

# Living with severe mental health and substance use problems

*Report from the Rethink Dual Diagnosis Research Group*

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**rethink**  
severe mental illness



# Executive Summary

## Introduction

Mental health problems co-existing with alcohol and substance use is an area of growing concern for health and social care service providers, local communities and government. An identified gap in the dual diagnosis literature is the reported lived experience of 'experts by experience' – service users and carers who manage mental health problems and substance use on a daily basis. This report is based upon a series of user-led in-depth interviews with service users and carers managing complex problems related to mental health, substance use and other inter-related issues such as homelessness, unemployment and contact with the criminal justice system.

## Method

The research is based on 28 in-depth interviews with 13 carers supporting a family member with severe mental health and substance use problems and 11 dual diagnosis service users recruited from across England. All the research interviewees in the project had personal experiences either of managing mental health difficulties or as mental health carers. The project has been run as a collaborative venture. At each stage of the research process, from questionnaire design to the final report, members of the research group were actively involved and a consensual approach to the writing of this report was adopted. Owing to time constraints in the study, notes were made from the interview tapes rather than verbatim transcriptions. A standard approach was used to analyse emergent themes and in the report the views of service users and carers are presented separately, alongside summary comparisons.

## Findings

The report contains five results chapters. The main findings from each section are detailed below.

### **(i) Managing health problems – six case studies**

A range of six case studies are provided to illustrate a range of life-contexts, taking into consideration gender, ethnicity and number of years contact with dual diagnosis issues in the study sample. The case studies seek to emphasise the pressures, responsibilities and challenges that people managing dual diagnosis face on a day-to-day basis. A strong theme running through the narratives was the desire to return to a 'normal' life, however this was perceived. The complexity of severe mental health problems and a dependency on drugs or alcohol frequently combines to erode ordinary life opportunities.

### **(ii) Understanding dual diagnosis**

The definition of dual diagnosis provided by the research team was largely accepted by service users and carers as being accurate and relevant. In the area of dual diagnosis there are concerns over the accuracy of diagnosis of both mental health and physical health problems with this population. Many people living with severe mental health problems and chronic substance use will not be officially diagnosed with a dual diagnosis label.

The research explored with participants the links between mental health and substance use problems. For some service user the prevailing perception was that there was a link between mental health problems and substance use though there were differing views as to which was the precipitating factor. In addition, they generally perceived the relationship to be problematic. It contributed to difficulties in their lives including unemployment, inactivity and poverty. Carers also reported a definite link between mental health problems and substance use. Members of this group were equally divided as to which was the precipitating factor. They also believed that the relationship had negative consequences: the distress and loss present in both their own lives and those of their relatives were immense.

In exploring explanations for drug and alcohol use both service users and carers provided four explanatory frameworks: self-medication to deal with the effects of mental health problems; mental health service user lifestyles including boredom; external triggers e.g. relationship breakdowns; drug culture and the attraction of substance use.

### **(iii) Impact of living with a dual diagnosis**

The service users we interviewed spoke primarily about the impacts of living with dual diagnosis on their own lives. Carers reflected on both the impact of mental health and substance use problems on themselves, and their family, as well as the direct effect of dual diagnosis on the person supported. The main impacts described were:

- *The diagnosis process helping and hindering recovery* – providing access to specialist services, but also potential labeling and discrimination or stigma. For carers the diagnosis was perceived in some cases to increase dependency reducing a person's motivation to self-manage and there were concerns over the perceived unreliability of both assessment and diagnosis;
- *Problems arising from management of dual diagnosis issues* - For service users there were almost equal numbers of people highlighting either mental health problems or substance use issues as most problematic for themselves reflecting the highly individualized nature of these issues. Among carers in the study substance use issues are highlighted as most difficult to deal with for the family.
- *Difficulties arising from living with dual diagnosis* - Both groups noted that substances can enhance well-being in the short term adding to difficulties in 'giving-up' substances but also long term substance use is extremely problematic because of the impact on life style, financial circumstances and reduced quality of life leading to chaotic life styles.
- *Health impacts of dual diagnosis* - Common themes identified by both service users and carers talking about their relatives was the sense of shame and guilt, loss of motivation or purpose in life, low self-esteem, and low self-confidence. The most frequently cited impacts on carers were: stress, powerlessness, anxiety and pessimism for the future.
- *Social impacts of managing mental health and substance use* – The social impacts of dual diagnosis are far reaching. For service users these relate in particular to relationships with family and others, inability to obtain employment and their involvement with crime to fund drug and alcohol addictions. For carers the social impacts for service users were identified as social isolation, stigma and lack of employment. For themselves the impact on the whole family, and particularly family relationships, was most noted

alongside their fear of physical and verbal abuse and loss of personal freedom as a result of their carer role.

- *Financial pressures from dual diagnosis* – Both service users and carers talked about the financial pressures as a result of living with a dual diagnosis both in terms of finding money for the addiction and in some cases families paying for private treatment in an attempts to get adequate help. This was considered to add additional stresses to an already stressful situation.

#### **(iv) Experiences of using services**

Each of the 28 people we spoke with described a range of different 'needs' for services to address, varied background contexts and variable experiences of seeking help from different agencies. None of the service users were being supported by a specialist dual diagnosis service or worker. One carer did describe the specific support offered by a specialist dual diagnosis worker within mainstream mental health services, though at the time of interview this worker had left the team and had not been replaced. Those interviewed talked of receiving a range of help and support from different 'service types', at various points. The services that users were most engaged with were voluntary organisations (explained by the recruitment process), community mental health teams (CMHTs), the police and drug/alcohol teams (DAT). For carers the most reported services were GPs, CMHTs, the police, in-patient services and DAT.

In addressing views on specific services for the dual diagnosis group, service users were particularly critical of mental health services inability to address drugs and alcohol problems alongside presented mental health issues. They related how mental health services don't routinely address drug use – they don't ask about it, are not interested in it and therefore are not helping service users address the duality of presenting problems. Some service users were positive about the quality of the help provided by specific individuals within either mental health or substance use services. For carers most of the issues concerned problems with services rather than positive feedback. In terms of dual diagnosis the main criticism was the lack of joint services and jointly trained specialists with knowledge of both mental health and substance use difficulties.

Many of the reported experiences were common to those described by other people with mental health problems and their carers. Service users identified the following 'common' experiences:

- Over reliance on use of medication;
- Mental health problems as a barrier to help seeking;
- Lack of service user involvement in care plan decision making;
- Lack of holistic focus in services;
- Importance of establishing quality relationships;
- Insufficient employment or work opportunities.

For carers the key common issues were:

- Difficulties accessing services;
- Available services are inappropriate;
- Lack of continuity of care;
- Insufficient access to talking therapies;
- Carers feel under valued and un supported by mental health services
- Information sharing and confidentiality problems;
- Variability in service quality.

Overall, service users were more positive about the contacts and relationships they had established with mental health and drug / alcohol services than those reported by carers. They were less critical of the structures in place to provide advice and 'care' but they too identified a number of problems as listed above. What worked best for them were quality relationships with staff that were non-judgemental and positive, providing time to listen to the service users. Carers were on the whole overwhelmingly critical of services. They acknowledged the help of key individuals, and the quality service provided at points in time but overall carers talked with a sense of frustration about service access and provision, particularly within the mental health field.

#### **(v) Gaps and problems with current services**

Service users and carers identified a number of problems and 'gaps' that needed addressing in order to improve the quality of services delivered to people living with severe mental health problems and substance use. These follow on from views expressed in (iv) above and include:

- Difficulties getting timely and appropriate help;
- Not being listened to by professionals;
- Inadequacy of services at first contact;
- Gaps in services for black and minority ethnic communities;
- Lack of crisis support;
- The impact of 'double' stigma;
- Lack of continuity of care;
- Lack of information and understanding of dual diagnosis;
- Lack of specific services for dual diagnosis carers.

In addition to problems relating to the structure of services e.g. access to help in a crisis, culturally appropriate service provision, and the approach of services with positive benefits reported from 'being heard', valued and respected, a strong theme from the interviews was the view that there should be more training and information about mental health problems and substance use difficulties. Training and information is required for service users, carers, service providers and the general public in order to contribute to a greater understanding of mental health and substance use issues.

## **Conclusions**

The picture that emerges from this study was one of a group of people, both service users and carers who struggle daily with the realities of living with dual diagnosis and for whom existing support services have often been inappropriate and/or inadequate. The lives of both users and carers were characterised by a series of losses: loss of an ordinary everyday life, loss of social networks, including loss of friends and family, loss or inability to obtain employment and loss of financial security. The responses of services, mainly mental health services, to the complexity that is dual diagnosis were varied in number and variable in quality. The lack of dedicated dual diagnosis staff was considered by service users and carers alike to be a glaring omission. This group require specialist supports provided by a number of skilled dual diagnosis practitioners and greater general awareness for all staff working in all health and social services.

## Recommendations

This research puts forward a number of recommendations to improve the support provided to dual diagnosis service users and their carers. These include:

- Mainstream mental health services, both statutory and voluntary, need to pay greater attention to the issue of dual diagnosis when planning and delivering services;
- Compulsory training for mental health and drug and alcohol service staff should be introduced. Training is needed to produce specialist dual diagnosis workers and increased awareness among all practitioners of working with the combined impacts of mental health and substance use problems. This includes staff in both the statutory and voluntary sector;
- Improved inter-agency protocols for supporting people with dual diagnosis and better communication and information sharing arrangements between mental health and drug / alcohol services in each locality;
- More provision to alternatives to medication should be made available to dual diagnosis service users such as motivational interviewing, crisis interventions planning and advocacy services.
- Self-management programmes for people with dual diagnosis should also be encouraged and developed as part of the NHS chronic disease management initiatives.
- Develop services for dual diagnosis carers including training courses, support groups and provide carers with access to information both signposting to local supports and explaining mental health and substance use issues.
- Information on mental health and substance use should be made more widely available to the general public and health promotion activities should address these issues in workplaces, schools and community settings.

Rethink publishes an extensive range of publications for service users and carers including *Only the Best* – a guide to getting the best fit medication, *Caring and Coping* and *What is severe mental illness?* To order copies or to find out more about Rethink publications call 0845 456 0455 or log on to [www.rethink.org](http://www.rethink.org)

Rethink, Turning Point and Adfam are also launching a series of tools to support people working with people with dual diagnosis. The Dual diagnosis toolkit can be ordered by calling Rethink on 0845 456 0455 or accessed by logging onto [www.rethink.org/dualdiagnosis](http://www.rethink.org/dualdiagnosis)

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