

THE STORY OF DRUG USER INVOLVEMENT



In this first part of a series, April Wareham of **Working With Everyone** visits the archives to piece together a story of pioneers, trailblazers, community activists – and the challenges they faced to be heard

Part 1. Learning from history



THE HISTORY OF PEOPLE and communities coming together to try and make positive changes for themselves and others is long, varied and continues to this day.

CAMPAIGNING FOR CHANGE

One form of this is where people campaign for change. It might be a peaceful demonstration such as marches, petitions or withdrawal of labour – or more confrontational and disruptive such as chaining yourself to railings or causing property damage.

Some examples of this are: Levellers, Luddites, suffragettes, suffragists,

Jarrow hunger marchers, Trade unions, CND, Occupy, Extinction Rebellion, Black Lives Matter

SERVICE PROVISION

Something else that has happened formally and informally – probably for the whole of history – is people coming together to support others from their community. This has happened spontaneously for time immemorial, where people have reached out a helping hand to others in times of need – sharing food when a harvest fails, raising a barn for a newly married couple. During the late 19th and early 20th century some of these

efforts became more formalised and groups set up services for themselves and others like them. In fact, The Fellowship started this way.

Examples include: veterans' support groups, women's refuges, housing co-operatives, drug treatment, workers' education.

ENGAGING WITH THE SYSTEM

From the mid-20th century onwards, as national services – for health, education, infrastructure and planning – became more common, they began to work with people and communities to plan and deliver services. These attempts, at least initially, focused on letting people know what was happening, such as informing people that their homes would be demolished to make way for a new motorway!



Pics: A suffragette meeting in Caxton Hall, Manchester, England circa 1908. Emmeline Pethick-Lawrence and Emmeline Pankhurst stand in the centre of the platform. Extinction Rebellion protest, Regent Street, London, April 2022, credit Alisdare Hickson.

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As time went on, the ways that statutory agencies work with people and communities evolved significantly, and will continue to evolve as new ways of working are developed.

Each of these approaches will continue to make a difference to people's lives – and it is entirely possible that two groups from the same community that want the same outcome will choose different methods to achieve it.

COMMUNITY INVOLVEMENT IN HEALTH

The NHS was set up in 1948 to deliver acute healthcare services that were free at the point of delivery. The NHS then also began to deliver services to prevent people from becoming acutely unwell. These included immunisation, screening and antenatal care.

'The concept of including patients in health and health system decision-making has been around for over 50 years. Patient involvement in various aspects of healthcare, from improving healthcare quality to promoting patient safety, has emerged as a critical priority...'
[Understanding patient engagement in health system decision-making: a co-designed scoping review | Systematic Reviews | Full Text \(biomedcentral.com\) BMC Systematic Reviews.](#)

By the time the NHS produced the *Long-term Plan* in 2019 people were living longer overall and in many cases with long-term health conditions, such as diabetes and cardiovascular disease, so the focus was on working with patients to help them self-manage their own health. They used components of good healthcare such as supported self-management, personalised care and social prescribing, which are a formalising of things that people and communities have been doing for themselves and each other.

There is currently an acknowledgement that the best way to deliver health services effectively and safely is to work alongside people and communities.

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Because the possession and use of drugs is not only illegal, but also highly stigmatised, it has been historically quite difficult for people to be public about actions that they have taken to help themselves and others. Many of the things that happened were not even spoken about at the time, let alone written down. In writing this a number of people were interviewed – both those that use drugs, and the professionals and system partners that worked with them. This document aims to

bring to life a perspective of that story and doesn't claim to have captured everything that happened.

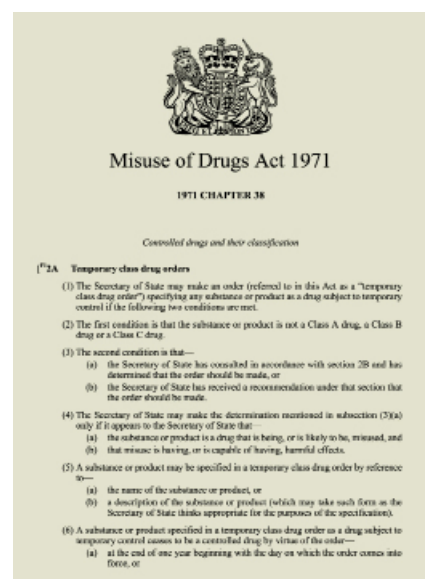
Using both collective and individual perspectives it will offer some insight which utilises people's honest memories and therefore might not be completely factually accurate. Some of it happened a long time ago, and now, as we look back, it probably doesn't matter whether it was 1992 or 1993. What matters is that we remember what happened and the truly amazing people who made it happen.

THE PURPOSE(S) OF DRUG TREATMENT

To understand the history of people who use drugs and how they have interacted with the system, it is important to understand the policy context in which drug treatment has been provided and, maybe more importantly, how it has been funded.

THE EARLY YEARS

After the introduction of the *Misuse of Drugs Act* (1971) which followed the need for a licence to prescribe diamorphine for opioid dependency (in 1968), and before the beginning of the HIV outbreak in the mid-1980s, the majority of drug treatment was



Pics: Aneurin Bevan, minister of health, on the first day of the National Health Service, 5 July 1948 at Park Hospital, Davyhulme, near Manchester. The Misuse of Drugs Act 1971 enshrines in UK law the provisions of the 1961 UN Single Convention on Narcotic Drugs.

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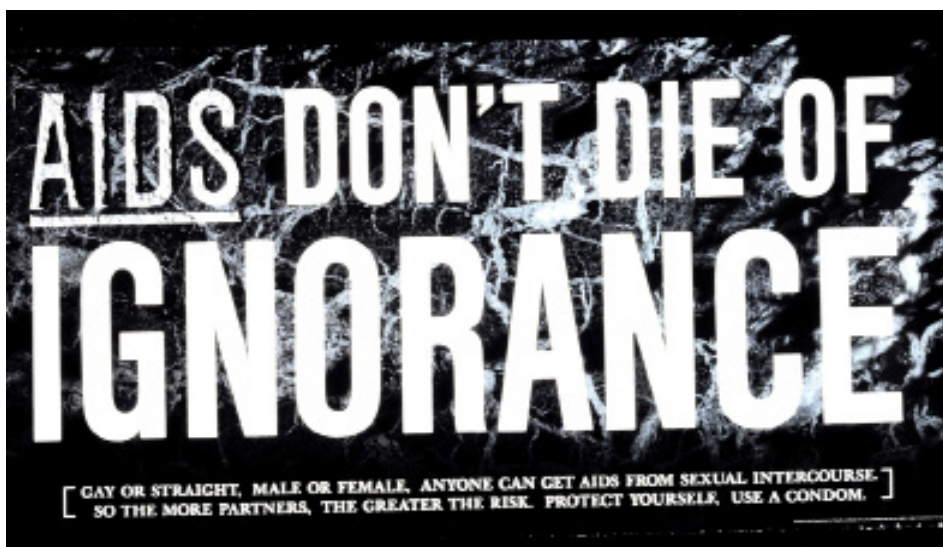
focused on achieving abstinence. Prescribing was limited to 'friendly' GPs and drug dependency units, which were based in hospitals and often had restrictive regimes, specific criteria of eligibility and long waiting lists.

Other treatment mainly consisted of various forms of residential treatment and was provided (and funded) in a piecemeal way. Some was funded or supported by religious communities, and some was set up by former drug users and supported by fundraising, donations, or individual patients paying for treatment (either personally or being funded by their local social services).

There was no consistent treatment offer across the country and little or no centralised funding.

Injecting equipment was available for sale to people who inject drugs (PWID) since the 1960s, but between 1982 and 1986 the Royal Pharmaceutical Society recommended that needles and syringes should only be sold to 'bona fide patients with a therapeutic need'. Not all pharmacists adhered to this guideline, but it created a serious inconsistency in the availability of injecting equipment across the country.

In the early 1980s there were a number of serious outbreaks of hepatitis B



amongst PWID across Europe and some early needle exchanges were set up, including one by Junkiebond, a drug user organisation in Holland.

At this point in the UK, any involvement of people who use drugs, their family members or people who had stopped using drugs took the form of setting up services. For the most part these were residential programmes that aimed to help people become abstinent.

THE HIV YEARS

The 1980s was a decade of social unrest which saw mainline politics clashing with industries, in particular coal mining. As

unemployment hit the highest rate since records began, the climate of unrest coincided with an influx of 'brown' heroin in the UK and an unfolding public health crisis. Our story begins in 1986.

There were many memorable events in 1986 – Halley's Comet reached the closest point to Earth, mad cow disease hit the headlines, the Iran-Contra affair revealed that the US had sold arms to Iran, NASA's Space Shuttle Challenger broke apart over the Atlantic Ocean, the Chernobyl disaster occurred at the Chernobyl Nuclear Power Plant. In mainstream media news this was the year that *The Oprah Winfrey Show* premiered, while *Top Gun*, *Crocodile Dundee*, *Platoon*, *Aliens*, and *Ferris Bueller's Day Off* were all notable films. In pop culture performers like Grace Jones, Mick Hucknall, Nick Kamen and David Byrne were all cover stories in *The Face*, an in-demand magazine of the '80s. It was a significant year for Nintendo as they released *The Legend of Zelda* in Japan, while *The Phantom of the Opera* opened in London.

From the beginning of the 1980s, across the world, there were deaths attributed to a previously unheard-of disease – AIDS. At this time it was considered to be fatal; there was no direct treatment and, on average, patients were dead within 15 months of diagnosis.

[Timeline of The HIV and AIDS epidemic | HIV.gov](#)



Pics: In 1984 members of MDHG and Junkiebond occupy the GG and GD registration office in the Netherlands to protest against central methadone registration. *AIDS - Don't die of ignorance* was a public health campaign begun in 1986 by the UK government in response to the rise of HIV/AIDS.

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By 1986 AIDS was considered a significant public health threat by the UK government. They ran the *Don't die of ignorance* public health campaign, which included a television advert featuring a tombstone and an iceberg, and a leaflet was delivered to every household.

One of the routes of transmission was injecting drugs using contaminated equipment. The UK faced the possible rapid spread of HIV infection among PWID. The combination of the growth and spread of drug injecting, high levels of syringe-sharing risk behaviour caused by a lack of access to sterile injecting equipment, and an outbreak of HIV infection in Edinburgh with prevalence levels of 50 per cent or more, made this route of transmission a significant risk. In response to this risk, targeted HIV prevention activities began for PWID.

There were some local needle exchanges set up in 1986, but needle and syringe exchange services began officially in the UK in 1987 when the Department of Health and Social Security funded a pilot study.

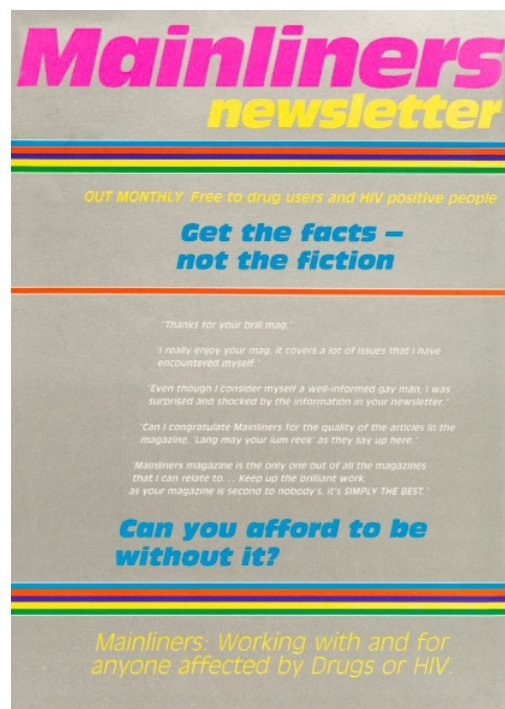
These services began to develop and led to exciting new models of practice in places such as Liverpool in 1988. [Public health and the origins of the Mersey model of harm reduction – ScienceDirect \(International Journal of Drug Policy, March 2010\).](#)

In 1988 The Advisory Council on the Misuse of Drugs (ACMD) published a report on AIDS and the misuse of drugs. The report normalised evolving ways of working with PWID. It increased the ability to distribute needles and syringes to PWID and at the same time increased access to opioid substitution therapy (OST) – mostly, but not entirely, methadone – for opioid dependency. This meant that PWID were offered an approach that was more flexible and accessible.

It also introduced to individuals, communities and service providers the notion of harm reduction as an intervention. [AIDS and injecting drug use in the United Kingdom, 1987-1993: the policy response and the prevention of the epidemic – PubMed \(nih.gov\)](#)

Around the same time as the HIV outbreak, and interwoven with it, are the reported cases of hepatitis B. Trends of hepatitis B infections are monitored over time by the Public Health Laboratory Service Communicable Disease Surveillance Centre, through laboratories in England and Wales. A total of 9,252 cases of acute HBV infection were reported between 1985 and 1996. How the disease was contracted was probably known for more than half of the cases – and of these, injecting drug use was the most reported.

While the infection rate fell by the late '80s, most likely with the implementation of the harm minimisation approach, by 1993 the rate had started to rise again. One report suggests that selective vaccination and/or needle syringe provision may not have contained ongoing transmission rates.

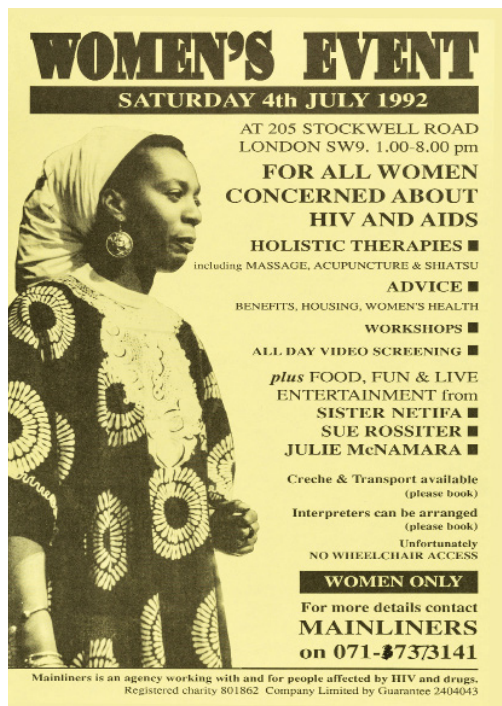


[Acute hepatitis B infection in England and Wales: 1985–96 | Epidemiology & Infection | Cambridge Core](#)

There was a significant, maybe even unprecedented, community response to HIV from those who were infected or affected. They set up peer support groups, hospital visiting, testing, and counselling. If there was a need, community members were there, delivering services that were either unfunded or partially funded. This community response included people who used drugs and their loved ones.

Community members also became heavily involved in campaigning for support services, research and good medical treatment. As it was such a new area of medicine, it was possible for anyone to stay up to date with developments in research and treatment and many patients and their family members knew as much, or more, about the subject than the medical professionals around them. In some ways they became the original expert patients.

Community members also demanded, and were invited, to be part of policy decisions that affected them, in a way



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that hadn't really happened before. They began engaging with the UK government, the United Nations, and the World Health Organization.

Although by 1986 the NHS Patient's Charter was encouraging service user/patient involvement and there was some activity occurring, the involvement of community members in this way and on this scale was practically unheard of.

Given the urgency of the situation and the level of fear generated by this new disease, both people who use drugs (PUD) and the professionals supporting them took significant risks to deliver services that probably wouldn't have happened otherwise. There were several early needle exchanges that were funded by drug dealers and run from a rucksack or somebody's home.

A number of services were started in response to local need. They were run by a mixture of community members and/or professionals and focused on HIV prevention and harm reduction. Some of these groups became the third sector providers that are still in existence today – often rebranded – and others have ceased to exist. Two well-known organisations that were set up by PUD were Mainliners and Open Road, who described themselves at the time as being founded by failed Phoenix House graduates.

Services were often funded patchily by a mixture of statutory (government) HIV prevention money, direct fundraising, grants from charitable trusts and money from local organisations. These funding sources covered different aspects of service delivery for varying



amounts of time. It wasn't uncommon to visit a service and be told that they had money for the building for two years, needle exchange for two years, and a couple of outreach posts for the next 12 months.

During this period it wasn't uncommon for current users to be employed in needle exchanges and as outreach workers.

By 1990 involving people who used services in the planning of services became a requirement of the NHS Community Care Act.

'...community care reforms strongly support the view that planning at whatever level should be conducted through a process of collaboration between all relevant stakeholders.' (HMSO: *Negotiating care in the community*)

This was taking place inconsistently in health and social care services but was not really happening in any meaningful way for people who used drugs. As before, if PUD felt that there was a service 'missing' that would benefit themselves and people like them, their only recourse was to set it up themselves.

In 1993 the ACMD stated:
'In appropriate circumstances, drug

user groups can provide valuable information to other drug services, helping them to adapt their work to make it more appropriate for drug users...'; 'volunteers and drug user groups will need training and support similar to, but more extensive than, that for peer educators...'; '[there is a] need for consolidation and a reassessment of the objectives, organisation and delivery of outreach interventions.' (*The AIDS and drug misuse update, ACMD*)

As can be seen, the system view of community organising for PUD was still limited to service delivery.

'It was around 1993, maybe 1994... I don't remember if they visited Brugerforingen or Junkiebond... maybe it was both... they came to see us to talk about drug users organising themselves... about us setting up a group here...'

As a result of this visit a number of areas developed a 'junkies union', one of which was VOID (The Voice of the Independent Drug user) in Essex. The core members of this group had been recruited by the local health promotion team to a project that provided support, training, injecting equipment and expenses, involving local drug dealers and users as outreach workers.



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These groups formed with the idea of a national organisation developing from local roots. At the time the majority of PUD didn't have landlines – and certainly not smartphones – and many moved address frequently. Groups drifted, closed down when the original members moved on, and the attempt failed.

The widespread funding of outreach posts in this period led to some badly managed and poorly focused services. Some of the original members of VOID were arrested for dealing once the funding for the project stopped. In other services PUD had been recruited to an outreach post that had funding for a year, loaded up with a rucksack full of syringes, given no training or support, and cut loose when the funding ended.

In 1996 the Department of Health (DOH) stated:

'User groups do appear to provide valuable support, at little or no extra cost, for some drug misusers' and 'purchasers should be aware of the possible benefits of self-help networks and should encourage the development of a wide range of self-help groups and self-help treatments; where possible self-help should be evaluated more vigorously.' (DOH, 1996)

As can be seen, the involvement of PUD was still seen purely as a way of providing additional support at little or no extra cost to the system.

In the first ten years, 1986 to 1996, drug user involvement was very variable. A lot of the work was based on service delivery. Lots of people became involved, but as projects were unfunded or had limited time-restricted funding, they mostly didn't continue for long. Because drug use was (and still is) illegal, many people involved didn't tell anyone outside of their immediate circle what they were doing and very little was written down at the time.

FOR CONTEXT...

Drug/substance use has been well documented across many civilisations throughout history. By the early 20th century, most western societies had developed a criminal justice approach to the usage of psychoactive substances by the public, see [The Harrison Act USA Federal Law 1914](#) *'...this Act was the first use of federal criminal law in the United States to attempt to deal with the nonmedical use of drugs.'* [What is the Harrison Act? \(with pictures\) \(unitedstatesnow.org\)](#) and [The Defence of the Realm Act, DORA, 1914](#) – *'Prior to 1916, there were no restrictions on the possession and use of cocaine, opium and other psychoactive drugs in Britain.'* [Drugs and DORA | World War I Centenary \(ox.ac.uk\)](#)

The 1970s saw the introduction of the 'war on drugs' – *'an effort in the United States since the 1970s to combat illegal drug use by greatly increasing penalties, enforcement, and incarceration for drug offenders.'* [History of the War on Drugs – The War on Drugs: History, Policy, and Therapeutics – Research Guides and Class Pages at Dominican University.](#) This approach 'demonised' certain groups in society by associating them with specific drug use behaviours. Other western governments followed suit by applying a similar attitude and approach to drug usage. While there have been some efforts to 'soften' this approach, in the mainstay it and its vestiges influence many policymakers and governments of today.

By the mid-1990s there had been significant developments in HIV treatment and some of the urgency seen in earlier years relaxed. HIV organisations became more focused on supporting people to access the new treatments.

In the UK in the mid '90s policymakers and politicians yet again tried to grasp the challenge of what to do about drug use. Today it has been widely accepted that the increase in acquisitive crime

in the '80s and early '90s was a direct result of the increase in heroin and (particularly in the '90s) crack cocaine use. *'This "epidemic" spread from area to area, but the national peak probably occurred between 1993 and 2000. Crime peaked between 1993 and 95.'* [\(The heroin epidemic of the 1980s and 1990s and its effect on crime trends - then and now: Technical Report Nick Morgan July 2014\).](#)

The John Mordaunt Trust was set up in 1996 to campaign for the health and human rights of ex/current injectors affected by HIV and other blood-borne infections. In recent years it has become more focused on drug policy reform.

In 1995 a white paper presenting the government's strategy for *'tackling the misuse of drugs'* was presented in Parliament. *'The policy centres on effective action by vigorous law enforcement, accessible treatment and education and prevention.'* It was an approach reminiscent of the 'war on drugs' rhetoric. [Tackling drugs together: a strategy for England 1995-1998](#); presented to Parliament by the Lord President of the Council and Leader of the Commons, the Secretaries of State for the Home Department, Health, Education and the Paymaster General, May 1995, [Social Care Online \(socialcareonline.org.uk, a website that has now closed down\).](#)

This focus on crime reduction, rather than public health, continued after the election of a Labour government in 1997.

From 1996 onwards, it became less common to meet people who were openly using drugs and working in treatment services, and those that continued to work in services hid their drug use.

'The work of some drug users is sometimes obscured, such as when drug user identities are not declared within services.' (Robbins, 2004)

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It should also be acknowledged that PUD continued to contribute to the development of good practice:

'It is important to recognise that while many harm reduction services are delivered by professionals, much harm reduction innovation comes from within drug using communities.' (Southwell 2010)

Black Poppy was set up in 1998 to produce a publication that would address some of the health and lifestyle issues affecting PUD on a daily basis.

The Methadone Alliance was formed in 2000 to advocate for individuals to get access to appropriate treatment and support. In their early years they became well known for helping people get appropriate OST prescriptions at a therapeutic dose.

During this period there were groups that were set up and run by PUD. These focused mainly on helping people to access appropriate treatment, supporting people to give up using, or providing harm reduction services. There was little or no coordinated strategic involvement at a national level outside of HIV prevention and treatment.



NHS
National Treatment Agency
for Substance Misuse

It could also apply to non-NHS service providers who run services for patients through contracts and service level agreements, or a commissioning partnership where the NHS is one of the partners.

By 2001 the NHS guidance explicitly refers to the drug treatment sector:

'The principles behind community development in the drug sector must lie within the needs and preferences of users, their families and carers.' (*Your guide to the NHS*)

And in November 2001, Paul Hayes the chief executive of the NTA stated:

'Involving drug treatment service users in the planning and monitoring of treatment is a priority for ministers and will inform all areas of our work.'

These statements set the stage for the move away from the involvement of active drug users and towards service user involvement as part of the NHS consumer model of patient involvement.

In the early NTA years national level engagement was with people from the John Mordaunt Trust, *Black Poppy* and the Methadone Alliance. There was also a national group called The National Drug Users Development Agency (NDUDA), who were commissioned to write a national user involvement strategy (which went out for consultation and was never published).

THE NTA YEARS

In April 2001 the National Treatment Agency for Substance Misuse (NTA) was launched. The NTA was a special health authority, created to bring together the interests of both the criminal justice and health agendas – something never done before:

'The commissioning of drugs services is undertaken locally by partnerships representing primary care trusts, local authorities, and criminal justice interests (police and probation). The NTA's role is to allocate central funding, provide support and guidance to local areas, and measure outcomes to assure value for money. The NTA is accountable to government for the objectives agreed in its business plan every year.' *House of Commons - Home Affairs Committee – Drugs: Breaking the cycle: written evidence submitted by the National Treatment Agency for Substance Misuse (DP062) (parliament.uk)*

The *Health and Social Care Act 2001* placed a duty on NHS organisations to make arrangements to involve and consult patients and the public in:

- *planning services they are responsible for*
- *developing and considering proposals for changes in the way these services are provided*
- *making decisions that affect how those services operate*



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Within a few years the NTA, who were directly responsible for setting the treatment budgets for local areas, began to insist that every local area had a service user group. Local areas were expected to have one or more service users attending the meeting where they presented their treatment plan each year. These groups were (mostly) funded by their local drug action team (DAT) or drug and alcohol action team (DAAT). And although some retained a level of independence by setting themselves up as charities or being hosted by another organisation (such as a local voluntary service), most were directly controlled by their DA(A)T.

In the early years of NDUDA a few independent local groups successfully applied for start-up funding from either Comic Relief or The National Lottery's Awards for All. It became increasingly difficult (if not impossible) for local groups to obtain sustained funding outside of the NTA/DA(A)T pathway, so the majority of these groups ceased to exist and were replaced by service user groups.

Some DA(A)Ts directly employed a member of staff (a service user co-ordinator) to manage this involvement and while some areas employed a current or former service user in this role, the majority did not.

The Methadone Alliance continued to provide national advocacy services and some areas funded them to train and support local service users to deliver independent advocacy. They were also regularly invited to attend national level NTA meetings to represent the interests of service users.

On 1 November 2004 the first ever *Drink and Drugs News* (DDN) magazine was published. An independent publication, free of charge to everyone working in and using services, it positioned itself as a central point for 'user interest/activity'.

By 2005, NDUDA had ceased to be functional due to a combination of internal and external factors. But by this time the majority of local areas had a service user group of some kind and the NTA had established regional forums, which were open to any service user or group to attend. They had also, very briefly, supported a national initiative called the National Users Action Group (NUAG).

In 2005 The National Users' Network (NUN) had its first meeting. Initially it was set up to share learning and for more experienced groups to help newer groups become established. For the first year or so it held regular face-to-face meetings across the country.

The International Network of People who Use Drugs (INPUD) was set up in 2006. The first annual DDN service user conference was held in 2008. By this time, apart from at the DDN conference, much of the interaction between NUN members was taking place online through a closed Yahoo group. By 2008 some NUN members sat on a number of national strategic committees.

Through these years there was an increasing tension between human rights-based organisations (such as INPUD) and those in local groups who were increasingly focused on the provision of drug treatment. Some local areas would only allow people



who were abstinent from street drugs to be involved, and there was much disagreement and variation between areas about who exactly could or should take part. There was never an agreement about who was a service user or a drug user, let alone any agreement on what service user involvement or drug user organising might look like.

Perhaps this quote acts as an indictment in its summary:

'Done to, done over, doing it for ourselves' – The History of the Drug Users' Movement (Byrne, 2000).

There were a few areas, such as Kensington and Chelsea, where local groups managed to provide direct services. But this was rare, and the price they paid was that they still had to attend strategic DA(A)T/NTA meetings.

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It should also be noted that, for the most part, these service user councils and groups were entirely separate from patient groups or other forms of broader community engagement. This was true at both local and national level.

'If the using community is not careful, we will look back and see we have become "ghettoised" in the treatment field, our voices not reaching out into the society and the communities in which we live. We are more than our treatment!' - ('Keeping one foot independent of the system', Black Poppy, 2008)

Through these years there was lots of activity – forums, consultations, training, reports, conference speakers and committees. Most of this activity was system led and ultimately, did not lead to sustained change in drug treatment or drug policy.

It does need to be acknowledged though, that the NTA did standardise drug treatment across the country,

provided a single route of funding, and attempted to embed at least some form of service user engagement in their work.

At this time the word 'recovery' entered the mainstream vocabulary of the drug and alcohol treatment world and also became very visible – there was a recovery walk held in Liverpool in 2009, which was attended by a few hundred people.

THE RECOVERY YEARS

The first UK Recovery Forum (UKRF) meeting was held in Glasgow in 2010 and was a group of people in recovery, some of whom had met through taking part in the WiredIn blog and a few professionals who were interested in recovery. The first three directors of UKRF were people with lived experience of recovery of one type or another.

One of the ideas discussed at this meeting was the concept of making recovery visible through recovery events, and in particular recovery walks. The first UKRF event was held in Preston in 2010 and was attended by a few hundred people, mostly service users. The conference was free to attend, but the idea was that service providers would sponsor their service users to attend.

Participants recall this event as happening on a Thursday, the day of the general election.

'So we had our first event... I think it was literally the day the Tories booted Labour out.'

The new Conservative/Liberal Democrat coalition government led to the publication of a new drug strategy, which contained the words: *'To tackle crime and reduce the harm and costs to society, we need to reduce the demand for drugs. People should not start taking drugs and those who do should stop. For those who are dependent, their continued drug use should be challenged...'* [Reducing Demand, Restricting Supply, Building Recovery: Supporting People to Live a Drug Free Life' drug-strategy-2010.pdf](#)

By July 2010 the newly elected government decided to transfer the key functions of the NTA into Public Health England (PHE). This process was completed by 2013.

As had always been the case, some people who had accessed drug treatment – those who wanted to become abstinent – were exiting treatment drug-free. The stats were impressive to the government, the performance indicators were being met, the joint treatment approach,



Pics: Morphin', the popular fanzine-style publication of Southampton user group Morph, was fun as well as factual

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advocated by the NTA was working – for some. The number of people entering treatment was reducing and, most importantly, the crime figures were down. There was little public awareness, and even less government sympathy, for those who were benefitting from long-term maintenance.

With this change in emphasis there was a move away from service user involvement of the ‘patient engagement’ type that had been seen in the preceding decade, and a shift towards the health champion of community involvement – where patients who have benefitted from treatment are encouraged to educate others about it. Again, this is a model used by other patient groups and is widely used to encourage vaccine uptake, antenatal care and screening

services. In drug treatment this came to mean ‘being in recovery’.

The definition of the word ‘recovery’ in the context of the drug and alcohol field has been debated far and wide. Despite a number of user groups and professionals loudly and actively resisting this definition, it is fair to say that in the context of 2010, the word had become synonymous with abstinence-based recovery –

‘...complete cessation from substance abuse of any kind’. (Anonymous)
What Is Drug Abstinence in Addiction Treatment? – Renewal Lodge

With more and more emphasis being placed on this model, recovery came to be recognised as a social contagion – ‘Recovery is contagious!’ was a rallying call at this time.

The UKRF definition of recovery was quite broad and did not necessarily imply or require abstinence, but many of the events were primarily attended by those who were, or would like to be, abstinent and so there was a disconnect for those who were not abstinent:

‘I know that there was a broad definition of recovery – but quite honestly it felt to me that I was having abstinence rammed down my throat.’

PEER SUPPORT

Peer support became increasingly popular outside of the treatment system, as a way of enabling individuals to connect with others and receive additional help. Peer support services varied in their offering, with some providing weekend drop-ins and others choosing to provide one-to-one support to individuals – everything from meeting them at the prison gate, right through to abstinence-based housing. These services were often responding to a local need and were set up by people who identified support that had been missing for them. There are almost as many varieties of peer support as there are groups providing it. Peer support is a well-evidenced part of healthcare and may be even more important for those who use drugs or alcohol. Having a problem with drugs or alcohol is highly stigmatised and many people benefit from meeting ‘somebody like me’:

‘There were times, sometimes even now, when survivor guilt and shame affected how I felt. Being with others with similar experiences really helped me.’
(Anonymous)

From a system perspective not only did these groups provide invaluable support, but they were also extremely good value for money for the public purse, particularly when compared with the cost of providing the more traditional medical



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services. Many of the local groups that had been funded by their DA(A)T found that their funding was removed or that the remit of their group changed significantly. While some welcomed the change, others felt increasingly disenfranchised:

'It felt like a purple carnival came to town. Neither was I on the list to get in, nor did I want to.' (Anonymous)

It was apparent that by 2012 the abstinence-based groups far outnumbered, in terms of both groups and people, those who were actively using drugs or being maintained on OST. These groups and individuals were more popular in mainstream society and politics than those who were currently using or receiving maintenance treatment, and they were offered the opportunity to 'tell their story' in many settings. During this time it was not unheard of for people who had chosen to stop using

to say they felt that 'providing needles and syringes was encouraging drug use' or that methadone is 'state sponsored drug dealing'. Although the clinical evidence supports both needle and syringe programmes (NSP) and OST, this rhetoric coincided with popular opinion and there was little opportunity for people with alternative views to speak.

'A few people fell by the wayside... there were people who were well established, you know, had a lot of years in recovery that that relapsed... a lot of people getting stressed, burning out.' (Anonymous)

People who were two or three years previously considered to be successes of a treatment system that valued retention, were now seen as 'parked on methadone'. Overt and covert pressure was put on them to reduce or stop their medication and they were no longer invited to participate.

By 2012 the groups attending the DDN conference were very different to those that had been there three years previously, and many of the original groups had disappeared entirely. A few of the old groups who had achieved more financial separation from their DA(A)T by becoming a charity or using a sheltering organisation survived. The groups that had wholly, or in part, provided a peer-led service continued, but no longer had to attend DA(A)T meetings.

There were various disagreements about the running of UKRF and its purpose. At one point it was mooted that UKRF should accredit recovery organisations and funding. Some felt that UKRF should take money directly from service providers or from pharmaceutical companies; others felt that this was inappropriate. One of the bigger disagreements was about whether the recovery walks were 'owned' by UKRF or whether



Service user groups from Cardiff, Lancashire and the North East in action at the DDN conference

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they belonged to the local people/ organisations that ran them. By 2012 two of the original founding directors had left to be part of (or to set up) other recovery organisations and a new director with lived experience of recovery was recruited.

There was significant contention between recovery groups about what 'real' recovery looked like and there was the same fragmentation in umbrella organisations that had characterised the previous models. After the recovery walk in Birmingham in 2013, UKRF stopped organising the walks and the UK Recovery Walk charity was born.

The first Recovery Games were held in 2013. It was around this time that the Alliance (formerly the Methadone Alliance) dismantled its structure, made regional staff redundant, and disappeared from view.

In 2013 the NTA ceased to exist. Some of its functions were transferred to PHE and funding for drug and alcohol treatment was given directly to local authorities as part of a public health grant. This is the point where the funding for drug and alcohol services came from the same place, through the same route as the funding for drug

treatment. Previously, in many areas the two were slightly separate, and some areas had a dedicated alcohol service. This changed the composition of some of the groups. Both drug user involvement and service user involvement from the previous models was fractured and, in the main, service providers had brought the concept of service user involvement 'in-house'. The majority of service providers created national groups, often with local or regional forums.

FACEBOOK AND SOCIAL MEDIA - IMPACT ON GROUPS

In 2014 it was decided, after a consultation period, that it was time for an update to the 2007 guidance around the clinical provision of treatment and support services. *Clinical management of drug misuse and dependence: an update*, *The Pharmaceutical Journal* (pharmaceutical-journal.com)

It was a project led by PHE, and they decided the best way to do this in England was to recruit a service user 'pod' from the remains of the NTA regional forums. A similar method was used to involve family members/carers.

The mechanisms for engagement with service users in the devolved nations were entirely separate. Each region in England either elected or selected two representatives to be part of the pod. Each of the regions used different criteria for who was sent. Unsurprisingly, given the composition of the groups that were being funded, the resulting group was heavily biased towards those who were abstinent. After much discussion it was decided that representatives from NUN should be invited.

There was serious disagreement about how people should be chosen to sit on this committee, and whether they should be elected or selected (based on who was prescribed which drug for OST, or based on their competence). People who had played no active part in NUN in the previous



Pics: The Recovery Games and The UK Recovery Walk charity in action

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five years, or who had never been part of it, demanded to be included. The process of choosing who would sit on the committee was the end of NUN and it ceased to exist.

The majority of the pod meetings were spent arguing over who should represent the pod on the main committee and all of the arguments about who was a 'real' service user, or a 'real' drug user were rehashed.

The infighting was impactful, and many of the people involved felt hurt, attacked and not listened to by their so-called collaborators, both within the pod and by professionals on the main committee. Many felt that the following publication was heavily influenced by a 'professionals know best' attitude. In 2017 the fourth edition of UK guidelines on clinical management, known as 'the orange guidelines', were introduced to the sector:

'The new guidelines have a stronger emphasis on recovery and a holistic approach to the interventions that can support recovery.'

Drug misuse and dependence: UK guidelines on clinical management (www.gov.uk)

In 2015 the UK Recovery Walk charity was transferred to Faces and Voices of Recovery UK (Favor UK).



THE SURVIVAL YEARS

As alluded to in the 2010 drug strategy, the Building recovery in communities framework (BRIC) was an approach adopted by PHE and it heavily influenced service delivery – *Building recovery in communities* (publishing.service.gov.uk)

This approach replaced the four-tier approach of *Models of care*. Often user involvement under the BRIC banner was utilised in a health champion sense; 'people in recovery' told their stories, inspired others, facilitated activities to help perpetuate abstinence – 'it's contagious' – all in the name of the recovery agenda. Often, individuals who experienced the natural cycle of relapse felt vilified. People who were managing their drug use had no part in an 'asset-based approach'. There was very little motivation to gather feedback from those people who weren't 'signed up' for the recovery lifestyle. Most people who participated in this form of service user involvement were experiencing abstinence and thriving as a result.

Those who were not abstinent now found themselves even more marginalised. Many people who had participated in user involvement under the NTA felt that they had wasted a decade or more of their lives – and for them, it was too late to do anything else:

'One year after the orange guidelines happened support diminished, there was no help, we were too far in, there was no way of getting out, we had to stay, we couldn't go back and, say, do a degree or something else with our time.' (Anonymous drug user activist)

UKRF received little income outside of operating costs for delivering events and a couple of pieces of work that went into UKRF was done by the directors and community members on a voluntary basis and in 2016 the organisation had no income, was unable to continue, and ceased to trade as a company.



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Recovery-based peer support services and individuals who were in recovery and volunteering were used as a cheap way to plug the gaps in service provision.

Perhaps unsurprisingly given the contract and bidding process with mainstream providers, competition was the name of the game – for independent service user and recovery groups too. Because recovery was more politically acceptable, most independent drug user and service user groups either stopped existing or were only ever consulted when a ‘specialist’ approach was needed by the system.

Community involvement in national committees was now controlled by professionals, and community members were individually selected and invited by the host organisation.

By the time it ended in UKRF had organised recovery walks in Glasgow in 2010, Cardiff in 2011, then Brighton in 2012, and helped to grow the Birmingham walk in 2013, which was attended by about 5,000 people. It had also promoted and supported Recovery Month and the Recovery Games and helped organise many local events.

and the people involved lost their livelihoods and left the field. Those who had gained employment as service user coordinators were mostly out of a job.

When speaking about their lives, many who had been involved in the NTA model of service user involvement expressed regret:

‘I don’t regret the drugs, the violence, homelessness or prison... they made me who I am... but if I could go back and change one thing in our lives it would be getting involved, this service user involvement... if I could do it all again, I wouldn’t do this.’ (Anonymous service user rep)

By 2017 austerity had taken its toll on the addictions field and budgets were shrinking. The majority of local DAT/DAAT groups had ceased to function. More and more of the remaining user groups, even the ones who were charities or had sheltering organisations, lost their funding

At the DDN conference in 2017 a special meeting was held to discuss the formation of a national group. It was organised and facilitated by the DDN team. A representative from PHE attended to show that PHE thought community involvement was important – and because the organisers hoped they might commit to funding the group. PHE was unable to commit to financial support beyond the odd train fare or the use of a room.

Discussion at the meeting went over old ground – ‘who is a service user’, ‘who is a drug user’ and ‘we should elect one person from every region’... ‘no, we



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should select the best person for the job' – arguments that had been raging since the early 1990s. Admittedly the 'what is recovery' and the 'my recovery (abstinence based) is better than your recovery (OST or controlled use based)' discussions were new. With no funding available and no feasibility of running such a disparate group on a voluntary basis, inevitably nothing happened as a result of the meeting.

At the DDN conference in 2019 an entire session was dedicated to discussing the formation of a national group in an effort to move the agenda forward. It was facilitated by the DDN team. A number of individuals/groups were invited to speak. These were: Tim Sampey (Build on Belief – a peer-led service), Rada Allen (B6 – a peer led service), Pete Yarwood (Red Rose Recovery – a recovery infrastructure

organisation), Mark Pryke (national service user lead for Change Grow Live – national expert patient group for a service provider), Rosie Flexor (Wandsworth Service User Council – expert patient group for a local authority), and Jon Roberts (Dear Albert – a peer-led recovery service).

The selection of speakers was probably an honest attempt to represent all the types of community involvement happening in the addictions field at the time. Once the speakers had finished there was a discussion from the floor, mixed with answers from the panel.

'Didn't we have that meeting two years ago? ...The only difference this time was that there were more people.'

The opinions expressed at the meeting reflected the one held two years

previously – in some cases almost word for word. The only difference was that more people were present. Some people left their contact details in case a funded model could be set up, but nothing happened as a result of the meeting.

MOVING FORWARD?

Drug-related deaths (poisonings) are at an all-time high, and deaths of people using addiction treatment services from unidentified or untreated health conditions are also at an all-time high. Adulterated heroin containing potent synthetic opioids caused a number of deaths in the UK in 2021. Many areas are achieving hepatitis C elimination at a micro-level. Scotland is launching a safer consumption room and heroin-assisted treatment in Glasgow. Drug treatment need is changing again.

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The Dame Carol Black reports, part 1 (published 2020) and 2 (published 2021), and *Building Recovery in local Communities* (publishing.service.gov.uk) were very supportive of peer-led services, which have become referred to as lived experience recovery organisations (LEROs), but they do not mention involvement of current drug users, current services users or people in recovery being involved in strategic or policy decisions that affect them. These reports and the recent drug strategy *From harm to hope: a 10-year drugs plan to cut crime and save lives* (www.gov.uk) have resulted in increased funding to the sector.

In 2020 a small group of LEROs, mostly represented by their chief executives, were individually invited to set up an umbrella organisation called the College of Lived Experience Recovery Organisations (CLERO). It was initially convened by professionals and two of the founding members do not identify as having lived experience. There were quite a few meetings with the original invited group before a public launch. CLERO is quite specific about what does and does not constitute being a LERO. There is a set of standards that defines the difference between a peer-delivered project and the various stages of LERO development.

There have been lots of discussions about the difference in value between living (current) experience and lived (previous) experience in policy and commissioning, and these haven't reached a conclusion.

Some groups who may identify as a LERO do not feel welcome within CLERO:

'I would say we are a LERO ... but they [CLERO] wouldn't ...' (staff member in a peer-led service)

Around the same time that CLERO was launched, FAVOR UK launched the Association for Recovery Community Organisations (ARCO). To join you need to show that you adhere to the ARCO criteria and (if you are a recovery community organisation over a certain size) pay a membership fee and answer questions about how your organisation is funded.

Annual recovery walks have been organised by FAVOR UK since 2015 and the Recovery Games – organised by Aspire drug and alcohol services and run by Rotherham, Doncaster and South Humber NHS Foundation Trust – occur annually (with a break during COVID restrictions). Both

events are well attended, popular and much enjoyed by people who identify as being in recovery.

In the world of recovery, there is limited mention of opiate substitute treatment/ opiate agonist therapy (OST/OAT) – and mostly it is framed in negative terms. Whatever is said in public (or on websites) reflects significant stigma between people who are abstinent and those who are not. There are very few people who are on OST, or are currently using, that work in the sector – unlike those in abstinence-based recovery. There appears to be significant ignorance about the purposes and benefits of controlled use or OST.

There is limited involvement of people and communities in policy and strategy at a national level in the drug and alcohol sector, and in many parts of the sector 'involvement' has come to mean service delivery, promoting visible recovery or 'helping people like me'.

WEBSITES REFERENCED AND VIEWED

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[Home Affairs Committee – Drugs: Breaking the Cycle, Written evidence submitted by the National Treatment Agency for Substance Misuse \(DP062\)](#)