

## **A Strategy to Address the Stigmatisation of People and Communities Affected by Drug Use**

**-We all have a part to play**

This strategic document was compiled for the Scottish Drug Death Taskforce in collaboration with Scottish Drugs Forum (SDF), Scottish Families Affected by Alcohol and Drugs (SFAD) and Scottish Recovery Consortium (SRC).

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## **Aim of the Strategy**

The aim of this strategy is to lead a more informed and compassionate approach across society toward people with a drug problem, lived experience of drug use and their families. We acknowledge that people across society use drugs. This strategy is focussed on those for whom drug use is, or drug use has been, problematic.

## **Terminology Used**

*People who use drugs:* In broadest terms this term is used to cover all people who use substances defined in law as psychoactive substances including those substances exempted from The Psychoactive Substances Act. Where this term is used here, the focus is on people who use illegal substances.

*People with a drug problem:* This term is used for people whose drug use causes harm to them or others. For the purposes of this paper, this includes people in treatment.

*People with lived experience of drug use:* This broad term includes anyone with experience of drug use. This paper focuses on people who have experience of problem drug use.

*Families:* Scottish Families Affected By Alcohol and Drugs uses a broad definition of 'family' which will be applied in this document: Family is anyone who is concerned about someone else's drug or alcohol use which includes family members, carers, friends, neighbours, work colleagues and concerned significant others.

## 1. Background and Context

The stigmatisation of people who have a drug problem, people in recovery from problem drug use and families of those affected by drug use has been increasingly recognised. In a sector that can at times be divided there is a strong and united call that stigma needs to be addressed in Scotland to enable people (both affected individuals and their families) to seek the support and treatment needed (Scottish Affairs Committee, 2019; Scottish Government, 2018; Pauly *et al*, 2015; Lloyd, 2013). The Drug Death Task Force recognises the importance of stigma as a key underlying component of the current drug death crisis. Addressing stigma is therefore vital to enable the work of the Task Force to address this crisis whilst also facilitating the Rights, Respect and Recovery action plan to deliver a human rights based approach to drug and alcohol use in Scotland.

The Task Force recognises a strategic plan is required to direct activities to reduce stigma. The strategic plan presented here builds on the valued work of the PADS community group and draws on evidence directly from our Scottish communities including the Dundee Commission report (Dundee Drugs Commission, 2019) [A Matter of Life and Death, Community Engagement event, August 2019], Task Force engagement activity feedback] as well as international academic literature and reports relevant to the Scottish population (Scottish Drugs Forum, 2017; Tweed *et al*, 2018; Hamilton, 2018). Before we can address stigma we must understand what stigma is, and how it can manifest. Thus we must first ensure people are informed before moving on to present the evidence based strategy for addressing stigma.

## 2. Understanding Stigma

### 2.1 The broader context

The use of substances is common in all human societies and in all human history. Over much of human history there has been a consistent sense that substance use should be controlled by those in authority. This is achieved in various ways through:

- social taboo
- religious stricture
- societal norms (including the ritualisation of substance use)
- punishment of people who use (some) substances (in some circumstances) –
- laws restricting production, consumption and supply
- national drugs policy and strategies
- international treaties and conventions

All of these means of control can result in the stigmatisation of (some) people who use (some) substances. Even in societies where controls, including oppressive legislation and the strictest religious instruction have been introduced some form of substance use has flourished. The widespread use of heroin and alcohol in Iran or khat in Somalia are modern examples.

Over many years a sophisticated anti-substance use discourse has developed. This has various forms – public discourse, political discourse, criminal justice discourse, public health discourse, media coverage etc. These discourses have different facets and focuses but all stigmatise (some) people who use (some)

substances. As long as we have a discourse that is anti-substance use, we will perpetuate and sustain the stigmatisation of:

- people who use drugs
- family members
- people who have a drug problem
- people with lived experience

It is insightful to consider a 'hierarchy of stigma' where people in these groups (and subgroups) are clearly differentiated and can be attributed different levels of stigma. Stigma exists to varying degrees according to the substance used, the route of administration, the quantity and frequency of use, level of dependency ('addiction') and association with other behaviours and circumstances – sometimes not necessarily related to the substance use, for example, poverty, involvement in crime, violence. These behaviours and situations are differentiated and members of different groups are stigmatised and can stigmatise each other to varying degrees - even people using the same drug e.g. people who have a drug problem that focuses on snorting cocaine may stigmatise people who inject cocaine or use crack, a smokeable version of the same drug.

## **2.2 Stigmatised people**

Stigma occurs only when a person is discovered to be, or is presumed to be, a member of a stigmatised group or category. This can occur as a consequence of different situations and circumstances including:

- physical appearance ('stigmata')
- personal behaviour
- personal reputation
- engagement with certain services (a drug treatment service, for example)
- disclosure in event of participation in a bureaucratic process – recruitment or applying for insurance or a loan, or
- personal disclosure (telling someone one's personal history of substance use)

Stigma is reinforced by notions that 'justify' the stigmatisation of individuals and groups. Thus personal characteristics are projected onto the stigmatised person / group. These are moral judgements and based on perceptions that may be, in reality, not universal, atypical or completely unjustified. People who use substances have been portrayed variously as bohemian, louche, decadent, lacking self-control, lacking will power, feckless, reckless, immoral, weak, escapist, lazy, hopeless failures. Substance use has been described or considered as a lifestyle choice, the result of poor decision making, the consequence of moral weakness, a mistake. These portrayals of substance use can be, in themselves, stigmatising and unhelpful.

This association between substance use and personal deficit(s) allows substance use to be portrayed as a failure of character or morals. This is an ideological framing of (problem) substance use as a solely personal issue. This justifies and re-enforces stigma.

Stigma is re-enforced and made more complex when the person is a member of more than one stigmatised groups. Thus stigma is made more complex if a person who uses substances / has a drug problem is also a person who:

- has a mental health problem
- has a blood-borne virus (BBV)

- is disabled
- lives in poverty
- is homeless
- is unemployed
- is involved in crime / the criminal justice system
- is in receipt of state benefits
- is involved in transactional sex
- has no or little formal education

Other statuses can compound the stigma of substance use / having a drug problem. Stigma intersects with other axes of disempowerment and marginalisation in ways which create further disadvantage (Stangl *et al*, 2019). These include:

- being a woman (and most especially a mother)
- being from a minority racial or ethnic minority group
- being LGBTQ+
- being a victim of neglect and abuse, including abuse or neglect in childhood.

Stigma is absorbed and internalised by people who have been subjected to persistent stigma. People with a drug problem often have a perception of themselves that simply reflects the prejudices of others that are based in their stigmatisation. Sometimes these seem to be their overwhelming view of themselves and to over-ride any sense of self-worth or self-esteem. There are strong links between stigma, internalised stigma, well-being and mental health problems. The link between these phenomena, drug use and drug overdose deaths seems obvious.

Like sexism and racism, stigma is a cultural phenomenon. Without active challenge and education, stigmatising attitudes to people who use substances, and particularly people who have a drug problem, exists across society. People who have a drug problem themselves, their partners and friends, neighbours, people who work with them in a professional capacity, politicians, service planners and commissioners, all health, social care and criminal justice services,... all of us... are not immune from these attitudes and consciously or unconsciously act from perceptions and decisions based in stigma. These impact significantly on the lives and well-being of people affected by a drug problem.

### **2.3 Stigma and Families**

Stigma can be considered 'contagious'. Stigma can, and often does extend beyond the person who uses substances / has a drug problem. Thus partners and families bear stigma as a consequence of others' stigmatised behaviour. This can be hugely impactful and limit the family and others' ability to support the individual and also to support themselves, seek help and so on. There are serious implications in terms of the stigmatisation of children.

Families experience stigma in similar ways to people who use substances, those in treatment, those with lived-experience and practitioners working in services. The stigma experienced by family members leads to feelings of shame, guilt, anxiety, blame and a sense of responsibility by association that is reinforced through public attitudes, the political discourse and structural processes. This applies to children and young people (CYP) as well as adult family members (AFMs). How best to think of the family members of relatives with drinking or drug problems remains surprisingly controversial. The modern history of professional thinking has been dominated by models that view family members in a negative, pathological light (Orford *et al*, 2005).

The experience of family members in relation to stigma, and the impact this has, is linked to the language that is used in everyday settings, common representations of people who use drugs (and those around them) in the media, and the ways in which services are configured and delivered. This shapes and influences a range of mixed beliefs about whether support or help is deserved or if family needs or experiences should be heard, seen or cared about.

The collective impact of these different forms of stigma directly influence the relationships family members have with their loved ones, internal relationships within the family structure and interactions with others in their lives. This includes extended family members, neighbours and work colleagues as well as levels of trust between families and people working in services.

Stigma for families can be absorbed and internalised through persistent judgements around their 'choice' to support or care for their loved ones (or not) which can lead to increased secrecy and isolation through avoidance of social situations and fears around negative opinions or unwanted treatment (McCann *et al*, 2018). Stigma experienced in this way can often have a detrimental and lasting impact on overall health and wellbeing and, when internalised, shapes decisions around seeking support in their own right (often delaying until crisis point). Where crisis becomes the point of intervention the levels of support required to meet the needs of each person in the family can be more intensive and costly. This is significant when we consider adverse experiences, coping strategies and cycles of substance use behaviour.

Families cite being overlooked as a supportive or protective factor in the care of their loved one as a further stigmatising and isolating experience often driven by common perception that families are broken, fractured, problematic or troubled as a result of a judgement being made around substance use or 'families like that'. AFMs are often referred to in unsympathetic and derogatory ways, as possessing character defects, or having co-dependent relationships that perpetuate the person's substance misuse (Orford *et al*, 2013). An example of this is whole-family support provision which is still very limited across many parts of Scotland. Where this does exist the common focus is on the needs of children exclusively. The current approach does not always meet the specific needs of adult family members and contributes to feelings of '*being different*' to others in a caring role; instead being viewed with suspicion, as undeserving of support or responsible for their loved one's substance use.

Other examples of stigma and the effect this has, provided by the DDTF family reference group, include:

- Disenfranchised grief – following a substance related death families do not feel like they deserve support or sympathy which complicates the grief point.
- Support for families is seen as conditional on the basis that a loved one needs to be accessing or engaged in some form of treatment for families to receive help or support.
- Levels of trust in services are affected and vice versa; as families detach from services there are delays in seeking support that come with increasing risk of harm within the family.
- Families are afraid to come forward for fear of threats from speaking up about illicit behaviour, supply of substances and stay silent to avoid exposure, negative consequences or threats from violence over debts.
- Families can become complicit in hiding or minimising the extent of substance use in the family or seek to prevent those using substances from making changes; often leading to tensions/conflict within the family.
- The broader prevention agenda can be hampered if there is a lack of visibility of families. The result being limited access opportunities for early intervention to reduce cycles of substance use, This in turn may impact on mental health/wellbeing/relationships and future coping strategies for C&YP.

## **2.4 Stigma and Communities**

Communities with actual or perceived higher levels of problem substance use are also stigmatised. This can increase the stigma borne by individuals and families. Whole communities (locality) become defined by perceived substance use/illicit behaviour and the 'types of people' who live there. Those outside can be more reluctant to engage. Communities & local residents feel cut off, isolated and perceptions can influence decisions around levels of investment/how services are configured and impacts on a range of opportunities accessed (or not) by those living there.

## **2.5 Stigmatised Services and Treatment**

Services that work with people with substance use problems are stigmatised. This may explain under investment and the often poor physical location and condition of these services. Such services can seem isolated within wider treatment and support systems. Some people who may benefit from using these services refuse to engage with them because of the associated stigma. People delay engagement with services because the services themselves are stigmatised. In Scotland, the medical treatment received by people with an opiate-based drug problem is stigmatised and people in receipt of this treatment can be doubly stigmatised.

Medication assisted treatments are often stigmatised by the following assumptions, frequently propagated through the media; that compulsive drug use is a choice, that methadone is a crutch, that methadone simply replaces one 'addiction' with another, and that methadone prolongs addiction. Further, those on methadone maintenance are encouraged to lower their dose and end treatment as soon as possible. White suggests this can lead to relapse (White, 2009). It seems likely that this stigma delays engagement with treatment and that the stigmatised nature of treatment impacts on people so as reduce the positive impacts of treatment and to contribute to drug-related deaths.

White notes there has never been a model that integrates addiction treatment and recovery taking into account i) medicine, ii) control of activity deemed undesirable, and the iii) holistic needs of long-term recovery. Many in recovery report brief and superficial interactions with counsellors and other support workers, when on methadone maintenance treatment; these include arbitrary dose restrictions, restrictions on duration of treatment, disciplinary discharge from programmes for other drug use, and shaming rituals such as public queueing and observed urine drops for testing. This exacerbates notions of stigma for those in treatment. Furthermore, internalised stigma can lead to an elaborate pecking order within the illicit heroin culture which often carries over into the culture of methadone treatment. (White, 2009).

People engaged in treatment and support as well as 'lived and living experience' activity should bear in mind the nature, extent and impact of this internalised stigma. Many personal narratives, including recovery narratives, are often imbued with notions based in stigma and so transmit rather than challenge stigma.



## 2.6 Stigma as an Equalities Issue

Prejudice, stereotype and discrimination are three related concepts. Understanding these reveals the close link between stigma and inequalities.

**Prejudice** can be understood as a preconceived negative attitude often associated with stigma.

**Stereotypes** are common, oversimplified or even totally false, conceptualisations of a group of people based, in part at least, on stigma. Stereotypes help perpetuate stigma.

**Discrimination** occurs when people's action reflect their prejudice in ways that impact on people who are the subject of their prejudice. This has practical impacts on the lives and wellbeing of the people affected. Discrimination is rooted in a power imbalance between people.

Stigma therefore results in inequalities and is an equalities issue. This perpetuated by the Equality (Disability) Act 2010 which explicitly excludes an individual's drug or alcohol dependence from creating an impairment qualifying for protection under the 2010 Act, unless that addiction "was originally the result of administration of medically prescribed drugs or other medical treatment." There are very few explicit exemptions to the Equality Act - others include, tendencies "to set fires", "to steal", and "to physically and sexually abuse people". Categorising drug and alcohol dependence with these behaviours promotes the concept of deviant behaviour. It clearly categorises problem drug use as a behaviour that should be punished (Scottish Affairs Committee, 2019).

## 2.7 The Role of the Public

Public opinion is influenced by a range of factors including the media and legislation. Positive or educational stories are regularly tainted by a stigmatising image that changes the reader's perspective, language is used to emphasise the "horror" and "urgency" of a situation (for instance, "new drug epidemic sweeps Britain"), and guidelines around the reporting of mental illness and suicide are not adhered to despite the close connection of mental health with drug use. (SRC, SFAD media monitoring project, 2020).

Public opinion, in turn, influence political discourse and decision making so the importance of changing public opinion is clear. (Matheson *et al*, 2014). Access to the public is possible through a number of routes local events, local campaigns, national media campaigns and via the media. Previous research suggested local responses such as via pharmacies, drug treatment services and health centres could have a role in educating local communities.

# 3. Addressing Stigma in Scotland

## 3.1 The Evidence for Strategies to Reduce Stigma

Several frameworks addressing the social (e.g. cultural and gender norms) and structural (e.g. legal environment and health policy) pathways leading to general health stigma have been proposed (Stangl *et al*, 2019). A number of reviews and evidence based toolkits exist for strategies to address stigma. Some target all substance use, some refer to 'addiction' (Landry, 2012), and some on mental health including drug and alcohol use (NAS, 2016). The comprehensive review by Lloyd on stigma was specific to people with a drug problem (Lloyd, 2013). This covered the nature of stigma, particular stigmatised

groups (as discussed here) and the role of the media rather than evidence of strategies to address stigma. However Lloyd does discuss what can be done to tackle stigma, drawing on evidence from the mental health literature which was all that was available at that time. He specifically draws on Corrigan and Penn (1999) who identified three approaches to address the stigmatisation of mental health: i) protest, ii) education and iii) contact. These strategies are developed further in a more recent review by the US National Academy of Sciences report which provides a comprehensive review of the evidence on what works for Stigma Change (NAS, 2016). This review details five areas, which are essentially an expansion of the three areas already noted above.

1. protest and advocacy,
2. education,
3. contact (social contact),
4. peer programmes,
5. media campaigns.

These are briefly described below.

**Protest and Advocacy** is the formal objection to negative portrayals of people with drug problems or lived experience. Groups such as journalists, politicians, community leaders, professional groups can be targeted. Legal challenge could be considered, for example challenging the Equalities (and discrimination) Act (2010) exemption for people with drug or alcohol dependence. The evidence base for this approach is less well studied than other strategies but there are parallels with the HIV/AIDS movement in which campaigns were considered successful at addressing misperceptions. One study advocated that using professional voices can help to advocate and counter negative perceptions (Peek et al, 2015).

**Education based campaigns** use factual information to address stigma by confronting negative beliefs and incorrect information. A robust meta analysis review of public stigma-reducing interventions found educational programmes reduced stigma towards mental illness (Griffiths *et al*, 2014). Some education campaigns also aim to improve health literacy. This approach aims to inform and educate, not only on the condition, but on how to seek help. The evidence from the mental health field suggests this can be effective and evaluations of targeted groups such as young people, ethnic minorities and families were effective. This is of relevance to the drug and alcohol field in which there is a need to increase engagement with support services.

**Contact** with people with lived/living experience has proved effective in the mental health field. There is also evidence from professional groups in Scotland that experience of working with people with drug problems is associated with improved attitudes towards that group over time (Matheson et al, 2016).

**Peer Programmes** are a form of contact that have been found to be effective (NAS, 2016). Peer service include using people with lived experience in health and support services which *“provides a counterbalance to the discrimination, rejection and isolation people may encounter when trying to seek mental health or substance use treatment or services”* (NAS, 2016).

**Media Campaigns** were discussed at length in the NRS review with several high profile media campaigns around mental health considered such as the ‘See Me’ campaign in Scotland. There is evidence from the mental health field that public information campaigns can have a role in addressing negative perceptions (Corrigan *et al*, 2012). Evidence suggests that campaigns based on contact with people affected, or education have been considered the most effective at reducing the stigma of mental health (Corrigan and Rao, 2012). The NRS (2016) review was supportive of media campaigns but strongly

endorsed the application of communication science to ensure appropriate messaging to targeted audiences. From assessment of a number of national campaigns this review also found that changing attitudes of the general public is a long term project that requires sustained effort. Important to the success of any media campaign are that it should have well defined goals, be targeted to defined audiences in a manner in which messages are repeated and reinforced (Griffiths et al, 2014).

However some might feel concerned that media campaigns confer a fixed identity to whereas people's identity can change and there needs to be careful messaging to not fix a person to a particular identity. Using a communication science informed approach requires the range of attitudes and beliefs in the target group to be identified. Development of a message strategy and an implementation plan are key components of a successful campaign. The message source must be credible and the message should be specific and focussed.

In conclusion there is evidence to support the use of Protest and Advocacy, Education and, Contact based strategies and these can be delivered through targeted 'protest', contact based education, peer support and targeted, media campaigns that use communication science to ensure messaging is appropriate. The application of these approaches will be taken forward in the Scottish context in this strategy.

### **3.2 Developing a Strategic Plan**

**Assumption:** It is acknowledged that many people use a range of substances without harm. This strategic plan is underpinned by an understanding that substance use in society should not in itself be stigmatising. However, the focus of this strategic approach to reducing stigma is targeted at those for whom stigma is a means of *disempowerment, disadvantage and inequality*. The strategic plan should consider the actions required to address the stigmatisation of people affected by drug use at the following levels:

**Individuals:** [including self stigma and whether this prevents engagement with any services or treatment including general NHS services, employment opportunities etc]

- People with a drug problem (who may use services such as injecting equipment provision)
- People in treatment
- People with lived experience

#### **Groups of Affected or Associated People**

- Family: families may feel stigmatised if there is a family member who is affected by drug use
- People that work in services
- Communities: communities e.g. geographical can be negatively perceived to be associated with high level of drug use
- Treatment services

**For each of these groups it is important to address the following:**

- Why is it important to address stigma?
- What action/actions can be taken to address stigma in each group?

- At what level might this be addressed? E.g. individual level intervention, local community, service, national i.e. government, media, etc

These are detailed in the following section. Following this the next stage will be to develop an implementation plan that takes these forward to the next stage. The Scottish Government will take this forward. This will consider:

- Who should take the lead in delivering this action? E.g. ADP, third sector, SFAD, SRC, SDF, PADS community group, NHS Education, DDTF, local government, national government legislation etc
- What is a realistic timescale for this action to be initiated and completed?

## Stigma Action Plan

<b>Why is it important to address stigma for this group/ what are the issues for them?</b>	<b>What action can be taken? (note there may be several)</b>	<b>At what level is this action required?</b> e.g. individual intervention, local community, services, area E.g. ADP or local authority, national i.e. government, media, et
<b>People with a drug problem</b>		
<p>Stigma plays a significant role in the development of problem drug use.</p> <p>Stigma impacts on personal relationships with families and others diminishing their capacity to support a person in addressing their (problem) drug use.</p> <p>Stigma results in people with a drug problem being marginalised and excluded by mainstream services and a wider cultural stigma means this is regarded as acceptable/normal/desirable.</p> <p>Self-stigma results in people excluding themselves from services by making people feel not worthy or uncomfortable in approaching and engaging with services. For this reason people with a drug problem reach crisis before addressing issues in health, housing, debt etc.</p> <p>Stigma can mean people are more socially marginalised and become part of narrower social networks - often composed of people who likewise have a drug problem and are involved in seeking, obtaining and using drugs. This helps drive their drug use and increases harms.</p>	<p><b><u>Protest and Advocacy</u></b></p> <p><b>Empower people with a drug problem.</b> Active engagement of people with a drug problem in the development of local and national responses to problem drug use is still rare in Scotland. The recent work in this area is pioneering in a Scottish context and potentially transformative for individuals and for the whole way in which Scotland responds to problem drug use / engages with people who have a drug problem.</p> <p>More widely, people with a drug problem should be empowered / encouraged / supported to identify and challenge stigma and to resist the stigma to which they are subjected. This can be done by providing people an opportunity to reinvent their personal narrative by exposure to people with Lived Experience working within treatment to support them. Identification with a LE practitioner not only helps build a therapeutic alliance but also empowers service users to destigmatise themselves.</p> <p><b>Positive messages to people with a drug problem –</b></p> <p>Perhaps actions speak louder than words. <i>‘Your life matters’</i> (supply of naloxone, IEP services) <i>‘Your health matters’</i> (outreach around physical and mental health e.g. wound</p>	<p><b>National-</b> This activity already occurs in small pockets driven by good people doing good work. However for an effective strategy to develop it will require the co-ordinated involvement of a full range of stakeholders. Leadership will be required.</p> <p><b>National</b> - It is important that all of these activities described here co-ordinate and articulate with each other to maximise impact. Lead agencies for professional groups and healthcare educators e.g. RCGP, RPS, NES as well as those support PWDP i.e SDF, SRC, and families (SFAD) would have to work together effectively to ensure this.</p> <p><b>Local –</b></p> <p>Services need to engage with and invest in training opportunities for staff. E.g. training on trauma informed care.</p> <p>Services should link to advocacy opportunities such as advocacy organisations for their clients if this is beyond their own service remit.</p>

<p>Marginalisation, exclusion and peer norms, all promoted by stigma, lead to feelings of low self-worth and desperation – leading to more drug use and more harms.</p> <p>The stigmatisation of this group leads to more drug related harms and prevents progress in almost all areas of life including addressing their drug problem.</p>	<p>care services) <i>'Your wellbeing matters'</i> (outreach e.g. to socially isolated) <i>'It matters that you are safe'</i> (housing first).</p> <p><b><u>Contact</u></b></p> <p>The development of stigma-free spaces for people with a drug problem to discuss the local and national response to problem drug use and emerging issues would be a hugely significant step. The work in Glasgow with the City Centre Engagement Group shows that, in these contexts, people can decide their own priorities and the actions that they want taken; can communicate effectively with professionals – planners, managers of services etc - and comment / hold them to account. This practice could be developed across Scotland.</p> <p><b>Work with families</b> – recognition of role, capacity building and support. To be informed / empowered / encouraged / supported to identify and challenge stigma.</p> <p><b><u>Education</u></b></p> <p><b>Work with mainstream services</b> – Frontline staff and management in mainstream services need to understand the causes and drivers of problem drug use; recognise their role in stigmatising people with a drug problem and the negative impacts for all parties; revise their policies and practice with respect to people with a drug problem; be trained and otherwise build their capacity to improve their work with people who have a drug problem and their joint working with other agencies. For some, development of outreach provision may be appropriate.</p>	<p><b>Individual –</b></p> <p>All people must stand up for a rights based approach and seek support to do so e.g. through advocacy opportunities.</p> <p>Staff should feel enabled to access advocacy services for clients/patients.</p>
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<b>People using treatment services</b>		
<p>Stigma plays a significant role in determining the effectiveness and outcome of treatment systems and for individuals in treatment.</p> <p>Engagement in evidence-based effective treatment delivered to high standards is the most significant protection against drug related death that the state can provide. Early engagement is important to prevent drug harms that further complicate recovery and can involve increased levels of stigma.</p> <p>Yet treatment itself has become stigmatised – and so stigma is a key driver in Scotland’s drug problem and particularly in relation to drug-related deaths.</p> <p>The way in which services are designed and delivered is shaped by stigma and as a consequence, treatment itself becomes less effective than it may have been otherwise. For individuals, this means that they are denied a person centred, non-judgemental, empowering and healing relationship with their treatment provider and instead often perceive their treatment as engagement with an untrusting, inflexible and sometimes punitive regime which is eased sometimes by members of frontline staff who try to mediate with this on their behalf. For comparison, it may be helpful to consider what sexual health services particularly those for marginalised or stigmatised groups, would look like if they were delivered in this way.</p> <p>In terms of medically assisted treatment, stigma has driven a risk-averse approach to prescribing and dispensing medication which has been applied to the vast majority of people in treatment. This has been</p>	<p><b><u>Protest and Advocacy</u></b></p> <p><b>Positive messages to people in treatment –</b></p> <p><i>‘You are at the centre of your treatment; your voice matters’</i></p> <p><i>‘Your health and well-being matters and is the priority of this service’</i> – this is not necessarily only about MAT but wider wellbeing.</p> <p><i>‘Your ideas, opinions and experiences are valued’</i> – involvement in service development that aims to achieve a non-judgmental, non-stigmatising and empowering basis for treatment engagement.</p> <p>All people using treatment services should be empowered and supported to engage in and shape this necessary cultural change and the development of service provision. There are various means of achieving this but priority should be given to the involvement of those currently most disempowered and marginalised</p> <p><b><u>Education</u></b></p> <p>Specialist treatment and support services require significant cultural change to create systems and environment that are not only stigma-free but challenge stigma. The expressed purpose of these services should include that they challenge stigmatisation and marginalisation that fosters and supports problem drug use.</p>	<p>A full range of stakeholders is required leadership and co-ordination at a national and local and service level. It is important that all of these activities described here co-ordinate and articulate with each other, locally and nationally, to maximise impact. Lead agencies would have to work together effectively to ensure this.</p> <p><b>National –</b></p> <p>National guidance e.g. via MAT standards on what patients/clients can expect.</p> <p><b>Local -</b></p> <p>Local service level – provide mission statements, information for patients and clients on their rights.</p> <p>Local services and people with lived experience could engage with local communities: <b>Education and contact.</b></p> <p>MAT standards and the implementation and communication of these is key.</p> <p>Regular staff survey/audit at local level but with national feedback.</p>

<p>aggravated by the common perception among service staff and others that abstinence is the purpose of treatment. This has led to a notion that lower doses of medication are ‘better’ than higher doses – a notion based in stigma and resulting in the further stigmatisation of people on higher doses. And again, stigma results from the fact that people almost inevitably ‘top up’ their under-prescribed doses of medication with street drugs. This vicious circle is driven by stigma and is a key driver of drug-related deaths</p> <p>People drop out or are forced out of this treatment system and are at heightened risk of relapse, overdose and death. Because treatment services are stigmatised, people who leave in a drug free state are reluctant to return, as they should, when they are struggling or in the early stage of relapse. This is partly due to stigma. This results in overdose deaths.</p> <p>The stigmatising nature of media coverage and especially political discourse around drug treatment is a striking and a long term feature of public discussion on problem drug use in Scotland.</p>	<p>All service delivery should be based in rights. Services need to change the way in which they reach out and engage with people who have a drug problem.</p> <p>In terms of medical assisted treatment areas of obvious immediate concern may be susceptible to an analysis that prioritises de-stigmatisation - the length of time people wait to receive medical treatment; the personalising and optimising of their dose; the flexible personalisation of their dispensing arrangement. There are also issues here for GPs and pharmacists relating to the stigmatisation of people in drug treatment.</p> <p>Managers of specialist services need to build capacity to foster cultural change that links an empowering person-centred non-judgemental approach that is trauma informed and challenges stigma and to recognise the inter-related nature of these developments. Recognising and challenging stigma is key to this.</p> <p><b><u>Contact</u></b></p> <p>Frontline staff in treatment services need to be empowered to identify and challenge stigma and stigmatising practice – this includes their own and that of the service in which they work. They need to be involved in the development of their own, and wider, services.</p> <p><b>Work with families (as defined)</b> – To be informed / empowered / encouraged and supported to identify and challenge stigma as it relates to treatment. To recognise the potential for treatment to help a person achieve what they would want for them.</p>	<p>Patient/client feedback on their service e.g. using apps or via audit of local, regular surveys with national feedback. Patient involvement in service reviews.</p> <p>Local services – family support groups, family information resources.</p>
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<b>People with lived experience</b>		
<p>Stigma can pose a great risk to those in early recovery from problem drug use. The process of coming to terms with and becoming comfortable in a new identity as someone who is in recovery can be negatively impacted by the individuals' sensitivity to attitudes of others towards them if their past is disclosed. This can manifest itself negatively in interactions with family, friends and neighbours; employers or potential employers; police and health services, housing services, engagement with DWP.</p> <p>People in early recovery can be highly concerned by how the general public react to them as a person in recovery with lived experience of problem substance use. Social media and mainstream media channels play a significant part these narratives.</p> <p>As people progress in their recovery they may start to engage with peer support groups / mutual aid/ visible recovery communities. These groups can experience stigma. This is often caused by the ignorance or lack of understanding of local residents, prospective letting organisations or organisations who are established within a locality community to provide community supports.</p> <p>People with lived experience can also encounter stigmatising behaviour associated with volunteering, training and education or transitioning into paid employment. The setting of generalised criteria for volunteering, being accepted on to an educational course or a work placement which demand a certain amount of time substance free is in of itself discriminatory and reinforces on the recipient of such behaviour that they</p>	<p><b><u>Protest and Advocacy</u></b></p> <p>Training and Education Approaches delivered by people with lived experience will help people in early recovery become confident in their new identity. Building internal efficacy to self-advocate and educate those around them safely and effectively. (Stigma and Me : Stigma and Us- SRC Training Course)</p> <p>Mutual Aid and Visible Recovery Communities offer people in early recovery a place of acceptance, empathy and understanding and a means to campaign or advocate on a personal or public basis. Visible Recovery Communities taking part in generic local community events or inviting local communities to interact with them reduces stigma through proximity.</p> <p><b><u>Education</u></b></p> <p>Evidence tells us:</p> <ul style="list-style-type: none"> <li>• Most effective ways to reduce are combo of Educational and Lived Experience Proximity,</li> <li>• professionals are one of the hardest groups to engage in resistance and positive behaviour</li> <li>• targeted approach tailored to TG needs/ behaviours/ role,</li> <li>• campaign could have same core messaging and radiate out ( with targeted messaging) from Treatment ( professionals) to non- generic services to wider community )</li> <li>• LE should lead this approach with support from relevant structures and using information science to communicate. Who better to lead narrative change</li> </ul>	<p><b><u>National:</u></b> Targeted Message Campaign from SG outwards into <u>Locality</u> workforce then radiate outward into more generic services.</p> <p><b><u>National:</u></b> People First Language Campaign.</p> <p>Recovery Walk Scotland is a <u>national</u> event that celebrates the value of recovery and lived experience</p> <p><b><u>Local -</u></b> Training given on media and public relations LERN and Recovery Community Training Programme (SRC).</p> <p><b><u>Media:</u></b> Voluntary Code of Conduct for journalists would be a long tern <u>national</u> campaign actualised within <u>localities</u> by Lived Experience activists.</p> <p><b><u>National -</u></b> <u>National</u> strategies within agencies like DWP should be encouraged and linked into practice of Visible Recovery Communities on a <u>Locality</u> basis.</p> <p><b><u>Local -</u></b> Managers of services should understand as a fundamental responsibility of their role to actively</p>

<p>are different and less than other candidates for such opportunities.</p> <p>In recent years as people with lived experience have taken advantage of volunteering and training opportunities within traditional treatment structures through service user involvement initiatives, peer to peer support projects and Visible Recovery Communities autonomous from but closely connected to treatment services. This group has started to interact with professionals, clinicians, academics and decision makers in a very different way. These innovations have largely been designed by - and all rely on, people with lived experience bringing additionality and new value into treatment alongside traditional interventions and approaches. This process of established approaches and cultures accepting a new group into its milieu has, in some cases, made stigmatising behaviour apparent.</p>	<p>than people who understand that process from personal experience and now play very active citizenship roles within their communities,</p> <ul style="list-style-type: none"> <li>• Social Media and Mainstream Media Messaging - for journalists-Social Marketing- Key Messages- delivered by LE (Educational and Proximity approach) targeted focus – radiating out from Treatment.</li> <li>• People First Language in combo with above.</li> </ul> <p><b><u>Contact</u></b></p> <p>VRC s and individuals can gain insight and competencies into working with their local communities, local and national media and social media through support from SRC.</p> <p>Media portrayal of Substance Use and Recovery could be changed by proximity, local Visible Recovery Communities promoting their events and value working with local media.</p> <p>A voluntary set of guidelines for adoption by journalists and editorial teams could also contribute to a wider societal change in attitudes towards those who experience problem drug use and recovery.</p> <p>Local and National Events celebrating Recovery and Lived Experience, educate, advocate and promote the benefits and value people with lived experience bring to their local communities and wider society. Replacing ignorance, fear and stigma with compassion and connection.</p> <p>In some European countries (notably The Netherlands) positive discrimination is exercised towards people in recovery with a view to gaining employment.</p>	<p>promote 1) Rights Based Approach 2) Person Centred Approach 3) People First Language 4) Relationship Based Practice amongst their staff teams and actively reduce stigmatising behaviour on a structural and individual level.</p> <p>Work Force development: Training</p> <p>Evidence around National Mass Media Campaigns would discourage this approach within this sector. A <u>National</u> targeted message approach (educational) designed to encourage positive behaviours could start within <u>Local</u> treatment services and Visible Recovery Communities and be conduct face to face, through Social Media and with involvement of local media and communities.</p>
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	<p>Workforce Development should ensure that all practitioners in this sector stop thinking of “Lived Experience” as cohort that “must be included” and start treating them as resources of a unique perspective who offer competencies and empathy that can bring additionality and value into every area of practice. Managers of services should understand one of their fundamental functions is to facilitate this culture change and ensure effective and equitable acceptance of lived experience volunteers and staff is optimised.</p>	
<p><b>Women</b></p>		
<p>Stigma affects women who have a drug problem and women in treatment in ways that cause significant harm to them and to others. This includes drug related death.</p> <p>Some women are disempowered in their drug use and are not in control of the purchase of, nor the administration of, the drugs they use. For these women their drug use is so intimately involved in the power dynamics of their relationship, that they may be unable to approach harm reduction or treatment services.</p> <p>Women involved in transactional sex are doubly stigmatised. They may be criminalised for their involvement in transactional sex as well as their drug use.</p>	<p><b><u>Protest and Advocacy</u></b></p> <p>There is a need for specific targeted anti stigma work around issues faced by women who use drugs. Women need to be empowered by the services they engage with. The development of specialist services or projects within existing services may be required.</p> <p><b><u>Education</u></b></p> <p>Specialist treatment and support services require significant cultural change to create systems and environment that are not only stigma-free but challenge stigma against women.</p>	<p><b>Local –</b></p> <p>ADPs should ensure women are given specific consideration in service provision. This will include women involved in transactional sex.</p>
<p><b>Mothers</b></p>		
<p>Women who are mothers may be doubly stigmatised and reluctant to present at services for fear of stigma and as she may feel that her custody of her children is at risk.</p> <p>Women in this situation have shared their own experience of stigmatising attitudes from service providers.</p>	<p><b><u>Protest and Advocacy</u></b></p> <p>A principled approach is required that focuses on the rights of women.</p>	<p><b>Local -</b></p> <p>ADPs and Social Work – specialist support services for expectant and new mothers. These already exist in many areas.</p>

<p>While there may be legitimate concerns around child protection, the system fails that child if their mother remains in the midst of problem drug use or dies because stigma and fear stop her successful engagement with harm reduction and treatment services.</p>	<p>Mothers need to be empowered by the services they engage with. The development of specialist services or projects within existing services may be required.</p>	
<p><b>Ethnic minorities</b></p>		
<p>There are particular stigmas for some people from ethnic minorities with a drug problem. These prevent people from approaching services.</p> <p>Mainstream service provision has had challenges in engaging effectively with people from ethnic minorities.</p> <p>There is a perception that substance use issues may be changing within minority ethnic communities reflecting the diversification of the minority ethnic populations in Scotland.</p>	<p><b><u>Education</u></b> There is a need for specific targeted anti stigma work around issues faced by people from minority ethnic and religious populations.</p> <p><b>Work with treatment services –</b>  Specialist treatment and support services require significant cultural change to create systems and environments that are not only inclusive of minority ethnic and religious populations but are sensitive to particular stigmas experienced by members of these communities. Joint work with minority ethnic health and other projects and with communities of interest.</p>	<p>ADPs should conduct needs assessments that take account of ethnic groups in the wider community. Specialist groups and or services should be considered where a needs is identified.</p>
<p><b>People living in rural communities</b></p>		
<p>Access to services can be challenging due to distance, cost of transport and time required to attend appointments (e.g. if working). This can make people disinclined to engage with services or they may find it challenging to attend appointments.</p>	<p><b><u>Contact</u></b>  Consider decentralised services e.g. outreach to peoples' homes or via remote clinics, perhaps located in health centres, pharmacies or other clinics or locations.</p>	<p><b>National -</b> UK Government –Clarify/ revise The Equalities Act (2010). Removal of the exemption for drug or alcohol dependence would enable free public transport for attending appointments.</p> <p>Scottish Government could provide guidance on a range of services model options.</p>

		<p><b>Local -</b> ADPs should undertake needs assessments to review access challenges.</p>
<p><b>LGBTQ+</b></p>		
<p>There are particular stigmas for some people from the LLGBTQ+ community with a drug problem. These come from wider society and from within the community. These prevent people from approaching services. Work by the Equalities Network has raised issues about problem substance use among trans people and the lack of adequate service provision.</p>	<p><b><u>Education</u></b></p> <p>There is a need for specific targeted anti stigma work around issues faced by LGBTQ+ people.</p> <p><b><u>Work with treatment services</u></b> –Specialist treatment and support services require significant cultural change to create systems and environments that are not only inclusive of LGBTQ+ people but are sensitive to particular stigmas experienced by members of these communities. Joint work with LGBTQ+ health and other projects and with communities of interest may support this cultural change.</p>	<p><b>Local -</b> ADPs. Target local media campaigns may be needed to appeal to the LGBTQ+ community. Seek involvement of LGBTQ+ activists at a local level to shape services and the communication required to encourage engagement.</p>
<p><b>Families</b></p>		
<p><b>Self-Stigma/by association/structural &amp; public</b></p> <p>Language, current practice and the policy response can often shape and influence how families and PWUD feel and how they respond to each other and those around them. Stigma has the potential to limit opportunity, restrict choice or act as a barrier to change – structurally and socially.</p> <p>Stigmatization of families supporting an adult member with substance misuse is common and undermines their</p>	<p>Tackling stigma – ‘best buys’ remain:</p> <p><b><u>Protest and Advocacy</u></b></p> <p>Families need to be viewed and recognised as assets for change and a valuable source of support.</p> <p>Investment in adequate bereavement support networks, access to counselling, appropriate resources and a relevant campaign to destigmatize and increase engagement/uptake sooner.</p>	<p>All across Scotland involved: ADPs/HSCPs/Local communities/services and families.</p>

capacity to support the person and maintain their own well-being.

Disenfranchised grief – following a substance related death families don't feel like they deserve support/sympathy which complicates the grief point.

Whole-family support provision which is limited across many parts of Scotland. Support for families is seen as conditional on the basis that a loved one needs to be accessing or engaged in some form of treatment for families to receive help or support.

Levels of trust in services are affected and vice versa; as families detach from services there are delays in seeking support that come with increasing risk of harm within the family.

Families are afraid to come forward for fear of threats from speaking up about illicit behaviour, supply of substances and stay silent to avoid exposure, negative consequences or threats from violence over debts.

Families can become complicit in hiding or minimising the extent of substance use in the family or seek to prevent those using substances from making changes; often leading to tensions/conflict within the family.

Hampers prevention agenda. Families being hidden limits access opportunities for early intervention to reduce cycles of substance use with potential to impact on

### **Contact**

Increase engagement with families across Scotland with commissioning directives setting out duty for families as set out in RR&R. Requirement for all family support options, choices and provision to be promoted through clear messages for family members in their own right.

Families need to be involved in co-production of services and responses to tackle stigma at all levels to break down common misconceptions on 'both sides' whilst seeking to build understanding and trust.

Develop clearer actions on building relationships and relationship development - using the range of tools/methods including CRAFT - SMART F&F to support healthy relationships for prevention, minimising harm and taking a whole-systems approach across services and within the family. Training & Development/resources and increased opportunity for social contact.

### **Education**

Resources & training at strategic level. (across universal services/3rd sector and workplaces).

The unique challenges faced by families in this situation need to be better understood - families should be supported and protected when living in fear. Work should be done to collaborate with key agencies to protect vulnerable families from exploitation.

**Families & Communities** - lead on change & innovation with investment to tackle stigma at a variety of levels. e.g. Local

<p>mental health/wellbeing/relationships and future coping strategies for C&amp;YP.</p>	<p>action funding to focus on activities that will reduce stigma/develop our understanding of the impact this has &amp; evidence the most appropriate responses at a grassroots level. <b>social contact and education</b></p>	
<p><b>Communities</b></p>		
<p>Whole communities (locality) become defined by perceived substance use/illicit behaviour and ‘types of people’ who live there. Those outside can be more reluctant to engage. Communities &amp; local residents feel cut off, isolated and perceptions can influence decisions around levels of investment/how services are configured and impacts on a range of opportunities accessed (or not) by those living there.</p> <p>Stigma has an adverse impact on efforts to engage/support change from these communities.</p>	<p><b>Families &amp; Communities</b> - lead on change &amp; innovation with investment to tackle stigma at a variety of levels. e.g. Local action funding to focus on activities that will reduce stigma/develop our understanding of the impact this has &amp; evidence the most appropriate responses at a grassroots level. <b>social contact - education</b></p>	
<p><b>People who work in services</b></p>		
<p>Demoralisation of the workforce People leaving posts Deskilling</p> <p>People who work in drug services and perhaps particularly drug treatment services, can experience a form of stigma. It would be helpful to address this along with other stigma-related issues as, in doing so, other manifestations of stigma may be more readily addressed.</p> <p>The stigma, where it exists, is most obvious to people who have a standard work qualification, e.g. a nursing</p>	<p><b><u>Protest and Advocacy</u></b></p> <p>Empower through access to training and protected training time. Encourage career development. Review model of service e.g. case load approach, appointment systems, meaningful interaction with service user group. Involvement with/in <b>protest and advocacy</b> for their client group may be empowering.</p> <p>In order to perform their work, members of frontline staff, like everyone else, need to feel valued and have some</p>	<p>Action is required at all levels national, local and service.</p> <p><b>National -</b></p> <p>The Scottish government, working with NES and other partners should develop a framework for workforce development which values expertise, professional development and supports career progression is recommended.</p>

<p>qualification and are working in substance use treatment services. They have similarly qualified colleagues in very different services working with other groups of people. For many, it is obvious, when comparisons are drawn, that drugs services are less well funded and under-invested compared with services for other groups.</p> <p>This under-investment can be manifest in the quality of accommodation, and its location, the size of caseloads (given the work that is meant to be done,) the lack of flexibility in the work regime, the lack of opportunities for promotion etc. These are the result of stigma – while similar issues may arise with other staff working with other groups they seem to be far more consistent in drug treatment services.</p> <p>The impact of this for workers can be stress, burnout and being unhappy in a post that is difficult to move on from even within your own professional field. Similar issues occur for less qualified and non-NHS staff. This impacts on the service experience of people who have a drug problem and are in treatment and is a significant issue.</p>	<p>control over issues that affect them and the people they work with.</p> <p>As part of the development of a de-stigmatising culture the active involvement and ‘buy in’ of frontline staff is crucial.</p> <p>Staff development will be key to the delivery of an anti-stigma culture as will representation and involvement of staff in decision making. The capacity of services to undertake this involvement will be key to the delivery of this strategy.</p> <p><b><u>Education</u></b></p> <p>The anti-stigma culture will only develop and maximise its impact if all professions have a shared understanding of the issues and the ways to address them. This includes medical and nursing staff as well as social care staff and newer posts that have been developed recently around lived experience peer roles. This can be achieved through training and effective joint work and communication.</p>	<p>Service level workforce review required at Scottish Government level.</p>
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### 3.3 Applying an Evidence Based Approach to Challenging Stigma in Scotland

The evidence identified three key approaches to address stigma i) protest and advocacy, ii) education including media campaigns and contact (social contact) including peer programmes. The detailed breakdown above has reviewed how these could be applied to specific groups and individuals. These have been pulled into a summary of key actions and recommendations below. A separate framework that can be applied to commission specific work components is in development.

### 3.4 Summary of Actions and Recommendations

Recommendations	Actions
Scotland should have a national and local mission statements on addressing stigmatisation – including self-stigma, stigma by association, structural stigma and public stigma.	The Scottish Government and Public Health Scotland must publish a mission statement on addressing stigmatisation. National professional bodies*, local drug services and third sector partners should adopt or adapt that into meaningful relevant mission statements from them.
	Mission statements should be supported by all services (not just drug treatment) through the adoption of a rights-based approach to service provision and delivery.
All responses to problem drug use must be co-developed or co-produced with those who deliver services to people with drug problems and people with lived experience.	The Scottish Government and Public Health Scotland must set the tone for co-production of responses to problem drug use.
	Integration Authorities and ADPs must ensure co-production and co-development of service responses locally.
	The Scottish Government and Public Health Scotland should work with IAs and ADPs to develop a national standard for addressing stigma supported by guidance for services – including front line staff in any commissioned service.
	The Scottish Government should work with IAs and ADPs to develop a standard and reporting mechanism to help IAs and ADPs evidence how they co-produce responses to problem drug use.
	The Scottish Government should work with Public Health Scotland to co-produce guidance to services on groups with specific needs such as

<p>All responses to problem drug use must pay specific attention to clients and groups who are most likely to experience stigmatisation.</p>	<p>women, children and families, ethnic minorities, LGBTQ+, and people living in rural communities.</p>
	<p>ADPs must conduct needs assessments to take account of the needs and stigma risks faced by these groups.</p>
	<p>The Scottish Government should review current legislative arrangements which present barriers to potentially stigmatised groups – for example where some groups are excluded access to free bus travel.</p>
<p>All services must help reframe the narrative around problem drug use wherever possible. Drug services should celebrate the success of recovery communities and focus on and communicate strong messages about the positive outcomes PWDP can expect when engaging with them.</p>	<p>Services must raise awareness among frontline staff (through education and training) of the existence and impact of stigmatising behaviours, processes and service environments.</p>
	<p>Services must ensure that take every opportunity to utilise practitioners with lived experience within services – to help normalise exposure to people with lived experience and improve the positive, open and stigma-free nature of services.</p>
	<p>Services must ensure that all messaging to clients, families and communities etc are seen to be positive messages about inclusivity and wellbeing. It is important to demonstrate that services are listening to people who use treatment services.</p>
	<p>To become more visible, recovery communities should actively seek to take part in wider community events and initiatives. Recovery communities should also extend invitations to meet and gather with wider community groups.</p>
	<p>National and local media campaigns promoting positive messages around treatment and recovery and events supporting improving the wellbeing of people with drug problems and people with lived experience should be visibly developed and supported.</p>
	<p>Nationally and locally, all opportunities should be taken to provide the media with a more positive narrative on treatment and recovery, respect for individuals, families and communities and the contributions which the sector has to wider communities and wellbeing.</p>

	Stigmatisation by the media of any part of the sector must be challenged by the Scottish Government and all partners.
Services must actively promote opportunities for anyone – from the client group, from families and communities and from the workforce – to be able to challenge stigma or stigmatising behaviour, process or environments	IAs and ADPs must have transparent processes for reporting stigmatisation and must record and report actions they have taken in response.
	Services should involve people with lived experience in developing training and education for the workforce – to develop the capacity of people with lived experience and to improve the understanding of stigmatisation among the workforce.
	Services must establish and run routine “stigma-free spaces” as part of service design and operation to ensure clients, families and communities, and the workforce are engaged on stigma and empowered to challenge it.

\*including the Royal College of General Practitioners, the Royal Pharmaceutical Society of Great Britain (Scotland), the Royal College of Psychiatrists (Scotland), the Royal College of Physicians.

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## Appendices

### Appendix one: Case Studies

The cases below are short descriptions of real situations from people across Scotland.

#### Case One: North Lanarkshire Female under 30 years old, (not in treatment)

A group of people, could not get their drug of choice. They had been drinking heavily and when they tried to score their drugs were unable to get what they were after so they decided to buy some street valium. They all went back to one house and took the street valium. 2 men from the group went back to their flat. Tragically 5 of the group died in 2 different household, all were dead on arrival at hospital. There was only one survivor.

Comments were made after the event to the survivor. Her mother tried to get support to help her daughter through the impact and trauma the deaths had had on her. She in fact ended up being hospitalised in a psychiatric ward due to the trauma. Some of the comments made to her, and her mother after the event were:

*“This is what happens when you use drugs”*

*“they have always looked for trouble”*

*“They were just junkies”*

*“you reap what you sew”*

*“serves them right for breaking the government guidance on social distancing”*

#### Case Two: Stigma and disenfranchised grief in a partner

P's partner died 5 years ago. He was a private man who had struggled with his heroin use for a number of years. He was found in the shopping centre toilets having overdosed after a period of abstinence. For 5 years P has never sought support for her grief and told people that he had died of a heart attack. She did not feel that he would have liked people to know about his drug use but also found that she got a more empathetic response from people when she told them it was a heart attack. P began drinking to deal with the grief she felt unable to process safely. Now in recovery from her own drinking behaviours she recognises it was the incongruence in what she was telling people and what had actually happened that she was struggling most with. P felt the judgement that she (and he) would receive if she told the truth about his death was stopping her from 'telling his story' honestly.

#### Case three: A Parent

J, After a number of sessions regarding her sons' drug use mentioned that her daughter had died following drug use 6 years previously. J seemed to be living to 'the rules' of the small town where her own family, and the whole community, didn't appear to mention anything about drugs. She spoke in euphemisms that were accepted by everyone that meant different things around substance use and her experiences with her son. So, 'over the water' meant that someone was in jail. So when her son went to prison people would say 'he is over the water.' None of her family or friends spoke about her daughter who had died and it was almost as if she just didn't exist. We worked together for some time and it took a long while before she eventually did speak a little about her daughter. J had put her daughter 'in a box that is locked away in her mind and she is not willing to open it.' I was the only person she had ever

spoken to about her daughter and that if she had died of other causes she would find it much easier to talk about. J also recognised that her inability to talk about her daughter impacted her relationships with other family members who wanted to talk about their sibling.

#### **Case four: Young person with parental drug use**

S is 15 and both parents use drugs. S has disengaged from school because she feels teachers judge her without really knowing what she has to deal with on a day to day basis. S often cared for her younger siblings as her parents couldn't always cope. Both parents had been reported to social work due to their excessive substance use. S has been placed in the care of her Gran. S feels that most people in her community and school know her parents and she has been called names at school, the shopping centre at the local swimming pool because of what people think about their substance use. S tried to hide what was going on at home from friends because she didn't want people to know or think of her family this way but some of their actions in the past made that impossible to hide. S finds it easier to avoid most social situations as she doesn't want to experience those comments anymore. 'I knew people would judge me and say, 'Oh her mum's this or her dad's that'. I now realise there is nothing for me to be ashamed of but people make you feel so bad for something you can't control'

#### **Case five: Rural community (described by a researcher Wendy Hatrick)**

D, a male, Islander, IDU, Hepatitis C Virus negative, previously incarcerated, 37 years. Started injecting career at 15 years. D has lived mostly in Shetland and on Scottish mainland. He experienced perceived and actual stigmatisation regarding: injecting drug use, incarceration, involvement in a fatality. *"there is stigma, folk do look down their noses at you, but what you were doin [doing] or maybe still are, is wrong... folk have long memories, I'll always be tarred with it... it's so inspiring when someone smiles and says something kind to you"*

The secrecy and covert nature of the local island drug culture and the reported negativity perceived by users is testament to the stigma reported. A personal moral self which may be hidden beneath the reported hard, stoic and selfish persona often associated with the injecting drug using population could challenge misconceptions. The lack of anonymity, and challenges of rurality are real. *"The suppliers will treat you differently, they'll hand you smaller deals, because they know you are injectin... like they know you don't have many other options .."*

*".. as soon as folk hear my name they just ain't interested in knowin me .."*

*"The same with handin back the syringes to the chemist .. your family would find out in no time .."*

Challenging stigma may benefit not only professionals working with injecting drug users and IEP services, but users themselves, their wider family members and the population around them.

#### **Case six: From a Black and Minority Ethnic Perspective**

A, 34, Is British Indian male, he has being using alcohol, heroin and prescribed medication over the past 10 years. He has experienced mental health issues including anxiety disorder and agoraphobia and has been involved in the justice system as a result of his substance use. The stigma attached to addictions in the community and family honour being an added layer, meant that the family's decision was to disown A. This isolation made it difficult for A to access help and treatment in the past. A wants to build his relationship with his parents, ex-wife and children. He has received support from the local mosque, the Imam and A's father to help build their relationship. A's family expressed that they could not cope with A's addictions (past heroin use), the feelings of shame and guilt.

### **Case Seven: Stigma in the time of Covid-19**

D spoke of his friend, C, who was ahead of him in a queue to collect her ORT prescription as the pharmacy rules are currently 1 in and 1 out. C was before him in the queue, but when it came to her turn they told her that her prescription was not ready, and she would have to go back to the end of the very long queue. C was embarrassed and upset because she felt everyone in the queue knew she was there for methadone. She has said that even before the pandemic she is frequently made to wait while other customers are served, and has been late for other commitments and appointments in the past due to this.

### **Case Eight: stigma at the pharmacy**

N and his partner Y have both been forced to seek another pharmacist after they were blacklisted at their former service. N has COPD and a frequent cough, which is unrelated to Covid-19, but their pharmacist blacklisted them following the pandemic announcement and also advised another nearby pharmacy not to serve them. B and Y now have to travel to a third pharmacy by public transport to get their ORT prescriptions, exacerbating N's symptoms and contravening current guidelines as he is supposed to be shielding from the pandemic. They now live in dread of accessing their prescription. Both N and Y say that some of their friends are detoxing at home due to lack of services.

### **Case Nine: Health Professionals**

Stigma can also be experienced by the health and social care professionals delivering services.

Community pharmacies provide a range of NHS services across all care groups. These services include patients attending drug treatment services and many pharmacies are at the forefront in providing harm reduction advice and equipment due to their extended opening hours and local accessibility. Pharmacies are inevitably highly publicly visible spaces and are often the target of adverse media reporting related to their provision of services for PWUD. This type of media reporting contributes to the stigma that has been experienced by pharmacists, their staff and in some instances by their families.

In an extreme example, one pharmacist reported having to move house twice due to sustained public abuse directed towards himself and even extended to his family when walking in a local park. He also had cars deliberately damaged and tyres slashed. This abuse and stigmatisation also affected members of staff who were associated with a pharmacy providing services for large numbers of patients in receipt of methadone or buprenorphine.

Many pharmacists regularly have to respond to vocal and verbally aggressive community groups objecting to the provision of OST and IEP services from their premises. This stems from stigmatisation of the patient group and a lack of public understanding of the individual and community benefits of the pharmacy services. Despite these challenges pharmacists continue to deliver essential healthcare interventions and the wider community should continue to support them and their staff.



