

Rethinking Homelessness:
Clinical Perspectives

Pathway is the UK's leading homeless healthcare charity. We work with the NHS and other partners to create improved models of care for people experiencing homelessness.

Pathway helps to improve the quality of healthcare homeless and excluded groups receive by: developing and sharing best models of care like our hospital teams; increasing specialist skills of workers in healthcare; influencing policy; and reducing stigma in healthcare against people experiencing multiple exclusion.

Foreword

I am delighted to introduce 'Rethinking Homelessness: Clinical Perspectives'.

Improvements to services happen for all sorts of reasons, but very often it is the inspiration we take from a colleague that gets us to change what we do.

Over the last ten years, Pathway has had the privilege to work with clinicians from nearly every professional group in the NHS. To mark our tenth anniversary year, we thought we would invite some leading practitioners in the inclusion health sector to share what they have learned and their ideas about what needs to change.

In interview format, this booklet presents the results. Each of our contributors talks from their own unique clinical perspective but between them some common themes emerge: the terrible impact that austerity has had on homeless services in general and on the lives of their patients; the urgent need to address the underlying factors that frame the lives of too many people experiencing homelessness – childhood poverty and trauma, addictions, mental illness, chronic poor health; and the shockingly obvious need for decent, affordable housing. But they also call for specific changes: investment in targeted, specialist education for healthcare professionals, a national commission of inquiry into service responses to complex compound trauma, and visible, informed inclusion health leadership from the NHS.

I also think that each piece reveals something of our colleague's kindness and compassion. I thank them for their dedication to improving healthcare for people experiencing homelessness and for their contribution to our shared endeavour. Our challenge for the future is to use our collective knowledge, our evidence and our experience to demand whole-scale system change. The NHS has a huge part to play in ending homelessness for good. We need to get on with it.

Alex Bax

Chief Executive, Pathway

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Inclusion Health Nursing

Samantha Dorney-Smith

Samantha Dorney-Smith is Pathway's Nursing Fellow. Her role includes managing a variety of Pathway service developments and undertaking service evaluations. She also leads on several campaigns for Pathway, such as improving access to GP registration, challenging the impact of NHS charging, lobbying for the routine recording of housing status in health data sets, and the monitoring of the deaths of people dying homeless. Sam is also the Queen's Nursing Institute's Homeless Health Programme Lead, and the Secretary of the London Network of Nurses and Midwives Homelessness Group (LNNM). Prior to joining Pathway, Sam was a Nurse Practitioner working with inclusion health groups in both the community and in hospital.

How would you define Inclusion Health?

Inclusion health is concerned with improving access to healthcare and reducing inequality for the most disenfranchised groups in society. This includes people experiencing homelessness, vulnerable migrants, gypsies and travellers, sex workers, and people leaving prison. We know that these groups live at the sharp end of health inequality. A recent, much publicised, Lancet article demonstrated that standardised all case mortality rates for many of these groups were eight times worse for excluded men, and twelve times worse for women ⁽¹⁾.

However, for me, inclusion health is not just about these groups. We also know that lots of other groups of people experience inequalities in health e.g. people with learning disabilities, those with severe and enduring mental health problems, and those simply living in poverty. In one study the difference in life expectancy between the richest and poorest wards in Glasgow was 14.3 years ⁽²⁾. I believe inclusion health must level the playing field for everyone.

At its core inclusion health is about enabling access to effective health care for all. This is not just about enabling access to GP registration, although this is important. It is about ensuring that health services can proactively assist people with literacy, language and cognition difficulties. It is about ensuring that all services are trauma informed, and that people suffering psychological trauma feel safe and welcome. It is about ensuring that all health services can and do accommodate difference, and know how and when to go the extra mile. To quote the words of Professor Sir Michael Marmot: 'To reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. We call this proportionate universalism.'⁽³⁾

How has the issue of homelessness changed over the last ten years?

I first became interested in the issue of homelessness around thirty years ago. I remember when I first moved to London, heading down to Cardboard City (the subway under the South Bank) to chat to people and understand how they felt. People will remember that visible street homelessness improved quite a bit after the time when Cardboard City was cleared, in the 20 years between 1990 and 2010, in part due to the Homeless Mentally Ill and Supporting People initiatives (both now gone).

However, homelessness levels have risen year-on-year since austerity was introduced in 2010 – notably a 165% increase in rough sleeping in London during this time. Reasons have included welfare reform, hostel bed closures, 40% cuts to Local Authority budgets affecting floating support and addictions services, and the ongoing impact of housing policy. Current levels of homelessness will not be reduced without attention to these causes.

EU migration has also played a major role, especially in London. Many EU migrants end up on the street – last year 51% of 8,555 rough sleepers in London were non-UK born, and 31% were from Central and Eastern Europe⁽⁴⁾. Lower skilled migrants often seek cash-in-hand work, and never register as workers or pay tax. As a result, when something goes wrong, they have ‘no recourse to public funds’ – which means that they are not entitled to access welfare benefits or housing. Without a job or state income, people rapidly become destitute, and many of these people have additional alcohol and health problems. If they are not going to return home, I think we should be providing comprehensive alcohol treatment for this cohort, and then afterwards help support them into work. Without this we see awful results - a gradual deterioration on the streets, and early death – which causes huge vicarious trauma to outreach staff along the way. Not treating people also doesn't make any economic sense either, because these are potentially highly functioning members of society who want to work. We also have lots of failed asylum seekers who are in a similar position. Just allowing this problem to exist is a form of human rights abuse.

Has it become easier for homeless patients to access healthcare?

When I worked in A&E, we used to get lots of homeless patients who did not have any other form of access to healthcare. To be honest I don't think that has changed at all. If anything, it has got worse. When the rules changed to say that GP practices needed to provide access to appointments in 48 hours, nearly all practices changed to early morning telephone booking. The evidence suggests A&E attendances from people experiencing homelessness are going up significantly, and this is no great surprise⁽⁵⁾.

Getting registered with a GP remains difficult, because homeless people are asked for personal identification and documents to prove their address. However, guidance from the Department of Health and NHS England clearly states that patients do not need to provide ID to register, and that not having documents should not be a barrier to accessing healthcare. Despite this, the Royal College of General Practitioners recently conducted a spot-survey in London – and found that 75 of the 100 surveyed GP practices ‘required’ ID to register ⁽⁶⁾. If GP practices turn someone away, then they are required to give them a letter explaining why and keep a record of this. I have never seen an audit done of these letters.

GP practices are private providers to the NHS. If practices are not doing something that is not in line with NHS guidance – in this case, failing to register some of the most vulnerable people in their local area – then the NHS has a duty to step in and hold them to account. But the system is not doing that. It should definitely take action.

Having said that there are some really excellent examples of the voluntary sector working to mitigate the challenges though – for example the work of Groundswell with the ‘My Rights to Healthcare’ cards ⁽⁷⁾, and the Doctors of the World ‘Safe Surgeries’ ⁽⁸⁾ programme. These projects are making a massive difference to many people’s experience.

Does a mainstream or specialist service better serve homeless patients?

I started my inclusion health career in the Health Inclusion Team (then called the Homeless Team) in South London, where there aren’t any specialist GP practices. Instead they have a specialist nursing team, and the idea is that the nurses work with the local GP practices to facilitate care within that GP practice. This is so that patients can get accustomed to mainstream GP care, and are then equipped to be in a mainstream GP practice when they move on. As a model of care, this has been very successful, and it does have the advantage of spreading inclusion health skills across the practice staff in those mainstream practices.

However, I do understand why patients say that they prefer specialist GP services. Obviously, there are many simple practical barriers in mainstream care – e.g. the early morning telephone booking previously mentioned. I once had to wait 22 minutes on the line to get through to a GP practice for a patient at 8am, and when we got through all the appointments were gone! Lots of homeless people have phones, but almost none of them have credit. And if they are sleeping rough and have addictions or mental health problems, they are very unlikely to wait several minutes on the phone to book an appointment.

Of course, we also know that patients routinely get treated with kindness and compassion in specialist services, and time is taken to understand their needs, so it is unsurprising that patients prefer this.

However, my worry is that we need to get mainstream services to think more inclusively, and compassionately and not put barriers up – and that by having specialist services we allow mainstream care to get away with it. Ultimately, we need mainstream services to work for everyone.

I do think homeless health peer advocacy is a way forward. This is where people with experience of homelessness are trained to buddy up with a currently homeless patient and help them to overcome the challenges inherent in accessing mainstream care. Evaluation of this approach demonstrated a 42% reduction in unscheduled care ⁽⁹⁾.

What is the future of clinical Inclusion Health nursing?

The core elements of inclusion healthcare are expert patient engagement and complex case management, which fall primarily under the jurisdiction of nurses, and it feels like this is a natural clinical area for nurses to excel in. I think we now have about 1000 inclusion health specialist nurses in the UK, and they are making up the backbone of the inclusion health workforce.

I've known so many amazing inclusion health nurses over the years. They are all really inspiring, creative people, dedicated to the cause. I've recently had the pleasure of running a project for nurses working in homeless hospital discharge nationally ⁽¹⁰⁾, and I have frequently felt really humbled when I have shadowed them. I love the fact that a key part of all my roles is to bring inclusion health nurses together, so they can share best practice, but also so that they can support and encourage each other.

I think the future of inclusion health nursing is around delivering systems change for the whole NHS. Inclusion health nurses operate at the frontline of broken systems – they know what works and what doesn't. Many of these nurses have worked really hard to successfully design and develop solutions locally. Such skills have much wider applicability, and could help change all health care systems for the better. Most large health organisations have Safeguarding Lead nurses that deliver the safeguarding agenda - in the future, I would like to see health organisations having Inclusion Health Lead nurses, leading on quality improvement from an inclusion health perspective.

However, first I would like to see the clinical discipline of inclusion health nursing formally recognised and supported. All the current support is being provided by the voluntary sector from charitable funds – via Pathway, the

Queen's Nursing Institute Homeless Health programme ⁽¹¹⁾ and the London Network of Nurses and Midwives Homelessness Group ⁽¹²⁾. These nurses (as well as other allied professionals working in this area) deserve access to quality continuing professional development, regular reflective practice, a work-based infrastructure that enables growth and creativity, professional recognition, and remuneration in line with their seniority. It is important to note that burn out is common in this area due to the complex and emotionally challenging nature of the work, and attention is needed to mitigate this. I personally remember many of the clients I have worked with over the years that have died, and I still feel the impact of their deaths very keenly.

At the beginning of the last decade, we had a National Inclusion Health Board ⁽¹³⁾. The role of the Board was to provide cross-sector leadership and ownership of inclusion health nationally. It was formed in 2009, because the Government at the time recognised that the emerging discipline of inclusion health required national leadership and championing. Work streams included Leadership and Workforce, Data and Research, Promotion and Prevention, and Assurance and Accountability. However, the work of this Board suddenly stopped in 2013 - there was no formal closure, the Board just disappeared. I would like this Board reconvened to continue with the excellent work it started. Even if there was just an Inclusion Health Lead within the government, I think this would make a massive difference.

I would also like to see specific inclusion health training introduced for all healthcare professionals at pre-registration level. Although students are effectively taught about the social determinants of health, they are not taught what they can personally do to reverse these inequalities. Rights to healthcare, cultural competence, inclusive care and health justice should be taught to everyone. The NHS has mandatory training for healthcare professionals already, so there is an existing infrastructure to bring in such standard training. You could also easily teach staff the basics of housing and human rights, and staff would be much better equipped in their approach to homeless people as a result. Having said that, even if we could simply include rights to GP registration on the core training agenda, this would make a positive difference.

What would you say are the biggest things that would help specialist homeless nurses and their patients?

I think there are five key things I would concentrate on:

1. The NHS should actively enforce current GP registration regulations, and encourage more inclusive service provision with monitoring;

2. There should be a national commitment to provide core inclusion health training for all pre-registration health care professionals;
3. The specialist inclusion health nurse role should be professionally recognised, and adequately invested in and supported;
4. Clear national leadership within the UK health and care system is necessary to make all health services more inclusive and accessible;
5. Homeless health peer advocacy should be further invested in.

However, a really important thing that would help is for us all to take stock sometimes, and realise that we are part of a very committed movement that is making progress. Slow progress maybe, but definitely progress. Before I came into inclusion health I worked in A&E where no one ever really thought about considering why someone was homeless, let alone whether we could do anything about it. Currently, there are 12 Pathway teams across the UK. We just need to keep focused on the vision of inclusion and keep on going. ●

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Complex Trauma

John Conolly

John Conolly is the Lead Counsellor for the Central London Community Healthcare NHS Trust, Westminster Health Counselling Service. He leads a team of counsellors located across Westminster day centres and GP surgeries, specifically for homeless patients. His service offers 'drop-in' counselling sessions and discussion groups; and includes a specialist female counsellor to support homeless women. Many of his patients suffer from complex trauma, personality disorder or what he has come to understand as a 'traumatised personality' (Conolly, 2018a, 2018b).

What is complex trauma?

Complex trauma occurs when a person is confronted by and/or has experienced a series of different traumas. It can have many different causes and guises.

For homeless people who are native to the UK, there may have been several traumas leading to them becoming homeless. Imagine the following - a nurse has a major car accident in which she breaks her spine. She therefore can't work and loses her only source of income. Her husband can't cope with the situation. As a result, the marriage breaks down and her husband leaves the family. She becomes addicted to pain killers and social services take away the children, as she cannot look after them. She is not able to maintain her rent payments. She becomes homeless. This is one example of a particular kind of complex trauma.

Another particular kind of complex trauma occurs when an individual is raised in an already dysfunctional family. They may have alcoholic parents who have abused them as children. Thus, the children grow up internalising the 'trauma/threat reaction'; they develop a traumatised personality, which is labelled as a personality disorder. They become unruly children and fall behind at school, not so much due to learning difficulties, but to emotional over-arousal and an inability to focus and concentrate. They may eventually end up in prison where they may experience further trauma and become homeless upon being released. They go from crisis to crisis because they were deprived of the opportunities to learn basic social skills and to develop their ability to manage their emotions, like you and I do, but take for granted, given that our carers did this as a matter of course. These individuals are disadvantaged right from the very start of their lives. Their experiences are now commonly referred to as 'adverse childhood experiences' or ACEs.

The third kind of complex trauma occurs when individuals have been in a civil or all-out war situation abroad. As a result, they flee from their home country and arrive in the UK. These individuals may have had their homes bombed and lost their friends and family. They may have been tortured and/or lost body parts. They accumulate several traumas over a short period of time. And their

journey to the UK is often also incredibly traumatic. Many women get raped on their way here, many having been already raped in their home country. When they arrive in the UK, they then have to navigate all of our cultural systems and bureaucratic institutions; all whilst traumatised, not speaking English and being isolated with no social support.

Another scenario is that of a low earner from a European country who comes over, works, but sustains an injury and is unable to work, he has no social network to offer him support, he loses his room, becomes homeless and turns to drink.

I see around 20 patients per week. Out of all the patients I see, I'd say that over 80 per cent have some form of complex trauma. That might also involve depression, an eating disorder, uncontrolled anger, and anxiety, and possibly an addiction to help cope with these very distressing symptoms.

Out of that 80 per cent, I would estimate that 30 per cent have been exposed to adverse childhood experiences. The remainder is split between people fleeing to the UK from abroad (around 40%), and those (about 10%) who are UK born and suffering extraordinary events, such as accidents impacting on their lives in a catastrophic way. However, we mustn't forget that homelessness in itself is also a trauma which exposes homeless people to further trauma, like being assaulted on the street, belongings being stolen, being shouted at, being spat at, urinated on etc.

What are the effects of complex trauma?

One of the effects of complex trauma is that it shatters logic, rational thought, discourse and narrative. So, when you speak to someone who has been highly traumatised, they will be silent and look dazed, or will be jumping all over the place. There won't be a thread or a theme to their communication – there will be lots of different unrelated themes with many contradictions in their speech. Some people believe that they may be psychotic because they are talking and interacting in such a strange way. Once I realised that all of this was trauma-driven, then I knew that my first task when speaking to people was to reassure them and make them feel cared for. Once I had done this for several weeks and months, I saw a great deal of change in the patients that I saw – they became relaxed, their trauma reaction began to weaken, and their speech became more rational and understandable, and therefore their backstory better able to emerge. I have often had to question diagnoses made too hastily, by psychiatrists or GPs.

When an individual is traumatised, they also struggle to engage with people. If a hostel worker is assessing them or has lots of questions for them, they

are taking the homeless patient back to their trauma. It therefore kicks off their trauma reaction, and they can no longer concentrate or understand what the hostel worker is saying. The worker usually doesn't understand what is going on and believes that the individual is being wilfully obstructive. Or the individual may lose their temper due to an inability to manage their emotions, which may stem from their adverse childhood experiences. They are therefore labelled as 'difficult' and someone who doesn't want to engage, rather than someone who is traumatised and has mental health problems.

These types of interactions are common across all the institutions a homeless patient may come across – so not just hostels, but also the council's housing and benefits departments. Employees in those institutions expect certain norms or behaviour when engaging with people. However, those expectations are completely wrong for homeless patients who are traumatised. It is unrealistic to expect homeless patients to interact with those employers and institutions in the same way that you or I would. Thus, complex trauma has several consequences for homeless patients – the primary ones being that they struggle to get a job and they struggle to engage with the healthcare professionals that are trying to help them. This is why mainstream services are not particularly useful for homeless patients; these patients often need and benefit from specialist care.

How have your experiences of homelessness and complex trauma changed over the last ten years?

Over the last ten years, there has been a steady growth in psychological knowledge and psychological awareness in the field. More psychologists are being employed by charities. Westminster City Council, for example, is becoming much more psychologically aware.

The introduction of the Housing First approach in the UK is also promising. Previously, someone with complex trauma or alcoholism would have been told to address these issues before they could get housing. Realistically, this was never going to happen – people don't sort out their problems whilst living on the streets. The Housing First approach says that homeless patients should be given accommodation first; once they are settled, they are then offered treatment to address their personal and health issues. The evidence has shown that this approach is much more effective, especially in smaller cities where the housing market is not so ridiculously inflated as in London, where the costs of acquiring properties offset any savings made from resettling, treating and re-integrating people.

The emergence of such initiatives such as PIES (Psychologically Informed Environments) for hostels and day centres based on the recognition of Complex

trauma being so prevalent for homeless people, and also the Trauma Informed Care approach is also hopeful. However, I have reservations about their implementation on the ground. Services are under pressure and there is very high staff turnover. I'm not sure that services invest enough in regularly training and updating their staff in the skills needed to care for traumatised people. My own experience is that many services exist in 'crisis management' mode, due to under-resourcing, where only immediate and primary priorities, usually organisational ones, are aimed for, invested in, and delivered.

I have seen a dramatic increase in the number of homeless patients visiting our services. Some people blame this on the introduction of Universal Credit – there can be a gap of three to six weeks, sometimes even more, between people having their old benefits stopped and the new Universal Credit payments coming through. So, for that period of time, people become destitute and this has caused lots of issues. Cuts to the welfare system and the decreasing supply of social housing have played a key structural role in the levels of homelessness we see today. Housing benefit has not kept up with increasing rents, and the rental market is incredibly volatile with landlords selling their properties or renovating them, and terminating tenancies. There is also a continuing barrier to employment for people moving out of homelessness. When an individual is settled in a hostel and wants to work, they cannot because housing benefit pays for their hostel. They have to earn quite a high salary in order to replace the housing benefit they lose when they start working. As a result, individuals often decide not to work – this is a waste because a lot of homeless patients I see would much rather work. They know that work is good for them, but there are very real systemic obstacles.

When I began working in the field of homelessness eleven years ago, I felt I was missing something; morale was low in the team and patients did not come back to their second appointments. Over time, I realised that people needed and craved a human connection, which could relate to them as individuals – a connection which didn't judge them, label them or diagnose them (1,2). When you are homeless, you don't belong anywhere and you have no position in society, you not only don't have a home, but you don't have a job, friends, family, and relatives. You end up becoming invisible, voiceless and incredibly lonely; hence addictions and outbursts of anger.

Humans are social animals, so we gain a sense of existing only through social contact and getting feedback from other people. We all unconsciously fear going mad or disintegrating psychologically, and it is through relationships with others that we can maintain a sense of stability and wholeness, especially when we are under duress. Many people experiencing homelessness lack that and often only

receive negative feedback, like negative comments or looks from others. As a result, there is an enormous need for people experiencing homelessness to feel that they are cared for.

Once I began to understand this, I changed my whole psychological approach – I couldn't expect homeless people to come to me for regular appointments, given their chaotic circumstances. So, I introduced 'drop-in' clinics where people could drop in without needing an appointment or a referral. As there was no expectation of them attending regularly, every encounter was maximized as an opportunity to make it worthwhile for that person to want to come back.

When people come to see me, I won't assess them or ask them lots of questions about their lives, (as this can re-traumatize them), apart from a very relaxed conversational exploration of possible risks for them. I allow them to tell me their story in their own way and at their own pace. Of those people that come to my regular appointment-based counselling sessions, I would say that 80 per cent make substantial improvements. This could mean that they reconnect with people, there is a reduction in their symptoms, or their relationship towards their symptoms changes, so as to no longer hold them back; they engage with homeless services, they get rehoused in a hostel, their addictions become more manageable, they become less chaotic, they attend A&E less, they do voluntary work, they do training etc. In the counselling process, their narratives become more coherent and their inter-relational style more apt. This is why I feel so passionately about my work – if you can engage with a person by adapting to their needs, you can achieve an incredibly high rate of improvement.

What changes would you like to see in addressing homelessness and complex trauma?

I believe there should be one centralised record, which can be accessed by all the different services that a homeless patient may interact with. This would be much better than having the individual retell their traumatic histories and experiences to multiple people, which only causes them further trauma. Alternatively, counsellors could write a report for the individual – this report could then be given to the employees in those other services. At the moment, homeless patients have to start from scratch every time they begin a new interaction.

A further practical solution would be to provide training to all employees of these services and institutions. The training would teach employees how to interact with someone who is homeless and get the information they need from them, but in a way which values them and avoids triggering their trauma. This can be taught, as it is the way in which counsellors are trained – the first thing

we learn is active listening skills. If every employee could be trained in active listening, that would go a significant way in helping people integrate back into the community.

I have also noticed a chronic lack of academic research in the field of homelessness. There is a critical need for more education and training on homelessness and social exclusion. There needs to be sustained institutional investment in these types of social issues. Why aren't there more university departments exploring the psychology of homelessness? I suspect the simple reason is a lack of funding. This is why the work of organisations, such as Pathway, is so vital, in highlighting the issues of homelessness and producing evidence-based research.

In the last ten years, Pathway has helped an institutional voice to emerge from isolated and embattled practitioners in the field of homeless health. My own thinking, practice, writing and publishing has certainly been galvanised by Pathway, and I believe many of my colleagues in the field have had a similar experience.

This gives me hope for the future. I think that Pathway should lead a campaign along the lines led by the National Institute for Mental Health in England (2003), developed in the wake of the National Service Framework for Mental Health (1999). That campaign responded to the realisation that people with personality disorders were one of the most excluded groups in society and experienced incomprehension and a lack of tolerance from services across the board. One of the major thrusts of the campaign was to raise awareness of the need for staff training across all services working with people suffering from personality disorders. On the back of that, a skills escalator framework was delivered via the Knowledge and Understanding Framework for personality disorders (KUF) funded by the Department of Health and the Ministry of Justice (2007).

Pathway should consider carrying out a feasibility study to raise funding for, initiate, and, lead an equivalent consortium to deliver a National Homelessness Competencies Framework. ●

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Multidisciplinary Approaches to Inclusive Palliative Care

Caroline Shulman

Caroline Shulman is a GP who has worked with people experiencing homelessness and other forms of social exclusion for over eleven years. This includes working in a GP practice that specialises in providing primary care for asylum seekers, refugees and people experiencing homelessness; in-reach into a complex-needs hostel and currently, as the lead clinician for a Pathway team in South London. Caroline also leads research on palliative care within homeless populations, based within the Marie Curie Palliative Care Research Department at UCL and at Pathway.

How has homelessness and inclusion health changed over the last ten years?

Looking back on the last ten years, many things have really not improved – if anything, much has got worse. The number of people experiencing all forms of homelessness has increased while the number of beds in supported hostel accommodation and floating and other community support has reduced. This has made inclusion health as a clinical specialty ever more essential.

Chronic homelessness is often characterised by tri-morbidity. What is this referring to?

Homelessness is very much a health issue. Tri-morbidity is the combination of both a mental and physical health problem, along with substance misuse issues. This combination is very common in people experiencing multiple exclusion and homelessness, and often stems from past complex trauma such as adverse childhood experiences.

In my service, we see people who are extremely unwell with multiple and complex needs at appallingly young ages.

Have you seen a change in supportive care services over the last ten years?

There has been a marked decline in so many services. One example is the decline in drug and alcohol services. Addiction services fall within Public Health Departments and since 2012 Public Health transferred out of the NHS to local authorities, the budgets of which have been severely cut by central government. There has also been a decline in the number of addiction psychiatrists over the years. People with complex mental health difficulties together with substance misuse are often turned away from mental health services until they have addressed their addiction. In addition, there has been a change of drug strategy since 2010, away from ‘harm reduction’ and instead to one that puts ‘achieving abstinence’ in the centre. This means that targets and incentives are driven by getting people off of treatment. This has resulted in increased barriers to

access of drug services and needle exchanges for people who have the most challenging problems and who need long term, flexible support.

In my clinical job, I see a lot of people who are intravenous drug users. Many are in hospital for long periods of time (often weeks or months), due to complications of injecting such as infection of their heart valves, bones and abscesses (particularly in difficult to treat organs such as the lung, spine or brain). Most of these illnesses are a result of unsafe injecting practices, including sharing or re-using needles, and contribute significantly to deterioration of health.

On a positive note, when someone is in hospital for a significant amount of time, the admission often serves as an opportunity to help them address their addictions and reflect on where they want to go. For some people, it serves as a 'light bulb' moment and fosters a desire to turn their lives around. Yet in many cases, they would have no option but to return to the hostel system. Our Pathway team will strongly advocate for someone not to go back into the hostel system, particularly if they themselves feel this will jeopardise their recovery. But today the only alternative is often temporary accommodation with very little support, which can contribute to them relapsing. What might be considered as the best option would be to go straight into a rehabilitation setting. However, this is virtually impossible due to delays in securing funding. There are so many missed opportunities within the system resulting from fragmentation and a lack of responsiveness and flexibility and so, a lack of person-centred care.

What were the motivations for your research on end of life care for people who are homeless?

The general public is often very shocked to hear about the growing number of deaths on the street and that the average age of death for a homeless person is in their 40s. Our research, which I started a few years ago, was driven by a desire to understand what was happening to people who were homeless or vulnerably housed, in the last months of life. We knew that many people who were homeless were dying in an undignified way and without support, with their last months often punctuated with frequent unplanned emergency hospital admissions. We wanted to explore this to see what needed to change to make this better.

Can you outline how you undertook your research? And what you discovered?

We conducted the research in three London Boroughs where we interviewed and conducted focus groups with 126 people. These included: people experiencing homelessness and living in hostels or attending day centres;

people with previous experience of homelessness who were now working as volunteers or as peer advocates; hostel and outreach staff and managers; people working within addiction services, including addiction psychiatrists; healthcare providers including specialist nurses and GPs, Pathway teams and people working within palliative care within hospitals, hospices and the community. To ensure our research remained grounded and appropriate, we worked alongside an expert by experience throughout.

We found that many people who are potentially in the last months of life with advanced ill health, are living in hostels. Hostel staff described the complexity of need of people being referred to their services as increasing, while their age was decreasing. In other words, people are getting sicker at a younger and younger age.

Staff described challenges in getting enough healthcare and social services support for their residents, particularly where their clients do not engage well with health services. This results in staff feeling an immense burden of responsibility. Hostel staff described how they are often left to support people who are self-neglecting, living in squalor and not able to look after themselves. If they don't help, then nobody does, particularly where residents are reluctant to engage with outside health or addiction services. Yet, hostel staff didn't feel that this should be their role. They are not carers and have no training in health. They are meant to be supporting people into recovery. Hostels are temporary accommodation meaning that people would usually be placed in a hostel for a time-limited period, usually up to a maximum of 24 months. But the reality is that many people living within the hostel system are extremely unwell with deteriorating health and are unlikely to recover without a radical change within the system.

The research also highlighted that there is a huge lack of places of care. When somebody has an addiction and/or mental health problem, there are virtually no other places they can go, however high their care and support needs. For example, a nursing home or sheltered accommodation would find it very difficult to accommodate and support somebody who has these complex needs. The other significant barrier, in addition to addiction and mental health issues, is age. People experiencing homelessness frequently have early onset ageing, with illnesses at a younger age than people who have not experienced this exclusion. The services that are available are often only for people over the age of 60 or 65, rather than people in their 30s, 40s and 50s.

Recognition of when someone might benefit from referral to palliative care services is another significant barrier. It rarely occurred except when someone

had a cancer diagnosis. This is because some of the conditions that people have, such as advanced liver disease, have unpredictable trajectories. People can be really sick and in intensive care for several weeks, but then be discharged from hospital and able to live for many more months until their next hospital admission. It is very difficult to predict which of those hospital admissions is likely to be their last due to this uncertainty. It is clear that we are dealing with a high number of very unwell people within the hostel system, but without the formal recognition of such by health and social care services.

Since completing this qualitative research, we have moved into an intervention phase to try and improve the care and support received by people living in hostels. As a way of improving in-reach support for residents who are unwell, and improving the skill set and confidence of hostel staff, we are twinning palliative care teams with hostels. Palliative care teams have a holistic approach, are excellent problem solvers and so able to look at complex situations from different perspectives. They are also aware that they cannot 'fix' everything or everyone. The palliative care teams provide additional training and support for hostel staff and also try and bring a multidisciplinary approach to care.

What recommendations came out of your research?

The main recommendation is joined-up, responsive, person-centred care at every stage of someone's journey. We need a non-fragmented system where health, housing, social care, palliative care, mental health services, and addiction services all work together to support people. Support has to be based on what that individual's priorities are, and what 'living well' means to them. We need to be "parallel planning", i.e. 'hoping for the best and planning for the worst'. We have developed a toolkit, which includes information on palliative care, and resources to support person-centred communication and care planning. It is aimed at frontline staff (but is also being used by other professional groups) to help increase knowledge and understanding in order to navigate systems and empower people to advocate for a multidisciplinary approach to care and support.

Our other recommendation is the need for more choice for people in terms of their place of care. At the moment, we are working to make the best of what we have and make hostels more supportive in addressing people's needs.

If a person considers the hostel their home and where they want to be, we need to make sure we bring the support to them at the hostel. This will involve continued advocacy for services to provide wrap around support within the hostel, as would happen for a patient in their home. However, if the hostel is not

the place someone wants to spend the last months of their life, we need to work hard to support getting them into an appropriate place of care, potentially one that provides 24-hour care and support if needed.

I, alongside other colleagues, have worked with politicians to see what we could do to improve the choices for people who are homeless and approaching the end of their life. Although the law is yet to be changed, we have stimulated a conversation with the Department of Health and the Ministry of Housing, Communities and Local Government. Furthermore, the government has made some additional recommendations for local authorities. Specifically, if people are within the last 6 months of their life, local authorities are required to liaise and coordinate with health and social care services to put people into appropriate places of care, and to regularly review that place of care. This is a good start, but there is still a long way to go before equitable end of life care services become a reality.

How would you summarise what's needed?

Working effectively to prevent the root causes of homelessness, as well as early interventions to support people who become homeless, should be possible with political commitment and partnership working. While this should be a moral and equity-based imperative, the financial costs to society of inadequate action are huge and needlessly growing.

In order to reduce missed opportunities at every stage in someone's journey we need to rethink our homelessness strategy. We need change at individual, community and national levels.

For support at an individual level, partners in health, housing, substance misuse and social care need to work collaboratively with shared goals with a flexible, responsive person-centred approach. In addition, recovery is not all about health, housing, and social care. It is also important that people are helped to find a purpose. One of the things I often hear when people have been in hospital for a while and are now seeing life through a different lens, is that they want to help others who are in the same situation as they were. Helping people get a purpose back in their life, is often an essential part of healing and recovery. We must not miss such opportunities.

At a community level, each borough could identify an inclusion health lead, potentially at the Primary Care network (PCN) level, who can monitor what is happening and advocate for change in their local area. This could mean more specialist primary care practices, more health/substance misuse in-reach into hostels or day centres, or more outreach services. Lessons learned should then be fed into the national picture to influence wider change.

At a national level, there needs to be a commitment that preventing and addressing homelessness and exclusion is an urgent issue of social justice and should be a key priority. This needs a cross-departmental strategy, but in addition, national bodies, such as NHS England need to take more responsibility for disseminating evidence-based change throughout the system. People may know what works in pockets, however the localised nature of healthcare and support services prevents change having widespread impact.

At all levels, the inclusion of people with lived experience is essential and has many benefits, both in guiding us to develop the right policies and in supporting people who are currently marginalised.

Over the last ten years, I have had the privilege of working alongside truly compassionate and courageous people, who despite a decade of adversities, continue to inspire me with their determination and tenacity. ●

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Biographies

Samantha Dorney-Smith, Pathway Nursing Fellow

Sam is a Registered Nurse, Specialist Practitioner, and Nurse Prescriber. Having started her career in General Medicine and A&E, she has been working with people experiencing homelessness and other excluded groups since 2004. Sam previously managed the Health Inclusion Team (a nurse outreach team working in hostels and day centres in Lambeth, Southwark and Lewisham, London), and more recently set up Pathway inpatient services for homeless patients in Guy's and St Thomas's, and King's College hospitals, and the South London and Maudsley. Sam works as a Nursing Fellow for Pathway, focusing on national inclusion health service improvement and development. Her particular interests are the development of nursing practice and inclusion health education, homeless health data capture, and medical respite, as well as supporting the setup of new Pathway teams. Sam has had several journal articles published, has sat on numerous homeless health related steering groups, and was previously seconded to the Department of Health. She is also currently the Nurse Project Lead for the Queen's Nursing Institute Homeless Health Programme, and is the Secretary of the London Network of Nurses and Midwives Homelessness Group.

John Conolly, Lead Counsellor, Westminster Homeless Health Counselling Service, Central London Community Healthcare NHS Trust

John is Lead Counsellor at the Westminster Homeless Health Counselling Service. He took on the role of (honorary) Chair for the Camden and Islington Foundation NHS Trust, Recovery College in 2019. He is also a Pathway Clinical Fellow. John is a Member of the Council for Psychoanalysis and Jungian Analysis College, and a Member of the Centre for Freudian Analysis and Research. He is a United Kingdom Council for Psychotherapy (UKCP) registered Psychoanalytic Psychotherapist, and Lacanian Analyst. He has taught at the Tavistock and Portman NHS Trust, as well as at Middlesex University, Mental Health Department. He is presently working on a book entitled 'Stories from the Basement – A Psychotherapist's Reflections on Caring for Homeless People and the Obstacles to Compassion'.

Caroline Shulman, Clinician and Researcher in Homelessness and Inclusion Health

Dr Caroline Shulman is a clinician and researcher in Homeless and Inclusion Health. She is clinical lead for a multidisciplinary homeless Pathway team based in a hospital in South London. She previously worked as a general practitioner providing primary care in a specialist homeless practice.

Caroline is also a Pathway Clinical Research Fellow and Honorary Senior Lecturer at University College London. She led a large qualitative study on Palliative Care in homeless people, in collaboration with the Marie Curie Palliative Care Research Department (UCL) and the homeless charities Pathway and St Mungo's. This explored the challenges and barriers to accessing palliative care for this marginalized group, as well as potential strategies for improving care and support. Recommendations from this research have been widely disseminated and shared with frontline staff, commissioners, policy makers and academics to try and facilitate change. Findings have contributed to reports from the Care Quality Commission, NHS England, Hospice UK and the Faculty of Homeless and Inclusion Health. Caroline and her team are currently undertaking further work, evaluating the impact of twinning community palliative care teams with hostels as a way of facilitating a multidisciplinary approach to supporting people experiencing homelessness with advanced ill health.

