

A close-up photograph of several purple thistle flowers. The flowers are in various stages of bloom, with some showing the intricate, spiky structure of the heads and others with more developed, feathery petals. The background is a soft, out-of-focus green, suggesting a natural outdoor setting. The text is overlaid on the top left portion of the image.

Families on the Frontline
Stirling 28-29 March 2023

Conference Report

WHAT WAS FAMILIES ON THE FRONTLINE?

The Families on the Frontline conference was held in at the University of Stirling on 28-29 March 2023. This national event aimed to bring together families affected by someone else's alcohol or drug use with those delivering and influencing treatment, care and support services. Day One was for family members only, with a focus on empowerment, rights, advocacy, learning and self-care. A conference dinner and overnight accommodation were part of the Day One programme. Day Two brought family members together with those involved in services, aiming to help services strengthen family support and family-inclusive practice by sharing positive and practical tips, tools and strategies in a 'masterclass' format. This included sharing real-life scenarios and contributions from family members and practice experts.

The full programme and presentations are available at: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

There was no charge for the conference, with financial support provided by the Scottish Government's national drugs mission funding. The funding also covered transport and additional accommodation costs for those attending from island areas, and this enabled their participation.

The event was organised by a planning group comprising Scottish Families, Families Campaign for Change, My Support Day (on behalf of the National Family Carer Support Alliance) and the Scottish Government. Administrative and planning support was provided by Scottish Families.

This conference report summarises the presentations, group discussions and activities, and participant feedback. The event was also covered on Twitter, search for #FamiliesOnTheFrontline.

HOW DID IT GO?

We had attendance from almost every area of Scotland, from Shetland and the Western Isles down to the Scottish Borders and Dumfries and Galloway. We felt that our decision to use our own networks and contacts for the family invitations, and to ask each ADP to nominate three local representatives for Day Two, really helped us reach more of Scotland and have equitable representation from across the country, rather than bookings being quickly flooded by central belt delegates. All delegates were personally invited by the Minister, which was also helpful – the invitation letters are on the conference web page.

Participant numbers included 107 family members (and some family support staff) on Day One, and 181 participants on Day 2 when those involved with services joined. Maximum capacity was 200 – we had a few late call-offs due to illness and so on. A very small number of Alcohol and Drug Partnerships (ADPs) did not field anyone for Day Two, which was disappointing for those who were centrally located, but understandable for those further afield.

The event was chaired by four family members, leading a half-day each. This was well received, keeping the event grounded in families' experiences, and clearly demonstrating this was a family-led event.

Feedback on the conference described it as "*phenomenal*", "*brilliant*", "*so positive*":

“It was literally one of the biggest privileges of my career to come and work with as inspirational people as your family members and team. The passion, resilience and amazingness shone through.” (Presenter)

“I thoroughly enjoyed the conference and have come away with so many ideas to put into practice here. Thank you to all for an empowering day with wonderful, like-minded people.” (Day Two participant)

“It was an amazing conference and I was really quite inspired by the energy and wisdom of the families that were there – the power of community 😊” (Day Two participant)

“Your team did an incredible job. The conference was amazing!! So powerful to see so many families coming together and I know the individuals we brought along came away feeling positive with a renewed sense of hope and empowerment. 😊” (Family Support worker, attended both days)

Many of the families who attended had never previously attended a large-scale national event or families’ event, and many had little or no experience of respite from the daily pressure of living with their loved one’s substance use. The dinner and the overnight accommodation were greatly valued, including supporting family members to build new connections. The logistics and complications for family members of taking this kind of time for themselves cannot be overstated, and we’re grateful to all those involved in supporting families to attend.

The Day One conference content was described as mind-blowing for many, who did not realise that they had rights as family members and carers. Giving family members the first day on their own worked well to grow their confidence and connections. It was an emotional and profound experience for many who attended, realising *“I am important and families do have a voice”, “I now understand the importance of me”,* and being able to see *“families need to be at the front of everything”.*

We were so delighted that the then Minister for Drugs Policy, Angela Constance, delivered on her commitment to open Day Two of the conference, despite significant political developments that day (namely her promotion to the justice portfolio later that day). This being her last official engagement as Drugs Minister sent out the strongest of messages about her commitment to families, and it was greatly appreciated. Elena Whitham was subsequently appointed as the new Minister for Drugs and Alcohol Policy, and soon after met with the conference organisers to illustrate her commitment to building on the event’s legacy.

The focus for Day Two on practical and real examples was described as *“inspiring”.* The table discussions bringing together family members and services enabled some challenging conversations. It was felt more time for table discussions would have been very helpful, as the agenda was fairly packed.

There were some minor issues with the venue, particularly on Day Two when the room felt very busy and we could have done with a larger space, so some learning points have been noted for future events.

DAY ONE – TUESDAY 28 MARCH 2023 - FAMILIES

Day One will bring together family members who are affected by someone else's alcohol or drug use from across Scotland. The aim of Day One is for family members to connect with each other, learn from one another and from a diverse set of speakers, and to continue to develop Scotland's family recovery movement. The focus will be on empowerment, rights, advocacy, learning and self-care.

Day One is open to family members only, and a number of staff from family support organisations will also be in attendance. We have capacity for 100 participants to join us on Day One, representing all areas of Scotland.

Day One includes a full day Conference Programme (10am registration, closes 4.30pm), followed by Dinner (6.30-9pm) and Overnight Accommodation. (Note that Dinner and Overnight Accommodation are optional for those who wish).

Programme

10.00am Registration with tea/coffee available

10.30am Morning Welcome from Colin Hutcheon (Family Member)

10.35am Developing a Charter of Rights with Prof Alan Millar (Chair, National Collaborative)

11.30am Break with tea/coffee available

12.00pm Carers Rights with Shubhanna Hussain-Ahmed (Coalition of Carers in Scotland)

1.00pm Lunch (will be served in the restaurant)

2.00pm Afternoon Welcome from Karen Llewellyn (Family Member)

2.05pm Mental Health and Substance Use – a 'How To' guide for families with Kathleen Taylor (Mental Welfare Commission)

3.00pm Break with tea/coffee available

3.30pm A Wellbeing Treasure Chest with Karran Bonner (Brightside Inspiration)

4.30pm Close of Day One day programme from Karen Llewellyn (Family Member)

6.30 – 9.00pm Evening Programme: Conference Dinner (with dinner in the restaurant) and after dinner speaker Neil Hunter (Chair, Whole Family Approach Implementation Working Group)

Source: Families on the Frontline Invitation and Programme

DAY ONE: WELCOME!

Colin Hutcheon, Family Member

On Day One we welcomed 107 family members and family support staff to the Stirling Court Hotel at the University of Stirling. Participants came from all corners of Scotland, from Shetland and the Western Isles to Dumfries and Galloway and the Borders. We had representation from all but three Alcohol and Drug Partnership (ADP) areas. We had reached out to contacts in Orkney, Perth and Kinross and Moray, but unfortunately we didn't manage to reach any family members in these areas.

There was great excitement and a real buzz in the room as everyone gathered to be welcomed by the Scottish Families Chair, Colin Hutcheon. Colin was one of four family members who chaired each half-day of the conference.



DAY ONE: WHO'S HERE TODAY?

Participants introduced themselves at their tables, using these worksheets:

Hello my name is ...
I have travelled from ...
I am here because ...



Responses indicated 6 main motivations and reasons for attending:

1. Connection
2. Sharing
3. Support
4. Learning
5. Campaigning
6. Change

I'm adding my voice to the drive that will include families in the quest to "Stop drug deaths!" Much discussion is required on the hows and wheres of removing stigma across the board

I need support to be able to manage my emotions and behaviours whilst trying to be understanding and supportive to my son who misuses a substance. My mental health has been badly affected and I need to practice more self-care. Hoping to learn some tools.

I want to meet people, expand my connections, learn more

I have a family member currently in addiction and past experience of poor care. I also work in services and want to hear of others' experience

I want to learn to help myself in order to lead a happier and healthier life

*More Info.
More Power!!!*

Wanting to help families to get more help and recognition. This must include what happens when a loved one dies

I want to become a stronger and more informed person and to look after myself better

I am looking for information to support my son but to support me too! Give families a voice.

We have no family support group in the town and so I have to start one

I want to hear the views of family members about their experience of being involved with alcohol and drug services

I want to share and gain knowledge around whole family recovery. To feel the hope and also the necessity that families can recover

DAY ONE, SESSION ONE: DEVELOPING A CHARTER OF RIGHTS

Prof Alan Millar, National Collaborative



Our first speaker was Professor Alan Millar, lead for the National Collaborative of Lived and Living Experience, which is part of the National Drugs Mission (<https://www.gov.scot/groups/national-mission-on-drugs-national-collaborative/>).

The presentation summarised the Vision and Purpose of the National Collaborative; the Roadmap which is being followed to develop a Charter of Rights; the roles of the Change Team, Reference Groups, and the Leadership & Learning Network. The National Collaborative are starting an evidence gathering process around barriers to realising rights, including the right to health (healthcare and social determinants), the right to participation, the right to private and family life, and criminal justice rights (alongside the right to life and the right not to be subject to degrading treatment).

National Collaborative

VISION:
to integrate human rights into drug and alcohol policy development, implementation, monitoring, and evaluation leading to better outcomes for people affected by problem substance use.

National Care Service Human Rights Bill

The Roadmap

- Charter of Rights
- Using FAIR model

FAIR

FACTS - Develop an evidence base of experience of problem substance use.

ANALYSIS - Co-produce an analysis of the human rights engaged in experiences of problem substance use.

IDENTIFICATION - Identify an action plan to respond, protect and fulfil the relevant human rights.

REVIEW - Review and monitor the implementation of the action plan.

Evidence gathering around barriers to realising rights

1. The right to health (specifically healthcare) + right to life, right not to be subject to degrading treatment
2. The right to health (social determinants) + right to adequate standard of living
3. The right to participation
4. The right to private and family life
5. Criminal justice rights + Right to life, right not to be subject to degrading treatment

The right to health

The right to the highest attainable standard of physical and mental health means that drugs and alcohol services need to be designed, delivered and regulated to ensure....

Availability – e.g. choice of service in sufficient quantity and adequately funded
Accessibility – e.g. services are geographically and financially accessible
Acceptability – e.g. services are person-centred
Quality – e.g. services are evidence-based and trauma informed

Availability Accessibility Acceptability Quality

The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

The 'AAAQ' framework was outlined in relation to the right to health, ensuring the following in relation to drug and alcohol services:

- Availability
- Accessibility
- Acceptability
- Quality.

This AAAQ framework formed the basis for a table discussion on the Right to Health, led by Scottish Families.

**TABLE DISCUSSION ON ...
THE RIGHT TO HEALTH: AVAILABILITY, ACCESSIBILITY, ACCEPTABILITY, QUALITY**

Participants were asked to discuss the following questions at their tables, using a worksheet to record key points:

<p>Thinking about the rights you have heard about today and the 'AAAQ' themes:</p> <ul style="list-style-type: none"> • What does this look like for you NOW? • How SHOULD this look for you? • What is getting IN THE WAY of this happening? • What would HELP? 	
Availability	Accessibility
Acceptability	Quality

The worksheets suggest that most of the discussions focused on families' experiences of trying to support their loved one (rather than support for families in their own right), so the comments around Availability, Accessibility, Acceptability, Quality unsurprisingly tended to focus on services for individuals, rather than for families.

There were many common and overlapping comments across the four themes of Availability, Accessibility, Acceptability, Quality. These are summarised on the tables below.

(1) AVAILABILITY

<p>What does this look like for you NOW?</p> <p>All comments on this were negative illustrating the <i>“gulf between services as they are and rights to be ascribed”</i>.</p> <p>Specific comments included services not being available to meet health needs (mental/physical including underlying conditions), postcode lottery/patchy availability, lack of early intervention, poor resources for NHS/councils, services not linking/being disjointed, <i>“Constantly judged and let down”</i>, workforce shortages (e.g. psychiatrists), lack of choice.</p> <p style="text-align: center;"><i>“Families have begged for help”</i></p>	<p>How SHOULD this look for you?</p> <p>There was much less feedback on this, suggesting families need additional time and support to imagine a positive, alternative future.</p> <p>Some suggestions included:</p> <ul style="list-style-type: none"> • Free trauma counselling • More availability of SMART training • More assertive outreach • 24 hour/weekend services (a good example was shared of Turning Point Scotland’s Harm Reduction Service, available 10am-10pm, 7 days).
<p>What is getting IN THE WAY of this happening?</p> <p>Families identified a huge list of barriers here, including:</p> <ul style="list-style-type: none"> • Being passed from service to service, lack of communication between services • No same day access, lack of cover at high risk times, (e.g. outwith Monday-Friday 9-5, on weekend, public holidays) • Finding out about services by accident/<i>“having to do your own research/advocacy”</i> • Access depending on abstinence (e.g. housing), blame and stigma by services (including the focus on positive/negative drug tests as <i>“a form of shaming”</i>) • Families being let down by services and <i>“all the responsibility left with them”</i>, being <i>“told the problem isn’t bad enough – where is early intervention?”</i> • Inconsistent services, short-term and inadequate funding, unclear how funds are allocated • Waiting lists, time constraints • Rural and island challenges including lack of choice, capacity and quality, policy being focused on the central belt. <p style="text-align: center;"><i>“Housing must not be dependent on abstinence – families struggle with the choice between making their loved ones homeless or having them live with them”</i></p>	<p>What would HELP?</p> <p>The feedback to this question was unsurprising, responding to comments made under the other three questions:</p> <ul style="list-style-type: none"> ✓ Clear referral pathways, knowing pathways to services ✓ Knowing staffing of services ✓ Joined up services, <i>“have everything together”</i> ✓ Holistic approach to health, individual assessed by needs not problems, don’t box ‘mental health’ ✓ Individual should be able to decide the course of their treatment ✓ Equality impact assessments ✓ Bring funding to same level as UK (NHS & mental health) ✓ Some thought behind where services are placed (accommodation)

(2) ACCESSIBILITY

<p>What does this look like for you NOW?</p> <p>As with Availability, all comments around current Accessibility were negative, including services not linking, dual diagnosis (mental health/substance use) not being treated together (<i>“Can’t be separated yet service providers separate it”</i>), a culture of blame (<i>“It’s your fault”</i>) leading to police involvement, analysis of parents/parenting rather than the needs of the child, lack of awareness of what is available – for families and their loved ones, and being discharged for non-engagement, yet appointments are challenging.</p> <p><i>“None of the services work well or at all. There needs to be a lot of work to link all the services – without this change, won’t do what it needs to.”</i></p>	<p>How SHOULD this look for you?</p> <p>Again there were few suggestions of how things could look in the future, but these reflected comments elsewhere:</p> <ul style="list-style-type: none"> ✓ People should not fit around the service – the service should fit around the person ✓ Workforce should work out the service level across the board ✓ Right service at right time <p><i>“Health’ needs to be dynamic dependent on needs”</i></p>
<p>What is getting IN THE WAY of this happening?</p> <p>Again families identified many barriers and challenges, including:</p> <ul style="list-style-type: none"> • No clear signposting to where to go to for services, <i>“finding support is difficult, knowing services”</i>, especially if you live in another area than your loved one • Not enough funding, not enough services or workers, lacking resources • People who are using substances are getting younger, but services are not there • Postcode boundaries, postcode lottery • <i>“No easy support model for families”, “No clear library of contacts for support for families and those with addictions”</i> • Being told you have to be abstinent to access mental health services • No communication, jargon, <i>“sharing info on behalf of loved one is not entertained”</i> • Rural and island challenges, lack of public transport, location of services, <i>“how long does it take to visit, how far away are centres, how to get there?”</i> • Stigma, <i>“The ‘System’ – police, care, health – violence used, pathologizing”, “Pushed down criminal route as soon as drugs are mentioned”</i> 	<p>What would HELP?</p> <p>There were fewer suggestions here than under the barriers section, but the following were mentioned:</p> <ul style="list-style-type: none"> ✓ Family inclusion ✓ Importance of outreach ✓ Actively encourage people to engage ✓ Focus on safety of people using drugs and their families ✓ More rehab <p><i>“It can happen to anyone. As a family you think it can’t happen to you. Have to work on own stigma thoughts. Families have to educate themselves.”</i></p>

(3) ACCEPTABILITY

<p>What does this look like for you NOW?</p> <p>As with the previous themes, all these reflections were negative, including the current system being described as “unethical and unsafe”, “not person-centred”, with people “pushed from pillar to post” and “poor response times when asking for help”.</p> <p><i>“Very hard. Everything is just so bloody HARD!”</i></p>	<p>How SHOULD this look for you?</p> <p>Once again there were few suggestions of an ideal scenario:</p> <ul style="list-style-type: none"> ✓ Families are a key asset – not a problem ✓ GP culture must be pro family ✓ Services to show empathy and compassion ✓ Range of services should be on offer ✓ Keep people safe and alive as a pathway to recover/improve life standards <p><i>“Respect unpaid carers/families as part of the solution”</i></p>
<p>What is getting IN THE WAY of this happening?</p> <p>Numerous barriers were identified, reflecting many of the previous themes:</p> <ul style="list-style-type: none"> • Families and loved ones required to repeat their story over and over to different staff/services • Lack of communication about pathways • Family not being heard/ acknowledged • Families are often not included and are not seen as part of solution • Families have to co-ordinate services – find services on your own • NHS stigma/ apathy • Services are clinical and based on their needs rather than users’ needs, <i>“One size does not fit all”</i> • When ready for support (e.g. rehab) <i>“you’re not seen as bad enough”</i> • Still judged, still stigma • Language used – stigmatising, created by media/ media has a role • Cost of wellbeing activities for families, e.g. gym/pool • Debt/money - paying for rent etc. for loved one – <i>“what is the right thing to do?”</i> • Having to go down legal route to have voice in child’s care <p><i>“Feel have to jump through hoops, have to be worst of worst to get support that is person centred.”</i></p>	<p>What would HELP?</p> <p>There were lots of suggestions here in terms of improving Acceptability, although again many reflect previous suggestions and themes:</p> <ul style="list-style-type: none"> ✓ More visible recovery ✓ Importance of loved one <i>“finding their tribe”</i> to sustain their recovery ✓ Reducing stigma and blame ✓ Each case should be looked at individually, see a <i>“human being with a story”</i> ✓ Both services and individuals should be allowed flexibility ✓ Listen to voices of service users and families, be person-centred and family-aware, <i>“Family must be involved – communication!”</i> ✓ Respect from staff and services ✓ Decriminalise <i>“what is actually a health matter not justice”</i> ✓ Families are greatest advocates ✓ Women have pushed for rights in family/social justice <p><i>“It has to be OK to keep drinking. Immediately focusing on reduction, they withdraw from the service.”</i></p>

(3) QUALITY

<p>What does this look like for you NOW?</p> <p>For this theme, participants did identify a couple of positive examples (<i>“Care team – good communication”, “Paramedics are fantastic”</i>) but otherwise, as with the other three themes the current experiences were negative.</p> <p>This included experiences of hospital wards being too quick to discharge (<i>“Let’s get you out of here”</i>), lack of community follow-up/delayed follow-up after hospital discharge, a sense that <i>“In crisis families are left isolated and responsible for care but not with tools”</i>, lack of consistency, postcode lottery (mentioned in three of the four themes), services being <i>“completely disjointed”</i>, families being <i>“marginalised”</i> and experiencing trauma, and only one treatment service option <i>“but not necessarily a quality option”</i>.</p> <p><i>“Negligence, malpractice, lack of care, dropped balls”</i></p>	<p>How SHOULD this look for you?</p> <p>There were lots of suggestions as to how quality could be improved and how it should look:</p> <ul style="list-style-type: none"> ✓ Carers Act – families should be informed and involved in discharge ✓ Importance of trauma-informed practice ✓ <i>“Realistic, flexible, elastic tolerance”</i> ✓ <i>“Trauma is the root – solutions have to be rooted in trauma”</i> ✓ Multi-disciplinary meetings ✓ Mental health & substance use services to work together – not separate ✓ NHS staff/ GP practices to have family inclusion and assessment (<i>“complete overview”</i>), be trauma informed, do CRAFT training, ensuing <i>“all following same approach”</i> ✓ Safety & Harm Reduction Services, with supervised accommodation and drug professionals onsite ✓ MAT[Medication Assisted Treatment] for all addictions – not just opiates ✓ Recognise impact of substance use on whole family <p><i>“The whole menu of services should be made available. Important that families are consulted about this also.”</i></p>
<p>What is getting IN THE WAY of this happening?</p> <p>Many of the barriers echoed earlier themes:</p> <ul style="list-style-type: none"> • Blame/ stigma including in workforce • Social Work won’t even share SFAD with families • Waiting times for mental health, e.g. psychology • Lack of resources • Aftercare needed • CAMHS <i>“needs total shake-up – new services required”</i> • Not treating root/ need, <i>“only treat surface issue or criminalisation”</i> • Failure to legislate accurately. <p><i>“One key worker should be given – not several as retelling the story over again”</i></p>	<p>What would HELP?</p> <p>Many of the suggestions also reflected previous comments:</p> <ul style="list-style-type: none"> ✓ Workforce development; more trauma-informed training for workforce ✓ Training for wider workforce e.g. schools ✓ More funding ✓ Look at prescribers, impact of increased demand ✓ Communication is key between services ✓ Make individuals feel heard when attend A&E with poor mental health ✓ Transparency on how money is being spent/ outcomes achieved <p><i>“Advice given needs to match with care provided i.e. ‘Present at A&E if suicidal’, attend, then told to call next time”</i></p>

OUR RIGHTS CAN GROW AND FLOURISH!

Participants were asked to create a tree image, with the leaves representing rights which are important to them, and the trunk representing what needs to be in place for these rights to be real. In reality it looked a bit more like a bush or shrub, but you get the idea! Many participants identified rights relating to their loved one, rather than families as such, and identified barriers and challenges in the way to realising their rights. This activity suggested that families do not naturally think about their own rights, or the strengths/assets/opportunities we can build on.



Rights which are IMPORTANT to families (the LEAVES)

<p>Right to Health This includes the right to mental and physical health support, and the right for mental health and substance use to be treated at the same time.</p> <p><i>“For services to understand what ‘the right to health’ means”</i></p>	<p>Right to be Seen, Heard and Listened To This applies no matter the age of your loved one, and at all levels of recovery.</p> <p><i>“Don’t only listen but hear us also”</i></p>	<p>Right to be treated with Dignity and Respect This includes the right to be treated as a human being, acceptance, and the right to empathy and understanding.</p> <p><i>“See the whole person”</i></p>
<p>Right to Family Life This includes the right to whole family support, and the right for families to recover from trauma.</p> <p><i>“Family’s rights as well as the individual”</i></p>	<p>Right to Participate – as Partners This includes the right to information, be involved in your loved one’s care/treatment plans and options, the right to be acknowledged by services and work as a team, and the right to communicate on behalf of your loved ones.</p> <p><i>“Families are demonised for questioning those with ALL the power”</i></p>	<p>Right to Equal and Easy Access to Help and Support This includes the right to adequate and appropriate treatment and a person-centred, holistic approach, the right to have your needs recognised, the right to detox and appropriate medical help, and the right to genuine choice.</p> <p><i>“Availability, accessibility, acceptability”</i></p>

What needs to be in place for these rights to be REAL for families (the TRUNK)

<p>More Family Support This includes more family support, more services engaging with families, services connecting with family support groups, specific agencies for family support, opportunities for family members to talk to people who understand</p> <p><i>“Make family support available with ‘hubs’ like Maggie’s Centres</i></p>	<p>Rights and Accountability This includes using the existing Human Rights Act, developing a Charter of Rights, new legislation, and clear, consistent and effective accountability</p> <p><i>“Include every family member in this room in the National Collaborative Process”</i></p>	<p>Compassion in Care This includes breaking the stigma, changing attitudes of staff, reducing stigma and shame, showing empathy, a culture of hope and respect, trauma-informed, support when someone dies. This requires proper training of all service providers, but also realistic caseloads for workers.</p> <p><i>“Every person to CARE not just do a job!”</i></p>
<p>Joined Up Services – especially Mental Health and Substance Use This includes more GP-based mental health practitioners, a distress response from emergency services, combined drug & alcohol with mental health services, better communication and information sharing between organisations, and no more silo working.</p> <p><i>“The current system needs to be completely scrapped and rebuilt from scratch”</i></p>	<p>No Closed Doors This includes 24-hour services (not Monday to Friday, 9-5), joined up services, support plans involving family and other service providers (regularly reviewed), outreach workers, out of hours provision, crisis services, a clear pathway to services, not being pushed from pillar to post, perseverance by services, knowing what’s out there, choices/ range of services, and services fitting around the person and family (not fitting around the service).</p> <p><i>“No help for my son. All doors were closed.”</i></p>	<p>Respect for Families as Part of the Solution This includes respect from services for families’ knowledge of their loved one, communication between all services and family members, recognition of families as key allies, using their expertise, transparent services, and not using GDPR to create barriers and prevent families’ involvement.</p> <p><i>“We always have their best interests at heart”</i></p>
<p>Funding a Whole Country Approach This includes Scotland-wide services, funding/ improved investment to ensure services are available everywhere.</p> <p><i>“It’s a postcode lottery”</i></p>		

DAY ONE, SESSION TWO: CARERS' RIGHTS

Shubhanna Hussain-Ahmed, Coalition of Carers in Scotland

This session focused on family members as carers, and was described as one of the highlights of the conference – a real game-changer for families. Reflecting on the overall event, this was seen as the most informative session and also the most talked-about. It was described as really boosting and empowering participants.

Many family members affected by a loved one's alcohol or drug use do not identify or recognise themselves as carers. This means they are not accessing carers' rights and carer support services. Shubhanna gave a very detailed presentation outlining what we mean by 'carer' and examining the rights which carers in Scotland have. She asked participants to raise their hands if they classed themselves as carers, illustrating that many did not.



Participants were very engaged in this session, and quickly started asking questions. The session explored what is preventing this shift for families in thinking about themselves as carers, and accessing their rights and essential support.

What do we mean by carer?

“ A carer is someone who provides unpaid support to a family member or friend. They may care for an older person, someone who is disabled, has a long-term illness, mental health problems or is affected by alcohol or drug use. Carers can be any age, from children to older people, and from every community and culture. Some carers may be disabled or have care needs themselves. They may be parents, spouses, grandparents, daughters, brothers, same sex partners, friends or neighbours. ”

Definition adapted from EPIC (Equal Partners in Care)

Carers have some specific rights under the Carers (Scotland) Act

Carers in Scotland have the right to...

- be consulted on services for them and the person they are caring for.
- access a local information and advice service.
- be included in the hospital discharge of person they are caring for.
- access support if they have eligible needs.
- request a Young Carer Statement if 16 years old or under.
- request an Adult Carer Support Plan if over the age of 18.

Carers have the right to be involved in discussions around hospital discharge for the person you care for.

Hospital Discharge Checklist for Carers

- Let hospital staff know that you are the carer and how they can contact you.
- Get consent from the person that you care for to discuss their care with hospital staff.
- During discussions be clear about how much caring you are able and willing to do.
- If there are any changes to your caring role, request an adult carer support plan or young carer statement.

What can you do if you think you are being denied your rights?

- IDENTIFY WHICH RIGHTS ARE BEING DENIED** - Use your human rights knowledge to decide which rights are involved.
- ARE THESE ABSOLUTE RIGHTS?** - If they are absolute rights raise this immediately with the public service using human rights language.
- ARE THESE NON-ABSOLUTE RIGHTS?** - If they are non-absolute, is the restriction lawful, legitimate and proportionate?
- RAISE THE ISSUE FORMALLY** - Write a letter or email to your local authority or HSCP. Explain that you know there is a legal duty which is not being met.
- SET UP THE INTERVENTION** - This can include making a complaint, contacting a regulator, contacting a lawyer.

The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

DAY ONE: AFTERNOON WELCOME

Karen Llewellyn, Family Member

The afternoon session on Day One was introduced by family member Karen Llewellyn. She talked about her own journey, the support she had received and the change this had made for her and her family. Karen spoke about finding her voice through the process of support. In particular she wanted to shine a spotlight on Scottish Families' My Family, My Rights advocacy skills course. (Karen was one of the family course advisers who helped shape this course). She talked about the course, the difference it had made and urged family members to consider signing up and joining it.

Karen is pictured here (left) with Kathleen Taylor from the Mental Welfare Commission.



DAY ONE, SESSION THREE:

MENTAL HEALTH AND SUBSTANCE USE – A 'HOW TO' GUIDE FOR FAMILIES

Kathleen Taylor, Mental Welfare Commission

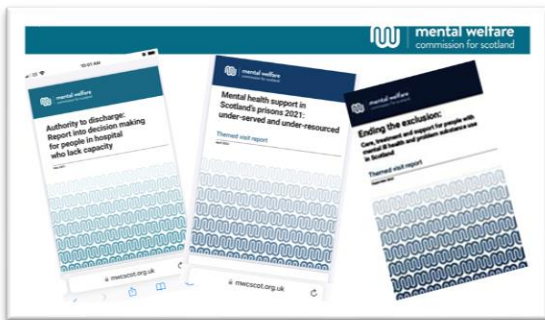
Kathleen started her presentation by talking about her own experience as a family member. Sharing her story really connected her to the family members participating in the event, and she showed her care for families.



Her session started with an overview of the role of the Mental Welfare Commission. She encouraged families to actively engage with the Commission, and use it to assist in their own situations. For example, she encouraged participants to copy the Commission into complaints or correspondence with health and social care services.

Kathleen introduced a scenario-based role play for each table, with the person at the centre and different roles around them in a spider diagram. Participants were asked to take on different roles, and discuss what is actually being said in each scenario, versus what people would like to be said.

Reflecting on this session, families liked the way Kathleen wore 'both hats' as a family member/carer and in her role with the Commission. Participants said they felt heard and understood. They appreciated that Kathleen shared her Commission contact details with participants and encouraged them to stay in touch.



The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

DAY ONE, SESSION FOUR: A WELLBEING TREASURE CHEST

Karran Bonner, Brightside Inspiration

This final session for Day One aimed to encourage family members to take some time for themselves, and focus on their own self-care. The earlier sessions during the day had focused on information and discussion about rights, advocacy and empowerment, and we anticipated that participants may need a closing session to help them decompress and get some headspace back!

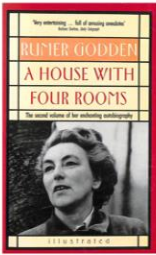
We invited Karran Bonner from Brightside Inspiration to lead this session, and she shared a wide range of tips, tools, techniques and materials to support participants to focus on their wellbeing – on the day and into the future. The session included a body scan exercise, reflection cards sharing positive affirmations, mindful colouring materials and more.



This was a fantastic end to the daytime programme – a real change of pace and focus.

House of Four Rooms


Indian proverb that says that "everyone is a house with four rooms, a physical, a mental, an emotional and a spiritual. Most of us tend to live in one room most of the time but, unless we go into every room every day, even if only to keep it aired, we are not a complete person."




Body Scan

How is Body Scan Meditation Helpful?



- You get more aware of your physical self
- You better regulate emotions
- You manage physical discomfort more effectively
- You improve concentration and focus



Starting Your Day: Healthy Morning Routine




- Thankfulness
- Insight
- Meditation
- Exercise

Creating your Wellbeing Treasure Chest...

Draw a treasure chest and note what things you want to incorporate into your wellbeing treasure chest...

- Your morning routine
- Asking for support
- Inner self-talk
- Reducing the negativity and mood Hoover time
- Bringing the banter
- Exercise
- Getting fresh air
- Taking time to relax
- BREATHE!**



The self care tracker might help you with some ideas

The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

DAY ONE, EVENING PROGRAMME

Our Evening Programme included a drinks reception, with alcohol-free drinks provided by RapsCALLION Soda, followed by dinner. This was a lovely opportunity for family members from all over Scotland to relax and unwind together, and to get to know each other in a more informal setting.



The after-dinner speaker was Neil Hunter, Chief Executive of the Scottish Children's Reporter Administration, and Chair of the national Whole Family Approach/ Family Inclusive Practice implementation group. The latter role involves overseeing the development, publication and implementation of the national Whole Family Approach/ Family Inclusive Practice framework, '[Drug and Alcohol Services – Improving Holistic Family Support](#)'.

Family members fed back very positively about Neil's after dinner speech ("The star of the show!"), which tracked his career in social work and health care, including in substance use services. He talked about being told in his early training not to involve families, as they were seen as part of the problem. Whereas now we recognise the importance of supporting and including the whole family. This history was helpful and healing for families to hear from someone who is now a figurehead for family developments in Scotland – many have experience of these stigmatising attitudes and felt vindicated to hear Neil's recollections.

His speech was described as very informative and clearly explained, with families feeling very included – this was a very personal presentation, and very down to earth. He made clear that the Whole Family Approach framework is not just a document gathering dust – there is a strong focus on implementation.

DAY TWO – WED 29 MARCH 2023 – FAMILIES AND SERVICES

Day Two will be opened by the Minister for Drugs Policy, Angela Constance. On Day Two, family members attending Day One will be joined today by those delivering and influencing treatment, care and support services across Scotland.

Day Two aims to help services strengthen family support and family inclusive practice by sharing positive and practical tips, tools and strategies in a 'masterclass' format. There will be the chance to hear directly from family members, and work through a number of real-life scenarios in collaboration with practice experts. We have capacity for a further 100 participants to join on Day Two, including 3 representatives from each ADP area across Scotland.

Programme

10.00am Registration with tea/coffee available

10.30am Morning Welcome from Gavin Heron (Family Member)

10.35am Opening Address by Angela Constance (Minister for Drugs Policy)

10.50am 'Yes we can!' How to build and embed a Whole Family Approach in practice with Mel McPherson (My Support Day), Rosie Welsh (South Lanarkshire ADP), Mark Healy (The Beacons) and Family First Responders

11.30am Break with tea/coffee available

12.00pm 'Show me the evidence' An overview of family support interventions with Lynne Wandrum (Scottish Families)

12.30pm 'What does change look like for families and for services?' A conversation with Tracey Clusker (Public Health Scotland), Lena McMillan (Scottish Families) and Lisa Kerr (My Support Day)

1.00pm Lunch (will be served in the restaurant)

2.00pm Afternoon Welcome from Sandra Holmes (Family Member)

2.05pm 'For me, it means...' Defining family-inclusive practice – a tabletop discussion and workshop with Scott Clements (Scottish Families)

2.50pm Break with tea/coffee available

3.15pm 'Let's Do This!' Panel Discussion, Q&A and Commitments with Sandra Holmes (Families Campaign for Change), Orlando Heijmer-mason (Scottish Government) and Simon Jones (Stirling & Clackmannanshire ADP)

4.00pm Close of Conference from Sandra Holmes (Family Member)

Source: Families on the Frontline Invitation and Programme

DAY TWO: MORNING WELCOME

Gavin Heron, Family Member



Gavin Heron opened Day Two by welcoming back the Day One participants and setting the scene for the new arrivals with an impassioned summary of the previous day's programme.

Gavin drew our attention to some of the key moments that were presented, acknowledged, or discussed including:

- ❖ Families understand more than anyone else and should be part of the solution;
- ❖ Families' loved ones have the right to the highest standard of health;
- ❖ An acknowledgement of the clear shift in thinking that had taken place in the room around people identifying as carers, and a recognition around what might be preventing that shift in thinking, both for individuals and for services;
- ❖ An increased understanding of mental health care, treatment and legislation; and the key message that confidentiality issues can be overcome in part by families sharing information with, and being listened to by, services even if they can't get the information they ask for;
- ❖ As family members, our own self-care is paramount;
- ❖ A sense of connection and solidarity amongst participants, and a growing movement of families finding their voices.

DAY TWO: WHO'S HERE TODAY?

Participants introduced themselves at their tables, again using these worksheets:

Hello my name is ...
I have travelled from ...
I am here because ...



Responses indicated 7 main motivations for attending, very much aligned with Day One (i.e. Connection, Sharing, Support, Learning, Campaigning, Change). Many Day Two participants noted that they were attending as professionals but that they were also affected family members:

1. Sharing, demonstrating and modelling good practice
2. Supporting families to take part; sharing views of those unable to attend;
3. Learning, including from elsewhere in Scotland
4. Meeting families, hearing from families
5. Connecting, networking
6. Improving family support and family inclusive practice
7. Creating change; learning how to make change happen.



I want to take learning back to our local area to influence practice, inform decision making and improve outcomes for people affected by alcohol or drug use.

I have a new role ... and want to make sure I shape services in the right way & clearly align it with ADP family support.

I work to improve support for families. I want to hear from families today.

I want to show that family recovery and whole family approach is possible in every community.

I want to make sure more families are involved in our ADP.

I'd like to hear about family support around the country & meet lived experience people.

I am here to learn, share and be part of change.

To further incorporate whole family approach.

Whole family approaches are key. I am excited to see what learning I can take from today.

I want to learn what the ADP can do better and how I can help make that happen.

I would like to learn from families what is important in development and delivery of services.

I am new in post and have to find out more and meet new contacts. 😊

DAY TWO, SESSION ONE: OPENING ADDRESS

ANGELA CONSTANCE, MINISTER FOR DRUG POLICY



Angela Constance opened her speech by reiterating the importance of supporting the whole family to recover from drug harms. She spoke about how important it had been to her in her role as Minister for Drugs Policy to meet with families and hear their views and experiences. Although hearing those stories can be difficult as they highlight the ways in which people's loved ones were failed they were often also full of hope and showed the strengths that families bring to their loved ones.

She then went on to say that that is why the conference was so important as it brought together services, decision makers and families together to learn from one another and identify ways forward.

In her speech, Angela Constance reaffirmed that people affected by substance use must be meaningfully involved in the design and delivery of local services. Although we know that everyone has the right to the highest attainable standard of mental and physical health our loved one's still face barriers to the realisation of this and their other human rights. Enabling people to participate in decision making is a key part of a human rights based approach and without that participation the decisions we make will not be as effective as they need to be. She then spoke about Professor Alan Miller who had delivered a session on day one of the conference. He is leading the National Collaborative which is bringing forward a vision for how human rights will be integrated in to all levels of decision making.

As well as the National Collaborative, participation is also key to family inclusive practice. Angela Constance highlighted work that Scottish Families have agreed to do with the Scottish Government to deliver further guidance for services to ensure that they can deliver their services in a family inclusive way. She referenced Neil Hunter, Principal Reporter and Chief Executive of the Children's Reporter Administration, who delivered the after dinner address on day one. Neil spoke to the importance of shifting the power dynamic between services and families to improve services. Angela Constance agreed with Neil that we have to shift the culture of services to work alongside families.

She then went on to speak about the intersection between substance use and mental health, which is very concerning to families. She described a statement she had made to Parliament the previous week about ensuring mental health and substance use services are joined at the hip. To achieve this, Scottish Government are asking all local areas to agree a protocol and make this available publicly so that it is clear how people will get help for both their mental health and their substance use issues. This will contribute to the embedding of Medication Assisted Treatment (MAT) Standard 9. Angela Constance reminded attendees that it is clear in the MAT standards that families should be included in the treatment of their loved one, if that is what they choose.

As well as being involved in their loved one's treatment, she also highlighted the importance of families being supported in their own right. Often this comes from a local family support group, after years of closed doors. To ensure more people can access this kind of support, Angela Constance announced that the Family Recovery Initiative Fund which provides small grants to grassroots family

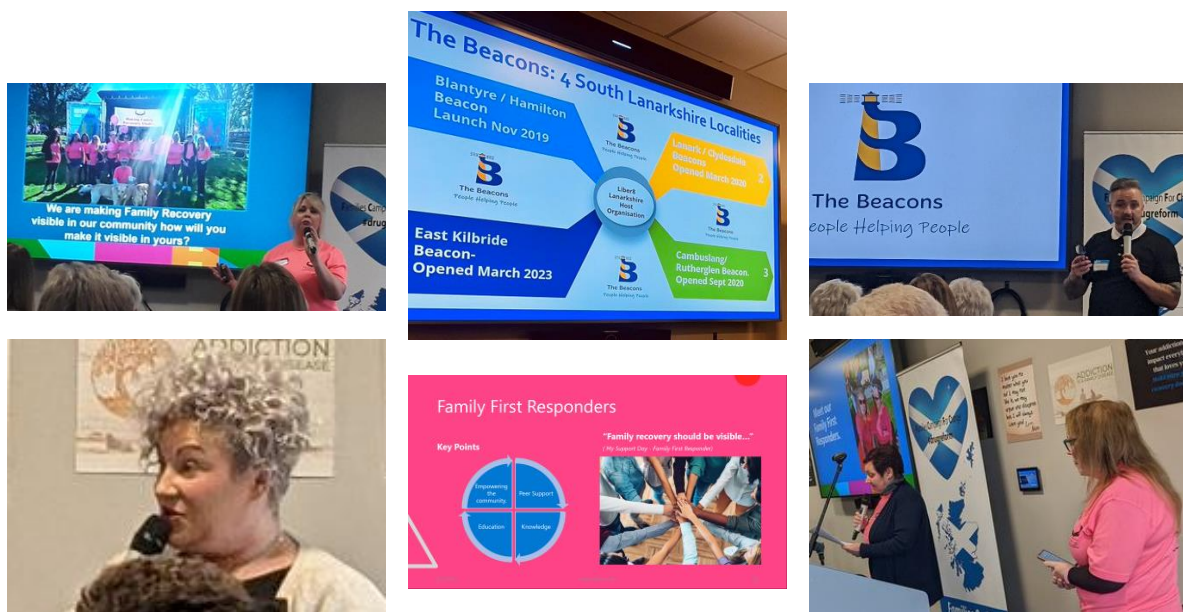
support groups will be expanded from £30,000 per year to £100,000 per year. This is administered by Scottish Families on behalf of the Scottish Government.

Angela Constance concluded by describing the conference as a step change for the family recovery movement in Scotland and thanking attendees for their participation.

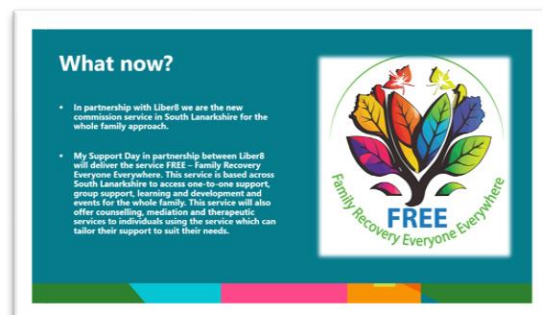
DAY TWO, SESSION TWO: 'YES WE CAN!' HOW TO BUILD AND EMBED A WHOLE FAMILY APPROACH IN PRACTICE

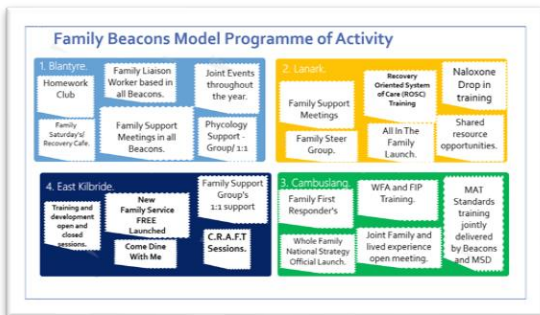
MY SUPPORT DAY, THE BEACONS AND SOUTH LANARKSHIRE ADP

Following the Minister's opening speech, the next session on Day Two brought together a group of presenters from South Lanarkshire, including My Support Day (family support organisation); The Beacons (community hubs) and South Lanarkshire Alcohol and Drug Partnership (ADP).



My Support Day presenters included staff and family members who are Family First Responders. Mel McPherson, CEO of My Support Day, opened this session with an inspiring and informative film about the development of the organisation and its day to day work, and how it had led the development of a whole family approach in the area.





The other presenters shared their own organisations' contributions to building and embedding this whole family approach. The purpose of this session was to demonstrate to services, commissioners and planners from other areas of Scotland that implementing a Whole Family Approach is possible – and to share a range of practical advice as to how this has been achieved in South Lanarkshire.

The full slides for this presentation, along with the film shown, can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

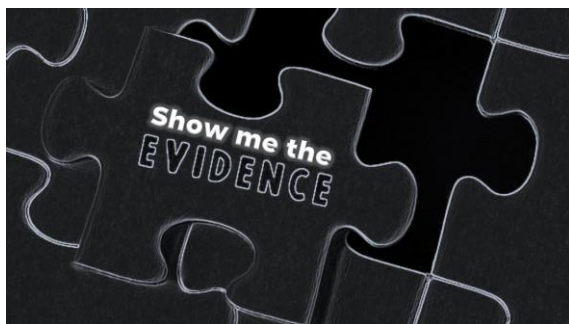
DAY TWO, SESSION THREE: 'SHOW ME THE EVIDENCE' – AN OVERVIEW OF FAMILY SUPPORT INTERVENTIONS

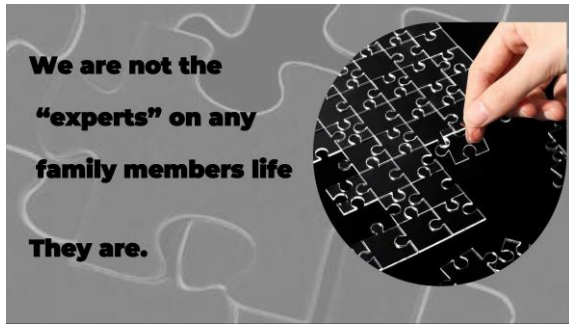
Lynne Wandrum, Scottish Families

Lynne Wandrum, Senior Family Support Development Officer, Scottish Families delivered a presentation and workshop on family support interventions. She started by emphasising that family members are the experts on their own lives – not services.

Lynne shared that Scottish Families has published multiple reports based on evidence from families, noting that you don't need to go further than the front covers to see the themes – from 'What about families?' to 'Ask the family!' to 'Constantly just holding it up and together'.

She provided an overview of a number of different interventions used by Scottish Families in our work with families: motivational interviewing, 5 Step, CRAFT, Peer Support Groups, SMART Family and Friends and Creative Coping. All of these interventions uphold our understanding that families prevent and reduce harm and risk; are supported by evidence; are relationship-based and are trauma-informed.

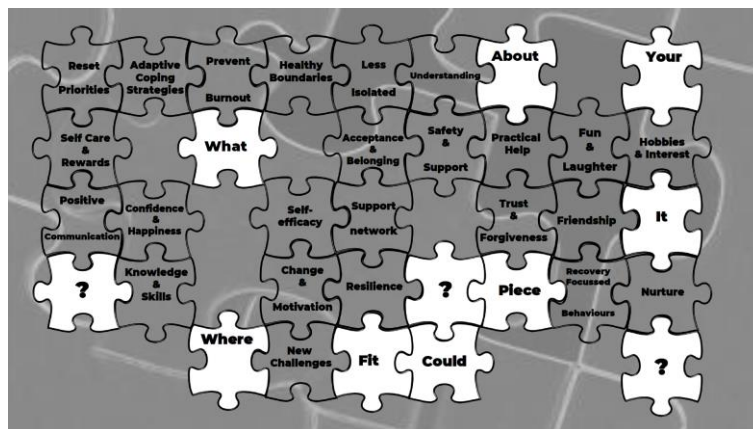




Together these created a large jigsaw puzzle, which each piece illustrating a different impact for family members, for example building confidence and happiness, safety and support, practical help, nurture, preventing burnout and so on.

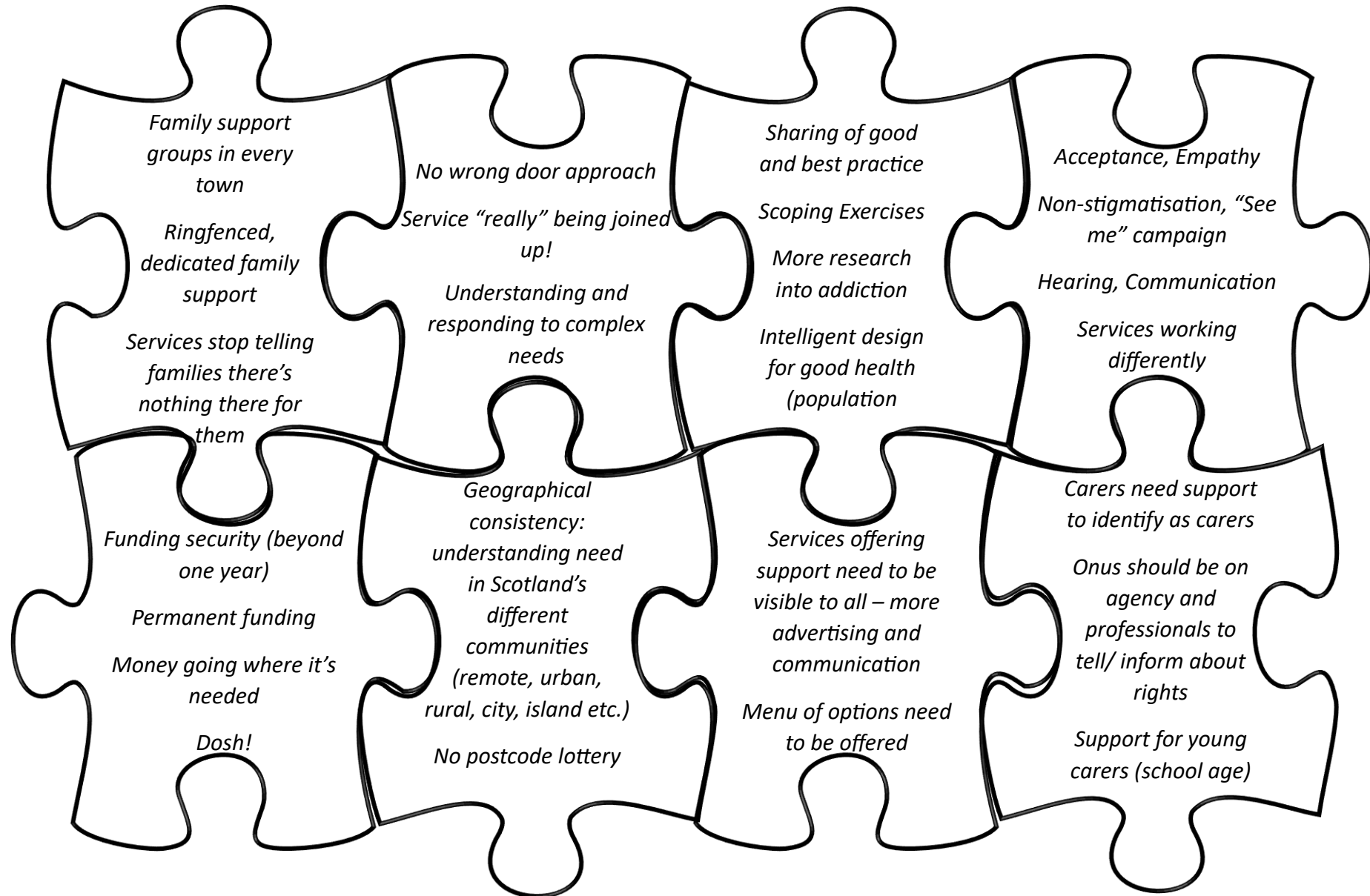
Lynne asked whether we now have every piece to complete the puzzle? Each participant was given a blank jigsaw piece and asked, ‘What about your piece? Where could it fit in?’

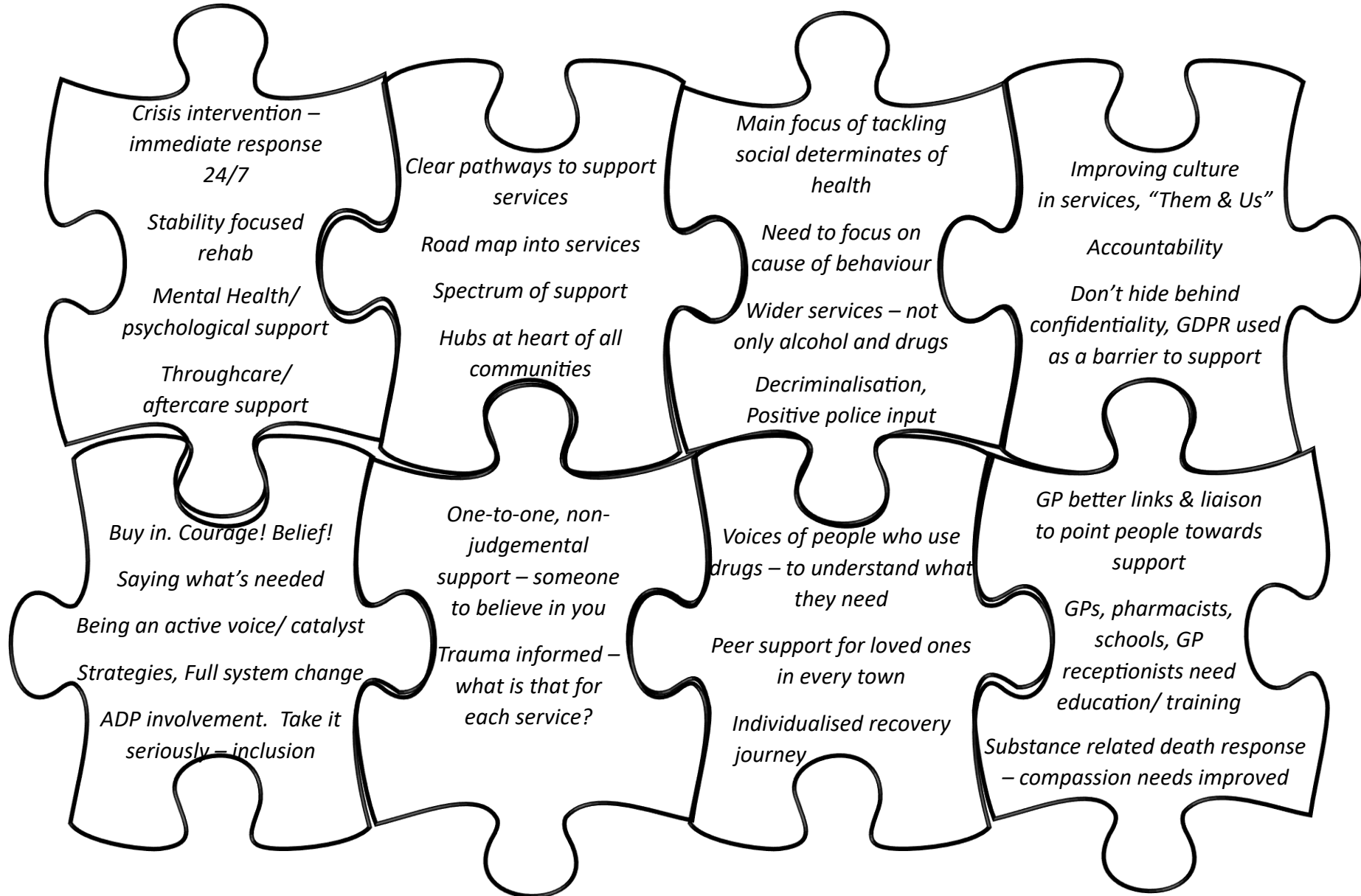
To capture this discussion, each table was given a sheet with a blank jigsaw puzzle drawn on, and asked to fill in the blank pieces: ‘What needs to be in place? What’s missing?’



The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

**Table Discussion on ...
What needs to be in place? What's missing?**





DAY TWO: AFTERNOON WELCOME

Sandra Holmes, Family Member



Sandra Holmes welcomed participants to the afternoon session on Day Two. Sandra established and runs the Midlothian Family Support Group, as well as setting up the national Families Campaign for Change group with other family members. It was Sandra who proposed the conference in the first place, recognising that families needed their own event alongside all the other events for professionals and services. She was instrumental in securing Scottish Government funding and Ministerial support for Families on the Frontline. Sandra was also part of the planning group for this conference, making sure that families' issues and priorities were at the centre. Reflecting back on her welcome speech, Sandra said she spoke from the heart, as a mum and as a family member.

DAY TWO, SESSION FOUR: 'WHAT DOES CHANGE LOOK LIKE FOR FAMILIES AND FOR SERVICES?' A CONVERSATION

TRACEY CLUSKER (PUBLIC HEALTH SCOTLAND), LENA MCMILLAN (SCOTTISH FAMILIES) AND LISA KERR (MY SUPPORT DAY)

This was a very informal session in a 'chat show' format. Tracey Clusker is currently part of Public Health Scotland's implementation team for the Medication Assisted Treatment (MAT) Standards. She previously led Midlothian's substance use service, and worked very closely with families (in particular Midlothian Family Support Group) in this role. Lena McMillan heads up Scottish Families' Forth Valley Family Support Service, and Lisa Kerr is a senior practitioner with My Support Day in South Lanarkshire.

They were asked to reflect on their experience around the theme of what change looks like for families and for services. Tracey spoke about the MAT Standards, how families had been involved in their development; and ongoing engagement with families during the implementation stage. Lena shared some family member journeys, and Lisa reflected on the kinds of differences they see in families who are supported by My Support Day.



Lena shared information on changes that family members have said they would like to see, based on a Whole Family Approach workshop held in Forth Valley last year. This included the financial, social and mental health impact of their loved one's substance use; as well as what families wanted to know from services, and what they want services to know and to provide.

The panel referred back to the earlier sessions at the conference around advocacy and rights, and the need for treatment services to be aware of and upholding these rights, rather than family members having to fight for these themselves.



DAY TWO, SESSION FIVE: 'FOR ME, IT MEANS...' – DEFINING FAMILY-INCLUSIVE PRACTICE – A TABLETOP DISCUSSION AND WORKSHOP
SCOTT CLEMENTS, SCOTTISH FAMILIES

Scott Clements, Head of Programmes with Scottish Families, led a session focusing on Family Inclusive Practice. He presented a historical timeline showing the repeated commitments to this in national policy, strategy and guidance documents over the past decade, from the Quality Principles (2014) to the National Drugs Mission (2022).



Family Inclusive Practice in Policy



	August 2014	October 2014	November 2018	May 2021	December 2021	July 2022	July 2022	August 2022
<p>Rights, Respect and Recovery Vision: Scotland is a country where "we live long, healthy and active lives regardless of where we come from" and where individuals, families and communities:</p> <ul style="list-style-type: none"> • Have the right to health and life - free from the harms of alcohol and drugs; • Are treated with dignity and respect; • Are fully supported within communities to find their own type of recovery <p>The framework for families affected by substance use focuses on improving holistic family support. It re-emphasises the importance of families as partners in supporting their loved one's treatment and recovery. It also stresses that families need and deserve support in their own right and recognises the need to support children affected by family substance use</p>	 The Quality Principles: Standard Expectations of Care and Support in Drug and Alcohol Services Scottish Government	 Outcomes Framework for Problem Drug Use NHS Health Scotland	 Rights, Respect and Recovery Scotland's strategy to improve health by preventing and reducing alcohol and drug use, harm and related deaths Scottish Government	 Medication Assisted Treatment (MAT) Access, Choice, Support Scottish Government	 Families Affected by Drug and Alcohol Use in Scotland A Framework for Holistic Whole Family Approaches and Family Inclusive Practice Scottish Government	 CHANGING LIVES Our Final Report Scottish Government	 "What about Families?!" Reflections and Recommendations for the Scottish Drugs Deaths Task Force – A Report by The Family Reference Group Scottish Families	 National Mission on Drug Deaths: Plan 2022 - 2026 Scottish Government
	<p><i>Services should be family inclusive as part of their practice</i></p>	<p><i>There is highly processed and review-level evidence that involving families in recovery care plans for affected individuals and providing support for family members themselves is beneficial to improve outcomes for both parties</i></p>	<p><i>Ensure family members will have access to support in their own right and, where appropriate, will be included in their loved one's treatment and support</i></p>	<p><i>The service will ensure people are aware of their right to have someone, such as a family member or nominated person, to support them while they are in MAT and staff will actively assist and support people who choose this option</i></p>	<p><i>Workforce: A trauma informed, compassionate, skilled and valued workforce who are family inclusive and able to increase feelings of safety and trust with families</i></p>	<p><i>Support and training on a family-inclusive approach should be provided for people working in services. This will help to ensure that engaging an individual's family in their treatment is effectively managed and supported.</i></p>	<p><i>Presumption of family involvement by treatment and care services – family inclusive practice becomes an 'opt out' option not an 'opt in' option</i></p>	<p><i>Family members are empowered to support their loved one's recovery</i></p> <p><i>Family members are supported to achieve their own recovery</i></p>

Yet from Scottish Families’ 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.

Scott outlined what Family Inclusive Practice looks like when it is implemented, what this means for family members (or other ‘nominated persons’), and what this means for families. He illustrated how it can be practiced in both tokenistic and meaningful ways; the interplay between values, beliefs and attitudes; and the many ways in which families can be an asset for services as well as their loved ones. A Spectrum of Family Engagement was presented from Excluding to Empowering, with benefits for individuals, families and systems, and opportunities for support, increasing from one to the other. Scott introduced the model of Family Sensitive Culture, which incorporates both unstructured interventions which consider families and structured family inclusive practices.

What is Family Inclusive practice?

- Involvement of significant members of an individuals social context (often their family) in assessment and care planning.
- Seeks to involve families in the scope of the work even though the main focus of the intervention may be an individual in the family. (Partners in treatment)
- Valuing families and recognising families have support needs in their own right (regardless of whether the individual using substances is in treatment).

Family Inclusion Triangles

Tokenistic family inclusion triangle:

- Professional perspective:** "The family is a barrier to care and they are only included to facilitate the service to the individual."
- Service perspective:** "The family is a barrier to care and they are only included to facilitate the service to the individual."
- Individuals families:** "The need to get services and support for things that..."

Meaningful family inclusion triangle:

- Professional perspective:** "We would like to get your knowledge and experience to help us understand the person and their needs."
- Service perspective:** "We would like to get your knowledge and experience to help us understand the person and their needs."
- Individuals families:** "We would like to get your knowledge and experience to help us understand the person and their needs."

Spectrum of Family Engagement

EXCLUDE	INCLUDE	INVOLVE	COLLABORATE	EMPOWER
Client-Exclusive Families are not considered or engaged in efforts to work with individual clients.	Person-Centred Family-Aware Provide families with information to assist them in understanding approaches and options.	Family Involved Invite feedback from families in service and decision-making to improve their experience and help us progressively understand and respond.	Family-Focused Build on individual and family strengths. Collaborate with families for advice on decision making at the service level.	Family-Centred Strengthen family relationships and confidence. Empower families to have a primary role in decision-making at both the service and system levels.
System Orientation Systems offer no promises to families regarding information, involvement, involvement or support.	Family Engagement Goals We will keep you informed to the best extent possible regarding the plan of care, effectiveness of interventions and opportunities for family involvement.	System Promise to Families We will listen to you and acknowledge your concerns and hopes. We will let you know how your input has influenced our decisions.	Family Perceptions Our affected family member(s) receives services and are informed.	Family Perceptions Our affected family member(s) receives services and are informed.
System Orientation Systems offer no promises to families regarding information, involvement, involvement or support.	Family Engagement Goals We will keep you informed to the best extent possible regarding the plan of care, effectiveness of interventions and opportunities for family involvement.	System Promise to Families We will listen to you and acknowledge your concerns and hopes. We will let you know how your input has influenced our decisions.	Family Perceptions Our affected family member(s) receives services and are informed.	Family Perceptions Our affected family member(s) receives services and are informed.

Greater Opportunity for Benefits for Individuals, Families and Systems

More Opportunities for Support for Individuals and Families

Involving Families

FAMILY SENSITIVE CULTURE

Structured family inclusive practices

Unstructured interventions that consider family

Specialised interventions

Structured Family Inclusion

Family Sensitive Practice

The full slides for this presentation can be seen here: <https://www.sfad.org.uk/families-on-the-frontline-2023-conference>.

Tabletop discussions followed, considering two questions:

- Q1: From a family perspective, what do you want services to do to include you?**
- Q2: From a services perspective, what can you do differently to include families more?**

From a **family perspective**, family members wanted services to:

- ✓ Advertise, signpost and make direct referrals to **family support** from all services, e.g. treatment services, primary care, social work;
 - Automatically refer family members for support in their own right when their loved one access treatment; and support families where their loved one is not in treatment;
 - Help develop/ provide family support services;
 - Offer 24 hour/ out of hours help to family members for guidance and support;
- ✓ Be aware of **family and carer rights**; offer advocacy support; and empower families to exercise these rights;
- ✓ Really **listen to families**, and make time for them, so they don't need to repeat their story "time and time again"; Listen to families even where their loved one has not given consent;
- ✓ Treat family members and their loved ones with **dignity, respect, empathy and courtesy**, "like human beings", the same as if they were affected by other conditions or illnesses; this may mean "attitudinal change"; Understand the journey family members have been on, and that they may be "grieving for their missing lives";
- ✓ **Assume families will be included**, or offer an 'opt out' not an 'opt in';
 - Include family members in care planning, treatment decisions, and the design of care pathways and aftercare; Follow up when family members escalate concerns about their loved one;
 - Invite family members to attend appointments, risk assessment meetings etc from the start, and offer separate conversations and information-sharing opportunities for family members;
 - Let individuals know that it's OK to have their families included;
 - Communicate, support and guide families through interventions like home detox, rather than leaving them to deal with this on their own;
- ✓ Nominate a **single trusted Point of Contact** or Nominated Person, so families and their loved ones don't have to deal with multiple agencies; introduce Family Liaison Workers;
- ✓ Don't use "meaningless language"; offer "**simple conversations**", plain English, family-friendly language, and no acronyms; and use consistent language and service names which explain what they do;
- ✓ Provide information about different support services and treatment options for their loved one, and **how to access these**;
- ✓ Value **family members as assets**, and recognise what they can bring to treatment and recovery (including whole family recovery), but "stop putting responsibility onto families";
- ✓ Introduce the **same standards for alcohol as for drugs**, e.g. "a MAT Standard for Alcohol".
- ✓ Be **honest and realistic** with families as to how they can help their loved one, including education around alcohol and drugs, mental health/dual diagnosis;
- ✓ Provide support for **mental health issues and criminal justice** (including prison) issues, as well as substance use issues;
- ✓ Offer **mediation, conflict resolution**, and relationship support;
- ✓ Consider the **whole family** as a unit, and see a holistic picture of the entire environment.



From a **services perspective**, ideas to include families more included many of the same suggestions. This is very positive, as it indicates that families and services are generally in agreement about what good practice looks like, and the actions which would improve family inclusive practice. Some barriers getting in the way of this were mentioned, including resourcing, different priorities, and confidentiality:

- ✓ Recognise **consent shouldn't only be sought at assessment**, the question needs to be asked on an ongoing basis; "Don't give up at the first 'No' you hear";
- ✓ **Assertive outreach** to families; more home visits; build relationships with families to understand their relationships and journey; bring families into support earlier; be approachable;
- ✓ **Involve** families in conversations; **consult** with family members; **advise** families they can be involved from assessment onwards and communicate this on websites; create a single point website with information for families;
- ✓ Keep communication open; **Listen** to what they say and **hear** it;
- ✓ Support escalation of concerns;
- ✓ Understand that **most information can be shared**;
- ✓ Find out what people's journey is to **evaluate** services; Involve families in **service redesign**;
- ✓ Family representation alongside professionals; **Family lived experience group** to inform service design;
- ✓ Be sure a **care plan** is in place, and **include primary carer/contact** in this care plan;
- ✓ Address the gap in workforce knowledge; **Retrain and upskill the workforce** (including all services) on family inclusive practice, including how to involve the family at every point in service delivery; deliver joint training with people with lived experience;
- ✓ Arrange **training for families** on what you can/ cannot expect from services; treatment processes and options; the steps families can take to support their loved one (e.g. reduce substance use); provide information sheets on harm reduction/risk/prescribed medication etc;
- ✓ Better **interagency working**;
- ✓ Less obstacles for **funding**; increase in budget; lower **caseloads/** less staff **turnover** to allow time for families/ building therapeutic relationships with families;
- ✓ Offer **Family Support Groups**; offer services just for family members; recognise not everyone needs to be getting the same service;
- ✓ Dedicated and embedded **family liaison officer**; including for hospital admissions/ discharge;
- ✓ Help families realise **their wellbeing and health** is important as well.
- ✓ Signposting/ be aware of **other services/support** in the local area; good practice in West Dunbartonshire with a QR code to link to services information;
- ✓ No wrong door – **don't ask people to repeat their stories** over and over again – have a better system to share the story;
- ✓ Ensure national consistency; need **support and guidance from government** to fill the implementation gap between policy into practice;
- ✓ Have a **team around the family**, not just a Team Around the Child (TAC); Understand we are all mutually trying to support and help their loved one;
- ✓ Introduce **"System plans"** for service users including criminal justice, homelessness, housing, substance use; take the initiative to link in with other services.

Workers should know what the rights of family members are. Human rights apply to everyone.

Ask questions – "How are you?"

Ask who supports the individual who uses the substance

Make a statement of intent on how to support/include families and have this on their materials

Listen hard and have humility – take on board what the family wants.

Respond to families' needs in the order they need - not how the service sees it.

DAY TWO, SESSION SIX: 'LET'S DO THIS!' – PANEL DISCUSSION, Q&A AND COMMITMENTS

SANDRA HOLMES (FAMILIES CAMPAIGN FOR CHANGE), ALISON CROCKETT (SCOTTISH GOVERNMENT) AND SIMON JONES (STIRLING & CLACKMANNANSHIRE ADP)


A lot was packed into the final session of the Conference, including a Panel Discussion, Q&A session and the chance for people to make their own commitments to next steps – so maybe a bit more than we had time to do by that point!

We are grateful to our Panel members – Simon Jones, Stirling and Clackmannanshire ADP; Sandra Holmes, Families Campaign for Change; and Alison Crockett, Drugs Policy Division, Scottish Government. Alison kindly stepped in to replace Orlando Heijmer-mason who had had to leave to brief the newly appointed Minister for Alcohol and Drugs.

Participants had had a chance to submit questions earlier in the day, to ensure that a range of questions could be posed to the panel. We have included just a sample of these in this report.

The panel discussed a range of issues, challenges and questions posed by participants, from very specific local or issue-based scenarios to the broad national policy framework.



<p><i>How can we reduce the number of people involved in our loved one's care plan?</i></p>	<p><i>What are you actually going to do to link mental health services and addiction services?</i></p>	<p><i>Why are services still a postcode lottery?</i></p>
<p><i>Where do you start if there are no family support groups in your area (as an ADP) and you want it to be community led?</i></p>	<p><i>What can be done better to help families get through the minefield that exists when they lose a loved one to alcohol or drugs?</i></p>	<p><i>How will you hold ADPs accountable who fail to implement family inclusive practice and MAT standards?</i></p>
<p><i>Is there any thoughts about legislation to make alcohol more difficult to obtain? It's possible to get several litres of vodka delivered to your door at 10am and there are many companies prepared to do so.</i></p>		<p><i>MAT standards are great but which drugs are covered as I believe cocaine and alcohol are not – what is a place for them? There is a lack of clarity as to what the MAT standards support. All addictions?</i></p>

<i>Are there plans for family support services to be funded equally to drug and alcohol services? How do we ensure family support already available isn't losing out?</i>	<i>How do you prepare to improve and increase the provision of residential rehab across Scotland, considering currently some areas have zero residential rehab provision?</i>	<i>How do you reconcile the police involvement of viewing addiction as a criminal issue with developing an empathetic family supporting framework?</i>
<i>Who is accountable for the ADP spend? How is it used – who gets what?</i>	<i>When is there going to be a National Telephone Helpline 24/7?</i>	<i>Can Scottish Government colleagues commit to a follow-up conference in one year's time?</i>

DAY TWO, FINAL REFLECTIONS

Participants were asked to finish the event by recording their own reflections, using these worksheet questions:

SOME REFLECTIONS

This morning I was feeling ...
Now I am feeling ...
You can add some comments if you wish ...

There was limited time for this reflective activity, but from those who did share their thoughts, participants had started the day with many different feelings, from curious, unsure, apprehensive, anxious, to hopeful, excited, enthusiastic and *"raring to go"*.

In most cases participants ended the day in a better place, saying they were now motivated, delighted, better informed, hopeful, inspired, optimistic, energised, invigorated, networked and even *"well fed"*! Some felt very fired up by the end of the event, writing *"EM-POWERED Fight Fight Fight"* and *"Full of fight and passion to help make the changes!"*

Some had been left with more questions or things to do, saying they were now *"Motivated but loads of actions to consider"*, would be *"going away with ideas"*, or were *"Determined to get answers and to question my local ADP as to where the money goes"*. For some their feelings were less positive, for example feeling *"Jealous because other areas have great services for families"*, or *"annoyed"* at the postcode lottery of family services they had learned about.

The Comments section included some suggested Recommendations and Next Steps which are picked up in the following section.

“WHEN’S THE NEXT ONE?!” – RECOMMENDATIONS AND NEXT STEPS

“It was a very good couple of days in which we were given so much useful information. I had never thought of myself as a carer but in fact each of us who support & look after our loved ones is in fact a carer and as such we have carers rights & I also learned that if we feel we are not being listened to or our needs met when we are advocating for our loved ones in a care setting we have a right to challenge it. We met so many amazing inspiring people and most importantly we as families have a voice and need to drive on for changes & policies to happen, the love we have for our loved ones is all the power we need to change the system for the next generation and hopefully they won’t have to face as many challenges when seeking out help, care & recovery.” (Family member participant)

Planning and delivering this conference was a significant undertaking, and we are keen to build on its legacy. The feedback from participants has been incredibly positive, including family members and those delivering and influencing treatment, care and support services (of course recognising some participants were members of both groups).

Immediate legacies from the event includes:

- ✓ Individual family members’ increased knowledge, skills and confidence; including around their rights as family members and carers; access to resources such as the Mental Welfare Commission; and ways to enhance and prioritise their own wellbeing and self-care;
- ✓ Individual family members sharing this learning with their own networks, including wider family members and family support groups;
- ✓ Professionals increased knowledge, skills and confidence in their work roles, including understanding the evidence base for, and need to improve, family support and family inclusive practice; identifying practical tips, tools and strategies for change; connecting with real practice experiences; and recognising family members’ experience and expertise;
- ✓ The development and strengthening of contacts, relationships and networks between participants over both days;
- ✓ A shared commitment to change and improvement across Scotland, recognising “*Things must change – [the] status quo is not an option*”:

“I hadn’t appreciated how much of a postcode lottery people experience but have been enthused by the example of good practice & ideas that have been shared. Although families experience barriers within services, many people delivering services and developing strategy are enthusiastic and passionate about change. Many of these people in services are also family members or people affected by substance use.”

There were some **immediate action points** to be progressed following the event:

- Following up with Alcohol and Drug Partnerships who did not send representation to Day Two;
- Sharing information with family members about how they can get involved in influencing changes and improvements in their own areas (e.g. via Lived Experience Panels).



This event was never intended to be a one-off, and our planning group has begun discussions on what happens next. In her Day Two opening address, Angela Constance described the event as a “*step change for the family recovery movement*”, and we have a real opportunity to move forward.

We had numerous enquiries about the event from people who were unable to attend due to the event capacity. The planning time and investment involved in such a large-scale residential and national event mean that this is unlikely to be repeated in the short-term, but there is interest in regional or themed follow-up events.

We would like any subsequent programme of events to:

- 1) Continue to be **family-led**;
- 2) Continue to build in **time/space for family members to meet in their own right** (e.g. a separate day or event for families, similar to the conference, although not necessarily the day before – future events are likely to be non-residential);
- 3) Be **planned and delivered in collaboration** with local family members, groups and services, using a co-production approach. This means the events may not look the same in each area;

- 4) Focus on **building on opportunities, strengths and assets across Scotland** – we are pooling our information and intelligence about where these lie, including the Scottish Government’s assessment of ADP returns alongside other knowledge about what is happening on the ground;
- 5) Ensure **sufficient time for conversations and engagement**, and make sure groups are not too large for this;
- 6) Recognise that **we always need to start with families**, and building their knowledge, skills, confidence and connections. We know that when families learn about their rights and are supported to use these rights, that things change for them and for their loved ones.



“Over the past 2 days, I’ve learned so much about our rights as carers and how we can help influence positive changes within addiction services. I have met some fantastic people that we plan to visit when they have a family group on. There was such a mixed bag of different people there, from fire brigade, ambulance service, addiction nurses, ADPs, and of course the families of people in addiction. I was astounded at some things I listened to and heard some stories from others about how their loved ones have been affected and how mental health and addiction comes hand in hand. Voices were definitely heard today and another government member has taken note of a lot of things we had asked and hopefully sometime soon Scotland will have a 24/7 helpline we can call as well as other improvements on standards that are already in practice. Again, thank you ... we had a blast.”

(Family member participant)

AND FINALLY ... THANK YOU!

The Families on the Frontline conference was a phenomenal team effort, and so a huge thank you to...

- ♥ Our conference planning and delivery group of Sandra Holmes (Families Campaign for Change), Mel McPherson (My Support Day), Justina Murray, Ayllice Millar, Susie McClue (Scottish Families); Aime Jaffeno and Amanda Adams (Scottish Government);
- ♥ The Scottish Government for funding support which covered all venue and catering costs, as well as travel and additional accommodation costs for island participants;
- ♥ Our family member Chairs – Colin, Karen, Gavin and Sandra; all presenters and table facilitators;
- ♥ Family Support services and staff from a number of organisations who helped us to identify family members from each area to attend, and who helped family members to attend and to participate over the two days;
- ♥ Alcohol and Drug Partnership leads for coordinating Day Two attendance from their own areas;
- ♥ The National Family-Carer Support Alliance for advice, support and contacts;
- ♥ All participants across Day One and Day Two for demonstrating such openness, enthusiasm, enquiry and commitment to change.



For further information, please contact:

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