Families, substance use and mental health

Supporting families affected by the co- occurring mental ill health and substance misuse (dual diagnosis) of a loved one

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CONTENTS

About Adfam

Adfam is the only national charity improving life for families and friends affected by the drug, alcohol or gambling habits of a loved one. We do this by:

- empowering families and friends affected by drugs, alcohol or gambling to get the support they need.

- building the confidence, capacity and capability of frontline practitioners to provide effective services.

- influencing decision-makers to understand the needs of thousands of people coping with the effects of a family member or friend mis-using alcohol or drugs, or gambling.

During 2019, we supported and worked with over 1,000 family members affected by drug or alcohol use; over 900 practitioners who support those families; and 300 strategic partners to affect positive structural change. We want anyone affected by someone else’s drug or alcohol use to have the chance to benefit from healthy relationships, be part of a loving and supportive family and enjoy mental and physical wellbeing.

Acknowledgements

We would like to that the family members and professionals who took the time to participate in the focus groups and interviews which informed the findings of this report. We would also like to thank the services that helped to facilitate these focus groups. This research project was thorough, requiring participants to provide potentially sensitive information. We hope and believe that this report is an accurate reflection of their views and opinions.

We would also like to thank the Sir Halley Stewart Trust for funding this work.

Introduction and Policy Context

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Introduction and policy context

Use of the term 'Dual Diagnosis'

Whilst we refer, throughout this report, to 'dual diagnosis', it is necessary to say at the outset, that many of the loved ones we refer to do not necessarily have a mental health diagnosis. They all experience significant mental health challenges, but one of the struggles families describe is accessing services, and therefore diagnoses, for their loved ones. We use the term 'dual diagnosis' because it is the widely used and understood term for the experience of someone with both a substance use problem and a mental health problem – regardless of diagnostic status. Whilst terms such as 'co-occurring mental illness and substance misuse', and variations of it, are used in policy and in the literature, and abbreviations of this are more commonly used in the US, 'dual diagnosis' is the most commonly used term amongst services and family members in the UK. Whilst we acknowledge that use of this somewhat inaccurate term itself perpetuates its use, we have nonetheless made the decision to use it for the reasons described.

Dual Diagnosis is the term used to describe people with co-existing drug or alcohol and mental health problems. The majority of people in drug and alcohol treatment services experience dual diagnosis, with recent data indicating that up to 70% of drug service users and 86% of alcohol service users experience mental health problems[1].

Despite it being such a prevalent issue, those with a dual diagnosis often fall through the net of public services which are struggling to combat ever-growing demands and ever-diminishing resources[2]. As a result, many people don't receive the support that they need. There has been a growing recognition of this issue, with research highlighting its many impacts[3] and policy guidelines[4] put in place for mental health and drug and alcohol commissioners in an attempt to combat this:

- The 2016 NICE guidelines for coexisting severe mental illness and substance misuse states that services must aim to meet the immediate needs of people presenting at services and that secondary care mental health services must not exclude people with mental illness because of their substance use[5]. It also advises that, in line with

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[1] Public Health England (2017) Available at: Public Health England (PHE) (2017) Available at: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/625809/Co-occurring_mental_health_and_alcohol_drug_use_conditions.pdf>

[2] Coombes, L., & Wratten, A. (2007). The lived experience of community mental health nurses working with people who have dual diagnosis: a phenomenological study. Journal of Psychiatric and Mental Health Nursing, 14(4), 382-392.

[3] Roberts, M. and Bell, A. (2013), "Recovery in mental health and substance misuse services: a commentary on recent policy development in the United Kingdom", Advances in Dual Diagnosis, Vol. 6 No. 2, pp. 76-83.

[4] National Institute for Health and Care Excellence (NICE) (2015) Available at: <https://www.nice.org.uk/guidance/ng58/documents/evidence-review-2>

[5] National Institute for Health and Care Excellence (NICE) (2016) Available at: <https://www.nice.org.uk/guidance/ng58>

the 2014 Care Act, carers providing support to those with co-occurring mental health and substance use problems are entitled to an assessment of their own needs.

- The 2017 PHE Guide for Commissioners and Service Providers, 'Better Care for People with Co-occurring Mental Health and Alcohol/Drug Use Conditions', reiterates that commissioners and providers of mental health and alcohol and drug use services have a joint responsibility to meet the needs of those with a dual diagnosis, and that there is 'no wrong door' for these individuals and their families to access support and treatment[6].

Despite these guidelines, in reality many services still find it difficult working together to support people with multiple needs[7] such as those with a dual diagnosis, and there is still little attention paid to families and carers who tell us that living with or caring for a loved one with a dual diagnosis can come with a whole host of challenges.

To fill this gap, Adfam has been funded by the Sir Halley Stewart Trust to carry out a detailed consultation with family members, to build an accurate and honest picture of the very real ways families are affected by dual diagnosis. By speaking with and listening to families, Adfam set out to understand what it is really like to have a loved one with a dual diagnosis, and what needs to be done to ensure the needs of families are met and not forgotten.

This report lays out the findings from this consultation. Many of the families reported very similar impacts to those affected by substance use alone, while some focused on impacts more specific to dual diagnosis. Where possible, this report focuses on the impacts that are specific to those with a dual diagnosis, but at times the overlap is so strong that the impacts cannot be distinguished. This is an important finding in and of itself, and its implications are discussed in the Comment chapter.

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[6] Public Health England (PHE) (2017) Available at: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/625809/Co-occurring_mental_health_and_alcohol_drug_use_conditions.pdf>

[7] Making Every Adult Matter (MEAM) coalition, 2015, Voices from the Frontline: Listening to people with multiple needs and those who support them

Methodology

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Methodology

Data was gathered using focus groups and telephone interviews. The 61 participants included individuals affected by a family member's dual diagnosis (n=54) and professionals working in family support, substance use, or mental health services (n=7).

Family members: focus groups and interviews

Six focus groups were run between July and November 2017, attended by a total of 42 participants. One each was held in Scotland, the North East, the East of England, and the South West, and two were held in London. Each lasted around two hours. The groups took place either in family services/groups' spaces, or in a meeting space hired by Adfam. All groups were facilitated by an Adfam member of staff.

Participants for three of these groups were recruited in partnership with existing family services and groups in the area, and all had previously engaged with these services. Participants for the other three groups were recruited via Adfam's partner network, or via social media. All potential participants were selected to take part, based on their self-reporting of having a family member with a dual diagnosis.

Eleven telephone interviews were conducted with a total of 12 participants between December 2017 and March 2018. The interviews lasted between 45 minutes and one hour. Participants were recruited through existing Adfam networks and via social media, and again participants were selected based on their self-reporting of having a family member with a dual diagnosis.

Professionals: interviews

Seven individual interviews with professionals were conducted, both face-to-face and over the telephone between December 2017 and February 2018.

Participants were recruited through Adfam's networks, and were selected on the basis that they have some experience or knowledge of the issues families faced when dealing with dual diagnosis, or of the related structural issues. They were from a range of disciplines, including commissioning, front-line support (both substance use and mental health), family support, and peer support.

Focus group/interview content

Focus groups and interviews were structured to cover the following themes:

- What are the particular pressures of living with/being in a relationship with someone with complex needs?
- What are the barriers families face in getting support?
- To whom do families turn when looking for support (organisations and/or individuals)?
- What services are available to families?
- Are services the answer / what would help?
- What coping strategies do families use?
- What are the tipping points in a family relationship which mean the relationship breaks down/is mended?
- What does recovery look like for families / do dynamics change and how?

All focus groups were recorded and transcribed, and a live transcript was taken for all interviews. All interviewees were sent a copy of the transcript once the interview was complete and given the option to make amendments or edits.

All participants are anonymised, and any potential identifying information such as names, services, and locations were removed from quotes.

Findings

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Findings

Supporting, caring or living with someone with a dual diagnosis can have a considerable impact on families, bringing with it a huge number of challenges. Some of these are common experiences shared by people affected by substance use or mental ill-health alone, and some are more specific to the experience of dual diagnosis. The ongoing and sometimes overwhelming nature of these challenges can create a 'new normal', in which situations and behaviours that would have seemed unthinkable a few years previously become normalised.

While there are stark similarities in many families' experiences, there is no one defining experience and no two families are affected in the same way.
We have grouped findings according to four key themes:

a) Practical Impacts
b) Relationships
c) Mental Health
d) Exacerbation of Impacts

a) Practical Impacts

The impacts experienced by family members supporting a loved one with dual diagnosis in practical terms were often described as 'life changing'. It has often become the main focus of their life, and they felt that they were left picking up the pieces where support services didn't do so.

> “
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> *When she's living with us, we descend into her chaos. Because she is such a chaotic person it takes up all of our time, there's no bandwidth for anything else. When she isn't with us, and on the streets etc., we're driving around looking for her*
>
> **Focus Group 4 Participant**

> *The families of people with mental health – you just live in a daze, it's awful. It infiltrates every single aspect of family life.*
>
> **Family interview 3**

Financial Impact

Supporting a loved one with a dual diagnosis can cause considerable financial strain. Many family members had loved ones financially dependent on them, totally reliant on them for day-to-day essentials, and often drugs and alcohol. Often it falls upon family members to pay off the debts accrued by their loved one, and for some there is also the considerable financial cost of paying for private treatment and support, which can be financially crippling, and especially galling if it is unsuccessful.

> I pay his gas and electric, do his food shops, rent is £6 a week because he's on benefits- I pay it because otherwise he'll be out the flat.
>
> **Focus group 4 participant**

> “
>
> *You get folks coming up at your door, ‘he owes me money, and she owes me money’. My daughter was supposed to be dealing for somebody, and instead of dealing she was using it. I tried to find the person she was selling it for. I had to pay all the money for the drugs she had used*
>
> Focus group 3 participant

> “
>
> *I just thought, ‘my god, is the penny ever going to drop with her?’ All this money spent on rehab and mental health services, it doesn’t work.*
>
> Focus group 4 participant

Loss of boundaries and impact on own life opportunities

For some families, particularly those acting as carers, a loss of boundaries and a disruption of day to day life was experienced. This then becomes ‘the new normal’ for some. Some families spoke about how supporting their loved one acted as an obstacle to them pursuing and engaging in life opportunities, including employment, social activities or other relationships.

> *He overdosed on methadone and I was at work at 8 am the next morning. I was like a zombie but didn't tell anyone. I shouldn't have been at work, they talk about absenteeism, and for me it was presentism, when you're there but shouldn't be. That went on a lot.*
>
> **Family Interview 2**

> *My life's changed. I've retired, and somehow thought that when I was this age she would be away and I'd be able to go on holiday with my friends. But I can't. I could – but I can't because I don't want to leave her…I would love to have a week away just with my friend or something, to have a life outside of caring. There's no prospect of things changing for me.*
>
> **Focus group 1 participant**

Impact on own wellbeing and health

It is far from unprecedented for the stresses and strains of supporting someone with a dual diagnosis to cause an impact on family member's wellbeing and health, both mentally as in a later section, and physically, as demonstrated by the quote below.

> *It impacts you on every level, it impacts you mentally, socially, physically – my body was burnt out by the time I was 30.*
>
> **Family interview 2**

Wider caring responsibilities

A number of the families we spoke to had taken on wider caring responsibilities such as looking after children as a result of their loved one not being able to fulfil the responsibilities themselves due to their dual diagnosis. In the case of most of the families we spoke with it was grandparents looking after their grandchildren, due to their own children not being able to do so, known as 'kinship care'. Some families spoke of feeling that they were assumed to always be there to support their loved one and "pick up the pieces" regardless of the extremity of their behaviour. This was reported as coming from both loved ones and services.

> *You've got no ends, it's not your fault you've got no ends. You can't be a grandparent anymore, you're the mummy, the daddy, the granny, and everyone else in that mix.*
>
> **Focus group 3 participant**

> *In their minds [referring to the professional] they think "Ive got mum at home she can deal with it if I can't*
>
> **Focus group 5 participant**

> *Community care, they feel that's just saying families should look after them. Where does that leave us?*
>
> **Focus group 5 participant**

b) Relationships

Relationships with the individual

Many families spoke about the impact on their relationships – with the person with the dual diagnosis, and with others around them. Many described the lies and deception that they experience in dealing with their loved ones. A common perception from family members was that the loved one that they were supporting was of an adult age, but their behaviour reflected that of a child. This was a frustration that was regularly emphasised and expressed in focus groups and interviews, with family members giving examples of how this was the case.

> “
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> *If he has to get to an appointment, I’ll give him money for travel and food but he’ll spend it on a 6-pack of beer. He lies; the lies get to you, makes you angry. It affects us so much; you have the worry, the anger, the fear.*
>
> **Family interview 6**

> “
>
> *He’s 29, but it’s like he’s stuck as an 18-year-old since he started, like he hasn’t progressed.*
>
> **Family interview 6**

Relationships with wider family members

Many families also brought attention to the strain it had on their relationships with other family members. This includes siblings, who as well as suffering directly from their loved one’s situation, can find parent/s diverting their energy and attention on their loved one with the dual diagnosis, neglecting other children in the family. This diversion of attention does not only impact the siblings of individuals with a dual diagnosis, but also of partners and other relatives and friends of those assuming caring roles.

> “
>
> *The bigger impact has been relationships with friends/family friends. I think that some friends just don’t know what to do to help. They don’t really ask.*
>
> **Family interview 5**

> *One of the big things I think is that it changes your sense of the joy of life. It's hard to celebrate the other things the other children do because all the time you're trying to protect the one who's not well from feeling desperate about their life.*
>
> **Focus group 1 participant**

> *Back home life became impossible. My marriage broke up due to the strain and my husband went to live elsewhere.*
>
> **Focus group 2 participant**

c) Mental Health

What became very evident was the almost overwhelming, and often constant, extreme worry and stress.

Ongoing worry and stress

Families report feeling near constant worry about their loved one. Many feel continually 'on edge', anxious, or concerned, waiting for the telephone or doorbell to ring and bring bad news. This is often exacerbated by feelings of hopelessness; while some families do see progress, with loved ones entering some form of recovery, others feel very little hope of this ever happening. A significant cause of worry is the ongoing risk of suicide and self-harm, which is a very real concern for many families. Some families also express resentment at having to deal with these issues constantly.

> “
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> *It’s just a living bereavement…There’s not a day that goes past where I think where he is, who he’s with, what’s he taken, what’s he planning to take, is he still alive? There’s always that fear factor when you have somebody in your life that lives in this kind of prison in their mind.*
>
> **Family interview 9**

Families express concern at the grave extent of their loved one’s situation, and the difficulties of trying to encourage their loved one to change and positively address their problems. It can be hard to envisage a future for their loved one where they are able to overcome their substance use problems, or manage their mental ill-health. This is especially true when their loved one does not acknowledge the extent of their problems, and lacks the willingness or capacity to engage in treatment or support.

> “
>
> *It’s like a long prison sentence and you don’t know when you’re getting out!*
>
> **Focus group 6 participant**

> *Getting my partner into treatment has been complicated by his attitude...he doesn't recognise he has a problem. A lot of it is denial, but it's also an element of his social isolation. How would it work for him to be in a community setting? That, to him, sounds like he has a problem and he wants to address it, which he doesn't acknowledge.*
>
> **Focus group 4 participant**

Stress is often caused by barriers to effective support

The biggest cause of stress is the range of difficulties encountered by their loved one in trying to get effective support; people with a dual diagnosis often 'fall between the gaps' of mental health and drug and alcohol services and end up not receiving any support at all. For some families, the rules governing support, especially from mental health crisis teams, are a big source of frustration. Demonstrated by the quote below, mental health support is often refused due to drug or alcohol use, which again highlights the lack of a joined up approach towards mental health and substance use. Individuals are also often denied support due to being 'low priority' compared to others with more complex or serious mental health issues, which can be very distressing for families of those experiencing what they feel to be very serious issues.

> *Getting my partner into treatment has been complicated by his attitude...he doesn't recognise he has a problem. A lot of it is denial, but it's also an element of his social isolation. How would it work for him to be in a community setting? That, to him, sounds like he has a problem and he wants to address it, which he doesn't acknowledge.*
>
> **Focus group 4 participant**

> *One side was telling him 'you need to stop taking these substances' the other 'you need to sort your mental health'; it was like being between a rock and a hard place. It was a horrible situation…mental health and addiction goes together. You really are struck in the middle with dual diagnosis.*
>
> **Family interview 10**

> *There's no requirement for my son to have treatment unless he's threatening others or threatening suicide – he doesn't do either of those things. Any treatment that he does get is the treatment that he chooses. He chose to go to rehab, and also chose when to leave rehab and chooses not to go there again. Never been sectioned, maybe that would be a sort of solution.*
>
> **Focus group 2 participant**

Lengthy waiting times and a lack of diagnosis

One particular frustration was the length of time loved ones had to wait for appointments for support. This was felt to affect the consistency of care and often have a highly detrimental effect, breaking up the structure of progress, and sapping energies. Many families feel that getting a formal diagnosis for their loved one's issues would lead to better treatment and support, and are therefore frustrated by the difficulties faced in doing this. Family members are often left baffled by the lack of diagnosis and frustrated by a lack of progress.

> “
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> *Weeks and weeks were becoming months and months, with a very sick child…All these counsellors are lovely, hugely well qualified people, but you have to wait forever to see anyone. We were just watching our daughter get iller and iller.*
>
> Family interview 3

> “
>
> *We’re still struggling with the diagnosis, with his mental health issues. Nothing has been diagnosed. And he’s addicted to these prescription tablets that he’s taking. Just feels like they are perpetuating the situation.*
>
> Family interview 1

Treatment is in silos

Many families, however, find that once obtained, the presence of a formal diagnosis has little impact on their loved one and doesn’t mean they have greater access to support. In fact, many families find that their loved one’s issues are treated in isolation by mental health, substance use, and other support services that work in siloes and do not communicate with each other. This can make it incredibly difficult for families to support their loved one to make progress through treatment.

> *With all the services in and around, why is it so fragmented? Why is there no single thing pulling everything together? It's all over the place, they're bouncing people around. Why isn't there one body drawing everyone together? You can't give somebody half a treatment, it's ridiculous.*
>
> **Focus group 5 participant**

> *I'd like for professionals to speak with each other, learn more from each other, and share information with each other to understand more…and then speak to us, the carers!*
>
> **Focus group 3 participant**

Lack of understanding and communication between families and professionals

Furthermore, many families reported that the support services did not understand how bad things really were, with a feeling that loved ones weren't totally open when discussing their issues. This resulted in professionals not being fully aware of their situation, which leads to needs not being taken seriously and an inadequate or inappropriate provision of support. Rules relating to patient confidentiality heightens this stress for family members, as they feel uninformed about their loved one's situation and the kind of treatment they are engaged in. They also felt that it prevented them advising professionals on their loved one's situation, which exacerbates issues of inadequate professional support, creating further stress and strain.

> “
>
> *At least giving people an overview, these are the sorts of services you can access; this is what might go on, rights about access to information and involvement in care…there obviously has to be a level of confidentiality around individuals, but there are policies in place for information sharing, and people aren’t aware that they can ask for those to be explored. We are by and large the ‘Forgotten Carers’ and we need recognition, support and above all information.*
>
> **Family interview 9**

> “
>
> *It transpired that he had a social worker coming out once a week to do recovery training with him. I’m all for that, but we needed a belts and braces approach - an all-recovery approach and once a week recovery training just doesn’t cut it. It felt like everything we had was just lip service as if they are contractually obliged to do something.*
>
> **Focus interview 4**

Lack of consistent care

Where care was assessed, families generally felt that it wasn't consistent, with services having high turnover or closure rates. There is an issue of a loss of knowledge among existing services when professionals move on, or when clients are referred on. Family members found this highly frustrating, often having to explain themselves again, and this lack of consistency affected the quality of care and had a detrimental effect on their loved one's health and progress. In addition to these inconsistencies, families discussed the challenge in ensuring that their loved ones attended appointments, and their frustration at being 'back at square one' if an appointment was missed. Many families also spoke of lack of aftercare impending progress.

> “
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> *Detox was great, but after then the support just stopped. No tailing off structure or follow through. People go into hospital detox for a week, but then there is nothing and they just relapse. It doesn't have to be like that.*
>
> **Focus group 1 participant**

> “
>
> *The mental health service he was involved with doesn't exist anymore. It seems like services come and go and change providers. We've sat in many a room where you hear from service users say they go to A, they take their details, get referred to B, they take their details. Then they change providers and they go through the same pattern. It does have an effect on carers, because we get angry and frustrated, as the people that care for them. I don't know what the solution is.*
>
> **Focus group 1 participant**

A number of family members acknowledge that these issues in part stem from the overloading of services and funding challenges. High service turnover rates, long waiting times and an absence of aftercare are attributed to a lack of resources. Despite this recognition, families are frustrated at what they feel is a lack of proper support for their loved ones.

> “
>
> *It’s all about cost-cutting, my son is now being discharged from services, and becoming an out-patient, they’re calling it ‘robust care-planning.*
>
> **Focus group 5 participant**

> “
>
> *The mental health teams down here are really overloaded. Emergency appointments you’re waiting 2-3 months at the moment. I know they’re very busy, but at the end of the day, there are families out there who really need mental health support and don’t get it.*
>
> **Family Interview 2**

Stress caused by associated harms

It is common for the issue of a dual diagnosis to overlap with other “chaotic” (Focus Group 4 participant) life challenges and associated harms. Family members commonly spoke of their loved one’s challenges maintaining employment and carrying out day-to-day responsibilities due to their problematic lifestyle. In some cases, this has led to them experiencing insecure housing or homelessness. Some family members also spoke about their loved one’s issues with offending and the criminal justice system, and the worry that this caused them.

> “
>
> *She’s currently homeless, that’s where we’ve just been, she can’t bear to live indoors or anywhere but the streets. We were just passing her over a tent and some sleeping bags, that kind of stuff. It’s quite severe and there’s no help out there whatsoever whilst she’s drinking.*
>
> **Focus group 4 participant**

> “
>
> *He was living homeless for a while. He would steal to get alcohol. He would do whatever he needed to do to get whatever substance he wanted. He ended up getting a 10-month prison sentence at a young offender’s institute.*
>
> **Family interview 4**

Some family members also spoke of other dependencies coming into play such as problem gambling, exacerbating their own and their family’s livelihood even further:

> *My son has had a gambling problem since 17…he takes every penny that I've got. I've got no savings left, had to bail him out of drug dealers, gambling addiction. Now I can't bail him out. And people are still allowing him to get loans online, it's dreadful.*
>
> **Family interview 4**

d) Exacerbation of Impacts

There is a general lack of parity between physical and mental illness

A prominent issue for family members and professionals was a general lack of understanding and awareness around the urgency of mental health, both in the treatment sector and in society more generally. As highlighted by the quote below, this was seen as a barrier towards getting proper professional support, both for people themselves with a dual diagnosis, and for the families affected by what their loved one is going through. Families feel there is little recognition of the fact that they themselves may experience poor mental health as a result of supporting their loved one with a dual diagnosis.

> *I've got good contact with my mental health services but at the end of the day it's all about my daughter. They'll check out how her children are, obviously if there's a risk they're obliged to know about it, but there's not any support from mental health services for the likes of me.*
>
> **Focus group 3 participant**

“

Mental health isn’t taken seriously enough within society…people are pushing the agenda much more – but it’s still no way as acceptable than talking about physical health. If it’s not got parity with physical health in mainstream media etc. we’re always going to struggle to push an agenda.

Professional interview 4

“

If you have a physical illness you go to A&E they observe you, and there’s a treatment plan set up for you, physiotherapy etc. If you go for mental health problems, they don’t have the resources. The brain is an organ of the body. It should be treated the same as a physical illness or condition, because you’re just dealing with another part of the body. But it gets boxed away to one side and neglected.

Focus group 1 participant

Services and professionals can be stigmatising

Some families felt that their experiences were tainted by the lack of understanding or recognition of their needs from services, which sometimes came across as insensitive or judgmental. This was particularly felt around attitudes towards substance misuse. This in some cases had a damaging impact on family members, particularly considering they will have been dealing with the stresses and strains of supporting their loved one and already feeling sensitive, this kind of attitude further compounds their difficulty. Furthermore, it runs the risk of putting family members off from seeking support for them and their loved one through fear of being judged or criticised.

> “
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> *I’ve also found they’re really judgmental. You feel like you’re painted, stained. Their attitude is really poor. If it was just mental health, we probably would have got support much quicker. But the minute they see substance misuse, there’s that attitude. People that use drugs alcohol a real barrier. They almost treat you as half a person.*
>
> **Family interview 7**

> “
>
> *That’s the problem, at the hospital it felt like the health care professionals are looking from the outside and judging. People are very sensitive and acutely aware of when people are judging them.*
>
> **Family interview 8**

Practitioners themselves recognize that stigma exists, both within services and in wider society:

> “
>
> *Sure there is stigma for people with mental health, but with dual diagnosis – people are not only frightened of the mental health aspect, but condemnatory of people with drug and alcohol problems, on the basis that is their own fault – a self-inflicted injury. There is a range of stigmas that are attached. A lot of it is behind this issue of “these people don’t want help, they’re not willing participants in their own care, so we can’t have sympathy for them”. And I think that is still fairly prevalent within society and to a degree within services.*
>
> **Professional interview 3**

Lack of empathy and understanding from friends and family

In addition to the stress caused by the judgement felt from some professionals and services, families can also experience stigmatising attitudes from those close to them: friends, colleagues, neighbour and also other family members. These attitudes can be directed both to the person with the dual diagnosis themselves, receiving negative remarks, or can be directed to the family member themselves for their role in supporting their loved one. Families often find they have to be selective in who they talk to, avoiding speaking with people that they feel may not understand and fear of being judged. Similarly, to their experiences with professionals, family members said that they found the stigma around substance use to be much more prevalent than mental health.

> “
>
> *Some family members won’t speak about their loved one at all. They just don’t want to talk about it anymore…In terms of stigma, people say they get told a lot what to do by family members – “You should never see them again”, “you shouldn’t be doing this”. In terms of it not being accepted as an illness, you wouldn’t do that to somebody in a wheelchair.*
>
> **Professional interview 1**

> “
>
> *I wrote a play – my way of coping, I had no one to talk to about my situation.*
>
> **Family interview 1**

Isolation

All of this leads to families feeling isolated, particularly if support isn’t available from services, leaving family members to deal with the situation themselves. This can be compounded if you don’t have a great knowledge or understanding of drugs, alcohol and mental health and how best to support and get support for someone experiencing these issues.

> *I didn't really know how to express what I needed. I didn't speak with confidence about the situation, didn't understand the situation, know what existed, wasn't informed about substance misuse, it was a new topic for me that I was trying to process for myself, in terms of what it meant to me, the effect it had on me.*
>
> **Family interview 9**

> *It's difficult being a carer on your own. You need that infrastructure around you. Otherwise you're pissing in the wind!*
>
> **Focus group 4 participant**

Comment

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Comment

In the findings section above we have sought to present the data objectively, simply grouping it and breaking down the information into sections. In this section, overview, analysis and comment is offered. For over thirty years Adfam has worked, in various ways, to improve life for families affected by substance use. This experience is used as a backdrop to inform a close reading of the findings and highlight some cross cutting themes of particular relevance and potency.

a) The love and ties of family can be incredibly strong

What clearly comes through above is the immense love for and dedication towards their loved ones that many family members had. Years, and in some case decades, of stress and struggle has occurred for many, who felt society had given up on their partners, children and siblings.

For some families the love bond seems boundless and unbreakable. Family members spoke movingly of supporting their loved ones through enduring long term mental ill health, as well as severe mental health crises, including suicide attempts.

Even for those that spoke about adopting a ‘tough love’ approach and ejecting their loved one from the family home, often following a period of extreme stress and unhappiness, these events did not signal a ‘giving up’ on the relationship. They were characterised as acts of self-protection and were often driven by the belief that the loved one needed to hit rock bottom, un-cushioned by familial support, before being really motivated to change.

b) The emergence of a typical family dynamic

Whilst attempting to reduce a mass of complex human experience into a set of simplistic typologies is often of limited use it does strike the authors that there is a situation which appears so frequently it is worth noting. Whilst we spoke to families with a range of different kinds of relationships to the person with dual diagnosis the most frequent relation was predominantly mothers, and children, most commonly sons.

Indeed of the 54 family members who shared their experiences, 39 were mothers. This is of course based on a self-selecting sample of people who were both in contact with the community support service which acted as gatekeeper and felt emotionally and socially able to speak about their experiences, in some cases in a group setting. Nevertheless, a very familiar story starts to emerge of a mother, usually in her fifties or sixties, ‘picking up the pieces’, that is to say providing sustained care to her family member (in many cases an adult son) through the most adverse of conditions.

This was an interesting finding and some mothers that we spoke to articulated why this was the case, noting that there was an everlasting love between mothers and sons, regardless of how grave their situation had become. The lengths to which mothers reported going to do their best for their children was extremely moving, from endlessly pursuing referrals through fractured systems, to going out to hunt for family members in crack-houses when worried about their safety, setting up family support groups to lobbying MPs.

> “
>
> *For a parent there is an unending love that allows you to keep going in spite of all the horrors, I keep trying to support my son – I haven’t given up on him.*
>
> **Focus group 2 participant**

> “
>
> *All the family have washed their hands of my son, bar me.*
>
> **Focus group 6 participant**

> “
>
> *From my experience women attend to it, men shut down from it. My husband couldn’t handle it so he buries himself in work. Family support meetings are predominantly all women.*
>
> **Focus group 2 participant**

This gendered aspect was deemed by the authors to be worthy of further exploration. Adfam held a roundtable event to this end in January 2019, which brought together policy-leads, project managers, academics and experts by experience to discuss why it is so often mother left as the hub of families experiencing serious and multiple adversity. Conversation covered the gendered aspects of the practical, financial and emotional costs to family members, experiences with institutions and services, and wider discussions around societal gender norms.

c) Positive experiences of support show it can have an impact

In line with much of Adfam’s previous research work, families reflected the immense positive value support can hold for them. This support includes liaising with caseworkers, care coordinators and trained professionals as well as benefitting from peer support. Whilst a healthy therapeutic alliance can work to increase wellbeing, the importance of the provision of accurate information was also noted. Information around drugs and alcohol and harm reduction can help families who are feeling confused and lost.

Families benefit from support in their own right

Many families expressed how useful being supported properly in their own right was, both in supporting their own wellbeing, and in enabling them to better support their loved one. It resulted in them being in a better emotional and physical condition, but also being better informed about their loved one’s situation and how best to support them.

> “
>
> *Family support…The focus is on yourself rather than the user, that makes a big difference, focus on your own recovery. I’ve heard of so many people I know saying that their loved ones wouldn’t be in recovery, if they hadn’t sorted their own recovery. They’ve helped them get well by stopping enabling them. So much you need to learn along the way.*
>
> **Focus group 2 participant**

> “
>
> *We learnt how to do the, non-confrontational, not checking up on him all the time – look after our own welfare, and that meant we were better at looking after him.*
>
> **Family Interview 10**

> “
>
> *We were recommended a support group…It was the best thing we’ve ever done. We realised we were doing everything backwards; we know about all sorts of things on drugs to look out for that we had no idea about.*
>
> **Family Interview 6**

Many professionals we spoke with discussed the importance of ensuring the needs of families were recognised and that they were supported appropriately. The process of incorporating family support into their service specification to ensure it was an integral aspect of service delivery was raised by some professionals as a solution to realise this. It was also alluded to how having families involved wasn't just better for the person with dual diagnosis, but also better and more beneficial for services as it enabled them to carry out support more effectively.

> “
>
> *I think services should see each individual as a family member from the beginning. And I think they need to plan care, and to respond to incidents and difficulties with a constant strong theme, that this is a member of a family, and the whole family is part of the issue, part of the problem and part of the solution.*
>
> **Professional Interview 3**

> “
>
> *The best outcomes are when families and carers are involved and you have that wrap around care…They can provide the infrastructure that services can't…someone who is a bit depressed say, needs an alcohol detox and lives alone, they need to go in somewhere. If they have a family member, they can be detoxed at home much more rapidly. And most patients don't want a residential treatment option. We should always encourage them to be involved and ask the question. I'm a keen advocate for involving families, and asking the question 'do they want to be involved?'*
>
> **Professional Interview 6**

Value of peer support for families

Peer support was flagged as being particularly useful, with families highlighting the direct empathy that exists when being supported by someone who's really 'been there' as providing something different to a practitioner view. As discussed/ presented earlier, many families report intense feelings of isolation and the constant worry that they are the only ones going through these kinds of challenges. Peer support shows that to be untrue, with great reported value in engaging with others that have been through similar experiences was reported as effective in reducing isolation, and giving clarity on their situation and how best they can support themselves and their loved one.

> “
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> *Being around other people that are going through the same stuff, it helps in making you feel less isolated, you feel like you can go there and have a good cry, and not do that at home where it impacts on your personal relationships. Get out the stress, confusion, pain and bewilderment. Also learning from other people about how they dealt with the situations, and being part of that shared experience was helpful.*
>
> Professional Interview 6

The value of peer support was also expressed by professionals, many of whom advocated for peer support to be made available to family members.

> *For families it helps them get an understanding of what their loved one is going through, and they'll get that understanding from professionals, and people that have been through it themselves…It's a simple programme, doesn't require big expense, and doesn't cost a lot.*
>
> **Professional Interview 7**

> *The support group was useful because it breaks down isolation and promotes social inclusion. It enables people to meet others in similar situations that they can talk to freely without stigma. Often people wouldn't be sharing with others in their family, and because others understood them in the group, they could share more freely.*
>
> **Professional Interview 5**

Importance of effective and supportive case-work

Many families spoke about the importance of having someone act as a first point of contact to coordinate and develop a care plan, and to liaise with other agencies. These are often case workers or care coordinators. In some cases, both the families and their loved ones built up a trusting relationship with this person and this was seen as invaluable to progress. However, as highlighted in the 'barriers to effective treatment' section, if that person moves on it can cause further complications, putting things "back at square one". Despite initially feeling hopeful when a care plan was originally agreed with a caseworker, some families have been disappointed to find that their loved one’s care plan was not followed through, particularly when staff moved on or services shut down.

> “
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> *This one health visitor who stuck it out with her for about two-and-a-half years, she’s got a relationship with all of us and she’s got a good relationship with my daughter, not judgmental in any way, really compassionate, really respectful…She’s always available when I ring her, and rings me back*
>
> **Family interview 7**

> “
>
> *Our son’s care coordinator gave me lots of information, supported me by talking to me. Then that all disappeared. You want clear communication, and for them to share information.*
>
> **Focus group 5 participant**

> “
>
> *We would have raised the issue about who is actually following through with this care plan? That was the big let-down, nobody reviewed it.*
>
> **Focus group 1 participant**

Different needs for different people

A lot of family members spoke about the positive and negative aspects of the support they and their loved one achieved, articulating what was helpful and what was not. However, it is important to recognise that everyone's needs are different, and whilst someone might find a particular kind of support ineffective, someone else might find it useful – and it is important to understand that both families and people with dual diagnosis are very varied and have varying needs and requirements. There is not a 'one size fits all' approach. Some families prefer structured programmes and support groups, whilst others like to engage in more private, personalised types of support such as gardening.

> “
>
> *I don't particularly like structured group support. I don't like the procedure, the routine the doctrinal aspect etc. I'm not very comfortable with it. I seek solace In gardening, cooking… watching the news.*
>
> **Focus group 2 participant**

> “
>
> *I colour in, that helps me get into a meditative state. We all have something that helps. My husband goes to spin classes, but that's not for me…We all find different coping strategies that manages to anchor us and keep us grounded when things go wrong…There are times when you think this is enough now. You find what you need to get past it somehow. This whole experience has taught me that we're all a lot stronger than we think we are. That's human nature, until something is thrown at you, you don't realise the depths of the reserves we have.*
>
> **Family Interview 5**

d) A dual diagnosis can close down close down horizons and create ‘a new normal’

As with any kind of serious challenge, sustained involvement in the problems presented by a loved one’s dual diagnosis can lead to real changes in the lives, aspirations and horizons of family members. As discussed in the findings section, this includes both mental changes caused by constant worry about their loved one, as well as more practical impacts such as financial implications and an impact on day-to-day jobs and activities. Whilst this is clearly not limited to those family members dealing with dual diagnosis, and would apply if there was a substance use issue without an accompanying mental health challenge, the dual nature of the issue compounds the effect.

As stated earlier, a ‘new normal’ is created whereby situations and behaviours that would have seemed unthinkable a few years previously become normalised. Time and energy (or ‘bandwidth’ as one person describes it) are drained by the drug, alcohol and mental health problem and can leave little energy for the pursuit of meaningful or pleasurable activities.

> “
>
> *You start living in your own world; this becomes the normal way of life. You start to just accept that’s the way it is. As a normal way of life*
>
> **Focus group 2 participant**

> “
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> *You deal with it on your own, day after day. Not knowing when the phones going to ring, not knowing when the next crisis is going to be.*
>
> **Focus group 3 participant**

e) The ‘system’ is hard to navigate

Many families spoke of the complexity of ‘the system’ and difficulties they encountered when trying to navigate it and get support for their loved one. This includes drug and alcohol and mental health services but also related areas such as housing, employment, benefits and criminal justice, adding further complexity to an already complicated situation. Characterised by treatment in silos, the system doesn’t work well for people with diverse and complex needs. Although this is a truth long recognised, hearing the first-hand accounts of family members brings it home very powerfully.

What emerges from the very rich data set is a picture of human beings grappling with a confusing system characterised by inconsistency, change and ravaged by funding cuts. Even a healthy, logical and high functioning system would be hard to navigate for anyone dealing with the stresses and strains of a loved one’s dual diagnosis. Once additional historical and cultural challenges and the erosion of capacity due to funding structures are added in, the challenge begins to feel insurmountable.

It can be tempting to think of support systems in ‘hard’ terms, made up of standardised policies, referral pathways and joint protocols. Whilst these kinds of formal guidance does (or should) provide the outline of the system, those who work within this system to deliver services provide its character and tone. A warm receptionist or practitioner can provide a ‘soft landing’ of sorts to a stressed mother who has finally convinced her son to come to the local drug service for help. Correspondingly, an austere welcome can put people off, and represent a lost opportunity for engagement and change. Getting effective support is not only a postcode lottery in ‘hard’ terms, whereby some local authority areas allocate more funding to dual diagnosis support services, but also in ‘soft terms’, with family members reporting varied levels of professional understanding and client care across the country.

The recognition at national policy level of the problems that exist in the linkage between substance use and mental health services is of course encouraging. There has been clear guidance from NICE (2016) and Public Health England (2017) on the issue. What came across strongly in talking to family members was the complete failure of this to translate to meaningful change on the ground for people with co-occurring issues – and their families. It transpired that NICE guidelines are often ignored by practitioners when services are overloaded. When asked if the ‘no wrong door’ mantra commonly cited by policymakers resonated with their experiences, some participants just laughed.

Whilst this report has focused on the challenges and impacts that a dual diagnosis can have on family members, many of these impacts cannot be distinguished from those experiencing substance use alone. Indeed, previous research carried out by Adfam into the implications for family and friends supporting a loved one through substance misuse echoes many of the findings in this report[8]. For instance, facing stigma or experiencing “life changing” practical changes such as financial difficulties are also common for families of substance users alone. Substance users face similar barriers to treatment, however those with a dual diagnosis have the added difficulty of “falling through the gap” between mental health and substance use treatment services.

f) Stigma exists but it is getting easier to talk about mental health

Some professionals alluded to the continued presence of cultural stigma around mental health and substance use and the challenges this posed for people with dual diagnosis. Practitioners frequently mention how stigma wasn’t limited to people with dual diagnosis themselves but also extended to their family members, who often felt marginalised due to judgmental attitudes from family, friends, practitioners and wider society.

A common discussion was the notion that it is becoming easier to talk about mental health openly. Mental health, like drugs and alcohol, is an area that has been highly stigmatised for many years and marginalised in health services. As indicated by the quote below, it was also suggested that despite mental health being talked about openly, there is still disparity in the support available for people with dual diagnosis and their families. However, many families did speak about the improvements they have experienced. However, they felt that despite progress in mental health, drugs and alcohol still carried a considerable taboo and it was still difficult to talk about.

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[8] https://adfam.org.uk/supporting-professionals/resources

> *I think it is getting better [stigma]. But I still think for a lot of people it's a way to massively discredit you. For example, if I was to say to somebody, I've got bad anxiety, they'd say you're mental. That still happens a lot. Unless you're Prince Harry or Rihanna, on a day to day basis they'll think you're unreliable and less trustworthy.*
>
> Family interview 2

> *I do think there's more information generally, whether it's in the paper through the media coming out, celebrities owning up and more increased awareness of mental health issues.*
>
> Focus group 1 participant

> *It's more in the forefront now because celebrities are talking about their issues. That's fine, but they have the money to go off to a retreat or rehab somewhere. I can't afford to do that. The celebrities can. It's nice to talk about, but let's put things in place so everyone has the access to the same treatment as those who can afford to pay for it.*
>
> Focus group 1 participant

Conclusions and Implications

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Conclusions and implications

Dual diagnosis and its impact on family's needs to be addressed!

Whilst the issues that people with dual diagnosis face are accounted for and becoming increasingly well recognised, the consultations we carried out highlight that it remains a huge issue, not least for its impact on the wider family. Those individuals with a dual diagnosis, and their families, continue to miss out on the support they greatly need. This report shows that families supporting their loved ones through a dual diagnosis face many practical, emotional and whole-life challenges that can make life extremely difficult. The positive impact that support for family members can have, when it is available, has been highlighted. The need for more funding and support for individuals with a dual diagnosis, as well as family members in their own right, is urgent. This final chapter identifies four key areas that need to be addressed in order to work towards achieving this.

a) Better integration needed between drugs and alcohol and mental health

b) Lack of funding and systemic failure

c) Better advocacy for families

d) Stigma needs to be addressed

a) Better integration needed between drugs and alcohol and mental health

The consultations carried out with both family members and practitioners highlighted that there is an urgent need for better integration between drugs and alcohol and mental health. An overwhelming finding from professionals in both substance use and mental health services was that services are not joined up. The lack of coordination was felt to impact heavily on family members trying to get support for their loved ones, who often fall between the two. This major barrier to treatment is a huge source of worry and stress for family members. Despite clinical guidance suggesting that services should work together, the lack of an integrated approach remains, and generally communication between services is felt to be poor. NICE guidelines state that people should not be excluded from mental health treatment due to substance use or vice versa. However, the respondents to our surveys suggest that this often remains the case. This is seen to be because services are overstretched and underfunded, which is discussed in the next section.

A common issue cited was the lack of understanding and knowledge amongst professionals, with some mental health workers not knowing enough about substance use, and vice-versa. This meant that inappropriate advice was sometimes given to people with dual diagnosis, or their families. It was discussed how professionals could be better trained, not just in identifying and supporting people displaying signs of mental ill health, but also in acting appropriately and supportively towards family and carers. We know that a dual diagnosis is more common than not for people with a substance use problem. It is therefore vital that drug and alcohol workers receive adequate training around mental health, and vice versa, as well as being supported to communicate effectively with their counterparts in other services.

b) Lack of funding and systemic failure

Funding cuts and constraints were cited as another key issue which restricted the ability of services to adequately support people affected by dual diagnosis and their families. A treatment environment characterised by low resources and high competition for public health funding does not encourage collaboration between mental health and drug and alcohol services.

A common feeling amongst professionals and family members was that the lack of support for people with dual diagnosis and their families wasn't down to a lack of desire from professionals, but that the system in place to provide support was flawed. It is felt that regardless of how hard professionals worked to support people, the infrastructure around them was failing people and their families. Whilst services can try to work more collaboratively and efficiently, if adequate funding is not available for infrastructure and training, then the issue will persist. There is much acknowledgement that services need to work collaboratively to provide better support for this complex group, but whilst there is a clear desire and understanding to address this, it is proving highly challenging in practice. This difficulty in turn has a detrimental impact on families and carers, who are left to deal with the situation themselves, whilst their own important needs are also overlooked, not recognised or understood.

It makes financial sense to provide adequate support for those with a dual diagnosis, and their families. Many families were acutely aware of the cost of dual diagnosis to the state, and in particular the impact and strain it was causing on other services, for example the NHS, police, emergency services and criminal justice. This further emphasises the need for people with a dual diagnosis to receive proper support in the first instance to prevent further impact on other services.

c) Better advocacy and support for families

The results from interviews with both family members and professionals highlight that families of those with a dual diagnosis need better support and advocacy.

Some professionals discussed ways that people affected by dual diagnosis and their families could be advocated for strategically, and how systems could be best configured to meet their needs. Suggestions included:

- To embed family support into substance use and mental health treatment.
- To involve families and carers in service design and delivery, putting people with first-hand experience at the forefront of decision making.
- Ensuring families are informed of their rights and options on the front-line. Professionals and family members feel that substance use and mental health workers have a role in advocating for the needs of families on the front-line- something that is not always the case when workers are overstretched.
- To provide opportunities for peer support – chances for individuals to meet others affected in similar ways.

d) Stigma needs to be addressed in the same way it has for mental health

Families living with a loved one with a dual diagnosis typically reflected on experiences of stigma. These were based on the behaviour or comments of others, their own fears of how others might react, and experience of how certain social situations have unfolded. The stigma experienced by families of drug and alcohol users is nothing new. What is different for dual diagnosis is that two factors come into play – the substance use and the mental ill health. Whilst families reported that it is becoming easier to talk about mental health, stigma around substance use still persists. As well as contributing to poor emotional health of those with a dual diagnosis, and their family members, this was seen to have affected the treatment and support available to both parties. Families felt that addiction to drugs and alcohol is still seen by many members of the public, and professionals, as a choice, and some reported feeling judged by treatment services. This is a huge barrier in accessing treatment, as well as in the amount of funding made available for support for those experiencing a dual diagnosis, and their families. Until this is addressed, families will continue to feel isolated and unsupported in their experiences, even if more funding for treatment is made available.

Training for practitioners working in mental health services, as well as GPs, around substances, addiction and dual diagnosis, will help to improve understanding and hopefully reduce feelings of judgement amongst individuals and their families. The general public need to be made more aware of the prevalence of the issue, through campaigns led by organisations such as Adfam in the drug, alcohol and mental health sectors. The increased awareness of mental health issues that we have seen in both the public and professional psyche is evidence that stigma can be reduced by effective campaigning, and the same needs to be achieved around dual diagnosis, and substance misuse in general.