Review of Co-existing Mental Health and Substance Misuse Disorders (Dual Diagnosis) Protocol Version: 3, April 2017.

Updated Feedback from Carers' Group – July 2020.

Note: This updating feedback is separate to the previous feedback exercise, led by Healthwatch Hertfordshire, published in September 2019.

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)[i], Public Health England (2017)[ii] and NICE, 2016[iii] and 2019[iv] 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 intervening 17 years; it is all about working together, being inclusive and holistic. In fact, the 2017 Public Health England guidance states "The Guidance covers all mental health problems – both common and severe mental illness and personality disorder" and " is intended to be used alongside and in support of implementation of NICE and other clinical guidance". To now be talking only of severe mental illness in the existing protocol could be seen as a retrograde step.

To address the issue in Hertfordshire, 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. In October 2018 Carers in Hertfordshire convened a Dual Diagnosis Protocol Focus Group and the resulting feedback from carers formed a report which was sent to the Integrated Mental Health and Substance Misuse Governance Group to be included in their review of the Protocol. However, the review was further delayed.

Since May 2020 Carers in Hertfordshire has been convening fortnightly online meetings of the Drug and Alcohol Carers' Forum to support carers during lockdown due to the coronavirus pandemic. Given that all of the carers who attend the virtual meetings have experience of caring for someone with both mental health and substance misuse issues and that the review of the Protocol is long overdue, a sub-group worked together produce this update of the original 2018 carers' report.

The Dual Diagnosis Protocol:

In brief, the Protocol sets out how HPFT and CGL (Spectrum) will work together to provide 'comprehensive service user focused services to those with Co-existing Mental Health and Substance Misuse Disorders'.

1) Carers' feedback based on lived experience

Carers recognise that the services detailed in the Protocol have changed since their last report. For example, since April 2019 CGL (Spectrum) has been offering a re-modelled, all age drugs and alcohol service across Hertfordshire. HPFT has implemented some major changes including a mental health crisis telephone triage service open to all adults in the county. The current pandemic has had an inevitable impact on service delivery from both organisations, therefore carers have tried to give balanced feedback on how the Protocol works in practice based on their lived experience mainly before lockdown.

The main issues raised were:

- Terminology: use of the term 'dual diagnosis' as a shorthand for co-existing mental health and substance misuse disorders
- The Protocol is inflexible and its scope limited
- Service user needs outside of mental health and substance misuse are not always met, in particular the need for stable housing and all-round medical care
- The wait between detox/demonstrating progress in treatment, mental health assessment and receiving a mental health intervention is too long
- Referrals to CGL need to be followed up persistently to engage the service user
- Sharing information – consent and confidentiality
- Management level integrated governance meetings
- Carers' support

2) Terminology: use of the term 'dual diagnosis' as a shorthand for co-existing mental health and substance misuse disorders:

Carers felt that the term 'dual diagnosis' as a shorthand for 'co-existing mental health and substance misuse disorders' was misleading as it implied that the service user had an existing diagnosis of a mental health condition (see below regarding scope of the Protocol). Many people misusing substances remained undiagnosed, especially where they have not been able or willing to access mental health services to get an assessment. Carers preferred the term used by Public Health England (PHE) (2017), which was felt to cover a broader range of conditions: 'co-occurring mental health and alcohol/drug use conditions'.

3) The Protocol is inflexible and its scope limited:

Carers recognised the challenges in accessing appropriate care for people with co-occuring mental health and alcohol and/or drugs misuse issues as set out in page 2 of the Protocol. Public Health England (2017) quotes research showing that mental health problems are experienced by 70% of drug and 86% of alcohol users in community substance misuse treatment. Over half of all completed suicides in people experiencing mental health problems are attributable to a history of alcohol or drug use. Carers agree with PHE's two principle aims: 'everyone's job' and 'no wrong door', which they believe should be reflected in both the Protocol and its practical implementation. It was vital to address these issues for the sake of individuals, their families and society as a whole.

From their lived experience, carers believed that in most cases substance misuse was the symptom and not the cause of mental health issues and that their loved ones were self-medicating to deal with trauma or other underlying, unresolved issues. Carers challenged the belief that mental health issues could not be addressed while someone was actively using. This view is echoed by NICE in its 2019 quality standard document: 'people aged 14 and over with severe mental illness and substance misuse……can receive care and support for both conditions at the same time.' Carers felt that psychotherapy could help people understand their addiction and motivate themselves to change. If this support can be offered in private rehabilitation settings why not in community or inpatient services?

Carers felt that there was a lack of clarity in the eligibility criteria for HPFT support. Examples of severe mental illness are given on page 3 of the Protocol, in line with NICE definitions (2019) but do not include Personality Disorders (PD), despite the tendency of people with a PD to misuse substances, whether alcohol or illicit or over the counter/prescription drugs. It is interesting to note that during the consultation stage of NICE's 'Co existing severe mental illness and substance misuse Quality standard [QS188]' (published date: 20 August 2019) many organisations including CGL suggested that the definition of Severe Mental Illness to be expanded to include Personality Disorder. Self-harm and self-neglect were not mentioned either. Carers also questioned whether repeated suicide attempts and/or suicidal thoughts qualified under 'severe depressive episode(s)'. In spite of improvements in crisis services, carers' lived experience showed that people in crisis were not always offered inpatient admission and, even if they were, they were being discharged back to CGL without mental health support (such as an HPFT Care Co-ordinator, care plan or risk management) when they were still a risk to themselves and others. This has put an intolerable burden on carers to keep their loved ones safe and to encourage them to engage with CGL at a time when their loved ones are most vulnerable to relapse. Carers felt that irrespective of whether a suicide attempt/suicidal ideation was down to the use of or withdrawal from substances, it was still a serious condition and a 'person centred approach' (page 4 of the Protocol) was required in order to get joined up help and prevent the vicious cycle starting all over again. There was concern that lockdown would increase the number of drug and alcohol users presenting in mental health crisis.

In 2012, the Government published the cross-Government National Suicide Prevention Strategy, which was updated in 2017 [v], to strengthen delivery of its key areas for action, including expanding the scope of the strategy to include addressing self-harm as an issue in its own right. This plan outlines the key actions that includes Local Government to ensure every Mental Health Trust has a zero-suicide ambition for mental health in-patients by 2018/2019. A recent experience of inpatient admission for suicidal intention resulted in the carer making a formal complaint that the patient was able to attempt suicide at Kingfisher Court in Radlett within 24 hours of admission in April 2020.

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. This includes but is not limited to: hospital medical staff, staff in health and social care settings, housing, the criminal justice system and GPs. NICE recommend a protocol for information sharing between services. NICE (2016 [vi])

Those not in drug and alcohol 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 good practice where the services worked holistically and flexibly in a crisis situation. However, this should happen as a matter of course across all service delivery and should also be considered as an effective harm reduction approach. The co- location of CGL Complex Needs workers with HPFT staff was welcomed but carers asked specifically for the re-instatement of a CGL nurse at Kingfisher Court to ensure better liaison between the two services in the treatment of patients with co-occurring conditions.

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. However, carers felt sometimes there was an element of ‘offloading’ between services due to lack of resources. Furthermore, it was felt that due to cutbacks CGL seemed to have focused more on prescribing medication than on one to one support and preparation for detox/rehab. We would suggest that a more flexible approach which includes more joint working, awareness raising, prevention and education as well as harm reduction would reduce the human cost as well as the amount of money spent on expensive crisis services and interventions.

4) **Service user needs outside of mental health and substance misuse are not always met, in particular the need for stable housing and all-round medical care**

It is recognised that people with complex needs have ‘significantly poorer outcomes’ than those who have mental illness or substance misuse alone (NICE 2019). They are more likely to have physical health problems, contact with the criminal justice system and experience homelessness.

Although the Protocol focuses on collaborative working between HPFT and CGL, carers felt there should be details of joined up working with other agencies to ensure stable housing and adequate, all-round medical and nutritional support. This is in line with a holistic person-centred approach.

Carers felt that one of the biggest barriers to recovery for their loved ones was stable housing, especially after discharge from hospital, detox or rehabilitation, when regular, sustained contact and support were essential to avoid relapse. The experience of carers whose loved ones lived with them was that they felt they were propping up services with no hope of respite and some carers had been subjected to domestic abuse. There is also no overlap in older clients for dementia/Korsakoff's/cognitive decline assessment. Thus a complete joined up approach addressing all aspects of health, housing, and social support should be considered as part of any care assessment.

5) 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 CGL doctor, be referred/self-refer (with support) to the Single Point of Access (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 CGL does not fill the gap and this leads to service users relapsing and increases the pressure on carers.

In addition to the delay in being seen by HPFT, one client when finally assessed by SPA was told that there could be no counselling or help offered until he had been clear of drug use for three months. When the drug use is caused or exacerbated by trauma and/or emotional issues this requirement is not likely to be fulfilled and this client like others ends up in a vicious circle. Access to Dialectical Behaviour Therapy (DBT) for those with a concurrent mental health condition was mentioned by several carers, who said that their cared for person had been refused DBT because of their substance misuse, despite their having engaged with CGL, shown progress in treatment or being clean of alcohol. This is difficult for carers to understand especially when the 2017 Public Health Guidance states "People who use alcohol and/or drugs often find themselves excluded from improving access to psychological therapies (IAPT) services, in spite of NICE recommendations that they should be able to access psychological interventions such as cognitive behavioural therapy (CBT) for depression and anxiety." A recommendation in the same Guidance states that "Commissioners and Providers should review service access criteria with experts by experience. Make sure they are not used to exclude people based on levels of alcohol and/or drug dependency, or on diagnoses (or lack of diagnoses) of mental illness, but are used to actively support people to get the help they need."

6) **Referrals to CGL need to be followed up persistently to engage the service user:**

Referrals are made in both directions between CGL and HPFT and vice versa. Carers felt that where HPFT referred a service user to CGL for help with drug or alcohol issues there should be assertive and persistent follow up by both organisations to try to engage the person. Although engagement with CGL is voluntary, it is recognised that those with complex needs may require more help and encouragement to see the benefits. NICE provide helpful guidance on how to follow up those who are reluctant or fail to attend services.

NICE [vii] in the implementation of Early Intervention in First Psychosis (EIP) has mandated an access and waiting time standard, including that associated with substance abuse. An EIP service should comprise staff who have experience and skills in working with people who have co-occurring problems with substance misuse, a history of trauma and neurodevelopmental disorders. The clock starts regardless of referral source, the age of the person being referred or comorbidities such as learning disabilities, substance misuse, personality disorder or autism.
Interventions for coexisting mental health problems to be offered for depression, any of the anxiety disorders, emerging personality disorder or substance misuse. Provision must be made for substance misuse services, i.e. substance misuse treatment and substance misuse therapy. One carer reported that this standard was violated; their cared for person with the diagnosis of Cannabis-induced Psychosis was told to 'self-refer' to CGL.

7) **Information sharing:**

Consent and confidentiality are 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, November 2002[viii]). Indeed, much of the guidance available stresses the need to involve carers in treatment plans. Although one carer shared an example of good practice by HPFT practitioners, most carers are still telling us that this is not happening as a matter of course, and neither are opportunities to share with loved ones' Recovery Workers information which could be vital to their treatment and care. It is particularly important that with or without consent a carer's input is sought for a Mental Health Act assessment as some loved ones can mask their conditions in order to avoid inpatient admission.

Equally a carer's views on their loved one's request for voluntary admission should be taken seriously. In some cases, carers had not been contacted at all in spite of emergency in-patient admission. 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. There have also be instances of incorrectly addressed or inaccurate paperwork which had not been updated following carers' requests.

8) Management level integrated governance meetings:

Carers expressed concern about overall acceptance and implementation of the Protocol in its current form. They asked for clarification about arrangements for the intended continual joint working of HPFT and CGL to ensure that the Protocol is fully implemented. It is stated on page 12 of the Protocol that a "senior joint governance meeting" should be convened and held quarterly. Carers asked whether such meetings had taken place, and if so, when and where these quarterly meetings were held, and whether any minutes were available. In particular, they queried what (if any) actions were proposed and agreed at these meetings and whether they had all been implemented fully. They also asked whether all 5 of the intended attendee types had been invited and whether they had always attended. Finally, they asked which organisations represented the views of service users and carers.

9) Carers' support:

Support for carers of someone with complex needs 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 complex needs, 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.

10) Conclusion:

In spite of some improvements since the last review and considerable efforts by individual professionals during difficult times, carers felt that the delivery of the services to meet the needs of people with co-occurring conditions fell short in practice of some of the expectations as described in the Protocol.

They felt services would be more effective if the following primary and urgent issues were addressed through joined up working.

10.1) 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 and/or drug and alcohol interventions. The wait between assessment, referral and mental health or CGL involvement is too long. 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. At the moment there appears to carers to be little emotional support given to clients.

10.2) We would recommend a change in terminology and more clarity in the definitions of mental health conditions. The scope of people eligible for HPFT support should be extended. 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) [ix]. Specific procedures and support for those who attempt suicide and/or are frequent users of crisis and emergency services should be agreed so that they do not fall between services and remain at risk.

10.3) The Protocol should include information on waiting times from referral/self-referral to HPFT via SPA and vice versa and should also detail eligibility criteria for mental health interventions, with specific reference to DBT and other therapies.

10.4) 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.

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

10.6) 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 as well as opportunities to share information vital to their loved one's treatment. Offer all carers support in their own right, irrespective of consent or whether their loved one is in treatment or not. The 2016 NICE guideline states "the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian".

Produced by a sub-group of registered carers attending the Carers in Hertfordshire Drug and Alcohol Carers' Forum. Supported and facilitated by the Carers in Hertfordshire Involvement Team.

Contact the Involvement Team at contact@carersinherts.org.uk or call 01992 58 69 69 for further information.

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References and notes

[i] Department of Health: Mental Health Policy Implementation Guide. Dual Diagnosis Good Practice Guide' 2002.

[ii] Public Health England: 'Better care for people with co-occurring mental health and alcohol/drug use conditions. A guide for commissioners and service providers.' 2017

[iii] NICE: 'Co-existing severe mental illness and substance misuse: community health and social care service - guideline.'2016 https://www.nice.org.uk/guidance/ng58

[iv] NICE: 'Coexisting severe mental illness and substance misuse – quality standard'. 2019. See also https://pathways.nice.org.uk/pathways/coexisting-severe-mental-illness-and-substance-misuse-assessment-and- management-in-healthcare-settings

[v] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/772210/nati onal-suicide-prevention-strategy-workplan.pdf

[vi] Information sharing

1.4.6 Agree a protocol for information sharing between secondary care mental health services and substance misuse, health, social care, education, housing, voluntary and community services (see the Caldicott Guardian Manual).
1.4.7 Adopt a consistent approach to getting people with coexisting severe mental illness and substance misuse help from the most relevant service by:

- sharing information on support services between agencies
- ensuring all providers know about and can provide information on the services
- taking responsibility, as agreed in referral processes, providing timely feedback and communicating regularly about progress.

[vii] https://www.nice.org.uk/guidance/qs80/resources/implementing-the-early-intervention-in-psychosis-access- and-waiting-time-standard-guidance-2487749725

[viii] Department of Health: 'Developing services for carers and families of people with mental illness'. November 2002.

[ix] The Royal College of Psychiatrists' Research Unit. 'Co-existing Problems of Mental Disorder and Substance Misuse (dual diagnosis) (An Information Manual).' 2002.