teachers, I have gradually realised that there is nothing wrong with the "wobbling out". Nothing wrong with the slowness, either. In addition, trying again – the repetitiveness of getting into and holding *asanas* – allows for developing greater bodily awareness and for deepening the practice. In fact, neither slowness nor repetitiveness are unpleasant experiences. The only obstacle, really, lies in the feeling of frustration and negative self-judgement that accompany our attempts at getting on with working on the yoga sequence – and it is wonderful to be able to rely on a teacher who will remind us about it.

I completely agree with Wenger (2015: 3) when she admits: "I can no longer think of writing and yoga as separate processes". I am full of gratitude and appreciation for what doing yoga has done for my writing – especially, for how learning to embrace the slowness and repetitiveness of yoga practice has helped me approach my writing practice differently, strengthening my sense of wellbeing along the way. It required, though, replacing the frustrated voice of my inner critic: "you're way too slow", "this is banal and trivial", "you're never going to finish this text" – with the wise voice of a compassionate teacher: "you are doing your best", "it's normal for focus to come and go, it's good that you have noticed it, take a deep breath and try again", "trust the process"…

It also required giving up on my assumptions about what my writing practice "should be" like – for example, immersive, confident, efficient – and on the misguided belief that it is a skill that can be acquired once and for good, and then it will be always available and ready for me to "switch it on" at any time. There are times when writing unfolds smoothly and pleasantly, and other times when it feels like ploughing through frozen soil. But now I know that there is nothing wrong with the slow assembling of sentences. There is nothing wrong with reworking the same sub-section of a text again and again, modifying it, ever so slightly, each time. The practice of yoga has allowed me to feel through my own body-mind how beneficial repetitiveness is, the process of going through the same sequence of exercises time and time again, introducing only very minor changes. As a result of practising yoga, the body gradually becomes more supple and stronger over a period of time, but even more obvious is the difference in how it feels to be in the body at the end of the class compared to the beginning. Likewise, by the end of a day of writing, the text and the knowledge it constructs and conveys will have moved forward: on the screen and within the body-mind.

Yoga and encountering difference

It is necessary to acknowledge the common critiques of the commercialised dimension of yoga, such as Delaney's (2017) point about the "narcissistic" aspect of the yoga enterprise, or Warner's (2011: n.p.) worry that many young women choose to practise yoga since, for them, "there is no sense that personal liberation can be found by taking a more active role in the public world". No doubt, the image of an affluent Western yoga practitioner, whose "yogic lifestyle" revolves around a particular type of conspicuous consumption – Lululemon or Sweaty Betty apparel, overpriced cold-pressed organic juices, and all-inclusive yoga and detox "retreats" in five star surroundings – evokes connotations of self-centredness and superficiality rather than an openness to others and self-reflection. Notwithstanding the problematic consequences of the operations of the yoga industry and of an unquestioning subjection to its profit-generating logic, the reality of who we encounter when participating in yoga classes is, from my experience, very different from what marketing images would have us believe.

The classes I attend in my neighbourhood are populated by bodies of different shapes, ethnicities, genders and ages, predominantly in their forties and fifties. Some of us go regularly, others pop in from time to time, yet others come to class once and are not seen again. For each *asana*, the teacher suggests several "options" – levels of difficulty – and so for everybody, there is effort involved. Sometimes my body feels clumsy on the mat, sometimes less so. Sometimes the body of the person next to me looks clumsy, finding it hard to bend and stretch as instructed. We are all physically close to each other, sweating, breathing loudly, trying to concentrate, getting distracted, working out the direction in which our shoulders, hips and toes should be turned. The teacher will remind us to "find our edge", to challenge ourselves without hurting or straining ourselves.

Practising yoga poses in the company of other people supports the development of a relational, embodied perspective on self and others. Over time, a sense of togetherness emerges, even though we do not speak to each other during the class. An awareness of one's own body as well as the presence of other people's bodies deepens, and with it comes a greater gentleness and acceptance of self and others. We are together, although each of us faces different challenges and our bodies are not moving in harmony with each other. This does not matter, however. The co-presence of a group of strangers – all working hard, all doing the best they can in a given moment – feels supportive and reassuring.

The experience of collective yoga practice – working with my body and sensing others' bodies around me – has made me more aware of and reflexive about my own prejudices, biases and stereotypes projected onto others. As an organisation studies scholar, but also as someone who often finds herself in the position of being a member of a minority group – a woman, a professor, a foreigner, a Central European, a non-Anglophone native speaker – I feel strongly about the need to make our organisations and society places free from prejudice and discrimination. For a long time, I was conscious of the significance of "difference" and its impact on how we relate to each other. However, until I started to become aware of the biases that surfaced in me during yoga classes, I had not seriously reflected on the judgements I make about others; judgements that emerge even before words are exchanged. The proximity to others' bodies that is afforded in a yoga class setting can become a powerful source of knowledge. When we tune into what our body-mind tells us, we realise that it communicates the feelings we carry within ourselves and project onto others. From this point, compassion can develop: towards the yoga co-practitioners, colleagues, students and strangers. The grip of judgement becomes looser, a sense of wellbeing increases.

Yoga and pedagogic practice

"Well done, guys. Beautiful practice this morning" says our yoga teacher at the end of the class, and regardless of the clumsiness and difficulties we experienced over the past hour, we feel better about ourselves and are grateful to her for guiding us through the *asana* practice. From each yoga teacher I have encountered – be it in Newcastle, Brisbane, Colchester, Kraków, Copenhagen, Auckland or London – I have learned and continue to learn not only about yoga but also about being a teacher. The yoga teachers I have met have been calm, reflective, non-judgemental, encouraging and compassionate. Many times I have observed, in admiration, a yoga teacher's ability to gently connect to the emotional landscape of the participants, to acknowledge their apprehensions and insecurities, and then to tap into their potential to become more present on the mat, to find and explore their "edge", and even to do something unimagined and extraordinary – like a headstand!

Teaching yoga is linked to a particular ethos of self-care, looking after one's health and wellbeing, showing commitment to the practice, and in many cases trying to follow a lifestyle that also draws on the tradition of the remaining seven "limbs of yoga", not only the physical *asana* practice. In addition to being influenced by the ethical-spiritual dimensions of yoga, yoga teachers are also subject to the demands of the "gig economy". They are paid per hour and their work tends to be scheduled outside the "standard" working hours as clients are usually available for yoga classes either before or after day-time work. It is not uncommon for classes to take place at 6am or at 9pm; it is not uncommon for these classes to be delivered by the same person. Since their main "tool" is their own body, the risk of injury or even a seemingly minor illness such as a cold adds to the precarity of yoga teachers' position – not being in good physical form means not being able to teach; every class that is not taught is lost income. Perhaps as a result of both an individual commitment to the ethos of yoga and due to the challenging working conditions in this occupation, those who choose to become yoga teachers are usually genuinely passionate about what they do and follow a calling to share the benefits of yoga with others. The yoga community popularises a certain ideal of a yoga teacher, for example through lists such as "10 Qualities of an Amazing Yoga Teacher" which include:

1. They connect with everyone in the class;
2. They have a way with words;
3. They leave their ego at the door;
4. They love (and respect) yoga;
5. They let their authentic personality shine through;
6. They are prepared;
7. They cater to all levels;
8. They share their knowledge;
9. They gain trust;
10. They share their light. (Coventry, 2019: n.p.)

It has been 20 years since I first started teaching in the higher education context and I would like to think that I am continuing to develop as a university teacher and supervisor. If there has been, indeed, a positive development in my pedagogic practice, it has been possible to a large extent thanks to my own yoga practice and thanks to the vicarious learning of the teaching practice of my yoga teachers. There is an atmosphere of warmth and positivity that usually fills yoga classes. The messages that come from yoga teachers are encouraging and affirmative: "Well done! Good work! Beautiful!". The teacher motivates the students to work hard enough to get to a point in their practice beyond which additional effort would be excessive. At the same time, students receive advice to become aware of their own boundaries and to be in touch with what they are capable of doing on a given day, so that when someone feels that they might injure themselves if they try any harder, they can take a break at any time and rest for a few breaths. Above all, good yoga teachers create a safe space for students to practise for themselves, not to impress the teacher and not to compete with others, and to enjoy the learning process.

My experience of observing – and being on the receiving end of – yoga teachers' "craft" over the years has inspired me to try to follow a similar approach in my own university teaching and supervision. It is not easy to teach with passion and compassion, to connect with and include all students, to encourage them, to make them feel that it is safe and fun to open up to something new and challenging, and to explore and reflect on oneself and on learning. Nevertheless, it is a worthwhile aspiration to pursue, and I am grateful to my yoga teachers for showing me through their pedagogic practice that this is possible.

Yoga and physical health

I developed the unhealthy habit of spending many hours, nearly every day, in a sitting position, many years ago – and have persisted with it ever since. When I was much younger, sitting at a desk used to fill the major part of the day at school, and then it extended over additional hours of sitting at another desk at home, doing homework. As an undergraduate, this pattern continued: sitting in a lecture theatre, then back home in front of a computer screen, preparing coursework and revising for exams. Before I was 20, I would find it normal that during an intensive study time, I was walking around with a stiff neck and shoulders, and once or twice a year the pain caused by a "spasm" in the neck would almost immobilise me for a few days. Many people around me – often my fellow students and later on fellow lecturers – suffered from similar problems: one person would complain about a discomfort in the hips, someone else about a painful lower back, yet another person about an overall sense of stiffness around the spine that felt like something might "snap" if they try to turn in the "wrong" direction or too fast. From what I recall, in my late twenties I thought that a pain-free life experienced through a tension-free body was something only children could be lucky enough to enjoy, that getting older would inevitably involve getting stiffer and less mobile, and that there was nothing that could be done about it.

And yet, a sense of hope managed to surface from underneath those self-defeating – and possibly self-fulfilling – beliefs. I turned up at my first yoga class, driven by the wish to get rid of back and neck pain, and perhaps even to prevent another immobilising "spasm", and relying on ibuprofen and a physiotherapist's skills to bring me back to form. Alleviating stiffness in the body was a benefit of yoga practice which I experienced very quickly, and which got me "hooked" in the first place.

Even now, the power of yoga to counter back and neck pain remains my opening gambit when I encounter a not-yet-convert who is willing to listen and embark on praising the wonders of yoga. I can wholeheartedly recommend it, even if only for this pain-relief reason, to everybody. Most of us in academia – regardless of whether we are a student or a university employee – tend to spend a lot of time during the working day in the sitting position. As one yoga teacher explains in her blog:

> *They say that sitting is the new smoking because of all the negative impacts of a sedentary lifestyle. Sitting at a desk or computer all day takes a toll on more than just your eyes. It affects your posture, metabolism, risk of anxiety or depression and can lead to obesity, just to name a few… Bad posture can lead to serious issues like back pain, cardiovascular issues, digestion issues, and eventually changing of the curve of the spine itself, which will create a whole new level of back pain.* (Mason, 2017: n.p.)

Fortunately, she also adds: "Yoga is a fantastic way to combat the negative effects of sitting at a desk all day and other things that contribute to bad posture" (ibid.).

That yoga brings about a range of benefits for physical health should not be surprising, bearing in mind that yoga is part of Ayurveda, a traditional Indian medical system (Birch, 1995). The popularity of different varieties of physical yoga has triggered studies investigating its effect on the body, especially with regard to the treatment of musculoskeletal issues. For example, in people suffering from chronic neck pain, significant reductions in pain levels were reported following at least nine weeks of weekly yoga practice (e.g. Nambi *et al*., 2015; Wattamwar and Nadkarni, 2012; Williams *et al*., 2009). Other research findings addressing the benefits of yoga for the musculoskeletal system have included improved strength, flexibility, balance and posture (e.g. Sarosky *et al*., 2008; Tekur *et al*., 2010). Apparently, after a minimum of four weeks of yoga practice once a week, significant reductions in back pain have been reported, whereas consistent yoga practice for a period of between six and 12 months has been reported to result in sustained improvement in back pain (Tilbrook *et al*., 2011). It certainly works for me, and nowadays it feels liberating to be able to go about my day without pain in my neck and shoulders. But as far as my health is concerned, there is much more I owe to yoga, thanks to the effect it has had on my mental health and wellbeing.

Yoga and anxiety

The word "yoga" denotes "union" or "unification"; this notion of a union refers to the inseparability of body and mind. The objective of yoga is to achieve a state of body-mind integration and to maintain all aspects of the body-mind in good health. By contrast, the etymology of words such as "anxiety" and "worry" points to the opposite state. "Anxiety" derives from the Latin word *angere*, *anguere* which means "to choke", "to squeeze", and is akin to the ancient Greek word *ankho*, which means "to constrict the throat", "to strangle". The root of the verb "worry" has a similar meaning. Its origin can be traced back to the Middle English word *wirien*, meaning "to slay, kill or injure by biting and shaking the throat" and to the Old English *wyrgan*, "to strangle". Anxiety and worry, then, describe a state in which we feel metaphorically "strangled" – and so have our head, which we typically consider to be the "location" of the mind, cut off from the body. Put differently, anxiety and worry are the reverse of the yogic ideal of body-mind integration.

While the images of yogi(ni)s promoted by yoga bloggers, yoga teachers' websites and the marketers of yoga-related products convey serenity and calmness, there is also a plethora of research that demonstrates the effectiveness of yoga as an antidote to anxiety, worry and other mental health-related problems that are common in the 21st century western world. For example, a study by Taherkhani *et al*. (2003) showed beneficial effects of yoga on individuals with Obsessive Compulsive Disorder (OCD). Other researchers have demonstrated significant improvements in individuals with anxiety and depression, after a period – sometimes as short as two months – of practising yoga (e.g. Gupta *et al*. 2006; Javnbakht *et al*., 2009; Khalsa, 2004; Michalsen *et al*., 2006; Pilkington *et al*., 2005; Woolery *et al*. 2004).

Yoga has been shown to help in reducing anger, decreasing verbal aggression, improving sleep, decreasing the symptoms of Post-Traumatic Stress Disorder (PTSD), and improving mood. One of the physiological effects of yoga is an increased heart variability (HRV) which, in turn, helps calm the autonomous nervous system and regulate emotions. As Hutchinson (2019: n.p.) explains:

> *Decreased HRV is correlated with negative affective states such as anxiety, stress, PTSD, and anger. Individuals who suffer with depression, anxiety, flashbacks, and angry outbursts often have trouble regulating their emotions. People who have poorly regulated autonomic nervous systems can be thrown off balance easily both on a mental and physical level. Examples include being 'set off' by a minor hassle, road rage, or crying in public when it isn't warranted. By practicing activities that increase your HRV—like yoga—you can help retrain your heart and physiology, which can lead to emotion regulation and a calmer state.*

The feeling of being strangled by an overwhelming sense of anxiety, where the mind races and the body seems to lack a solid base from which to slow down the thoughts of worry and fear is very familiar to me. But so is the feeling of the floor underneath my feet, grounding and supporting me, and the feeling of connection between breath and movement as the body-mind calms down and transitions from one *asana* to the next. Yoga practice has taught me that this calm state is not only achievable but normal; it is a natural state to which it is possible to return and to overcome anxiety and worry.

Stress always accompanies life and we need to be able to develop ways of dealing with the negative consequences of its excess. Working in higher education has its own, non-trivial stresses: we work with and for other people, we differ in opinion and in personality, we have our own ambitions to meet as well as objectives that others set for us. There are always new tasks to accomplish and diverse pressures to meet, and with all this, we do not know what the future brings for our universities. Of course, structural change, rather than yoga, is necessary to address the causes of a lot of the anxiety and worry that feature in the professional lives of university employees and students in Brexit Britain. Nevertheless, yoga practice can be an important aspect of our self-care, of looking after our body-minds and helping them stay well regardless of external circumstances.

Conclusion

In this chapter I have reflected on the personal experience of the influence of practising yoga on my professional life as an academic. In particular, I have discussed how yoga practice has supported me and facilitated my development in five areas: academic writing, relating to others, pedagogic practice, living and working without physical pain, and dealing with stress and anxiety. Since I have found yoga highly beneficial to all aspects of my professional practice, I would like to encourage my colleagues and students to undertake yoga practice – especially if, upon reading this chapter, they think it might also support them.

Obviously, I am aware of the criticisms directed at yoga that refer to its “dark sides”, for example those associated with the potential for encountering teachers who behave inappropriately towards students or with the problematic nature of commercialisation of the “yogic lifestyle” and its individualising, consumerism-oriented effects. I recognise that not everybody will have had the same positive experience of encountering yoga as I have. I would like to emphasise that I have written this chapter solely on the basis of the – often surprising – benefits of yoga which I have observed in my case over an extended period of time. My experience of yoga and how it has helped me live the life of an academic has led me to enthusiastically affirm the benefits of yoga practice, and I strongly believe that yoga provides a very helpful way of approaching our professional practice from a body-mind perspective.

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2. Academic labour, athleticism and wellbeing: An alphabet of reflections on doctoral study and early career academia

Charlie V. L. Smith

An introduction to The Academic Athlete

When I was a doctoral student at the University of Essex, in the Business School, I used to go to the gym early in the morning, then drive to Colchester and work on my thesis all day. In the lighter seasons after work I would then head out running along the Wivenhoe trail, or around campus in the darker months, before returning home and finishing my day's toil. Whilst the idea of taking out life and indeed work frustrations with some form of exercise producing the release of endorphins (e.g. runner's high) is well-known and was at play here, I was also beginning to seriously identify and recognise myself for the first time as an athlete. Even though I had been into sport since a young age, during my PhD I grew in confidence and started to understand myself as someone who is proficient in sports and other forms of physical exercise as well. My habits and routines became ingrained so fast that I never reflected on them properly until my first academic posting after completing my thesis though. There was something much more meaningful going on here but, admittedly, even when I did engage in reflexivity it was prompted by friends and colleagues who frequently noticed my athletic side spilling over into my academic life, usually through what I was consuming or wearing. It is these supportive and inquisitive friends who have often encouraged me to formally write about and develop my thinking on my ideas pertaining to 'The Academic Athlete'.

During my PhD, and in those early lecturing years, I also became aware that I had started out in a career that has many systematic threats to an individual's wellbeing, and I grew more curious about whether and how my athletic activity could help academic life, beyond providing an endorphin rush. My contemplation was helped by being a scholar in management and organisation studies who had a general research interest in how people organised and managed their performances, experiences and themselves at work. As Schmidt and Hansson (2018) have recently summarised, doctoral studies are often characterised by constant peer pressure, frequent evaluation, tight deadlines, low status, high workloads, publication burdens, insecure employment and generalised worry about the precarity of their uncertain future. Whilst I submitted my thesis in the allotted time frame (typically between 3-4 years in the UK), I had an accompanying degree of stress, anxiety and depression that these days seem a normalised part of doctoral student life. Fast forward a few years, and not long into my lecturing career, I completed my first *Ironman* (a triathlon race comprised of a 2.4-mile swim, followed by a 112-mile bike ride and then finished with 26.2 miles running, all which must be finished by a cut-off time of 17 hours). Shortly after this first long-distance triathlon I then became a Team Great Britain (GB) Age Group triathlete, an amateur athlete who is selected and races for their country at international level. As I accumulated further Team GB selection (by either being highly ranked in international races when racing for GB or by being in the top ten per cent nationally) it prompted further serious thought about the commitment entailed and the nature of labour involved in becoming and staying an athlete. Particularly, I wondered about the interplay of my lifeworlds and the effects they had on my wellbeing during the turbulence of embarking in early career academia. I had perhaps not been more forthright in discussing or believing in my athletic prowess because I had been knee-deep in a prevalent but a successful doctoral culture that bred single-minded focus on our PhDs, at whatever cost to ourselves. I remained afraid that those hours spent training each week (even though I worked more than standard full time) should instead be spent on other academic activities like publications or writing my first lectures.

In this chapter, I explore the notions of academic and athletic labour and performance, considering where the traits of athleticism intersect, compare and contrast in support of academic wellbeing. I do not write with a background in sports science or psychology but instead use my knowledge and understanding of my autoethnographic reflections on my self-governance as someone who has used this approach to manage themselves as an amateur athlete and academic for a period of time. This is opposed to the now managerial preoccupation with Western organisations managing people's health and fitness at work in the purist sense of efficiency and productivity (Holmqvist and Maravelias, 2010). What have I learnt from being an amateur athlete to help the life of an early career academic? What are the material parts of my athletic practice that are useful for academia? What are the dangers for one's health of treating their PhD like a competition? My hope is that some of my discussion may be a useful means of reflection for anyone beginning their journey in academia. Readers do not need to be exercise junkies to continue. Whilst my case may come across as extreme, and not least because the boundaries between amateur and professional sport are becoming more indistinct (Howe, 2003), the general traits and arguments about the practice of academia and sport more generally are widely applicable. The notions of wellbeing and flourishing can be highly contested, therefore before I present a series of my reflections organised as an alphabet, I briefly outline my theoretical background focusing on human flourishing and wellbeing.

Human flourishing, eudaimonia and sport

Eudaimonia is the Greek word for *happiness* or *welfare*, which today is often termed “wellbeing”, “wellness” and “happiness”. It is the highest good for humans, the energy of the soul in its completeness (Roumpou, 2018). Methodologically speaking, it is also a process of self-discovery, the perceived development of one’s best potential as they seek a sense of purpose and meaning in life and enjoy activities as personally expressive, in thoughtful relationships and in accordance with their deeper principles. It involves many ways of behaving including: striving for excellence; acting in line with one’s self and deep values; developing oneself and promoting personal evolution; using the fullest range of what one is (including unpleasant emotions); striving to serve a greater good and sustainable long-term goal; actively applying oneself and being deeply immersed; focusing on the quality of the means to an end; and contemplating one’s actions and acceptance of oneself as they are (Huta, 2012). Human flourishing has long been connected and valued in competitive sport because it creates excitement, challenges and mastery of a sense of belonging and identity (Loland, 2004). Integral to this are “performer theories”, that if utilised and practiced in the right manner can become a sphere of human flourishing which individuals use to realise their talents and abilities (Loland, 2004). As Hochstetler and Hopsicker (2016) have noted, this human flourishing is closely connected to and created with *phronesis*, or practical wisdom, a process dependent on an athlete’s individual subjectivity and practice-based attentiveness. I therefore understand sport as something that carries some universal or essential meaning, as something that is culturally embedded, and which holds its meaning in relation to dominant cultures (Howe, 2003). Alongside this, I understand my body and mind/psyche in a transparent unity – inseparable elements of one indivisible substance pursuing the same goal (Roumpou, 2018).

In the following I present an alphabet of my autoethnographic reflections and ideas on "The Academic Athlete", including key contextual details on the difficulties of doctoral study and early career academia. I have chosen to organise them as an alphabet for the simple reason that I needed a tool to help me arrange my thoughts and reflections. Obviously, I only have 26 letters in total, but the process of choosing these has been a much longer one. There have been a multitude of options to choose from that have required choices of inclusion and exclusion that on the whole cover all the broader aspects of my practices that I considered prudent to discuss. More specifically, I have chosen these words in association with the idea of creating performances which appears to be the considered goal that justifies or defines the means in both of my worlds in pursuit of the approach to human flourishing noted above. One of my particular interests is how these two worlds coincide and corroborate to maximise wellbeing and human flourishing. I have also chosen these letters and words on the basis that I would like to offer some more optimistic points that move beyond existing literature in higher education that gives a very detailed and harrowing picture of how depression, anxiety and general threats to wellbeing affects academics of all standing at some point in their careers. Each of these words have occurred to me over the past five years as part of my experiences of learning to be an academic. I hope readers can accept its casual nature. It makes sense front to end, but each excerpt can be read selectively.

The academic athlete alphabet

Authenticity ~ "Describes something that is real or genuine and not counterfeit".

One of the greatest pleasures I get from engaging in, watching and playing sport is the notion of authenticity, appreciating the uniqueness and specialty of a team's or individual's performance. Not dissimilarly, when I started out as an academic and became a more serious athlete (on both occasions not really knowing if I could make it), I have only ever promised myself one thing: to try my very best whilst being myself. As time has passed, I have realised that acting in line with my deep values and doing so authentically extends to the conjunction between the broad spheres of academia and athleticism. As I have relished in the existence of these two domains, I have continually fostered a supportive environment that has enabled me to realise my true self. Academia too easily renders academics as machines in large institutions operating in fluctuating environments – for me it's been important to remain true to who I am and part of that means being an athlete as well.

***B**ravery ~ "Ready to face and endure danger or pain; showing courage".*

The values I have internalised as an athlete have given me a significant degree of normative autonomy as a source of performativity in further competition, but also outside of sport and in academia (Loland, 2004). When training and racing, I have done many things that have terrified me because of their associated danger (e.g. riding bikes down mountains at serious speed in hideous conditions) but also because of their overwhelming amount of energy expenditure required (e.g. riding a bike for 24 hours non-stop). I continually draw on this athletic courage in the more performative aspects of academia. For example, being nervous about a lecture, or talk, or learning a new task.

***C**ompetition ~ "An activity of striving to gain or win something by defeating or establishing superiority over others".*

In sport I have long been used to embracing a social logic that measures, compares and ranks competitors according to their performances which are often (especially at elite levels) determined by the smallest of margins. Admittedly, when I entered early career academia, I was not expecting such a competitive ethos to be in existence there too. This was perhaps one of the greatest threats to my wellbeing. I was comfortable donning a competitive mindset in sport and to some extent this gave me the determination to keep fighting academic battles, but ultimately, on reflection, I felt that I was operating in an environment in which I could not be truly competitive as I was competing with more established academics beyond my career stage.

***D**iscipline ~ "The practice of training people to obey rules or a code of behavior".*

The obligation to follow rules throughout sport is widely accepted and rarely contested (Ciomaga, 2013). Given the duration of an *Ironman*, this discipline especially plays out in the amount of commitment (averaging 15 hours training most weeks annually) but also in the required consistency of training. Taking a disciplined approach to triathlon has significantly affected my academic routines positively and both psychologically and practically. On a practical basis, I have become disciplined into a routinised way of life which equates to training before and sometimes after work, eating 6 regular meals daily, and maintaining adequate sleep patterns that all foster excellence in my general wellbeing but also in broader spheres of life and work (Hochstetler and Hopsicker, 2016). This naturally leads to a consistent way of living. Beyond practical routines, discipline also extends to my approach towards academic work. I have often thought that if I have enough discipline and dedication to maintain grueling training programmes and nutritional regimes, then I am capable of upholding similar control towards making decisions in my academic and work-related behaviours (Hochstetler and Hopsicker, 2016).

***E**ndurance ~ "The ability to tolerate an unpleasant or difficult process or situation without giving way".*

Completing a doctoral thesis or an *Ironman* both take inordinate amounts of time and effort and can often be difficult and unpleasant. As I begun to finish *Ironman* competitions (on a bad day up to 15 hours in duration) I have noticed how my ability to push my body physically, and carry on when it is screaming in pain, has been a confidence booster to help me deal with the painful and harder parts of academia. This is not to say that difficult taxing thinking utilising the mind is pain-free, but rather knowing that I can push my body to breaking point often gives me the safety net of a reservoir of power, knowing I am less likely to do that with my work. Long distance endurance events have often been said to have the purpose of allowing people to find out 'how far' they can push their bodies (Howe, 2003). Having that other breaking point allowed me to consider that my PhD was not the only thing that could break me, and I was safe in the knowledge that I could break myself elsewhere.

***F**low ~ "Proceed or be produced continuously and effortlessly".*

Flow is a state wherein no time and ego exist, when one is entirely involved in their activity, being able to engage with it for the reason they love it and with even a feeling of transcendence or connection to a greater whole (Roumpou, 2018). In sport, this often means training the body so there is perfect immediacy between body and mind, and thus getting the body to do things effortlessly. Pedaling perfectly, or swimming with exemplarily technique, being obvious examples. The important aspect of this is the state of absorption it creates, letting oneself flourish and perform their best without constraint. It is also when an individual can be at their happiest (Csikszentmihalyi, 1990). I have long aspired to replicating this flow in my academic labour, important in allowing myself to work without inhabitation. However, like in sport, I have found that creating this state and overcoming these gaps in academia must be worked at, as it will not necessarily be smooth from the start or come naturally, with much of my thinking here stemming from Cal Newport's (2016) principles and practices of beginning 'Deep Work'. One of these aspects is ensuring the environment I am working in is conducive to my best work, and from a physiological basis, I have found that being fit helps me maintain concentration levels to create this state.

***G**ame ~ "An activity that one engages in for amusement or fun".*

Whilst I take my triathlon activity seriously as an amateur, it remains fun for me, and it is something I consider a 'game' in the loosest sense of the word, otherwise I wouldn't do it. When academic anxiety is furious, or I feel I am restraining my ideas by overthinking when writing, I find treating my approach to work as a game helps. Applying this attitude gives me the pretense to have a 'bit of fun' and as such lets my ideas run wild without restraint. Essentially, it is giving myself a chance to just 'have a go' and experiment.

***H**ero ~ "A person who is admired for their courage, outstanding achievements or noble qualities".*

Having a favorite player or looking up to a hero has long been a part of sports spectatorship. It has been no different for me, especially concerning professional cyclists, which is my best sport of the three (cycling, running and swimming). Heroes usually incarnate excellence in their field, perhaps even ascending towards perfection as they continuously provide new sources of sporting excellence that other athletes and amateurs can transcend towards themselves (Aggerholm, 2016). However, we do not always consider somebody a hero because they are the very best at what they do. Of course, they might be this, but we can equally admire other aspects of their being – perhaps their courage, tenacity or alternate noble qualities. Unsurprisingly then, I had academic heroes too. Who we choose as heroes is quite personal, but the most helpful part of having a hero in mind in academia has been that it has allowed me to reflect on what I think their attitude might be, what would they do in difficult circumstances and so on. There was never the expectation that they were perfect, and I did not idolise them, but aspiring to someone with noble qualities has always helped me keep academia in perspective throughout the better and worse times.

Intuition ~ "The ability to understand something instinctively without the need for conscious reasoning".

An athlete is astute at knowing when something is 'just right' or when they should take their chances (e.g. in a race) given a sound understanding of their body and knowing its capacity. Being well versed in the idea of intuition and knowing to trust my body in triathlon has helped me trust in my abilities in academia. Academia can require considerable conformity and orthodoxy to how we should think and feel, or even what we are expected to write and say. If I wanted to work with an idea that wasn't so mainstream, or perhaps a little brave, reminding myself of the capacity of intuition has greatly expanded my confidence to try something different. It has also helped me place boundaries around my performance and especially when meeting deadlines or finalising a piece of work (e.g. 'it's done', 'because it feels right'). Beyond assessing quality, I have also learnt patience and the knowledge that the moment when a piece of work 'feels right' will come with time.

Journey ~ "An act of travelling from one place to another".

A PhD is often described as a journey, yet many doctoral students understandably feel pressured to get from A to B as fast as possible. Being an athlete is also a journey, albeit a slower one representing and recognising a conversation towards the self in preparation for being open to and ready for challenges that may occur later (Aggerholm, 2016). I wish I had allowed myself the patience to accept deviations from that direct path during my PhD as it would have reduced an inordinate amount of unnecessary self-imposed deadline stress.

K*nowledge of the self ~ "The fact or condition of knowing something with familiarity gained through experience or association".*

An athlete is more attentive to the abilities and disabilities of both their mind and body. They are also assumed to be better equipped to deal with shortfalls through recovery and re-adaptation (Howe, 2003). This has helped me in academia because being indoctrinated to conduct regular self-assessments of my body has meant that I can identify when academia (or indeed triathlon) is starting to affect my health and when I need to take early reparatory actions. On a very practical level, such knowledge has taught me when to take a break.

L*uck ~ "Success or failure apparently brought by chance rather than through one's own actions".*

An athlete is educated in the regime that intensive training and skill lead to superior formal results and achievement (Hämäläinen, 2014); they make their own luck through measured approaches. One of the hardest parts of being an academic for me has been that there remains an element of luck, especially with external factors and subjectivities involved in assessing our work e.g. grants and publications. This has often threatened my wellbeing, and I try where possible to adopt the philosophy often seen in sport of "make your own luck".

M*easureability ~ "The extent, dimensions, quantity, of something ascertained by comparison with a standard".*

A definitive aspect of an athlete's performance and subsequent living of their lives is the practice of measuring against their own standards or those of competitors; essentially rational calculations to achieve the optimal means (Guttman, 1978). For an athlete, it is not enough to finish a training session or eat an unknown quantity of food. Instead practices like these must be set in context to sustain and develop performances. Underpinning measurability is therefore an attitude of quantification that continually expects enhancement and growth. If something is counted, then an athlete always expects a better result than previously. Setting expectations in this quantified way has been paradoxical for my academic work. In some senses setting myself targets (e.g. the number of words to write in a day) helped, and especially with allocating myself a sensible amount of work to do (something physiologically possible to do in a day). However, certain parts of the academic craft should simply not be measured, and forcing standards onto something that should not be standardised sometimes left me without a backstop.

***N**utrition ~ "The process of providing or obtaining the food necessary for health and growth".*

As mentioned above, throughout the course of a training year, my weekly amount of hours training – unless I am injured or unwell – will never go below fifteen hours. Considering that on average a triathlete burns anywhere from 600-1000 calories per hour, that's a reasonable amount of energy required, which must be replenished. Over the past decade, the importance of nutrition has escalated and is now said to equate to roughly 80% of an athlete's performance, with the calories taken in having to be of the highest quality. Having a measured approach to eating and hydration has considerably helped my academic work as I seek to ensure my body and mind is supported in the best way possible with the sustenance they need. On a practical level, needing to eat regularly (around 6 small meals per day) to support my training has also helped me structure my working day, ensuring I take breaks when necessary and also ensuring I do not reach for suboptimal food that will not support either kind of performance.

***O**bsession ~ "A persistent disturbing preoccupation with an often-unreasonable idea or feeling".*

The adjectives 'excessive' and 'compulsive' are well associated with athletes (Howe, 2003) and there have been many discussions of over-training and training addictions (e.g. Landolfi, 2013). However, the idea of having an obsession or preoccupation has always been helpful in both sport and academia for me, and specifically with the energy and drive they determine. In sport, I have found that being 'obsessed' has always led to the completion of training sessions, even when the exertion is hard, and my body and mind want to stop. In academia, whilst I haven't become quite so obsessed with the development of my work performance on a broader level, I have found this mindset has instead transpired with the craft of writing, leading to meticulous practice at every level from rephrasing and rewriting sentences, to formatting, to saving references and so on.

***P**ersuasion ~ "The action or process of convincing someone or of being persuaded to do or believe something".*

A considerable amount of sport is about persuading others or persuading oneself. Examples might include persuading a coach that you are the best athlete to select for the team, or persuading yourself to endure the parts of training you least enjoy. Early on in academia I could see persuasion was key too. Environmental aspects like a crowded job market and short resources meant smaller chances of success. Furthermore, competition against well-established academics also means there is more risk involved when it comes to choosing early career academics for jobs, tasks and awards. Persuasion is therefore doubly important here too. An example is when I feel less confident – I try to persuade myself to at least, have a go, at a difficult task and not readily accept defeat, and this at the very least gives me a feeling of accomplishment. Another example is that this approach helps foster my best performance and self-esteem as I carefully evaluate my own traits and consider the best way to present myself.

Q*uota ~ "A fixed share of something that a person or group is entitled to receive or is bound to contribute".*

Just like anyone else, an athlete has a set number of hours available in any week to perform their tasks, and, even if they are the best athlete in the world, they wouldn't be able to do any more training because there simply are not enough waking hours. They often divide their training into blocks of several months using a process of periodisation. As part of this, a quota is therefore a limit, and this limit is very important because it makes no judgement on the person, but instead is an external boundary beyond which further activity cannot proceed. I have learnt to think of my quota of energy each week in hours, dividing it into academic, sleeping and training time. This helps me realise there is more to life than academia and balancing my two worlds enables them to corroborate.

R*esilience ~ "The capacity to recover quickly from difficulties; toughness: the ability of a substance or object to spring back into shape".*

Academia has a contemporary and somewhat unhealthy fixation on competitive success as a mark of achievement which systematically overlooks self-care around rejection, and undervalues the importance of resilience (Russell, 2016). After a few acceptances early in my lecturing career, I then had a tough period of multiple rejections. I found this excruciatingly painful because I had thus far learnt from my sport that input, followed by process, leads to output. Essentially the onus is on me, and if I train properly and effectively, with the right consistency, then I am rewarded on race day. However, often in academia decisions on our performance or pieces of work are subjectively made by others outside of our control and with whom we sometimes disagree. I therefore found it incredibly hard to accept these 'rejections' and 'losses' and unhealthily internalised them until I could make a better and helpful comparison with sport that appreciates resilience differently. I realised that athletes continually overcome their weaknesses in training, and in competition with their more or less equal rivals, that affords them another opportunity for self-transformation requiring the use of 'physical skills' (Tuncel, 2015). Some of these obstacles are also voluntary encounters and beyond an athlete's control (Suits, 2007). Whilst athletes internalise the so called defeats, they do so with a *pathos* that enables them to grow and fulfill who they become – meaning that they rarely direct their misfortune at someone else or lay blame on others, but instead turn it productively onto themselves for future learning and enhancement.

Surrender ~ "To give up completely or agree to forgo, especially in favour of another or something else".

One of the hardest parts of academia is our ever-growing workloads which are situated in a culture that makes it far too easy to take on whatever we are asked or invited to do. For me, part of the problem lies with the fact that we are passionate and enjoy what we do, but also because of the blurred boundaries delineating what counts as academic work, which make it easier to agree to do more, even without capacity. In my earliest days as an academic I would say 'yes' to everything, but I soon learned that this was far from the impressive badge of honour that I considered it to be. Even though I had a warrior athletic personality that meant I knew I could work 20 hours a day if needed, I realised that working every possible hour outside of training was not a sustainable long-term prospect, drawing on the more appreciated notion of surrender in sport. I noticed that I was far more able to surrender my participation in a race, for example, than I was in comparison with an academic task. In sport, I was also aware that it is appreciably more acceptable to surrender yourself (e.g. if you are injured) than it is to have pushed yourself beyond your limits and end up being carried to the finish line. Slowly but surely, I am learning to say no, without justification or feeling inadequate, instead understanding that I have surrendered an academic task in pursuit of my wellbeing. There is some way to go.

T*alent assessment and management ~ "Natural aptitude or skill, planning and organising to realise those skills".*

An athlete is often likened to a craftsman who develops their skills alongside their work. Unsurprisingly, the organisation of sport has a very specific and direct approach to managing and investing in such talent. This management also embraces an integral element of self-assessment. In addition, an athlete often learns to sell his own activity and athletic persona (and craft), viewing his own body and skills as a marketable commodity (Howe, 2003) – the key part being knowing their unique and best aspects. For me, recognising the parts of my academic practice that I am not so good at, as well as the ones I am best at, is very important for supporting flourishing and wellbeing. Academia has become enduringly commodified itself, requiring staff to be exceptional at all aspects of the practice with often inhumane constraints. I have found taking on a realist approach to my skills and viewing it as talent management helps me to invest in personal development myself, gain some sense and sensibility of what is doable with the dominant and prevalent skills I have available, and lastly enhance and protect my unique skills that are most valuable to me and my academic career.

U*nderdog ~ "A competitor thought to have little chance of winning a fight or contest".*

Academia is relatively good at creating spaces where all those on the hierarchy from PhD student to Professor can often mix and work together, even if they can't compete on the same grounds. Naturally, this can be a bit daunting to those in their earlier stages, such as when a doctoral student presents their research at a conference to a leading Professor in the field; or when an early career researcher applying for a grant is in a pool of applications that is open to any career level. When I have encountered these times, and more often than not labelled myself as an 'underdog', it has been helpful to remember that in sport, this label may be disputed at any point (Fry, 2017). So whilst I have accredited myself with this pessimistic label, it has simultaneously given me the greatest optimism about myself because it allows me to believe that the unexpected is possible, surprises do happen and that an underdog often exhibits grit, determination and hope prevailing against the odds (Fry, 2017). Reinforcing the possibility that I might do OK, or even better than OK, is prevalently more than enough for me to give something a try.

***V**ictory bearing ~ "An engagement ending in such triumph". "The act, capability, or period of producing or bringing forth".*

An instrumental purpose for an athlete is to win, and since the earliest days of sport and Greek athletics, victory-bearing has been a special task. The victorious athlete was not supposed to boast or exuberate arrogance but instead be modest with their victory (Tuncel, 2015). This approach differs considerably from what I have seen in modern academia thus far. Either we do not celebrate our achievements (e.g. a paper acceptance or a funded bid) at all, or they are calculably forced into the public domain by our institutions who want to show off their staff. Whilst I have disagreed with and critiqued the competitive regimes of academia already, they do exist and I have accepted that they will remain a steadfast part of the industry for the foreseeable future. I therefore try to deal with these by making an effort to celebrate whenever and whatever I feel is a worthy achievement for myself and do so in the same way that I would a race victory. This usually means cake, a rest, and spending time with those who relentlessly help me get there.

***W**inning ~ "Gaining, resulting in, or relating to victory in a contest or competition".*

The central purpose of sport and contest is to determine which athlete or team is superior and to provide an accurate measure of athletic superiority (Hämäläinen, 2014). Naturally this is conducive to a structure that compares and ends up in a 'better than' or 'worse than' conclusion (Kretchmar, 2012). There is then a dangerous trend in the spirit of sport, the notion of winning at all costs, in whatever way possible (Tuncel, 2015). This trend is also sadly prevalent in academia and admittedly I have found this aspect to be one of the greatest threats to my wellbeing, being an athlete who in their sport strives for winning at whatever cost, even though I may celebrate. The only way I have been able to manage this is to consider that I am in competition with myself and not with other academics. In sport I am happy to engage with the winning mindset, but in academia, for the sake of my wellbeing, I try to ensure that the only wins I strive for are those for myself and personal development. With the compulsiveness and obsessiveness of an athlete engrained, it would be too threatening for my mental wellbeing to do otherwise, and especially in academia where there is often unfair and unbalanced competition.

***X**enial ~ "A friendly relationship between two parties, especially to strangers or foreigners".*

In the beginning, as I have mentioned already, I speculated on the incompatibility of serious sport with an academic career owing to the perceived conflicts between time and energy. As I have worked through these practices and ideas over the past few years, and indeed in this text, I have realised how incorrect my early thoughts were. Whilst these two worlds might have originally seemed incompatible given each of their required time and effort, I have found they have a friendly relationship. On the serious sport side, my experiences are that it has positively influenced my academic practice. I have found that the more and harder I train, the better I work and write, probably because it means I take a more structured approach to my life generally and feel more energised. It might be expected that if I am more physically tired then I would be suboptimal at work, but this certainly has not been the case.

Y*earning ~ "A feeling of intense longing for something".*

The idea of sport as a constant and continual search for improved performance stands strong (Loland, 2004), connected with the personality and psychological traits of an athlete who never loses that intense longing to grow on their journey. Allowing this relentless attitude of yearning from sport to apply in pursuit of my PhD and not just see my thesis as a means to an end, supported me with a permanent stream of motivation. It allowed me the space and capacity to let myself enjoy and engage with knowledge for the sake of knowledge, rather than in instrumental framed terms of getting from A to B. Of course, this is much easier now that I have a PhD and a permanent post.

Z*en ~ "A state of calm attentiveness in which one's actions are guided by intuition rather than by conscious effort".*

I understand why many people consider all the three triathlon sports (which I admittedly do for hours on end) to be monotonous, banal, boring and repetitive. This is not something I have experienced though, as sport provides a sanctuary and solace for me. Whilst pleasingly simple to do, I find it permits a degree of control that enables reflection on my academic achievements and self-worth. Not only is affect configured in this way, I also find that thinking about the zen-like state of riding my bike at work provides an equally calming effect. Just an hour's training in the morning is enough for me (although I normally train for around 1 hour 45 minutes) to remember snippets of such pleasure and re-live the happy and positive thoughts I had at the time throughout the rest of the day (Cauldwell, 2015).

Conclusion

Herein I have shared some of my early career academic journey, exploring the notions of academic and athletic labour and performance, with a key focus of this discussion being how these two worlds have supported and helped my wellbeing. I'll inevitably continue this journey a lot longer, but if readers wanted a take home point then I suppose I would encourage doing your best to create a working environment and career that doesn't necessarily feel like work, or one in which you permanently feel you need a break from. Those are the best careers and jobs, and I know from my experiences included here that enabling my two worlds to collaborate has helped me go a long way towards achieving that. It does not necessarily have to be a sport or exercise, it could be any hobby – find some way of using those non-work academic practices to help you love what you do either as an academic or in your life aside from it.

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3. Being ‘recovered’ and doing research: the challenges and complexities of using autoethnography to conduct doctoral research into anorexia nervosa

Lauren O’Connell

Introduction

As I tear the brown paper off the four, heavy packages on the table in front of me, my hearts pounds and I whisper to myself ‘oh my God’. I am opening copies of medical documents from my four long-term stays as an inpatient in an eating disorder unit, the last of which was around seven years ago. These piles of paperwork are a slice of my past. It is a past which often doesn’t feel real, with so much of it now existing only in my memory. Here I can glimpse it via the experience of others; a piece of myself, viewed through a clinical lens. I flick through the paperwork and am momentarily transported back. The weight graphs, the nurses’ handwriting, the sectioning paperwork, the meal plans. Here is a material representation of my personal crisis, with intimate and personally meaningful details littered throughout the organisational structure of the documents. In addition to the clinical functions they once served, these documents are also to become data for my PhD. I look at them and wonder what will happen to the content and its meaning as they transform into their new purpose. What will be left behind and forgotten, and what will be created?

In my doctoral research, I am exploring individual’s subjective experiences and meanings of being diagnosed with anorexia, their shifting relationship to the diagnosis over time, and the ways in which the diagnosis informs their ongoing identity-work. I am using autoethnography. Broadly, this is a research approach which involves "the study of the self" (Reed-Danahay, 1997: 9). Sociological autoethnographies "… draw upon the experience of the author/researcher for the purposes of extending sociological understanding" (Sparkes, 2000: 21). I am analysing my own experiences of being diagnosed with and treated for anorexia, drawing on memory, diaries and medical documents. In doing so, I am utilising my experiences as a vantage point for addressing broader sociological, theoretical concerns (Anderson, 2006; Vryan, 2006). I have also carried out in-depth interviews with fourteen others who have been diagnosed with anorexia. I have done so as a known 'insider', having been open with my participants about my identity as a 'recovered anorexic' throughout, and sometimes sharing aspects of my experiences with them.

In this chapter, I address challenges that I have faced as a PhD student using autoethnography. These challenges have been multifaceted, often cutting across the realms of the theoretical, practical, personal, and professional. Specifically, I discuss the problems and complications involved in designing and implementing my autoethnography, identifying myself as an autoethnographer, revealing my identity as a 'recovered anorexic' to different audiences, and continuing to manage my own 'wellness' throughout my research. I also consider potential impacts of my autoethnography on my future career.

Designing and implementing autoethnography

When I first considered using my own experiences for research, I had not heard of autoethnography, and had been exposed to little academic writing that incorporated the experiences and identity of the researcher in any significant way. I therefore first found autoethnography while actively searching for an appropriate method. Initially, the term was confusing. It seemed to mean something different in each publication I read, and much of what I read didn't seem like research (as I knew it) at all. Partly, this confusion stemmed from there being numerous 'types' of autoethnography, each varying in their emphasis on the researcher's self, wider culture, the research process, traditional analysis, and interaction with others (Ellis *et al.*, 2011; Ellis and Bochner, 2000). Further, my reading led me to such methodological approaches as autobiography, reflexivity and narrative research, and the boundaries and relationships between these and autoethnography were not immediately obvious. Wall (2016) notes the confusion that exists over naming material autoethnography, and the tendency to call approaches autoethnography when, prior to the term becoming relatively popular, they might have been called otherwise; her observations resonate with my experiences of 'getting to grips' with autoethnographic literature.

Through continued reading, I began to make sense of the different approaches to autoethnography. Two which are often invoked as polarising stances are *analytic* and *evocative* autoethnography. Analytic autoethnography (Anderson, 2006) is conducted in a context of traditional ethnography. It values conventional research practice and has a strong emphasis on interpretation and analysis. Conversely, evocative autoethnography (Ellis, 1995, 2004; Ellis and Bochner, 2000, 2006) is emotional, narrative, literary-based, postmodern-influenced and heavily emphasises the self. These two distinct approaches can be understood as occupying either end of a continuum, such that in practice, research may fit anywhere between these extremes (Wall, 2008, 2016). By critically reflecting on existing autoethnographic practice, I began to locate my own research preferences in terms of this continuum. I came to share others' concerns regarding the limited social scientific and analytic potential of (some) evocative autoethnography (Anderson, 2006; Atkinson, 2006; Chang, 2008; Delamont, 2009; Walford, 2009; Wall, 2016) and I wanted to distance myself from the postmodern sensitives associated with this approach. Specifically, I was concerned that privileging evocation and the experiential value of writing can undermine the scholarly goals of analysis and theorising (Atkinson, 2006), and restrict the writing to the level of descriptive autobiography (Chang, 2008). Analytic autoethnography resonated more strongly with my research values. However, I did not agree that autoethnography need be limited to only being what is essentially heightened reflexivity and researcher visibility in ethnographic research (Vryan, 2006; Wall, 2016) and I needed an approach that would allow me to directly analyse my own experiences as a case in their own right (while also interviewing others). I therefore developed my own stance to autoethnography. The result is akin to Wall's (2016) moderate autoethnography; it sits somewhere between the two extremes of analytic and evocative autoethnography (but towards the analytic end). My research is heavily influenced by analytic autoethnography in that it is orientated towards explicit analysis and seeks to address broader conceptual and theoretical issues (Anderson, 2006). However, my research is not couched in traditional ethnography and I am free to engage with my own experiences and related material in innovative ways.

Following this explication of my theoretical stance on autoethnography, an ongoing challenge has been translating this into practice. There are no 'how-to' training courses that one can attend for autoethnography like there are for conventional methods, and existing guidance and suggested techniques (E.g. Chang, 2008; Hughes and Pennington, 2017; Muncey, 2010) have been of limited use. Autoethnography is as personal and idiosyncratic as the experience that it draws upon, and as such there cannot be guidance that is applicable to all. My autoethnography – which is 'moderate' (Wall, 2016), analytically focused, uses memory and extensive personal diaries and medical documents, and is being conducted alongside interviews – is unique. An implication of this is that the implementation of my autoethnography, in terms of the practical steps I take, is proving highly emergent and constantly (re)negotiated. This occurs with all research to varying extents, but autoethnography feels especially unknown, and it is harder to 'plan ahead' than it is for other methods.

In practice, then, I have sought to find a way to both *tell* and *explicitly analyse* my own experiences. I began by writing the narrative of my experiences drawing on memory and my personal diaries and medical notes. Here, I began to 're-immerse' myself in my past and structure my memories into chronological order. During this process I also began documenting initial analytic insight as I noticed connections to existing sociological themes and generated ideas that were relevant to my research questions. I am now in the process of analysing interview material, and I intend to later use the insights generated from this to make sense of my own experiences. Thus, the two methods are iterative; insights from my own experiences have shaped the interviews, and my engagement with interview material has in turn shaped the analysis within my autoethnography.

However, this approach is not set in stone, and remaining open and willing to be 'experimental' has been a necessity. I have also had to be very clear about my epistemological and ontological stance, and the specific purposes and scope of my autoethnography, since early on in my research.

Identifying as an autoethnographer

I have adopted autoethnography during a time when it is becoming increasingly popular. Indicative of its growing acceptance as a viable research method is the new 'Journal of Autoethnography' due to be launched in 2020, which is to be the first journal "devoted to the purposes, practices, and principles of autoethnography" (University of California Press, 2019). Nonetheless, autoethnography remains a relatively marginalised method. The subjective nature of self-study is contested in some areas of social science, and autoethnography is therefore sometimes viewed as not being 'proper research'. This is the case particularly in areas in which conventional 'scientific' notions of researcher impartiality and silent authorship have pervasive influence. Even where scholars do not completely accept traditional notions of objectivity, methodology still tends to be strongly affected by it (Hammersley, 2011).

Sociology is a varied discipline which is shaped by its methodological divides, and the issues raised in the accusation of autoethnography being 'too subjective' draw on long-standing epistemological debates. It is normal and expected for researchers to hold conflicting ideas about what makes research valuable and how it should be conducted. Nonetheless, I do sometimes feel weary of identifying as an autoethnographer. In situations where there are other researchers present who adopt more (so-called) 'scientific' approaches to research, I am aware that doing so would require me to justify and defend my approach (lest my PhD be judged as lacking worth). As a doctoral student, I do not have the title 'doctor' or a history of successful research to defend my credibility in the face of such judgements. However, I have found that in other situations, autoethnography is actively valued. I often attend academic events which centre on sociological and critical approaches to health or mental distress. In my experience, autoethnography tends to be valued at such events, especially those that centralise critique of the traditional privileging of 'objective' professional knowledge over the 'subjective' experiences of service users. In these situations, I more readily identify as an autoethnographer.

At times, I describe my approach as a 'personal experience method' (Wall, 2016) rather than autoethnography. This is a deliberate attempt to sidestep the 'baggage' that goes with the term due to the 'evocative vs analytic' debate. Moreover, it is to avoid my research being wrongly identified as evocative autoethnography; this could easily occur given that evocative autoethnography tends to be more widely-used and well known than analytic autoethnography, and may be considered as synonymous with 'autoethnography' (Adams and Manning, 2015; Muncey, 2010; Wall, 2016). My reason for not wanting to be identified as an evocative autoethnographer is simply that this would be a misrepresentation of my approach, which is closer to the analytic rather than evocative end of the spectrum. Furthermore, I wish to avoid opening myself up to the critiques that are levied at evocative autoethnography – particularly those that I personally agree with (such as the aforementioned concerns regarding the lack of explicit analysis).

Revealing anorexia through my research

My 'recovery' from anorexia necessitated letting go of my identity as a 'sick anorexic' in need of care, and recreating it as someone 'normal' and 'well'. Literature supports this idea that anorexia 'recovery' involves reclaiming a past identity or discovering a new one (Conti, 2018; Dawson *et al.*, 2014; Patching and Lawler, 2009; Smith *et al.*, 2014). After four long term admissions to an eating disorder unit, the latter three of which were spent detained under the mental health act, the freedom that came from adopting a role as a 'normal person' was immense. However, it was also fraught with contradiction, and letting go of anorexia was simultaneously a painful loss. Anorexia can provide a sense of belonging and become a valued part of one's identity (Espindola and Blay, 2009; Fox and Diab, 2015; Rich, 2006; Warin, 2010). For me, it had been both source and solution to a deeply personal crisis (Lavis, 2016; Rance *et al.*, 2017) and while it severely limited and almost ended my life, I had simultaneously felt empowered by the label of disorder (Warin, 2010). I dealt with this sense of loss, and the distress of out-of-control 'overeating' which ensued shortly after my final discharge, by moving on from anorexia quickly. I completed the postgraduate degree that I had begun prior to the interruption of anorexia, and then moved to a new area and began a career in teaching. In doing so, I deliberately parted from the physical spaces which held memories of my eating (dis)order; the places I associated with the drama and excitement of weight loss, the dark monotony of self-starvation, and the despair of not being able to stop eating. After I moved, no one (beyond my family and close friends) knew me as Lauren who had had anorexia. The fear of someone seeing me and thinking 'is that Lauren, didn't she used to be thin?' lessened. As just another ordinary person, it was OK that I was normal-sized, because the expectations on me were the same as they were on anyone else. I began to build a life that had nothing to do with eating disorders or psychiatric care, and I mostly did not mention my past.

Gradually, over the course of the next five years, I began to feel more able to face my past, and when exploring potential topics for doctoral research, I felt motivated to critically explore the diagnosis and treatment of anorexia. Within this topic, I felt that the most valuable approach I could take would be to make use of my experiences as a unique opportunity to gather rich data, and that attempting to 'bracket them out' and eliminate them from my research would be dishonest and artificial. It was this position that led me to autoethnography.

Since the outset of my PhD, I have (necessarily) regularly informed others of my identity as a 'recovered anorexic'. Among academic colleagues and peers, my previous experience of anorexia and treatment is well known. It is one of the first pieces of information that my supervisor and cohort of fellow PhD students learned about me, and it only takes a short conversation about my research with a new acquaintance at an academic conference for them to realise this. Revealing personal information to people I do not know well sometimes makes me uncomfortable. I spent many years keeping my past hidden, and as such, readily revealing my previous diagnosis and details such as having been detained under the mental act, can feel alien. I also imagine that me revealing this information might make the other person feel uncomfortable. I tend to deal with this by attempting to define the situation for them (Goffman, 1959); I portray myself as being comfortable with the interaction, as if the information I was revealing were not 'sensitive', in order to help them feel comfortable, and this then feeds back into reducing my own discomfort. However, while it can feel strange, revealing details of my personal experiences in academic contexts does feel relatively safe. Somehow, I imagine as if the information will be received through an academic lens, and thus more neutrally, with less judgement and fewer detrimental personal implications (or at least with awareness on the part of the other person that they *ought* to treat the information in this way).

However, academia is not the only context in which I discuss my research. Any situation in which someone alludes to what I do for a living – such as in conversations with my hairdresser, a taxi driver, or other parents at the school gate – can potentially lead to questions about my research topic. These times, I tend to reveal as little as possible, stating only that I am undertaking a sociology PhD in the field of eating disorders. Both in the context of discussing research and otherwise, I generally choose not to reveal my past diagnosis to new people (aside from those who become close friends). I often expect that the other person 'wouldn't understand', and that they may hold reductionist, simplistic ideas about anorexia, such as believing that it is only about 'wanting to be thin' or 'feel in control'. I am not alone in wishing to hide my past diagnosis for these (or similar) reasons. Many participants in my research described being selective about with whom they reveal their diagnosis because of how they imagine others understand anorexia. Relatedly, Dimitropoulos *et al.* (2016) found that individuals undergoing treatment for anorexia were often reluctant to publicly identify as 'anorexic' due to their belief that the general public stigmatise anorexia by portraying it as a volitional choice resulting from sociocultural influences.

The personal impact of autoethnography

The potential detrimental impact of autoethnography on the researcher's self is an ethical concern (Chatham-Carpenter, 2010; Dashper, 2015; Pearce, 2010; Tamas, 2009; Tolich, 2010). Tolich (2010) argues that autoethnographers should treat all persons addressed within an autoethnography as vulnerable. Here, he alludes to relational ethics. This concerns the researcher's responsibilities to 'intimate others' and how they are represented and identified within the text (Ellis, 2007). However, he also specifies that this recognition of vulnerability ought to include the autoethnographer themselves.

Most days, I am very *aware* of the size and shape of my body. I often feel 'large' (compared to how I once was), and sometimes, 'too-large'. I tend to deliberately avoid attaching to these embodied feelings and sensations or affording them too much meaning. As someone who has previously struggled intensely with and through their body, they will probably always be there. However, while I mostly experience these in a non-intrusive manner, I am none the less sensitive to others' (and my own) judgements about my body. When others learn of my previous diagnosis, this sensitivity is accentuated. Anorexia tends to be associated with bodily emaciation. I imagine that when others learn of my previous diagnosis, they assess this in terms of my current bodily appearance; they acknowledge that I appear 'normal', and from this deduce that I must now be 'recovered'. This assumption (which it seems to me that others sometimes make) feels difficult because it negates the ways in which struggles around food and weight – although now far less problematic and different in form – continue to impact on my day to day life. Indeed, the very idea that I am 'recovered' does not account for the complexity of my lived experience (Conti, 2018).

Further, even as someone who no longer seeks food restriction or desires the diagnosis of anorexia, knowing that my body no longer lays claim to my previous intense struggles with food can feel difficult (at times). Relatedly, I sometimes wonder whether I ought to become a little thinner – not drastically so, but enough to attest to my previous diagnosis. These are not imaginings that I act on or believe to be 'true', but nonetheless I *feel* their ebb and flow as I move through the social interactions in which my identity as an 'ex-anorexic' is at the fore. They could be interpreted as a kind of 'anorexia hangover'; evidence that I still have a little 'pathological thinking' hanging around. However, as my PhD research itself is exploring, I would tend to understand these experiences in terms of different forms of identity work (Snow and Anderson, 1987; Wagner et al., 2017) as opposed to pathology. I also would not draw sharp lines between 'well' and 'unwell' thinking, but recognise the fluidity and dynamic nature of such internal experiences for individuals who have moved through 'recovery'.

As alluded to above, autoethnography affects my everyday experience of living in a 'recovered', normal-sized body. Similarly, Dashper (2015) describes how, when others learned of the damage done to her teeth and mouth in a horse riding accident through her autoethnographic publication, she became more self-conscious of the appearance of her teeth. However, for me the research process has not led to a "strong pull to go back into anorexia" as it did for Chatham-Carpenter (2010: n.p). Any sense of feeling compelled to reduce my food intake or seek anorexia that results from my research is no more intense than that which I experience in day to day life anyway (and that is mild). Chatham-Carpenter suggests that "you have to be in a certain space to feel comfortable to write." (2010: 9). Ultimately, I feel that I am in that certain space.

Professional impact of autoethnography

There are professional implications of undertaking autoethnography (Chatham-Carpenter, 2010; Jago, 2002; Tolich, 2010). While in the early stages of trying to carve myself an academic career, it goes against the grain to bring very personal and vulnerable aspects of my past experiences to the fore. Such information would normally remain 'backstage' in the performance of an academic self (Goffman, 1961); one does not ordinarily perform as a professional (whether in the context of academia or otherwise) by making others aware of very intimate aspects of their personal life. Even when scholars purposefully decide to make personal disclosures, they tend do so selectively, in adherence with norms which govern the limits of sharing (Veletsianos and Stewart, 2016). At times, conducting autoethnography can threaten these limits, because information about one's personal experiences that would ordinarily be kept private is publicly known and is apparent in a whole range of professional social encounters.

Tolich argues that, when a novice researcher is planning to write about a stigmatised experience such as bulimia or attempted suicide "they should imagine dressing up in sandwich boards and walking around the university proclaiming their stigma […] Like an inked tattoo […] the marking is permanent. There are no future skin grafts for autoethnographic PhDs" (2012: 1605). A reviewer warned Jago (2002) against publishing her autoethnography of major depression, due to the possible damage posed to her career resulting from stigma. Jago suggests that if publishing her story were to damage her career for this reason, then this is "the best reason" to do so; it is an opportunity to "demystify and demythologise depression", by making "my version of the story part of the permanent record" (2002: 753). Chatham-Carpenter (2010) wondered what impression of herself as a college professor she would give if she were open about her ongoing struggles with anorexia in her autoethnography. Controlling the 'face' that she presented in relation to her anorexia became tied up with how she managed her presentation as a researcher and professional.

There is, then, the question of whether the potential stigma of anorexia, or specific details of my experiences (such as having been sectioned), may have lasting implications for my academic career. Anorexia is a *potentially* stigmatising diagnosis; stigma is relational, emerging out of social interaction (Goffman, 1963), and therefore shifts depending on context. Research suggests that in treatment settings, anorexia is experienced as a stigmatised identity due to its reductive construction as a pathologised, medicalised condition, and that this can lead individuals to feel misunderstood, isolated, invalidated or stereotyped (Boughtwood and Halse, 2009; Eli, 2014; Malson *et al.*, 2004; Rich, 2006). Rance *et al.* (2017) note that women with anorexia are often perceived negatively in wider society as well as in treatment contexts. Indeed, research suggests that the general public hold stigmatising attitudes towards anorexia (Crisp, 2005; Stewart *et al.*, 2008). Individuals with eating disorders are viewed negatively due to beliefs that these conditions are self-inflicted, and anorexia in particular is often trivialised (Crisp, 2005). Further, as alluded to above, individuals with anorexia describe perceiving general others as misunderstanding anorexia and holding stereotypical, stigmatising and simplistic views (Dimitrilous *et al.*, 2016; Rance *et al.*, 2017).

I can remember well how it felt while in treatment to be positioned as pathological, incapable, irrational and childlike. As previously discussed, the academic (as opposed to medical) lens through which my experience of anorexia will be 'read' *feels* as though it would at least mostly avoid this positioning. Importantly, I am writing about my experiences of anorexia and treatment in retrospect as someone who can claim to be 'recovered', and this feels far less problematic (in terms of feeling exposed and risking stigma) than writing about current struggles. Nonetheless, I have questioned the possible future professional implications that may result from me exposing details of my experiences, especially my apparently 'irrational' and 'extreme' behaviour while in the midst of food restriction and in treatment, and the more 'severe' aspects of my treatment. Unlike Jago, I would not say that potentially stigmatising aspects of my experiences are the 'best' reason for publishing an autoethnography, but I would say that they are not a reason to avoid doing so. Also, the potential benefits of my autoethnography (gaining valuable insight into my research questions and producing a meaningful thesis) seem to me to outweigh the risk of select others holding negative judgements about me, and the even smaller risk that these judgements would then have direct implications for my career.

Conclusion

Undertaking my PhD has felt like a continuous moving in-and-out of being an insider and an outsider, of sharing commonalities and feeling 'other'. As a doctoral student, I occupy a space somewhere *in between* a student and researcher. I have a shared identity with other PhD students in my cohort by nature of our common educational experience, but feel different to them due to the overtly personal nature of my research. With regard to my interviewees, I shared with them a significant experience which (I felt) 'bought us together' and facilitated the interviews. However, our experiences were also diverse, and we were differentiated by our respective roles as 'researcher' and 'researched'. In my part-time work as a lecturer, I present and draw on different aspects of my self (as an academic researcher, teacher and 'ex-service user') in a myriad of ways, but do not feel as though I belong wholly or properly in each of these categories.

I imagine that most doctoral students experience some extent of difficulties around justifying and explaining their research, managing their academic identity and keeping themselves 'well' during their PhD. However, autoethnography brings its own, specific challenges, which can shape the doctoral experience significantly. This is in part due to autoethnography being a relatively new and contested method, and it also derives from the ways in which the personal and professional intertwine in autoethnography. This adds additional layers of complexity in terms of establishing oneself as a potential academic, during a process which can already feel very tentative and unknown.

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4. Mental Wellbeing in Higher Education: a pedagogical perspective and manifesto

Abby Shovlin

Introduction

With recent research indicating a notable decline in levels of student wellbeing (Thorley, 2017), and higher levels of mental illness and low wellbeing among students in relation to the UK general population (Neves and Hillman, 2017), student mental health has become an area of growing concern for the Higher Education sector. In response, Universities UK's (2017) S*tep Change Mental Health in Higher Education* framework and the Institute for Public Policy Research report *Not by degrees* (Thorley, 2017) both stress the importance of developing a 'whole-university' approach to student mental health. This whole-university response is defined by Universities UK (2017) as a "population approach to student mental health [which] asks universities to reconfigure themselves as health-promoting and supportive environments". It is clear that a whole-university response involves all staff, but as recent research has highlighted, an academic's role in a "health-promoting and supportive environment" remains less clear (Hughes *et al.*, 2018). This chapter acknowledges this current lack of clarity and, by way of response, aims to present a clearly delineated pedagogical perspective on student mental wellbeing. In order to do so, it will outline current concerns surrounding an educator's role in student mental health before presenting a self-determination theory (Ryan and Deci, 2017) informed approach to mental wellbeing supportive pedagogical practice and curriculum design.

Mental wellbeing in and through the curriculum: a contested area

Firstly, it is important to acknowledge that many elements of this debate predate current drives to embed mental wellbeing in the curriculum (Houghton and Anderson, 2017). Concerns that a pedagogical focus on mental wellbeing will blur boundaries between education and therapy and/or pose a risk to academic standards are not new. Both of these concerns featured in Ecclestone and Hayes' (2009) argument against what they termed *the therapeutic turn* in *The Dangerous Rise of Therapeutic Education*. According to Ecclestone and Hayes (2009), educational practice was increasingly affording the affective precedence over the academic, which they saw as "therapeutic" and "profoundly anti-educational" (Ecclestone and Hayes, 2009: xiii). Moreover, Eccleston and Hayes (2009) not only argued against this 'therapeutic turn' on academic grounds, they also criticised it for creating what they described as "the diminished self" (Ecclestone and Hayes, 2009: xi). This diminished self, as Eccleston and Hayes (2009) explained, was the product of therapeutic education's emphasis on students' "emotional needs" and "perceived emotional vulnerability" which resulted in an "emotionally diminished human subject" and promoted "a life focused on the self and self-fulfilment rather than with understanding and changing the world"(Ecclestone and Hayes, 2009: ix & 164). Whilst it is beyond the scope of this chapter to provide a critique of *The Dangerous Rise of Therapeutic Education* in its entirety, it is necessary to address and respond to the authors' key points and ideas, including that of 'the diminished self'. As this chapter will demonstrate, taking student needs into account is a requisite part of mental wellbeing supportive pedagogies, and this in no way leads to the creation of a diminished self. Instead, mental wellbeing supportive curricula (see Houghton and Anderson, 2017) arguably facilitate the creation of a self that is limitless in its capacity for personal and academic growth.

Secondly, in addition to acknowledging this pre-existing educational debate, the concern that mental wellbeing is the domain of mental health professionals and not educators must also be addressed. A recent qualitative study (Hughes *et al.,* 2018) which interviewed 52 staff across 5 universities has indicated that this concern is of particular pertinence to those staff who have a remit for personal tutoring. Whilst it is generally accepted that a personal tutor role includes an element of pastoral care, Hughes *et al.'s,* (2018) study highlights that lack of clarity around the meaning of pastoral care results in "uneven responses for students, uncertainty for staff and unequal levels of accepted responsibility for student mental health" (Hughes *et al.,* 2018: 5). Hughes *et al.,* (2018) therefore emphasise the need to adequately address this ambiguity as it can "lead to weak and uncertain boundaries and increased risk to students, staff and universities"(Hughes *et al.,* 2018: 5). Whilst the focus of this chapter is teaching and curriculum design and not the role of the personal tutor, it acknowledges the importance of clearly delineated boundaries between roles. In this way, it presents a case for mental wellbeing supportive practice within the pedagogical domain and by doing so, seeks to facilitate a clear delineation of the boundary between the roles of mental health professionals and educators.

Thirdly, but no less importantly, is the concern that a mental wellbeing supportive curriculum is unfeasible because of curricular time restraints and increasing staff workloads. This is a relatable concern for all teaching staff; time is both in short supply and high demand. Time therefore, is a concern that any curricular initiative needs to take seriously and address effectively. However, as this chapter will demonstrate, mental wellbeing supportive pedagogies are not an added extra but can instead be woven into everyday teaching practices and are therefore not necessarily time intensive enhancements.

Self-determination theory and basic psychological needs

Self-determination theory focuses on understanding and supporting human development, growth and motivation and was developed by researchers and clinicians Richard Ryan and Edward Deci in 1985 (Ryan and Deci, 2017). Since its inception, a large corpus of empirical evidence has been produced on its efficacy and application in a wide variety of fields, including education (Ryan and Deci, 2017; Vansteenkiste and Ryan, 2013; Niemiec and Ryan, 2009; Ryan, 2009). Organismic theories, such as this one, operate from the tenet that humans have an inherent capacity for growth which can either be supported or hindered by their environments. More specifically, self-determination theory is "centrally concerned with the social conditions that facilitate human flourishing [and] examines how biological, social and cultural conditions either enhance or undermine the inherent human capacities for psychological growth, engagement and wellness" (Ryan and Deci, 2017: 3). Self-determination theory is macro in nature as it is composed of six mini-theories: cognitive evaluation theory, organismic integration theory, causality orientations theory, goal contents theory, relationships motivation theory and basic psychological needs theory (Ryan and Deci, 2017). It is the latter mini theory of Basic Psychological Needs and its application in the field of education that this chapter will specifically focus on.

According to Ryan and Deci (2017), autonomy, relatedness and competence are universal human basic psychological needs, and their theory posits that environments which support these needs provide the psychological nutriments that are a prerequisite of wellbeing. Conversely, environments in which these needs are thwarted frustrate an individual's inherent propensity towards self-organisation, growth and flourishing and are associated with a variety of "ill-being indicators" including emotional exhaustion, anxiety, aggression and increases in levels of immunological proteins in the body associated with stress (Ryan and Deci, 2017; Vansteenkiste and Ryan, 2013: 268-269) Before mapping basic psychological needs onto a pedagogical context, it is important to define and describe each of these three constituent elements of autonomy, competence and relatedness in turn.

Firstly, when defining autonomy, it must be highlighted that the autonomy of basic psychological needs is not to be misunderstood as an assertion that an individual always requires choice in and control of every element in their environment. Instead, the autonomy of basic psychological needs is concerned with an individual being able to align their actions and choices with their values through "the experience of volition and the self-endorsement of one's activity" (Vansteenkiste and Ryan, 2013: 264). In this way, self-determination theory research highlights the key role that autonomy plays in supporting intrinsic motivation, demonstrating that "the more autonomous the person's motivation, the greater their persistence, performance and wellbeing in that domain" (Ryan, 2009: 2). In the domain of undergraduate education, research has indicated that intrinsic motivation is also linked to psychological wellbeing (Burton *et al.*, 2006). Burton *et al.'s* (2006) study, which investigated the relationships between undergraduate students' intrinsic motivation, psychological wellbeing and academic achievement, found a significant association between intrinsic motivation and psychological wellbeing, independent of academic achievement (Burton *et al.*, 2006).

The second element of Basic Psychological Needs theory, *relatedness,* describes an individual's need to experience a sense of belonging and feel part of a community. Ryan and Deci describe relatedness as "feeling socially connected and significant among others" (Ryan and Deci, 2017: 11).When describing this basic psychological need in workshops, I highlight that relatedness also includes a sense of *"mattering"* (Schlossberg, 1989). *"Mattering"* as Schlossberg identified, plays a key role in successful transitions into a new environment. Her research on transitions pre-dates the recent focus on transitions in Higher Education (Thomas, 2013), but continues to bear relevance and provide insight. In this way, her observation that "institutions that focus on mattering and greater student involvement will be more successful in creating campuses where students are motivated to learn" (Schlossberg, 1989: 7) is now recognised as good practice in transitions at sector level (Stuart, 2008; Thomas, 2013). However, as this chapter will demonstrate, students' sense of belonging and mattering is strengthened if relatedness is not only a focus of inductions and transitions, but is also woven into course design and everyday classroom interactions.

The third basic psychological need, *competence,* is noted by Ryan and Deci (2017: 11) as a fundamental element of motivated actions as it supports the satisfaction of an individual's basic need to have an element of control over their environment (effectance) and independently accomplish moderately challenging tasks within it (mastery). More specifically, in the context of Higher Education, competence is described as "the experience of being good or effective at what one does, or the belief that one can become so" (Baik *et al.,* 2016a). Becoming good or effective at learning, studying, coursework, and assessment in Higher Education has traditionally been seen as the focus of 'study skills' centres within universities. In order to support students' academic development in these areas, many academic skills centres offer students 1:2:1 support in addition to a wide range of resources on study management. Whilst this competence supportive provision is helpful to those students who make use of it, in my own experience, academic skills development is not universally embedded in the curriculum and thus only a percentage of students benefit from it. Additionally, this *"add on"* approach to students' academic skills development can operate as a *"deficit model"* in which the students themselves are seen as *"lacking"* (Wingate, 2006; Lea and Street, 2006). Alternate approaches to developing students' sense of competence, such as academic literacies (Lea and Street 2006), focus not on *"fixing"* students, but on pedagogy and course design as a vehicle for the academic skills development of all students (Drummond *et al.*, 1999). This chapter contends that the basic psychological need of competence in a Higher Education context is fully supported through a combination of academic skills development within the curriculum and the provision of study skills services rather through the latter alone.

Thought experiment

Before mapping each basic psychological need onto a learning and teaching context, I would first like to invite you to experience the theory in action by way of a thought experiment. Whilst a thought experiment cannot count as robust empirical evidence, it does provide us with a valuable opportunity to test the efficacy of the theory in relation to our own experiences[1]. Interestingly, in addition to the large literature base on the validity and application of self determination theory, Ryan and Deci (2017) point out that "we can also see natural experiments everywhere in which promising human potentials are diminished by impoverished or oppressive social conditions" (Ryan and Deci, 2017: 4). In this short experiment, I am going to ask you to think about work.

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[1] For a detailed meta-analytic review of self-determination theory in the workplace research, see Broeck, A. and Rosen, C. (2016) 'A Review of Self-Determination Theory's Basic Psychological Needs at Work'. *Journal of Management* 42 (5): 1195-1229.

From my own experience of running workshops for staff this is often an unexpected question to ask in a session on curricular design; however, it is an illuminating one. The instructions I give to workshop participants are as follows:

> *Think of a working environment that you are part of/have been part of. Try to think of one positive and one negative work environment.*
>
> *How was your sense of autonomy, competence and relatedness supported/thwarted in each environment? How was your mental wellbeing in each environment?*

This pause for thought and reflection allows staff to think about the factors and conditions which have and have not supported their own sense of mental wellbeing in working environments they have experienced. It is useful to have identified tangible personal examples of what can support or thwart autonomy, relatedness and competency before applying the lens of basic psychological needs theory to the working environments that we create for ourselves and our students in Higher Education.

Mapping Basic Psychological Needs to pedagogy and curriculum design: what works?

As indicated previously, there is an evident synergy between psychological needs satisfaction, and good practice in learning and teaching in Higher Education such as enhanced academic transitions (Thomas, 2013) and academic literacies development (Lea and Street, 2006). Filak and Sheldon (2003) have also demonstrated a significant association between basic psychological needs supportive practice and students' evaluation of their teachers in a study of undergraduate students. This study examined the relationship between students' psychological needs satisfaction and "instructor evaluation" in two undergraduate programmes (with 268 and 179 participants, respectively) and, in both programmes, needs satisfaction "positively predicted instructor and/or course ratings" (Filak & Sheldon, 2003: 244).

However, pedagogical practice informed by basic psychological needs provides a theoretical and empirical framework not only for enhancing learning, but also for supporting students' mental wellbeing. In this way, recent case studies and research on basic psychological needs supportive pedagogies and curriculum design describe a positive impact on both learning and mental wellbeing (Baik *et al.,* 2016b; Field *et al.,* 2014; Slavin et al. 2014). The following summary, informed by the case studies in Baik et al.'s (2016b) *Enhancing Student Mental Wellbeing: A Handbook for Academic Educators* and current Higher Education good practice, provides concrete examples of how pedagogy and curriculum design can support students' sense of autonomy, competence and relatedness and, in turn, their mental wellbeing:

> *Autonomy*
> Providing students with a choice in assessment method; involving students as partners in course design through student representation in curriculum approval processes; incorporating space in the curriculum for students to share their experience and perspectives; goal setting with students to help build their intrinsic and autonomous motivation which in turn facilitates engagement (this tasks fit well with the remit of personal tutors); and the provision of meaningful rationale for non-choice elements in programmes.
>
> *Competence*
> Providing students with early formative feedback; embedding contextualised academic skills within programmes; not making assumptions about students' current knowledge/academic skills set; promoting growth mindsets and sharing our own stories of 'failure'; introducing challenge such as problem based learning or interdisciplinary projects in a supported environment early on not only in the final years of an undergraduate programme; design-

ing programmes that gradually increase in complexity with each stage of learning thus providing a solid foundation for the next stage.

Relatedness
Promoting peer support and peer mentoring schemes; incorporating group and pair work (such as think/pair/share) in lectures; providing open space and/or offering drop ins; running initiatives and projects in which staff and students work together; extending (or developing) academic community building initiatives to online students; replacing Welcome Week talks with enhanced inductions that engage students in activities or tasks.

As the above summary suggests, there is an element of overlap between basic psychological needs supportive practice and good teaching. However, this chapter supports Baik *et al.'s* (2016a) assertion that good teaching is a necessary but not sufficient element of mental wellbeing supportive pedagogies. These pedagogies are more than 'good teaching' as the former require knowledge of i) the psychological nutriments for human flourishing and ii) how to translate this knowledge into pedagogical practice, course design and everyday interactions with students.

Addressing objections

After presenting a case in support of basic psychological needs supportive pedagogy, this chapter will now turn to addressing the three areas of concern it outlined at the outset. Firstly, in response to Ecclestone and Hayes' (2009: xiii) claim that affording importance to the affective in education is "anti-educational", it would seem appropriate to highlight how pedagogies informed by basic psychological needs support students' academic development and ability to engage with complexity and abstraction. As the summary of good practice illustrated, basic psychological needs informed practice emphasises the need to support students' sense of competence through curricular design. This competence supportive curricular design introduces elements of academic complexity gradually through building in opportunities for students to experience and grapple with challenge and uncertainty in a supported environment early on in their studies. Recent research (Shovlin and Docherty, 2017) has indicated that without the introduction of these elements in a supportive environment in first and second year, students can find the transition to higher levels of learning in third and fourth year of undergraduate programmes to be troubling. The third and fourth years of an undergraduate programme generally require students to engage with higher levels of complexity more autonomously which can, as one student described, be an entirely new experience:

> *in the second year a lot of what you could do is just study at the last minute, pick up the notes and learn. Whereas in third year you've reached the stage where it's like 'Oh, I can't do that anymore!' it isn't just a case of reading the notes and turning up on the day… So, I think third year required a lot more understanding of the material rather than just being able to learn it by rote almost . . . and now I have to sit and think through the material and almost be able to teach myself in it.* (Shovlin and Docherty, 201: 85)

In a similar way, staff in this small-scale, qualitative study also commented on the unhelpful 'gap' between second year and third year and suggested how it could be remedied:

> *I think having students work more with a little bit more of the abstract stuff in the earlier classes for a little bit and then you know, they get used to sort of working this way over a time period… I just think it takes a long time to develop and it's not something you can quickly do.* (Shovlin and Docherty, 201: 88)

All of the teaching staff interviewed in this study echoed the comment above with one member of staff suggesting that "by leaving the introduction of these elements [of abstraction and complexity] to Honours years, we are doing our students a disservice" Shovlin and Docherty, 2017: 89).

It is important to point out that although the fourth-year students in this study had not been able to benefit from it, the School has recently developed a new first-year course on 'Proofs and Problem Solving'. This first-year course supports students' basic psychological need for competence as it introduces first-year students to elements of challenge, abstraction and complexity in a supportive and 'lower stakes' environment. Feedback on the new course has been overwhelmingly positive with students informing staff that "this course is really hard, and I loved it" (Shovlin and Docherty: 87). This approach to course design serves to illustrate that basic psychological needs informed pedagogies foster students' capacity to engage with academic complexity and therefore provide the opposite of the "anti-educational" experience that Ecclestone and Hayes (2009: xiii) predicted as a consequence of the therapeutic turn.

Secondly, in response to the concern that a curricular focus on mental wellbeing will blur the boundaries of an academic's role, this chapter has demonstrated that building curricula that support mental wellbeing does not require educators to operate outside of their academic remit. Therefore, instead of blurring boundaries between teaching, student support and mental health services, basic psychological needs informed educational practice clearly delineates pedagogical and curricular approaches which teaching staff can employ to support mental wellbeing. This approach to mental wellbeing in and through the curriculum focuses on how educators can build positive learning environments for themselves and their students and it does not require educators to provide mental wellbeing support that they are not trained for and feel uncomfortable with. It does, however, ask educators to think deeply about the learning experiences they create and how the academic environment can support or thwart both student learning and mental wellbeing.

The pedagogical position this chapter espouses is perhaps best illustrated by revisiting the classic educational debate of teaching subjects vs. teaching students (Moje, 1986). Ecclestone and Hayes' (2009) argument clearly gives precedence to the former as they claim that "knowledge can be taught passionately or indifferently by and to people who may be distraught, upset, happy. It does not matter. Knowledge, as it were, conquers all. What we are teaching is not touched by the emotions" (Ecclestone and Hayes, 2009: 153). The knowledge-centric pedagogy that Ecclestone and Hayes (2009) describe is one that this chapter strongly contests on the grounds of both student learning and mental wellbeing. If we accept Eccleston and Hayes' (2009) proposition, then it would appear that the infamously knowledge-centric classroom of Dickens' Thomas Gradgrind in *Hard Times* meets the necessary conditions to qualify as education:

> *Thomas Gradgrind, sir. A man of realities. A man of facts and calculations. A man who proceeds upon the principle that two and two are four, and nothing over. Thomas Gradgrind now presented Thomas Gradgrind to the little pitchers before him, who were to be filled so full of facts.*
> *'Girl number twenty,' said Mr Gradgrind, squarely pointing with his square forefinger, 'I don't know that girl. Who is that girl?'*
> *'Sissy Jupe, sir,' explained number twenty, blushing, standing up, and curtseying.*
> *'Sissy is not a name,' said Mr Gradgrind. 'Don't call yourself Sissy. Call yourself Cecilia.'*
> *'Let me see. What is your father?'*
> *'He belongs to the horse-riding, if you please, sir.'*
> *'Very well, then. Give me your definition of a horse.'*
> *'Girl number twenty unable to define a horse!' said Mr Gradgrind, for the general behoof of all the little pitchers. 'Girl number twenty possessed of no facts, in reference to one of the commonest of animals! Some boy's definition of a horse. Bitzer, yours.'*

> *'Quadruped. Graminivorous. Forty teeth, namely twenty-four grinders, four eye-teeth, and twelve incisive. Sheds coat in the spring; in marshy countries, sheds hoofs, too. Hoofs hard, but requiring to be shod with iron. Age known by marks in mouth.' 'Now girl number twenty,' said Mr Gradgrind. 'You know what a horse is.'*
> *She curtseyed again, and would have blushed deeper, if she could have blushed deeper than she had blushed all this time […] She was very young, and she looked as if she were frightened by the matter-of-fact prospect the world afforded'.* (Dickens, 1995: 4-6).

Sissy Jupe, might now 'know' what a horse is, but the state of fear that she is in by the end of this passage is arguably conducive neither to deep and effective learning nor mental wellbeing. Evidently, it would be unreasonable to infer that Eccleston and Hayes' (2009) argument explicitly supports a Gradgrindian approach to education. However, it is equally important to highlight that their 'knowledge conquers all' definition does not include the qualities that would automatically rule this classroom experience out as 'anti-educational'. Moreover, their assertion that knowledge "can be taught to people who may be distraught and upset" (Eccleston and Hayes, 2009: 153) is called into question by basic psychological needs theory's large corpus of empirical evidence on the detrimental effects of needs thwarting environments (Ryan and Deci, 2017; Vansteenkiste and Ryan, 2013)

This chapter therefore supports Wright's (2014) assertion that Ecclestone and Hayes' argument is based on "a false dichotomy that separates rationality and emotion" (Wright, 2014: 145) as we teach both subjects and students. Laurence Krieger's (2008) extensive work on humanising the legal education curriculum operates from a students and subjects perspective as he reminds educators that "human nature [must] be a primary guiding philosophy for our educational responsibilities . . . as human nature is the primary resource with which educators inevitably work" (Krieger, 2008: 248). As this chapter has demonstrated, basic psychological needs theory provides us with knowledge of the environments in which humans feel well and therefore features as a key component of educational practice that seeks to support both mental wellbeing and learning (Field *et al.,* 2014; Larcombe *et al*., 2015).

Thirdly, the last objection to be addressed is that of time constraints. As this chapter has argued throughout, basic psychological needs supportive curricula and pedagogies are fundamental to both effective learning and mental wellbeing and not 'added extras'. As a corollary, this type of practice is also not an extra in terms of time demands. Instead, as this chapter has shown, basic psychological needs informed practice can be incorporated into simple actions which can be woven into everyday teaching and interaction with students. Evidently larger scale initiatives such as embedding academic skills development into programme design are more time intensive, but as recent case studies from Australia demonstrates (Baik *et al.,* 2016b), mental wellbeing can be supported in our teaching and course design in simple yet impactful ways.

Conclusion and manifesto

In conclusion, this chapter contends that a pedagogical and curricular focus on mental wellbeing is a requisite element of an effective whole-institution response to mental health. Whilst it is essential to continue to focus on strengthening and developing extra-curricular mental wellbeing activities and initiatives, this chapter argues that an institution's wellbeing strategy is limited if it fails to consider the ways in which the curriculum and pedagogies can either support or thwart students' mental wellbeing. As illustrated throughout, Ryan and Deci's (2017) Basic Psychological Needs theory provides a practical framework that educators can use to design curricula which can not only enhance learning, but also foster students' sense of autonomy, relatedness and competence, which in turn supports student mental wellbeing. The premise of this chapter's argument is simple: students learn better and feel better in classroom environments which foster belonging, competence and autonomous motivation. However, implementation of this vison at both an institutional and sector level in the UK is far from simple, as this calls for a fundamental shift in the way we conceptualise and provide support for teaching in Higher Education. Hence, the following seven point manifesto:

1. A whole university approach to student mental wellbeing includes pedagogical practice and curriculum design.
2. Universities have a responsibility to create working and learning environments which support, not thwart, staff and student mental wellbeing.
3. Curriculum and pedagogies can be designed to develop students' sense of autonomy, relatedness and competence, which in turn supports mental wellbeing. Conversely learning and teaching which does not consider these basic psychological needs is a missed opportunity to support student wellbeing and may even inadvertently undermine it.
4. Professional mental health support does not fall within the remit of the educator, but student mental wellbeing, supportive pedagogical practice, and curriculum design are not.
5. Learning contains both cognitive and affective elements and including a focus on the latter is not 'anti-educational' but a pre-requisite of pedagogical practice that supports both student learning and mental wellbeing.
6. As we teach both subjects and students, professional education for university teachers needs to equip them with the necessary skills and knowledge to address the needs of both subject teaching and learners by includ-

ing courses on the psychology of learning and mental wellbeing supportive pedagogical practice, and curriculum design.

7. If the Higher Education sector is to demonstrate a commitment to excellence in teaching, then it should consider bringing the professional education of university lecturers in line with that of teachers in others sectors of education by making some level of training for university educators compulsory

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5. Learning To Listen To Your Own Health And Wellbeing

Peter J. Martin and Edward M. Holt

Introduction

> *People know how to learn, they did it from birth until they went to school. It's a question of helping them remember how to do it. We need to help people have confidence in their perceptions and how to question their interpretation of reality, within a framework of competence.* (Hase and Kenyon, 2001:7)

Most people will have some form of lived experience of compassion either as the recipient of compassion or as the giver; but when we subject compassion to scrutiny in a classroom we render it a dry topic to be learned and risk losing its human dimension. We risk also losing a sense of the effort required to show compassion and the resilience needed to do so day-after-day in a stressful, under-resourced, healthcare environment.

It would seem self-evident that people in need of health and social care should receive it from compassionate professionals who are able to manage their own stress. However, this did not reflect the environment reported on by Robert Francis at the Mid-Staffordshire Health Trust in the United Kingdom (UK), leading to his assertion:

> *Improved support for compassionate caring and committed nursing: proper standards of nursing care lie at the heart of what is required to protect patients when in hospital. The majority of nurses are compas-*

> *sionate, caring and committed. They should be given effective support and recognition, and be empowered to use these qualities to maintain standards.* (Francis, 2015:7)

In citing Francis we are not seeking to align ourselves with the abundance of literature which exhorts nurses to be *'more compassionate'*. Rather, the lack of compassion seems to us to be symptomatic of a lack of resilience; an inability to maintain a compassionate stance towards those in need when faced with poorly contained anxiety and increasing workloads.

> *What made nurses at Mid-Staffordshire – or indeed any other hospital – change from being caring individuals with a vocation to help patients, to individuals who showed such an utter lack of compassion? Could it be that relentless demands, lack of appreciation for their efforts, an intolerable push for process, procedure, cost-savings, the desperate lack of staff and support simply drained the capacity of those nurses to respond with care and humanity?* (Haslam, 2015, n.p.)

This chapter outlines a teaching strategy developed specifically to enhance compassion in care and build resilience among mental health nursing students. The chapter will describe the problem with reference to contemporary research on the subject; this will be followed by an outline of the components of the strategy with exemplars from our own teaching experience.

We argue that if we, as teachers, can create a safe space in which students can share their experiences of compassionate care, then we can begin to acknowledge our unique responses to what we experience. In doing so, we can begin to recognise (without prejudice) our own strengths and weaknesses in order that we can build unique resilience strategies that will improve our health and wellbeing.

Context

The primary focus of the School of Health and Social Care at the University of Essex, which provides the context for this chapter, is in the delivery of pre-qualifying education to health and social care students. As such, the provision is externally scrutinised and validated by regulatory agencies as well as being monitored internally for academic quality.

For the past three years we have delivered a module within the University of Essex Nursing Programme entitled 'Delivering Compassionate Care as a Mental Health Nurse'. The module is delivered simultaneously on the School's two campuses at Colchester and Southend with Peter leading the module at Colchester and Edward at Southend.

This module was specifically designed in 2016; it was a response to what we saw as a growing number of our students who completed the mental health nursing programme and either became quickly disillusioned with mental health nursing or negatively affected by the stresses that being a mental health nurse in contemporary services can engender. It is one of the first modules studied and is underpinned by our belief that students, first and foremost, must be cognisant of their own health and wellbeing before they can begin to understand and work with those in mental distress.

In designing the module we decided that we should not 'sugar coat' the stresses that students would be required to manage both as student and future mental health nurse; it was important to us to offer a realistic view of working as a mental health nurse in the 21st century.

The problem

Anecdotally we were aware from our own experience, from research (e.g. Freeburn and Sinclair, 2009) and vicariously (from listening to our students), that working as a mental health nurse is challenging. The mental health nurse must balance the demands of people with whom they are working, the employing organisation and the UK regulatory body for nursing – the Nursing and Midwifery Council (NMC). Alongside this task, they must also listen to their own 'moral compass' and act in a manner consistent with their own beliefs.

The term 'emotional labour' (Hochschild 1983) implies that, to carry out people-facing jobs, the agent must present an acceptable public face; a face that may not reflect the underlying emotional state. So, we may be working with someone who is acutely disturbed and verbally abusive but, as a nurse, we must present a professional face in order to manage the situation despite (potentially) experiencing fear for our own safety or being personally offended.

In order to manage such situations we need to be resilient. Over the last decade building resilience and an awareness of personal wellbeing has become embedded in the nursing curriculum.

> *Mental health nurses must have and value an awareness of their own mental health and wellbeing. They must also engage in reflection and supervision to explore the emotional impact on self of working in mental health; how personal values, beliefs and emotions impact on practice, and how their own practice aligns with mental health legislation, policy and values-based frameworks.* (NMC, 2010 n.p.)
>
> *Approved education institutions, together with practice learning partners, must ensure that all students: […] are provided with information and support which encourages them to take responsibility for their own mental and physical health and wellbeing.* (NMC, 2018 n.p.)

The significance of including resilience in nursing curricula reflects the growing awareness of the potential harm that unmanaged stress and poor resilience can cause to nurses in the pursuance of delivering compassionate care.

In mental health nurse education stress amongst the student population has been reported on numerous occasions (e.g. Galvin *et al*., 2015; Jones and Johnston, 2000). Freeburn and Sinclair (2009: 341) report that the stress experienced during mental health nurse training can, on occasions, have "… significant negative effects on health and wellbeing and on their personal and professional development".

Tully (2004) used a questionnaire to explore the experiences of thirty-five psychiatric/mental health nursing students in Ireland. Comparable with other studies, student stress levels were found to increase through training. The study offers a number of insights into the degree and the sources of stress. Notably, however, students reporting higher levels of stress used coping mechanisms such as wishing things were better, drinking, smoking, medication and comfort eating. Those reporting lower stress levels employed strategies which built resilience such as talking to others, actively seeking help and seeking to change the stressful situation. Similar findings were reported in Jackson *et al.*'s (2007) literature review on resilience in nursing.

Turner and McCarthy (2017) undertook a review of the literature (2009 to 2015) with regard to intervention strategies employed to reduce stress and anxiety among nursing students. The authors identified twenty-six articles which they grouped into three areas (1) those reducing the number or intensity of the stressors (2) those focused on coping responses and (3) those which sought to reappraise the stressors. None of the studies were described by Turner and McCarthy (2017) as having strong methodological rigor and, they argued that, controlled trials were needed to gain a more precise understanding of the issues.

McAllister and McKinnon (2009), writing in an Australian context, reviewed literature in relation to resilience in nurse education. The paper lays out the importance of delivering an organised and visible preparation for resilience for students. Three strategies are outlined, which seem to help students build sustainable frameworks: identity building work; coping, capacity and strengths development; and learning leadership for change.

In the context of Higher Education institutions and students in general, Grant and Kinman's (2013) paper on developing emotional resilience within the curriculum outlines the competencies that tutors should attempt to instil in our students. They present the competencies that underpin an 'emotional curriculum' and suggest that educators should:

1. Enhance students reflective ability
2. Develop effective mentoring and peer coaching systems to enhance support
3. Encourage the use of mindfulness
4. Develop in students' greater awareness of experiential learning.

Such competencies, Grant and Kinman (2013) argue, are important to enhancing resilience in students training for the helping professions.

Heutagogy, the study of self-determined learning (Hase and Kenyon, 2000), has been explored by Canning and Callan (2010) who note that the development of emotional literacy is essential if students are to use past learning to influence current and future learning. This is a challenge particular to mature learners who:

- *Lack confidence in ability across a range of study skills;*
- *have had little encouragement to have high academic or career expectations;*
- *mature students often torn between competing priorities for study and daily life;*
- *feel unsupported by peers in the workplace;*
- *have a negative self-image which is reinforced by lack of status, pay and recognition in the workforce.* (Canning and Callan, 2010: 76)

Our students closely match these characteristics being, predominantly, mature and often coming into higher education from non-traditional routes.

The literature suggests that stress is an unavoidable aspect of being a mental health nurse. If students are not taught strategies to manage stress, their health and wellbeing are at risk. Furthermore, they are unlikely to remain in mental health nursing which will further exacerbate the current nursing staff shortages in the NHS. Heutagogy may provide a structure to enhance resilience. Consequently, we now explore how we facilitate the development of resilience through the Compassionate Care module.

Creating the safe space

> *Developing Heutagogy meant creating a self-directed learning environment for students to discover their own strategies for learning. It consisted of building confidence to actively participate to share their knowledge.* (Canning, 2010: 59)

At the outset our purpose in designing and delivering the Compassionate Care module was to create, within the constraints, a self-determined learning space where students could take ownership of their learning. Brookfield (2103) describes this as ‘a process of democratisation of the classroom’ and argues that the learning space is divided into thirds: teacher controlled third; student controlled third; and teacher and student negotiated third.

As teachers in a Higher Education institution, we were cognisant of our responsibilities in delivering a part of the curriculum in a safe, effective and efficient manner (teacher third). At the same time, we wanted each student to reflect upon their experience of compassion and of being resilient, taking control of their own learning (student third). This space had to allow students to openly examine assumptions associated with their own culture, beliefs and past experience in relation to compassionate care and resilience (negotiated third).

Treating the student cohort as a 'group' we co-constructed ground rules by which we would work together over the duration of the module. These ground rules were not static and were revisited throughout the module to keep them current as this random collection of people (the cohort) developed into a working group with all the shifting power dynamics that inevitably ensues.

The module begins with an examination of 'Who am I?'. Leading by example, we (the authors) talked frankly about our backgrounds, critically examining our own strengths and weaknesses – our assumption being that, if we were to make a difference within the relatively short time available within the module, there could be no room for 'masks', as students must recognise that there is strength in acknowledging one's own deficiencies.

A second thread of the first week is examining what causes individuals to experience disgust. This purposeful activity concerned our need to help students to experience what Hochschild (1983) described as 'surface' and 'deep acting'. Our experience is that students begin from a highly defended position "It is my job, I am not there to be disgusted or upset, I am there to do my job". As tutors we facilitate discussion on disgust until students feel able to openly acknowledge that handling a 'malodorous bowel movement' or a 'vibrant green sputum sample' is certainly part of the job, but is also something which many may find disgusting even though professionally this may not be displayed facially. Through this experience students begin to understand, in practical terms, 'surface' and 'deep' acting in emotional labour; perhaps, most importantly, they also learn that emotional labour is as exhausting as any other part of nursing work.

Compassion stories

Sharing our experiences of compassionate care

The recounting of individual compassion stories is fundamental to the teaching of the module. It is through these stories that students begin to take control of the learning space.

In week one, leading by example, the session is tutor-led; thereafter, students volunteer to lead sessions by telling their own story. Each story tells of the lived experience of compassion; such stories may be about being compassionate, receiving compassionate care or witnessing compassion. Hereafter, exemplars reflect the 'nature' of student contributions rather than the 'detail' of any single story. Students have recounted stories:

- where they have been able to intervene and offer support to someone in need
- where they have been able to prevent abuse of a vulnerable person
- where they have simply reached out in silence to hold the hand of someone in distress
- where the careful and sensitive delivery of an aspect of personal care has given someone a sense of hope.

Importantly, these are rarely stories of 'fame and glory'; they are most often stories of everyday events which would have gone unnoticed without the opportunity to share them with others – the 'taken for granted' emotional labour of nursing.

Acknowledging our unique responses to our experiences

In the student-led sessions it is up to the student how they tell their story and how they manage the ensuing discussion. The role of the tutor is to help the student group as a whole to appreciate that, whilst each story is unique, each is underpinned by principles which can be understood through theory and research. For example:

- When a student talked of sitting holding the hand of an elderly person, in terminal stages of illness, and just being silent – we might explore this through the concept of 'silent immersion' (Parse, 1998).
- When a student talked of trying to ascertain from a terrified person experiencing auditory hallucinations what they could do to make it less terrifying – we might explore this through Barker's Personal Security Plan (Barker and Buchannan-Barker, 2005: 95).
- When a student talked of a felt need to help a young person who was self-harming because they understood, having been there themselves – we might explore this through the concept of 'wounded healer' (Nouwen, 1994).

It would, perhaps, be easier to move to a more teacher--centred approach and deliver a lecture on 'silent immersion' or 'wounded healers', but this would risk rendering the subject dry and theoretical. By bringing theoretical understanding to the lived experience of compassion we retain the human dimension, and students can experience, for example, 'silent immersion' as a live account of a lived experience.

The interpretation of each compassion story becomes a form of coaching which could be described as 'joint experimentation' (Schön, 1987). As tutors we do not know what the story will be about so we have to listen and try out ideas through clarification with the storyteller, whilst taking account of competing theoretical positions from the student group.

Through joint experimentation the group develops a sense of competence in interpreting and bringing theory to elucidate the exemplar. The freedom to explore the story offers a sense of growing autonomy in the ability to construct arguments. It also powerfully establishes relatedness between the theory and practice on mental health nursing.

The challenge of assessing compassionate care

To enable us to assess student learning, we decided that, maintaining the perspective adopted throughout the module, we would turn the assignment back onto the student. Having observed the process and developed skills in making meaning from the compassion stories, the student is tasked with making meaning from their own unique personal experience.

Selecting the right story

The assignment requires the student to reflect on a personal experience of stress and distress experienced whilst in their practice placement (hospital ward, clinic, community mental health team and so on). Students will often talk about dramatic incidents from their practice, tales of aggressive or bizarre behaviour; however assignments that discuss complexity and the reality of practice are equally powerful. The following narratives, whilst fabricated and as such rendered anonymous through pseudonyms, draw upon our experience of a number of student submissions for this module; it represents the power of such pieces of work to bring to the surface a form of existential crisis faced by many nurses.

> *Jay [a student mental health nurse] wrote about working intensively with Cal [a mental health service user] to prepare them for discharge from an in-patient unit following a psychotic episode. Jay wrote that they had been helping Cal to explore and practice ways in which they could keep themselves healthy and not resort to self-medicating with illegal substances. Cal had left the unit feeling very positive about the future and expressing gratitude to Jay for all their input.*

> *Whilst Jay was still on placement, Cal had been re-admitted with a recurrence of psychotic symptoms brought about, to some extent, by using non-prescription drugs. Jay met with their placement mentor where they were tearful and expressed dismay about what they described as the 'pointlessness of being mental health nurse'.*
>
> *Jay had a supportive mentor who helped them to reframe the situation, helping them to understand that there are limits to the role of the mental health nurse and, ultimately, Cal was an individual who was entitled to make his own decisions about his own life.*

Recognising (without prejudice) our own strengths and weaknesses

In the second part of the assignment students are asked to examine their own strengths and weaknesses in relation to the event. We ask the student to identify why they experienced emotions such as fear, disgust or sadness in response to the incident they had outlined.

This is a demanding assessment requiring students not only to analyse their own experience, but be willing to surface, and expose, their own weaknesses to 'public' scrutiny. The assignment can only work when the student feels supported and in a safe environment where they will not be adversely judged.

Building unique resilience strategies

The third part of the assignment requires students to construct an action plan for building their resilience should they be confronted with a similar situation.

The action plan may relate to practical activities such as improving sleep hygiene; it may also concern invoking relaxation or mindfulness principles when confronted with stressful situations. Both plans may be effective in helping the student to construct strategies that will help them be more resilient in their future practice; importantly, the plan is a unique strategy written by the student for the student.

Evaluation

Student ‘reaction’ to the module gauged through the Student Assessment of Module Teaching (SAMT) has been very positive. From the narrative feedback students responded to the question “What did you like best about the module”:

> *Hearing everyone share their compassion stories – the lesson were structured, but didn’t seem too planned.*
> *The module was taught in an interactive way, such as the compassionate care stories each week.*
> *How it enabled me to examine myself, my values, insights ad attitudes about many things.*
> *The module was empowering and I enjoyed every bit.*

The positive reaction of students to module teaching and their engagement with the learning style becomes evident through the quality of the assignment submissions. In our experience to date, students have presented work which is academically sound and which evidences their ability to write in an open and creative manner.

An improved state of health and wellbeing

> *Nobody escapes being wounded. We are all wounded people, whether physically, emotionally, mentally, or spiritually. The main question is not ‘How can we hide our wounds?’ so we don’t have to be embarrassed, but ‘How can we put our woundedness in the service of others?’. When our wounds cease to be a source of shame, and we become a source of healing, we have become wounded healers.* (Nouwen, 1994)

Nurses, amongst others in the caring professions, all have lived experiences which impact daily on their ability to deliver compassionate care. Many will never notice or choose to give the time to examining the complex interplay between a nurse and a patient within a caring event, described by Watson (1988) as the phenomenological field. Such endeavours may be perceived as uncomfortable, unimportant or an unaffordable indulgence.

It will require a longitudinal study to ascertain whether these students leave our HEI more equipped to manage the stresses and strains of practice; but as Jackson and colleagues note "… combating these adverse effects through minimising vulnerability and promoting resilience has the potential to impact positively on nurses' daily experience." (Jackson *et al.,* 2007: 7).

Conclusion

In 'Delivering Compassionate Care as a Mental Health Nurse' we facilitate students to better understand their own identity through critically considering their unique responses to everyday scenarios. We have argued that, through the delivery of this module, the learning space is made available for students to build their resilience and, consequently, their ability to deliver compassionate care.

Through the module assignment students develop a strategy which is unique to their own needs for resilience. Importantly, they can return to this strategy throughout the programme of study and into their future careers. We also encourage students to recognise that, by responding rationally and with resilience to stressful situations, each student becomes a leader in that environment.

As we have constructed this account of our journey in the development of 'Delivering Compassionate Care as a Mental Health Nurse', we have looked closely at the thinking that underpinned the design module. We hope that our colleagues, and readers with an interest in developing resilience and compassion, will draw from the account perspectives that may help develop their own teaching practice. Such perspectives, we believe, will help to better prepare students to deal with the stresses of working in contemporary health and social care services.

Acknowledgment

We would like to thank all the students who have studied our module over the past three years. You have shared stories of compassion that inspired the group; these were stories that challenged us to value humanity and provide the necessary theoretical frameworks to enable you to produce astounding assignments. We hope that we have been able to inspire you and help you to find learning from within your own experiences.

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6. Fifteen

Nileema Vaswani and Ilaria Boncori

Introduction

All of us are affected by bereavement, in different ways, and probably at multiple times in our lives. Experiencing bereavement can be challenging on a personal, psychological and social level. The manner in which we think about bereavement in the presence of ourselves, how we present our grief to others, and what we perceive is required by society of someone who is grieving, are often different.

The process of grief is also heightened when the bereavement upsets the natural order of life. The death of a baby is one such experience. An "out of order" experience brings with it traumas that are distinct from other types of bereavements. There are also few memories of that life-in-becoming to bring relief during times of grief. Bereavement support, accessed formally through organisations, or informally through family, friends or employers, is critical for parents to enable them to grieve that death and continue to live their lives as they wish. In recognition of the needs of bereaved parents, there are a number of professionals and also national charities in the UK that specialise in supporting different types of loss, namely miscarriage, stillbirth, neonatal death and cot death. Sands is one such charity and it specialises in supporting families through stillbirth and neonatal death.

This chapter briefly explores how understandings of bereavement grow and change, and considers more generally the opportunities and challenges for those who work in bereavement. We aim to offer some insight into the world of baby loss from the perspective of professionals who work in this environment and those who may choose to access relevant support services. In order to do so, this contribution is enriched by the presentation of a reflective dialogue between the two authors, providing two different perspectives: a personal view on the first author's work at Sands as Bereavement Support Services Manager, and a commentary from the second author as a woman who has experienced and researched perinatal loss. The views and experiences shared in this chapter are the authors' own and are not in any way representative of Sands or other professional bereavement support service providers.

Fifteen

Nileema: *A few months ago if you had asked me what the number 15 meant to me, I would have thought this a strange question. Had I answered it, I might have said, "the middle of the month" or "a quarter or an hour". I'm not actually sure at all what I would have said. Now, however, I have a clear answer. The number 15 has just one association for me: the number of babies who die before, during or shortly after birth every single day in the UK.*

> Ilaria: *Five. Five is more meaningful for me. That's the age of my baby when they died. We had not yet been able to probe about in search of their gender, we had not seen the frantic fluttering of their heartbeat, we had not bought onesies, mittens, or teddy bears. Only five weeks; it wasn't even a baby yet. Wasn't it, though? They were for me. A baby is only really dignified with that status after 24 weeks, when their death is legally recognised as stillbirth. Otherwise, they are a miscarriage. 24: that's another interesting number.*

Published figures for 2017 show that 15 babies a day are stillborn or die within four weeks of birth in the UK (Office for National Statistics, 2018). It is estimated that of these fifteen babies, nine are stillborn and six die as neonates (*ibid*.). In 2017, one in every 238 babies delivered in the UK was stillborn (*ibid*.). In 2017, one in every 363 babies born in the UK died in the first four weeks of life (*ibid*.). Each year, one third of stillborn babies (approximately 1200 babies) die after a full-term pregnancy when a baby should otherwise have the greatest chance of survival (MBRRACE-UK, 2018). Every year, around 280 babies die at the end of pregnancy from an intrapartum-related event – that is, they start labour alive but die due to something that happened during labour (Royal College of Obstetricians and Gynaecologists, 2016). A recent enquiry found that eight out of ten of these deaths might have been prevented with better care (MBRRACE-UK, 2016). For one out of four of these deaths, a hospital review to learn lessons either didn’t take place or was of unacceptably poor quality (Royal College of Obstetricians and Gynaecologists, 2016).

Working at Sands

Sands was set up in 1978 by Hazelanne Lewis and Bel Mooney, two bereaved mothers who noticed how inadequate support was for parents who had experienced the death of a baby. The charity has a national presence and has grown considerably over the past 40 years. Sands aims to support anyone affected by the death of a baby, work with health professionals to improve bereavement care in hospitals and in the community, promote improvements in maternity care, and fund research to save babies’ lives.

The first author led a team that offers support at the frontline by talking with parents over the helpline, offering email contact, facilitating peer support on the online community, providing accessible information on the Bereavement Support App, developing 'memory making', creating print information and organising remembrance events. The wide range of support is intended to enable people to choose options that fit their individual needs. As the team offers support to bereaved families during the day, 15 new bereaved families will be created. The cycle is relentless; the work is never-ending. The number 15 is as reliable as night and day. It is a hard fact to swallow, a fact that must be changed.

Pregnant colleagues at Sands enter into a world of baby loss that contains more information than they would have had otherwise. They are surrounded by a wealth of resources for bereaved parents. While everyone hopes that 'one of our own' won't have to make use of any of these resources, sadly there is no immunity from loss for anyone. No one says this but everyone knows. In some sense, having this knowledge skews staff's view of childbirth and it is often not easy to remember all the healthy babies who are born every day.

Nileema: *The innocence and joy created around pregnancy can be dampened when working in a baby loss environment. During the commute to work, I notice pregnant women on the underground. At one time, I would make sure they had a seat or offered them mine; now, I find myself thinking "I hope your baby lives". I find myself entering the world of a stranger in a way that I would not have done previously, simply because she is pregnant.*

> Ilaria: *All of a sudden all you can see are pregnant women; they are everywhere in town, and there are babies playing hide and seek under their fluffy covers in cosy prams. Would my baby have looked anything like that? Would they have had my eyes, his lips, our shared cheekiness? I look at pregnant women speeding past behind the bus window; they walk slowly, caressing their bump, perhaps even being annoyed with back pain and swollen feet. Interestingly, I am not jealous of their motherhood, I am somewhat worried for them. 'I hope you and your baby are safe. I hope you never lay awake at night, for hours, endless minutes, wondering if*

> *you will ever be able to have another baby, if there is something wrong with your body, if it was really ever meant to be.'*

In addition to Baby Loss Awareness Week, Sands organises two key remembrance events for parents every year: the Garden event held at the National Memorial Arboretum in Staffordshire every June, and the Lights of Love service held in December in London. These events are well attended and offer opportunities for collective grieving, understanding and hoping. There is an inherent tension between organising an event to enable parents to remember their babies in a collective space and the sad fact that such an event is necessary. Whilst the remembrance events at Sands provide a visual representation of this tension, the very existence of Sands speaks to this tension.

Nileema: *As proud as I am of our services and as rewarding as my job is, there is something terribly sad about any of this being necessary. The etiquette at these remembrance events is fascinating. A lady I had never met before started talking with me and within about 30 seconds asked, "Have you lost a baby?". Many people assume that the only way to understand the experiences of a bereaved parent is to be a bereaved parent oneself. I do not know if this was her assumption but, if it was, she wouldn't be alone. Sometimes, I believe, there is the assumption that if you work for a baby loss charity you have a direct or at least an extremely close personal experience to the death of a baby. Equally, if people believe that you don't have this connection, there are a few who think that the quality of support offered by a "non-bereaved" member of staff would be inadequate. Sometimes staff who are not bereaved parents themselves feel the need to assert their connection to the death of a baby.*

It is of course a myth that high quality support is exclusively dependent on personal experience. No one who works in any of the caring professions would have the breadth of personal experience that is needed to match every professional scenario that they encounter. A counsellor would not be expected to have lived the lives of their clients to be able to offer them counselling, and an Accidents and Emergency department doctor would not be expected to have been in a severe accident and nearly died to be able to help those in that position. Yet, there is something so emotive about support for baby loss that it often occupies a space that is fiercely restrictive. To question these assumptions and make the space more inclusive is an ongoing challenge. However, not everyone who does hold a connection to the death of a baby may feel able to announce this. Working in a baby loss environment might create the space for some people to be more expressive while, for others, it might feel too painful to let their colleagues know of this connection. It is important, therefore, to have an awareness not only of those colleagues who are bereaved by the death of a baby, but also of others who might well bear a similar connection.

When personal and professional spaces overlap

Working in bereavement hour after hour, day after day, provides a connection with the subtlest of similarities. The sensitivity that is developed towards those who seek help also creates a gateway for a further understanding of staff's own experiences and an opportunity for unresolved emotions to rise to the surface. As useful as this is, it can be immensely unsettling.

Nileema: *The movement between one's professional and personal spaces can be rapid. There I was making sure that the event was running smoothly, trying to offer support to those who needed it, and generally functioning very much in "work mode" when I found myself in a personal space. I was struck by how personal a question I had been asked and how it could only be passable, if that, at a remembrance event. The interface between oneself and bereavement is broader than having direct or indirect experience of the death of a baby. Working in bereavement can create the most unexpected triggers. When I started my current role, and given my experience as a counsellor, I mentally prepared myself for mem-*

ories of personal events that could be triggered. However, all the triggers that I have experienced have been unexpected.

Where triggers are fresh rather than historical, there can be a tendency to compare one's bereavement experience to that of the death of a baby and undermine the other experience. There is an unspoken language that the death of a baby is the worst possible experience anyone could have. It is certainly an extremely sad and traumatic experience, perhaps even the worst. However, there are numerous other traumas that need similar levels of support. Perhaps the baby loss space is so confined that it does not recognise with sufficient seriousness many other types of bereavement. These may be experienced by members of staff who then underestimate the impact of these bereavements on themselves because these do not 'measure up' to the standard of baby loss. The emotion attached to the premature loss of a life, rather than, for instance, that which is associated with someone who might have died of illnesses connected to their old age, is also significant. The latter is often seen as a death that fits the natural order of life: people grow old and die. However, the impact of any bereavement should not be underestimated both for those who seek and those who offer bereavement support.

Notwithstanding the triggers and the heightened awareness that comes from working in bereavement, there is also a certain normalising and desensitising of the situation. For example, working on post-mortem materials can, for the Bereavement Support Services team, sometimes feel like just work that needs to be done. For a few people from other departments, however, it could be distressing to see. As staff count memory boxes, edit resource on funeral arrangements, and then take lunch breaks, there is a certain 'normal' in their world. Everyone knows, though, that the death of a baby is not and should not be normal. It is hugely traumatic and, yet, to provide support to families who are bereaved, a work space must be created that is 'normal'.

Experiencing perinatal loss

Experiencing perinatal loss can be a profoundly touching experience for all parents, whether the pregnancy was planned, desired, natural or occurring in different circumstances. Although a number of charities are available to support those in need, parents who have not previously experienced or witnessed such events may be unaware of the support available to them in those circumstances. This is also due to the fact that miscarriage, abortion, death, illness and bodily processes are still treated not only as taboo at the social level, but also often within families and close communities. Organisations and workplaces often fail to offer specific support in terms of bereavement and perinatal loss, and also miss the opportunity to promote internal networks, public resources or free external services that staff could take advantage of in order to process and manage such difficult circumstances. However, many people choose not to report their loss in the workplace and hide it behind personal or sickness leave without publicly acknowledging the nature of their bereavement at work.

> Ilaria: *I didn't tell people to start with. I definitely did not want to talk to strangers about it, or even to my family. It is such a personal, intimate, emotional experience that I wanted to find my own way to deal with it. My way is writing, which I find cathartic and really the only effective way to deal with emotional challenges. I have been practising cathartic writing since I was a child. I shared that text about my miscarriage with a few people whom I thought would be able to understand it. Then I started mentioning the miscarriage to some colleagues and acquaintances. Surprisingly, men and women then shared stories of their own baby loss. Those statistics regarding the common nature of miscarriage suddenly became people, individuals with names and eyes, suddenly jumping out of spreadsheets and inhabiting real life. I wasn't alone. But it's rare for people in organisations to share this, even though there is no shame in bereavement. So why wasn't I sharing my story? And so I did.*

Losing a baby is something that happens in a nebulous domain suspended between the privacy of one's organs and the public nature of one's changing body. The loss is not just of a physical foetus, or a child, as it is also the loss and disintegration of possibilities, dreams, anxieties, nightmares, commitments, and consequences. Perinatal loss is challenging to deal with on many levels – physically, psychologically and emotionally. This is enacted at the individual, couple and collective level. Many people do not want to disclose this plurality to others who might be in their physical proximity at work and yet not in their intimate emotional sphere.

The use of language

It is worth pausing to look at language here. At Sands, 'I lost my baby' is a phrase that is taboo as it implies agency and blame, and Sands would not want any parent to feel responsible for the death of their baby. The word 'died' is more acceptable in terms of the organisation's culture. The word is cold, harsh and yet true. It reflects something that happened rather than something that a parent did. While this approach recognises the feelings of loss, it focuses on helping parents recognise that they did nothing wrong. It is important to distinguish between 'I lost' as a point about agency, and 'feelings of loss' as a descriptor of what has gone. It has often been pointed out that one loses keys and not babies. The death of a baby is not an act of absent-mindedness or carelessness on the part of the parents.

Nileema: *I am reminded of Miss Prism from Oscar Wilde's* The Importance of Being Earnest. *Miss Prism did lose a baby. She left the baby in a large handbag in the waiting room at London's Victoria station. Miss Prism might have also lost her keys. She was absent-minded. However, she did not experience the death of a baby. I notice that I am careful to use* *the word "died" not only at work but also in my personal life. While this might be more accurate, most of the people I speak with are used to language that is softer and use terms such as "lost" and "passed away". As much as this language might conform to social etiquette, I also see these phrases as coping strategies. Using softer language might delay pain and acceptance. For some, it is not possible to confront pain straight away; for others, they move into that space with less difficulty.*

> Ilaria: *I thought very carefully about the use of language to describe what happened. The first words in the title of the article I wrote on perinatal loss in organisations are "I lost my baby today" (Boncori and Smith, 2018). These are strong words to me, a slap in the face, a punch in my empty belly. I was only able to finish writing that article once my second baby was born, healthy and happy. I always think of her as my second baby, always remembering the first child I never had. For some reason, in my mind, they were a boy. There is also some statistic somewhere claiming that miscarriages tend to be correlated with male babies, but I am only going with my instinct. I know that they died, and it wasn't my fault. I recognise the fairness in the language suggested as it lifts the weight of agency from my shoulders in terms of the biological end of a life. But that's not all it was. To lose can mean to misplace, to fail, to evade or waste. Loss can also mean the detachment and the disappearing of something, a damage, a defeat, a deficit of something, or someone – not by accident, not from being absent-minded or forgetful. I literally lost a part of my flesh, it's gone. I was permanently damaged in my soul by a deficiency that will never be compensated ever again. I lost some of that joy and carelessness I would have approached my second pregnancy with instead of obsessing over the baby's health every single day. So, yes, I lost my baby that day.*

Fighting against the taboo of baby loss is something that Sands has been engaging with for many years. One of its campaigns, "Finding the Words", focussed on helping people understand what to say when a family member, friend or colleague has experienced the death of a baby. It highlights behaviours such as crossing the road to avoid a friend whose baby has died as negative behaviour, and encourages people to start talking by simply saying

"I'm so sorry". This campaign not only raised awareness among those who were too afraid to talk, but it also helped more parents who had experienced this type of avoidance from friends and family to come forward and say that this is what had happened to them. The death of a baby should not be a subject that must be avoided; people need to acknowledge it and offer help if possible.

Nileema: *This campaign has made me think of how much or little I am able to talk about my work and whether I am playing into the same avoidance by not sharing aspects of my work. There is a great deal of my work that is confidential, but I know that even what I would like to share with friends and family, simply because I am passionate about my job, is carefully edited. A colleague of mine told me once how they are careful about dinner party conversations as they do not want to scare their friends. I could understand this straight away as I have a parallel fear that I might upset my family and friends.*

> Ilaria: *I know, they are just trying to help and be supportive. I probably wouldn't know what to say to a friend either. I cannot even remember what I said to my sister when it happened to her. Maybe just that I was sorry. People said "it was only five weeks, so that's lucky". Not quite the way I feel about it, but I understand logically that it would have been worse later on. They said "don't worry, I am sure you'll have other children". Well, they don't know that I will, and that's not the point anyway, is it? I wanted this baby. "It happens to one in three women", they said. I know, I know, I know the stats, but it doesn't make me feel any better now; I don't care about others now, only about that little life that died prematurely in me and is never going to live outside of me. One of my friends looked me in the eyes stating "I am sorry, that's really shit" and gave me a tight hug. And that was the only thing that really made sense to me.*

Providing support for bereaved families

Bereavement support services help people acknowledge pain and process it in a way that is right for them. There is no rush to move on and there is never an expectation that anyone should ever ‘get over’ the death of a baby. The specific bereavement support model that Sands offers is evolving from a model where support is available as soon as someone needs it to one that considers more carefully when support should be available. On the one hand, a service that is ‘on tap’, as it were, is comforting and reassuring while, on the other hand, it carries a message that people should not process pain on their own and that it is only with the help of others that they can they heal from their traumas. The balance between availability and the creation of self-sufficiency would be the ultimate goal of that bereavement support model.

Providing support entails understanding each person’s individual situation, entering their world, walking alongside them, appreciating what they need at that moment and on that day, and still ensuring that professionals are just a visitor to their world and do not start residing in it permanently. This interaction could last five minutes, an hour, or anything in between. As soon as it is over, the process re-starts and preparations are made for the next email or the next phone call. There isn’t always time for staff to process what has just happened, causing a cumulative effect of holding numerous stories and experiences at the end of a shift.

People access support for a wide variety of reasons. They might have been recently bereaved and need practical information on post-mortems, funeral arrangements, or ‘memory making’; they could be contacting a support organisation because of their baby’s anniversary, the impact of their baby’s death on their relationship, because they are concerned about their other children, or for many other reasons. Bereavement and grieving can also result in anger. How anger manifests itself can depend on the medium of support being accessed. On the helpline, people can feel angry about their situation and the anger can be expressed through vulnerability; on the online platform, the anger is often directed at what someone else has said and is louder, more expressive, hidden behind their anonymity and the anonymity of others. Staff who work on the helpline and the online community need to be especially skilled at managing these different forms of anger from those who use these services. Families might also be, as one might expect, sad, distressed or confused.

The need for self-care and support for staff

It is easy to forget about oneself when providing support to others, and to notice that something is unravelling only when one reaches a breaking point. Sands encourages bereavement support staff to access external professional supervision; this is arranged by the employee and funded by the charity. In addition to this, staff are encouraged to be aware of the impact that their work is having on them, to debrief with colleagues and line managers, and to learn to identify what they need when their work creates personal triggers.

Where there is a specific event like a bereavement, in many other organisations, staff might be offered compassionate leave where they can focus on their critical life event and then enter a work-space that is bereavement-free. At Sands, staff would always re-enter a work space that is bereavement-focussed, so even those who do not work specifically in bereavement support within the organisation would still work in areas where there is a clear connection to the death of a baby. This type of environment would not then be able to provide a distraction or any respite for staff who wish to return to work after having experienced a bereavement as a way of taking themselves away from the ongoing activities and emotions of their home life. This is why the management of staff's own grief through reflection and relationships is crucial in order to be able to function in this professional environment.

As professionals in this particular field of bereavement support, many staff also hold knowledge of grief theory, and it is possible that they see themselves at a point in their recovery which is frustratingly slow. There might be the risk of becoming impatient with oneself, even though one would be patient with someone else in the same situation. Equally, understanding grief theory offers an insight and understanding that can enable someone to translate that to their own situation and thereby be more compassionate towards themselves.

One of the most positive aspects of working in bereavement at a time when one is experiencing a personal bereavement, is that there is a level of empathy and understanding that one is unlikely to find in most other places. This may be due to the nature of the work undertaken by the organisation, as well as because the culture of the organisation is such that staff are supported in ways that are specific to their needs. This is an approach that could be adopted in any type of work environment. Just as there is no formula for bereavement support for the families that contact the charity, staff are also asked what their individual needs are to help them through difficult times. This could include time off, working from home, a phased return to work following a bereavement, flexible working, or a conversation with their line manager or a colleague. There are also designated bereavement support staff available to support colleagues in other departments. Such a personalised and flexible approach to staff can be incredibly powerful in terms of staff wellbeing, retention and performance.

> Nileema: *For me, even when I have chosen not to share details of a bereavement or a death anniversary at work, I have felt supported simply by knowing that if I did share my feelings and experiences, these would be understood. Staff support is not always about accessing different forms of support but simply knowing that these are available. Moreover, it is about the environment and just as much about what is unsaid as is about what is said. The culture here is a space where, whether I share personal*

> *experiences or not, I still feel well supported. It is a space where care is offered and self-care is encouraged.*

Boundaries form an integral part of self-care. This means being able to recognise which emotional experiences belong to the member of staff and which pertain to others. It is also about identifying areas of overlap and exploring these at supervision. On a day-to-day basis, it is about making a determined effort to end work, at whatever time that might be, and do something specific as a wind-down activity. Neglecting to do so may result in negative effects not only on one's personal life and mental wellbeing but also bring difficulties in being able to provide support to others.

> Nileema: *Understanding boundaries for me is also about recognising where my help is needed and wanted, and where I need to step back. I have noticed that since working in bereavement support I have felt the need to support certain people in my personal life perhaps more than I might have done otherwise. On reflection, these are people who are not necessarily close enough to me to want my help and yet something in me felt that I had to offer it. I have learnt that working in bereavement makes it hard to step back and it is therefore important to be aware of whether my help is actually wanted.*

The need for self-care does not mean that working in bereavement support services is a 'sad job', as is sometimes assumed for those who choose to work in the field. However, it does mean that this is sometimes an emotionally challenging job, one that often requires people to 'recharge' to face another day, create conscious spaces for reflection, and develop mechanisms for coping with that emotional labour. Enabling support is positive, rewarding, and can make staff immensely happy.

Conclusions

This chapter intended to present two varied, although not necessarily contradictory, perspectives on baby loss. We have presented the personal feelings of loss and the sensitivity around talking about baby loss for someone who has experienced the death of a baby. For a professional offering support, we have highlighted the importance of self-care and reflection, boundaries, and the power of language. Where personal and professional spaces collide, we have explored how it is necessary to find a way for them to co-exist.

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Part 2

7. The Disability Wage Gap: Economic Literature, Theory and Measurement

Filippo Sinicato

Introduction

In this chapter, we first review the economic literature on wage discrimination, its causes and effects. We point to both positive and negative effects, including the negative effect of wage discrimination on the incentive to acquire skills. We then review the empirical work on the disability wage gap. While this is generally an under-researched area, the overall conclusion is that a significant wage gap exists. Furthermore, the gap cannot be explained fully by differences in productivity across disabled and non-disabled groups, and seems ‘stubborn’ in the face of legislation. We outline the Blinder-Oaxaca decomposition as a method of studying the disability wage gap and apply this technique to a sample of males in the UK. We estimate that the portion of the wage gap that can be attributed to discrimination is between 14% and 40%, depending on our specification. We conclude with some caveats on these findings and an appeal for further work.

Wage discrimination in the labour market has been brought into focus recently with discussions of the ‘gender wage gap’, ‘age wage gap’ and ‘race wage gap’. These gaps refer to the difference across subgroups of the population in the amount of pay they receive for equal work. For instance, older workers or female workers or workers from certain ethnic groups might earn less in the same or similar occupation.

Despite the fact that disabled people represent the largest minority in the world, accounting for 15% of the global population (World Health Organisation and World Bank, 2011:28), they have not been the focus of research on wage discrimination. As a result, a 'disability wage gap' is much harder to discuss or address based on existing analysis. Indeed, the first empirical analysis was carried out during the 1980s by Johnson and Lambrinos (1985), drawing academic attention to the situation of disabled workers. Since then, a number of countries have implemented targeted laws to help disabled people better integrate into the labour market and the general social fabric. However, this academic work and the legislation associated with it appeared relatively late compared to both race or gender wage gap analysis and legislation.

This paper reviews the economics literature to date on wage discrimination of disabled workers. We outline a structured approach to diagnosing the magnitude of wage discrimination and apply this approach to UK data on disabled workers as an illustration. While the work contains limitations, discussed in the conclusions, this analysis nonetheless provides an idea of the scale of the problem facing those with disabilities in the UK. For comparison, the figures in this work are not out of line with the level of wage discrimination detected for other groups, although those literatures have shown that the magnitudes vary considerably across samples, countries, and time periods. Hence, we see that wage gaps, which we can potentially attribute to discrimination, exist for a number of groups in similar magnitudes.

The theory: why do we observe discrimination?

Some, perhaps most notably Nelson and Winter (1982), have made an "evolutionary" argument that discrimination in the workplace should not persist in a competitive environment. Any firm that restricts its ability to hire the best workers for the lowest cost will tend to be less efficient than a firm that recruits from the widest possible pool. Hence, a firm that discriminates should be less efficient than a firm that does not discriminate and so the discriminating firms should be the first to be ‘killed off’ by competition. This type of argument implies, then, that discrimination should be disappearing as a simple result of competition. Little direct policy action is necessary, other than ensuring that competition is free to operate. It ‘solves’ the problem of discrimination on its own.

This is not what we observe, however. Casual observation suggests that there is widespread and persistent discrimination even in highly competitive economies. Becker (1971) provided a partial answer to this conundrum by postulating that wages are lower for discriminated groups because people have an aversion – a distaste or a fear – of certain groups. As a result, people may have a ‘taste’ for discrimination in the sense of getting pleasure out of not associating with certain groups. This can make discriminatory workplaces more desirable for people and more functional, thus reversing the efficiency argument we have just made above.

To see the implications of this theory for hiring and compensation more clearly, we first must think that we experience the characteristics – such as skin colour or disability or personality – of our co-workers whenever we interact with them. If these characteristics are pleasing to us, we get pleasure out of the experience but, if they are not, we suffer. For example, a combative colleague can make everyday interactions a chore whereas a humorous or obliging colleague may make interactions a pleasure. Closer to our theme of discrimination, if working with an individual from a ‘disfavoured’ group feels unpleasant for a ‘favoured’ group member, then workers from the ‘favoured’ group may demand a higher wage from the employer to tolerate a work environment that has a mixed population across favoured and disfavoured groups. They may also avoid working with such people, making the team function less efficiently.

If the firm must pay a higher wage or must 'work around' any problems in team working, then this drives up the cost of production and so puts the firm at a competitive disadvantage compared to the alternative of avoiding hiring a mixed workforce. Equally, this effect could lead to segregated workforces even within the same employer. For example, a firm that paints houses might construct each crew from a single sub-group. Of course, this in itself may not create a wage gap: we need an additional effect on top of segregation to create lower pay for some sub-groups compared to others. For example, two crews may contain exclusively members of a single nationality (one Polish, one Spanish), but both groups could be paid the same wage for the same work. A second implication of this theory, however, is that consumers might be willing to pay more for products produced by firms that employ certain types of workers if consumers, too, value interacting only with certain sub-populations. For example, customers may have a preference for buying products produced only by local workers. If there is a price premium for hiring from certain groups, this may result in firms' discriminating or paying more for a favoured group of individuals where the price premium drives up margins despite the higher cost of hiring.

As this source of discrimination is associated potentially with higher profitability, normal competitive mechanisms in the market need not overturn it. Indeed, discrimination and competitive advantage go together in this second theory of discrimination. Equally, discrimination is not necessarily bad: if all people prefer to associate with their own sub-group then perhaps apartheid makes everyone happier and is consistent with maximising societal welfare. Hence, we have the evolutionary theory suggesting that discrimination is bad but should not be a direct policy concern and a taste-based theory suggesting that discrimination should persist but is not necessarily detrimental to social welfare.

A third, contrasting, theory (see Milgrom and Roberts, 1992) assumes that employers that cannot observe all the characteristics of employees that may lead to high productivity. If they cannot readily judge who will be productive once hired, employers may resort to looking for observable 'signs' that are not important to productivity in themselves, but may indicate that a worker will be very productive once hired. For example, suppose that productivity in a particular role is correlated with some characteristic that is easy to observe but is not directly related to productivity itself such as height, gender, ethnicity, or disability. Suppose further that it is costly to find out whether a particular applicant is truly more able to perform the job. For example, this might require employing the worker for a period of time, observing productivity, and then undertaking a costly firing process if the worker did not turn out well. In such a case, the employer may hire only those with the observed 'signal of success'. This can result in hiring only tall people or only people of a certain gender or ethnicity or without disability. It is a rational response of employers if they believe that there is a strong enough correlation between the observed signal and success as an employee (Phelps, 1972; Arrow, 1973; Milgrom and Roberts, 1992).

The implication of this 'signalling' theory is potentially quite damaging for disabled workers. If, for example, all firms screen in this way, then no disabled workers will be hired at all. As a result of facing no opportunity or incentive to obtain the skills they need to be productive, disabled individuals may not invest in skills in the first place: the investment would never pay off so it is rational for them to decline to invest. The resulting true difference in qualifications between disabled and non-disabled workers confirms the original discriminatory beliefs since all observed disabled workers will in reality now be relatively un-skilled compared to non-disabled workers. In other words, a perceived difference can lead to an actual difference in productivity as the disabled become discouraged so that the beliefs can be self-reinforcing. This final theory suggests that discrimination is a problem and also is persistent: it creates a disincentive to become productive and so potentially reduces the overall social welfare of society (and in particular the disabled workers).

Empirical work: is there wage discrimination against those with disabilities, and how much discrimination exists?

In data-based work, Metts (2004: 32) shows that lack of labour force opportunities for those with disabilities could result in a loss of 1.71-2.23 trillion USD to global GDP. The magnitude of this figure is partly due to the loss per worker, but also is the result of the large number of workers in this group. Indeed, Jones (2016) shows that, for OECD countries alone, one in eight working age people is disabled.

More sophisticated studies use the Blinder-Oaxaca decomposition, explained below, to obtain a more precise estimate of the source of wage differentials. This technique was used in the Johnson and Lambrinos (1985) study, cited above, to show that in the USA and before the Rehabilitation Act of 1973 was passed, wage discrimination accounted for about one third of the difference in wages between disabled and non-disabled males.

Baldwin and Johnson (1994) traced the evolution of wage discrimination facing disabled males between 1972 and 1984 in the US and found little change over this time, with about 40% of the total differential in wages traceable to wage discrimination. Later work by Jones and Latreille (2010) made the further point that where regulations require employers to make reasonable accommodation for disabled employees, a fraction of the discriminatory behaviour is traceable to effectively "charging" disabled employees for the additional cost of these accommodations.

These figures were repeated in broad strokes in a first study of the UK by Kidd *et al.* (2000). These authors used data from 1996 to observe substantial differentials in wages and employment opportunities across disabled and non-disabled groups. One half of the total difference was due to differences in productivity whereas the remaining portion could be attributed to discrimination.

The effectiveness of legislation attempting to address wage differentials has also been investigated in structured data work. The Americans with Disabilities Act of 1990 (ADA) enhanced the protections of the earlier Rehabilitation Act in the US. Repeating their earlier analysis, Baldwin and Johnson (2000) used data from the 1990 Survey of Income and Program Participation to show a persistent and substantial unexplained wage difference compared to non-disabled workers. It also showed a notably lower probability of employment. Using data from 1986-1995 that spanned the implementation of the new legislation, DeLeire (2000) show that disabled worker participation fell throughout the period, even though wages tended to remain stable. Later work by the same author (DeLeire, 2001) showed that the passage of the ADA did not reduce the estimate of the amount of the wage differential attributable to discrimination, although the amount of this discrimination cost was low at about 5-8% of the total wage differential.

Finally, Acemoglu and Angrist (2001) found that employment of young disabled people aged 21-39 declined in absolute and relative terms with respect to the non-disabled, whereas for older people this did not change substantially. Longhi *et al.* (2012) conducted a similar more granular study, finding that the wage gap for those who suffer physical disability was smaller than for those who suffer mental disability. Finally, the effects of gender-based discrimination added to disability discrimination can make the difference in wages more significant: Baldwin and Johnson (1995) and Jones *et al.* (2006) found that discrimination against disabled women was more significant than for men in the US and UK, respectively in their study periods.

Overall, then, legislation appears to have had a modest effect on wage gaps over the short term. There also appears to be a decline in the gap over the longer term, at least for certain subgroups.

Dissecting the Wage Gap: the Blinder-Oaxaca decomposition

The Blinder-Oaxaca decomposition is a statistically based technique to study the composition of a wage differential. By splitting a data sample into two groups, in our case the disabled and the non-disabled, it divides any observed wage differential into components of productivity differences and potential discrimination.

More precisely, suppose that we correlate the wage of each individual with various individual characteristics, such as their disability, gender, education level or any other observable characteristic that the researcher finds relevant. Then, a similar correlation between wages and these characteristics across groups could potentially indicate a lack of discrimination. For example, if education is correlated with wages in a similar way across disabled and non-disabled groups, then one could take this as evidence that there is little discrimination: disabled and non-disabled workers with similar educational backgrounds seem to be treated similarly by employers, at least as far as wages are concerned. Another way to think of this is that an investment in education by a disabled worker ‘pays off’ in a similar way to an investment by a non-disabled worker. On the other hand, if a given amount of education has a much larger impact on wages for a non-disabled group than for a disabled group, then we might take this as evidence of discrimination. In other words, if for some reason the same educational investment does not 'pay off well' for a disabled worker, then we might conclude that this is due to discrimination in the employment at the end of the educational period.

Hence, the Blinder-Oaxaca decomposition breaks down the average wage gap across all disabled and non-disabled groups into two components. The first one includes all differences in education (implicitly assuming a similar effect of education on wages for both groups), while the second component represents the difference in impact of education on wages between a disabled person and a non-disabled person. The first component is interpreted as the difference in wages due to a true difference in productivity, attributable to obtaining a higher or lower educational qualification (for example, a university degree or a high school degree). The second component is generally interpreted as the magnitude of the wage discrimination faced by workers. Hence, the first component measures the benefit of becoming more productive, while the second component is the difference in wages not attributable to productivity. This second component can be thought of as "discrimination" since paying different wages for the same productivity and for the same task would normally not be an optimal choice for employers or workers in any economy where workers can move relatively easily across jobs and wages are posted.

We need to exercise caution in this interpretation: the only thing that the decomposition can detect is the wage differential that is attributable to specific 'explanations' and then a second 'unexplained' differential. This second component cannot be attributed to any particular difference among the worker groups, such as education, but potentially also other factors that could be controlled for by the researcher such as age, region, sex, or other characteristics that were not measured. It could be due to discrimination, but equally could be due to a characteristic that we have simply not observed. Hence, to draw a conclusion of discrimination, we must make a further assumption that the unexplained difference is due to discrimination, even though we cannot show directly that discrimination is the culprit. Another way to put this is that we assume that our specification was correct, and took into account all relevant factors. Returning to our example, more factors than just education can affect wages and productivity and so the decomposition would often include a wide set of worker characteristics.

There is further debate concerning this technique that has to do with technical – but often important – niceties. For example, if we analyse the wages only of those who are employed, we exclude from our analysis those who were discouraged. The total participation of a group will affect employment and investment decisions, so omitting the effect of non-participation on the activities of those who are active participants in the job market can be misleading. This defect can be corrected, at least in part, by including a second step in the analysis that describes the decision to participate in the job market at all. Usually, this is done by adding an equation that says that participation is more likely as the wage increases above a specified minimum that one would normally expect an individual with a given qualification or characteristic to demand in order to search for a job at all. With this second element in the model describing the decision to look for a job, we have both the wage behaviour and the decision to work included in the analysis.

An application of the decomposition: is there wage discrimination against disabled males in the UK?

As an example of this analysis, we use the Blinder-Oaxaca technique to study up to date data drawn from the Understanding Society dataset, which is part of the “British Household Panel

Survey" project (University of Essex, 2018). This is a representative longitudinal survey of the British Population that has been ongoing annually since 2009, which systematically traces changes in the British population. Unfortunately, not all years have phrased their questions on disability in the same way, introducing some ambiguity in interpretation across time. Hence, this study will be based on the years 2009-2010, where a consistent terminology was used. Furthermore, the British Government enacted the Equality Act in late 2010, which should have affected behaviour. To keep a constant institutional environment, we use only the information collected before this passage. Clearly, behaviour may have changed in anticipation of the law, which may affect our results. Furthermore, comparing these results to later years could be informative as to the effect of the new law even though we do not attempt this extension. Finally, in order to reduce the heterogeneity of the population so as not to confuse the effects due to disability with those of other characteristics such as gender, we limit our study to males of standard working age (23-64 years old). Those with low work hours, those on long term sickness leave (and so unable to work), and the self-employed are eliminated in order to avoid difficulty in comparability across the sample.

With these restrictions in mind, we proceed with the analysis. We classify the data into those with and without a disability by signalling the difference using a 'dummy variable'. This is an indicator that takes a value 1 or 0 and allows us to classify the data into two distinct groups. We compare these groups to evaluate the wage gap, stratifying the sample by occupation so as to compare 'like for like' jobs. Furthermore, we compare those at the same age and job tenure so as not to confound the effects of being in a job longer with those of being disabled. For example, if we found a difference in wages but this was because most disabled people were simply newer hires than non-disabled people, then we could wrongly attribute this difference to discrimination instead of tenure. We also divide up the data by region of the UK, marital status of the employee, and some other demographic information to allow us to compare – to the extent possible – 'like for like' across disabled and non-disabled populations. The final sample contains 7088 observations, divided into 2087 disabled and 5001 non-disabled wage observations, respectively.

We performed a Blinder-Oaxaca decomposition on this data and analysed both cases with and without taking into account the effect of being employed at all. In our main specification, however, we find that the portion of the wage gap attributable to different endowments of characteristics (such as education) amounts to about a 4% differential, whereas the effect of the disabled earning less for a given set of characteristics (possibly due to discrimination) amounts to about 3% as a maximum. Hence, of the total wage gap of 7%, about 40% may be due to discrimination in our analysis. The disabled appear to be less educated, in fact, compared to the non-disabled in the data as well as having a somewhat lower payoff to the education they receive.

Conclusions

In this work, we have reviewed the explanations for why we should observe discrimination in the workplace. These vary widely from the relatively benign view that discrimination should disappear under evolutionary pressures to the view that discrimination may be positive for social welfare if it allows people to enjoy the benefits of associating with whom they choose, to the view that there can be important negative social welfare consequences as the disabled become discouraged from achieving. Empirically, wage discrimination appears to exist for the disabled. As the disabled form a very large group, this adds up to a significant sum even if on an individual level the amount of discrimination may not be very large. Recent work has used the

Blinder-Oaxaca decomposition to diagnose the degree to which discrimination rather than true differences in productivity can explain observed wage differentials. This paper explained the technique and applied it to recent data from the UK, finding that among males in 'regular' employment, between 14% and 40% of wage differentials could be attributable to discrimination depending on whether unemployment as a labour market outcome is taken into account or not, respectively.

The technique is not by any means perfect. This method of diagnosing discrimination is not direct: we can explain away some wage differentials due to true differences in productivity across individuals. The unexplained portion is attributable to discrimination but could also be due to model mis-specification. Hence, our estimate of discrimination is potentially more severe than actual discrimination in the workplace. At the same time, we have to be aware that true differences in productivity can well result from discrimination in the workplace in a sort of vicious circle. Where workers perceive the payoff to an educational – or other – investment in their own productivity to be low, they will decline to invest, resulting in true (and explained in our analysis) differences in productivity for which a lower wage is justified. In this sense, the decomposition that we use underestimates the pernicious effect of discrimination on disfavoured groups.

Continued work on the methodology for dissecting the causes of wage differentials needs, then, to be honed in order for us to see the true extent of discrimination. Importantly, given the results to date on the effectiveness of legislation to correct discrimination in the workplace, further and more precise work is needed to better design legislation to address discrimination where it is both found and found to be a negative effect on social welfare.

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8. Health and welfare decision-making in mental capacity law

Jaime Lindsey

Introduction

This essay explores the use of mental capacity law to empower and protect disabled people. The intervention of law in disabled peoples' lives has been a persistent feature throughout the years, and the intrusion and surveillance of the lives of disabled people continues today. However, in recent times, a greater focus has been placed on the empowerment of disabled people. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), to which the UK is a signatory, sets out various rights for disabled people including equal recognition before the law (article 12), freedom from exploitation, violence and abuse (article 16), and the right to live independently and be included in the community (article 19). The change that has emerged under the influence of the CRPD has been to move away from substituted decision-making for people found to lack the mental capacity to make decisions, towards supported decision-making. This means that the person lacking capacity should not have decisions imposed on them in their best interests but should instead be given the support to make their own decision. How supported decision-making would be implemented in practice is not made clear within the CRPD. However, these issues are being discussed in socio-legal and disability scholarship (Arstein-Kerslake and Flynn, 2017; Harding and Tascioglu, 2017; Harding and Tascioglu, 2018). Despite the positive developments resulting from the CRPD, substituted decision-making remains in English law and disabled people still routinely have their decisions overridden.

This chapter considers one area of English law, the Mental Capacity Act 2005 (MCA), which applies to people who are deemed unable to make decisions for themselves. I outline how mental capacity law applies to the lives of disabled people, arguing that they are still often paternalistically prevented from making their own health and welfare decisions in the name of protection. In particular, I consider the way that the MCA has failed to promote decision-making by disabled people over their own health and wellbeing. Many scholars have argued that it is important to protect people from non-autonomous decisions about their health and welfare, particularly where those decisions lead to exploitation or abuse (Herring, 2016; Kong, 2017). While I am instinctively sympathetic to this view and the need for protection, I suggest this should be done through support and empowerment rather than by overriding the choices of individuals. The essay starts with an accessible overview of mental capacity law for those who are not familiar with it. It then proceeds to a discussion of three important areas within the mental capacity law framework: decisions about healthcare, decisions about welfare and participation in decision-making.

Overview of mental capacity law

Mental capacity law is an area of the civil law of England and Wales. It provides a legislative definition of when people lack the mental capacity to make decisions for themselves. Assessing whether or not a person has mental capacity means considering whether they have the necessary mental functioning, according to the criteria under the MCA, to make a particular decision about a particular matter at a particular time. Where individuals are found to lack the capacity to make decisions, section 4 MCA requires that decisions are made on their behalf in their best interests. Yet before a best interests decision can be made, it is important to first establish that the person lacks the mental capacity to make that decision.

Whether or not a person has the mental capacity to make a decision is determined by reference to section 2 and section 3 MCA. Section 2(1) MCA states that:

> *a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.*

This means that the person must have some form of impairment in their ability to make decisions, whether that be permanent or temporary, lifelong or momentary. It is this feature of the law that is generally viewed as meaning that it predominantly applies to disabled people, more particularly those with cognitive or mental health difficulties such as a learning disability or severe depression (Ruck Keene *et al.*, 2017). However, the legislation does not single out disabled people. In fact, many cases relate to people with other categories of impairment, such as those in a minimally conscious state or with impaired mental functioning as a result of their own actions.[1] The starting point, though, is the need for an impairment or disturbance in the functioning of the mind or brain and, therefore, in practice at least, the vast majority of cases in this context relate to adults with learning disabilities or mental health difficulties.

The second part of the test for mental capacity comes under section 3 MCA. This test sets out that a person is unable to make

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[1] See *In re L (Vulnerable Adults with Capacity: Court's Jurisdiction*) [2012] EWCA Civ 253, *Aintree University Hospitals Foundation Trust v James* [2013] UKSC 67, *In re M (An Adult) (Capacity: Consent to Sexual Relations)* [2014] EWCA Civ 37, *Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80.

a decision if they are unable to understand the information relevant to the decision,[2] unable to retain it[3] or unable to use or weigh it to make the decision.[4] There is a further requirement that the individual must be able to communicate their decision[5] and have an appreciation of the reasonably foreseeable consequences of the decision.[6] This is commonly referred to as a 'functional test' and looks at how the individual with the impairment actually makes the decision in question. For example, in cases concerning consent to medical treatment, the individual would have to understand information about the proposed treatment, such as the risks and alternatives. The more complex the decision, the higher the threshold for functional understanding.

These two tests together form the basis of decisions about whether an individual has mental capacity. The tests work to identify who has the ability to make their own decisions and whose decisions can be overridden in their best interests. The law takes a very clear stance that adults who have the requisite mental capacity to make the particular decision are allowed (and facilitated in many instances) to do so, even if that decision is deemed unwise.[7] In contrast, for people who are found to lack the mental capacity to make decisions, they face the concerning prospect of having medical treatment forced against their wishes,[8] being deprived of their liberty[9] or being kept apart from their

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[2] S 3 (1) (a) MCA.

[3] S 3(1) (b) MCA.

[4] S 3(1) (c) MCA.

[5] S 3(1) (d) MCA.

[6] s 3 (4) MCA

[7] *St George's Healthcare NHS Trust v S* [1999] Fam 26, *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWCOP 454.

[8] For example, as happened in *A NHS Trust v K* [2012] EWCOP 2922, *Mental Health Trust v DD* [2015] EWCOP 4, *A University Hospital NHS Trust v CA* [2016] EWCOP 51.

[9] For example, see *RB v Brighton and Hove Council* [2014] EWCA Civ 561, *N v A Local Authority* [2016] EWCOP 47.

intimate partner or spouse.[10] As explored in more detail in the following section, the decisions that can be made under the MCA are wide-ranging. It is for this reason that an understanding of mental capacity law is so important; it can impact on everyone's life at some point and intersects with many different areas of law and policy. A full analysis of every type of decision covered by the MCA is not possible here. Instead, I focus on decisions relating to health and welfare. This means decisions about medical treatment and general day to day life, such as where to live and who to see.

Decisions about healthcare

Healthcare decisions might include a person deciding that they wish to have a particular treatment or, more commonly, that they do not wish to undergo a particular medical treatment. For example, in *Wye Valley*,[11] Mr B, a 73-year-old man with a severely infected leg, refused to give consent to medical treatment which would have involved amputating his foot to save his life. Mr B had a history of paranoid schizophrenia, schizo-affective disorder, and diabetes, and he also had peripheral neuropathy which caused the problems in his feet. The healthcare professionals agreed that without the operation he would likely die but with it he would probably survive for a few years.[12] The issue under the MCA concerned whether or not treatment was in Mr B's best interests as he had been found to lack the mental capacity to make the decision himself. Section 1(5) MCA states that "[a]n act done, or decision made, un-

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[10] For example, see *The London Borough of Tower Hamlets v TB and SA* [2014] EWCOP 53.

[11] *Wye Valley NHS Trust v B* [2015] EWCOP 60.

[12] Para 1.

der this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests." This means that where a person is found to lack capacity, decisions can only be made on their behalf that are in their best interests. Factors that can be taken into account under the best interests test include all of the relevant circumstances such as "the person's past and present wishes and feelings",[13] "the beliefs and values that would be likely to influence his decision if he had capacity"[14] and "the other factors that he would be likely to consider if he were able to do so".[15] Therefore a person's best interests go beyond solely their medical interests to include wider factors. For example, for many Jehovah Witnesses, their religious belief system means that they do not accept blood transfusions, even where it is medically necessary to save their life.[16] These wider factors include the person's wishes and their particular belief system, albeit a person's wishes are not determinative of their best interests. This means that where a person lacks the mental capacity to make a decision, the court can order that treatment is carried out, even against the patient's will, if the treatment is found to be in their best interests. This does not mean that the court will always order treatment against a person's wishes, but in many cases they do.[17]

The *Wye Valley* case mentioned above went to the Court of Protection (CoP) for a decision about whether the doctors could proceed with the amputation. Cases should typically only go to court where there is some dispute or where it is a particularly

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[13] S4(6)(a) MCA.

[14] S4(6)(b) MCA.

[15] S4(6)(c) MCA.

[16] See for example *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWCOP 454.

[17] As in the following cases, *A NHS Trust v K* [2012] EWCOP 2922, *Mental Health Trust v DD* [2015] EWCOP 4, *A University Hospital NHS Trust v CA* [2016] EWCOP 51.

serious decision[18] and therefore the vast majority of decisions about mental capacity will inevitably be made in the community. In *Wye Valley* the court held that even though Mr B lacked the mental capacity to make the decision about his foot amputation, it was not in his best interests to have the amputation *against his will*. Therefore even though it *was* in Mr B's *medical best interests* to have the treatment, wider factors were taken into account, particularly Mr B's expressed wishes and the impact of forcing treatment on a person against their will. The decision, that treatment could not be given to Mr B against his wishes, reinforces the importance of respecting someone's clearly expressed views, even against medical advice. In this respect, patient autonomy appears to have prevailed over paternalism. The judge in *Wye Valley* stated that "[t]here is a difference between fighting on someone's behalf and just fighting them. Enforcing treatment in this case would surely be the latter."[19] I agree with this analysis, and being able to make our own decisions about medical treatment is something that most of us take for granted. In fact, the MCA provides important and valuable protections for adults who want to make decisions for themselves. The MCA is underpinned by values of empowerment and clearly states at the start that "[a] person is not to be treated as unable to make a decision merely because he makes an unwise decision".[20] However, the interpretation and application of the MCA in practice can work against and restrict disabled people from making their own medical treatment decisions. This can be seen in the many more cases where medical treatment has been forced on adults against their wishes.[21]

[18] Department for Constitutional Affairs. 2007. *The Mental Capacity Act 2005: Code of Practice*. The Stationery Office: London, chapter eight.

[19] Para 45.

[20] S(1)(4) MCA.

[21] At n 8.

Decisions about welfare

Decisions can be made under the MCA about a person's welfare as well as for healthcare treatment. Welfare decisions are some of the most varied under the MCA but often centre on issues such as decisions about contact with family members or intimate partners, decisions about where to live and decisions about day to day care (such as washing, cooking, help with shopping etc). This highlights the breadth and impact of the MCA. Welfare cases also include decisions about sexual relations, marriage and divorce. Under the MCA, if a person is found to lack capacity to marry, divorce or engage in sexual relations, a decision cannot be made on their behalf in their best interests.[22] Therefore any findings of incapacity in respect of these areas mean the individual in question is prevented from having any intimate relationships. This is understandable as it would seem inappropriate for a court to, for example, consent to sexual relations on someone's behalf. However, there are problems with the current legal approach to these capacity domains, which have been considered in more detail elsewhere (Clough, 2014; Lindsey, 2016). Interestingly, and perhaps a feature of the nature of these disputes, many of the cases that reach the CoP in this area involve allegations of abuse. That is, the nature of the capacity decision may concern sexual relations or care or contact, but the underlying factual element of the case is often that there are allegations of abuse against the subject of the proceedings (Lindsey, 2019b). If abuse cases dominate welfare decisions in this area, then that may help to explain the paternalism within mental capacity law as there is a perceived need to protect victims of abuse.

An example of a case in this category is *WBC v Z*.[23] The case concerned a 20 year old woman, Ms Z, described as having

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[22] S27 MCA.

[23] [2016] EWCOP 4.

Asperger's and a borderline learning disability. The local authority brought the case to the CoP primarily for decisions as to whether Ms Z had capacity to decide on where to live, her care and her contact with others. Ms Z lived at home with her mother but wanted to live independently. She did not have a job but was undertaking music and performance exams. Ms Z was described as taking "many risks in the past in the way she has lived her life"[24] and "some of that risk-taking has probably caused her harm".[25] The local authority therefore appeared to be concerned about sexual exploitation and Z's inability to keep herself safe from harm. Despite psychiatric evidence to the contrary, the CoP held that Ms Z did have the mental capacity to make the decisions in question. This meant that Z was not subject to any restrictions on her care, residence or contact with others, which would have been imposed had she been found to lack capacity in those domains. However, she was likely still the subject of safeguarding investigations and, hopefully, ongoing support from the local authority. Whilst this is a relatively typical factual scenario in the welfare category, many cases have different outcomes and lead to the individual's decisions being overridden against their wishes.

Another similar welfare case is *Manchester City Council v LC*.[26] The case concerned a 23 year old woman, Ms LC, described as having significant learning disabilities and Autism Spectrum Disorder. The case at the CoP had a lengthy history which I will not go into here. However, in the judgment Ms LC is described as having an "obsessional interest which was sexual in motivation in relation to men. This it requires to be said, in unambiguous terms, is a feature of her Autism."[27] Again, the case appears

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[24] Para 2.

[25] Para 2.

[26] [2018] EWCOP 30.

[27] Para 3.

to have been brought by the local authority because of these concerns about sexual harm and exploitation, highlighting that allegations of abuse are at the heart of many of the welfare cases under the MCA. An earlier decision of the judge in the case, Jackson J, found that Ms LC had capacity to engage in sexual relations, marry and make decisions in relation to contraception. However, he also found that Ms LC lacked capacity to conduct the proceedings, make decisions on her contact with men, make decisions about care and residence, make decisions as to whether to enter or terminate a tenancy and decide whether or not she should access mobile phones or social networking sites.[28] The range and specificity of capacity domains covered in this case reflects the breadth of the MCA's welfare jurisdiction and the extent to which it can lead to control being exerted by professionals over the lives of disabled people. It also highlights a common outcome in mental capacity law welfare cases – that individuals are often found to have the capacity to make decisions about sexual relations and marriage, but are found to lack capacity in other areas, such as capacity to decide on contact with others. This means that the individual's relationships can still be monitored and restricted by professionals, even though they have capacity to engage in sexual relations.

This tension within the law is problematic for disability rights. On the one hand, a person is found to have sufficient understanding of what sexual and marital relationships involve such that they should be able to pursue intimate relationships like any other adult in society. On the other, that same person can be found to lack the capacity to decide on contact with other people, such that their relationships (sexual or otherwise) with particular individuals can be monitored and, ultimately, pro-

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[28] In the hearing that underpinned this judgment, there were no formal findings regarding LC's capacity. However, the decision is included here to highlight the findings because the previous judgments were unreported.

hibited. Tensions such as these highlight that the welfare jurisdiction of the CoP can be regarded as being highly restrictive of individual decision-making. Even in cases where a person is found to have the mental capacity to make particular decisions, their incapacity in other areas can lead to their decisions being constrained by others.

Participation in decision-making

The final issue within the MCA decision-making framework that I discuss here is participation. This typically means some level of involvement in the decision-making process. Participation in this context might include being involved in and consulted on the decision in question from an early stage, being asked to give evidence either to a professional or the court, writing a statement or attending court and speaking to the judge directly. Participation by the person who will be affected by the capacity decision is essential. The long held view of disability rights activists has been that there should be "nothing about us without us" (Charlton, 1998). Yet, in many ways, this does not seem to have been the experience of disabled people under the jurisdiction of the MCA. For example, a recent report on proposed changes to the MCA commissioned by a Disabled Peoples' Organisation, Inclusion London, found that disabled people do value the right "to have decision-making autonomy" and advocacy is a key element of that right (Loomes, 2019:3). Yet there was a stark contrast in their findings between disabled people who responded to the research and non-disabled respondents. For example:

> *For Disabled respondents, the right to be supported to make their own decisions is unequivocal. Their responses demonstrate a strong attachment to this right […].*

> *The contrast presented in the responses of non-Disabled supporters is of concern. In particular, the degree to which they represent equivocation regarding the rights of individuals to access decision-making autonomy […]. (Loomes, 2019: 10-11)*

Therefore if disabled people, who are most often impacted by the MCA, view participation in decision-making as a right to which they have a strong attachment, then there is a strong case for participation by the subject of mental capacity law proceedings (typically referred to as ″P″). However, if their non-disabled supporters are less attuned to this right, it may lead to a failure to facilitate participation in practice. This is confirmed by evidence from two recent studies regarding participation in the CoP, which suggest that P rarely participates (Series, Fennell and Doughty, 2017; Lindsey, 2019). This lack of participation often comes as a surprise to people. Partly, I think, because in most other areas of law the person affected by the proceedings does routinely participate. In criminal law, for example, it is extremely rare for the Defendant to be absent from proceedings as it their participation is seen to be fundamentally linked to their right to a fair trial (Lindsey, 2019). Similarly, in family law proceedings there has been an increasing movement towards participation across the board (Brammer and Cooper, 2011). Yet, within the CoP, P almost never gives witness evidence in proceedings.

Furthermore, P rarely participates in other more informal ways, such as by attending court. P's participation is primarily secured through having legal representation, albeit this does not always take place (Green, 2016). While having a legal representative is extremely important, and litigants have suffered in other areas of law where legal aid has been cut, it misses a fundamental part of justice: the need for the judge to see the person about whom they are making a decision. These cases, as highlighted above, involve life and death medical treatment decisions, the ability to deprive someone of their liberty and the possibility of preventing a person from having sexual (or any form of) contact with their husband or wife. If any area of law requires the judge to face the person who will be affected by their decision, I suggest it is mental capacity law. This is particularly so given the serious consequences of decisions that a person lacks capacity.

Elsewhere I have suggested ways that participation in CoP cases might be improved (Lindsey, 2019). These include legal changes such as amending the CoP procedure rules to include a presumption that P gives evidence in cases that reach the court. Additionally, greater funding and availability of special measures would be an important step forward in facilitating participation. Special measures include things such as allowing P to attend court before any hearing through a familiarisation visit or allowing P to give evidence remotely via video link. Of course, a broader change is needed in social attitudes to fully incorporate disabled people into society and ensure that they are able to participate in decisions that fundamentally have the potential to change the course of their lives. However, at the very least, I suggest the law has a duty to facilitate their participation.

Concluding Remarks

This chapter has provided an overview of mental capacity law in England and given an insight into how health and welfare cases are dealt with in the CoP. As has been emphasised throughout, many health and welfare CoP cases involve adults with learning disabilities and mental health difficulties, despite there being no specific medical criteria in that regard under the MCA. The essay has aimed to highlight the jurisdiction of the MCA and how it applies to disabled people. That is not to suggest that decisions should never be made on a person's behalf. There may be instances where there is necessary, for example where they are minimally conscious. However, I have highlighted some of the challenges with a paternalistic approach that allows the decisions of adults to be overridden.

Empowering individuals affected by mental capacity law to make their own decisions may not be easy. Legal change is gradually taking place, particularly with the impact of the CRPD. However, attitudinal change towards disability is also required. To some extent this means that professionals, whether social workers, doctors, nurses, police, will need to get used to providing support and allowing "unwise" decisions to be made. That does not mean that people should be left unsupported and unsafe, but that attempts should be made to engage with and identify the support needs of that individual rather than forcing them down a particular route through substituted decision-making. While many of us take the advice of others when making health and welfare decisions, we do so in the expectation that when something is important to us, or does not fit with our values, we can say no and pursue our own life goals. The aim of this chapter has been to highlight that this is not always the case for people subject to the MCA.

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9. Questioning the patient participation imperative

Ewen Speed, Susan McPherson and Peter Beresford

Introduction

In the respective worlds of healthcare research and healthcare provision, an insistence on Patient and Public Involvement (PPI) is ubiquitous. Numerous national policy documents in the last ten to fifteen years have stated and restated the legal obligation for health and local authority commissioning bodies and service providers to involve patients and members of the public in the design and delivery of care. This is now commonly referred to as PPI and encompasses the involvement of family, carers and anyone who might use health and social care services, and public health services. The 2007 Local Government and Public Involvement in Health Act (n.p.) established a legal obligation for every local authority to make “contractual arrangements for the purpose of ensuring that there are means by which [PPI] can be carried on in the area”. This included the requirement for “promoting, and supporting, the involvement of people in the commissioning, provision and scrutiny of local care services”. Similarly, the National Health Service (NHS) constitution sets out PPI as a right of patients to be involved in decisions about their own care as well as in the design and delivery of services, and is at the core of key health legislation (Department of Health, 2007; HM Government, 1983, 2005). In this vein, the 2010 White Paper Liberating the NHS (Lansley, 2010), the policy document that underpinned the 2012 Health and Social Care Act, established HealthWatch, a ‘consumer champion’ with a statutory remit to ensure PPI occurs locally and nationally.

As such, in a myriad of ways, throughout the UK healthcare system, across NHS bodies and others, such as the National Institute of Health and Care Excellence (NICE), PPI has been incorporated in a formal way into structures and decision making processes. The patient and public participation policy for NHS England states that PPI should be incorporated into aspects of governance, clinical strategy and management (NHS England, 2017). For example, Clinical Commissioning Groups (CCGs) must now have PPI members acting as full members. Similarly, NHS Trusts usually have PPI groups who are involved in board level work and feed into service development at various levels of the organisation.

In the context of healthcare research, this PPI imperative is evidenced in the requirement that anyone applying for National Institute of Health Research (NIHR) funding is required to demonstrate, in their application, that their proposed project meets a set of stated PPI criteria, which are purportedly designed to ensure that patient and carer voices are included and consulted in any funded research project. The NIHR is the state-funded body which commissions health-related research. Across the numerous NIHR funding panels, there were 50 lay members during 2016/17 and 187 lay individuals were involved in reviewing applications (NIHR, 2017). Similarly, all NICE Guideline Committees have a minimum of two lay members who can “provide a lay point of view”; NICE also has a “Citizens Council” of 30 members to give views on “moral or ethical questions important to NICE” (NICE, 2013, n.p.). In addition, some medical publications, such as the *British Medical Journal* (BMJ) now require all submitting authors to report on the extent of PPI in all articles submitted for publication (Wicks *et al.*, 2018).

On the face of it, this expansion of patient and public voice appears to be a positive development. However, this expansion is not universally endorsed or applauded and there are a number of reasons why. In this chapter we address some of the main components of a critique of PPI which concern the nature of the political imperative for PPI; the potential for tokenism; and the tendency of PPI in its dominant technical manifestations to exacerbate rather than reduce the marginalisation of disadvantaged groups in society.

Questioning the participation imperative

Underpinning the drive for PPI is a prevailing orthodoxy that encumbers western democracies, all typically seen to be labouring under a democratic deficit (Norris, 2011; Madden and Speed, 2017). Purportedly, as the rise of PPI shows, there is a perception that an increase in levels of public participation in public life and decision-making will improve the public services that are available. This begs a question (perhaps best left unanswered) as to whether increased suffrage in the UK has led to more representative democracy. The act of giving someone a voice (or a vote) is not the same thing as acting upon what that voice says.

The embedding of PPI in the UK healthcare context has to be regarded as part of a wider ‘participatory shift’ in policy which encourages citizens to participate in democratic decision-making by actively contributing as partners, collaborators and consultees in political processes (Petersen and Lupton, 1996). This crosses over into a wider political context (national and international), marked by shifts toward models of new public governance which push involvement toward a more consumerist model, “in which the relationship is between the layperson and a particular service or organisation” (Taylor, 2007: 100-101). This move is often legitimated by concomitant shifts which regard “people as citizens with rights to receive public services and responsibilities to be involved in their development and accountability" (ibid.). This 'rights and responsibilities' trope is redolent of New Labour social policy. Frequently, this appeal to public participation is dressed up in rhetoric around increased accountability, and, after Hirschman (1970), questions of 'voice' and 'choice'. That is to say, the appeal to PPI is often couched in assertions that this will make 'wasteful' professionals more accountable to the taxpayers who are making the provision of the service possible. This false equivalence between publics and paymasters is one that more ultimately appears to suit politicians looking for a stick to hit the professions with, than it does any members of the public (see Speed, 2018).

This would suggest that a powerful critique of PPI as policy is that it functions to mobilise patients (or more specifically, patient expectations) as a means of constraining the professions. In this respect, PPI functions as a means of moderating the power of professionals in the dynamic between government and doctors. Salter (2004) identifies a triangle of mutual benefit which acts to offset the expectations of constituent actors (e.g. the government, the medical profession and the public). The public expectation that government provide a population-level of healthcare provision is met through a mutually beneficial contract between government and the professions, whereby the professions are granted autonomy in return for providing population healthcare. In turn this keeps the public happy. Recent changes in policy, such as payment by results, and the push towards patient-centred medicine, have corresponded with an attempt by government to inveigle its way into the perceived trusted relation between the public and the medical profession. This can be evidenced in the dominance of New Public Management-derived command and control metrics, coupled to a rhetoric around wasteful professions. These were developed from the 1980s as an approach to running public service organisations based on a commitment to private sector ideology, premised on the idea of making public service more 'business-like'.

These dynamics between professionals, the public and the state have a complex history in the UK relating to the status of medicine as a state function (versus medicine as a private function) and the role of medical compulsion, for example state vaccination programmes (see Durbach, 2005). Up to and even after the 1858 Medical Act, which outlawed unqualified doctors, medical professionals competed for their livelihood with heterodox practitioners such as herbalists. The public were (and to some extent still are) amenable to a variety of theories about health and illness and tended to distrust state intervention. The British Medical Association (BMA) became increasingly protectionist in the early twentieth century in a drive to reduce the influence of heterodox practitioners (denigrated as 'quacks') and to draw a boundary around what constituted acceptable medicine. This involved, among other strategies, public education on scientific principles (Weatherall, 1996). At that time, doctors and the public alike distrusted any proposals for state-funded health programmes as the idea was associated with military-style dictatorship designed to curb public freedoms; a hangover from British military medical compulsions imposed on soldiers conscripted during World War One. A proposal for a fully-funded state service put forward by the Minister for Health in 1920 was roundly mocked and dismissed by professionals and media alike (see *The Times*, 24 November 1920). But when the BMA realised that state-funded programmes would employ many of its members and provide a good source of work for BMA members to the exclusion of the herbalists, they were more enthusiastic. This meant that the BMA relinquished its opposition to a state-funded service for the treatment of sexually transmitted diseases, and later to maternity and infant health centres, which emerged in Labour-run councils in the 1930s (Evans, 1992). A growing and gradual acceptance of the need for a role for the state in terms of the provision of medical care was evidenced in the 1948 establishment of the National Health Service; but tensions between this triumvirate (the individual, the state and the medical profession) over who had responsibility for what, in terms of our bodies (and minds – for example, psychiatry) has remained. As in any triumvirate, the risk for the public and patients is that rather than having an equal share of power, their voice is used as a pawn in a bilateral power struggle between the two more powerful organisations.

Tokenism

This leads us to the issue of tokenism, where people are typically offered a say in proceedings, but where their voice is not necessarily listened to. Issues of power dynamics and identity are at the heart of recent criticism that PPI has tended to be tokenistic and has failed to allow full democratic engagement of service users (Madden and Speed, 2017; Abahney *et al*., 2018).

In spite of a comprehensive strategy for involvement of lay people in NIHR processes (NIHR, 2017), the net result of these policies means that the role of lay people remains largely circumscribed to what are deemed to be lay matters. Similarly, the role of lay persons on NICE committees tends to be focused on lay issues. NICE offers a number of clinical guidelines, comprised of current best international evidence for the treatment of specific conditions. These guidelines are intermittently updated, to take account of new or emergent evidence. This was the case for NICE depression guidelines in 2018. In terms of lay involvement in the drafting of the new guidelines, the role of lay persons was described as "providing advice on outcomes most relevant to service users and carers, helping to ensure that the evidence addressed their views and preferences, highlighting sensitive issues and terminology relevant to the guideline, and bringing service user research to the attention of the Guideline Committee"

(NICE, 2018, n.p.). The task of systematically identifying, assessing and synthesising 'scientific' evidence for NICE guidelines falls to guideline developers who work in teams with significant resources and skills allocated to the task; this information is then fed into the guideline committees. This sits in stark contrast to the notion that two or three lay individuals on a committee become alone responsible for drawing alternative forms of experiential knowledge to the attention of the rest of the committee. There is a clear hierarchy in terms of types of knowledge and differential functions and roles of committee members. Where publishing requirements are concerned, as in the example of the BMJ noted earlier, the author requirement is merely to make a statement about PPI, not to have given it serious consideration or actually undertaken any. A statement could simply read 'there were no patients or members of the public involved in producing this article'.

Tokenism can play out particularly in the context of PPI in mental healthcare. For example, Hodge (2005) examined a small-scale implementation of top-down PPI policy by analysing the discourse of members of a mental health service user forum in an English city. The case study examined the extent to which it was possible for patient contributions to forum discussions to have equal value in the context of an existing power differential. While the forum membership represented a range of service users, the forum itself was instigated by and supported by the more powerful mental health agency. Because professionals were present, typically the participants were construed as having less 'competence' in relation to the professional experts. This highlights something that service users identify as a key issue, and draws attention to the difference between PPI as a system-led policy and a grassroots user empowerment movement driven by and from within the community. A review of PPI practices in mental healthcare (Storm and Edwards, 2012) found barriers to PPI were characterised by concerns about capacity and severity of illness, and questions around particular prejudices of staff about the capacity of patients identified as psychotic or aggressive to be involved in care decisions.

Issues of power differentials are reiterated by McDaid (2009), examining service user participation in advisory committees in Ireland. She highlighted the inequality intrinsic in professional-service user relationships and noted that structural disadvantages need to be addressed to facilitate more meaningful participation; participation will not of its own accord break down structural inequality and may in fact reinforce it. Tokenism in PPI might therefore be seen as a symptom of the underlying political imperative which is more concerned with limiting the power of professionals than increasing the power of patients and the public. It might also be seen as a potential cause of those instances where PPI tends to mirror and even exacerbate existing structural inequalities.

Mirroring marginalisation

As noted earlier, asking whether democracy has become more representative as a result of PPI offers only a limited perspective on the field. Another critical question is about what impact this increased representation has on people experiencing inequality and disadvantage. For example, have increased opportunities for voice functioned to move people out of a marginal position, where they are more empowered and more able to participate in civil society?

In 2018, the NIHR published a review of progress in their efforts to develop and implement public involvement in research (Staniszewska *et al.*, 2018). This review identified a number of barriers and enablers to progress including attitudes, resources, infrastructure, training and support and leadership. In terms of ensuring the integrity of ongoing PPI processes, the review identified the importance of evidence to underpin practice and continuous improvement. Co-production was also identified as a concept central to strengthening public involvement. What is missing from all of these barriers or enablers is any nascent or extant social context for how we might think about questions of participation.

The evidence suggests that attempts to involve people in policy and practice are more likely to mirror the exclusions of traditional politics and policy processes than overcome them. Shaping Our Lives, a 'user-led organisation' (ULO) undertook a Department of Health-funded research and development project called 'Beyond the Usual Suspects'. This project found that there were five key groups that tended to be seen by service users as excluded and marginalised by schemes to involve patients and service users. Such groups were excluded according to:

- Equality issues: on the basis of gender, sexuality, ethnicity, class, culture, belief, age, disability and so on;
- Where they live: if they are homeless, travellers, in prison, in welfare institutions, refugees and so on;
- Communicating differently: if they do not speak the prevailing language, it is not their first language, they are deaf and used sign language, and so on;.
- The nature of their impairments: if these are seen as too complex or severe to mean they could or would want to contribute;
- Where they are seen as unwanted voices: if they do not necessarily say what authorities wanted to hear, are seen as a problem, disruptive, and so on. These include neuro-diverse people and people affected by dementia.

Key routes to challenging these exclusions include reaching out to involve people, rather than expecting them to come to you, developing more accessible and inclusive approaches to involvement and outreach work with conventional and other community leaders (Beresford, 2013).

These issues point to a need to consider the interplay between health and participation in social life. We know that a long-term condition mediates the ability of people to meaningfully participate in social life because of the barriers they are likely to face, so for example, limiting their ability to undertake paid employment (Bambra, 2011). We also know this difficulty can extend to their family or carers. We further know that there is a social class gradient for health and illness (Arber, 1987) and that people who are from more disadvantaged backgrounds have higher rates of mortality and morbidity, and that they frequently die at a younger age. We also know there is an inverse care law (Hart, 1971), where those most in need of care are least likely to receive it whilst those with least need of healthcare tend to use services more.

In the context of PPI in healthcare services and research, it would seem obvious that these relationships between social context and health will also apply to the ability to take part in PPI. We might therefore ask, how does PPI help marginalised and excluded groups who are bearing the brunt of myriad, health, cultural and economic inequalities? Any period of illness, whether it is chronic or acute, life-limiting or a temporary inconvenience, has a very real impact upon a person's ability to participate. These participation imperatives seldom acknowledge this issue or put in place arrangements to ensure necessary physical, communication, or cultural access. PPI is geared towards those who are already in the system, and therefore, it might be argued, is actively failing to engage those groups in society that it should.

Another important and neglected component of this participatory 'zeitgeist' is the question of stigma. This is a crucial issue in understanding barriers to participation, but yet again, it does not appear as an explicit feature of much of the participatory imperative. This line of argument suggests two outcomes. Firstly, that participation, as it is considered in terms of healthcare, is conceived of too narrowly, with the net effect that many people who should be included continue to be excluded. This is connected to the second point, that this continued exclusion underlines the deficiencies in this existing model, and highlights the need to identify alternative ways of thinking about participation that will address these failings. And, it should be borne in mind, that such reconsideration may include the need to broaden how participation is considered and operationalised.

In this context, it is imperative that participation addresses its own democratic deficit. Drawing from the work of Dean (2017, 2018, 2019), we identify a need to consider underlying processes of sociality and negotiability in participatory practices. Sociality relates to the extent that participation is seen to be either agonistic or solidaristic. Agonistic participation is "conflictual with individuals and groups predominantly concerned with promoting and defending their own interests and values against other participants" (Dean, 2017:4). Solidaristic participation is where, "participants view themselves as interdependent members of a social collective and participation is oriented towards collective ends and the common good" (Dean, 2017:5). In the context of inverse care laws and social class gradients, it is imperative that any participatory practices address the solidaristic component, enabling questions of social justice to be interpolated into the debate, and moving beyond narrow questions of self-interest and ongoing exclusions.

In terms of questions of negotiability, this relates to how the conditions of participation must be determined by the participants themselves, as part of the practice of participation. In prevailing participatory processes, issues of who participates and how they do so "are determined outside of the space (perhaps by the commissioning organisation, perhaps by circumstance) and imposed upon the participants, who thus have little scope to determine the conditions of their participation" (Dean, 2017:5).

In turn, this also serves to further push the wider processes and problems of exclusion and social justice into the background.

Alternative paradigms for participation

For some time there has tended to be a conflation of PPI and user-led research or user-led movements as if the two were essentially the same. In fact, user-led movements have different origins and different, conflicting ideological relations. PPI, as implied earlier, derived from an essentially consumerist/managerialist ideology seeking to balance out the power of professionals and inject market forces into welfare services. In contrast, user-led movements have been essentially committed to empowerment and democratisation derived from grassroots movements. With the continuing impetus and impact of neoliberal social policy both in the UK and globally and its association with the regressive restructuring and cutting of welfare services and benefits, it has become increasingly difficult to hold on to such ambiguity. Instead, a growing rift has shown itself between reactionary state and liberatory service user intentions for democratisation of health and social care services (Stewart, 2018; Rose *et al.*, 2018; Beresford, 2019).

The limitations of a technocratic and tokenistic 'PPI' have become increasingly evident during the period of austerity policy and ensuing welfare reforms in the UK. It has become evident that formalised arrangements for PPI no longer offer hope for marginalised groups and that PPI as a policy is ideological rather than a genuine attempt to reduce inequalities. There have been increasing problems with the financial sustainability of user organisations, with closures and decline in numbers owing to reduction in funding of these organisations. Policies have increasingly employed discourse that attempts to make welfare recipients responsible for their own care (for example 'self-care', 'recovery', 'peer support') while in practice subverting empowerment and co-opting concepts of empowerment to support the ideological tenets of neoliberal individualism and managerialism.

This is reflected in the growing concerns expressed by service user movements and organisations as neoliberalism calls into question their activities and even existence, and in their increasing preparedness to articulate their distinct concerns and objectives. Thus while experiencing much suffering in recent years, service users and their organisations have extended both their critiques and their action in relation to health, social care and other policies and services (Beresford, 2019).

This increasing sense of disempowerment, disillusionment with PPI, and further marginalisation has led to what might be seen as a renewal in marginalised groups' activities to challenge exclusion and to campaign for more inclusion. The demands for more say and control in and over their lives from disabled people, service user movements and organisations has emerged in parallel to the development of PPI discourse and critiques of it. This arguably offers an alternative paradigm in which participation comes from a grassroots movement rather than a tokenistic policy imperative (see Windle and Chibulka, 1981). These demands have focused on campaigning for wider involvement (for example, Shaping Our Lives); greater involvement in professional and occupational training (for example, 'PowerUs' in social work education); and involvement in health-related research and knowledge production (Askheim *et al.*, 2017; Beresford, 2018).

While there have been overlaps, here the call has primarily been for 'say' and 'control', rather than just 'involvement' or 'engagement'. This has been reflected in the language used, which has primarily been framed in terms of service users being in control, for example, 'survivor controlled research', 'user-led research' and 'emancipatory disability research', with the constituencies previously positioned on the receiving end of research now explicitly identified as leading or shaping it. Now its purpose is redefined to privilege the individual empowerment of such constituencies, as well as the need for broader political and social change to challenge the barriers they face – rather than the mere accumulation of data. This purpose is also to be achieved by a changed ethics of research which treats the research participant and their experiential knowledge as having equal value to and validity as the researcher (Faulkner, 2010; 2018).

A further development in this domain has been that of 'Mad Studies'. This term represents an emerging academic field concerned with mental health in which there is an explicit divorce from the biomedical model – enabling other disciplines to have influence. There is an explicit value placed on first person knowledge, giving individuals the right to speak about themselves and their own context when discussing research and knowledge production. Survivors' first-hand knowledge has equal value with scientific knowledge (Le Francois *et al.*, 2013). One form of knowledge is not privileged over other forms, rather all forms of knowledge are considered in terms of what they might contribute to more progressive understandings of madness.

These developments represent both strategies and objectives far removed from the narrow abstracted focus of a technocratic PPI, raising further questions about and offering some prospect on the role of service users, even in difficult times – in turn seeking to point out how we need to consider renewing both debates and developments around involvement in inclusive and anti-discriminatory ways.

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10. The need for inter-professional working between teachers, health and social care professionals

Francine Bailey

I have been working for eight years with teenagers who have been out of school long-term with extreme anxiety. The volume of young people being referred out of mainstream schools to alternative education provision with anxiety has reached shocking proportions. The *Guardian* recently ran a front page article on the crisis point of Special Educational Needs provision for young people in this country, stating that "Children with special educational needs and disabilities (SEND) are being failed by a system 'on the verge of crisis' as demand for specialist support soars and threatens to bankrupt local authorities" (Weale and McIntyre, 2018, n.p.). I believe that this crisis was caused by the decision 18 years ago to close special needs departments and special needs schools, and to focus on 'inclusion', without any teacher training on how to fully understand the health and behaviour issues of young people with SEN.

As a teacher, between 2002 and 2007, I witnessed the collapse of a secondary school in Sheffield that had an incredible reputation for working with young people with SEN. It had a highly successful special needs department, in which the young people felt safe, and wanted to be in school. The exceptional staff who led this department ran training events across the country on how to work with Special Needs. Teachers went to the Special Needs Classrooms, to work with the small groups in each Special Needs class, with their Teaching Assistants (TAs) who were with them all the time, and who they knew really well and trusted. The national curriculum could be bypassed for these classes, and lessons could be designed utterly to suit the needs of the young people in the room. The art classes were highly kinaesthetic; we made life-sized cardboard sculptures of guitars, cars and microphones, and role-played a 'Feeder gig' and the 'Grease Lightning' driving scene. All the young people in the room, with a huge variety of Special Learning Needs and Statements of Education, were completely engaged.

A Statement of Education is:

> *a document which sets out a child's SEN and any additional help that the child should receive. The aim of the Statement is to make sure that the child gets the right support to enable them to make progress in school. A Statement is normally made when all the educational provision required to meet a child's needs cannot reasonably be met by the resources within a child's school at School Action or School Action Plus (known as Early Years Action or Early Years Action Plus in Early Years Settings).*
>
> *Most children with SEN should have their needs met within a mainstream school. Before a Statement will be considered, additional help may be provided to the child at School Action. If the child still does not seem to be making enough progress then the school may seek advice from external professionals at School Action Plus. If this additional help is still not enough then the child's school or parents can apply to the LEA for a Statutory Assessment of the child's SEN in order to try and obtain a Statement of SEN. (Douglas Silas Solicitors, 2018, n.p.).*

However, after the Government's Inclusion Policy was made compulsory, this Special Needs Department had to shut. A 1997 Green Paper entitled "Excellence For All Children: Meeting Special Educational Needs", stated "an increasing proportion of those children with statements of SEN who would currently be placed in special schools will be educated in mainstream schools" (n.p.). This led to the Special Educational Needs and Disability Act (May 2001), which made inclusion mandatory, but without the provision of compulsory SEN training for mainstream classroom teachers. This had a catastrophic impact on my school, which had 600 of its 1000 pupils on the SEN register. The young people with Statements of Education were dispersed across the school, without their TAs, and bedlam ensued. These young people no longer felt safe. Many stopped coming to school, became involved with anti-social behaviour outside school, and had ongoing problems with the police. Those that stayed in school could not cope in classrooms of 30 children, so poor behaviour escalated, and the three to five statemented students in each class would then soak up the attention of the teacher, affecting the learning of the other 25-27 students in the room. The school steadily fell into decline, many teachers went on long-term sick leave with stress or resigned, and the school eventually went into special measures.

Other commentators share this view. In April 2004, the *Telegraph*'s Education Correspondent, Liz Lightfoot, wrote:

> *The education of all children is being harmed by the Government's 'disastrous' policy of closing special schools and sending pupils with learning difficulties and unruly behaviour into mainstream classes. The second biggest teacher's union called for an end to the closure of special schools saying the 'one size fits all' model of inclusion did not serve the needs of some of the most vulnerable children and disrupted the education of others. David Blunkett brought in the inclusion policy when he was Education Secretary in 1997. He said at the time it was inspired by the experience of feeling 'separated out' from society at a boarding school for the blind where he was denied the opportunity to gain national qualifications. Mavis Garnett, from Kirklees, commented that "however admirable in principle, the reality of inclusion was unworkable. The special needs assistant who signs for the hearing impaired pupil gets in the way of the large screen computer provided for the visually impaired while trying to avoid the open route way required by the physically disabled while not obstructing the language specialist" (Lightfoot, 2004, n.p.).*

18 years on, I am fully seeing the effects of this disastrous decision on a national level, with thousands of young people across the country with SEND not feeling safe or understood in school, and so falling out of the mainstream school system. The only special schools that still exist have huge waiting lists, and are often not geared up to cope with autism and young people with anxiety. Autism Hubs are beginning to be implemented across the country. In Essex:

> *Essex Local Authority has worked in partnership with a network of primary and secondary mainstream schools to develop specialist autism support centres. There is a primary and a secondary school with this provision in each of the four Essex quadrants. While many pupils with autism already attend and succeed in their local mainstream schools, there are others with more complex needs, including high levels of anxiety, who require further specialist support.*
>
> *The new centres aim to enable those young people who are of mainstream ability but may have high levels of anxiety as a result of their autism, to access mainstream schooling and spend most of their time in classes alongside their peers. Admissions will be managed by the council's SEN Statutory Assessment Service, working in partnership with the schools. All of the pupils admitted will have an Education, Health and Care plan. (Essex County Council, 2017, n.p.)*

However, these centres cannot be accessed by young people who have already become too anxious to set foot in a busy playground, and barely touch the surface of the vast numbers of young people who are out of mainstream education as they 'do not fit' the current education system. Many young people with SEND do well in mainstream schools, as they are academically able enough to cope, and the levels of support provided suit their needs, but many other young people with SEND struggle academically and 'do not fit' the current system. I am now retraining as an occupational therapist, as I can no longer see how I can fully help young people with special mental health needs, when I have absolutely no training in mental health.

My teacher training, 19 years ago, did not mention SEN. It skirted across the variety of learning styles, such as kinaesthetic and visual, but was very much subject-specific. During a first year Occupational Therapy BSc lecture on inter-professional working, a speech therapist was interviewed on the theme of inter-professional working. She felt strongly that there is a need for teachers to be trained alongside health practitioners; in other words, to be trained inter-professionally. This struck me as absolutely the best way forward. As a teacher, I never had any training on how to understand or to work with special needs. In my subsequent experience as a teacher, such training would have been invaluable.

It is a relief to talk to people currently in teacher training, who, as from this year, will have to cover special education needs in some depth, attend a placement in a special needs school, and write an assignment on a special health or learning need of their choice. These changes have been introduced thanks to Stephen Munday, who was commissioned by the Secretary of State for Education to develop a framework of core content for Initial Teacher Training (ITT) in England, following Sir Andrew Carter's report on ITT published in January 2015. This report highlighted that there were "significant gaps in a range of courses in important areas such as […] special educational needs and disabilities" (Carter, 2015:6). In May 2016, the *Independent* reported that:

> *In response to a question posed during Prime Minister's Questions, Chancellor George Osborne confirmed the Government's intentions to make autism a mandatory training subject for teachers in England. "My right hon. Friend has stressed the importance of ensuring that teachers are properly trained to support young people with special educational needs and specifically autism. As a result, the chairman will include recommendations in the report on how core teacher training should cover*

> *special educational needs. He said: "The Education Secretary shares her concern and has personally raised the issue with the chair of the initial teacher training review, Stephen Munday". (Pells, 2016, n.p.).*

This has now led to the core content for this year's PGCE students finally including provision for new teachers to be trained how to adapt their teaching strategies "to ensure that pupils with SEND (including, but not limited to, autism, dyslexia, attention deficit hyperactivity disorder (ADHD), sensory impairment or speech, and language and communication needs (SLCN)) can access and progress within the curriculum". Furthermore, providers are required to "ensure that SEND training is integrated across the ITT programme" (Department for Education, 2016: 17).

Another exciting step towards achieving the goal of teachers, health and social care professionals working effectively together is in the ground-breaking work of Peter Fonaghy, the chief executive of the Anna Freud National Centre for Children and Families (AFNCCF), who is in the process of setting up a new school in Norwich. "The proposed Your Place academy in Norwich has had input from leading psychiatrists and psychologists and aims to create a template that could be copied elsewhere" (Weale & McIntyre, 2018, n.p.). According to the *Guardian*, in this school teachers and healthcare professionals will work side by side. It aims to be the "UK's first school for children who have experienced early-life trauma such as neglect or abuse and are currently being failed by the education system. The short-stay school would provide children aged four to seven with therapy and education to prepare them to re-join mainstream schooling". The article also emphasises that:

> *As well as helping troubled children and their families by preventing exclusions, the Your Place team estimates it can deliver £8.7m of savings within five years. If one were opened in each of the 152 local education authorities in England and Wales, this would translate to £1.3bn over*

> *the same period. The benefit over the longer term would be far greater as the figures do not take account of potential costs such as demands on the health, welfare and criminal justice systems. (Weale & McIntyre, 2018, n.p.).*

As this report suggests, there are high social and economic, as well as personal and educational, costs to the failure to adequately provide for children with SEND. How has the situation ended up this bad? There have been attempts to make the policy of inclusion work, but for various reasons, these have not been successful. For example, in 2014, a significant change in SEND provision was made that had the potential to provide greater levels of support to young people with SEND via inter-professional working. In September 2014, as part of the Children and Families Act, Statements of Special Educational Needs were replaced by Education, Health and Care (EHC) Plans in England. These plans aimed to improve:

> *joint work across education, health and social care services and agencies with an assessment coordinator taking the lead; participation in decision-making by children, young people and their families; the focus on outcomes; its scope by covering children from 0-25, including colleges, academies and free schools; the distinction between statutory (must) and non-statutory (should) duties on schools, local authorities and joint commissioning. (HemiHelp, 2014, n.p.).*

Yet although young people now need EHC Plans to access special support in schools, in reality there is hardly any communication between the education, health and social care professionals involved in each young person's support.

In theory, the annual reviews of each young person's EHC Plan are an ideal opportunity to bring education, health and social care professionals together. However, there is often confusion from the Education Commissioners over who to invite, with the result that these reviews are often education-heavy, and health and social care professionals are not even invited. I have been to many reviews where social workers, doctors and even surgeons have been present; these have been highly successful reviews, and because the student has had adequate support from all the organisations involved, they have been able to progress well back into education. But when families who do not have a social worker, or the student's anxieties are so severe that they struggle to attend their medical appointments, reviews are less successful.

The Government renamed the student's SEND documents as EHC Plans, rather than Statements of Education, to reflect the belief that there should be an equal weighting between the education, health and care support of these young people. However, often the healthcare or social care thirds of the EHC Plan are completely missing. This must change in order for the needs of all young people out of mainstream education to be fully met. It is vital that education, health and social care professionals work inter-professionally. The government spent time and money changing the Education Statement to an EHC Plan. I believe this is actually a good idea, but only if education, health and social care professionals are able to work inter-professionally. Otherwise it is simply a money-saving exercise with no real intention to fully help the young people it is supposed to support. My personal experience bears this out. At two recent annual reviews I attended, there was no representation from health or social care professionals. When this was queried, both of the different commissioners involved said, with varying words, "This is an Education Review, I know it's called an Education Health Care Plan Review, but it's about Education".

The cases that I have witnessed are extremely distressing. One student who became a school refuser due to anxiety, and so was referred to a special needs school, became so school-phobic that he could not set foot in the school building. After months of not getting beyond the school car park, he was allotted an outreach support worker from the school to try and engage him to be able to go into the school building. However, funding for this support stopped, and the student's confidence in leaving his house with anyone at all diminished to the extent that he became fully agoraphobic. Any trips out of his house, even to the shops, would trigger weeks of insomnia. He was out of school for nearly two years before he was referred to an organisation that could teach him in his own home, for as long as was necessary, to try and engage him to connect with the world around him, without fear of funding cuts. His mother tried to get him counselling through Child and Adolescent Mental Health Services (CAMHS), but funding restraints meant that he had only two outreach visits. As he was unable to leave his room for either of these visits, he was discharged. Because he was nearly 18 years old by this point, he was supposed to be referred to the Mental Health team at Adult Social Services. However, as this student has a diagnosis of autism, there is confusion as to whether he should be referred to the Learning Disability or Mental Health team, so the referrals keep bouncing from one department to another. Meanwhile, this young man is unable to leave the house, and his mental health is deteriorating. A few months ago he could build himself up to a cinema visit, but now even that is impossible, as his anxiety about noise and crowds has worsened. He cannot even attend doctor's appointments. An unconsidered impact of his agoraphobia is that as he never leaves the house, he never wears shoes, so is also beginning to develop foot pain.

At this student's annual review, there were no representatives from health or social care. A specialist employment and skills adviser was invited to the Review, but it became apparent that this young man would not be able to engage with any work or college placements until his anxiety had been worked through. The only partners of the EHC Plan who would be able to tackle this aspect of his problems, the health and social care thirds, were completely absent from the Review. This case vividly illustrates how the potential of EHC Plans is lost through lack of inter-professional working, and lack of understanding from high up the system as to who should be responsible and involved with the process. In this student's case, the social care team did not show awareness of the urgency of the case, as he was shunted between different parts of the system. In part this is because they did not have access to all the information about his case, perhaps because of lack of involvement with his annual reviews. Serious problems are caused by the inability of different organisations involved in the care of an individual to access relevant information. The only way to remedy this lack of engagement would be to refer this student to the Vulnerable Person Panel which includes members from statutory organisations and non-statutory organisations providing support to individuals and their families. Once an individual has been referred to a Vulnerable Person Panel, personal information can be shared for the purposes of early intervention to provide support to individuals, to prevent crime and disorder or anti-social behaviour, and for safeguarding and promoting welfare of adults at risk of abuse and harm (Nottinghamshire County Council, n.d.). Richmond's Vulnerable Adult Multi-Agency Panel states:

> *We have formed the Vulnerable Adult Multi-Agency Panel in partnership with other organisations to consider cases of adults who remain at high risk of harm despite previous intervention efforts.*
> *The panel includes representation from Richmond Adult Social, Housing and Mental Health Services as well as the Metropolitan Police and London Fire Brigade.*
> *The purpose of the panel is to ensure that multi-agency communication and information sharing takes place on a regular basis.*
> *One of the key changes in the Care Act with regard to safeguarding is to give consideration to 'Self-Neglect' as a form of adult abuse or neglect.*
> *The role of the panel is to discuss all available options for increasing the safety of the adult at risk and to develop a co-ordinated action plan (Richmond Council, 2019, n.p.).*

One of the warning signs that indicates self-neglect is non-attendance to vital health appointments – clearly relevant in the case discussed above.

In the past, these panels were only used for crime prevention, but their remit has been widened to include people in the care system, and those at risk of social isolation and poor mental health. The Vulnerable Person's Panel has a legally binding information-sharing agreement, and so has a much higher status than an EHC Plan review. All partners involved in an individual's care are legally obligated to attend this panel. Is legally binding partners to attend meetings the only way to get organisations to work inter-professionally? This is perhaps the only way to ensure that all partners are able to discuss the mental health concerns of an individual, and so create the meaningful changes that will positively alter a person's life – with the support that should have been provided in the first place by the EHC Plan.

Why do these failures in the system occur? Again, the case described above provides some clues. For this young man, and for others, there is the expectation that a young person with autism will learn how to cope with their autism through their education support, and often therapy is not even suggested. Healthcare professionals can give young people with autism strategies on how to cope with daily life. However, until now, teachers have rarely been trained in how to work with autism, and such training was not mandatory. It has been entirely up to their employer to decide whether to implement relevant training or not. But at an annual review, a teacher is not allowed to ask for their student to be referred for therapy, as it is not in their remit. So if no healthcare professional, who does have the remit to refer the student for therapy, is invited to that Review, how is that student supposed to move forwards?

Politicians who regularly rewrite education policies only ever seem to consider short-term money-saving goals. They consistently fail to comprehend the impact that these new policies have on the lives of people in the long term. Funding that is taken away from education at the beginning of a child's life then has to be spent ten times over later on – on more expensive alternative education provision, on health needs generated by inadequate provision for a student's multiple needs, and even on prisons provision for the young people that have been failed by inadequate education systems. Young people excluded from mainstream education feel excluded from society, and this has a huge impact on their mental health and wellbeing, and their ability to function in life first as children and then as adults.

Teachers are trained as teachers; healthcare professionals as healthcare professionals; and social workers as social workers. There is currently little or no inter-professional working between the three. If the government is so focused on cutting costs that it implements an EHC Plan instead of a Statement of Special Educational Needs, then the three professions need to begin training alongside each other to have any chance of making this system work, and to stop failing thousands of young people across the country who are now at risk of being isolated from society, as well as from school.

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11. Utopia, dystopia, and human flourishing

Sean Seeger

Utopia

Within western literary and intellectual history, there is a rich tradition of thought concerned with imagining alternate societies. This tradition encompasses many strands and crosscurrents, some of them in tension with one another. With footholds in literature, philosophy, religious discourse, political economy, and social theory, it is a lineage which can be hard to define and which sometimes threatens to disappear before one's gaze into the thicket of intellectual currents which surround it. Despite its composite nature, however, and despite some of the difficulties raised by scholars regarding definition, texts in this line are generally known as 'utopias'. Perhaps unsurprisingly given its diverse origins, the utopian genre encompasses a very broad range of texts, written from an array of often incompatible perspectives. Insofar as a common identity can be established, though, one thing that unites such texts is their attempt to envisage a form of society which is an *improvement* on the one inhabited by the author.

The utopian genre has roots in the ancient world, most notably in Plato's *Republic* (380 BCE), a philosophical dialogue that outlines what its author saw as the form of society most likely to afford the good life for human beings. In the case of Plato's idealised republic, this is a society ruled by an elite class educated in philosophy and able to access a form of higher truth unavailable to the majority of the citizenry. It was partly in response to the *Republic* that the early modern English writer Thomas More was to compose his own philosophical dialogue, *Utopia*, first published in Latin in 1516 and translated into English in 1561. The word 'utopia' was in fact coined by More in this work, and constitutes a deliberate play on words, meaning both 'no place' as a result of its Greek derivation ("*ou*-topos-ia") and 'good place' ("*eu*-topos-ia") through being indistinguishable from the word 'Eutopia' when spoken aloud. The ambiguous status of utopia implied by this wordplay has, as we shall see, remained a key tenet of the genre ever since. Scholars of More's work have debated, and continue to debate, his intent in signalling both the desirability and the impossibility of an ostensibly ideal political state. In More's narrative, this takes the form of the society of Utopia, an island-dwelling community located in the Americas. The functioning of Utopia is conveyed to More – who himself appears in the narrative in the guise of a literary character also named More – by an inhabitant of the island, Raphael Hythloday, whose name constitutes another pun, which can be translated from the Greek as either 'nonsense pedlar' or 'expert in nonsense', thereby casting further doubt on how we ought to take the account that follows.

The society of Utopia represents a very significant departure from the laws and institutions of the still broadly feudal society in which More himself was living. Key features of Utopia include the absence of private property, universal healthcare, euthanasia on demand, universal education, lifelong learning, a comparatively short working day, a comparatively generous allowance for leisure time, legal divorce, and religious toleration of all variants of monotheism. It is worth emphasising that these radical innovations, many of which remain a dream for much of the world's population today, flow from the pen of an inhabitant of the court of King Henry VIII. Even if More's *Utopia* were intended as nothing more than a thought experiment or diverting fantasy, it would remain an exemplary instance of the modern habit of imagining alternate societies, and of provoking speculation about how our practices and institutions might be transformed. Framed in this way, More's various attempts to qualify, minimise, and even undermine the vision conveyed in *Utopia* could be seen as a strategy for blunting the edges of the challenge his book indirectly posed to the status quo. While it is highly unlikely that More harboured anything like revolutionary sentiments, it seems equally unlikely that he could have been unaware of some of the more far-reaching implications of Hythloday's 'nonsense'. Whatever More's intentions in writing *Utopia*, by describing a conceivable type of society which differed in essential ways from the feudal regimes familiar to Europeans of the time, he made a decisive contribution to the modern social imaginary, enabling others to follow in his footsteps and engage in further such experiments.

While generally foregoing the layers of irony and misdirection built into *Utopia*, subsequent utopias have retained the basic structure and orientation of that earlier work: to offer something like a 'guided tour' of a society which is, at least in principle, an improvement on the author's own. This improvement can, in turn, take many forms and vary greatly in the extent to which it requires a departure from the world as it stands. Since the early sixteenth century, the *content* of utopia – the nature of the desirable change it anticipates – has likewise undergone many changes, corresponding to wider social and cultural developments. In order to give a sense of the varieties of modern utopia, and of the diverse conceptions of human flourishing it has espoused at different times, it may be helpful to offer a brief overview of some of the competing visions advanced by writers in this tradition.

While some utopias take as their starting point the abolition of the entire existing world order – as in the classless, stateless global communism envisaged by Karl Marx and Friedrich Engels in *The Communist Manifesto* (1848) – others have a more local, small-scale focus – as in Henry David Thoreau's impassioned call for a return to a life of simplicity and self-reliance in *Walden* (1854). Likewise, just as some utopias enthusiastically pursue the advancement of science and technology – as in H. G. Wells's *A Modern Utopia* (1905) – others are built on a rejection of industrialism, often accompanied by a partial reversion to premodern values – as in William Morris's *News from Nowhere* (1890). While some utopias subordinate all concerns to ensuring stability and predictability – as in the 'scientific' utopia of behaviourist psychologist B. F. Skinner's *Walden Two* (1948) – others enthrone aesthetic beauty as the highest good – as in Oscar Wilde's *The Soul of Man Under Socialism* (1891), which looks toward a leisured society where individuals cultivate themselves as works of art. Whereas some utopias are militantly secular, envisioning the abolition of religion – as in Auguste Comte's *The Catechism of Positive Religion* (1842) – others assign religious experience and ritual a central role – as in Aldous Huxley's *Island* (1962), which depicts an isolated utopian community whose ethos draws on various Eastern religions. Just as some utopias are pacifist – as in the nonviolent matriarchal society depicted in Charlotte Perkins Gilman's *Herland* (1915) – so others are more militaristic – as in the case of More's *Utopia* itself (1516). While some utopias regard the natural world as an obstacle to be overcome in the pursuit of material progress – as in the industrial socialist utopia of Edward Bellamy's *Looking Backward* (1888) – others take ecology as their primary concern – as in Ernest Callenbach's *Ecotopia* (1975), which depicts a community that cares for the environment through the responsible, selective use of modern technology. Lastly, while some utopias anticipate the end of homophobia and the liberation of gay people – as in Edward Carpenter's four-volume utopian poem, *Towards Democracy* (1905) – others call for the abolition of gender itself in the pursuit of equality – as in Laboria Cuboniks' *The Xenofeminist Manifesto* (2018).

As can be gleaned from the foregoing list, the nineteenth century was a particularly rich period in the history of the utopian genre. This trend began to slow during the early years of the twentieth century, however, before giving way to a quite different and potentially antithetical kind of writing during the 1920s and 1930s. The consensus among academic commentators on utopia is that this pattern is best accounted for by the impact of new political ideologies, in particular those of the Bolsheviks in Russia and the Nazis in Germany. The utopian ideology and rhetoric of both parties served to encourage the view that any alternative to the liberal-democratic mainstream was liable to devolve into a form of dangerous extremism, with potentially disastrous consequences for society. This view appeared to many observers to be vindicated when the scale and severity of the atrocities committed under Hitler and Stalin began to become apparent throughout the later 1940s and 1950s. It was to receive further support in the wake of events such as the widely publicised and debated trial of Adolf Eichmann in 1961, which provoked deep reflection on the significance of the Holocaust, and the publication of Aleksandr Solzhenitsyn's influential study, *The Gulag Archipelago* (1973–1976), which detailed many aspects of life under Stalinism, including the immense Soviet gulag system of forced labour camps. Taken altogether, these revelations about the Stalinist and Nazi regimes, combined with an awareness of comparable atrocities committed in China under the Communist Party and in Cambodia under the Khmer Rouge later in the century, led many to recoil from utopian thinking of any kind, and to instinctively associate utopianism with some of the greatest crimes of the modern period.

Dystopia

The course of events in the first half of the twentieth century led to a re-evaluation of the utopian genre, often to the detriment of the latter. Many modern utopias look very different in the wake of the Holocaust and the gulag, sometimes revealing sinister aspects which had previously remained invisible. To take just a handful of representative examples, it is hard for contemporary readers to ignore the role of slavery in More's *Utopia*, scientism in Comte's *The Catechism of Positive Religion*, racism in Gilman's *Herland*, and the potential for dehumanisation in Skinner's *Walden Two*. More generally, the uniquely modern phenomenon of totalitarianism has led critics to detect a tendency toward authoritarianism in many classic utopias. Here a single observation may stand in for many. While anticipating in some ways the social democratic welfare states of the mid-twentieth century, More's *Utopia* also bears an uncomfortable resemblance to modern totalitarian regimes. Allowance for personal freedom is negligible in Utopia, privacy is non-existent, and citizens' movements are closely monitored, with even a stroll in the countryside requiring the permission of a local magistrate.

One conclusion that some commentators on utopia have drawn from resemblances of this sort is that utopias are *inherently* authoritarian owing to their need to plan and regulate seemingly every aspect of social life. On this view, there is bound to be a conflict between utopian planning and individual autonomy. If the realisation of utopia requires all participants to live according to a precisely defined template – namely, the template prescribed by the utopia itself – then it would seem that many familiar forms of freedom, including the freedom to express oneself and criticise the existing order, must be sacrificed. This curtailment of freedom would clearly require the exercise of extensive disciplinary techniques in order to prevent any deviation from state-sanctioned ways of thinking and acting. Real-world examples of this highly oppressive combination of unchecked state power and pervasive disciplinary mechanisms abound.

Given these misgivings about utopia as a social and political form, it is hardly surprising that the early decades of the twentieth century would give rise to a kind of writing in which the shortcomings of utopia take centre stage. Whereas the precise origins of utopia are more debatable, having in some cases been traced as far back as the Hebrew Bible, the birth of the *dystopia* can be determined with more confidence. The 1920s, 30s, and 40s saw the publication of three seminal dystopian novels which were to define the parameters of the genre down to the present day. Each of these responds, albeit in very different ways, to the history of utopia which we have been tracing.

Although dystopia as a literary phenomenon was unknown before these decades, the term itself had in fact been coined fifty years earlier. Addressing the British House of Commons in 1868, the philosopher and Liberal politician John Stuart Mill labelled the members of the incumbent Conservative government 'dys-topians', or 'caco-topians' on account of their unsuccessful political and economic policies in Ireland. Mill's own side in these debates having previously been branded unrealistic 'utopians', Mill employed the term 'dys-topians' to signal the harm liable to be done if the government continued to pursue its current course. Like More's 'utopia', Mill's 'dystopia' and 'cacotopia' were of Greek derivation: 'dys' from the Greek "*dus*" meaning bad, diseased, or dysfunctional, and 'caco' from "*kakos*" meaning wretched, hideous, or vile. Although 'cacotopia' seems to have left almost no impression on the English language, by the end of the nineteenth century 'dystopia' had begun to appear sporadically in books, journals, and newspapers. The word appears to have become somewhat more widespread during the 1920s and 30s, but it was not until the 1950s, with the deepening awareness of Nazi and Soviet atrocities, signalled by the publication of books like the political philosopher Hannah Arendt's ground-breaking study *The Origins of Totalitarianism* (1951), that 'dystopia' became an everyday term for any radically dysfunctional society. Nevertheless, despite the term not yet having entered more general circulation, and despite the fact that none of the authors themselves was to apply it to their own work, it was during the late 1890s, 1900s, and 1910s that recognisably dystopian fiction was first to appear. Among the notable initial contributions to the genre we may count H. G. Wells's *The Time Machine* (1895), Jack London's *The Iron Heel* (1908), and E. M. Forster's *The Machine Stops* (1909).

Wells's novella *The Time Machine* has generally been interpreted as a comment on the social divisions of Victorian England. In Wells's story, the scientist protagonist is transported to the year 802,701, where he discovers that humanity has split into two distinct species incapable of breeding with one another: the childlike, surface-dwelling Eloi and the bestial, subterranean Morlocks. Although the device of time travel is a contrivance which distinguishes Wells's story from the more realistic focus of later dystopias, the innovation of using literature to freely extrapolate from current social trends – in this case the widening gulf between the upper and lower classes that Wells observed in the England of his day – was to provide a key component of the emerging genre.

London's *The Iron Heel* is written from the point of view of a scholar in the year 2600, though the events it describes take place during the years 1912-1932. Eschewing the more speculative elements typical of Wells's fiction, London takes as his focus a development which diverges only to a comparatively slight degree from actual history: the rise of a monopoly of trusts – known in the narrative as the Oligarchy – which comes to dominate American society. Like Wells's *The Time Machine*, *The Iron Heel* imaginatively extends various existing social tendencies from London's own time, including worsening inequality, concerted anti-union activity, and the rise of monopolies. Although it has tended to occupy a more marginal position in histories of the dystopian genre, there is a case to be made for seeing *The Iron Heel* as the first dystopian novel.

Forster's *The Machine Stops* is both a dystopia and an important early work of twentieth-century science fiction. This remarkably prescient story describes a society in the distant future in which humanity has become so dependent on technology that it has lost the skills to perform even the most rudimentary tasks without the mediation of machines. In this future, people live underground in isolated cells and all needs are administered by an omnipotent computer known as the Machine. Direct human interaction has virtually disappeared, with most contact taking place via a combination of an early version of instant messaging and video conferencing. Forster's dystopian story constitutes a third important episode in the history of the genre. Its main innovation is to address the dystopian potential of modern technology. In the wake of the Victorian era's faith in scientific and technological progress, Forster encourages his readers to consider how the displacement of human activity by machines could give rise to both social alienation and individual powerlessness.

Wells, London, and Forster, then, each helped to define what has since come to be known as dystopian fiction. Histories of the dystopian genre proper nevertheless often begin with a text from the 1920s, one which responds in a very direct way to events taking place in Soviet Russia in the aftermath of the October Revolution of 1917, namely Yevgeny Zamyatin's pioneering novel *We* (1924). Like Forster's *The Machine Stops*, *We* is both a dystopia and a classic work of science fiction. Zamyatin's novel, believed to be the first work of literature to be banned by the Soviet censorship board, extrapolates from the reality of revolutionary Russia to a future in which a successor regime to the Soviet Union has conquered the world. The story takes places in the totalitarian One State, a society in which citizens are assigned numbers rather than names, and mathematics has been elevated to a virtually religious status.

Zamyatin's *We* is the first work of modern fiction to depict an attempt to engineer a 'perfect' society – that is, a society which is not just an improvement on the present in some respect or other but actually *unimprovable*. It is also, as the tone and style of the book make clear, a *satire* on the idea of such a society, with Zamyatin suggestively employing mathematics as a vehicle for imagining what such static 'perfection' might consist in. The ideology of OneState effectively translates the whole of reality into an immense equation, encompassing not just the natural world but the social domain as well, with the consequence that human experience becomes monotonously standardised. Under this regime, any element which cannot be rationally integrated becomes an unlawful anomaly, meaning that all manner of familiar human experiences, including love, are outlawed. At the end of the novel, a technique is even introduced for surgically removing the faculty of imagination, closing off the possibility of dreaming of alternatives to the established order.

The satirical intent of *We* connects it with More's *Utopia*, which had already raised questions about the viability of utopia at the very outset of the genre. It also looks forward to Aldous Huxley's *Brave New World* (1932) in the following decade. *Brave New World* may be thought of, like *We*, as a form of 'dystopian utopia', meaning it portrays a society where an attempt to 'perfect' human life has profoundly oppressive consequences. One thing that sets Huxley's novel apart from earlier dystopias, such as London's *The Iron Heel*, and many later ones, including George Orwell's *Nineteen Eighty-Four* (1949), is the fact that the inhabitants of the World State are controlled and manipulated not through violence, imprisonment, torture, or brute force, but through the systematic application of softer kinds of power and a form of hedonistic consumerism.

In *Brave New World*, human beings are genetically engineered for specific occupations, with intelligence levels raised or lowered on demand, in order to prevent anyone from feeling dissatisfied with their position in society. Promiscuous sex is universally mandated, while monogamy is regarded as a form of social deviance. Mass consumption is likewise obligatory, with sleep conditioning and state propaganda used to discourage frugality or attempts to repair broken goods. All citizens are addicted to a state-sponsored drug called Soma, which allows them to enter a blissful, euphoric state at the onset of troubling thoughts or emotions, and spend much of their free time distracted by lurid, sensationalist mass entertainment. All material needs are automatically met and medical science has advanced considerably beyond the present, meaning there is no poverty, crime, disease, or poor health. At the same time, there is also no room for original thought or personal initiative of any kind, and the life of each citizen follows a predetermined format and pathway. On a collective level, meanwhile, the sole purpose of society is to ensure that the productive mechanism that underpins the World State continues to function. In sum, *Brave New World* projects a 'utopia' in which material abundance has been secured and many of the major barriers to human flourishing have been overcome, yet the result is a way of life which is existentially and spiritually empty.

The 1940s saw the publication of George Orwell's *Nineteen Eighty-Four*, a novel which, as its author acknowledged, was deeply indebted to Zamyatin's *We* and which, like that earlier text, was intended as a comment on the nature of totalitarianism. Whereas Huxley's *Brave New World* had envisaged the elimination of human freedom in the context of a superficially alluring consumer paradise, Orwell's novel extrapolates from the totalitarian regimes of the 30s and 40s, in particular that of Soviet Russia, to imagine how an even more fully realised and unopposed form of totalitarianism might function. All of the most readily recalled features of *Nineteen Eighty-Four* – Big Brother, Newspeak, doublethink, thoughtcrime, telescreens, the memory hole, the two-minutes hate – have since become familiar, and in some cases almost clichéd, tropes in contemporary culture. This assumed familiarity with *Nineteen Eighty-Four* on the part of many readers has, however, led to neglect of an important innovation made by Orwell, one which arguably represents a departure from earlier texts in both the utopian and dystopian genres.

This is that the government of Oceania, the fictional superstate in which Orwell's novel takes place, has not set out to design a 'perfect' world, as in the cases of the architects of Zamyatin's One State and Huxley's World State. Rather, their aims are to maintain their grip on power, keep the rival superpowers at bay, and ensure that no dissent arises within their territories. These are decidedly pragmatic ends, lacking the drive toward perfection voiced by Zamyatin's Benefactor and Huxley's World Controller. There is no pretence in Oceania that heaven on earth has either been achieved or lies just around the corner. In place of the promise of utopia, cynical and often self-contradictory justifications having to do with national security and the war effort are offered for the state's use of mass imprisonment, ubiquitous surveillance, and the torture and execution of alleged dissidents. Whereas Zamyatin and Huxley had both satirised the idea of designing a society of static perfection, Orwell used his novel to imagine the means by which a totalitarian government could keep itself in power indefinitely and the effects of this on those subjected to it. Allowing for this crucial difference, however, all three writers can be seen as having helped to turn twentieth-century literature away from visions of a better world and toward cautionary tales of where we may find ourselves if we take the wrong path.

Human flourishing

With the fall of the Berlin Wall in 1989 and the collapse of the Soviet Union in 1991, many commentators were quick to see these events as hailing the 'end of utopia'. Utopia had, of course, already been undermined in the eyes of many by events in Germany, Russia, China, Cambodia, and other countries where promethean projects to abolish the past and establish a fundamentally new social order had proven to be catastrophically destructive. The failure of the Soviet Union, often regarded as the largest utopian social experiment ever conducted, signalled to observers that utopia was, at best, a pipe dream and, at worst, an attempt to violently force reality into a shape it could never take. It was in this cultural climate that the political scientist Francis Fukuyama was to announce 'the end of history' in his bestselling book, *The End of History and the Last Man* (1992), by which he meant the end of the ideological conflicts that had characterised the modern period, and the beginning of a new epoch in which global capitalism, having defeated all its opponents, would reign unchallenged for the foreseeable future. For Fukuyama, the only practicable utopia had already been realised during the 1980s via a combination of free markets, globalisation, and information technology. In this context, the need for further utopian speculation was suspended.

Today, however, in the early decades of the twenty-first century, utopia has once again become a live topic of conversation. After several decades spent in a state of near oblivion, the category of utopia has recently re-emerged in academic, political, and popular discourse. The reasons for this are no doubt overdetermined, with roots that may reach all the way back to More's *Utopia* and to the birth of modern social thought in the fifteenth and sixteenth centuries. Several reasonably clear contributing factors behind this 'utopian turn' can nevertheless be identified. The first is a growing sense of dissatisfaction with the world as it is, combined with an often acute anxiety about the possible futures it would seem to imply. Whereas the utopian thought of the nineteenth century tended to centre on images of earthly paradises, those seeking to revive interest in utopia today tend to write out of a desire to avoid the kind of scenarios described in the twentieth-century dystopian tradition, from Huxley's *Brave New World* and Orwell's *Nineteen Eighty-Four* to J.G. Ballard's *The Drowned World* (1962) and Margaret Atwood's *The Handmaid's Tale* (1985).

The case for the relevance of utopia today has been forcefully made in recent years by the social theorist Ruth Levitas, who has emphasised the connection between the ecological crisis and utopia. As she argues in her book *Utopia as Method* (2013), what is impossible today – and hence 'utopian' in the pejorative sense of the word – is to act as if our current unsustainable and unequal social arrangements can continue. What are needed now, Levitas contends, are alternatives to the fossil fuel-based societies to which modernisation has given rise. To attempt to imagine such alternatives, however, is necessarily to engage in utopian speculation. Perhaps there are lessons to be drawn here from works such as Callenbach's *Ecotopia*, with its suggestive account of how modernity might be 'greened', or Thoreau's *Walden*, with its portrayal of a life lived closer to nature.

A second reason for the resurgence of interest in utopia is the increasingly dystopian condition of life under late capitalism. As numerous critics have argued, under neoliberal capitalism a growing number of people's material needs are going unmet, with affordances such as employment and housing becoming increasingly precarious. This sharp decline in living conditions has been accompanied by the rise of what the cultural theorist Mark Fisher has termed 'capitalist realism', an ideology which, as he explores in his book *Capitalist Realism* (2009), serves to render alternatives to capitalism unthinkable, and which has helped to normalise conditions of extreme inequality and artificial scarcity.

Another dimension of today's utopian discourse is that of queer politics. In his important study, *Cruising Utopia: The Then and There of Queer Futurity* (2009), José Esteban Muñoz makes a case for viewing contemporary queer politics as intrinsically utopian. Just as, for Levitas, to imagine a green alternative to extractive capitalism involves drawing on the resources of utopian thought, so for queer commentators like Muñoz, imagining a world in which heteronormativity no longer structures human relations is an equally utopian gesture. As Muñoz suggests, it may be that in attempting to think queer futurity, utopian literature and art constitute a necessary supplement to more conventional modes of social analysis.

Utopias, as we have seen, are attempts to imagine societies which are improvements on the ones we find ourselves inhabiting. In the wake of the failures of each of the major utopian ventures of the twentieth century, utopia was declared dead. Since then, however, Fukuyama's prediction of the end of history has been falsified. The prevailing social and economic system of global capitalism, which Fukuyama saw as the culmination of human progress, now poses a threat, not just to human flourishing, but to the existence of civilisation itself. The ideological straightjacket of capitalist realism has made it hard for us to think coherently about alternative forms of collective life. Yet we must learn to do so if we are to avoid the dystopian outcomes attendant upon the ecological crisis, spiralling inequality, and the resurgence of familiar forms of hatred and tribalism. One thing this will require is careful consideration of what utopia may still have to offer us today.

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