



HEALTH AND CARE FUTURES

AN ESSAY COLLECTION





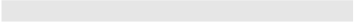
At Turning Point, we constantly find ways to support more people to discover new possibilities in their lives. We are a leading social enterprise, designing and delivering health and social care services in the fields of substance use, mental health, learning disability, autism, acquired brain injury, sexual health, homelessness, healthy lifestyles, and employment. We currently work in over 270 locations across England, empowering those we support to improve their health and wellbeing, learn, and bring about positive change in their lives.




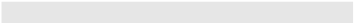
FOREWORD



JULIE BASS
TURNING POINT CHIEF EXECUTIVE



**IT IS INCREDIBLY
ENERGISING TO
FEEL THE HOPE
AND OPTIMISM
THAT IS WOVEN
THROUGHOUT THE
COLLECTION.**



In 2024 Turning Point turned 60. Over the last 60 years we have grown from a single alcohol project in South London to the organisation we are today with over 5,000 colleagues working in more than 270 locations across England, providing drug and alcohol, mental health, learning disability and sexual health services.

Following a year of celebrations marking this important milestone, we are turning our attention to the future, to the challenges facing us in 2025 and beyond.

The range of services that Turning Point delivers gives us a unique perspective on some of the issues currently playing out across the health and care system in the UK. Widening health inequalities, the social care crisis, a fragmented health and care system, stigma, continuing human rights abuses within institutional settings, the emergence of synthetic opioids in the drug supply and growing alcohol harm are some of the challenges we face.

This collection brings together essays from some leading thinkers in the field who are sharing their experiences and their expertise as they offer some ideas on how challenges can be met.

Themes that emerge from the essays are the critical role of both political and personal leadership, of collaboration and partnership, of the importance of strong guiding values – social justice, solidarity and inclusion. They also highlight the resilience of individuals in the face of adversity, their courage, their determination and their strength. It is incredibly energising to feel the hope and optimism that is woven throughout the collection which inspires possibility and is galvanising as we seek to collectively respond to these challenges.

Bringing together clinical expertise, operational strength and deep rooted lived and living experience, Turning Point has a crucial part to play in providing systems leadership that places community, involvement and those in receipt of services at the heart of decision making. This collection underlines the importance of working together to mobilise the current complex, fragmented system to deliver holistically focused services, as close to home as possible with an emphasis on prevention and early intervention alongside treatment pathways.

I hope you find this an inspiring read. I would love to hear your thoughts, should you wish to share them, as we continue to learn, and innovate, working together with partners, current and future. Thank you for reading the collection.



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ABOUT THE AUTHORS

The Rt Hon Patricia Hewitt started her career working in the third sector before becoming MP for Leicester West between 1997 and 2010. In 1998, she was appointed Economic Secretary to the Treasury and in 1999 she became a Minister of State for Small Business and E-Commerce at the Department of Trade and Industry and created the Social Enterprise Unit. She joined the Cabinet in 2001 and served as Secretary of State for Trade and Industry from 2001 to 2005, and Secretary of State for Health from 2005 to 2007. She is Chair of NHS Norfolk and Waveney Integrated Care Board and in 2023 she led a national review of the oversight and governance of integrated care systems (ICSs).

Tom Shakespeare CBE is Professor of Disability Research in the medical faculty at the London School of Hygiene and Tropical Medicine. He is a campaigner for disability rights and a writer on disability, genetics and bio-ethics and frequently appears on BBC Radio 4. His books include *The Sexual Politics of Disability* (1996), *Disability Rights and Wrongs* (2006) and *Disability - The Basics* (2014) and he co-authored the 2011 *World Report on Disability*, published by the WHO.

Professor Jon Glasby is a qualified social worker by background and Director of IMPACT, the UK centre for implementing evidence on adult social care. IMPACT works across the four nations of the UK to get evidence of what works used in practice to make a difference to front-line services and to people's lives. Specialising in joint work between health and social care, personalisation and community care, Jon is involved in regular policy analysis and advice, for example as a special adviser to the House of Lords Adult Social Care Committee. He is the author of a series of leading textbooks on health and social services, has served as Editor-in-Chief of the *Journal of Integrated Care* (2012-18) and is a Senior Fellow of the NIHR School for Social Care Research. He is a Non-Executive Director of an NHS Hospital Trust and of a local authority children's service, as well as a former Trustee of the Social Care Institute for Excellence (SCIE). Jon is based at the University of Birmingham, and has previously been Director of the Health Services Management Centre (HSMC) and Head of the School of Social Policy and Society.

Professor Robin Miller is Professor of Collaborative Learning in the Department of Social Work and Social Care at the University of Birmingham. Robin is an applied academic with an international reputation in relation to integration and leadership in health and social care. He is the Co-Editor in Chief of the international journal of integrated care. He co-ordinates the community asset theme of the national priority programme for adult social care and social work and is a Senior Fellow of the NIHR School for Social Care Research. He is the UK Demonstrator Model lead for the IMPACT Centre which uses evidence to address issues of strategic importance. Robin co-ordinates the lived experience panel for adult social care research at the University of Birmingham. He was a Co-Investigator on *Why Are We Stuck In Hospital? Understanding Service User, Family And Staff Perspectives When Transforming Care For People With Learning Disabilities And/or Autism*.

Olivia is supported by Turning Point. Until recently she had lived in long-stay institutions for most of her life. Olivia has learning disabilities, mental health needs and profound hearing loss and she has experienced traumatic events in her past. In hospital, Olivia had very little freedom. Her weekly escorted leave was often withheld as a punishment. Olivia moved into her own home in 2024. When she was first referred to Turning Point she was assessed as needing 3:1 support at all times. Within just a few months of moving, Olivia had settled into her new home and built trusted relationships with the staff supporting her. Her support subsequently reduced to 1:1 and she is able to have periods of time on her own. She is the proud owner of a rescue cat, Bonnie.

Isaac Samuels is a member of the National Co-production Advisory group, Think Local Act Personal (TLAP), co-chair of the working group of the All-Party Parliamentary Group on Adult Social Care and is a committed community-minded individual working within the third sector for many years. Their primary focus is supporting a systematic approach to improve services for the people who need to access them and ensuring they meet the needs of the population by embedding community voices at every level. They are a LGBT+ rights and social justice campaigner. All of this is achievable for Isaac as they receive support from a personal assistant (PA) through a direct payment. Isaac is a passionate advocate for self-directed support and supporting people to retell their narratives in a way that makes them stronger.

Michael Linnell did his BA (hons) in Fine Art and his MSc in Health Education and spent nearly 30 years working for the national drugs charity Lifeline as Director of Communications. He has established and co-ordinates a number of Local Drug Information Systems (LDIS), which are based on the national guidelines he wrote in 2016. He also co-ordinates UK and Ireland DrugWatch and is commissioned to work on the annual Greater Manchester Testing and Research on Emerging and New Drugs study. He is a designer and illustrator specialising in providing accurate information, and harm reduction advice in an accessible and realistic way to people who use drugs.

Deb Hussey has worked in the drug treatment sector for over 12 years. Starting out as a volunteer with Bristol Drugs Project, she has spent her entire career in harm reduction-focused roles, delivering outreach and needle and syringe provision, as an LGBTQ+ specific drug and alcohol worker, and developing and managing a team of specialist harm reduction workers in her current home county of Somerset. As someone who was a direct beneficiary of the work of the original UK harm reduction pioneers, through access to sterile injecting supplies and naloxone, Deb is passionate about raising the profile of harm reduction and advocating for the rights of people who use drugs. She is currently Turning Point's National Safer Lives Lead, where she supports the organisation's harm reduction strategy and has a specific interest in widening accessibility to naloxone and preventing avoidable overdose deaths.

Dr Richard Piper is Chief Executive of Alcohol Change UK, a leading UK alcohol charity which works for a society that is free from the harm caused by alcohol. Alcohol Change UK works to: increase knowledge and understanding of alcohol harm; improve policy and regulations; influence our culture, so that alcohol is treated as optional to our lives, not as the default setting of our society; support behaviour change among heavy drinker through initiatives such as Dry January® and campaign for a stronger, properly-funded and fully inclusive alcohol treatment system.

Heather successfully completed treatment with Turning Point's drug and alcohol service in Wakefield in 2019. She has since qualified as a peer mentor and volunteers with the service, running and aftercare group for others in recovery providing vital ongoing support for people on completion of treatment. She is a passionate advocate for recovery and has shared her story with the APPG for Complex Needs and also the NHS Confederation's Mental Health Network.

Professor Sir Michael Marmot is Professor of Epidemiology at University College London, Director of the UCL Institute of Health Equity (IHE), and Past President of the World Medical Association and the BMA. At the request of the British Government, he conducted the Strategic Review of Health Inequalities in England, which published its landmark report Fair Society, Healthy Lives (also known as the Marmot Review) in February 2010. Professor Marmot and his team at the IHE have been commissioned by cities and regions to bring their evidence-based approach to health equity into action at local level. Now, over 40 communities in England and Wales have declared themselves as acting on Marmot principles.

Dr Jessica Allen is Deputy Director at the IHE. She leads the Institute's work with global organisations including the UN, leading the current WHO Special Initiative, UNAIDS, and led the production of WHO regional health equity reports including the Eastern Mediterranean Region Commission on the Social Determinants of Health, Pan American Health Organization (PAHO) Commission on Equity and Health Inequalities in the Americas and the Review of Social Determinants of Health and the Health Divide in the WHO European Region. She was co-author of the 2010 Marmot Review Fair Society, Healthy Lives, the 2020 Marmot Review 10 Years On report and Build Back Fairer: The COVID-19 Marmot review.

Clare Wightman is Chief Executive of Grapevine Coventry and Warwickshire, a community organisation working to "strengthen people, spark action and shift power" across Coventry and Warwickshire. Earlier this year she received an Honorary Doctorate of Arts from Coventry University in recognition of her exceptional contribution to enhancing the lives and wellbeing of marginalised individuals and communities in Coventry and Warwickshire. Clare has led Grapevine since the year 2000 and under her leadership, it has evolved from a charity advocating for individuals with learning disabilities into an award-winning organisation skilled in empowering Coventry and Warwickshire communities. The group's work has been profiled nationally and recognised as leading a new way of 'doing' services and reducing reliance on shrinking public services.

ESSAY

THE ROLE OF COMMUNITY, VOLUNTARY AND SOCIAL ENTERPRISE ORGANISATIONS IN THE DELIVERY OF PUBLIC SERVICES



BY THE RT HON PATRICIA HEWITT
CHAIR OF NORFOLK AND WAVENEY
INTEGRATED CARE BOARD

“The NHS is broken”: Wes Streeting’s message on his first day as our new Health Secretary.

He is right that if we keep trying to meet 21st century needs with a 20th century model of health and care, we will never have enough staff, hospital beds or money to care for an increasingly ill and unequal population, let alone achieve the health and wellbeing we all want.

We urgently need the three shifts that Lord Darzi described in his recent report on the state of the NHS: from hospital to home; from illness to health; and from analogue to digital.

COMPLEXITY AND PARTNERSHIP

We also need recognition that people’s lives are complex. People need support that’s joined-up around the individual. The challenges faced by the millions living with health conditions which are invariably connected to their social and financial circumstances, to their relationships with family, their mental wellbeing, their work and housing situation can’t be solved by the NHS or the public sector alone.

The Pathways to Work Commission, chaired by Alan Milburn, recently examined the factors that keep people trapped in poverty in Barnsley, finding that ill-health, both mental and physical, was the single biggest barrier to employment and a decent wage. Residents’ top priority, they found, was personalised support to meet their specific needs, build skills and confidence and overcome the practical problems that stopped them moving forward. Instead of a fragmented, impersonal system they - and millions of others - want a ‘relational’ welfare state that strengthens our communities, relationships and social capital. This is the focus of the Demos Future Public Services Taskforce which highlights the important role for civil society organisations in the delivery of ‘liberated public services’¹.

That personal support, those human relationships, are exactly what many VCSE² organisations provide. These are ‘passion projects’. No Act of Parliament or government decision requires them to be there. They only exist because people want and need them to: their founders, members, service users, their volunteers and staff, their funders. At their best they combine the selfless dedication of outstanding NHS and other public service staff with the agility, innovation and sheer bloody-minded determination of private sector entrepreneurs. And like any business or voluntary organisation, they only survive by managing the money, by being commercial as well as compassionate.

I know that in Norfolk and Waveney, even with an NHS budget of over £2.6 billion a year, cannot meet the health needs of our 1.1 million residents on our own. Our new NHS Talking Therapies service, for instance, will be more effective because of the partnership between our mental health trust, MIND Norfolk & Waveney and Relate than

1 <https://demos.co.uk/research/liberated-public-services-a-new-vision-for-citizens-professionals-and-policy-makers/>

2 VCSE - Voluntary Community and Social Enterprise

if it was just the NHS alone. Our Norwich-based Inclusion Health service can support hundreds of very vulnerable people struggling with homelessness, addiction, mental illness and trauma because it's a collaboration of primary care, mental health and hospital clinicians, local council housing and social care staff as well as a community interest company providing housing with care next door to the GP surgery and walk-in centre.

DIVERSITY AND TENSION

The great variety of the sector - from the very large national organisations through to thousands of small local groups - helps to make it such a rich part of our national and community life. But this variety can also make for real tensions within the sector as well as in its relationships with the public sector. The number of people needing support keeps growing, but finding enough money and volunteers is a constant struggle. Intense competition for resources can make it difficult for organisations to collaborate, although national coalitions bringing together organisations with a similar focus and expertise can play a vital role, lobbying for legislative change or greater attention for groups of people with particular needs. When it comes to the NHS or local councils commissioning health and care services, however, voluntary sector organisations may be competing against each other. In some cases, a national VCSE organisation or one based in a different part of the country will win a contract, perhaps at the expense of a local group previously providing the service. Or VCSE groups find themselves struggling to recruit volunteers in the face of well-publicised volunteer recruitment drives by the NHS.

THE NEXT TEN YEARS

Today, we have a once-in-a-generation opportunity to transform health and care - with the VCSE sector playing a vital role.

Following Lord Darzi's report², the Prime Minister has promised nothing less than a 're-imagining of the NHS', with a 10-year Plan to be published in spring 2025.

Integrated Care Systems, and their equivalents in Scotland, Wales and Northern Ireland, have a vital role to play. Established by the 2022 Health and Care Act, they have four key aims: to improve the health and care of the residents they serve; tackle inequalities in health and wellbeing as well as access to services; enhance productivity and value for money; and ensure the NHS supports broader social and economic development. Crucially, they require each ICS to bring together all the main partners: the VCSE sector as well as local government, social care providers and other statutory services as well as the NHS. That

² <https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england>

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has already provided a powerful institutional framework within which VCSE organisations and other partners can build a common purpose, reflecting the work of local Health and Wellbeing Boards, develop an Integrated Care Strategy and agree priorities and a plan.

ICs vary considerably in their maturity as well as in size, geography, demographics and so on. Many are building on strong foundations and relationships established over years, or even decades while others are at a much earlier stage. But the government has made it clear that they will not waste time and money on another top-down NHS reorganisation.

The Government has also made clear its intention to increase the number of Mayoral Combined Authorities that already cover nearly half the population of England. In particular, directly-elected Mayors will lead on one of the government's most pressing priorities: supporting people who are now trapped in poverty through unemployment and ill-health to get back to work, into work and on in work. In the words of the Work and Pensions Secretary, Liz Kendall: "we will give local places the responsibility and resources to design a joined-up health, work and skills offer that's right for local people... so that our Mayors, local councils, the NHS, businesses, colleges and the voluntary sector can work together to deliver real employment opportunities."³

The need for collaboration with the VCSE sector is clear. The local institutions and partnerships exist. But more is needed. Although the NHS is building collaboration rather than competition between NHS providers, VCSE organisations still find themselves too often trapped in short-term contracts with wholly disproportionate bidding and reporting requirements. Small community groups are vital social assets: but it is simply too time-consuming, and therefore expensive, for an ICB to contract separately with hundreds of small local groups, particularly as that can then leave stranded those people with equally pressing needs but living outside the reach of a group.

Sometimes a VCSE consortium, or lead contractor approach can combine the benefits of 'hyper-local' with the need for scale and reach. But sometimes a procurement will result in an outside organisation (perhaps a national VCSE group, or one based in a different part of the country) winning the contract, quite possibly to the detriment of the locally-rooted community group. "Social value" is increasingly important in commissioning and procurement regimes: the development of the 10 Year Plan is an ideal opportunity to consider how best to promote social value - including supporting and developing social capital within disadvantaged and excluded communities.

Social prescribing, now well-established across the NHS, can sometimes feel to local voluntary groups as if they are being asked to pick up the pieces for a growing number of people, often with increasingly complex challenges, without any extra resources. Meanwhile, because of NHS financial pressures, staff providing NHS services under a contract with their ICB may find themselves denied the NHS pay rise, even though the financial pressures in the VCSE sector are even more acute.

³ <https://www.gov.uk/government/speeches/getting-britain-working>

But the public sector can sometimes act as if it assumes that VCSE groups will be there to provide the right support, regardless of how many people they refer. Indeed, it can sometimes feel as if statutory organisations are creating a new army of social prescribers and community connectors, separately employed by the NHS, the Job Centre, the local council and so on, rather than working together with VCSE partners to make the best use of very limited resources and build VCSE capability in communities where needs are great but social (and financial) capital may be weak.

Harnessing the potential of digital is one way in which the NHS can work more effectively with VCSE organisations to maximize outcomes. There are numerous examples of successful, proactive programmes that combine smart data analytics with effective communication and personal contact (e.g. health coaching, patient education, peer group support, community-level action) to achieve sustainable change for individuals, families and communities.

In many systems, a VCSE Assembly enables the sector to have a strong voice on matters of common concern, including the approach to commissioning, as well as on the development of strategies, plans and service specifications for specific groups of residents, patients and service users. But it takes time to build the necessary trust and understanding between the sector and the NHS itself, as well as between different VCSE groups, particularly if one organisation fears that another is using its position within the ICS to get inside information or some other advantage for itself rather than the sector as a whole.

In Greater Manchester, for instance, over 50 social businesses, each commissioned by the NHS to provide NHS services, have come together to create an Alternative Providers Collaborative, supported and partly funded by the ICB. Their goal is to work in partnership with other NHS provider collaboratives as well as with commissioners, to achieve better outcomes, more effective services and better value for money - in other words, to be seen as part of the "solution-finding world of the NHS" rather than as part of a different sector.

Just as there is no one size fits all for ICSs, there is no single model for VCSE relationships with systems. Voluntary and community organisations are a hugely important part of our society, our culture and our personal lives. Social and for-purpose businesses are increasingly important as a growing number of people reject a purely profit-driven form of capitalism. We must cherish and support the sector. We can't just assume that Turning Point and thousands of other groups will be there when we need them. We need the sector working with the NHS and other partners to find better solutions to the challenges that face our country, our communities, our neighbours, families and ourselves.

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ESSAY

WHAT IS TO BE DONE ABOUT CARE?



BY TOM SHAKESPEARE CBE



Care is not in a good state. The political leader who gets care fixed will earn the nation's thanks, even if it comes at a cost. Everyone says they have the solution to long-term care from David Cameron to Boris Johnson to Keir Starmer, and all have so far shirked the task. Long term care has become a political football, for example with the Dilnott Commission recommendations being called "a death tax". Instead, the problem is outsourced to yet another Inquiry or Commission to explore and recommend. Because the solution seems too expensive, nothing is done, and the long-term care can is kicked on down the road. But the cost of doing nothing is no less real, even if it is less visible. There is a crisis in staffing, in care places, and above all in funding. Meanwhile, families bear the brunt, both in terms of catastrophic financial costs that mount up and eat up households, but also social costs of unpaid caring. Everyone is getting older, which is good news, except that longevity brings difficulties for people in the last stage of life. Politics ignores the issue, and yet the side-effects of political moves, such as Brexit, are to make care ever more difficult, as migrant carers disappear. Failures of care have a knock-on effect, as people who need care are stranded on NHS wards, because there is very limited care integration with other services..

We do not need another Inquiry. Ten years ago, the Dilnott Commission was clear: a ceiling has to be placed on long-term care costs, so that every family contributes something, and yet not everything, which is fairer. The results are a bill for government, but so it should be. Like healthcare, long-term care is a pooled cost, which we can solve if we work together, but risks destroying us if we try to address it separately. Dilnott said that the asset threshold for those in long-term care should be £100,000: under that, people should get help. No one should have to pay more than approximately £30,000 in lifetime care costs. There should be an end to the postcode lottery which means people in one area have more to pay than someone somewhere else. Disabled people should be supported by the state, throughout their lives. So far so simple, but the government does not want to take on another financial burden, for fear of becoming unpopular.

Social care is not only long-term care for older people. It is also support for younger disabled people throughout their lives, and there are some major problems. The Conservative governments did two bad things for social care. First, they starved local authorities of cash, as a way of weathering the Global Financial Crisis of 2008. Second, they abolished the Independent Living Fund (in England and Wales) in 2015. This means that cash-poor local authorities see disabled people with high costs – those who have 24/7 support or near that – as potential sources of funds. If they can cut personal assistance costs to those individuals, they have more money to play with. As a consequence, disabled people who live in the community through personal assistance, who would have been in residential institutions if it was still the 1970s, are facing tough options. I would like to see funding for 24/7 support taken away from local authorities and given to a revived Independent Living Fund,

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that was equitable across the UK. This is what some Nordic countries do. And I would like to see social care, whether it is to a revived ILF or to local authorities to be properly funded. This means the hourly rate for personal assistants to be commensurate with that responsible and sometimes difficult role, not set at the equivalent that supermarket staff are paid. We do not want to exploit care users or care workers.

As we are trying to get long-term care and social care right, I want us also to remember and resolve a third and a fourth problem. The third issue is more deep-seated: we need to change the relations of care, as well as to resolve the financial problem of social care. By this I mean we need to understand caring solidarity across the lifespan: each of us has received care as children, and almost all of us will receive care as older adults. None of us likes being infantilised. As soon as they become teenagers, it becomes deeply unwelcome to treat those who we are responsible for as if they have no voice, no rights and no choice. For example, we patronise and infantilise most older people, and many disabled people. Rather than speaking to and about those who receive care as if they are our dependents, we should speak to people as if they are adults and able to speak and decide for themselves. This has wide ranging implications for the rights of all disabled people, and particularly those who have intellectual disabilities, older people and people with dementia.

The independent living revolution, where disabled people employ their own workers to assist them, was designed to challenge this idea that those who receive care are suddenly unable to do anything for themselves. It was intended to put disabled people in the driving seat. This idea of the driving seat was an explicit intention of the Dementia Voices approach to the human rights of people with dementia, through the national network of DEEP groups. Again, Think Local Act Personal was an initiative intended to further the concept of co-production, aimed at all who use social care, particularly people with intellectual difficulties. All of these reforms were about ending dependency and promoting the choices of those who receive care. They are as relevant to older people as they are to younger people. One structure – for example personal assistance – will not be right for everyone. But there are shared values implicit in all these approaches, which are to listen to and value the user of care. This is the disability rights revolution, that has relevance far beyond disability.

The final change I would like to see might be regarded as going against the idea of personalisation. This is to promote the importance of community and collective solutions. Too many people are isolated, even if their care needs are met. Too many day care settings have been closed down, saving costs even as they individualise care solutions. Day centres were often unpopular, out of touch and even oppressive. Yet the problem remains, and the solution seems out of reach. Day centres needed to be reformed, not decimated. We need to build more connections between peoples, especially those who do not have a workplace.

**TOO MANY PEOPLE
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In my own life, most of my best moments have been alongside other people. I remember boarding school and college very positively, as times that I lived in congregate settings and had friends everywhere. The best places I have lived, whether on Tyneside, in France, or in South London, are places where I have known my neighbours and spent time with them. As a disabled person, I need the help of others from time to time, because there are things I cannot do. I do not want to be so independent that I forget mutuality. My own expertise I can share, where people ask. We all have skills – driving, cooking, childcare, home maintenance – as well as possess assets – step ladders, drills, ice-cream makers – which could be of great use to those around us. As more work is done away from work, there has been a rising popularity of collective spaces, where you can go to work alongside people, or to print out documents, or to have meetings, or simply have coffee or lunch. This shows that even when people prize flexibility and independence, they also value connection and collectivity.

I think we should restore the ‘social’ in ‘social care.’ This means achieving real connections between households, not only valuing independence and separation. This might well mean ensuring inter-generational solidarity, so we bring together children with those in the third age of life. Valuing our elders, when biological grandparents may live far away means finding a role for older people with young children. This probably also means teenagers doing things together, and the restoration of youth clubs and other positive activities for young people. It means making space for community celebrations and festivals: the barbecue for everyone who lives in the building, or the French tradition of Fête de la Musique, or the Nordic celebration of Midsummer, or the North American celebration of Halloween, or the Scottish celebration of Hogmanay, or even the British celebration of Bonfire Night. The third sector, comprising voluntary organisations such as Turning Point and many others, is deeply part of this “coming together” and “communal responsibility.” Devolving responsibilities to the regions gives the chance for more joined-up thinking around care, where voluntary organisations are part of the jigsaw.

In conclusion, I think grasping the nettle of social care requires four things. First, it requires solving the problem of long-term care funding for older people. Second, it is about time we restored social care for younger disabled people, so we truly have Independent Living. Third, we need a change to the relations of care, so that we value both those who receive care, and those who give care. Fourth and finally, we should try and build the community that cares for each other, so that people are not isolated and all the solution are not left to the market.

I hope we can resolve all four problems, from the superficial to the deep. It would be easy to think the solution is just fixing long term care. We need more and deeper than that. We need to think again about the support we desire and the assistance that we require. And finally, we need to reach out for the collective, instead of venerating the individual as the solution. Most of all, we need it now.



ESSAY

RECREATING VICTORIAN ASYLUMS? WHAT NEXT FOR PEOPLE WITH LEARNING DISABILITIES AND/OR AUTISTIC PEOPLE IN 'LONG-STAY' SETTINGS



BY PROFESSOR JON GLASBY
AND PROFESSOR
ROBIN MILLER, UNIVERSITY
OF BIRMINGHAM

**BY THE 2020s,
THERE WERE STILL
SOME 2,000 PEOPLE
IN SUCH 'LONG-STAY'
SETTINGS.**

In the nineteenth and twentieth centuries, far too many people with learning disabilities, people with mental health problems and people with dementia were locked away from the rest of society in asylums. This was meant to be for their own safety – but was probably also because society was scared of or embarrassed by those who were seen as different. Some people were hospitalised for being unmarried mothers, for example, or for being gay – challenging the ‘rules’ of polite society.

While abuse can occur in any setting, the evidence suggests that it can often take hold in isolated, locked environments which are short-staffed and poorly supported. Even when outright ‘abuse’ is avoided, there is a risk of what’s known as a ‘corruption of care’. This is when the member of staff’s aim ceases to be looking after people who need them, but getting through the working day in a way that still leaves them sane at the end. When this happens, we stop caring for people and focus instead on maintaining order, cutting corners, and just getting through the day. As a result, awful treatment and conditions can develop and become normalised within those cultures. It’s easy to look at the many different long-stay hospital scandals and ask how things like this could ever happen – but perhaps the signs were always there to suggest that they might.

From the 1960s to the 1990s, the UK closed most of its long-stay hospitals, focusing instead on ‘care in the community’. This really improved many people’s lives and was a major step forward. However, there was always a fear that poorly funded and patchy community services might struggle to provide good support to people with the most complex needs. In a worst case scenario, the concern was that this might lead to such people moving constantly back and forwards between hospital and the community, ending up in prison and/or becoming homeless.

In 2011, the abuse scandal revealed by the BBC documentary programme, *Panorama*, at Winterbourne View shocked the nation, and led to a prolonged period of soul-searching, formal reviews and promises that things would be different in future. It quickly became apparent just how many people with learning disabilities and/or autistic people were still spending many years of their lives in various hospital settings (whether mental health hospitals, forensic units for people who have committed offences or ‘assessment and treatment’ units). We would call these ‘long-stay hospital settings’ as a shorthand – and to make the point that the closure of the Victorian asylums doesn’t seem to have fully solved the problem. Almost accidentally and without anyone really realising, it seemed as if a new set of ‘long-stay’ services had grown up, sometimes in the private sector and away from people’s local communities, resulting in far too many people locked away.

By the 2020s, there were still some 2,000 people in such ‘long-stay’ settings, often for many years and with no sense of when they might be able to leave. We know that such care is often the wrong way to support people for at least four reasons:

- Locked services can sometimes enable poor care to take place behind closed doors, and there have been ongoing accounts of abuse, inhumane treatment, premature deaths and human rights abuses.
- People are often 'out of area', many miles away from family, friends and communities.
- Hospitals aren't designed to help people lead ordinary lives, and most people would want to go back to their local neighbourhoods if they could.
- Hospital services cost large amounts of money, meaning there's less available to keep people well in the community and help people leave hospital in a timely way.

Against this background, the University of Birmingham has worked with the rights-based organisation, Changing Our Lives, to carry out national research and to find new ways forward. In the past, we believe that too many of our policies have been developed by senior leaders without fully understanding the lived experience of people in hospital and their families, or the practice knowledge of health and social care staff. To redress this balance, our research focused solely on this lived experience and professional expertise – leading to a national policy guide to help more people come out of hospital and lead more ordinary lives in the community. This takes the form of 'ten top tips' which people can use to think about their own experiences, reflect on their own practice, challenge their own services and lobby senior decision-makers. There is also a free training video for care staff who might not usually have access to training resources, and more accessible versions of the guide and video for people and families.

The 'top tips' include:

- Getting some 'oomph' into the discharge process as many people not only experienced considerable delays but had no sense of when, and indeed if, they would be able to move back into the community.
- Staff seeing people as being more than their diagnostic labels, which seemed to be relatively easy to accumulate in the often-stressful environment of a long stay ward but hard to move beyond even when recent behaviours suggested substantial progress in being ready for discharge.
- Not making people jump through what seemed to be endless hoops in justifying that they could move onto community-based options – some assessments are undoubtedly required but being clear what these are for and their likely timelines will help people and their family to understand the process.
- Not letting people fall through the many cracks in the system, including the difficulties of getting timely responses from criminal justice agencies, hospital based staff not always knowing what is available in the community, and coordinating with support providers and accommodation agencies.

**WE ALSO THINK THAT
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We also think that it's important to raise awareness with the general public and in the media. This is a truly shocking situation – nothing short of a national scandal – and yet it took a TV programme to start calling this situation out, and progress has since been painfully slow. To help with this process, we worked with an amazing artist and gallery to create an exhibition and run a public billboard campaign in Birmingham and a number of other cities (see coverage in *The Guardian* for a summary). While health and social care services need to do much more to solve these issues – part of the problem is that we don't care enough about people with learning disabilities as a society. If this was happening to a different group of people, it would generate major protest – but the sad reality is that it can happen (and continue happening) in services for people with learning disabilities without too many people even noticing.

As Turning Point celebrates its 60th anniversary, it's frustrating to see how policy and society can undertake worthy changes (closing existing asylums) only to create alternative problems (recreating modern-day equivalents of the old system). All in all, while much has changed for the better, some things are still the same and the challenge will be for all of us, practitioners, commissioners, providers and academics to work harder to make things better in the future.

FURTHER INFORMATION

To find out more and to read the original research, see: www.birmingham.ac.uk/schools/social-policy/departments/social-work-social-care/research/why-are-we-stuck-in-hospital

We are grateful to the National Institute for Health and Care Research for funding the original research study. This essay represents the views of Jon and Robin, not necessarily of NIHR or the Department of Health and Social Care.





ESSAY

A LIVED EXPERIENCE PERSPECTIVE:

OLIVIA'S STORY

This is the transcript from an interview with Olivia who moved into supported accommodation with Turning Point in March 2024 following a very long stay in a number of secure hospital settings. Olivia has learning disabilities and mental health needs.

HOW LONG WERE YOU IN HOSPITAL FOR?

"I've been in hospital for about 45 years. Different hospitals. I've been travelling all around. All around the country, in different ones.

WHAT WAS IT LIKE IN HOSPITAL?

I didn't like it at all because you couldn't have ornaments, you couldn't have china, couldn't go in the kitchen or nothing.

So I went to C- House and I stayed there for about nine, ten years. I felt really bad because you used to get wee everywhere. I didn't like it at all. It was filthy. We couldn't go out. Only once a week. Do your shopping. Then you only got about three to four hours to get there and back. Certain times be in bed.

WHAT'S IT LIKE LIVING IN YOUR OWN HOME?

I love it. Now I can have everything. I can have ornaments, I can have glass stuff, I can have china, I can have cutlery, I can make my own drink. I go bed when I want.

I've got a cat, which I like, named Bonnie. And I like her a lot. I looked at two but one was only a kitten and it wouldn't come to me, and I thought "oh why won't it come to me, it doesn't like me or something". She was meowing at the door straight away. Yesterday was the first time she slept across my legs.

I can't wait to go on my holiday on Friday. I'm going for two nights on my holiday to Dymchurch. I just can't wait for it because last year Dr L- who was my doctor at the hospital, she did write to the Home Office about it and that was to get me some time to go on holiday. But they said no, the Home Office, so I got let down. So I'm going this time. [The last time I went on holiday was] about 50 years ago. I'm going to go to the caravan. When we get there, we're going to get all our clothes and everything out and get all sorted out. Then we're hoping to go out for a meal and perhaps go for a little drive somewhere around. Then the next day we're hoping to get up early and go to like second hand shops and arcades and that.

SO HOW DID YOU FEEL WHEN YOU WERE TOLD THAT YOU WERE MOVING TO YOUR OWN HOME IN THE COMMUNITY?

I was happy. I couldn't wait. I used to say to Dr L- "Have you heard anything yet? Have you heard anything yet? Am I moving yet?" And she'd go "Not yet. I've got nothing yet." And this come up, they came and told me straight away. "They're going to start coming to see you quite soon, the people" so I thought "Oh lovely". When they were telling me about it and that, each day I was going "Is there anything yet? Am I moving right now? Have I got a date?" And she's going, "No, not yet" and I'm going, "Well, hurry up then". She goes "Alright, we'll hurry up, we'll try to get that pushed along".

WHAT WOULD YOU LIKE TO DO IN THE FUTURE?

I'd love to work at the church place you know, helping them to put stuff out and that. Price the stuff and stuff like that. When I come back off my holiday, I'm hoping to go and you know, try it out. I'm very, very happy and pleased.

I'm out of hospital and living out here in my own flat with my cat, with my stuff, what I got around me. It could be no better for me."

To watch the interview with Olivia visit

<https://www.youtube.com/watch?v=NHn9ibOS1r4>







ESSAY

A MESSAGE OF HOPE AND TRANSFORMATION FOR FUTURE GENERATIONS: 2084

BY ISAAC SAMUELS

INDIVIDUALS WITH MENTAL HEALTH CHALLENGES CAN THRIVE, NOT JUST SURVIVE.

Let us not forget that my journey into the netherworld of mental health 'services' started off in the most horrendous way. It began with the harrowing experience of being conveyed to hospital in the back of a police car, forcibly sectioned and losing my liberty. During those bleak times, I was told by professionals that I would never be able to work, or indeed, amount to anything. I believed these very words and internalised them, allowing them to shape my perception of myself and my potential.

As if this wasn't traumatic enough, my journey was further marred by abuse within the institutions where I was confined, unable to speak out or advocate for myself. The weight of despair felt unbearable, suffocating any flicker of hope for a better future. Yet, even amidst the horror of it all, a resilient spirit persisted within me, a glimmer of defiance against the oppressive forces that sought to define my worth and dictate my destiny.

Hello, my name is Isaac, and my life has been a journey of resilience and transformation, fuelled by both personal and collective action. (Can you have one without the other? I don't think so.) From battling mental health struggles, addiction and homelessness, I have witnessed the profound impact that empathy, support and advocacy can have on an individual. Today, I write to you from a time brimming with potential, standing on the brink of transformative change in 2024, poised to shape a future of profound mental health acceptance for the generations yet to come.

In sixty years' time I will be one hundred and three years old, so I might not get to see these changes first-hand. However, my hope for mental health provision in the UK is that everyone will have access to high-quality mental health support at the earliest opportunity. I envisage marginalised communities receiving the same equitable experience as their peers, with a holistic approach to mental health care offered to everyone. Those with dual diagnoses, such as people living with mental health and substance use challenges, must receive the right support at the right time. Every conversation about mental health is valuable and can be an opportunity to prevent suicide. Trust me, I know - I have lost someone to suicide because this basic kindness was not offered to him.

We must foster an inclusive workplace and workforce where individuals with mental health challenges can thrive, not just survive. Additionally, there should be a clear strategy and vision enabling those with severe and enduring mental health issues to receive the necessary support. Mental health must become an everyday conversation, free from taboo, regardless of class, gender, race, disability or anything else. Embracing mental health as a fundamental aspect of overall health is essential, as there can be no true health without mental health. Even as I sit here writing this, I am critically aware how stigmatising living with mental health challenges can be. Stigma kills: reluctance to seek help, reluctance to admit to struggling, hostility from others. We need to kick this into the long grass of history. Mind's 'Time to Change' campaign, for example, set out to bring conversations about mental health

into everyday conversation. I'm hopeful we can get to a place where campaigns are not necessary and talking about mental health - openly and without stigma - becomes the norm.

Or to use a slogan from the Disability Movement, Nothing About Us Without Us. People know what they need to survive and thrive; they don't need professionals to do their thinking for them.

Through my own experiences, I have seen how transformative it can be when society collectively acts with empathy and a commitment to support those in need. Together, we can create a future where mental health is fully integrated into our understanding of overall well-being, ensuring that everyone, regardless of their background or circumstances, has the opportunity to live a life of dignity and fulfilment.

You might well be asking how I can make such claims about the future. Here is a little bit about me. I am a dedicated community campaigner and co-production advisor with 25 years of experience in the health, social care, and housing sectors. My work is centred on supporting those at risk of disadvantage due to social, political, and environmental barriers such as poverty, health issues, racism and disability, helping them live their best lives. I have personal experience of every one of these and I use this lived experience to enable people to share theirs in order to shape policy and achieve their desired life outcomes, despite the systemic barriers they may face. I can also attest to the power of lived experience story telling; as a Community Reporter I have captured so many different voices and experiences. If you'd like to know more, check out Covid Conversations which illustrate the value of people authoring and privileging their own narratives.

But to do this we must confront the harsh reality of our current mental health services. People are dying due to poor service provision. The lack of investment and governmental vision for better mental health resources leads to many people suffering - unnecessarily. Whilst my message is one of hope, it is also rooted in the reality of widespread inaccessibility and systemic racism that marginalised communities face.

For those with dual diagnoses, the experience of being shunted from pillar to post is all too common. Many are unable to access the right support, often only receiving help when they are in crisis. It can feel like you have to prove you are ill enough to be taken seriously and if you are able to request help before reaching crisis point then you are deemed well enough to not need help at that point. The system is broken, and this does not even begin to encapsulate how people like me feel about the current state of mental health services. My experience of being listened to with empathy began at a very low point in my life when I met someone in hospital who explained to me about the importance of having a voice and what it meant to her. She was visiting her son, and I was a patient in the same mental health ward. Not much made sense to me at that point but hearing June talk about co-production ignited a spark within me. It means working for mutual benefit to enable people

to have good lives - e.g. those who lived it know it best! Ghanaian saying: 'If a toad jumps out of the pond and tells you the crocodile is dead, make no mistake - this is not fake news. This is the voice of lived experience.' (With thanks to Adelle A'sante).

THE DISTANT DREAM OF COMPREHENSIVE MENTAL HEALTH SERVICES

Martin Luther King's iconic 'I Have a Dream' speech remains a powerful reminder of the aspirations that have driven significant social change. His words captured a vision of equality and justice that, though seemingly so distant as to seem impossible at the time, have since seen substantial progress. Similarly, the quest for robust mental health services represents another profound dream—a dream that, despite the progress made, remains far from fulfilled.

Mental health has long been stigmatised and neglected in societal discourse, overshadowed by more visible physical health issues. However, the importance of mental health is now gaining recognition, paralleling the civil rights movement's aspiration for racial equality. The need for accessible, effective and compassionate mental health care for all is akin to King's dream of a just society where all individuals are treated equally, regardless of their background.

The reality, however, contrasts starkly with this dream. Mental health services today are marred by numerous challenges that inhibit their efficacy. A critical shortage of mental health professionals, inadequate funding and societal stigma are formidable barriers. Many individuals struggling with mental health issues find themselves navigating a fragmented and under-resourced system, often leading to prolonged suffering and, in severe cases, tragic outcomes such as self-harm and even death.

To understand the gravity of this issue, consider the statistics: one in four adults in the UK experiences mental health problems each year, yet a significant proportion do not receive treatment. This gap highlights a systemic failure to address a fundamental aspect of public health. The situation is even more dire for marginalised communities who face additional barriers such as lack of access to culturally competent care.

Despite these challenges, there is hope. Advances in technology, increasing awareness, and policy initiatives aimed at integrating mental health care with primary care services are promising developments. Initiatives such as 'Black men on the sofa' and peer support have emerged as vital tools, expanding access to mental health care for those in remote or underserved areas. Additionally, campaigns to reduce stigma and educate the public about mental health issues are gradually changing perceptions, making it easier for individuals to seek help.

The path forward requires a multifaceted approach. Increased funding

A CRITICAL SHORTAGE OF MENTAL HEALTH PROFESSIONALS, INADEQUATE FUNDING AND SOCIETAL STIGMA ARE FORMIDABLE BARRIERS.

for mental health services, comprehensive training for healthcare providers, and policies that promote mental health parity with physical health are essential steps. Furthermore, embracing innovative care models that prioritise holistic and preventative approaches can significantly enhance the efficacy of mental health care.

At the same time, we must remain grounded in the reality of the current shortcomings and work diligently to transform this dream into reality. As with all great societal advancements, it requires collective effort, perseverance, and unwavering commitment to the cause.

Finally, my personal experiences with health and social care support needs have instilled in me a deep passion for helping others overcome the barriers in their way. Living with life-changing health conditions has significantly shaped my knowledge and approach. As I tap away on my keyboard, my words carry hope and anticipation for a future filled with endless possibilities and monumental impact. With a profound sense of purpose and boundless potential, I invite you to imagine a world free of stigma; a world where mental health is embraced with the same understanding as physical wellbeing. Imagine a world where individuals feel empowered to seek assistance without fear of judgement, where conversations about mental well-being are met with empathy and where support and compassion are readily extended to all who seek it. While the dream of an equitable and effective mental health care system may seem distant, it is not unattainable. Drawing inspiration from Martin Luther King's enduring vision, we must continue to dream of a future where mental health care is accessible to all, free from stigma and inequality.

Note to my one hundred and three year old self - you did it, you modelled it, you lived it. Let's hope people now feel it.

**WITH A PROFOUND
SENSE OF PURPOSE
AND BOUNDLESS
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STIGMA.**







ESSAY

NITAZENES: RESPONDING TO THE LATEST 'NEW' DRUG THREAT



BY MICHAEL LINNELL

Forty years ago, when I started working in the drugs field, ecstasy, ketamine and 'Spice' were unheard of, the heroin 'epidemic' was in its early stages, and HIV was an unknown threat. To prevent the spread of HIV, advice on injecting safely was provided and needle exchanges were opened to swap used injection equipment for a sterile supply. This approach to a 'new' drug threat was innovative, pragmatic and stunningly successful in preventing the spread of HIV.

Illicit drug markets are dynamic and respond to price, quality, availability, legal regulations and complex world-wide events. As a result of a ban by the Taliban regime, opium production in Afghanistan fell by 95%. Chinese chemists responded to domestic legislation by switching from making one group of potent synthetic opioids to another. These are known as 'nitazenes'. They were developed in the 1950s but considered too dangerous for medical use. Local suppliers are adding nitazenes, along with a veterinary tranquilizer called xylazine to poor quality heroin and fake prescription drugs.

Different drugs are used by different people for different reasons. It is no coincidence that people who use heroin, a drug that numbs physical and emotional pain, are much more likely to have experienced childhood trauma, time in care and have come from the most economically deprived areas. Most of the estimated 340,000 heroin users in England, are middle aged, have been using heroin for decades, have a mental health need, will have spent time in prison and/or sleeping rough, and faced stigma in their day-to-day life.

There have been about 200 deaths in the last year involving nitazenes. A major incident in Birmingham resulted in over 30 deaths in just a few days. Drug deaths were already at record levels, most commonly involving heroin along with the concurrent use of fake prescription drugs. They occur in an aging population in poor general health. People often die when alone.

Any effective response should be multi-agency and intelligence led. A local drug early warning system (EWS) model was developed to ensure an effective response to incidents of new or adulterated drugs. Most local authority areas in England now have or are developing a local EWS and an action plan for major incidents.

Scotland has a new national EWS, and a similar one is being developed for England. These aim to enhance health intelligence and information sharing, such as NHS reporting of overdoses. In some areas, coroners are engaging with EWS and sharing toxicology results when deaths occur. However, this is far from a universal response and a solution is required.

For any EWS to be effective, you need to know what you are dealing with by testing the drugs involved. This requires a Home Office licensed lab and a legal way to get drugs to the lab. A system developed in Greater Manchester means when incidents occur the police transport drugs to a lab for rapid public health testing. A new scheme in Bristol allows people to bring drugs into a treatment service for testing at a pop-up lab. A

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similar system is planned in parts of Scotland. However, in most areas when serious incidents occur, testing is reliant on forensic labs, and can take weeks for results to be known.

The Welsh EWS allows people to post drugs with results then displayed on their website. However, this system was set up in response to 'legal highs', and it is not strictly legal for controlled (illegal) drugs to be posted. There needs to be much wider access to drug testing, further flexibility in the Home Office approach to licensing, and a simple legal process for getting drugs to any testing systems that are developed.

Naloxone is an antidote to an overdose of opioid drugs like heroin or nitazenes and is increasingly being carried by frontline professionals like the police. However, naloxone can only be supplied to people who use heroin by drug treatment services. It is hoped new legislation will allow supply by a wider range of professionals.

If someone overdoses alone, there is nobody to administer naloxone. 'Buddy' apps and other schemes are being piloted, but another response is to have places where people can go to inject where medical staff are on hand to administer naloxone. Plans are underway for these overdose prevention sites to be established in parts of Scotland. It is hoped this evidence based; lifesaving initiative is not rejected with the same spurious excuses used by the last UK government.

With any intervention, a partnership with people who use drugs is essential. One recent innovation are test strips which detect the presence of nitazenes in street drugs. These are supplied by drug services so people can moderate behaviour when results are positive, such as smoking rather than injecting heroin. However, although useful, they are currently unreliable and false positives are common.

Our response to nitazenes was shaped by previous 'new' drug threats. It is pragmatic, innovative, and aims to enhance information sharing. However, no system is ever perfect, and drug related deaths are inevitable with the use of potent synthetic opioids.

In the sixty years since Turning Point was founded there have been many changes to drug markets. Young heroin users are now as rare as hens' teeth, but it is inevitable new drug threats will emerge. The drugs may change, but those at most serious risk will still be the most vulnerable people in our society. Reducing barriers into wider health services by reducing stigma would help, creating a more equal, kinder society would be the ideal. Unfortunately, that is no nearer than it was sixty years ago.

**WITH ANY
INTERVENTION,
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ESSAY

INNOVATING FOR HARM REDUCTION



BY DEB HUSSEY, SAFER LIVES LEAD,
TURNING POINT



When we first opened our doors 60 years it was onto a very different landscape. There was no needle and syringe provision, opiate substitute prescribing or naloxone. But Turning Point has continually adapted and developed its services to meet the needs of a changing environment. In the 1980s we saw the emergence of HIV, and we opened projects providing care for people with AIDS, as well as the first continuing care unit for people living with HIV. We opened one of the first needle exchanges in the country, providing people who injected drugs access to sterile injecting equipment preventing further spread of HIV, with rates remaining low among people who inject drugs in England to this day.

The UK currently has the highest levels of drug deaths since records began. Half of the 5,488 deaths registered in 2023 involved an opiate, but there has also been a sharp increase in deaths involving cocaine, and a rise in women dying from drug related causes⁴. Add to that an unpredictable drug market with increasing prevalence of high-risk contaminants including synthetic opioids such as 'nitazenes', and there has never been a more dangerous time for people that use drugs. Yet again we need to adapt and innovate if we want to prevent more deaths. We need to advocate for evidence-based policy and to explore the evidence base for innovations such as overdose prevention centres, safer inhalation devices and drug checking services. We need to make treatment more attractive to people that need it, with easier access to a range of prescribing options. And when it finally comes, we need to make sure to fully utilise the amended naloxone legislation to ensure that anyone that needs a naloxone kit can get one.

There are lots of things the drug and alcohol sector does well, but there is always room for improvement. When the landscape changes services need to change, adapt and innovate. And to address the current risk from synthetic opioids, where our primary focus is saving lives, we must not gatekeep. In a sector where the commissioning system puts providers in competition against each other, we need to recognise our shared purpose, share best practice and foster collaborative approaches with the aim of saving lives. We should no longer be working in silos. Anything that proves effective in reducing the harms of synthetic opioids and other high-risk substances, needs to be promoted and shared. No single organisation can reduce these avoidable deaths alone.

There have been many changes over the last 60 years, and through it all Turning Point has always adapted to meet the needs of the people we support. Here's to continuing that for the next 60.

⁴ Office for National Statistics (ONS), released 23 October 2024, ONS website, statistical bulletin

ESSAY

ONE VISION, THREE PICTURES: A SOCIETY FREE FROM ALCOHOL HARM



BY DR RICHARD PIPER,
ALCOHOL CHANGE UK



WE CAN CREATE A SOCIETY IN WHICH ALCOHOL IS NO LONGER CENTRE STAGE.

At Alcohol Change UK, we exist to end the harm from alcohol, without being anti-alcohol. But what does that actually mean?

In short, we think that, while society should be liberal enough to allow all of us as adults to be free to choose to drink alcohol (however harmful it is), society should also actively encourage and support all of us to protect our physical and mental health and wellbeing from harmful substances like alcohol. I sketch out below a possible vision of such a society, in three pictures: the treatment system, our culture, and the policy environment.

That protection of health means, firstly, an outstanding alcohol treatment system. Outstanding means effective and properly funded, of course, but it also means a system that:

- is easy to find and easy to navigate, enabling people to move seamlessly from provider to provider (different local authority-funded services, AA, an Alcohol Care Team, a GP);
- is positively and creatively marketed so that 'need' translates into 'demand';
- is fully inclusive for people of all faiths, cultures, backgrounds and situations (e.g. built-in childcare, autism-friendly, accessible to Roma, Gypsy, Traveller communities, etc.);
- never creates barriers by insisting on sobriety as a first step (even if sobriety ends up as the final step) for example, or by insisting that mental health problems are addressed first;
- is delivered where and when people need it (e.g. in homes, in diverse community settings);
- assertively reaches those with the most serious and complex needs who are too often written-off as 'change resistant';
- has ongoing in-person and/or online community support;
- is well-connected to housing, healthcare, social care and employment support;
- has built-in support for family members always offered;
- is constantly innovating;
- actively undermines the disgraceful stigma that surrounds alcohol problems.

This last point about stigma hints at the second picture we need to create, if society is to protect health and wellbeing from alcohol harm: a culture without alcohol at its centre. That means, first and foremost, no-one feeling or believing that alcohol is ever necessary in any situation. Weddings, birthdays, Christmas, music festivals, football matches, holidays, sunny BBQs, winter nights by the fire in a pub – all of these situations can be great in their own right, without needing alcohol to make them 'better'. That's why our Try Dry® app, which has now been

downloaded over 1 million times, has missions that we can undertake, to show to ourselves that all of these situations can be enjoyed without alcohol, and may often be better without alcohol.

Alcohol can actually reduce our enjoyment of life, stopping us from being fully present, costing us money, stealing our time, leading us to hazily forget, becoming an unhealthy crutch to our times of rest, affecting our sleep, stopping us eating well or exercising, and causing us to make unwise decisions.

We can create a society in which alcohol is no longer centre stage, replaced instead by what really matters: people, connections and real experiences. Alcohol must be radically recast, back to where it was through most of British history, and where it is today for most of the global population: as optional, not essential, to a good life.

If our culture wasn't always like this, why is it like this now? The major reason is relentless alcohol marketing and promotion by huge alcohol companies. This leads to the third picture we must paint to protect us from alcohol harm: a policy environment that discourages alcohol use without banning it and that protects us all from these companies that profit from harm. Our current culture sees us awash with alcohol marketing, bottles of booze pushed on us from every supermarket aisle, finding ourselves unable to opt out of alcohol marketing on our phones, and subjected to the constant message that ingesting alcohol is normal, harmless, and should be at the centre of our lives.

The way to change this is evidenced and known: increase the cost of alcohol, reduce the number of places and times it is available (e.g. by tackling 'instant deliveries'), and most of all properly regulate its marketing:

- protect children from all forms of alcohol marketing
- give us all the right to opt out of online alcohol marketing;
- insist that marketing and packaging prominently communicate the dangers of alcohol and don't glamourise alcohol;
- ensure alcohol-free drinks are always marketed as substitutes, not additions.

Creating this change will save – and improve – millions of lives, increase our collective happiness (and productivity), and reduce obesity, smoking, cancer, strokes, anxiety, depression, injuries, heart conditions, and so on. Creating this change is totally possible – and urgent. The sooner we get started, the sooner we can all enjoy the benefits. Collectively, we have the power to do this and those involved as commissioners and providers in the treatment system have a central role to play. Join with us.

OUR CURRENT CULTURE SEES US AWASH WITH ALCOHOL MARKETING.







ESSAY

A LIVED EXPERIENCE PERSPECTIVE:

HEATHER'S STORY

I would like to share a story about young girl, aged 17, full of hopes and dreams for the future.

This girl had started to go out and enjoy parties with friends and drinking. She met a man on one of these nights out and she was smitten. Little did she know that this man would change her life forever.

You see this man raped her. As a result of the assault, she fell pregnant. Electing to have an abortion but too ashamed to tell anyone, she turned to alcohol. The guilt that followed led her to drink more and suddenly alcohol was a staple in her life.

Relationships became frightening and the guilt and shame would eat away at her.

Despite this she went on to marry and have children. The marriage ended and once again alcohol was by her side.

Years later the death of her brother, from alcohol abuse was probably one of the biggest catalysts in her life.

Some would think that this young woman would see it as a warning, a sign that she should distance herself from alcohol but by then it had taken hold.

She tried to kick the booze but she had hopes at that time of one day being able to drink socially, you know the kind where you only have alcohol on special occasions. Funnily enough, every day became a special occasion and before you know it, she was hooked again.

The alcohol abuse continued for years and this woman was now blacking out, coughing up blood and heading for certain death.

It was at that point her eldest daughter stepped in. Told her the consequences of what the drink was doing to the family and she knew this was it.

This woman took the brave decision to seek help. Through the support of her 2 daughters and special bond with her young son, she found sobriety. As of right now, this woman is almost 5 1/2 years sober. She plans to dedicate her time to helping others.

Who is this woman? Me

I used alcohol for a very long time to mask the guilt, shame and pain I felt since being sexually assaulted as a young teenager. There is a very fine line that you cross when you start to abuse alcohol and it's difficult to know precisely when you cross that line.

My GP told me to stop drinking and then the antidepressants would work. He gave me an out-of-date number for Turning Point and told me to self-refer.

This method of 'referral' needs to change. If I hadn't felt strong enough to pursue finding the correct telephone number for Turning Point, I may not have sought the help I so desperately needed. It could be that, at

the GP's discretion, they make the referral for the patient. A clinical practitioner would be an invaluable 'middle man' so to speak, between GP and Turning Point.

Even to this day, there is no advertising at my doctor's surgery for services to help with alcohol addiction. I had never heard of Turning Point and I'm certain I'm not alone.

We need to do better in educating across society of the risks of alcohol and harm it can cause you and others. Alcohol does not discriminate.





ESSAY

HEALTH EQUITY – AN ACHIEVABLE SOCIAL GOAL



BY PROFESSOR SIR MICHAEL
MARMOT AND DR. JESSICA
ALLEN, UCL INSTITUTE OF
HEALTH EQUITY

"If a government doesn't care or, worse, its venality is damaging people's lives, we are sunk. There is no prospect of action on social determinants of health to create greater health equity".

"Too pessimistic", said my colleague, "if government won't do it, we in civil society will."

The pessimism came from me (MM) when I began the task of leading the World Health Organisation Commission on Social Determinants of Health (CSDH), 2005-2008.

My colleague, Mirai Chatterjee, whose pragmatism was matched by the inspirational nature of her work, is a leader of the Self Employed Women's Association, a civil society organisation working with poor marginalised women – essentially a trade union for these women – in Ahmedabad, in the state of Gujarat India.

Mirai's lesson applies to what we have been doing in the UK. The lesson is of three forms. First, action on social determinants of health can, and must, happen at various levels: global, national, local. Second, such action must involve all the key areas of society relevant to health and not be confined to government. Third, change can come from the bottom up.

First, some background. After the 2008 CSDH report, Closing the Gap in a Generation, which was global in its scope, our 2010 English Marmot Review, Fair Society Healthy Lives, was for one country. Our review of the evidence pointed to six domains of action to reduce avoidable health inequalities and advance the cause of health equity:

1. early childhood;
2. education;
3. employment and working conditions;
4. minimum income for healthy living;
5. healthy and sustainable environments including housing and the social environment;
6. taking a social determinants approach to prevention.

We have now added two more:

7. tackle discrimination, racism and their outcomes;
8. pursue health equity and sustainability together.

It should be noted that all eight of these are oriented to the social determinants of health. Universal access to high quality medical care is vital, i.e. fixing the NHS, but to achieve health equity we need a more just society. The Conservative-led governments, elected in 2010 and beyond, and governing up to 2014, showed little interest in such a mission. Despite some emollient words, the focus on austerity and their approach to policy-making showed little prospect for action nationally on social determinants of health.

**"IF GOVERNMENT
WON'T DO IT, WE IN
CIVIL SOCIETY WILL."**

The need for action became ever more acute as the decade after 2010 progressed. The nation's health became a crisis before the Covid pandemic, even more so after. In a 14 year period from 2009 to 2023, life expectancy did not improve. There has not been another 14 year period, in peacetime since 1900, when life expectancy did not improve. Further, inequalities in life expectancy increased. The consequences for health of living in more deprived neighbourhoods, outside London, became more dire. All of this meant that by 2013, life expectancy had stopped improving, inequalities had got bigger, and both health and life expectancy for the poorest people had got worse.

It is highly likely that the government's policies of austerity, applied in regressive fashion – steeper cuts to poorer families and neighbourhoods – was responsible for much of this grim health picture. One analysis sums up the picture. In our 2010 report, we coined the phrase, proportionate universalism. We called for universalist policies with effort proportionate to need. It was an effort to combine the targeted approach common to British social policy, means tested benefits, with universalist policies more characteristic of Nordic countries. We plotted life expectancy in 2010-12 for every local authority and then examined the decline in local authority spending power in the subsequent decade. The shorter the life expectancy at the beginning of the decade, the steeper were the subsequent cuts in spending power – up to 50% reduction in the sickest areas. One could describe this as effort inversely proportionate to need. The shorter the life expectancy of a local authority, the greater the needed expenditure to put it right.

If the government won't do it nationally, we don't give up, but go to where the ambition and appetite is - at regional and local action. Coventry was the first and, in 2012, declared itself a Marmot City. It made our six recommendations the basis for planning and action in Coventry. Their argument was not just a negative one – the national government is going in the wrong direction. It was a positive statement that we, working at the city level, are close to the reality of people's lives, the conditions in which people are born, grow, live, work and age.

Following Coventry's lead, at the request of the Mayor, we worked with Greater Manchester. The City of Manchester used our report, Build Back Fairer in Greater Manchester, as the basis for their five-year plan, Making Manchester Fairer. The movement spread round England and to Gwent in Wales. By early 2025 it is likely that there will be 50 Marmot places. With Coventry, it began as a Marmot City; with Greater Manchester, a Marmot City Region. More appropriate now is Marmot places which include a London borough and rural areas.

The action at local level has been in spite of the steep, and regressive, cuts in spending power at local level, and central government policies that, to cite just two examples, led to increases in child poverty and a level of benefits in universal credit insufficient to meet the essentials for a healthy life. The commitment has been to improve lives for the community with the resources available. To oversimplify, the national

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government, through the tax and benefit system, decide what the level of child poverty should be. At local level the aim is to break the link between child poverty and poor outcomes for children and families, working with partners in business and the community and voluntary section.

In describing what constitutes a Marmot place, it is important not to forget the health and care system. The East London Foundation Trust was the first to declare itself a Marmot Trust. The aim, where possible is to take action on the social determinants of health. Such action should be extended to employees, patients and it should be pursued with partners in local places having a positive impact on the community. We are working with Barnardos and three integrated care systems to take action on key social determinants of health for children and young people. The three ICS have developed programmes with a football club to support young people to mix, get outside and learn vital skills; increase financial contributions to the community and voluntary sector and support parents and carers to bond and communicate with their babies. The NHS recognises that taking action on these social determinants will improve health and reduce inequalities for the long term.

The Institute of Health Equity produced a report, The Business of Health Equity, aimed at industry. We said there are three areas where industry can act to improve health equity: pay and conditions for workers; goods and services that the industry delivers; the wider impact on communities and environment. Our work with business continues as we involve businesses in Marmot places and work with national businesses.

Marmot places are characterised by three approaches: involvement of the community, learning from lived experience; collaboration of all the relevant actors, including local government, the voluntary community and faith sectors, health and care, other public services, business; adapting knowledge of what works to achieve health equity to local circumstances. In each case it has been important to set up a monitoring framework to assess progress.

Our health equity network, with over 5000 people involved indicates a great appetite for more action for health equity. With a change in national government in Westminster with what is likely to be a more favourable approach to social justice and health equity, the question arises as to which is more important: action at local level or at national level. The answer is clearly both. We need national action to set the context, reducing child poverty for example and funding local areas according to need. But action at local level will always be vital: to address the conditions in which people are born, grow, live, work and age. Thereby to achieve a fairer society and greater health equity.



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A photograph of a middle-aged man with a grey beard and mustache, smiling warmly. He is wearing a grey textured knit sweater over a bright blue collared shirt. A small silver pendant is visible on a chain around his neck. The background is slightly blurred, showing what appears to be a computer monitor and a desk. A large, thick, magenta curved line sweeps across the bottom right of the page, partially overlapping the text area.

ESSAY

ACHIEVING HEALTH EQUITY - THE VITAL ROLE OF COMMUNITY POWER

BY CLARE WIGHTMAN, GRAPEVINE COVENTRY
AND WARWICKSHIRE

What lives diminished by the inequity Michael Marmot describes need is a shift in power.

Health inequalities, like other inequalities, are mainly decided by how resources and opportunities are distributed. That's about who has power and who doesn't.

The first round of central government driven austerity landed hard in Coventry. There was a neighbourhood here with five times the city rate of lone parent families with children under 18. And yet the decision was made to close the children's centre, close the youth service and locate the replacement family hub somewhere else. Resources were taken away from those families with little or no protest and certainly no organised response.

In order to create better, healthier places, Grapevine works on the agency and capacity of people who live in the city so they can hold others to account when they need to as well as form and lead their own solutions. Without that work I believe we won't shift the dial on health inequalities.

But it's going to take a robust understanding of what community power is and what it really takes to build it or untap it. It's not as simple as – "there is community action happening in the 'wider determinants' space and the public sector needs to get better connected to it."

Here's a couple of stories to show you what I mean.


Dorothy is a Cameroonian refugee who set up an exercise class in Willenhall, an area with stubborn health inequalities.

Dorothy and 50 people in her community challenged themselves with the Dovedale and Thorpe Cloud circuit through the Peak District in September.

Dorothy knows about war. She knows about our depressing immigration process and about being moved with a new baby into an empty building in a place where she knew no-one. There were health struggles for Dorothy as an older mother, followed later by mental health struggles for her daughter brought on by school bullies which affected the whole household.

Next came the Covid-19 pandemic which became the reason for Dorothy and her family to get outside and walk together. "It united the family, revitalised our emotional health and uplifted us", says Dorothy. Despite many deep challenges Dorothy now leads an exercise group of 50 mainly migrant women.

When we asked her what was important about what she is doing in her community, she said: "One of our members had been facing deportation to Cameroon after finishing her studies. Another one is facing eviction from her home and she's got children. Others are here from Ukraine. Who cares about what the scale says when you have such weight on your shoulders? We are taking the weight off people's bodies and their



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shoulders. Willenhall [in Coventry] is an area with lots of people carrying both weights. No one else is dealing with these issues the way that we do."

But there was no 'hey presto' to this story.

We only found Dorothy with all her rich vision and leadership potential because:

- our community organiser immersed himself in her neighbourhood and started attending the same church services as her
- he talked to her many times in order to uncover what she'd like to change
- he walked with her on that journey of change – coaching, planning, refusing to give up, attending the class himself.

Only now, two years on, might she and her team stand a chance of being powerful enough in their vision and agenda for change to partner with say the NHS or the local council in anything like an equal and influential way.

Another quick story.

'Willenhall Coalition'. The Coalition team – people living in and caring for the neighbourhood – have identified priorities it needs to tackle first. Members decided that by focusing on the unused park they could help people improve their health, socialise, and support local children and their families. Their campaign is well underway and its first goal is improving the existing play area. The team has applied for their first batch of funding. Some developing ideas include better pre-school provision, an outdoor gym for older children and adults and a multipurpose court. The 'Friends of Brookstray Park' community group recently held a recruitment drive at the park in Willenhall where they are campaigning for improved park and play facilities.

This coalition started out as a pretty stormy public meeting. It took carefully handled meetings, door knocking, surveys, hundreds of one-to-one conversations with people to draw out passions, strengths and motivation. Then it required individual coaching, regular 'house meetings', and, thrown in along the way, there were still setbacks that called for skill and resilience, belief in people and that behind every door lay some wisdom and some insight.

The sheer skill and persistence needed to create what you see on the surface is the untold story of community power.

These stories are not to say this work is too hard.

They're to say – look at the beautiful, staggering, agency and leadership that is there potentially even amongst people and neighbourhoods experiencing the toughest of times.

They're to say – uncovering and growing community power requires method, infrastructure as well as committed and long term investment, if you really want dials to move.

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There is much talk now that to create the conditions for everyone to thrive, we need a new way of governing, one that combines the power of Westminster with the power of communities.

But it is an agenda that would be well served by a robust understanding of what community power is, how it can be developed, what is needed for it, what value it can create and what might limit it.



Head Office:

America House

Turning Point

2 America Square

London

EC3N 2LU

Web: www.turning-point.co.uk

Call: 020 7481 7600

Email: info@turning-point.co.uk