



“What about Families?!”

Reflections and Recommendations
for the Scottish Drugs Death Task Force
2019-2022

A Report By
The Family Reference Group
June 2022

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INTRODUCTION: ABOUT THE FAMILY REFERENCE GROUP

The Scottish Drugs Deaths Taskforce (DDTF) was established in July 2019 by the Minister for Public Health and Sport (Joe Fitzpatrick) to tackle the rising number of drug deaths in Scotland.

The primary role of the Taskforce was “to co-ordinate and drive action to improve the health outcomes for people who use drugs, reducing the risk of harm and death”. The Taskforce had a particular focus on examining and sharing evidence about what works, and rolling out good practice in Scotland. It also aimed to examine issues surrounding treatment, support and harm reduction services as well as the criminal justice system, and to review the Misuse of Drugs Act 1971. The Taskforce aimed to make recommendations for change around health and social care practice and the public health approach to drugs.

The Family Reference Group was established in October 2019 to support Colin Hutcheon as the sole family representative on the Taskforce. Scottish Families Affected by Alcohol and Drugs (Scottish Families) established the group and provides the secretariat support.

Members were identified via existing contacts and networks, including family members whose loved ones are in recovery, those where there is still active or intermittent substance use, and bereaved family members.

The Group members represent both urban and rural areas, including the Highlands, Aberdeen, Ayrshire, Inverclyde, Scottish Borders, Edinburgh and West Lothian.

The Group’s remit was agreed by the members as:

- Supporting Colin as the family representative on the DDTF to convey the views of families, including:
 - The barriers faced when engaging with services;
 - A recognition that families can be a significant factor in recovery; and
- To provide support through their own representation on the DDTF’s workstreams.

The Group held 16 meetings between October 2019 and June 2022, with further meetings scheduled in 2022. These include regular meetings and special interest meetings (including those opened to other family members and Scottish Families staff). Three of the Group meetings were held in person, before meetings moved online during the COVID pandemic.

The Family Reference Group was originally set up independently of the Drug Deaths Taskforce, however it was formally adopted as a DDTF sub-group when the Taskforce moved into its Phase 2 in 2021. This did not change the functioning of the Group in any way.

This report has been produced by the Family Reference Group with secretariat support from Scottish Families Affected by Alcohol and Drugs. It is an independent report which does not represent the views of the Scottish Drug Deaths Taskforce. However we hope that the Taskforce and the Scottish Government will consider our reflections and recommendations to inform future developments.

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1. FAMILY REPRESENTATION ON THE TASKFORCE

Reflections

Prior to its first meeting in September 2019, Scottish Families was asked to assist in identifying a **single family member** to join the Drug Deaths Taskforce (DDTF) to represent families affected by someone else's substance use. Colin Hutcheon was approached due to his role in establishing and running peer-led family support in his local community, and his experience as a family member in engaging with policy, practice and research networks at national level. Colin is the Chair of Scottish Families, however he joined the Taskforce as an independent family representative.

Whilst **welcoming the inclusion of family representation** on the Taskforce right from the start, which is to be commended, both Scottish Families as an organisation and Colin as the named representative had significant concerns about having a single family representative on the Taskforce. How possible would it be for one person to represent all of the different situations and experiences of family members right across the country? This includes different family relationships (e.g. partners, parents, adult children, siblings etc); different ages, genders and ethnicities; different substances of concern (e.g. opiates, cocaine, benzos, cannabis etc); local experiences of family support (including no support); experiences of local treatment services; and of course families whose loved ones were still actively using substances or in recovery (or somewhere in between), or had lost their lives through substance use.

A formal request was made to the Scottish Government, including to the Minister, to ask for at least one additional family representative, but this was refused on the grounds that the Taskforce had a limited size. Some late lobbying did increase the number of other lived/ living experience representatives on the Taskforce (from one to four) prior to the first meeting, however a parallel increase was not supported for family members.

The first Taskforce meeting in Edinburgh in September 2019 included a membership list of 26 people, 21 (81%) of whom were representing professional sectors, and 5 (19%) of whom were representing people with personal experience (1 x family representative; 4 x Lived/Living Experience representatives).

We recognise that there were other members of the Taskforce with personal experience of drug use/ harm, but this was not their formal role, nor something they would necessarily disclose publicly. So **formal family representation made up just 4% of the Taskforce membership**.

Scottish Families' 'Ask the Family' research (2021¹) found that **an average of 11 people were harmed for every person using substances**, reaching across a wide range of family members and social relationships (e.g. friends, neighbours, work colleagues). This should be reflected in the relative share of lived experience representation in strategic bodies such as the DDTF.

We believe it is hard to ever achieve system reform if those in charge of any change are largely made up of those who run the existing system. Later in this report, we reflect on the ways contributions from those representing lived experience were regarded, compared to those representing professional interests.

Family Reference Group Recommendations, June 2022

- Future Commissions and Taskforces should significantly enhance the proportion of family members (and others with lived experience) within their membership, to ensure a **true co-production approach** with those most affected by the issues, and with those who have most to gain from change and improvement;
- Families should not have a **lesser place or voice** compared to others with lived experience, with family representation at least equalling (if not exceeding) those using substances or in recovery.

¹ <https://www.sfad.org.uk/ask-the-family>

2. PROGRESS AGAINST OUR FIVE IMMEDIATE ACTIONS

“What one thing would you recommend that we could do now to stem the rise in Drug-Related Deaths we are experiencing in Scotland? Prioritise any responses you receive to a maximum of 5 ideas.”

[Request from DDTF to members, for its 2nd meeting in October 2019]

This question, posed by the Taskforce prior to its second meeting, was the focus of the first Family Reference Group meeting in Glasgow in October 2019.

Unsurprisingly it was a challenging task to identify “*one thing*” for families representing a range of personal experiences and situations, and many, many years of supporting their loved ones. There was universal agreement that *many things* have to change in the immediate, medium and longer term.

Following a lengthy discussion we identified the following **top 5 immediate actions**, many of which we felt did not require additional investment, but which would require a change in culture, attitudes and collaboration.

- a) An end to the postcode lottery in treatment and care services, to ensure **equality of access**
- b) Immediate **removal of all barriers** to treatment and care for all services receiving public funds (including treatment services and community pharmacies)
- c) Immediate introduction of a **presumption of family involvement** by treatment and care services. (This means that family inclusive practice becomes an ‘opt out’ option not an ‘opt in’ option).
- d) All workers coming into contact with individuals at risk of overdose **should carry naloxone** and be trained in its use.
- e) A **national anti-stigma programme** to challenge and change stigma towards those using drugs and their families.

We were strongly of the view that Scotland should review and adopt as appropriate the **whole system recommendations** made in British Columbia and Portugal previously, rather than re-inventing the wheel.

The full description and narrative for each action is attached at Appendix 1.

This section reflects on progress against, and makes recommendations for, each one of these five immediate actions.

(a) TREATMENT AND CARE SERVICES: EQUALITY OF ACCESS

PRIORITY ACTION (a), October 2019:

An end to the postcode lottery in treatment and care services, to ensure equality of access. E.g.:

- If services in some areas (e.g. Midlothian) can offer drop-in access and same-day prescribing as an option this should be offered to all.
- If some areas offer a choice of opiate substitution therapy (e.g. methadone, buprenorphine and potentially the new Buvidal option) these should be available in all areas of Scotland. This is currently not the case, for example Ayrshire only prescribes Methadone.
- If some areas have access to rehabilitation options, including residential rehabilitation (either locally or via funding places elsewhere), this should be available everywhere. Families recognise the value of structure, detox treatment and ongoing aftercare as part of rehabilitation provision.

Reflections

Through our own geographical spread and connections across Scotland, we identified a concerning **postcode lottery of treatment and care options**. We were aware that evidence-based and progressive practices known to reduce harm and risk of drug-related death (such as drop-in appointments and same-day prescribing) were only available in a small number of local areas. Also a choice of opiate substitution therapy (OST) medication was only available in limited areas – this included access to the newer ‘Buvidal’ medication which is injected weekly or monthly. Buvidal has been described as a “*game changer*”², not least because it avoids daily pharmacy visits which are a real risk and flashpoint for individuals and families. We were also aware of significant geographical inequalities in access to funded residential rehabilitation, and to community rehabilitation options.

The inequitable access to treatment and care options for individuals causes **consequent harm to their families**, who are desperately trying to keep their loved ones safe and alive with no or limited support from services. Tackling this postcode lottery to ensure equality of access was consequently our top priority action.

At **national level** we believe there has been **good progress** since 2019 through the development and ongoing implementation of the ‘Medication Assisted Treatment (MAT) Standards for Scotland: Access, Choice, Support’³ and the work of the Residential Rehabilitation Working Group⁴. We had the chance to feed into the MAT Standards as they developed, and family views and experiences have also been shared with the Residential Rehabilitation group.

However while there has been good progress at national level through clear written standards, guidance and additional funding, families are still commonly reporting that they and their loved ones are not seeing these commitments actually being implemented on the ground. While there is good practice in some areas, for example through rapid access to treatment and clear care pathways, postcode lotteries remain clearly in evidence. The words and actions of frontline staff do not always reflect what has been agreed nationally. So **actual implementation remains a ‘work in progress’**.

Family Reference Group Recommendations, June 2022

- All Alcohol and Drug Partnerships and substance use services must **fully implement** the Medication Assisted Treatment (MAT) Standards and Residential Rehabilitation recommendations, and be held to account for this;
- Assessment of progress against these commitments should include **families’ own feedback** as to what is actually happening on the ground, not just self-assessment or self-reporting by services.

² <https://www.bbc.co.uk/news/uk-scotland-54433312>

³ <https://www.gov.scot/publications/medication-assisted-treatment-mat-standards-scotland-access-choice-support/>

⁴ <https://www.gov.scot/groups/residential-rehabilitation-working-group/>

(b) TREATMENT AND CARE SERVICES: BARRIERS

PRIORITY ACTION (b), October 2019:

Immediate removal of all barriers to treatment and care for all services receiving public funds (including treatment services and community pharmacies). This includes:

- Immediate banning of punitive sanctions regimes (including withdrawal of medication for missing appointments, which families consider is a breach of human rights);
- Immediate introduction of same day, flexible drop-in options as well as scheduled appointments to ensure person-centred choice;
- Mandatory training for all staff on drug awareness, stigma and trauma informed practice.
- Immediate removal to other duties of any staff member who does not offer a humane and compassionate service based on kindness, respect and dignity.

Reflections

Our experience is that significant **cultural change** and **service redesign** still needs to happen to realise the ambitions of the MAT Standards and Residential Rehabilitation recommendations (and ‘Rights, Respect and Recovery’ commitments), and to ensure services are truly person-centred, trauma-informed and holistic.

We are still aware of **punitive and stigmatising practice** by treatment and care services and **multiple barriers to support**. This includes a lack of drop-in and unscheduled options, very little assertive outreach, an absence of out of hours or crisis services, quick judgements by services about ‘failure to engage’ (leading to unplanned exit), and a lack of appropriate response for those with both mental health and substance use services. Together this all contributes to ‘service-generated trauma’ for individuals and families, who often already have significant levels of trauma in their lives.

We are hugely supportive of the intent and ambition of the MAT Standards and steps to improve access to residential rehabilitation. However we have some pessimism that these changes can be delivered by the same staff and services who have judged and excluded to date. **Significant cultural and attitudinal change** is needed to deliver these ambitions, which is less about resources than leadership and accountability.

We have raised **questions about accountability** for many years, and we are no clearer from the work of the Drug Deaths Taskforce as to who is accountable within alcohol and drug services when the required level of care and treatment is not delivered. For example:

- If family members come up against resistance from workers in using the MAT Standards or accessing residential rehabilitation, who do they turn to?
- Why isn’t there an independent body to address any problems, to ensure families feel safe to raise concerns, and confident that concerns will be impartially and fully investigated?

We have shared **Karen’s Story** in Appendix 2 and **A Letter from Gillian** in Appendix 3 with their permission. Karen shared her letter, expressing serious concerns about her son’s treatment and care, with the Drug Deaths Taskforce, the Minister for Drugs Policy, her own local Health and Social Care Partnership and Alcohol and Drug Partnership, as well as the local treatment service. Although her concerns were heard by all of these individuals and groups, including many people in positions of power and authority, she felt accountability for the service and system failures she raised was never resolved. Similarly Gillian wrote to the First Minister expressing her serious concerns. A reply was received but in her view was inadequate.

Family Reference Group Recommendations, June 2022

- The Drug Deaths Taskforce and National Drugs Mission should introduce **commitments around cultural and attitudinal change** in treatment and care services;
- **Accountability** for delivering national and local service standards must be clearly defined;
- An **independent body** is needed so individuals and families feel safe and confident to raise concerns.

(c) FAMILY INVOLVEMENT IN TREATMENT AND CARE

PRIORITY ACTION (c), October 2019:

Immediate introduction of a presumption of family involvement by treatment and care services. This means that family inclusive practice becomes an ‘opt out’ option not an ‘opt in’ option (defining ‘family’ in its broadest sense as ‘who matters to you?’). This is in line with the existing Quality Principle 8 (‘Services should be family inclusive as part of their practice’) introduced in 2014, and new commitments in Rights, Respect and Recovery (‘Ensure family members ... where appropriate, will be included in their loved ones’ treatment and support’) introduced in 2018. The Group members all had extensive experience of being excluded by a wide range of services when they were trying to support their loved one, and when they were trying to keep them alive.

Reflections

Despite long-standing national commitments to supporting families and involving them in treatment and care (e.g. Quality Principles (2014); Rights, Respect and Recovery (2018); Carers legislation etc), there has been **very little progress in family-inclusive practice** or the provision of **support for families in their own right** over the life of the Drug Deaths Taskforce. This is disappointing and a missed opportunity.

From our own experience, and from our conversations with other families, we know **families continue to be routinely excluded by treatment and care services**, and are **rarely offered support in their own right**. When we contact services with concerns about our loved ones, we are told there is nothing to be done unless they are engaged in the service, or give consent to our involvement. Workers cite data protection; judge and stigmatise us (including blaming us for the substance use); and treat us as interfering. Workers are also nervous to reach out to families due to a lack of local family support services on offer, and limited understanding of how to effectively and easily involve families – and the benefits this brings to all involved.

The development of the Medication Assisted Treatment (MAT) Standards initially offered the potential to include a specific **MAT Standard for Families**. We hosted an open meeting for families about the Standards, with excellent engagement from Tracy Clusker from the MAT implementation team who has done so much to champion family involvement. We are hugely supportive of the intent of the MAT Standards, as they represents many issues that we as family members have been raising over many years. However we were extremely disappointed that a specific Families standard was not included. This would have pushed forward implementation of the written commitments in the Quality Principles and Rights, Respect and Recovery. We appreciate each of the MAT Standards includes a narrative on ‘What does this mean for families?’ and we fed into this. However it is not equivalent to a dedicated standard around families. We understand that this may be reconsidered in future, and we would strongly recommend this to ensure the MAT Standards deliver their potential and improve outcomes for the whole family – as well as services.

Workforce training in Family Inclusive Practice is offered by Scottish Families, however take-up by alcohol and drug services continues to be slow due to other pressures and priorities (including implementing the MAT Standards). This training offers staff a wide range of practical tools and techniques to involve families safely and effectively, as well as a deeper understanding of the benefits of family inclusive practice to individuals, families and to services.

Family Reference Group Recommendations, June 2022

- Families must be included as **partners in care** through a presumption of family involvement, in line with national policy and legislative commitments, and similar to other long term, chronic health conditions;
- There should be **mandatory training in Family Inclusive Practice** for all staff working in alcohol and drug services;
- There should be a specific **MAT Standard for Families** including family support and involvement.
- Family members must be offered **support in their own right**, regardless of their loved one’s situation.

(d) NALOXONE

PRIORITY ACTION (d), October 2019:

The Family Reference Group consider Naloxone to be a critical part of saving lives. A number of the Group members had personal experience of their loved one's life being saved through the administration of naloxone. **All workers coming into contact with individuals at risk of overdose should carry naloxone and be trained in its use.** This includes police, fire, ambulance, prisons, housing/ homelessness, primary care and pharmacy services, as well as substance use services. Group members said that other groups such as taxi drivers and street pastors have also shown an interest in carrying naloxone and this should be pursued. The new nasal spray form of naloxone should be promoted and easily accessed to increase availability and use by families and others. The Group supported the points made by Kirstin Horsburgh from the Scottish Drugs Forum (SDF) at the first Taskforce meeting that existing commitments made in the national naloxone programme must be delivered, and barriers to implementation addressed. Any postcode lottery in naloxone provision must be removed, e.g. the group's experience was that ambulance staff in Edinburgh carry naloxone but not ambulance staff in Scottish Borders.

Reflections

During the lifespan of the Drug Deaths Taskforce there has been a **transformation in the provision of naloxone in Scotland**, and there has been **excellent progress** against this priority action. This includes the commitment by **Police Scotland** to roll out intranasal naloxone across the national force following a successful pilot;⁵ the development of a voluntary national scheme by the **Scottish Fire and Rescue Service**;⁶ and the **Scottish Ambulance Service's** ongoing programme offering naloxone kits and training to those at risk of an overdose or likely to witness an overdose, including family members.⁷

In May 2020, **Scottish Drugs Forum** supported **Scottish Families** to launch Scotland's first national '**Click and Deliver**' take home naloxone service⁸ which conveniently and discreetly delivers either injectable or intranasal naloxone kits to the homes of anyone at risk of overdose or likely to witness an overdose. This includes people using drugs, family members, professionals (e.g. taxi drivers, security guards, housing officers etc) and members of the public. Between May 2020 and March 2022, **5645 naloxone kits** were delivered to homes across Scotland via Click and Deliver. Scottish Families is the national naloxone provider for the **#StopTheDeaths 'How to Save a Life' campaign**,⁹ and is working in partnership with Police Scotland, Scottish Fire and Rescue and the Scottish Ambulance Service to supply naloxone for community referrals.

We would like to commend **Suzanne Gallagher** (Scottish Families) and **Kirsten Horsburgh** (SDF) for their creativity, tenacity and achievements in rolling out naloxone to so many family members, frontline staff, and others across Scotland. We would also like to thank the **Drug Deaths Taskforce** and **Ethypharm** for assistance in sourcing naloxone kits in the early stages of Click and Deliver, and the **Scottish Government** for funding a test of change around intranasal naloxone, and funding Click and Deliver on an ongoing basis.

Family Reference Group Recommendation, June 2022

- Existing national workforce naloxone programmes for police, fire and ambulance should be **rolled out to other occupations**, e.g. housing, public transport, and all health and social care staff.
- The national **Click and Deliver service** should be continued and widely promoted (including active promotion by all local ADPs alongside their local provision), so all those at risk of, or likely to witness, an overdose across Scotland have convenient and discreet access to naloxone kits.

⁵ <https://www.scotland.police.uk/what-s-happening/news/2022/february/police-scotland-commits-to-national-roll-out-of-life-saving-nasal-spray/>

⁶ <https://www.firescotland.gov.uk/news/2022/february/firefighters-to-carry-life-saving-naloxone/>

⁷ <https://www.scottishambulance.com/news/1-000-naloxone-kits-delivered-by-the-scottish-ambulance-service/>

⁸ <https://www.sfad.org.uk/support-services/take-home-naloxone>

⁹ <https://www.stophedeaths.com/>

(e) TACKLING STIGMA

PRIORITY ACTION (e), October 2019:

A national anti-stigma campaign to challenge and change stigma towards those using drugs and their families. All Group members had many examples of stigmatising language, attitudes and behaviours by services, by colleagues (including those working in services such as health and education) and by their wider community.

Reflections

Tackling stigma was identified as an **immediate priority** at the very first meeting of the Taskforce in 2019, with Scottish Families, Scottish Drugs Forum and Scottish Recovery Consortium asked to work together with lived experience members to progress the development of a **Stigma Strategy** as a priority.

Many families across Scotland, and Scottish Families, were involved in significant developments around stigma through the earlier **Partnership for Action on Drugs in Scotland (PADS)** Communities workstream. This included a large-scale 'Recovering Connections: changing stigma to respect' event at The Tramway (2017¹⁰); a national stigma survey, follow up exhibition, and short film 'Recovery is everyone's business' (2018¹¹). A 'Flourishing Communities' event followed in Easterhouse in 2018. The PADS structure folded with the launch of Rights, Respect and Recovery (2018), and partners continued their own work on stigma.

It was suggested that, rather than starting afresh, the Taskforce should pick up on this PADS legacy, continuing this evidence-based approach (of social contact, education and protest), and building on the previous national momentum, investment and collaboration. However there was a clear instruction by the Taskforce that a new Stigma Strategy was required, branded by the DDTF, and that it was required quickly.

We worked with Scottish Families' staff to influence the content of this Stigma Strategy, including specific content and commitments around families. As family members with significant experience of being stigmatised due to our loved ones' drug use, we were supportive of this development, and our views were listened to and included. However we wanted to see **more specific, measurable actions**, to make it real for families, and we raised questions about **who would be responsible for delivery?** This detail, leadership and accountability remained unclear. The DDTF Stigma Strategy was published in July 2020,¹² with delivery (including development of an action plan) passing to the Scottish Government. Our understanding is that there has been **little progress since** which is disappointing – in particular given the initial time pressures.

We had some challenging encounters with the Taskforce when asked to support the development of a **Stigma animation** hosted on the DDTF website (we felt the content in fact increased stigma for families); a national **Stigma Charter** and a national **anti-stigma media campaign**. With the Stigma Charter we ultimately decided to step away from any involvement at all, as our questions about accountability could not be answered. In our view there is little point having written commitments around Stigma if families don't know where to turn if these commitments are not upheld. Our experience of these projects was that families' unique experiences of stigma (including the attitudes of some public services) and our proposed changes or solutions have not always been recognised or reflected, and at times have been dismissed.

Family Reference Group Recommendations, June 2022

- An **action plan** should be developed and delivered to deliver the commitments in the national Stigma Strategy, including clear lines of responsibility and accountability;
- **Family members' unique experiences of stigma** must be reflected in programmes to tackle stigma, such as public information and campaign materials, workforce training and policy documents.

¹⁰ <https://www.sfad.org.uk/content/uploads/2018/06/PADS-Report.compressed.pdf>

¹¹ <https://www.youtube.com/watch?v=4OQgSx2C2TE&t=2s>; https://www.youtube.com/watch?v=LONmjQmCF_4

¹² <https://drugdeathstaskforce.scot/news-information/publications/policy-and-strategy/stigma-policy-and-strategy/>

3. PROGRESS AGAINST OTHER PRIORITIES FOR FAMILIES

(a) DRUG LAW REFORM

The Family Reference Group hosted an online '**Drug Law Reform**' workshop for families in March 2021, to feed into the Drug Deaths Taskforce consultation on this issue. The workshop invitation was extended to other family members via the Group's own networks and families supported by Scottish Families. There were presentations on the background and context to drug law reform (Scottish Government); national 'Drugs, the Law and You' survey findings (Crew); and the 'Drivers for Change' identified by the Criminal Justice and the Law Taskforce sub-group (which included one of the Family Reference Group in its membership). There was then a Q&A session and discussion. Ten family members (and five staff members) took part in the workshop, with another family member feeding in views afterwards.

Reflections

All family members had **personal experience of their loved one being involved in crime, criminality and the justice system** through substance use. This included multiple periods in custody (including young offenders and adult prisons), frequent police engagement, and experiences of community sentencing. None of the family members thought that their loved ones' engagement with the justice system had resulted in any positive outcomes. Indeed **justice interventions had worsened existing substance use (and mental health) issues**. Families' experiences of being excluded by treatment and care services were echoed in being excluded by the justice system, with **decisions made without any recognition of the impact on the family**. The family members strongly believed that **current laws do not act as a deterrent** to drug use. This is due to a lack of understanding of the law, but also the nature of substance use. They noted it was not necessarily drug laws in themselves, but the impact of drug use (e.g. needing funds to purchase drugs, violent behaviour due to drug use, mental health issues co-existing with drug use etc) which had caused their interaction with the justice system. In many cases, getting involved in the justice system (particularly prison) had simply opened up new drug routes, knowledge and markets, and created a progression to more serious drug use and harm. Family members shared their own experiences of getting involved in criminal behaviour, sometimes to protect their loved ones. Despite widespread awareness of the relationship between poor mental health and substance use, the justice system response did not seem to take account of this. Family members felt a '**distress**' response (including 'places of safety') would be a far more proportionate, effective and humane response than a 'crime' response in such cases. Families suggested support for reform of the Misuse of Drugs Act regarding personal possession, as this would significantly reduce the impact of crime, criminality and the justice system on their loved ones and families. However many **procedural, attitudinal and cultural changes** could happen within existing laws and resources.

Family Reference Group Recommendations, June 2022

- A **public health approach** must be embedded in the justice system for all substance-related cases;
- At every stage of the justice system, individuals should be offered **options for treatment, support and recovery** as a voluntary alternative measure or disposal;
- Decision-making throughout justice should be **trauma-informed**, including system-generated trauma;
- All **justice professionals should be trained** in substance use and mental health issues, family inclusive practice, distress identification and response;
- Police as the first responders should take a '**distress**' not '**crime**' approach to substance use;
- Family inclusive practice should be standard, including a '**presumption of family involvement**';
- Implementation of the national **Stigma Strategy** should identify particular actions for justice partners to address stigmatising attitudes towards individuals using substances and their families.

(Further discussion and a full set of recommendations is available in the full Drug Law Reform report¹³).

¹³ <https://www.sfad.org.uk/content/uploads/2021/04/210325-FINAL-Response-from-DDTF-Family-Reference-Group-to-Drug-Law-Reform-Consultation.pdf>

(b) A TEST OF CHANGE – FAMILIES AS LIFESAVERS/ HOLDING ON

The term 'Families as Lifesavers' was coined following the Glasgow drug summits held in February 2020, when a whole two days of "summit fever"¹⁴ didn't include a single voice from families harmed by others' substance use. Any mention of families was restricted to passive descriptions of bereaved families or judging 'troubled' families. This overlooked the incredible efforts of families every day to care for their loved ones, to desperately seek support for them, and to keep them alive – often with little or no assistance from formal, funded services. In our view families were playing an essential and active role as lifesavers.

When the Drug Deaths Taskforce/ Corra Foundation offered an opportunity to apply for funding for new tests of change as part of their work, we decided to develop a project to test out a new model of working with families whose loved ones were at high risk of drug-related harm, risk and death. We were successful in securing an initial post in 2020, then in securing extension funding for an additional post in 2021.

Reflections

An early decision was taken to change the project name from 'Families as Lifesavers' to **Holding On** due to concerns that the former could be misinterpreted as suggesting families' are responsible for keeping their loved ones safe and alive – never the intention. Following consultation with family members and staff, the new name 'Holding On' was chosen. This deliberately had multiple meanings – that we were holding on to family members to offer support; and that they were also desperately trying to hold on to their loved ones to keep them safe and alive, as well as trying to hold on to other aspects of their life, e.g. work, other family members, friends and so on. We aimed to reach 65 family members over the lifetime of the test of change.

Holding On¹⁵ offers family members whose loved ones are at high risk of drug-related harm, risk and death an **intensive wraparound support service**. Both one-to-one and group support are offered through a national, virtual service via telephone and Zoom. Further detail about how Holding On works is included below. Holding On is hosted by Scottish Families, with updates to the Family Reference Group including a presentation and discussion with one of the staff members and our external evaluator in July 2022.

The test of change has been **externally evaluated** by Axiom Consulting, with the final evaluation report to be published in June 2022. The learning from Holding On has been shared with the Drug Deaths Task Force and the University of Dundee's reducing drug-related harms course in September 2021; via a Scottish Families webinar to mark 'A Year of Holding On' in December 2021;¹⁶ and at the Drug Research Network Scotland conference in June 2022. Holding On families shared their experiences as part of our response to the drug-related death statistics in July 2021.¹⁷ Scottish Families has delivered multiple presentations about Holding On to staff teams (e.g. local overdose response teams and community-based services) and other meetings and events, and is planning to release a short film in 2022 called 'A Day in the Life of Holding On'.

Holding On has resulted in a huge amount of learning for Scottish Families as an organisation, and for organisations who come across families in their work, including alcohol and drug services, about what works in terms of supporting families where there is a high level of drug-related risk, harm and death:

- Most family members were **not receiving any support for themselves** prior to engagement with Holding On, and had been unable to find information about family support previously, including via online searches and services such as GPs. For some, this situation had been ongoing for decades;
- Family members had extensive experience of their **loved ones not getting the support they needed** from substance use, mental health services and other key services;

¹⁴ <https://www.sfad.org.uk/catching-a-dose-of-summit-fever-and-trying-to-find-a-cure>

¹⁵ <https://www.sfad.org.uk/support-services/one-to-one-support>

¹⁶ View the webinar at <https://www.sfad.org.uk/a-year-with-holding-on-webinar>

¹⁷ <https://www.sfad.org.uk/families-holding-on-to-hope-as-drug-death-toll-continues>

- External services, including specialist overdose response teams, have been **extremely slow to refer to Holding On** (despite repeated promotion). This suggests services do not 'see' families, with most referrals coming from within Scottish Families (e.g. Helpline, Telehealth service, local services);
- Holding On identified **significant and serious mental health issues for family members**, including suicidal thinking, due to the pressure of living with their loved one's substance use. However family members were reticent to seek support for their own mental health, as they could see their loved ones were not able to access mental health support, and considered them to be even more unwell;
- The Holding On model includes many of the components of Scottish Families wider virtual support services, however it is delivered in a 'little and often' way, and is more unpredictable due to the **chaotic nature of family life** (influenced by the chaotic nature of their loved ones substance use);
- This level of chaos and unpredictability also **changed our evaluation approach**, as progress for family members was far from linear (with their situation – and feelings about this – fluctuating on a daily or even an hourly basis), and it was unrealistic to expect them to prioritise research interviews or questionnaires over other immediate needs;
- It is difficult for family members to get privacy or peace for support calls, or to make any regular commitments whilst **juggling so many interruptions and competing demands** and not being supported by their loved ones to protect any time for themselves;
- Staff have persisted to build **trust and relationships** with family members and to secure and sustain ongoing engagement in support. This includes welcoming families back into support if they have taken a break due to overwhelming competing demands on their time. There is no time limit on support from Holding On, which was really appreciated by families;
- Family members **connect with, and support, each other** via an online Holding On group and WhatsApp group. The online group is facilitated by staff and the WhatsApp group includes staff but it is not moderated by them. It has been positive to see peer relationships develop and strengthen;
- Families have learned more about **harm and risk** for their loved one, and how to reduce this, but they have also developed a better understanding of the harm and risk the family members are facing through their loved ones substance use – and how to reduce this too;
- **One to one support** is also essential, whether or not family members engage with group support. The complex nature of their family situation requires one to one support to fully understand and respond each unique set of circumstances, and some families do not want to join a group setting;
- Holding On has achieved **life-changing and transformational change for family members** through this empowering model of support, including positive communication and engagement, boundary setting, advocacy, self care, connection with others, harm reduction and recognising a way forward for the future, whether or not their loved one recovers. What may look like small changes from the outside in fact signify massive changes to family relationships and whole family wellbeing.

A full evaluation report, including detailed case studies and feedback from families, will be published in June 2022. Scottish Families plans to embed Holding On in its core service provision for families following the end of the Test of Change funding.

Family Reference Group Recommendations, June 2022

- Commissioners and funders must recognise the **life-changing and transformational impact** of evidence-based support for families, even where the harm has been present for many years;
- Families should always have access to **high quality family support** in their own right, no matter where they live, and regardless of whether their loved one is engaging (or wants to engage) with treatment, care or recovery. This should be **properly funded and widely promoted**.
- Referrals to family support should be embedded in all **Non Fatal Overdose (NFO) Pathways**, with assertive outreach to individuals experiencing overdose automatically extending to their families;
- Support for families should **not be time-limited**, including where their loved one recovers, and should be designed to respond to **levels of chaos and unpredictability** within some families;
- The **severe and enduring mental health impact for families** affected by a loved one's drug use must be recognised by health and support services – and that family members of those at risk of drug-related harm and death face **equivalent levels of harm and risk**.

(c) THE INFLUENCE AND IMPACT OF LIVED EXPERIENCE

At the first meeting of the Taskforce, the then Minister for Public Health, Joe Fitzpatrick, welcomed the recently appointed additional **lived experience representatives** to the meeting. (There had been a hasty addition of three further members to add to the one original lived experience member and the one family member on the group). The minute of the meeting notes very positively:

“The addition of three further individuals with lived experience to the taskforce was welcomed by Mr Fitzpatrick. The importance of listening to lived experience, acknowledging their experience of services, pathways and processes and how this might help avoid unintended consequences, while aiding service design, was also addressed by the minister.”¹⁸

However the **involvement** of people with lived experience (including families) in the work of the Taskforce has not necessarily equalled **influence**.

Reflections

As noted earlier, from the start of the Taskforce there was a seat (albeit one seat) around the table for families, as well as for four individuals with lived experience of drug harm. We have had very **good engagement** in the main Taskforce meetings, through Colin Hutcheon as our representative strongly advocating and speaking up for families throughout. At the meetings he has always been encouraged to feed in families’ views and experiences, and this is positive.

We were also invited as members of the Family Reference Group to get involved in the wider work of the Taskforce, through joining numerous **sub-groups**. Interestingly there had been no consultation with families or others with lived experience about the sub-group themes – they were announced at the first meeting. A suggestion that there could also be dedicated sub-groups around recovery, lived experience and families was hastily dismissed, on the grounds these would be themes running through all sub-groups. We nominated ourselves onto the different sub-groups at an early stage. However it took some time before we were actually included in some of the sub-groups (which we will put down to a communication breakdown at Scottish Government/DDTF level).

In practice, **few adjustments or accommodations** seemed to be made for family members, and others with lived experience, to actively participate in what were professional-led sub-group meetings (undoubtedly daunting and overwhelming for some). For example meetings were sometimes held at short notice; we were missed off the mailing list; there was no understanding that we may have other responsibilities to juggle (e.g. paid work, caring responsibilities, and for some of us the unpredictability of ongoing substance use within our families); and complex or large documents were emailed to us, with little in the way of time to digest, or interpretation or explanation as to the content or meaning. As a result, some of us didn’t ever manage to get involved in the work of our allocated sub-group, or had to step down due to other pressures, whilst others did manage to play an active and very involved role.

The arrival of COVID and all **meetings moving online** from Spring 2020 was a mixed blessing. In some respects this made engagement easier (for example at full Taskforce meetings, Zoom proved very democratic, with all members having the same sized square on the screen) and there was no need to travel to meetings. However online meetings are not for everyone, and so for some of us this proved a barrier to getting involved. We had been scheduled to host a family-focused, in-person Taskforce meeting in March 2020. We had an engaging and challenging agenda planned, focusing not on powerpoint presentations or written materials, but on live, face-to-face and real time conversations between family members and other partners. Unfortunately this meeting was postponed in March 2020 and was eventually abandoned due to

¹⁸ <https://drugdeathstaskforce.scot/our-work/meeting-minutes/meeting-minutes-2019/meeting-1-17-september-2019/>

the ongoing pandemic. A families agenda item was eventually included on the Taskforce agenda in September 2021, but on a much smaller scale and with more of a service focus (with presentations on Holding On, family inclusive practice and Click and Deliver naloxone).

As a Family Reference Group, we have had **significant opportunities to engage** with researchers, policy-makers, politicians and practitioners in our own right, to discuss developments of interest to families, and to feed in our views. This includes developments within and outwith the Taskforce:

- We engaged with teams working on the MAT Standards; the national drug-checking project; naloxone in hospitals; the National Drug-Related Deaths Database (including working with Police Scotland to agree changes to the way families are involved and informed following a drug-related death); the Reducing Harm, Improving Care Project (Health Improvement Scotland); the Mental Welfare Commission review of dual diagnosis; and the National Collaborative for Lived and Living Experience. We extended some of these conversations to include a wider group of family members.
- We met with journalist Karin Goodwin to share our experiences of drug-related harm and deaths, which she reflected in a published article.¹⁹
- We had a constructive meeting with Angela Constance as Minister for Drugs Policy, where she recognised how much is expected of families by services and systems, but with little support given in return; the tension between asking families to share their experiences and have a voice but feeling nothing changes as a result; issues around services supporting people with complex needs; and a lack of accountability within the system.
- We informed formal responses to consultations on the MAT Standards (unpublished), Independent Review of Adult Social Care,²⁰ Drug Law reform,²¹ and the Right to Recovery Bill.²²

Throughout the life of the Taskforce, we have been physically round the table from the start and have been listened to, but there have been multiple occasions where **we feel we have had to shout for families** to truly be recognised, and for our views and experiences to be seen as equally valid to professionals' views.

So we have been included, but **at times we have struggled to see our influence or impact** – how much has changed as a result of what families have said, compared to professionals' views? Arguably the family theme may thread through everything, however 'everywhere' can feel like 'nowhere' – inspiring the name of this report. We did have the opportunity to actively engage in the drafting of the final DDTF report, which was welcome, including the chance to influence and strengthen the family commitments.

Family Reference Group Recommendations, June 2022

- Family members should always be included as **equal partners from the start**;
- **Additional measures are required** to effectively involve family members in formal improvement bodies, such as taskforces, including recognition that many will be juggling involvement with a number of other priorities (including care or concern for others);
- There must be a **commitment to act on families' advice and recommendations**, not just listen to their views. Otherwise the involvement of lived experience looks like a 'tick box' exercise rather than a way to inform changes and improvements.
- Families should be actively involved in the design, development and delivery of the **new National Collaborative of Lived and Living Experience**.

¹⁹ <https://theferret.scot/families-fighting-save-lives-drug-deaths/>

²⁰ <https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2021/02/independent-review-adult-social-care-scotland/documents/evidence-submissions-volume-4/evidence-submissions-volume-4/govscot%3Adocument/evidence-submissions-volume-4.pdf>

²¹ <https://www.sfad.org.uk/content/uploads/2021/04/210325-FINAL-Response-from-DDTF-Family-Reference-Group-to-Drug-Law-Reform-Consultation.pdf>

²² <https://www.sfad.org.uk/content/uploads/2022/01/220112-Right-to-Recovery-Bill-Response-SFAD-FINAL-SUBMITTED.docx>

4. SUMMARY OF FAMILY REFERENCE GROUP RECOMMENDATIONS, JUNE 2022

1. FAMILY REPRESENTATION ON THE TASKFORCE – RECOMMENDATIONS

- Future Commissions and Taskforces should significantly enhance the proportion of family members (and others with lived experience) within their membership, to ensure a **true co-production approach** with those most affected by the issues, and with those who have most to gain from change and improvement;
- Families should not have a **lesser place or voice** compared to others with lived experience, with family representation at least equalling (if not exceeding) those using substances or in recovery.

2. PROGRESS AGAINST OUR FIVE IMMEDIATE ACTIONS – RECOMMENDATIONS

(a) TREATMENT AND CARE SERVICES: EQUALITY OF ACCESS

- All Alcohol and Drug Partnerships and substance use services must **fully implement** the Medication Assisted Treatment (MAT) Standards and Residential Rehabilitation recommendations, and be held to account for this;
- Assessment of progress against these commitments should include **families' own feedback** as to what is actually happening on the ground, not just self-assessment or self-reporting by services.

(b) TREATMENT AND CARE SERVICES: BARRIERS

- The Drug Deaths Taskforce and National Drugs Mission should introduce **commitments around cultural and attitudinal change** in treatment and care services;
- **Accountability** for delivering national and local service standards must be clearly defined;
- An **independent body** is needed so individuals and families feel safe and confident to raise concerns.

(c) FAMILY INVOLVEMENT IN TREATMENT AND CARE

- Families must be included as **partners in care** through a presumption of family involvement, in line with national policy and legislative commitments, and similar to other long term, chronic health conditions;
- There should be **mandatory training in Family Inclusive Practice** for all staff working in alcohol and drug services;
- There should be a specific **MAT Standard for Families** including family support and involvement.
- Family members must be offered **support in their own right**, regardless of their loved one's situation.

(d) NALOXONE

- Existing national workforce naloxone programmes for police, fire and ambulance should be **rolled out to other occupations**, e.g. housing, public transport, and all health and social care staff.
- The national **Click and Deliver service** should be continued and widely promoted (including active promotion by all local ADPs alongside their local provision), so all those at risk of, or likely to witness, an overdose across Scotland have convenient and discreet access to naloxone kits.

(e) TACKLING STIGMA

- An **action plan** should be developed and delivered to deliver the commitments in the national Stigma Strategy, including clear lines of responsibility and accountability;
- **Family members' unique experiences of stigma** must be reflected in programmes to tackle stigma, such as public information and campaign materials, workforce training and policy documents.

3. PROGRESS AGAINST OTHER PRIORITIES FOR FAMILIES – RECOMMENDATIONS

(a) DRUG LAW REFORM

- A **public health approach** must be embedded in the justice system for all substance-related cases;
- At every stage of the justice system, individuals should be offered **options for treatment, support and recovery** as a voluntary alternative measure or disposal;
- Decision-making throughout justice should be **trauma-informed**, including system-generated trauma;
- All **justice professionals should be trained** in substance use and mental health issues, family inclusive practice, distress identification and response;
- Police as the first responders should take a **'distress' not 'crime' approach** to substance use;
- Family inclusive practice should be standard, including a **'presumption of family involvement'**;
- Implementation of the national **Stigma Strategy** should identify particular actions for justice partners to address stigmatising attitudes towards individuals using substances and their families.

(Further discussion and a full set of recommendations is available in the full Drug Law Reform report²³).

(b) A TEST OF CHANGE – FAMILIES AS LIFESAVERS/ HOLDING ON

- Commissioners and funders must recognise the **life-changing and transformational impact** of evidence-based support for families, even where the harm has been present for many years;
- Families should always have access to **high quality family support** in their own right, no matter where they live, and regardless of whether their loved one is engaging (or wants to engage) with treatment, care or recovery. This should be **properly funded and widely promoted**.
- Referrals to family support should be embedded in all **Non Fatal Overdose (NFO) Pathways**, with assertive outreach to individuals experiencing overdose automatically extending to their families;
- Support for families should **not be time-limited**, including where their loved one recovers, and should be designed to respond to **levels of chaos and unpredictability** within some families;
- The **severe and enduring mental health impact for families** affected by a loved one's drug use must be recognised by health and support services – and that family members of those at risk of drug-related harm and death face **equivalent levels of harm and risk**.

(c) THE INFLUENCE AND IMPACT OF LIVED EXPERIENCE

- Family members should always be included as **equal partners from the start**;
- **Additional measures are required** to effectively involve family members in formal improvement bodies, such as taskforces, including recognition that many will be juggling involvement with a number of other priorities (including care or concern for others);
- There must be a **commitment to act on families' advice and recommendations**, not just listen to their views. Otherwise the involvement of lived experience looks like a 'tick box' exercise rather than a way to inform changes and improvements.
- Families should be actively involved in the design, development and delivery of the **new National Collaborative of Lived and Living Experience**.

²³ <https://www.sfad.org.uk/content/uploads/2021/04/210325-FINAL-Response-from-DDTF-Family-Reference-Group-to-Drug-Law-Reform-Consultation.pdf>

APPENDIX 1

THE FAMILY REFERENCE GROUP'S 5 IMMEDIATE ACTIONS FOR THE DRUG DEATHS TASKFORCE

October 2019

- 1. An end to the postcode lottery in treatment and care services, to ensure equality of access.** For example:
 - If services in some areas (e.g. Midlothian) can offer drop-in access and same-day prescribing as an option this should be offered to all.
 - If some areas offer a choice of opiate substitution therapy (e.g. methadone, buprenorphine and potentially the new Buprenorphine option) these should be available in all areas of Scotland. This is currently not the case, for example Ayrshire only prescribes Methadone.
 - If some areas have access to rehabilitation options, including residential rehabilitation (either locally or via funding places elsewhere), this should be available everywhere. Families recognise the value of structure, detox treatment and ongoing aftercare as part of rehabilitation provision.
- 2. Immediate removal of all barriers to treatment and care for all services receiving public funds (including treatment services and community pharmacies).** This includes:
 - Immediate banning of punitive sanctions regimes (including withdrawal of medication for missing appointments, which families consider is a breach of human rights);
 - Immediate introduction of same day, flexible drop-in options as well as scheduled appointments to ensure person-centred choice;
 - Mandatory training for all staff on drug awareness, stigma and trauma informed practice.
 - Immediate removal to other duties of any staff member who does not offer a humane and compassionate service based on kindness, respect and dignity.
- 3. Immediate introduction of a presumption of family involvement by treatment and care services. This means that family inclusive practice becomes an 'opt out' option not an 'opt in' option** (defining 'family' in its broadest sense as 'who matters to you?'). This is in line with the existing Quality Principle 8 ('Services should be family inclusive as part of their practice') introduced in 2014, and new commitments in Rights, Respect and Recovery ('Ensure family members ... where appropriate, will be included in their loved ones' treatment and support') introduced in 2018. The Group members all had extensive experience of being excluded by a wide range of services when they were trying to support their loved one, and when they were trying to keep them alive.
- 4. The Family Reference Group consider Naloxone to be a critical part of saving lives.** A number of the Group members had personal experience of their loved one's life being saved through the administration of naloxone. **All workers coming into contact with individuals at risk of overdose should carry naloxone and be trained in its use.** This includes police, fire, ambulance, prisons, housing/homelessness, primary care and pharmacy services, as well as substance use services. Group members said that other groups such as taxi drivers and street pastors have also shown an interest in carrying naloxone and this should be pursued. The new nasal spray form of naloxone should be promoted and easily accessed to increase availability and use by families and others. The Group supported the points made by Kirstin Horsburgh from the Scottish Drugs Forum (SDF) at the first Taskforce meeting that existing commitments made in the national naloxone programme must be delivered, and barriers to implementation addressed. Any postcode lottery in naloxone provision must be removed, e.g. the group's experience was that ambulance staff in Edinburgh carry naloxone but not ambulance staff in Scottish Borders.
- 5. A national anti-stigma campaign to challenge and change stigma towards those using drugs and their families.** All Group members had many examples of stigmatising language, attitudes and behaviours by services, by colleagues (including those working in services such as health and education) and by their wider community.

Overall the Family Reference Group members were strongly of the view that Scotland should review and adopt as appropriate the whole system recommendations made in **British Columbia** and **Portugal** previously, rather than re-inventing the wheel.

The Group also requested that the Taskforce:

- Discuss options for **community-based drug-testing services** (as are prevalent at festivals) as there was a view that these should be easy to access outwith a festival environment to keep people safe.
- Carry out a **full audit of funds allocated to Alcohol and Drug Partnerships (ADPs)**. The Group members believe that 100% of the funds allocated at Scottish Government level to ADPs are not in fact invested in local alcohol and drug support (across treatment, care and recovery), with varying percentages retained by NHS Boards rather than being passed to Alcohol and Drug Partnerships for investment. This is reducing the ability of local ADPs to respond to local need, including reducing drugs deaths, and also reduces their ability to be accountable for all funds which are passed to them by the Scottish Government.

APPENDIX 2: KAREN'S STORY

As a mother of a heroin addict who is now in recovery with no support from addiction services and a fight at every twist and turn or hurdles to continually jump over. I am tired of fighting to keep my son alive. My son Lee has been involved with drugs since the age of 14 and is now 33. I have had enough misery to last me a life time. My son has been involved with addiction services for 9 years and this was also a turning point in his life as to come off methadone. All they have done for him is keep him on Methadone and valium. At one point he was prescribed 120ml of meth and 10 yellow valium per day every day. Why there was need for this i do not know. His worker quoted ' all we have done is keep you on Methadone we have done nothing else for you. How would you feel about going to Turnaround in Paisley for 6 weeks' to which he jumped at the chance as there was no problem with benefits and housing issues. This was his turnaround in life but was disappointed that his worker did not turn up for his exit review. He decided after leaving Turnaround that he would reduce his methadone as he felt his body was telling him that he no longer needed the amount prescribed to him as it was making him feel sick. I attended his appointment with him at the addiction service after his release from Turnaround and he stated to his worker that he wanted to reduce 30ml from 110ml to 80ml. Worker said it was a large amount but my son was adamant that this is what he wanted and should be supported to do so. Worker said she would go see if a prescriber was available but returned and said he didn't have time. I found this to be a shocking attitude. Is it not for services to get people stabilized and then reduce their methadone and be continually supported to do so? Anyway worker stated that Lee should ask for a measuring cup on attending chemist on the following day. Take 80ml and give the pharmacist the 30ml back and continue to do this for 2 weeks and see how it goes. Lee attended the chemist on the Thursday with no issues but on the Friday he phoned me in the afternoon in a panic stating the pharmacist told him there was no script for him. I arrived at the pharmacy asking what the problem was and was told that there was no script for Lee. I stated that there was and were phoned from the addiction service on the Wednesday regarding the procedure and she just shrugged her shoulders. I stated that she should take heed of the notice regarding behaviour on the door of the meth room. I phoned the addiction service regarding this issue and the worker phoned me back saying he would sort it. A different support worker came to the chemist and Lee stated that she was probably picking his old script up. Pharmacist then stated it would be another 15 mins. Guy came in the chemist handed over script and walked straight back out and Lee told me that it was his worker. He never acknowledged myself or my son. Lee then received his methadone after a 2hr wait. Lee also stated that hadn't I intervened he would probably went out and used and ended back down the slippery slope of drugs misery. All this could have been easily avoided had the prescriber done a new script instead of the power trip. Professionals have no right to abuse their power. There's only one God and they're not it!!! Why does it take a family member to sort things out? Why are people with addiction issues not listened to?

My son also has never been in jail which is a rarity for a heroin addict for 15 years. However he did get community service and yet again had to jump over hurdles to get his methadone on the Monday night to enable him to get to community service on the Tuesday morning at 8.45am (chemists don't open til 9am). I asked to speak to a worker regarding my sons recovery and was told 'no this is not a drop in centre' so once again went down the complaint route as this was hindering my sons recovery. The reason they gave for not giving him his meth on the Monday night was that he hadn't seen a worker for x amounts of months. His worker was on long term sick and no one had bothered to allocate him another worker so yet again through no fault of his own.

He was also asked to sign a waiver (after being at chemist for over a year) at the chemist to say that he would not bring anyone in with him when he was attending for his Methadone. I challenged Boots on this as my son and I both felt this was discriminating and stigmatising him for being an addict. Pharmacist stated that I could imagine if 10 people were in receiving their medication and they brought someone with them the shop would be too busy. I replied 'well I'm sure you can appreciate 10 Joe Bloggs in collecting their medication with a friend. Are they asked to sign a waiver?'. There was no reply. She stated that she wanted to continue to support Lee and I said that Lee needs continual daily family support so would he be penalised for bringing someone with him. She said 'No'. Then why the need for the waiver?

I have been supporting my son regularly for the past 2 years since he returned from Turnaround in Paisley.

He has been asking for a suboxone detox since last year and was told when he got to 50ml then it would happen but again the goal posts have been moved. He was so fed up with services after being in them for 9 years he took it upon himself to not return to chemist or services. His friend M was also put off 55ml of methadone for no reason so the two of them are supporting each other staying 2 days at one house then the following 2 days at the other. They have also been buying df's to get them over the rattling off meth. My son Lee now has the determination of having a voice, largely due to family support, that he does matter. He is a human being and is rebuilding his life slowly with no thanks to services. He was also confident enough to make his own complaint as to why he was put back on a daily script and not notified about it til he got to the chemist. As a result of this complaint it was decided that clients will be notified prior to any change in scripts therefore why was this not implemented in the case of M (who is also a family friend) and is my sons friend? Why did a doctor sanction this that had no dealings with this client?

I got so fed up with no family support since our local support project received no more funding that I decided along with my friend J, we would start a support group for families as there was no where for them to go. This is my therapy as we are all in the same boat regarding being on the receiving end of addiction. Yet again its a fight to be supported from anyone at local level. Aren't services to be family inclusive? it would serve services well to start from within regarding stigma, respect, treatment of people and listening to what choices people wish to make for the better and if we all worked together instead of against each other it would better serve the community.

I am also very proud of my son and what he has achieved in the last 2 years with very little help or support from services. However he has continually used family support of myself, his brother and sister, gran, papa and auntie. He also has no intention of returning to services. I hope he is well enough to come out the other side of this experience and be able to voice how treatment of services affected his decisions that he chose to make. He would also like to make sure that there is a change in services for the better and the same does not happens to others.

Unfortunately he did not come out the other end successfully. He never realised that the withdrawals from Methadone are horrendous. It is easier to come off heroin than methadone. He ended up back down the slippery slope of heroin addiction in which he hurt himself jaggng his groin as he has no other usable veins left. He got an abscess which luckily enough subsided itself. He was suicidal that he texted me to let me know of his suicidal thoughts but hasn't got the balls to do it (I already have a family member commit suicide 28 years ago). Not a nice place for a mother and son to be in. Due to his mental health state he phoned our local mental health unit to ask the criteria for being admitted and was told they take people with addiction issues to drugs or alcohol or mental health but he would need a referral from his GP. He arranged an emergency app with his GP to which i attended also, which the minute you mention addiction issues the barrier goes up, plus the gp was very arrogant and spoke over us quite a lot. Its not his place to judge. He stated ' I can't refer you there. I can only refer you to the psychiatrist and he decides whether you get in or not'. Yes that is what we are here for. He said he would also refer my son to the crisis team. 4 months on there has been no communication from either the unit or the crisis team and ye wonder how people are dying?

Lee's GP had also re-referred him back into services the first week in June where he was assessed and was not to see the doctor til the middle of September- 12 weeks later and yet again you wonder why people are dying? Fortunately he involved his cousin who is on the council and a short time later he was given an app for 2 weeks later. Why does it take a family member to intervene? Met with the doctor on the 26th of July '19 and Lee was restarted on 20ml of methadone to which he was pleased about as he didn't need to inject anymore. The doctor told him he would discuss Lee at the meeting on Monday morning regarding getting a new worker as his worker is going on maternity leave. His worker had told him at his app in first week in June that she would have a meeting with Lee to introduce him to his new worker before she went on maternity leave. Yet again this has failed to happen and no one from services has got back to him to say if he has a new worker or not. Again chaotic and letting people down.

I've had a meeting with the head of the Health and Social Care Partnership and also the lead clinician of addiction services and both admitted they have got it wrong regarding myself and my sons treatment within services, so my question to you is ' WHAT ARE YOU GOING TO DO ABOUT IT?' There is currently a

crisis with drug deaths escalating every year. What are you prepared to do within services to help me keep my son alive? Services are keeping people addicted. Not everyone wants to be on methadone for the rest of their lives. My son for one does not. Why is there no treatment facilities for people wishing to come off methadone? There is only Turnaround in Paisley and you have to have commit crime to access it as its through the criminal justice system therefore in order for my son to return to this facility he will have to commit a crime or offence.

As a mother I am fed up talking and telling the same story time and time again. I have been telling the same story for 2 years and badgering services for change but I know its not their fault. Its you lot at the top of the tree. You might have brains but no common sense. Its time you started listening to the families with lived experience as the Roads to Recovery never worked since the day and hour it came out. Now you have Rights, Respect and Recovery, to which its supposed to be family inclusive, and that is not being implemented at local level either!! Why is that?

Here when you phone addiction services, messages are not being passed on. They keep saying there is a problem with the phone lines but make no attempt to sort the issue. People accessing these services are being made to travel all over the area to appointments as they have no central clinic. People with addiction issues are already chaotic they dont need the chaos of the services added into the mix.

Addiction services are proud of the fact they have a 3 week referral process but then its another 12 weeks to be seen by a doctor to get a methadone script. This is not good enough and if you wish to compare it to your statistics then that would mean that 15 loved ones have died in the 15 weeks waiting to go through this process. Not good enough and its not rocket science to work out. Treatment has to be done within the week like in Midlothian so why not here? Get people stable and then work on the issues as to why they take drugs in the first place. Give them a care plan also as I was told there are none within our addiction services. Every other service has a care plan so why not in this service? Why is methadone the only option available within services?

It also concerns me that prescriptions are done generically. Addiction services generate a 1000 a month. Therefore anyone that wishes to reduce their methadone intake has to wait til the next script change at the 28th of the month. Again this is keeping people on high doses needlessly. This has to change. When people are ready to reduce it has to be done when they decide not when its convenient for services. This in not a person centred approach at all!! My son reduced 3 times in 18 months and each time had to wait til the script change apart from the first reduction mentioned in a previous paragraph. He was also continually asked if he wanted to go back up to his original amount and each time said NO. What is wrong with addiction workers. I just wish they would support people in their choices of recovery. Whilst they might not like their choices they are there to support no matter the choice.

My last paragraph is regarding the fore mentioned M who is no longer with us. He was found dead in his mother and father's living room on return from their holiday. He had been lying for a few days. There has to be a post mortem and probably a toxicology report to establish the cause of death. I personally don't care what the cause of death is as had he not been put off his methadone in February (by a consultant who had no dealings with him or had ever met him) this boy would still have been alive and not returned to the slippery slope of heroin and other street drugs, which ultimately led to his premature death. He also refused to return to services as he was treated with no respect or dignity. This was my son's best friend and is distraught at the fact he will never see him again and will need bereavement counselling offered through Scottish Families. There is also 2 kids left without a dad. A mother and father without a son, brothers and a sister left without a brother. So terribly sad. When will you wake up and start putting changes in place to stop unnecessary deaths? Services are failing people.

I refuse for my son to be another of your so called statistics. We need a change and we need it NOW!!!

Karen

APPENDIX 3: A LETTER FROM GILLIAN

From: **Gillian (Family Member)**

Date: Fri, 18 Dec 2020, 09:25

Subject: Spiralling drug deaths.

To: <Nicola.Sturgeon.msp@parliament.scot>

Morning Nicola. I feel I need to send you this after the news on the deaths. I am a 41 year old single mother of a 20 year old son. Anyway, I just want you to hear a bit of my experience of what is going on where I live. My son at 17 started taking Xanax, which he bought so cheap on the streets. My life was then made an absolute misery for the next 2 years. He smashed up my house, I now have holes in every wall in my house. He would have all his friends in, bouncing about my house till all hours, mind I was up at 5.30am for a 12.5 hour shift as I work with NHS. I hated my son at times as these drugs turned him into a monster. At 18 he ended up in severe trouble with the police through his drug taking. I had to watch my baby boy being handcuffed and taken out the house because when he wasn't on these pills he was back to being my fantastic baby boy. So, optimistically thinking that this was maybe the turning point in his life, the drug use continued with STREET VALLIES now in the mix. Bearing in mind my son had phoned 111 a few days before, telling them that he felt as if he was going to do something bad. I had phoned his GP, alcohol and drug services, to which we never heard back from! Moving onto the morning of Monday April 8th 2019. I, again was going to work on 2 hours sleep and I found my son unresponsive. We were blue lighted to hospital where I was told that he couldn't maintain his airway shortly after arrival, that I had saved his life and he was being intubated and moved to Intensive Care to fight for his young life. I asked the nurse if my boy was going to die. We don't know was the answer because if he physically survived he could be severely brain damaged! To sit beside your son and see his chest rise and fall and to think at least he's breathing, then to hear a click and you are brought back to realisation that it's actually a machine that's doing it for him! I sat and held his hand and continually asked him to open his eyes, as I sat there in my NHS uniform. I'm used to helping others. My son very luckily survived, he was discharged, straight from intensive care the following day with no aftercare/advice. I was on my own again. Which followed was a horrendous week of psychosis. We walked out of that hospital with no one to help him apart from me. So again, I was on my own with no one to help. I tried alcohol and drug services over and over to no avail. One day he was so suicidal, as that's what these drugs do to you, I called them in tears asking for help as he was going to kill himself and I couldn't cope with that as I had already nearly lost him, to which I was told over the phone, YOUR SON IS AN ADULT, HE MAKES HIS OWN CHOICES! Again, I was on my own but i kept working whilst going through court appearances with my son to which again, I was terrified as I couldn't have him leave me again. So he now has a criminal record which means he can't get a job so the drugs continue through boredom and only me to help. I am now off sick from work as I now have PTSD, Anxiety and Panic. I can't leave my house in case my son dies! I have a councillor who referred me to Scottish Families of drugs and Alcohol. These are the most amazing people I have ever met. I wanted to share my story with you, I don't know if you will read it but I hope you do because the problem with the drug deaths is the fact that there is no proper help for them. The services are geared up for heroin users and addicts. They don't understand Benzos. I am now taking a 12 week course with Scottish Families on understanding drug abuse and the people that I have spoken to that can't get help for their family members is atrocious. Many young people are losing their lives unnecessarily as the services don't communicate and the help just isn't there for us. Unfortunately it then falls to families which in turn is ruining full families. I really hope you read and listen to what im saying as things need to change. Thank you for taking the time.

Gillian.

Scottish Families Affected by Alcohol and Drugs is a national charity which supports anyone concerned about someone else's alcohol or drug use in Scotland. We give information and listening support to many people and help them with confidence, communication, general wellbeing, and we link them into local support. We also help people recognise and understand the importance of looking after themselves.

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