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Criminal Justice; Health, Social Care and Sport; and Social Justice and Social Security Committees

Wednesday, 22 March 2023

Reducing drug deaths in Scotland and tackling problem drug use

Written submissions

1. To assist Members with this session, the witnesses were asked to provide written evidence on the implementation of the proposals to tackle drugs deaths in Scotland and what more should be done.
2. Written submissions were received from the following (see **Annex**):
 - Aberlour – Cowan Grove
 - Scottish Families Affected by Alcohol & Drugs

Clerks to the Committees
March 2023

Aberlour Evidence to Scottish Parliament Cross-Committee on Tackling Drugs Deaths and Drug Harm

March 2023

About Aberlour

Aberlour is Scotland's largest, solely Scottish children's charity. We work with vulnerable, marginalised and discriminated against children, young people and families throughout Scotland, providing services and support in communities around the country. We help to overcome significant challenges including the impact of drugs and alcohol on family life, growing up in and leaving care, poor mental health, living with a disability, or the impact of poverty and disadvantage. We aim to provide help and support at the earliest opportunity to prevent problems becoming intractable or spiralling out of control. We are committed to #KeepThePromise and to the incorporation of the UNCRC.

Introduction

Scotland has the highest rate of drug related deaths in Europe, with most recent statistics showing the number of drug related deaths of women has risen¹. Women with substance use issues are at significant risk in the perinatal period, including as a result of suicide. Too many women experiencing substance use issues are having their children taken into care. Many will not approach or engage with support agencies due to the fear of their children being removed.

The Confidential Enquiry into Maternal Deaths report evidenced that women with substance use issues are at significant risk in the perinatal period, including suicide and physical health complications. The report stated that for a significant proportion of these women who die in the perinatal period: *'their deaths are closely associated with child protection proceedings or the removal of a child into care'*.²

Through our work we see the impact of problem drug use on families every day and recognise that for too many families the support available does not meet their needs. We believe that the provision of rehabilitation and recovery services for mothers and their children which allows families to remain together is essential to further prevent drug related deaths of mothers during and after the perinatal period.

¹ <https://www.nrscotland.gov.uk/files/statistics/drug-related-deaths/21/drug-related-deaths-21-report.pdf>

² <https://www.npeu.ox.ac.uk/assets/downloads/mbrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202019%20-%20WEB%20VERSION.pdf>

Until 2015, and prior to the national mission to reduce drugs deaths in Scotland, Aberlour delivered a residential rehabilitation and recovery service for mothers and their children living in Glasgow. The service closed in 2015 due to a lack of funding. However, we have seen drugs deaths rise significantly across Scotland since then, including in Glasgow. Our knowledge and experience of delivering such a service has given us clear insight and evidence that such services work and are needed and that they must be part of the framework of treatment and recovery services for women and their families living with addiction across Scotland.

In a recent study published for the National Library of Medicine – ‘Why are drug-related deaths among women increasing in Scotland? A mixed-methods analysis of possible explanations’ (Tweed et al, 2022)³ – it was concluded that: *‘Policy responses to rising drug-related death rates require a gender-informed approach, recognising the commonalities and differences between men and women who use drugs; the diversity of experiences within each gender; and the intersections between gender and other forms of inequality, such as poverty.’*

It is clear that residential rehabilitation and recovery services for women and their children can play a vital role in our drive to tackle drug related deaths in Scotland and in addressing the rising number of deaths of women. Such services can also help Scotland to **#KeepThePromise** for families living with addiction by enabling families to stay together during treatment and recovery and reduce the likelihood of children being taken into care.

Supporting Families Living with Addiction

At Aberlour we see the impact of drugs and alcohol on children and families every day. Working in communities around the country we support families affected by substance use and living with addiction. We deliver a range of trauma-informed services across 26 Scottish local authorities providing both early intervention and intensive whole family support services. Substance use, alcohol and drugs are common issues in the lives of families we work with across our family support services.

We see the impact of drugs and alcohol on children, young people and families we work with across our family support services, and in the communities where we work. For children growing up in poverty and experiencing disadvantage too often drugs, alcohol and substance use are common issues they encounter affecting them and their families. We know that where there are higher levels of poverty and disadvantage these issues are more prevalent, and we see the evidence of this through our work in areas of multiple deprivation such as in parts of Glasgow and Dundee. The devastating impact of drugs and alcohol on families is also a common factor in the lives of children who can no longer live at home with their families and who live with Aberlour in our residential children’s houses.

We deliver two dedicated community based family support services for families affected by substance use and addiction – one in Dundee and one in Dumfries and Galloway. These services

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7612287/>

work with families who are struggling to cope as a result of drugs and substance use in the family. We work with whole families by supporting parents directly as well as children on their own, from birth onwards. Our family workers support children with emotional and practical help at home and at school, as well as working with parents to build confidence and parenting skills, establish routines and to access wider community networks and support. We deliver group work activities for the whole family and peer group activities for multiple families. We also work with parents at home to help them create a safe environment for their children.

Aberlour – Cowan Grove

Cowan Grove is a residential rehabilitation and recovery house located in Dundee for women and their children aged up to five years old. It was established as a national service and is funded by the Scottish Government. The service also looks to target local need around disproportionate drug deaths in Dundee. It has a capacity of four women with up to two children each. The aim of the service is to support mothers to stabilise their drug and alcohol use, prevent drug deaths of the women accessing the service, avoid children being taken into care and to keep families together.

Cowan Grove opened its doors on December 5th 2022 and welcomed two women the same week. The service currently has three women and three children residing at Cowan Grove. There are ongoing referrals from local authorities across Scotland to access the service. The service is gender specific to respond to the specific issues women living with addiction who are mothers face when seeking treatment and to enable and empower women to have choice in what services they can access.

The program on offer at Cowan Grove follows a holistic approach to recovery that includes support with life skills, parenting, emotional wellbeing and therapeutic input through the Parent Under Pressure Program. This includes wraparound nurture and safety within the first twelve weeks of the program through enabling women to build trusting and positive relationships before entering into positive risk taking and strategies for future community recovery management.

The development of the service at Cowan Grove aims to embed best practice and is consistent with the Medication Assessment Treatment (MAT) standards. The support that women receive is personalised and informed by the women directly enabling informed choices about how they are supported. The house has been designed to ensure it is a nurturing space and psychologically informed environment, and the focus is on community based support including prescribing through our GP practice partner.

However, it is important to highlight that referrals into our service appear to be a last resort when other options have been tired or exhausted. The option for residential rehabilitation must be recognised as a choice and an offer for women much earlier in their care planning.

We have provided a case study of a mother supported at Cowan Grove as part of our submission. We would also like to offer members on the Cross-Committee the opportunity to visit Cowan Grove and to meet and hear from the women supported by the service.

Intensive Perinatal Support Service

We know that substance using pregnant women and their babies face a multitude of health and social problems. Neonatal and obstetric outcomes are poorer amongst pregnant women with problematic substance use and the effects during pregnancy is well documented (e.g. ectopic pregnancy, placental insufficiency; reduced foetal growth; preterm delivery; Foetal Alcohol Syndrome; and Neonatal Abstinence Syndrome).

The child's experience in utero and during the early years can have a life-long impact, including learning difficulties, behavioural and mental health problems. These impacts can lead to the need for costly intensive resources at a later stage in children's lives. Children taken into care typically experience poorer outcomes than children in the general population.

Aberlour's Intensive Perinatal Support Service based in Falkirk provides support to pregnant women and new mothers who are affected by substance use and who have a baby under 12 months of age. The service was established in April 2021 and is delivered in partnership with statutory and community partners and through co-production with women. The primary aim is to maximise opportunities for new babies to remain safely in the care of their mother through facilitating recovery from problematic substance use and developing and enhancing parenting capacities.

The service provides family focused, relational support which encourages engagement in care planning and co-production of care/support, highlighting parent strengths and enabling disclosure of challenges that parents face. Working in partnership with other agencies helps to facilitate optimum outcomes for parents and families and for developing shared and consistent trauma informed practice.

The women who are supported by the service are at high risk of having their children taken into care prior to referral. In the last two years 21 women have been supported by the service and of those 17 have kept their babies in their care. The majority of women were referred into the service during pregnancy. This offers a longer period for building relationships, receiving support and maximising opportunities for babies to remain safely in the care of their mothers, through facilitating recovery from problematic substance use and developing parenting capacity and confidence. This illustrates that the earlier women receive support the better the outcomes for them and their babies.

Key Existing Challenges in Delivering Drugs Deaths Taskforce Recommendations

- We remain concerned regarding the continuing lack of holistic family support approaches and the disconnection within and between services at a local level resulting in a lack of early intervention and systems that struggle to take a strength focussed, practice led approach – we cannot say that we are Keeping The Promise for too many children and families affected by alcohol, drugs and substance use.

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- There is a clear gap in the availability of support for parents whose children are removed from their care. This is particularly acute during the perinatal period where services withdraw if the baby is 'safely placed', leaving parents with little or no support at a time when the risk of relapse, overdose and maternal suicide are heightened.
- From our experience there continues to be ongoing challenges around referrals and decision making within authorities regarding residential rehabilitation and recovery.
- Referrals to our Cowan Grove service still appear a last resort rather than as an early referral – the majority of enquiries so far have been for women who have already had children removed permanently from their care.
- We have had significant challenges in developing partnerships locally with key ADP partners to help us identify a prescribing partner. There is a drive for more GP's delivering community-based prescribing, however this does not appear to be having much traction in some areas where we work.
- Addictions services across the country are significantly under pressure and ADP budgets are insufficient to meet the demand for support for those affected by addiction – more funding is required across addictions services.
- We know through our partnerships that drug rehabilitation referrals are often time limited (12 weeks) due to funding challenges.

For further information contact Martin Canavan, Head of Policy & Participation

Cowan Grove – Case Study

**To protect the privacy of individuals within this case study, all names and identifying information have been changed.*

Sarah's Journey

This case study will focus on Sarah's journey and experiences within Cowan Grove and identify the successes and challenges that she has faced, since her admission in December 2022.

The study will consider operational, service and individual experiences to give a holistic overview of the service.

History and Background

Sarah is currently within the age demographic of women most at risk of fatal drug overdose, and before being welcomed to Cowan Grove, lived predominantly with her mother in the Tayside area. Sarah had previously secured a tenancy in the same area, however found this to be an unsafe environment due to links with known drug dealers and other substance users within the local community.

Sarah has 2 children. Sarah's first child was removed from her care due to long standing challenges with alcohol and drug use. Sarah's first child has been adopted and there are no current contact arrangements in place. Sarah gave birth to Jane while residing at Cowan Grove.

Sarah has shared that she started using street substances as a means of self-medicating in her early teens, influenced greatly by her peer group at the time and a number of traumatic experiences. Sarah has experienced a lot of grief and trauma and has shared that these early experiences were a catalyst to start using more substances regularly. Prior to admission to Cowan Grove, Sarah was regularly using a number of different street substances as well as having a community prescription to support her. Sarah currently has an opioid substitute treatment plan that is designed to support stabilisation.

Sarah has a range of different physical health needs that are managed by prescription medication and specialist medical professionals.

Sarah has shared that during a period of imprisonment she remained abstinent. Following this, Sarah has stated she had a long period of instability, including homelessness. Sarah has shared that this was a vulnerable time in her life, in which she experienced significant harm through exploitation that resulted in poor mental health.

Cowan Grove – Case Study

Successes

Sarah has shown a great depth of tenacity in engaging with the program and seeking to make the most of the support on offer to her and her baby. She has described the program as being a unique opportunity for her to make the changes she wants to make, whilst feeling safe, nurtured and without judgement.

Sarah has shown great progress and growth in the last 3 months and continues to grow and adapt on her recovery journey. Sarah's emotional wellbeing has been observed to have improved - with strengths in managing complex emotions and sharing her thoughts and feelings with the team around her.

Sarah has benefited from a non-judgemental, and nurturing staff team, stating that she feels she has a safety net around her if things are getting difficult. Choice is something that has been observed to be very important to Sarah. Feedback from Sarah has noted that having the space to voice her thoughts, feelings and suggestions have been beneficial as she feels more in control of her own journey.

Following her birth Jane was able to leave hospital care earlier than anticipated and was discharged to the care of her mother, which has given her a foundation in which to develop and strengthen attachment and bonding. Had Cowan Grove not been an option, Jane may have required longer clinical support that would not have included Sarah, resulting in potential disruption to her early attachment opportunities.

Fortnightly house meetings are scheduled to ensure the women have protected space and time to share their feedback, thoughts, and feelings. A journal has also been implemented as an indirect communication tool for women to write thoughts, feelings, wants and feedback in a more informal way. This enables the women to approach their recovery planning in a person-centred way that empowers choice and their voice to be heard.

Positive risk taking has been promoted and encouraged within Cowan Grove, including reviewing independent access out of the house, access to mobile phones and social media. This enables the women to adapt and strategize on how they will manage potential challenges and triggers in the future.

Adaptability has been a key feature of the service since its conception, with processes and practices changing alongside the needs of the women, the team, and the service. The women are encouraged to make decisions that are safe for themselves, their children and the group living environment as a whole.

Cowan Grove – Case Study

The staff group and women are able to work collaboratively, with the women sharing their lived experiences and providing learning opportunities for staff to deepen their knowledge through this peer learning.

The statutory service provision that has been involved in the families lives thus far have adopted a *can-do* attitude in challenging the status quo to support and seeing Cowan Grove as a service that can reshape and redesign recovery support for women and their children.

By having a coordinated approach through the support team network created in Cowan Grove, Sarah and Jane have been able to have one stop support for housing, health, benefits, counselling, community connections, parenting and recovery. This has meant not having to share their story with a number of professionals and actions identified at point of need.

By being able to offer community outreach support from the point of transitioning back to community, Sarah and Jane will continue to have service provision which is consistent and stable that can offer crisis intervention when it is needed.

Challenges

- Enquiries – of those received thus far, a high proportion of statutory partners have decided not to have the child in their mother's care which limits choice and autonomy, thus excluding women from being assessed for Cowan Grove support
- Group living comes with its own challenges of women's particular needs being met and ensuring that all families have a voice.
- Supporting the women to manage their triggers and feel safe enough to share their worries and fears of how this may impact future statutory interventions.
- Challenging Stigma and professional expectations that may stem from professional bias, particularly clinical need versus social need.
- Operational flexibility to ensure we adapt and develop the service in line with families' needs.

Future Planning

As Cowan Grove develops and grows over the coming months, the families will be key in ensuring that at the heart of service delivery is the desire to ensure that women and children's voices are heard, listened to, and acted on.



Introduction

Scottish Families Affected by Alcohol and Drugs (Scottish Families) supports anyone affected by someone else's alcohol or drug use. This written evidence focuses on the reflections and recommendations of our **Family Reference Group** around tackling drug deaths and drug harm. In October 2019 we established the Family Reference Group to support the sole family representative on the Drug Deaths Taskforce (DDTF), Colin Hutcheon. We had unsuccessfully requested further family representation on the Taskforce, given the challenge for one person representing the breadth of family experiences (e.g. age, gender, geography, family relationship, drugs involved etc).

Colin Hutcheon chaired the Family Reference Group, with Scottish Families providing secretariat support. The Group met throughout the lifespan of the Taskforce and is currently re-forming and extending its membership to work alongside the new National Collaborative of Lived/Living Experience. It includes family members whose loved ones are in recovery, those where there is still active or intermittent substance use, and bereaved family members. The members represent both urban and rural areas, from the Highlands to the Scottish Borders. The Group was originally set up independently of the Drug Deaths Taskforce, however it was formally adopted as a sub-group in 2021. This did not change the functioning of the Group in any way.

In July 2022, the Group published a companion report called '**What About Families?!**' at the same time as the main Taskforce report. This was an independent report, but it was published by the Taskforce alongside their main report, and many of the recommendations are aligned.¹ '**What About Families?!**' assessed progress against a set of 'Five Immediate Actions' which were submitted by the Family Reference Group to the Taskforce (at its request) for its second meeting in October 2019. These were:

- 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.

As well as reviewing progress against the above Actions, '**What About Families?!**' included reflections on Family Representation on the Taskforce, and commentary on three other Priorities for Families:

- i) Drug Law Reform
- ii) A DDTF-funded test of change (Families as Lifesavers/Holding On), delivered by Scottish Families
- iii) The influence and impact of lived experience.

The full set of recommendations by the Family Reference Group is reproduced in the Appendix. In these recommendations, the Group called for a **true co-production approach with families** (and others with lived

¹ <https://www.sfad.org.uk/content/uploads/2022/07/What-About-Families-Family-Reference-Group-Report-July-2022-FINAL-PUBLISHED.pdf>.

experience) in future commissions and taskforces if change it to be realised, and an **equal platform for families** alongside others with lived experience. There was strong support within the Group for the introduction of the **Medication Assisted Treatment (MAT) Standards**, most of which reflect what families have been calling for over many years. However there was some scepticism that the same workers and services who have repeatedly failed their loved ones, and judged and excluded the families over many years, would suddenly treat them with dignity and respect. The Group called for **cultural and attitudinal change** in treatment and care services, and **clear accountability for delivery** of local and national service standards. They called for a specific **MAT Standard for Families** – this had been requested when the Standards were developed, but there was apparently not room/time to include this, and it may be reconsidered in future.

The Group proposed an **independent body** so that family members and their loved ones would feel safe and confident to **raise concerns**. There was also a call for a **presumption of family involvement**, so that families would be included as partners in care, just as they are with other long term, chronic health conditions; and for **mandatory Family Inclusive Practice training** for all staff working in alcohol and drug services. Families called for **support for family members in their own right**, regardless of their loved one's situation.

One of the real successes over recent years has been the **roll out of naloxone** (including via Scottish Families' own Click and Deliver service, established with the support of the Scottish Drugs Forum and DDTF in May 2020²). The Family Reference Group has been very supportive of the naloxone programme, and called for national workforce programmes to be extended from police, fire and ambulance to other occupations such as housing, public transport, and all health and social care staff. They called for faster delivery of the national **Stigma Strategy**, and families' unique experiences of stigma to be recognised.

The Family Reference Group also reflected on their work around **drug law reform**, whereby all members had experience of their loved one's interaction with the justice system, and in their view this had never resulted in positive outcomes. The Group called for a **public health approach to justice**, including a **'distress' not 'crime' approach** to substance use, and **trauma-informed decision-making** throughout the justice system.

The biggest challenge following the Taskforce report is the ongoing **implementation gap** in Scotland between what we say we will do (our written commitments and ambitions), and what actually happens in practice. Families repeatedly find there is **no accountability in the system** – no-one is accountable for repeated service and system failures, and their concerns are just dismissed or they are directed to unwieldy, slow and unresponsive formal complaints processes.

The *'What About Families?'* report included letters from two family members on the Group to those in positions of responsibility, highlighting multiple service and system failures and asking for a better response if we are to reduce harm and save lives:

"I am tired of fighting to keep my son alive. ... I refuse for my son to be another of your so-called statistics. We need a change and we need it NOW!!!" (from Karen's Story)

"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. ... 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 I'm saying as things need to change. Thank you for taking the time." (from A Letter from Gillian)

² <https://www.sfad.org.uk/support-services/take-home-naloxone>

We will only have achieved the change we want in Scotland when our written commitments look and feel real for families on the ground.

APPENDIX: SUMMARY OF FAMILY REFERENCE GROUP RECOMMENDATIONS, JUNE 2022
(From 'What About Families?!', Scottish Families 2022³)

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;

³ <https://www.sfad.org.uk/content/uploads/2022/07/What-About-Families-Family-Reference-Group-Report-July-2022-FINAL-PUBLISHED.pdf>.

- **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 report⁴).

(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**.

⁴ <https://www.sfad.org.uk/content/uploads/2021/04/210325-FINAL-Response-from-DDTF-Family-Reference-Group-to-Drug-Law-Reform-Consultation.pdf>