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What are feasible and effective approaches to supporting individuals with substance use issues who are not currently in active treatment?

A review of selected approaches to widening and sustaining engagement in substance treatment

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Key Messages and Recommendations

Stigma - the stigma associated with those who use substances does not exist in a vacuum, but intersects with other characteristics such as race, socioeconomic status and disability. Some minority groups are already underrepresented in treatment services which could be the result of feeling doubly stigmatised. There is a significant interplay between structural, public and internalised stigma that inhibits effective engagement with services.

Recommendation - We have provided a guidance document on "destigmatising" services which examines solutions of services to consider.

Underrepresented populations in services - homeless and street-based people, older and elderly people, people from minority ethnic groups, younger people, people who identify as LGBTQ+ and sex workers are underrepresented in treatment services for different reasons. For some groups it is because services are not accessible for them, for others it is because there is a low level of awareness of the need for support among those groups of people. We explore the challenges of engaging with these groups and **discuss options** for services to become more visible and accessible to these communities.

In the section on **Engagement** we discuss the structural or systemic barriers people face in accessing services. These are well established and although moves have been made in services to reduce them, by and large they persist. This is in part because these barriers are an extension of those faced by people needing additional support, in the world outside of services. Engagement is not just a concern relating to accessing services initially, but of sustaining people in the early stages of treatment and also through to creating the conditions for them to sustain themselves in the community, post-treatment. This is a different concept of engagement (that of engagement in society) but one that has to be open to effective re-engagement in treatment when necessary.

Recommendations include: re-focussing the treatment pathways, particularly for alcohol services, in ways that build on people's motivation to enter services. To have a rapid re-engagement pathway for people who have exited treatment and need to return.

The section on **mental health** acknowledges the well understood challenges, within treatment services, of the interrelationship between substance use and mental ill health. There is a significant gap in support for people who do not meet the threshold for formal "dual diagnosis" or co-occurring needs treatment.

We **recommend** upskilling the treatment service workforce to provide improved mental health and well-being support as part of the substance treatment pathway. This means becoming more skilled in assessing for mental health needs and intervening early, being able to communicate with mental health specialists when making referrals, and avoiding more intensive support for individuals.

Trauma informed approaches and co-production are treated as two separate sections but in reality they are very much mutually dependent. Much has already been produced in West Yorkshire (through the Violence Reduction Unit and the West Yorkshire Health and Care Partnership) on trauma informed approaches. It is important to see these as being fundamental cultural building blocks of the whole health and care system.

If we were reduced to making a single **recommendation**, it would be to see these "as a journey, not a destination". Neither is ever likely to be perfectly formed, but the act of honest striving to achieve them in a changing environment is in itself a crucial form of engagement.

Introduction

Humankind has been able to compare their internal data with the figures collected for Leeds in the ONS 2021/22 drug related deaths data. It was established through this comparison that approximately 75% of individuals who died of drug-related deaths in the area were people unknown to substance use treatment services. This led to Humankind questioning how it could better support individuals with substance use issues who are not in active treatment.

Understanding this treatment gap has very obvious difficulties; we are unable to interview or question the population who could answer this question as they are unidentified. This review will therefore consider the findings of previous reviews alongside recent interviews with staff and service users alongside some of the wider literature on treatment barriers. It is known that there are traditionally certain demographic groups who are underrepresented in services and the paper will also consider the factors involved in this. In addition to there being a large proportion of people using substances being unknown to treatment providers, there is evidence to show that a significant proportion of the individuals who are involved with services are not fully engaged with their treatment. This paper will consider these issues, before making some recommendations for future research or changes to services which could help reach more individuals.

Stigma

Stigma is frequently cited as a significant barrier to accessing substance treatment. Stigma describes the disapproval or discriminatory attitudes held towards people or groups with particular characteristics, including substance use issues. It is a complex and powerful construct which can result in stereotyping and prejudicial attitudes. Research shows that individuals who experience prejudice are more likely to engage in behaviours that are harmful to their health (Richman & Lattaner, 2014), so tackling stigma would be an important step in encouraging treatment-seeking.

Stigma is generally based on misconceptions and assumptions about a particular subject. A recent YouGov poll indicated that 64% of adults in the UK know someone with an addiction (Action on Addiction, 2021). Almost three quarters of those surveyed recognised that mental illness and traumatic experiences can lead someone to develop substance use disorders. Despite this, over half also felt that a lack of self-control was equally to blame suggesting that whilst there is some understanding of the more complex reasons for substance misuse, people with substance use disorders are seen to be to blame for their condition.

Stigma is described as existing in three interacting types - structural, public and internal. This section will look at each one of these and how they relate to substance use services.

Structural stigma

Structural stigma refers to the stigma that exists at a macro level, it occurs through the enactment of rules and policies which serves to restrict opportunities of stigmatised groups. The relationship is complex, however, as there is evidence that while negative stereotypes of people with substance use issues can be sustained by social policy, those same stereotypes also guide the policy decisions. This creates an ongoing cycle that is difficult to break. In the context of substance use, structural stigma can be seen to maintain and even reinforce some of the stereotypes surrounding substance use disorders.

Lack of funding is one way in which treatment services could suffer due to this type of stigma. In 2021, Dame Carol Black's independent review into drug treatment services identified a system in distress due to years of underfunding (Black, 2021). Although the Government has since responded with a funding package which will invest £700 million in services over the next 3 years, the previous underfunding demonstrates how structural stigma affects treatment services.

The structure of health services in the UK means that substance use disorders are often separate from other mental and physical health providers. This can reinforce the idea that substance use disorders are something 'other' and contribute to the maintenance of stigma.

Within the healthcare system, not all substance users are equal. Restrictive policies on treatments such as methadone prescribing, where some service users are required to take their methadone on premises indicates a lack of trust and maintains the belief that substance use disorder is a moral failing.

Within drug and alcohol services themselves, service users are streamed into different pathways for the purposes of finding the most appropriate treatment. Treatments for drug services are often kept separately from alcohol services, for instance. Staff and service users have expressed in discussions that there is a disparity in terms of service provided. For instance, there are fewer harm reduction techniques offered to individuals with alcohol use issues compared to individuals seeking treatment for opioid use (Humankind, 2022). This can be discouraging for staff who feel they have nothing to offer service users who do not want to abstain from alcohol, and demotivating for service users who do not feel fully supported in their treatment goals. Separating service users in this way may be necessary but creates a disparity that can contribute to stigma.

The legal system can also be seen to contribute to structural stigma. The criminal status of substances other than alcohol means that novel approaches to treatment can go unexplored. For example, there is evidence that the use of Drug Consumption Rooms (or Safe Injecting Facilities) can minimise harms. They have been used in other countries but drug enforcement laws in the UK make exploring this idea politically and legally contested, so to date no such facility exists here despite evidence they would be well-received by service users.

There is a general lack of research into the effectiveness of reducing stigma at a structural level (Cheetham et al., 2022). Research which does exist has several gaps, making conclusive recommendations difficult. For instance, there is a lack of research showing the long-term impacts of stigma-reducing campaigns. For instance, the Time to Change campaign to reduce stigma around mental health was implemented for 4 years from 2011. Service users reported lower levels of discrimination following the campaign, however the evidence suggested that these improvements receded after time (Evans-Lacko et al., 2013). Research into this gap could help to identify improvements that could be made to such campaigns, ensuring their effects have a long-lasting impact.

Even short-term improvements should not be minimised, however, therefore a simultaneous campaign to improve public knowledge around substance use should be implemented. This should be aimed at all age groups with a different target message. For instance, in children and young people the breaking down of substance use being a social norm could be

delivered. In older people, information that can dispel the idea that substance use disorders are a ‘lifestyle choice’ or a ‘lack of will’.

Public stigma

Research shows us that stigma is reduced when people believe an individual is not to blame for the situation, they find themselves in (Kelly et al., 2010). However, it is still widely believed that people with substance use disorder have control over their condition. This idea is often maintained in the media. Media reporting about recovery ‘success’ stories is shown to decrease stigma; however, the media prefers to promote stories which may either trivialise or sensationalise the impact of substance use disorders. Additionally, the idea that there is a ‘hierarchy’ of substances is often promoted in the media. Cocaine use is often depicted as an almost acceptable form of substance use amongst wealthier individuals; however, the use of opioids is depicted as something that happens in working class communities.

There is evidence that stigma can be both sustained and reduced through choice of language. Language evolves over time, for instance the terms and phrases once used to describe mental ill health would no longer be considered acceptable. This is also the case with people who use substances. The phrase ‘substance abuse’ is no longer used due to the negative connotations linked to the word abuse. Instead, the term ‘substance misuse’ is preferred. However, there might still be more to do here. If we consider that many people use substances as a response to trauma, it can be viewed as a coping mechanism and therefore not ‘misuse’ (Lee, 2022). Similarly, the term ‘service user’, for instance, has been evidenced to be disliked by people receiving mental healthcare (Simmons et al., 2010). This led to the UK Royal College of Psychiatrists returning to the term ‘patient’ in 2013 (Christmas & Sweeney, 2016). Of course, any phrase or words used to describe groups could be perceived as a form of labelling which can have negative implications. Choosing language with care could help to reduce this negativity.

It is also important to remember that the stigma associated with those who use substances does not exist in a vacuum, but intersects with other characteristics such as race, socioeconomic status and disability. Some minority groups are already underrepresented in treatment services which could be the result of feeling doubly stigmatised. This will be explored later in the document.

Internalised stigma

Internalised or self-stigma refers to negative thoughts about the self and is thought to develop from identifying with a stigmatised group. Long term exposure to negative attitudes over a sustained period can lead individuals to endorse stereotypes and become more inclined to “live up” to them. As a result, they believe themselves to be less valued members of society and therefore anticipate social rejection. This is damaging as it reduces help-seeking behaviours. This type of stigma can be tackled on an individual basis however societal attitudes would also need to change so that these ideas do not become ingrained in the first place.

Trauma

The link between trauma and substance use is well-established. Early life traumas are shown to be a significant predictor of substance use disorders in later life (Cicchetti & Handley, 2019). The most widely accepted explanation of this co-occurrence is that individuals use substances to lessen the effect of traumatic memories. This type of self-medication could answer a reluctance of some individuals to avoid treatment seeking; if they have found something that works for them, they are unlikely to want to change it. Additionally, such coping strategies are often developed unconsciously. Individuals would therefore be unlikely to seek treatment if they were unaware that there was anything maladaptive about their behaviour.

Trauma survivors can often think that others will not fully understand their experiences, and they may believe that sharing their feelings, thoughts, and reactions related to the trauma will fall short of expectations. The type of trauma can dictate how an individual feels different or believes that they are different from others. Traumas that generate shame will often lead survivors to feel more alienated from others—believing that they are “damaged goods”. Such strong feelings would make it very difficult for individuals to seek help. Worrying that they may have to share their trauma and that they may be judged can be a significant barrier to talking about their issues.

When individuals believe that their experiences are unique and incomprehensible, they are more likely to seek support, if they seek support at all, only with others who have experienced a similar trauma.

Underrepresented populations

Alongside general barriers to treatment, there are several groups who are historically underrepresented in treatment services. Work within Humankind showed some staff had a lack of awareness of this underrepresentation (Humankind, 2022), however understanding the reasons why individuals have not accessed treatment could potentially improve engagement. This paper will now consider these population groups and the difficulties that have been identified with reaching them.

Homeless and street-based people

Up to two-thirds of homeless people cite drug or alcohol use as a reason for their homelessness (Pleace & Bretherton, 2017) but engaging this population in treatment has some challenges. Making homeless people aware of services is difficult as they may lack access to other services, for example a GP, who might make a referral for them. Campaigns to raise awareness of treatment options might be undertaken through channels that they are unable to access for example on TV or via social media. This lack of access also makes it difficult for this group to contribute to conversations about improvements that could be made to services, meaning their voices can go unheard. Additionally, where treatment is sought it can be difficult to maintain due to the practicalities of arranging and keeping appointments whilst balancing that with meeting their immediate needs.

Some of the difficulties in reaching these individuals were borne out in the Forward Leeds Review (Headley et al., 2021). Outreach workers spoke of service users in this group often being in chaos, meaning much of their contact time is spent solving critical problems such as finding a prescription or seeking medical attention, rather than working on more long-term goals. Often, staff in these roles are remote from their managers and so decision-making was processed through peer discussion rather than support from their supervisor meaning staff can feel isolated and not fully supported.

The Burnt Bridges report (Cullen, 2020) also highlights a number of difficulties faced by outreach staff. Something picked up in this report is safeguarding referrals, which outreach staff had made but had not received any feedback on. They felt that the rules around safeguarding and follow-up actions were not transparent and asked for more understanding on the process.

There was recognition in both reports that many homeless individuals have experienced some form of trauma, so it is essential for any outreach staff to be trauma-informed in their practices. This was exemplified by a service user in Calderdale, who recognised the perseverance of their worker. They had been able to build a trusting relationship with them

due to their failure to give up on him. The service user pointed out that he found it difficult to conform – suggesting the need for individual pathways rather than a 'system' to move through. It is worth noting that this relationship took 2 years to develop, showing the commitment and time needed.

Leeds and York Partnership Foundation Trust (LYPFT), partners within Forward Leeds, observed in the review that the homeless population do not get the same access/support as housed individuals, but that some people living a street-based life feel insecure in some of the temporary housing they are provided so choose to stay on the streets. They also recognised the need to develop rapid access routes for homeless people and the development of drug consumption rooms.

Drug consumption rooms were reviewed separately in an internal document for Humankind, the Safe Injecting Facility report (Crowe et al., 2021). Findings from interviews with staff suggest that potential service users who are not engaged could benefit from the use of drug consumption rooms. These spaces can be used not only as an immediate way of reducing harm but also to educate and inform on safer practices, discuss other issues etc. Specifically, they may engage users who do not want to enter formal or structured treatment but want to reduce intake or harm to themselves.

Many of these thoughts are echoed by service users who were generally positive about such facilities when interviewed (Humankind, 2023). Despite these positive responses to the idea of a safer injection facility, however, many of the same service users said they would not use such a service if it did exist. This raises questions about who such a facility would serve, and it is difficult to gauge impact due to the legal difficulties in acquiring and maintaining such a facility. Research from Canada and Australia (DeBeck et al., 2011; Salmon et al., 2010) indicates that the services are cost effective and have positive benefits for users, but no such research has been possible in the UK due to their being no similar service available for review.

These types of facility are viewed with suspicion by both the general public and substance users themselves. Among the public, although the presence of drug taking and paraphernalia on the streets is something they do not want to see, there can be a perception that these facilities are condoning or even encouraging drug use. Interviews carried out with service users in Leeds found that the idea of using a safe injection facility was met with positivity. Service users felt such facilities could serve as educations centres by promoting and teaching safer ways to inject and therefore contribute to reducing harm. Comments were received about the potential for mobile services to meet the needs of more vulnerable users which could also serve longer opening hours, rather than the 9-5 service offered by many

treatment providers. Amongst people who use drugs, worries about police intervention and internalised stigma seem to be barriers for using this type of service. Additionally, the impact of this type of service is difficult to gauge due to a lack of evidence-base.

Older/ elderly people

The most recent alcohol specific deaths data shows that the largest number of deaths occur in age groups between 50 to 64 (ONS, 2022), yet research suggests fewer than 15% of older people who drink problematically will access treatment (Alcohol Change, 2022). This could be due to the cumulative effect of alcohol or drug use over time however there is also evidence that older people begin to misuse alcohol later in life to deal with social isolation, physical pain or other age-related issues (Bangash et al., 2018). Barriers to identifying substance misuse in older people include some of the symptoms being masked by physical illness or conditions, cognitive impairment and the reluctance of the individual to discuss due to shame or denial.

Some service users commented on the hubs and spaces used for treatment services in the Forward Leeds review. They were found to be negative and even intimidating experiences for some, as they were forced to be around service users who continue to use substances. Participants commented on the buildings being difficult to access in terms of facilities (ie no lifts/ramps) and location (such as cost of public transport and difficult to reach by public transport). These factors could disproportionately affect older people, who may be more likely to have mobility issues. Solutions suggested by staff include holding drop-ins at GPs surgeries or community centres – places more likely to be frequented by older people - and spending time building relationships outside traditional spaces. Having a community presence was described by one service user as helping to display empathy, pointing out that Forward Leeds previously visited housing estates as part of their outreach work, and felt removing this service was a mistake.

Difficult to engage groups such as older adults and the elderly may benefit from seeing some of the wider ranging services Forward Leeds offer i.e., family support as a way of reducing stigma and not ‘othering’.

People from minority ethnic groups

Traditionally, it has been accepted that people from minority ethnic backgrounds are underrepresented in treatment services. The latest NDTMS figures show that people recorded as white British make up the largest ethnic group in treatment (83%), with a further 4% from other white groups (NDTMS, 2022). Although there is a paucity of research on the

topic, it is believed that the prevalence of substance misuse amongst this group is underestimated, particularly among cultures where drinking alcohol is taboo. Research into the topic has proven to be challenging, and it is difficult to know the scale of the problem amongst some minority groups due to a reluctance to give information.

As earlier established, stigma is linked to a reluctance to seek treatment in the general population. Amongst people of colour or from ethnic minorities, this stigma is magnified – they may already feel on the outskirts of society without adding a further stigmatising condition.

In 2017, a report by Lankelly Chase followed the treatment experiences of 10 substance users from ethnic minority backgrounds. The participants all accessed the BAC-IN service; a culturally competent and peer-led support group and were asked what their previous experiences of treatment services were. One of the themes uncovered in the longitudinal study was the feeling of 'not belonging' following negative, often racist, encounters with various service providers. This institutional racism had over years, translated into a lack of trust in services in general, including healthcare professionals. There is also evidence that mistrust in services could be intergenerational, with experiences being shared across generations. It was recognised in the Forward Leeds review that a presence in community centres or religious buildings could help to forge relationships and build trust. Offering treatment pathways built through co-production with people from ethnic minority backgrounds could also be a way of developing more culturally appropriate services.

The service users at BAC-IN had also experienced a lack of cultural understanding in services – from both peers and staff. In group work, some participants had felt unable to express themselves freely without the need to explain things further. For instance, one service user spoke about the particular shame of using alcohol in his Muslim family and feeling like this was not understood by those who were unfamiliar with Muslim culture. This lack of understanding can create a feeling of not belonging, a further barrier to treatment participation.

It could be that this has less to do with skin colour and more to do with culture, so although it can be easy to treat people from minority ethnic backgrounds together for the purposes of statistics, it is less helpful when trying to consider their differing needs. For instance, research indicates that people with substance issues from a Muslim background might be supported in their local community through attending a mosque (Mallik et al., 2021). This approach is unlikely to work, however, for refugee populations who may not be integrated into their local community and live separately from them. This was experienced by the

“second wave” of Polish migrant workers who initially found it difficult to integrate with the Polish population that settled in the UK after the Second World War.

Treatment options for people in this group should also consider the intersection of ethnicity with other characteristics such as age, gender, or deprivation.

Younger people

Government statistics show that since 2009, the number of younger people in contact with drug and alcohol services in England has fallen by 55% (GOV.UK, 2022). Although in recent years this has been explained by the Coronavirus pandemic, it is a trend that has been continuing for over a decade. Although young people can be heavy users of substances, it is unlikely that they will have developed dependence on substances which means that a different approach may be needed to the treatment that is offered to adults.

None of the reviews picked up on gaps in services for this group, however the consistent drop in engagement suggests something may be missing. The focus of services at this age tends to be around prevention through education programmes, however it may be that by the time some children are reached, more early intervention may be required. Outreach services across West Yorkshire offered to this demographic tend to vary according to age, with the recognition that school age children, teenagers and young adults may all have different needs. Looked after children and care leavers may also have additional needs beyond their age group status.

School aged children

The current Department for Education guidance recommends teaching about drugs, alcohol and tobacco to primary school children as part of the personal, social, health and economic (PHSE) topic (DfE, 2020). The focus at this age is on understanding the laws and how these substances affect us physiologically, with some mention of the dangers of abuse and addiction.

From year 7 (age 11) onwards, DfE data shows that suspensions and exclusions from schools start to increase (DfE, 2022). There are around 12,000 children in pupil referral units (PRUs) across England, and whilst the majority are of secondary school age there are a number of primary school age children too. For these children or those who are excluded this could mean the general curriculum is not applicable to them, and other resources are needed for this group.

Case Study – School Outreach

An interview with an experienced Humankind worker who has delivered lessons and support in schools around substance use for a number of years. The interview took place in January 2023.

The content of the worker's lessons is dictated by the school. She explained the differing approaches schools have. For instance, some schools put the lesson in with their science programme. Whilst this is logical academically, it didn't open up broader conversations around self-medicating or other social problems that can lead to problematic substance use. Sometimes the schools approached the service for input when drug problems had become critical, so the service has worked with them to try and embed the work into the curriculum and be more pro-active in their approach.

The worker described the engagement in schools being really good and that the children she speaks to are very open and interested but outcomes of this work are difficult to measure. The worker had attempted to 'track' some students through their school years and had anecdotal evidence that the prevention work has a positive impact. Children tell her that they use the resources she gives them to find "get out" clauses such as phrases to use when feeling peer pressure to use substances.

Often a secondary but vital result of work in schools is uncovering problems that students have which have not been communicated or gone unnoticed by teachers. During the last week in one school, the worker had made several safeguarding referrals, and all seemed to be underpinned by substance abuse in the child's family home. The worker explained that one of the problems can be the sense of shame children/young people have of revealing what is going on at home. Children can often be keeping their family system working by looking after siblings or other household duties, and they felt that whilst they were managing, they did not want outside services intervening and breaking up their family. These were all children who would not be involved in drug treatment services other than Jo delivering her lesson.

The worker had observed that schools often don't know what is going on at home and in some instances, children had been unaware too. This appeared to change during the COVID lockdowns; where children who had been shielded from substance use and other issues at home during school hours the forced closure of schools meant they had been exposed to activity they would not otherwise have seen (e.g., substance use, sex work).

Access and participation by parents and carers are important. The worker had organised events in the past where a school had arranged for several services to be present and available such as police, drug and alcohol services and DWP staff. She felt this approach was useful as it drove home the idea that substance use is not happening in isolation and encouraging a multi-agency approach. This is part of the work about challenging the perception of substance use as “normalised” behaviour in society.

There are three main reasons children and young people appear to use substances: boredom, peer pressure and therapeutic needs. The worker had liaised with a partnership who fund diversionary activities in local authority area. They had provided some resources for the worker and fund lots of local sports clubs and activities to try and engage young people. The worker lets her students know about what is going on in their local area and encourages them to take up activities and keep them off the streets.

Where the worker obtains local information, this is passed on to other authorities. For example, recently local shops were reported to Trading and Licensing Standards for selling alcohol/ tobacco to underage customers, and the details of a drug dealer had been passed on to the local police. The worker was also able to pick up on new uses of substances such as nitrous oxide, “dragon soup” (alcohol/ energy drink mixtures) and the impact of specific substance use for students who are taking medication (energy drinks countering the effect of medication for ADHD was the example given). These are all areas which would benefit from further research. What evidence there is, is anecdotal, coming from “chance” conversations rather than “objective research”. The worker felt that it would be useful to properly track a group of children in a longitudinal study to try and gauge the effect the prevention work has. An observation overall was that prevention work may be more of a necessity now/in the future as the number of people in treatment begins to grow.

Teenagers

Teenagers do not tend to enter treatment services voluntarily. Rather, they may have been referred through referrals via other organisations, for example the criminal justice system, where they might have been identified as at risk of harm and/or causing harm to others.

Curriculum guidance for this age group introduces more information about the harms caused by misuse and addiction. Teachers are encouraged to use any local knowledge they may have about substance trends relevant to their local area, which suggests children across the country may receive inconsistent knowledge depending on how much awareness their teacher may have.

Interviews with staff in adjacent services in Leeds and outreach workers within Humankind suggest that a significant issue they encounter with children who use substances is that the behaviour is seen as normal. This normalisation of substance use takes place both at home and amongst their peers and can have very long-term effects. We know, for instance, that the younger a person is when they use substances then the more likely they are to develop a substance use issue in the future (Patton et al., 2004). Challenging the idea that substance use is the norm could help to reduce these numbers.

Looked after Children and Care Leavers

Looked after children and care leavers have an elevated risk of drug and alcohol issues when compared to peers with no care experience (Meltzer, 2003). Despite this, there is a general lack of research into adapting treatment options for this specific group. Research which does exist suggests that time should be taken with this specific group to build up relationships of trust, again indicating the need for a trauma-informed approach for all treatment services (Alderson et al., 2019).

LGBTQ+

The LGBTQ+ community are between 2 and 6 times more likely than heterosexual and cisgender individuals to live with an alcohol use disorder (McGeough et al., 2022), and illicit drug use has been found to be more prevalent amongst people who identify in this category. Despite this, the LGBTQ+ community is under-represented in services as recognised in the Forward Leeds review.

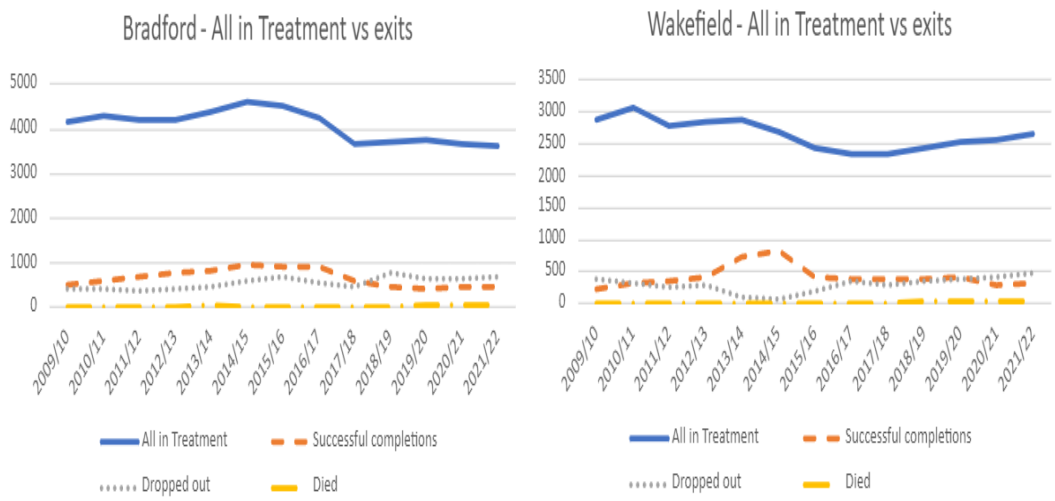
Sex workers

Many female sex workers in the UK are addicted to illegal drugs, and both trauma and stigma are thought to play a role in their reluctance to engage with treatment. However, there is also a suggestion that treatment services are simply not practical for sex workers given that they generally operate a 9-5 service which can be inaccessible to this group. Basis Leeds and the Joanna Project both felt their relationship with Forward Leeds had benefited from having a designated point of contact for referrals who understood the needs of this specific group. Basis Leeds has employed the use of the ‘Basis bus’, which they found was a positive way of reaching these service users at times appropriate for them.

Engagement

The available data on drug and alcohol services in West Yorkshire shows some worrying trends. The number of service users who drop out of treatment is trending upwards in

Bradford, Wakefield and Kirklees. In fact, in Bradford and Wakefield, the number of individuals dropping out of treatment exceeds the number of successful exits.



Nationally, data from the National Drug Treatment Monitoring System (NDTMS) shows that over a third (41%) of people in treatment have entered services 4 or more times. In addition, there is a national year on year rise in the number of deaths of people in treatment services. Taken together, these findings suggest that although a service user is attending treatment, they may not be fully engaged with the service. Previous research within Humankind provides some indications of where barriers to engagement may exist. These can range from practical barriers which may be easy to find solutions for to complex ones which may be beyond the scope of treatment services to fix but may be able to advocate for.

Circumstantial barriers

Practical barriers may make it more difficult for service users to attend appointments or groupwork. Feedback from service users in the Forward Leeds review raised the location of Forward sites, that they could be difficult to reach on public transport and the cost involved. Service users talked about some of the hubs being 2 bus journeys away which can make them inaccessible and impacts on the length of time the individual would need to invest in attending. Service users are individuals with other commitments to juggle alongside their recovery. Employment or caring commitments could affect how much time individuals can reasonably commit to attending meetings. Research nationally suggests that women may be more likely to disengage from treatment than men. Although the data from West Yorkshire does not support this finding it can help us to consider some of the practical barriers to engagement that service users may face. Women are more likely to have childcare responsibilities which could impact on the time they have available to dedicate.

Other circumstantial issues such as poverty is also likely to play a part. Service users may work more than one job, making them also time poor. For service users who are not working, the cost of travel may restrict their movements.

It is worth considering that, particularly for service users in the alcohol only group, dropout rates are particularly high immediately following assessment but prior to having a treatment plan in place. Staff point out that service users are expected to show their commitment and motivation to treatment by attending groupwork sessions, and that this may be off-putting for some. It is felt that there is a disparity between what service users expect from treatment and what happens in reality, for instance at the point of entry to the service an individual's motivation is likely to be very high, but this might dissipate as they wait for initial assessments.

There is a lack of consistency in approach to dis-engagement across services. Indeed, even within Humankind there is no single approach. The general rule is that any break of 3 weeks or longer must be treated as a new entry. However, this does not consider some of the barriers to engagement that individuals with substance use disorders may be facing. Having to return to the beginning of the treatment journey could be demotivating and, as a result, leave the service user with the feeling they are out of options.

Research indicates that individual's preferred goals in treatment are often incompatible with what is actually offered (Alves et al., 2017) and, as a result, they would like more involvement in the design of treatment services. Previous interviews with staff have revealed that they too recognise that treatment plans are inflexible however they have a lack of options available to them to combat this. In Barnsley, service users have set up their own Facebook group so they can rapidly re-access support whenever they need it. This initiative hints at the potential for exploring more co-produced treatment options and peer-led support.

Service users are sometimes expected to demonstrate their motivation and commitment to treatment through attending group work programmes. This, however, gives little consideration to those service users who have underlying trauma and may find it very difficult to take part in these types of groups.

Mental health

Many services users have a dual diagnosis ie are receiving treatment for a mental health issue at the same time as a substance use disorder. In Leeds, there are approximately 10% of service users under the COMHAD team however this belies the research showing the prevalence of cooccurring substance use and mental health issues. In 2021, UK

Government evidence suggests that approximately 63% of adults starting substance use treatment have a mental health need. This suggests that a great deal of service users may be experiencing undiagnosed and/ or untreated mental health issues.

It has been observed that there are significant difficulties in obtaining a dual diagnosis as practitioners may recognise either a substance use issue or a mental health issue, but not both (Priester et al., 2016). Research suggests that substance use treatment is more effective if treated at the same time as any other mental health issue, as treatment outcomes for individuals with a dual diagnosis are not as successful when compared to individuals with a single issue. This gap in treatment is likely to affect successful exits from treatment, if service users are not receiving the full range of interventions needed.

Poor investment in services adjacent to substance use is also a potential barrier. A recent poll of individuals with a range of mental health issues found that almost a quarter of them had waited over 12 weeks to start treatment (Royal College of Psychiatrists, 2022), with a further 43% saying the wait contributed to a worsening of their symptoms.

Even with a diagnosis, there are factors caused by mental ill health which can impact on the quality of their substance use treatment. The ability to build a therapeutic relationship with mental health professionals can be impaired in people with substance use issues, making treatment gains difficult to attain.

Finally, it is worth considering that mental health issues also continue to attract stigma, despite progress made under previous campaigns. The addition of a second stigmatised diagnosis adds a further barrier to accessing treatment.

We have produced a theoretical model for a mental health pathway which could be incorporated into treatment services. This pathway is designed to provide mental health and emotional wellbeing support for people experiencing less severe forms of mental health needs than the 10% or fewer that might be considered for treatment under a dual diagnosis team. The aim is to upskill frontline workers to identify and appropriately respond to people who have additional needs around their emotional and mental health.

Trauma-informed guidelines

Services should continue to work towards being as trauma informed as possible. The trauma-informed approach to practice involves a commitment to adhere to 6 key principles. The approach is not a prescriptive checklist of guidelines to be maintained rigidly due to the different settings in which trauma-informed practices are delivered. With that being said, there are some recommendations that can be applied to substance treatment services which relate to the key principles:

Safety

Staff should be able to recognise the signs of trauma and understand how it can affect physical and behavioural responses. Not all individuals who have experienced trauma will want to reveal this information, therefore awareness of how it can present will ensure they are treated appropriately without the need to share details. This can be done through training events/workshops which can also suggest useful ways to respond to trauma.

Physical spaces should be safe. For instance, there should be the offer of privacy as well as communal spaces.

“Triggering” language should be avoided. For instance, the word “must” can feel like an order and can result in disengagement. Thinking about better ways to phrase conversations can avoid this. Rather than saying “you must have done that by the end of the week” consider saying “how can we work towards getting this completed?”.

Encouraging connection with families where appropriate – work is already being undertaken in Restorative Practices which could be further rolled out across the service. Restorative practice acknowledges the importance of family and community in recovery and the integral significance of reconnecting previously hostile groups or individuals. Many of the key tenets of restorative practice are already consistent with recovery models. Staff tell us that they see some powerful results from this approach, which is led by the service user and changes they want to see.

Trustworthiness and transparency

Building trust with workers can be disrupted when service users are moved from one worker to another. This should be kept to a minimum but if it is unavoidable, the rationale should be explained to the service user.

Ensure that policies and procedures are readily available – displayed in appropriate shared spaces so they do not have to be requested will reinforce the idea that the service has nothing to hide.

Ask for evaluation at key stages of treatment and encourage feedback at all times. Showing that the evaluation has been considered shows that you trust individual’s opinions.

Peer support

Peer support can also help contribute to individual feelings of safety. Encouraging and maintaining these groups and allowing individuals to suggest different ways of supporting each other.

Collaboration and mutuality

Collaboration can be demonstrated by encouraging co-production of treatment plans. Encouraging self-monitoring and updating of plans can empower individuals and build trust. Collaboration and mutuality extends between services as well, acknowledging that service users are likely to be accessing other services and that by working together services can reduce the risks of re-traumatising service users and mutuality will achieve improved outcomes for service users across a number of services.

Empowerment, voice and choice

Validate individual's feelings and ensure they are "heard". If individuals make suggestions for improvement, keep them up to date with any changes this brings. If the suggestion is not carried forward explain what the obstacles are rather than dismissing their ideas.

Cultural, historical and gender issues

There should be recognition that trauma responses can sometimes be gender/age/culturally specific. This could be address through training and supervisions with staff.

A recognition of the intersectionality of characteristics and how these can affect people.

The key to success of all guidelines is that they are embedded across entire services at all staff levels. These guidelines are not exhaustive and should underpin other recommendations rather than replace them.

Co-production

Co-production is an integral part of trauma informed approaches in designing, developing and delivering services. As a process and a culture, co-production underpins each of the elements of the trauma informed guidelines above. Included in this report at Annex 2 is a guidance document for co-production practice, which explores the concept and issues in more detail.

Co-production is about understanding and making sense of the plurality of voices of experience – the experiences of providing, delivering and being in services. It brings into the process the voices not just of those immediately involved but meaningful involvement of

stakeholders, of families and of communities. In many ways the immediate challenge facing treatment services is generally understood as the treatment of the individual and supporting them to (re)discover a place for them in the community and society. This approach risks avoiding more fundamental questions of “how” and “why” people use substances on a personal level and why their use becomes problematic. It also begs the question of why only treat substance use at an individual level when there are wider public health dimensions to the supply and use of substances.

Co-production is most frequently cited as a means of collecting and curating wisdom which increases the value of research and service design. Co-production is more than the engagement of people and communities in the processes of service delivery. Co-production is essential to providing the “post-treatment” networks that sustain and build on people’s treatment outcomes. These co-produced networks have two primary benefits.

- The first is a functional one, to provide a “safe space” for networking, for activities, to build skills and develop new interests with others in a similar situation, to be able to access information and treatment support.
- The second is a symbolic benefit – that of providing visible examples of lives beyond the use of substances. This symbolism is important not only for people exiting treatment but also for those who have never entered treatment, for families and for communities.

Co-production should therefore be seen as central to the purpose of “place building”, enabling the values in communities that we acknowledge as important in service development:

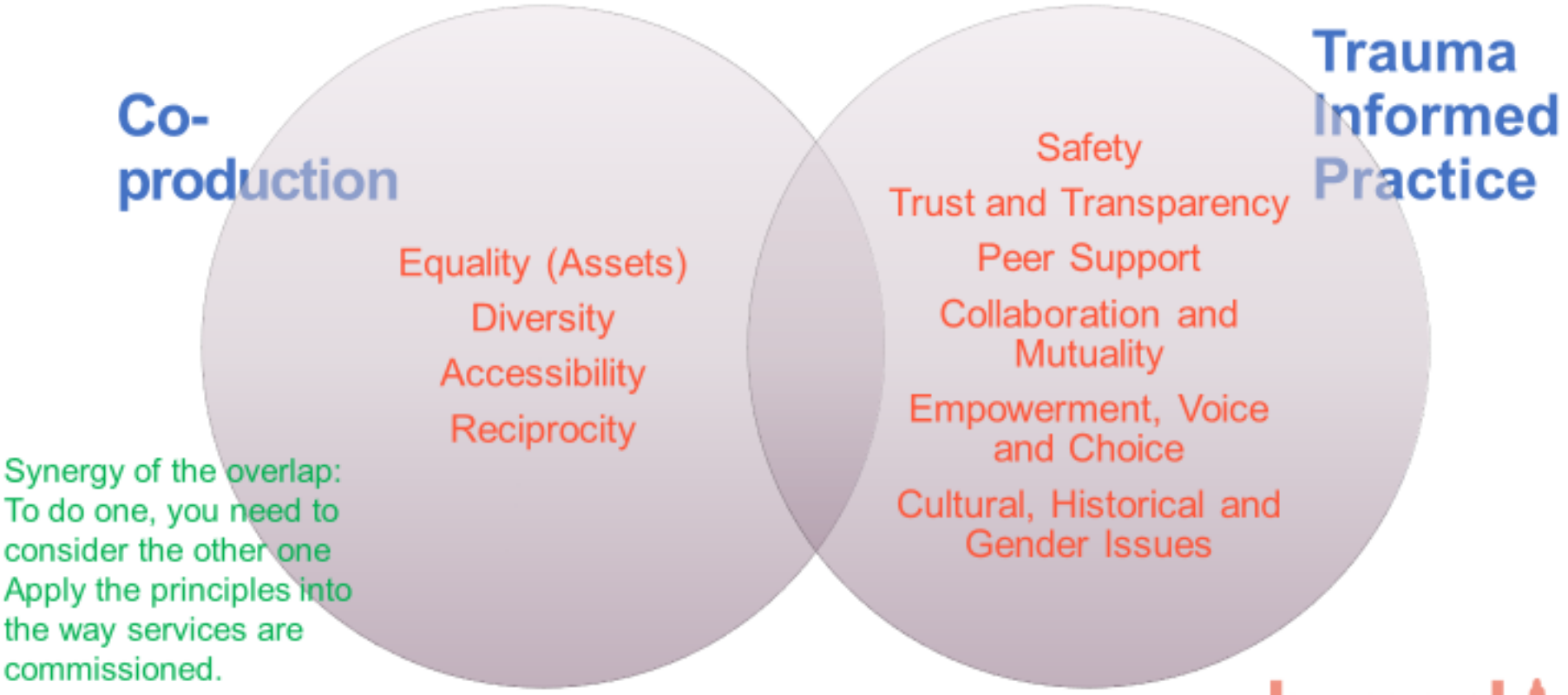
- Trust and transparency
- Safety
- Collaboration and Mutuality
- Empowerment, voice, choice
- Cultural, historical, gender understanding

These are as important for people who have been through treatment in their community as they are in services.

The intersectionality of substance use with other health and economic inequalities is inescapable. The roles of adversity, trauma and resilience play into these inequalities as both symptom and cause in their various imbalances. A way of conceptualising these relationships that link inclusion, reduced inequalities and locality strategies that are based on both wealth and care is demonstrated in the diagrams that follow.

The “Preston Model” (Preston Community Wealth Building) referred to in the final diagram is one of the first large-scale Community Wealth Building programmes. Public and non-profit organisations modified their procurement policies to support the development of local supply chains, improve employment conditions, and increase socially productive use of wealth and assets (Rose et al, 2023). This is an example of how engagement can be scaled up from individual engagement with services, by services themselves extending their engagement in the local economy and communities. In Preston this was achieved through some of the large public agencies making more of their purchasing decisions with local suppliers which had a significant effect. Even in the case of small, user led organisations it is an opportunity to embed themselves in wider networks and break down stigma.

Principles of Trauma Informed Practice and the Principles of Co-production



Synergy of the overlap:
To do one, you need to consider the other one
Apply the principles into the way services are commissioned.

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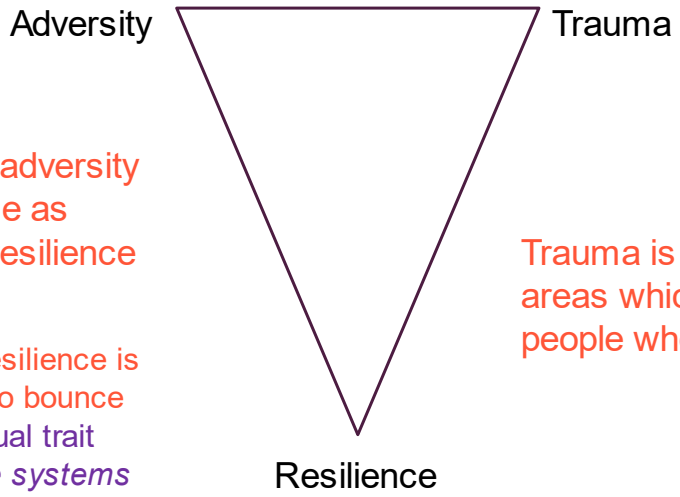
Adversity - Trauma - Resilience

Definition of Adversity:
The *stresses of situation* which reduce life chances (health/ wealth inequalities)

Trauma is more prevalent in areas where there are more adverse circumstances.



Definition of Trauma:
Traumatic event refers to an experience that causes an intense psychological or physical stress reaction in an individual (Quaile, 2020).

The actions to reduce adversity are principally the same as those which promote resilience

Trauma is less acute and less prevalent in areas which are more resilient and for people who are more resilient

Definitions of Resilience: Resilience is the personal attribute or ability to bounce back. Resilience isn't an individual trait but a *process involving multiple systems* – child attributes, family functioning, social relationships, and the surrounding environment.

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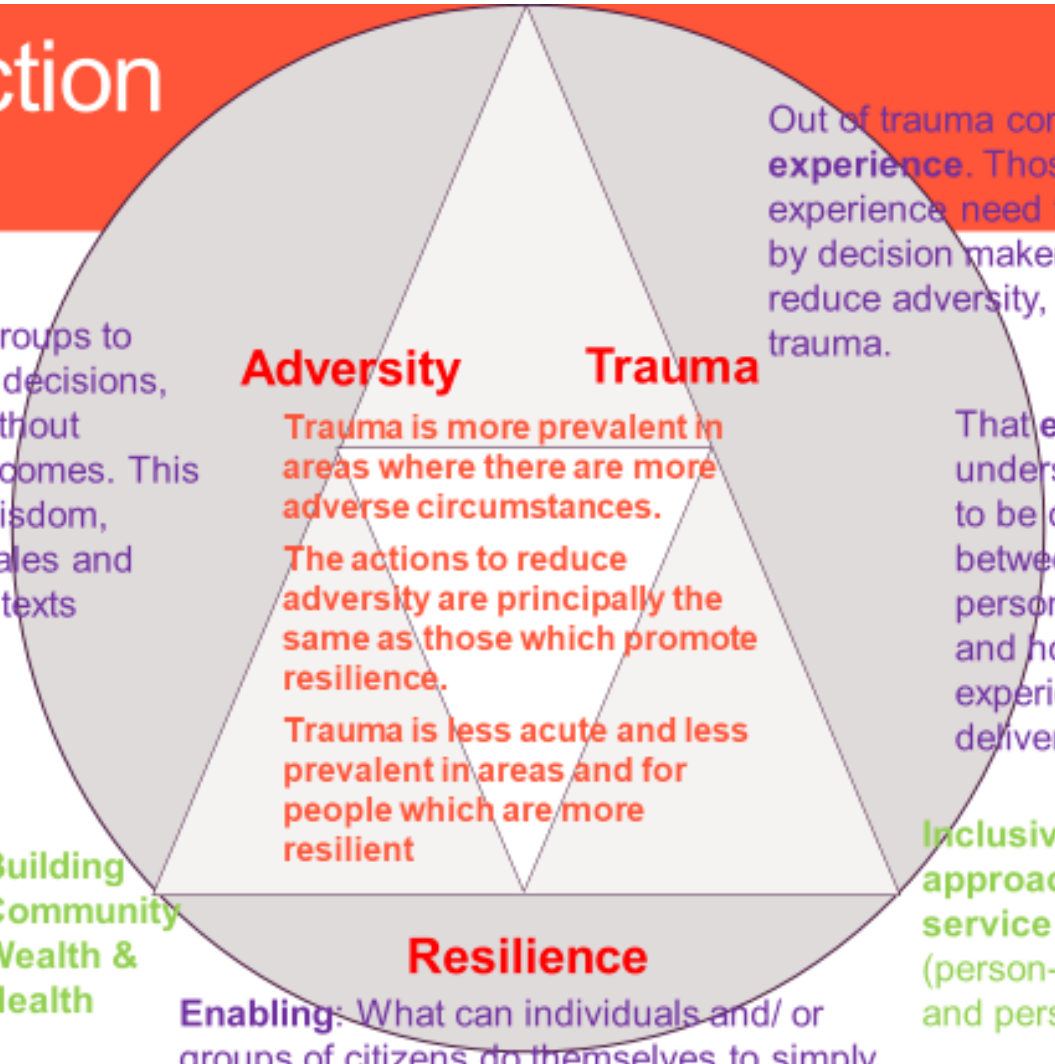
Co-production



Voice and choice
Allowing people/ groups to arrive at their own decisions, solutions, goals without predetermined outcomes. This involves sharing wisdom, information, rationales and understanding contexts

Collaboration and **empowerment** there is an imbalance of power which needs redistribution

Out of trauma comes **experience**. Those voices of experience need to be heard by decision makers in order to reduce adversity, and therefore trauma.

Trauma is more prevalent in areas where there are more adverse circumstances.

The actions to reduce adversity are principally the same as those which promote resilience.

Trauma is less acute and less prevalent in areas and for people which are more resilient

That **experience** is essential to understand how support needs to be delivered within and between services so that a person's needs can be met and how having lived experience as part of service delivery makes a big difference

Building Community Wealth & Health

Enabling: What can individuals and/ or groups of citizens do themselves to simply "make better" their lives?

Inclusive approaches to service delivery (person-centred and personalised)

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Co-production, ATR and Place

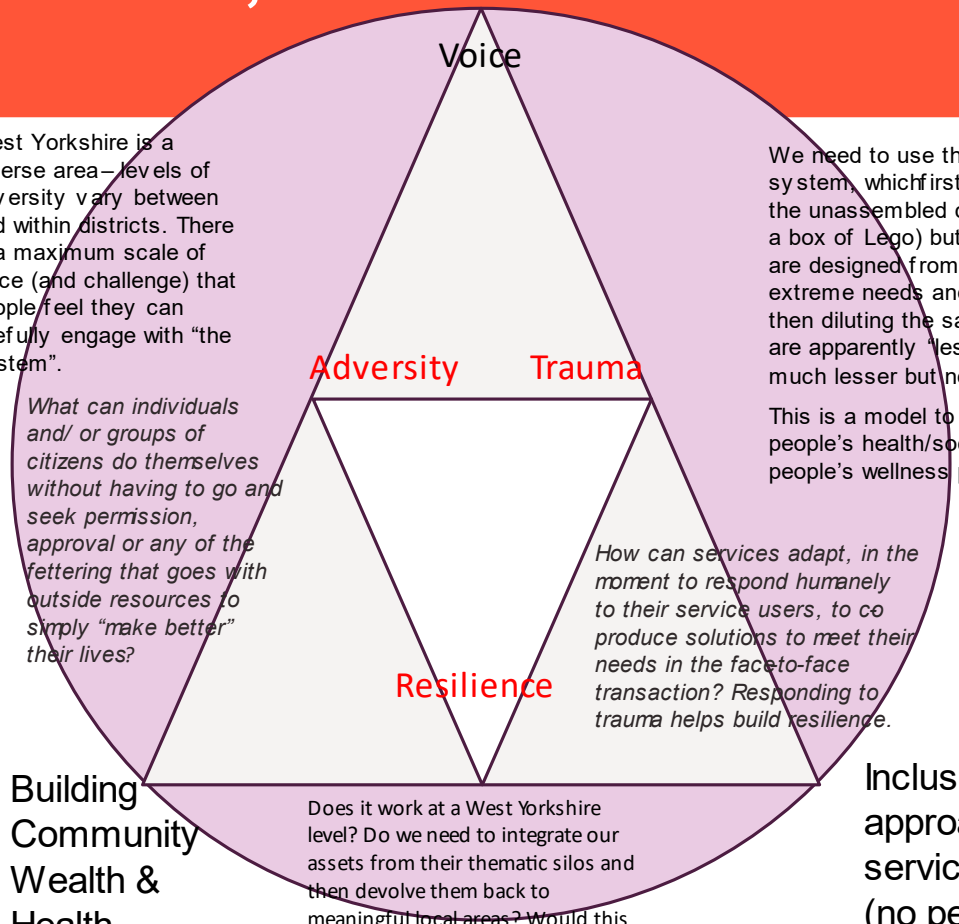
How can WYHCP and WYCA be enablers of the Preston model of building community health and wealth, of supporting self-help and mutualism in communities?

- Wealth that's there, assets in the health and social care system
- Workforce
- Land, property and investments
- Economic democracy

How can we consolidate health improvement, economic growth and the core economy, rather than continually seeking to expand them?

West Yorkshire is a diverse area – levels of adversity vary between and within districts. There is a maximum scale of place (and challenge) that people feel they can usefully engage with "the system".

What can individuals and/ or groups of citizens do themselves without having to go and seek permission, approval or any of the fettering that goes with outside resources to simply "make better" their lives?



We need to use these voices to talk about a system, which first of all isn't a system (rather the unassembled components of a system, like a box of Lego) but a collection of services which are designed from a first principle of meeting extreme needs and worst case scenarios and then diluting the same principles to meet what are apparently "lesser" needs. They're not so much lesser but needs of different origins.

This is a model to address deficits in individual people's health/social situation not to promote people's wellness positively.

How can services adapt, in the moment to respond humanely to their service users, to co-produce solutions to meet their needs in the face-to-face transaction? Responding to trauma helps build resilience.

Building Community Wealth & Health

Does it work at a West Yorkshire level? Do we need to integrate our assets from their thematic silos and then devolve them back to meaningful local areas? Would this make services more responsive to local needs?

Inclusive approaches to service delivery (no person left behind)

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Conclusion

An obvious but fundamental difficulty in understating how best to support individuals who are not in treatment is that the very fact they are unknown makes it a long-term project to locate, interview or question your target population. This paper is set in the context of other kinds of health and social care services in West Yorkshire becoming trauma informed. This approach is gaining value as a “common currency” and as part of the West Yorkshire Health and Care Partnership’s commitment to becoming a trauma informed health and care system by 2030. This paper has therefore considered the knowledge that is available from the literature, and observations from existing staff and service users in an effort to understand the themes preventing engagement with services.

Future research and recommendations

Carry out semi-structured interviews with service users to identify other barriers preventing engagement. Consider

- What flexibilities/options would be useful when trying to keep service users engaged?
- Would bespoke or separate services be helpful when targeting specific groups?
- Workshops particularly with individuals whose substance use may intersect with other protected characteristics.

Consider harm reduction models for alcohol use disorder in the same ways these have been implemented for opiate use, managing and reducing consumption to “safer” levels rather than expecting abstinence.

Alcohol liaison posts in hospitals to limit self-discharge without any treatment from accident and emergency departments and to put in place appropriate alcohol support for planned discharges following hospital admission for other treatment.

Flexible approaches to returning to treatment. Rapid re-engagement processes which bypass the need to start from the beginning and put the service user back into treatment at the point they feel is appropriate.

Consider “personalisation” type funding to help provide service user costs of engagement for example to cover ‘journey fares (or the purchase of travelcards) or support other costs linked to attending treatment to encourage attendance at appointments. Such a fund could also be used to meet immediate needs that are obstacles to engagement such as school uniform (to get children into school) or basic mobile phone (to keep in touch with services)

More research could be done to improve the number of service users from minority groups, including raising awareness of staff of some of the specific barriers to treatment individuals from minority groups face.

Specific training for staff in trauma informed engagement practices including the continued promotion and use of person-first language.

Develop co-production in all aspects of service design and commissioning as well as service development and delivery, in a way that sees people who use services or have other lived experience and their families are equal stakeholders in effective treatment services.

Embed the whole family approach into all services to sustain engagement and improve outcomes for service users in treatment and for family members over their life course.

Develop individual therapeutic approaches as part of the substance use treatment pathways to investigate and unpick internalised stigma and encourage help-seeking behaviours.

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