

What Do We Already Know? Our Whole Family Evidence Bank

Part of the Ask the Family Engagement Project

February 2021



Background

The Ask the Family engagement project was commissioned by the national Whole Family Approach/ Family Inclusive Practice Working Group in 2020 to bring together family perspectives on whole family support and family inclusive practice. The project aimed to test out a new set of national Whole Family Approach/ Family Inclusive Practice Principles to apply to all services supporting families affected by alcohol and drugs.

We carried out a national online survey, hosted a conversation café, and asked family members to share their views through various creative means (e.g. film, poems, letters etc). However we also felt it was important to review what families had *already* told us about what good family support and family inclusive practice looks like to them.

We picked five recent research reports produced in the past year by or for our respective organisations, and assessed them in the same way as the other family engagement activities in the project. This involved reviewing:

- How far are the Principles as *written* supported by families? (Top Down)
- How far do families' *own* descriptions of family support cross-check and align with the draft Principles? (Bottom Up)

We used a standard template to pick out key illustrative quotes from each report (What Did Families Say?) and recorded three 'take-home messages' for each publication.

The publications were:

1. Holleran, John (2020) 'Constantly just holding it up and together. Exploring family support in relation to problem substance use in Scotland', Scottish Families.
<https://www.sfad.org.uk/constantly-just-holding-it-up-and-together>
2. Alexander, Katie; McLaughlan, Lisa; and Gentile, Angela (2020) 'Conversations for Change: Family Rights and Inclusion for families affected by substance use in East Lothian' (A resource for families and professionals), Circle and MELD.
<https://circle.scot/families/family-rights-and-inclusion/>
3. Nugent, Briege (2020) 'Evaluation of Circle's East Lothian Children Affected by Parental Substance Use Project' (unpublished)
4. Scott, Jane (2020) 'Action for Children - What works for children and young people in family support? Executive Summary' (unpublished)
5. Scottish Families (2020) 'The Story of Behind the Numbers', Scottish Families
<https://www.sfad.org.uk/behind-the-numbers>.

1. Constantly Just Holding It Up and Together

What Is This?

This study was carried out by John Holleran (Families and Communities Manager at Scottish Families) as part of a Masters in Contemporary Drug and Alcohol Studies at the University of the West of Scotland. It aimed to address the gap in understanding about family members' experience of support in Scotland, including life with substance use in the family, routes to support, and the impact of support. The research was based on qualitative interviews with ten family members, all of whom were accessing evidence-based family support.

What Did Families Say?

Families only reached support as a last resort after many years, when they could no longer cope. Family support was described positively, a “safe place” which reduced isolation and developed knowledge and skills. Families found new coping and response strategies, improved self-care, reduced risk, and improved communication and family relationships:

“At the time it was just survive-survive-survive. ...You're worried [husband] is going to die, in your daily list of things that are gonna happen you're like... oh shit, he's gonna die today & it's constantly on your list of things to consider in today's shopping list - husband's dead! ... Constantly just holding it up & together.”

“As you grow through it, you grow in the knowledge of it and you recognise that person has the right to live their lives the way they want to and accepting that is very difficult to get to but it does come. ... I can be there but I can't change him and I can do the best I can with the support I have and the information I've got and it shows up that side of things to you and it makes it easier to deal with it all.”

“She [worker] helped me visualise the scenarios and prepare for how I might be if the worst of my fears happened.... She said, ‘when you go into the hospital and when he says that, when he says eff off – just get up and say I'll come back at a better time’ and just leave... It helped bolster me from becoming totally, totally overwhelmed and destroyed with the amount of chaos and sadness that was around so it was a really helpful tool and it worked.”

Three Take-Home Messages

1. Health, care and other services are missing opportunities to reach and support families until the point of crisis, leaving the onus on families to find support.
2. Many families give the impression everything is fine due to shame, guilt, fear and anxiety, and (where there are children involved) to avoid statutory intervention.
3. This research demonstrated that evidence-based family support for adult family members improves outcomes for the whole family.

Reference

Holleran, John (2020) ‘Constantly just holding it up and together. Exploring family support in relation to problem substance use in Scotland’, Scottish Families.
<https://www.sfad.org.uk/constantly-just-holding-it-up-and-together>

2. Conversations for Change

What Is This?

This project was a systems change initiative led by Circle and Meldap in East Lothian, which gathered families' and services' views about family inclusive practice, whole family approaches and family rights in the context of substance use. The project explored the barriers and challenges faced by families affected by substance use, and the solutions that families need from their communities and services. A website and resource materials have been developed for families and professionals (see link below).

What Did Families Say?

Conversations for Change gave space for families to share their own stories and case studies. They shared their understanding and experiences of family support and family inclusive practice. Good support meant workers “*never gave up trying*”, trust, and supporting families to develop new knowledge and skills. They noted there was not always support for adult family members in their own right, and recognition that there are many barriers stopping families reaching out. Discrimination, stigma and shame were common themes (“*It was great when (we) were on holiday, no one knew us and chatted to us like we were normal*”). The independence of family support was valued:

“...always knowing that there’s someone you can hit on speed dial when I’m really struggling. You can have the most loving family and friends, but sometimes you just want to speak to someone else, because you get a different perspective on things, you know. Even then, you might feel a bit embarrassed. It’s good to know there’s another person out there listening, who’s genuinely concerned.” (Family questionnaire)

“Family support allows families to live their lives and not put their lives on hold. ... Family support gives them the tools to start living again. It teaches families how to live with substance use in the family and live their lives. Family support allows people to share their experiences and stops them from feeling alone. She said families become obsessed with trying to save their loved one. Sandra says that families can’t save their loved one, but they can love and support them. Family support can give families hope.” (Interview with Sandra, family member)

“Andy thought that some of the challenges and barriers to receiving help were: not wanting to betray the family; feeling like he is being left to make decisions when things go wrong or change; not having specific support, feeling as though ‘we’re on our own’; and that there is nobody around to come and advise them. Andy understands that the social worker is for the children, but he asks, who is there for them, to support them and answer questions?” (Interview with Andy, kinship carer)

Three Take-Home Messages

1. Family support allows families to live their lives and not put their lives on hold.
2. How services engage is more important than what they do.
3. Families currently have limited awareness of their rights to health, a life free from harms caused by substance use, and to support in their own right.

Reference

Alexander, Katie; McLaughlan, Lisa; and Gentile, Angela (2020) ‘Conversations for Change: Family Rights and Inclusion for families affected by substance use in East Lothian’ (A resource for families and professionals), Circle and MELD. <https://circle.scot/families/family-rights-and-inclusion/>

3. Circle Families Evaluation

What Is This?

This evaluation of Circle's Children Affected by Parental Substance Use project in East Lothian was carried out by Dr Briege Nugent, an independent research consultant. Circle's Family Outreach Workers support families affected by parental substance use on an outreach and on a voluntary basis. They offer family group work and one to one support for individual family members, including emotional and practical support focused on building social capital and connecting with wider services. The evaluation was commissioned by Circle, and included interviews with family members, desk research, and videos of young people and their families produced by Media Education.

What Did Families Say?

These key quotes highlight the importance for families of Circle's whole family approach (not just supporting the adult or the child); their support for parents to advocate for themselves; the worker's 'stickability' ("*He has always been here*") and asset-based approach:

"This is different because with other services they either work with the adult or the child, they don't work with them both, but with this they do. He has helped us to come together and with attending meetings at the school with me he is helping me to understand and to be understood." (Mum supported by Circle)

"When we went to the Children's Panels, there were lots of services there and I find it hard to talk. At one of the meetings people were being really negative about the past and C (worker) spoke for us about how positive things are now and it changed the way the meeting was going. He helps me to have the confidence to speak too and when I am not good at getting my point across he helps with that." (Dad supported by Circle)

"He (worker) helps me to do things I never thought I would be able to do, like the volunteering...He always looks at things from my point of view and understands what is happening and is able to read the situation. He has always been here... Before I would have been missing appointments but now I can make them. We are seeing the kids more and our whole lives have changed from how they were." (Dad supported by Circle)

Three Take-Home Messages

1. The relationship between the worker and the family is central to any progress made.
2. Helping families to engage and overcoming mistrust of services requires time and persistence.
3. The level of practical as well as emotional support, and that this is a whole family approach, sets it apart from other services.

Reference

Nugent, Briege (2020) 'Evaluation of Circle's East Lothian Children Affected by Parental Substance Use Project' (unpublished)

4. Action for Children 'What Works' Report

What Is This?

This independent study by Jane Scott was commissioned by Action for Children to identify core elements in the organisation's family support approach, and strengthen the national evidence base. It focused on four diverse Action for Children services in Aberdeen, Highland, Glasgow and Dumfries & Galloway. All participants were asked to identify what changes for families could be linked back to support, and what might have happened without it.

What Did Families Say?

Many positive impacts of support were identified for families, including individual changes (e.g. self-confidence, increased trust in services, reduced stress/anxiety) and relationship changes (e.g. less family conflict). Families were "*helped to find their voice and be clear about their rights*", allowing greater participation in decision-making, and support to build connections to other services. Some families were fearful that asking for help would involve social work or police. In rural areas it was hard for families to access services anonymously. Most felt without support their situation would have stayed the same or worsened:

"Families ... were clear about the reasons why they had been referred to services and honest about the concerning behaviours of their child or young person, about possible neglect, parents' own mental health and feelings of isolation, anxiety and, at times, an overwhelming inability to cope." (p2)

"Values of being open, honest, respectful, able to listen and express empathy and the principles of services being needs-led, accessible, flexible, working at the pace of the individual, and providing both practical and emotional support were common to all four services which participated. Key to it all are relationships. This was also recognised by families." (p3)

"Families reported significant changes to their child's behaviour, to routines and boundaries and experienced more positive family relationships which had improved family life, parental stress and anxiety. Families were supported to build or re-build their relationships. ...There was less shouting and fighting with fewer arguments within the family." (p2)

Three Take-Home Messages

1. Taking a child-centred and whole family approach helps "*get underneath the issues*" and understand family dynamics. Getting the beginning and end of support right is vital.
2. Common principles underpinning family support included trust, openness and flexibility; non-judgmental person-centred support; workers as humans with relationships being key; and worker consistency and "*stickability*".
3. Effective service features included services "*being present*", accessible, quick to respond and flexible in terms of duration (including time for the family to effect change); offering a range of interventions plus advocacy; helping to build social supports.

Reference

Scott, Jane (2020) 'Action for Children - What works for children and young people in family support? Executive Summary' (unpublished)

5. Behind the Numbers

What Is This?

Behind the Numbers was a campaign launched by Scottish Families in July 2019 to highlight the hidden role of families in preserving and saving the lives of those at high risk of drug-related harm and risk. Through a series of short films, four family members talk about their own experiences of caring for their loved one and trying to keep them alive. They expose how a lack of family support and family-inclusive practice increased risk for them and their loved ones. 'The Story of Behind the Numbers' was then published in 2020, bringing together learning from the campaign with five recommendations for services.

What Did Families Say?

The four family members (three mums and a daughter) shared different experiences but there were many common threads, including the impact of stigma; the lack of family-inclusive services; the importance of dignity, respect and a human approach; and the importance of hope and belief that change is possible. Three of the four had ended up establishing their own family support groups due to the lack of other provision:

"There's that stigma that families are up against. ... The form of stigma I got was oh I was classed as a mother from hell. It comes from people who don't have any experience or don't have a family member which is a rarity, you're very lucky if you're not effected by addiction in your family nowadays. ... It's that whole thing about judgement. Until it comes to your door, you just don't know." (Karen, Mum)

"My experience going there was I was met by a worker, Kevin [son] and I, but I was excluded from the initial interview. I did say I would like to be with him because I want to know what's going on. 'Oh no he's an adult and we need to see him on his own'. So it was an experience for me of exclusion that I didn't like. Not that I was going in there to say 'I want this, I want that' but I just wanted to know what was available, how they would treat him with his problem. But as I say I was excluded from that. And I never really came into contact with other services." (Caroline, Mum)

"In our area, in Midlothian at the time, there was only six wee plastic chairs in the waiting room and there was a notice on the door to say you can't bring anyone with you because we don't have enough seats for anyone else to sit in them so I wasn't allowed to go to an appointment to help support her [daughter] when she was feeling quite vulnerable." (Sandra, Mum)

"We had lots of services [coming into our house]... You'd get one person that came in and seemed that they wanted to make a difference, and here was where we were going to go. And then within 2 weeks of working with them it was just as if they were fed up and had lost all hope. ... So many workers would come in and just sit in the corner, not really wanting to engage and seem like they just didn't want to be there. I felt a lot of the time you had more people coming in and judging than you did not." (Mhairi, daughter)

"Nobody ever asked her [M's mum] what she was doing at the weekend or how's the kids or anything else. ... I feel you can make someone feel so much more human if you talk to them like a human. ... I think a lot of the time people working with people don't feel that compassion is something they're allowed to show." (Mhairi, Daughter)

“I believe that if people that are working within services...start looking at people with a bit of empathy. That they understand what that person is going through. That it’s not a choice in life, it’s something that can happen to anybody, any aspect of life. And that people show a bit of dignity and respect to other people. The thing for me is, we’ll have to humanise health care.”
(Caroline, Mum)

“I’ve set up a family support group in Midlothian for other families so that they don’t experience what I’ve experienced as a mother and we have a fantastic group running now on a Monday night and its well-attended, well-advertised in Midlothian. ... We have a lovely nice comfortable room with sofas, with a radio and lamps, and treated with a bit of dignity and respect.”
(Sandra, Mum)

Three Take-Home Messages

1. Love is a powerful motivator for family members, but services generally don’t recognise this and see families’ interest, tenacity and passion as interfering and trouble-making.
2. Families recognise that services cannot always share information with them, but they do want to be listened to, and treated with dignity and respect.
3. Services believe they solely hold the risk for any decisions made, however risk can be shared by including family members and their loved ones in decision-making.

Reference

Scottish Families (2020) ‘The Story of Behind the Numbers’
<https://www.sfad.org.uk/behind-the-numbers>

Conclusion

The five publications reviewed for our Whole Family Evidence Bank are amongst a huge library of resources which give voice to families' views and experiences of whole family support and family inclusive practice. We simply picked five resources which were produced by or for the family engagement project partners within the past year, but many others could be added to this evidence bank.

There was strong consistency across the five publications in terms of what families told us about what mattered to them in terms of whole family support and family inclusive practice; what works for them; and what gets in the way. There was also a robust relationship between this evidence base and the output of the wider 'Ask the Family' family engagement project activities, as shown at www.sfad.org.uk/ask-the-family.

Comparing the content of our evidence base with the Draft Whole Family/ Family Inclusive Practice Principles tested out in the family engagement project, we found that all of the Draft Principles were supported by our reports (Top Down), and all of families' own descriptions of family support cross-checked and aligned with the Draft Principles (Bottom Up).

This gives us confidence in the Conclusions and Recommendations of the Ask the Family report, in that families have very consistent and clear messages about what Whole Family support and Family Inclusive Practice should look and feel like for them.

What is important? SAME as Draft Principles?	What is important? DIFFERENT than Draft Principles?
<ul style="list-style-type: none"> ✓ Able to work holistically with the whole family ✓ Children's rights ✓ Collaborative multi-agency approaches; <i>"Joined up thinking"</i> ✓ Driven by positive family values and a positive inclusive ethos ✓ Empowering families to 'reach in' for support, not just be referred by others ✓ Engaging the voice of families at every stage ✓ Family rights ✓ Focus on people's individuality, strengths and assets ✓ Fosters hope and positivity ✓ Free from stigma and judgement ✓ Help and support is available to individual family members in their own right ✓ Holds on until a family feels sufficiently ready to move on, <i>"Stickability"</i>; <i>"Never gives up"</i> 	<ul style="list-style-type: none"> ◇ Be yourself; show your human side; open up about yourself ◇ Choices and options (including how we are supported and by whom) ◇ Connecting with others with the same experience; peer support ◇ Empathy (not sympathy); understanding of the person's experience ◇ Equality between family and worker (on the same level) ◇ Friendship; be like a friend; relatable; use everyday language ◇ Goal setting and structure; solutions-focused ◇ Help and support as soon as you need it (early intervention) ◇ Help to navigate other areas of family stress, e.g. school, social work ◇ Helping; <i>"Invested in helping"</i> ◇ Honesty and openness (e.g. being blunt, direct, brave, assertive, challenging) ◇ Humour

What is important? SAME as Draft Principles?	What is important? DIFFERENT than Draft Principles?
<ul style="list-style-type: none"> ✓ Holistic approach; <i>“Look at the whole person”</i> ✓ Mutual respect ✓ Need to understand trauma ✓ Offer access to other supports such as food, financial ✓ Offer consistent support for woman (parents) where children have been removed ✓ Swift and responsive; Continually improve accessibility and availability; <i>“There when I need it”</i>; <i>“No postcode lottery”</i> ✓ Trusted relationship 	<ul style="list-style-type: none"> ◇ Included in loved one’s treatment and care (family inclusive practice) ◇ Kindness; consideration; caring; nurture ◇ Leads to change in my life; makes me feel better ◇ Listen (take time and show interest) ◇ Lived experience as a qualification/ Learning from lived experience ◇ Love and belonging; feeling valued and worthwhile ◇ Providing respite/ relaxation/ escape ◇ Safe space to talk and open up ◇ Support families to have fun ◇ Support me to advocate and make decisions for myself ◇ Support outside of the family; independent of the family ◇ Support to build confidence and self-esteem; reassuring ◇ Support to grow knowledge and skills ◇ Team approach with family; <i>“a two way street”</i> ◇ Time and Patience (going at our pace); recognise change can be hard work for families ◇ Visible family support and recovery ◇ Workers openly demonstrate and share knowledge and skills

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