Introduction

The question of who is helped by government has for centuries been a question of who is included and excluded from their communities. Many would see government help as a safety net which cannot capture everyone, but needs to ensure that the most sick and poor do not fall outside society. But the origins of the welfare state lie equally in decisions about who to exclude from the tangible, local communities in which we live.

The first Poor Laws, in Tudor times, were mainly concerned with punishing the idle workless and sending them back to their place of origin to work. These parish-administered systems were subsumed by the national system of the New Poor Law in the 19th century, which established workhouses as a combined form of punishment and 'relief'. They removed paupers from the streets into institutions designed to be less attractive than the most menial of independent circumstances.

There had been lunatic asylums in Britain from the conversion of the Priory of the New Order of St Mary of Bethlem from a centre for alms collection in the 13th century, to a hospital and lunatic asylum in the 14th century, which gained notoriety as Bedlam. 'Madness' was mainly regarded as a domestic and parish issue, with only a small number of religious and charitable asylums, until the 1808 County Asylums Act empowered magistrates to build asylums in every county for 'pauper lunatics'. These captured (literally) a broad range of groups including those we would today label as having a mental illness, a learning disability or a substance misuse problem, but also people who were considered to have stepped outside of contemporary moral boundaries, such as unwed mothers (Brunton, 2004; Porter, 2006). The number of institutions and of people inside

them grew into many tens of thousands by the 20th century. A medical model of mental illness was gradually introduced into the institutions, where it coexisted and became entwined with religious, criminal justice and charitable ideas.

Welfare legislation in the 20th century abolished the workhouse for healthy workless people, replacing it with largely financial assistance, and transferred responsibility for institutional care for the 'disabled, sick and aged' to local government and then, in 1948, to the National Assistance Board and the new National Health Service (NHS).

It's easy to read changes in long-term care since then as a gradual – if often painful and faltering – progression away from large institutions and towards support which takes place within 'the community'. Following countercultural revolutions in mental health care that started in the 1960s, long-stay hospitals for people with mental health problems have been closed, as have the largest and most visible institutions for people with learning disabilities or physical impairments.

But also in that period, the hospital has become the totemic symbol of healthcare, the large care home has remained and is on the rise as the default model of care for older people with high support needs, and the number of people with learning disabilities admitted into largely hidden 'special hospitals' grew and has proved resistant to reduction, despite the outcry caused by BBC's *Panorama* exposé of the Winterbourne View Assessment and Treatment Centre and subsequent high-profile 'improvement' programme. Meanwhile, in other parts of the public service world, prison sentences and populations grew, even as crime levels shrank and varieties of enforced labour are periodically resurrected as solutions to the 'idle poor'. As John Hills (2014) and others have argued, a distinction between the deserving and undeserving poor has been and is being 'hardwired' into welfare systems and the public consciousness.

So it is harder to find and see institutions, with their high walls and locked doors, but the language of public service assessment and eligibility is that of 'gateways' (with their 'gatekeepers'), 'thresholds' and 'pathways'. To enter our long-term health and care systems is to pass through an entrance which may open as

rarely – and shut as resoundingly behind you – as any workhouse or asylum door.

In the health and care sectors there is wide consensus on the need to keep people from arriving at hospital gates and other forms of institutional care. But while ideas of prevention and early intervention are based on the belief that the boundaries can be redrawn, not erased, they themselves rest on familiar assumptions about the divide between community-based citizens and the subjects of service land, rather than removing that divide.

There was a period in the middle and late 20th century when visits to the hospital were comparatively rare and brief, as the NHS became adept at treating many diseases and most deaths in old age followed relatively short illnesses. But as the rise in life expectancy outpaces the rise in healthy life expectancy, now 15 million of us live with at least one long-term condition (including the majority of over-60s), and by 2018, nearly 3 million will live with three or more conditions (Department of Health, 2012), each the domain of a separate set of services and professionals. Most of us will care for at least one family member at some point in our lives; 6.5 million and rising at any one time. Dementia affects 850,000 people and millions of their relatives. As we become more mobile and less family- and community-rooted, new epidemics of poor wellbeing or mental health are growing, such as the epidemic of loneliness which sucks the joy from life for hundreds of thousands of older people, including 4 million who say the TV is their main source of company (Davidson and Rossall, 2014). Loneliness is shown to lead to poor physical as well as mental health, even increasing the risk of mortality (Holt-Lunstad et al, 2010). Medical advances are enabling most people with learning disabilities to outlive their parents for the first time, but the 'special' education system does not yet routinely enable them to enter adulthood as confident, socially connected full citizens.

What happens on the other side of the public service gateway has always contained much that we would consider undesirable and would prefer to ignore. For some early institutions, punishment or correction of their deviant inhabitants was deliberately built in. Later, the dehumanising effects of the 'total institution' (Goffman, 1961) ossified relationships between

the keepers and the kept, with some institutions run for the employment of their staff, rather than for the benefit of their 'sub-human' inhabitants' (Foot, 2016). The 1960s saw physical institutions under concerted attack from radicals (R.D. Laing in the UK and Franco Basaglia in Italy, and the 'anti-psychiatrists') and the establishment: Enoch Powell, as Health Minister in 1961 talked famously of storming the defences of institutions which

> stand, isolated, majestic, imperious, brooded over by the gigantic water-tower and chimney combined, rising unmistakable and daunting out of the countryside – the asylums which our forefathers built with such immense solidity to express the notions of their day. Do not for a moment underestimate their powers of resistance to our assault. (Powell's speech to the Conservative Party conference, 1961)

Powell's ten-year plan to move care into the community took 20 to 30 years, but the most visible institutions were dismantled or repurposed during that time.

In recent decades, public service modernisation drew heavily from what were seen as the lessons of private-sector service industries, considered more dynamic and efficient by policy makers frustrated with the slow pace of change possible within long-established state services. The ethos of 'customer service' has made a positive impact on many brief service transactions. A 'customer' is likely to be treated with more courtesy and respect than a 'service user'. But the relationship between customer and supplier is a shallow and transactional one. The private sector has little track record of helping people to build and maintain relationships, sustain family life or become active in their community. For those using most health and care services, who are attempting to live well with a long-term – often lifelong – condition, spending lengthy spells inside institutionally organised buildings and systems continues to be an experience of living apart from the real life of family and community; of being a patient rather than a person; a customer rather than a citizen.

The people who find themselves with a long-term future inside service systems have historically been in a poor position

to demand change. But more and more of us have extended personal or family experiences of living within service systems. Meanwhile, the disability rights, family carers and patient voice movements have made more visible those systems' limitations and failures and social media enables people to communicate their experience with the outside world. These demographic and cultural changes continued to accelerate as austerity bit and many services' staffing, quality and safety went into real decline. The language of 'customers', 'choice' and 'quality' only compounds the dissonance between what people hope their experience of support will be and the often bleak reality, while people working in those services find themselves the representatives of systems which can feel as inhuman to work in as to live in.

This amounts to a crisis in our perception of public services and the welfare state, as both the ingrained and the recently created problems within public services become harder for the general population to ignore. It also offers an opportunity to bring into full visibility both what is precious and what is pernicious within our long-term support services: the asylum they offer us when our wellbeing is threatened, and the asylums they can become if their grip is too unyielding.

The most innovative services now recognise that requiring entrants to surrender their passports and citizenship at the door is not only morally wrong but also self-defeating, if the goal is shared responsibility for long-term wellbeing. Rather than 'gatekeeping' dwindling resources and practising 'demand reduction', they are beginning to explore how they can build a new partnership with the people they support. This change requires services and the professionals who work within them to have clarity and confidence in what they can achieve, and realism and humility about what they cannot. It is that most elusive of service transformations: a 'culture change'. New ways of working alongside people rather than for them can be experienced as liberating by front-line professionals, even as they unsettle managers and decision makers. But it will not happen through only cultural means: it requires a fundamental shift of power, money and responsibility, without which more human and relational ways of working are crushed by short-term demands and risk-obsessed bureaucracies.

Some UK public services have been at the forefront of attempts to 'personalise' their work and are increasingly keen students of 'asset-based' community-building approaches developed in the US and elsewhere. The NHS talks increasingly of being 'patient centred' or even, 'person centred', ideas seemingly so self-evident that the need for their introduction says a lot about where this £120 billion system has been 'centred' previously. Yet, as a *Journal of Clinical Nursing* editorial noted, there is still no agreed definition of 'person centred' and most nurses (in common with many other care and health professionals) work 'in contexts and cultures that are inherently unsupportive of person-centredness' (Dewing and McCormack, 2016).

While there has been some progress in recognising that 'patients' and 'service users' are individuals and citizens, with unique life goals and the potential to take or at least share responsibility for reaching them, attempts to bring citizen-power into service design and management have been scarce and, usually, effectively suppressed or subverted by the power structures they challenge. Trust and faith in people in general, and in citizens with long-term support needs in particular, has been limited on the Right to selfish-gene beliefs in market forces and largely absent on the Left, which (despite its roots in mutuality and the cooperative movement) reserves its faith for the welfare state and post-Blair, has regarded 'consumerist' ideas of public service choice and individual budget control with suspicion.

This book is not an attack on services, an argument for small government, nor wishful thinking about the capacity of voluntary action. No solution offered in this book would justify further cuts to public service budgets, which have already been cut below the GDP proportions of comparable nations with increasingly visible results. Mainstream public services as they stand remain vital to protect us against the most dramatic of life's calamities. But even with adequate funding, they are by their nature incapable of fixing problems, such as loneliness, which are rooted in our changing relationships with others. Community groups, meanwhile (typically small, patchy in coverage and fragile) are set up to provide the kinds of support which most closely resemble what communities do 'naturally', which doesn't

generally include the intensive and regular personal care of strangers.

Proponents of the Third Way (Giddens, 1998) set out an approach to public services which would remove the fossilised bureaucracies of traditional public services, replacing them with the pragmatism that they saw in the more dynamic private sector, driven by feedback, data and choice. Reforms that followed under Blair, however, accepted the underlying power differentials between people who live and work in services, and those who run and own them, instead putting faith in the ability of well-motivated and skilled managers, leaders and entrepreneurs to harness market forces and innovation for the common good. Public service leaders wrestled with how services could achieve outcomes, but did not enable people to define those outcomes for themselves. Theirs was a problem-solving mentality which, coupled with significant investment, fixed some failing services, but often slipped into the fallacy that people's lives can also be fixable.

Throughout that period of service reform some on the Right as well as some in the traditionally Left-wing field of community development argued that the state's role in promoting greater social action is simply to get out of the way. Sometimes the state does indeed get in the way, but what is often needed is a step sideways rather than back. Building on ideas of service 'personalisation' developed by Charlie Leadbeater (Leadbeater, 2004), Geoff Mulgan (Mulgan, 2010; Cooke and Muir, 2012) argued for a 'relational state': government seeing itself not as leader and provider but as convenor and commissioner. The relational state would seek to build relationships with and between people and to work wherever possible through partnerships, communities and networks. Similarly, David Halpern (2010) espouses a 'partner state'.

This book focuses on long-term support to disabled people, older people and other adults and families who may need years or decades of help. Relationships are by definition at the heart of those services and this book attempts to set out ways in which those kinds of public services in particular can find a new relationship with families and communities. This means that professionals would step in earlier but be more reluctant to

'take over'. They would be more realistic about the expertise and capacity that services have and deploy their resources where possible in a supporting role to the capabilities of the people to whom their help was offered, recognising that services on their own often create a poor simulacrum of family and community.

This book argues for a state which is not less resourced, but is scaled down to human size in its approach, enabling us more easily to take on responsibilities which feel shared, safe and manageable. This would both ask more and offer more, and it would be a state which recognises that state money is just one of many resources. It would be more concerned with the risks that matter most to us (loneliness, lacking purpose) and more pragmatic about others.

I started my career working within a care service within an ordinary house and run by an organisation that aspired to provide independence for people with learning disabilities (as well as to make money, in the newly outsourced world of long-term care provision). Subsequently, I worked with unpaid family carers, including children caring for their sick parents, and witnessed their vast, hidden contribution to the welfare state. I also saw how public services were congenitally unable to regard those unpaid carers as their partners, much less their equals, even where untrained, unpaid and unsupported family members were demonstrably achieving more health and happiness for their family member than expensive professional services could even aim for. I now work in the little-known Shared Lives sector, which for decades has quietly been providing long-term support to people with learning disabilities and more recently to a much wider group, in ordinary family homes. If you have a Shared Lives household on your street, you may not even have noticed: you will simply have seen a household in which you can't quite work out how everyone is related.

Shared Lives carers do not fit the accepted description of 'professional': some are registered nurses, but I have met others who are publicans, retired police officers or farmers. Their role is deeply personal and they and their families do much for which they expect no payment, but they are not unpaid volunteers. After an extended approval process, they are matched with adults who need support and it is only when both parties decide they actively

want to spend time together that they share home and family life. They are not family carers, but some have lived together as a household for decades and they typically say that the person who lives with them is 'just part of the family'. They talk about fun, laughter and love more than quality or risk management, but this model, which eschews much of the paperwork and process of most public services, is consistently rated as safer and more effective than all those models by government inspectors, while also being demonstrably lower cost.

Crucially, this is a model that has now taken root in almost every area of the UK, supporting nearly 14,000 people and growing while all other care and support sectors are in retreat (Shared Lives Plus, 2017). The experience of working first within the traditional care sector, then supporting unpaid family carers and finally working with people involved in a support model that combines elements of both those worlds, has led me to question almost everything in current public service thinking. It is impossible to witness people's experience of Shared Lives without starting to see traces of the asylum almost everywhere else.

For most policy makers, the asylum is part of public service history. Without clear sight of its malign legacy, attempts to reform public services which offer long-term support have been locked for decades in a cycle of failed initiatives. That failure has become unconscious: simply part of the reality of the public policy world, in which everyone expects government to come up with a plan every couple of years to 'integrate' disjointed services, or to 'shift' resources 'upstream' to prevent crises rather than wait for them, but no one expects those plans to work. This is seen as no one's fault, because no one really believes they have agency over the bureaucracies in which they spend their working lives. Throughout these change and improvement programmes, and their 'task and finish groups', the asylum remains intact and unseen: its assumptions, its relationships, its power dynamics, its iron grasp on scarce resources and its abhorrence of love.

As the first half the book attempts to demonstrate, this is not a 'heritage' issue, in which the outmoded models of the past have been hard to erase. Nor do I believe, as do many working within (or even managing) public services, that we are the subjects and

victims of 'the system': a vast, impersonal construct which is impervious to our puny, human attempts at change. There is no abstract system, only us, the relationships between us and the choices we make every day. Currently we choose constantly to ignore, patch up and even rebuild the invisible asylum, whether we are citizens who feel that the council is responsible for our wellbeing and the NHS for our health, or professionals who feel that their expertise is the key to 'fixing' the troublesome patients and customers they are there to 'fix' or 'serve'. Continuing to embed dehumanising practices and the need for building-based services, while wishing to become more 'person focused' and 'community based', crushes those working within our public services just as much as those using them. So the problems that the first chapters of this book identify as fundamental are not those which most commentators consider the most important. In fact, most 'serious' commentators ignore them completely, which is why the new system I outline in the second half has equally little in common with the solutions currently most prominent.

Watching people enjoy their lives in Shared Lives households, receiving support that can be highly sophisticated at times and at others completely improvised, while also contributing more to those around them than many believed possible, has convinced me that we can reject the divide between citizens of our communities and subjects of our services once and for all. We do not have to choose between public services exactly as they stand, or glib reliance on volunteers and the elusive 'big society'. We can combine our own resources and resourcefulness, the love of our families and communities, with the resources, backup and infrastructure of state support.

The second half of this book draws on those public service innovations that have already redesigned themselves around people and their relationships to outline a new model of public services and what its relationships with us could be. These approaches are scattered and small scale, but taken together, they model a completely new system: its ethos, practices, economics and results.

It is far from certain, however, how far into crisis our current system must go before we recognise that the risks of persisting with our current approaches outweigh the risks of radical

change. As with climate change, it is also hard to predict what will constitute the point of no return, after which the feedback loops of rising costs, ageing demographics, falling budgets and collapsing consensus lay to waste our much-cherished hospitals and care services. What is certain, however, is that the invisible asylums we have built with such care are overcrowded and crumbling, and that none of us dream of living inside them.