Review of the Hertfordshire Dual Diagnosis Protocol
Feedback from Carers

Background:

Historically having a diagnosis of co-existing mental health and substance misuse disorders resulted in service users being unable to access appropriate and effective support and treatment for either issue. Mental health services, in particular, refused to see anyone who was misusing drugs and/or alcohol until they had been abstinent for at least 3 months, something which was almost impossible for many service users to achieve, leaving them with little hope of recovery and leaving their carers to carry on coping, many unsupported and most unrecognised, with the fall out of their loved ones' behaviour.

Organisations such as the Department of Health (2002), and NICE (2016) have produced good practice guidance in an attempt to tackle the inadequacies in care and treatment of people with a dual diagnosis. Not much has changed in the 14 years between these two documents; it is all about working together, being inclusive and holistic.

To address the issue in Hertfordshire, Spectrum CGL (Spectrum) and Hertfordshire Partnership University NHS Foundation Trust (HPFT) developed the Co-existing Mental Health and Substance Misuse Disorders (Dual Diagnosis) Protocol. Service users and carers were consulted on the draft Protocol in February 2017 and the operational Protocol officially went live in April 2017; however, delays in delivery of training to staff meant the review of the Protocol, originally planned for April 2018 was put back until the end of September 2018.

The Protocol:

In brief, the Protocol sets out how HPFT and Spectrum will work together to provide 'comprehensive service user focused services to those with Co-existing Mental Health and Substance Misuse Disorders'. The presentation from our carers feedback forum on 16th October 2018 is included with this report to explain these services simply.

Carers feedback:

All of the carers who attended are currently caring for, or had previously cared for someone with a dual diagnosis. Most have had recent experience of the services detailed in the Protocol. Some have had positive experiences whilst others' experiences have not been positive at all.

The main issues raised were:

- The Protocol is inflexible and its scope limited
- Service user needs outside of mental health and substance misuse are not always met.
- The wait between detox/demonstrating progress in treatment, mental health assessment and receiving a mental health intervention is too long
- Sharing information – consent and confidentiality
- Recording information – serviceuser/carer records and letters
- Carer support

The Protocol is inflexible and its scope limited

Carers felt that, despite acknowledgement of the fluidity of mental health and substance misuse in the Protocol (p 4 & 5) the practice does not allow for this, neither does it consider the involvement of other services which come into contact with this client cohort and might have a significant role to play in their treatment and support. Including but not limited to, *hospital medical staff, staff in health and social care settings and GPs

The definition of dual diagnosis does not include Personality Disorders, despite the tendency of people with a PD to misuse substances, whether alcohol or illicit or over the counter/prescription drugs.

Those not in treatment are not covered by the Protocol and its delivery in practice does not lend itself to working to engage those people during that (often) very small window of opportunity when they are open to help.

There were some examples of very good practice where the services worked holistically and flexibly in a crisis situation. However, this should happen as a matter of course across service delivery, and should also be considered as an effective harm reduction approach.

We realise that resources are limited and that the approach of both services to treatment are different; substance misuse services tend to be working with people who have sought help themselves and are ready and willing to participate, whilst those in mental health services are seen as being in need of help. But we would suggest that a more flexible approach which includes, awareness raising, prevention and education as well as harm reduction would reduce the amount of money spent on expensive crisis services and interventions.

The lengthy wait for mental health interventions:

Arguably the most significant change, since the Protocol, has been the quicker access to mental health assessments, with the Protocol stating that (alcohol dependent) service users who have been detoxed and (opiate using) service users who have demonstrated progress in treatment can, after a conversation with a Spectrum doctor, be referred/self-refer (with support)to SPA, who will make a decision as to whether mental health involvement is required.

However, whilst the theory promises much, the reality, as reported by carers, is that the wait between assessment, referral and receiving a mental health intervention is far too long and the interim mental health support available from Spectrum does not fill the gap and this leads to service users relapsing and increases the pressure on carers.

Information sharing:

Consent and confidentiality is still an issue for many carers.
Where consent has not been given carers should still receive 'sufficient information in, a way they can readily understand, to help them provide care efficiently' (Department of Health: Developing services for carers and families of people with mental illness, November 2002) and yet carers are still telling us

that this is not happening as a matter of course, and neither are opportunities to share, with loved one's Recovery Workers, information which could be vital to their treatment and care.
Even where consent has been given some carers are reporting reluctance, by services, to share information or involve them in their loved one's treatment and care.

Recording of information:

This issue was raised at the Carers in Hertfordshire event for carers of someone with a dual diagnosis in October 2015, and appears to continue to be happening with carers reporting the following:

- Information given to paid staff by service users and/or carers was frequently recorded inaccurately and, when challenged, staff refused to rectify their mistakes or amend their records
- Letters containing confidential information were being sent to an incorrect address as records had not been updated, even though the agency had been advised of the change of address.
- Carers are not always receiving copies of paperwork; CPA was mentioned specifically, even where the service user had given consent.

Carers' support:

Support for carers of someone with a dual diagnosis was touched on briefly and should be considered. We need to:

- Enable identification of this caring cohort
- Enable easy access to generic carers services
- Establish whether support, specifically around living with the impact of a loved one's dual diagnosis, and its delivery might differ from other carers support.
- Develop a dual diagnosis carers support programme which should include information, education and support to distinguish between enabling and safety where they are caring for a dependent drinker for whom withdrawal is a risk.

Conclusion:

With some exceptions, the delivery of the services to meet the needs of people with a dual diagnosis is as described in the Protocol. However, services would be more effective if the following issues were addressed:

Mental health and substance misuse services must be able to work within the often brief window of opportunity where service users are 'ready' and motivated to engage .i.e. quicker access to mental health interventions. The wait between assessment, referral and mental health involvement is too long, with carers reporting waits of over a year. Quicker access must also apply to service users who do not have a severe mental illness but who suffer anxiety and depression which are often the most common mental health problems.

Personality Disorder should be included as a severe mental illness due to the tendency of this cohort to misuse substances and the difficulties they face in accessing treatment and support. "People with

personality disorder are at high risk of substance misuse and are at greater risk of mental illness. They also have difficulty in forming trusting and supporting relationships. This makes working with them a particular challenge." (The Royal College of Psychiatrists' Research Unit. 2002. Co-existing Problems of Mental Disorder and Substance Misuse (dual diagnosis) (An Information Manual).

The Protocol needs to be more flexible to meet the needs of this client group at all stages of their journey and not just in crisis. Some crises could be avoided by applying the good practice from delivery of crisis intervention to more appropriate treatment and support earlier.

Involve other partners in the delivery of the Protocol. Ensure that staff in primary and secondary care and adult care services are aware of and understand the Protocol to provide a more integrated approach and make sure that the frequent physical problems faced by this client group are addressed.

Ensure that where there is consent that carers are involved and informed, but also make sure that carers without consent are provided with relevant generic information which will help them care. Offer all carers support in their own right, irrespective of consent or whether their loved one is in treatment or not.

We would like a representative from the Integrated Mental Health and Substance Misuse Governance Group to attend a future Family Carer Forum to respond to this report.

Carers in Hertfordshire Family Carer Forum
16th October 2018.