NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Severe mental illness and substance misuse (dual diagnosis): community health and social care services

Topic

The Department of Health in England has asked NICE to provide guidance for local authorities, NHS England, health and wellbeing boards and clinical commissioning groups on effective multi-agency working to improve access to services for people with 'dual diagnosis'. Specifically, it is for those living in the community who may have multiple needs.

Who the guideline is for

Who should take action:

- Commissioners and providers with public health as part of their remit working within the NHS, local authorities and the wider public, private, voluntary and community sectors. In particular, those who commission and deliver health, social care, community and voluntary sector services for people with a severe mental illness who misuse substances.

It is also relevant to:

- People using services, their families and carers and the public.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive.

Equality considerations

NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified and how they have been addressed
- explains why any groups are excluded from the scope, if this was done.

1 What the guideline is about

This guideline will make recommendations for service organisation and delivery to meet the wider health and social care needs of people with dual diagnosis.

The term 'dual diagnosis' is used in a variety of ways by people working in health and social care in the UK. In the NHS, it usually refers to the occurrence of a mental illness alongside substance misuse. Some studies have used the term to refer to any co-existing mental illness, whereas others have restricted it to 'severe' mental illness. The latter usually includes schizophrenia, bipolar affective disorder and personality disorders (Todd et al. 2004[1]; Adult psychiatric morbidity in England – 2007, Results of a household survey Health and Social Care Information Centre). It may also include severe depression (Lehman 1994[2]).

In the UK social care sector, the term dual diagnosis is sometimes used when people have a learning disability and a mental illness.

The interplay between substance misuse and mental illness is complex and can change over time. It can vary between people and it may depend on the type of mental health problem and on the type and amount of substance misused. Someone may have:

- a mental illness that has led to substance misuse
- a substance misuse problem that has led to a mental illness
- 2 initially unrelated disorders (a mental illness and a substance misuse problem) that interact with and exacerbate each other

[1] Todd J, Green G, Harrison M et al. (2004) Defining dual diagnosis of mental illness and substance misuse: some methodological issues. Journal of Psychiatric and Mental Health Nursing 11: 48–54

[2] Lehman AF, Myers CP, Dixon LP et al. (1994) Defining subgroups of dual diagnosis patients for service delivery. Hospital and Community Psychiatry 45(6): 556–61

- other factors that are causing mental illness and substance misuse, including physical health problems.

For the purpose of this guideline, dual diagnosis is defined as a severe mental illness combined with misuse of substances. Severe mental illness in this guideline includes a clinical diagnosis of:

- schizophrenia, schizotypal and delusional disorders
- bipolar affective disorder
- severe depressive episode(s) with or without psychotic episodes.

Substance misuse refers to the use of legal or illicit drugs, including alcohol and medicine, in a way that causes mental or physical damage[3].

1.1 Who is the focus?

Groups that will be covered

- Young people (aged 14 to 25) and adults (over 25) who have been diagnosed as having a severe mental illness and who misuse substances (dual diagnosis) who live in the community. The age cut-off for young people has been set at 14 to reflect the small numbers affected below this age – and the fact that many early intervention services start at age 14.

Groups that will not be covered

- People with a severe mental illness but no evidence of substance misuse.
- People who misuse substances who have not been diagnosed with a severe mental illness.
- People with a severe mental illness who smoke or use tobacco but do not misuse any other substances.
- People who have a severe mental illness and misuse substances, but who are not living in the community.

[3] This may include low levels of substance use that would not usually be considered harmful or problematic, but may have a significant effect on the mental health of people with a mental illness such as psychosis.

1.2 Settings

Settings that will be covered

- Community settings. This will involve a range of services provided by the NHS, social care and schools, as well as the community and voluntary sectors.

Settings that will not be covered

- prisons and other custodial settings
- young offenders units
- forensic secure mental health settings.

1.3 Activities, services or aspects of care

Key areas that will be covered

1 The content, configuration and integration of community-based services to address the health and social care needs of people with a severe mental illness who misuse substances. This may include:
   - the structure and organisation of different service components, including information sharing and care pathways
   - capacity of services
   - location of services in terms of setting and geography (for example, rural or urban)
   - funding, commissioning of services, governance and overall accountability
   - first point of contact with health or social care services
   - acceptability of services to people who use them and their carers
   - organisational structure, staff roles and their views and skills, including their training and education needs.

2 Measures to ensure services are provided to meet the needs of people with a severe mental illness who misuse substances. Plus measures to ensure services are available when needed (this includes services available 24 hours a day, 7 days a week.)

3 Measures to promote the use of services. This includes activities to encourage adherence to treatment programmes, improve waiting times, and to improve transfer and referral protocols.

Areas that will not be covered

1 Identification and diagnosis of coexisting substance misuse and severe mental illness.
2 Clinical treatment including pharmacological, psychological or psychosocial therapies.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant and, if so, whether this is an area that should be prioritised for economic modelling and analysis.

We will take cost effectiveness into account when making recommendations involving a choice between alternative activities, interventions or services. The analysis will use a public sector and a societal perspective.

Due to the range and subtlety of the outcomes, a cost–consequences analysis of different service delivery scenarios will be undertaken. Where possible, this will compare differences in:

- health-related quality of life and general wellbeing
- how people's housing needs are being met
- levels and suitability of employment
- dependence on benefits
- levels of admission to a secure setting (including, for example, forensic secure mental health settings, prisons and other custodial settings).

It may also be possible to carry out a cost–utility analysis based on the above consequences.

1.5 Key issues and questions

While writing this scope, we have identified the following key issues and review questions related to them:

1 Epidemiology and current practice:
   - What are the health and social care needs of people in the UK with a severe mental illness who also misuse substances, and what services do they currently receive?

2 Service models: content, configuration and acceptability:
   - Which service models for health, social care and voluntary and community sector organisations are effective, cost effective and efficient at meeting the needs of people with a severe mental illness who also misuse substances?
   - How do service users, their families or carers, providers and commissioners view health and social care services for people with a severe mental illness who also misuse substances? What are their experiences of these services?

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

1 Rates of coexisting severe mental illness and substance misuse by sociodemographic characteristics.

2 Details of health and social care needs directly and indirectly associated with treatment of the diagnosed mental illness and substance misuse. For example: prevalence of other illnesses such as cardiac, respiratory and blood-borne diseases; social needs, such as safe and secure housing and employment.

3 Details of types of health, social care, community and voluntary services that are provided and how these vary according to sociodemographic characteristics. This would include: the timing and delivery of diagnosis and treatment; waiting times, transfer and referral to other services; the

availability and uptake of services; information on type of staff involved and staffing levels.

4 Service user experience and outcomes (including views on different types of service, satisfaction, awareness, knowledge and use of wider services).

5 Family and carer experience and outcomes (including views on different types of service, satisfaction, awareness, knowledge and use of wider services).

6 Commissioner and provider views (including views on: the content and configuration of community-based services; facilitators or barriers to providing services; and resource needs).

7 Changes in mental and physical health outcomes (for example, changes in relapse rates or incidents of overdose).

8 Changes in broader socioeconomic variables (for example, employment, housing, level of benefits claimed).

9 Processes to help service users access, attend and continue to use services. For example: physical accessibility and acceptability of services; practical help, such as reminders to attend; and non-clinical activities to get service users involved, such as ‘coffee mornings’.

10 Changes in processes and outcomes (for example, changes in transfer and referral processes and waiting times).

11 Changes in service use and costs (for example, measures of ongoing use of a service, including number of missed appointments and changes in adherence to any treatments delivered).

2 Links with other NICE guidance

2.1 NICE guidance

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to dual diagnosis:

- Patient experience in adult NHS services (2012) NICE guideline CG138

- Service user experience in adult mental health (2011) NICE guideline CG136

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

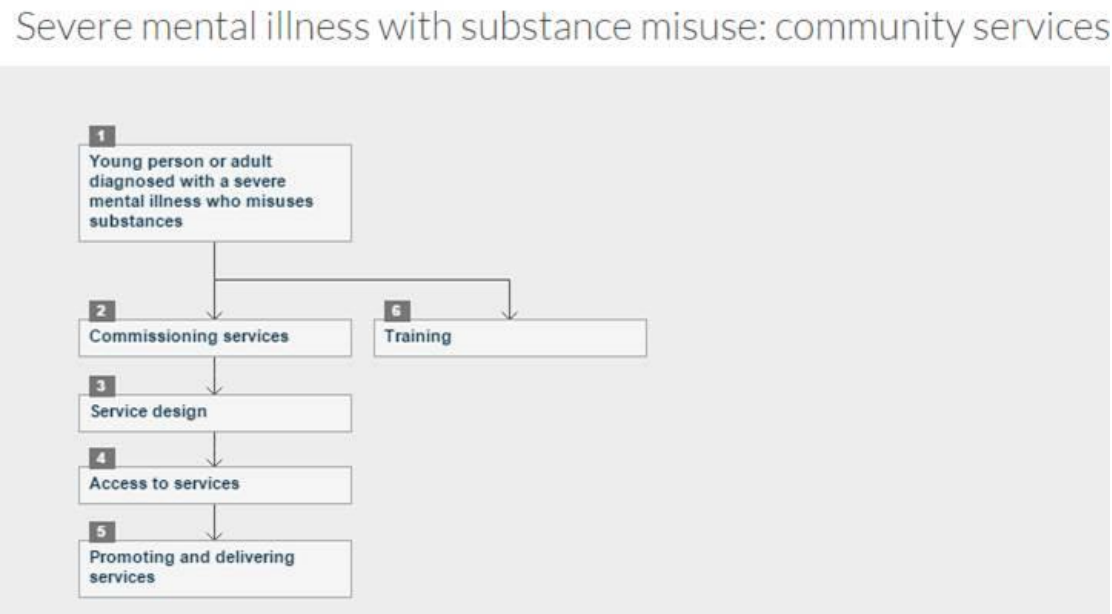
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE guideline. Publication expected November 2015.
- Transition between inpatient mental health settings and community and care home settings for people with social care needs NICE guideline. Publication expected August 2016.
- Mental health of people in prison NICE guideline. Publication expected November 2016.

2.2 NICE Pathways

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

A pathway outline for this topic has been drafted based on the scope and is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

The pathway will include links to NICE's pathway on psychosis with coexisting substance misuse, showing clearly how the recommendations fit together. It will also include links to the pathway on alcohol-use disorders and pathways being developed for draft guidelines on drug misuse prevention and the mental and physical health of people in prison.



3 Context

3.1 Key facts and figures

3.1.1 Adults and young people who have a severe mental illness and misuse substances are among the most vulnerable in our society. They experience some of the worst health, wellbeing and social outcomes (Relationship between dual diagnosis: substance misuse and dealing with mental health issues Social Care Institute for Excellence). This, in turn, places a significant burden on health and welfare services. For example, because of their situation they incur higher service costs than people who have a severe mental illness but do not misuse substances (McCrone et al. 2000[4]).

3.1.2 It is not clear how many people in the UK have a severe mental illness and misuse substances. This is due to several factors:

- Differences in how dual diagnosis is defined.
- Difficulties with diagnosis. For example, substance misuse may mask an underlying mental illness or vice versa (diagnostic

[4] McCrone P, Menezes PR, Johnson S et al. (2000) Service use and costs of people with dual diagnosis in South London. Acta Psychiatrica Scandinavica 101: 464–72

overshadowing); or people may come to acute services with unrelated health problems and their 'dual diagnosis' may be missed.

- Some people in this group do not use services or receive relevant care.
- A lack of national data.

UK studies have reported dual diagnosis rates of 20–37% across all mental health settings and 6–15% in addiction settings. Rates may vary by gender, ethnicity and geography (Variations in rates of comorbid substance use in psychosis between mental health settings and geographical areas in the UK Carrá and Johnson).

3.1.3 Evidence suggests that the number of people diagnosed in primary care with a severe mental illness and a substance misuse problem has increased in recent years (Prevalence of comorbid psychiatric illness and substance misuse in primary care in England and Wales Frisher et al.). Meeting their needs has increased demand on healthcare and other services such as social care, welfare and the criminal justice system. This group needs multiagency support to deal with their dual diagnosis and a range of other factors that may pre-date diagnosis – or be a consequence of it. This can include: disability and injury, family breakdown, social isolation, a history of being looked after or adopted, experience of (or witnessing) abuse, unemployment, homelessness or having spent time in prison (Annual report of the Chief Medical Officer 2013: public mental health Department of Health; Dual diagnosis good practice guide Department of Health).

3.1.4 The diagnosis, care and treatment of people who have a severe mental illness and who misuse substances is a challenge to health and social care services because people in this group:

- Are at a high risk of relapse (in terms of both substance misuse and mental health problems), readmission to hospital, serious

self-harm and suicide (‘Dual diagnosis good practice guide'; Annual Report 2014: England, Northern Ireland, Scotland and Wales National confidential inquiry into suicide and homicide by people with mental illness).

- Often have a delayed diagnosis. Or their condition worsens because of an interaction between the misused drugs and the medications they may be receiving for a mental or physical illness.
- Often have wider health and social needs due to the condition itself or high-risk behaviours such as sharing syringes.
- May be at an increased risk of cardiac or respiratory diseases and blood-borne diseases (‘Dual diagnosis good practice guide’).
- May have an increased likelihood of social isolation, unstable housing, or unemployment.

3.2 Current practice

3.2.1 Different models of service exist to meet the needs of people who have a severe mental illness and misuse substances. Services may be:

- ‘serial’ (people use 1 service at a time depending on their needs)
- parallel (people attend both mental health and substance misuse services during the same time period)
- integrated (1 team addresses both their substance misuse and their mental health needs at the same time, in the same setting).

Examples of collaborative services to meet the health and social care needs of this group include:

- Integrated approaches involving statutory, community and voluntary sector mental health and substance misuse services, with agreed local pathways to meet wider social care needs.
- Mental health services leading on, and helping with, access to other health and social care services. This includes primary

healthcare, housing and employment as well as substance misuse services.

3.2.2 People with ‘dual diagnosis’ have expressed mixed or generally poor experiences of health and social care services and difficulties accessing them. They say services tend to focus on 1 problem rather than looking at the whole range of issues affecting them. In addition, community-based ‘aftercare’ support is often inadequate, and people say they do not get sufficient information about the services they use. Positive aspects of service provision include practical help with housing and employment, and support in accessing a wide range of services (Mind the gaps – meeting the needs of people with co-occurring substance misuse and mental health problems Scottish Executive).

3.3 Policy, legislation, regulation and commissioning

Policy

3.3.1 The Department of Health’s ‘Dual diagnosis good practice guide’ provides a framework for planning services. This includes: developing locally agreed definitions of 'dual diagnosis'; joint planning between mental health and substance misuse services (with mental health services taking primary responsibility for treatment); and liaising with wider services (for example, primary care or homeless organisations). Core and extended services are likely to vary in different parts of the country. This guideline will aim to address these variations by identifying the wider health and social care needs of people who have severe mental illness and who misuse substances.

3.3.2 The Department of Health’s Refocusing the Care Programme Approach identifies people with dual diagnosis as key users of secondary mental health services. The policy highlights the need for a whole systems approach to their care, involving a range of services and organisations working together. The aim, it says, is to:

‘adopt integrated care pathway approaches to service delivery; improve information sharing; establish local protocols for joint working between different planning systems and provider agencies’. This guideline will make recommendations on how this may be achieved.

3.3.3 The Department of Health’s mental health and drug strategies (No health without mental health; Reducing demand, restricting supply, building recovery) both acknowledge the association between mental health problems and substance misuse. This guideline will address the organisation and delivery of community-based services, as outlined in these strategies. This includes commissioning and service provision.

Legislation, regulation and guidance

3.3.4 The Health and Social Care Act 2012 has led to changes in the commissioning routes for mental health and substance misuse services. This guideline will ensure recommendations on service content, configuration and integration reflect these commissioning arrangements.

Commissioning

3.3.5 Community mental health services in England are commissioned by clinical commissioning groups. Drug and alcohol services are commissioned by directors of public health who are based in local authorities. In mental health and substance misuse services, existing contractual arrangements between commissioners and providers are being replaced by new systems. The new systems base payments on the delivery of packages of care (in the case of mental health services) and on the outcomes services achieved for users (in the case of drug and alcohol recovery pilots). (See Dual diagnosis: a challenge for the reformed NHS and for Public Health England Centre for Mental Health.)

4 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in September 2016.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.