

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

EXECUTIVE SUMMARY



Introduction

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 problems¹.

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 resources². 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 impacts³ and policy guidelines put in place for mental health and drug and alcohol commissioners in an attempt to combat this. Despite these guidelines, in reality there is still persistent failure of services to work together to support people with multiple needs⁴ 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, as well as professionals working in mental health and drug and alcohol services, in this report 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.

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. Four key themes emerged:

a) Practical Impacts

The impacts experienced by family members supporting a loved one with a dual diagnosis in practical terms were often described as 'life changing', and has often become the main focus of their life. These impacts included financial strain, a loss of boundaries and

¹Public Health England (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 National Institute for Health and Care Excellence (NICE) (2015) Available at: <https://www.nice.org.uk/guidance/ng58/documents/evidence-review-2>

⁴ Making Every Adult Matter (MEAM) coalition (2015) *Voices from the Frontline: Listening to people with multiple needs and those who support them*

disruption to their day-to-day life, a negative impact on their own health and wellbeing and taking on wider caring responsibilities due to their loved one with a dual diagnosis not being able to fulfil their own caring responsibilities.

b) Relationships

Many families spoke about the impact of their relationships- with the person with the dual diagnosis, and with others around them. Many describe the lies and deception that they experience in dealing with their loved ones, as well as bringing to attention the strain it had on their relationships with other family members, who can suffer directly from their loved one's situation as well as having attention diverted away from them.

c) Mental Health

Many families spoke about almost ongoing extreme worry and stress about their loved one's situation. A significant cause of this is the ongoing fear felt by many families of the risk of suicide and self-harm for their loved one, and find it hard to envisage a future for their loved one where they are able to overcome their substance use problems or manage their mental health. 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. Other sources of frustration were the lengthy waiting times and the lack of formal diagnosis. Furthermore, 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 or the family members. When care was accessed, families felt that it wasn't consistent.

d) Exacerbation of Impacts

These impacts are exacerbated by a general lack of understanding and awareness around the urgency of mental health support, both in the treatment sector and society more widely. This, alongside stigma towards substance misuse, is seen as a barrier to getting adequate support. A lack of empathy and understanding led to families feeling isolated in their experiences.

Comment

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.

b) The emergence of a typical family dynamic

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. 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.

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 for both the loved one and the family members around them, 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.

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

A 'new normal' is created for families affected by their loved one's dual diagnosis, whereby situations and behaviours that would have seemed unthinkable a few years previously become normalised. 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.

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.

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

Some professionals and family members highlighted 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. Family members and practitioners felt that despite some progress being made in attitudes towards mental health, drugs and alcohol still carried a considerable taboo and it was still difficult to talk about.

Conclusions and Implications

Whilst the issues that people with dual diagnosis face are accounted for and becoming increasingly well recognised, the surveys we carried out highlight that it remains a huge issue, not least for its impact on the wider family. 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, is urgent. We identify 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

The full report is available to download from: <https://adfam.org.uk/supporting-professionals/resources>