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

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NICE guideline

Draft for consultation, May 2016

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This guideline covers how to improve services for people aged 14 and above who have severe mental illness and misuse substances. The aim is to provide a range of coordinated services that address their wider health and social care needs as well as other issues such as employment and housing.

Who is it for?

 Health, social care, community and voluntary sector organisations offering services for people with a severe mental illness who misuse substances.

It is also relevant to:

 People aged 14 and above with a severe mental illness who misuse substances who live in the community, their families and carers and the public.

This guideline contains the draft recommendations, information about implementing the guideline, context, the guideline committee's discussions and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the evidence reviews, the scope, and details of the committee and any declarations of interest.

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1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in <u>your care</u>.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

Commissioners of mental health services should ensure any service specifications take into account the recommendations in this guideline when it is finalised.

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1.1 First contact

- These recommendations are for all services and providers.
- 5 1.1.1 Ensure all staff working in health (including urgent care), social care,
 6 voluntary and community sectors, and the criminal justice system¹ who
 7 may come into contact with young people and adults with severe mental
 8 illness who misuse substances (dual diagnosis):
 - understand that it is important to meet the needs of people with dual diagnosis wherever they present because they may have chaotic lifestyles and are often excluded from accessing services
 - help people with any urgent physical health, social care, support or housing needs, either directly or by putting them in touch with other services.
 - 1.1.2 Ensure the person is referred to secondary care mental health services for assessment and care planning (see section 1.2).

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¹ NICE is developing a guideline on the <u>mental health of adults in contact with the criminal justice</u> system.

1	1.1.3	Be aware that people with dual diagnosis may have a range of physical
2		health conditions including:
3		cardiovascular, respiratory or hepatic conditions or related
4		complications
5		infectious disease
6		• cancer
7		problems with blood glucose management.
8	1.1.4	Be aware that unmet social care needs such as social isolation or poor
9		housing may lead people with dual diagnosis to have a relapse or affect
10		their physical health.
11	1.2	Care planning
12	These re	ecommendations are for all practitioners involved in developing and
13	deliverin	g a care plan.
14	On adm	ission to secondary care mental health services
15	1.2.1	Develop a care plan after admission into secondary care mental health
16		services (in line with the Care Programme Approach) for each young
17		person or adult that:
18		assesses the person's social care, physical and mental health needs
19		and any substance misuse problems they may have
20		 involves practitioners who can meet the person's needs from health
21		and social care disciplines, for example: medicine, nursing, social work,
22		occupational therapy and housing
23		 lists how the person's identified needs will be met and reviewed at
24		every contact
25		 includes how the person can help implement the care plan.
26		Also see NICE's guideline on <u>psychosis with coexisting substance misuse</u>
27		(recommendations 1.2.1–1.2.2 and 1.4.10–1.4.14).
28	1.2.2	Provide the person with a care coordinator within mental health services
29		in the community (in line with the Care Programme Approach) to act as a

1		contact for the person, their family or carers and to help with developing
2		and coordinating the care plan.
3	1.2.3	Ensure the care plan outlines how the safeguarding needs of all young
4		people and adults with dual diagnosis will be met. (See also
5		recommendations on safeguarding issues 1.1.14; and 1.1.16-1.1.20 in
6		the NICE guideline on psychosis with co-existing substance misuse.)
7	1.2.4	Share the care plan with the person and other services as needed (see
8		section 1.3 for recommendations on confidentiality and data sharing).
9	1.2.5	In line with the Care Act 2014 ensure carers who are supporting people
10		with dual diagnosis are aware they are entitled to an assessment of their
11		own needs. Ensure the assessment:
12		recognises that carers have needs in their own right
13		 offers support for the effects of caring on the carers' mental health
14		 takes into account carers' views about services that could help them
15		maintain their caring role and live the life they choose
16		 involves cross-checking any assumptions the person with dual
17		diagnosis has made about the support their carer will provide
18		advises carers that they may also be entitled to a personal budget to
19		buy care to support them, for example to have a break from their caring
20		responsibilities
21		gives information and advice on how to access services in the
22		community.
23	Involvin	g people in care planning
24	1.2.6	When developing and reviewing the care plan:
25		 involve the person and their family or carers (where appropriate) to
26		ensure the care plan is tailored to meet the person's needs (see also
27		recommendation 8 in NICE's guideline on behaviour change: individual
28		approaches)

1		 discuss with the person how their abilities, strengths (such as the
2		extent to which they can take part in activities of daily living) and their
3		past experiences can help support their engagement and recovery
4		 take into account the concerns of the person's family or carers
5		recognise that the goals the person may have decided for themselves
6		may differ from those identified by their service or provider
7		jointly decide with the person which services would best meet their
8		needs
9		stay positive when talking about the prospects of recovery with the
10		person, their family or carer.
11		See NICE's guideline on psychosis and co-existing substance misuse and
12		service user experience in adult mental health for the principles of using a
13		person-centred approach.
14	1.2.7	Consider the following approaches to help young people and adults with
15		dual diagnosis remain involved in their care plan:
16		one-to-one support
17		training in self-care skills
18		 providing practical help with tasks that are important to the person
19		 providing help for example:
20		 arranging or travelling with the person to hospital outpatient
21		appointments or attendance at support groups
22		 arranging for an advocate to accompany them at their appointments
23		(see section 1.5 for recommendations on encouraging people to stay
24		in contact with services).
25	Liaising	with other organisations to meet physical health, social care, housing
26	or supp	ort needs
27	1.2.8	Adopt a coordinated approach (with shared responsibilities and regular
28		communication) when working with other organisations to meet people's
29		wider health and social care needs.

1	1.2.9	Use every opportunity (including direct referrals if possible) to ensure
2		people have prompt access to local services and actively follow them up
3		to make sure their needs are being met.
4	1.2.10	As part of developing and reviewing the care plan, the person's care
5		coordinator needs to:
6		work with relevant primary care staff to meet the physical health needs
7		of people with dual diagnosis; consider involving staff in substance
8		misuse services
9		• work with relevant staff in local authorities, social care, community or
10		voluntary sector organisations to meet the social care, housing or
11		support needs. This can include:
12		 personal care and hygiene
13		 family and personal relationships
14		housing
15		employment
16		 childcare responsibilities
17		• ensure an assessment of social care needs is carried out (in line with
18		the Care Act 2014).
19		
20	1.2.11	Consider covering the following health behaviours in the care plan:
21		• <u>diet</u>
22		physical activity
23		• <u>alcohol</u>
24		• <u>smoking</u>
25		 other risky behaviours (see NICE's guideline on sexually transmitted
26		infections, and the NICE pathways on hepatitis C and needle and
27		syringe programmes).
28	1.2.12	Consider incorporating activities that can help to improve wellbeing and
29		create a sense of belonging or purpose into a person's care plan. For
30		example, encourage sport or recreation activities or attendance at

1		community groups that support good physical health. Ensure activities
2		take account of a range of different needs.
3	1.2.13	Consider a range of approaches to encourage young people and adults
4		with dual diagnosis to use services in the community. This could include,
5		for example, the gym, education opportunities, volunteering or use of
6		personal budgets (where applicable) for learning new skills such as return
7		to employment.
8	1.2.14	Consider the suitability of the type of support that is available (for
9		example, the type of housing, employment, detox or rehabilitation
10		services) and take the person's preferences into account.
11	1.2.15	Recognise that people will have differing housing needs (for example high
12		to low support or independent tenancies). Ensure safeguarding is in place
13	Review	
14	1.2.16	Hold multidisciplinary case review meetings annually as set out in the
15		Care Programme Approach or more frequently, for example every 3
16		months based on person's circumstances. Involve practitioners from a
17		range of disciplines, including:
18		secondary care mental health
19		substance misuse
20		primary care
21		• social care.
22	1.2.17	Check the person's physical health at least annually.
23	1.2.18	Consider reviewing the person within 3 months of them developing a new
24		physical health problem (including monitoring for any adverse effects from
25		medications).
26	1.2.19	Ensure the person's care plan is updated in response to changing needs
27		or circumstances, including their social care, support or housing needs.

1	Dischar	ge or transfer
2	1.2.20	Before the person is discharged or transferred between services
3		(including from inpatient care to the community):
4		• invite any new practitioners who will be involved in the person's care to
5		the multidisciplinary case review meetings and the discharge or transfer
6		meeting
7		ensure the person's care plan includes strategies for ongoing risk management and details how they can get back in centeet with
8 9		management and details how they can get back in contact with services.
10	1.2.21	Ensure support is in place to help young people with dual diagnosis move
11		to adult health or social care services. (See also NICE's guidelines on
12		psychosis and coexisting substance misuse recommendations 1.8.1-1.8.9
13		and transition from children's to adult services.)
14	1.3	Partnership working
15		These recommendations are for all services and providers.
16	1.3.1	Services in mental health, substance misuse, primary care, social care
17		and support services need to collaborate with each other and other
18		organisations in the community and voluntary sectors to provide a broad
19		range of flexible services for young people and adults with dual diagnosis.
20	1.3.2	Services could consider working together to proactively encourage people
21		with dual diagnosis to engage with services. This could be done:
22		within an agreed set of local policies and procedures that is regularly
23		reviewed by key strategic partners
24		 with good level of communication between all practitioners and a
25		willingness to work across traditional institution boundaries
26		 by being responsive to requests for advice and joint-working
27		arrangements
28		 by taking a shared response to risk management.
29	1.3.3	Ensure joint working arrangements are in place. This may include:

1		 services designed to ensure continuity of care and service provision
2		(for example, when commissioning contracts are due to expire)
3		 services based on a local needs assessment
4		 ensuring the needs of young people and adults with dual diagnosis are
5		part of other local needs assessment strategies, for example, on
6		housing, employment projects, alcohol, drug services or crime
7		prevention
8		 ensuring service quality is monitored and data sharing protocols are in
9		place (see also recommendations 1.3.6–1.3.8).
10	1.3.4	Agree joint pathways to:
11		meet the health, social care or other support needs and preferences of
12		people with dual diagnosis, wherever they may present
13		 give people access to a range of primary health care providers and
14		social care providers including GP practices, pharmacies, podiatrists
15		dentists, social workers, housing or benefit advisers.
16	1.3.5	Ensure referral processes and care pathways within and across agencies
17		are consistent and that governance arrangements are in place. This
18		includes local care pathways to meet the physical health, social care,
19		housing and support needs of people with dual diagnosis.
20	Informa	ation sharing
21	1.3.6	Agree a protocol for information sharing between secondary care mental
22		health services and substance misuse, health, social care, education,
23		voluntary and community services (see the Caldicott Guardian Manual
24		2010).
25	1.3.7	Ensure that services have a consistent approach to getting people with
26		dual diagnosis help from the most relevant service by:
27		sharing information on support services between agencies
28		 ensuring providers know about and can provide information on the
29		services

1		 taking up the responsibilities agreed in referral processes, providing
2		timely feedback and communicating regularly about progress.
3	1.3.8	Ensure providers share information on how to manage challenging or
4		risky situations (see also NICE's guideline on violence and aggression:
5		short-term management in mental health, health and community settings).
6	1.4	Improving service delivery
7	These red	commendations are for all services and providers responsible for delivery of
8	services.	
9	Adapting	g existing services
10	1.4.1	Adapt existing services rather than creating a specialist dual diagnosis
11		service.
12	1.4.2	Make sure interventions that aim to improve the uptake of services,
13		support harm reduction, change behaviour and prevent relapse are part of
14		the service offered (see NICE's pathways on: psychosis and co-existing
15		substance misuse; psychosis and schizophrenia in young people and
16		adults; bipolar disorders; alcohol misuse and drug misuse).
17	1.4.3	Offer the person individual, face-to-face or phone appointment sessions to
18		help encourage people with dual diagnosis to use services. Offer phone
19		sessions to their family or carers. Sessions could cover:
20		how the person is coping with their current mental health and
21		substance use and its impact on their physical health and social care
22		needs
23		 progress on current goals or changes to future goals
24		ways to help the person stay safe
25		 monitoring symptoms
26		getting support from family, carers or providers.
27		Determine how often the sessions take place based on the person's
28		needs.

1.4.4 Consider the following:

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- contingency plans within services to help the person (and their family or
 carers) with a potential crisis and ensure these are updated to reflect
 changing circumstances
 - support to sustain change and prevent relapse
 - discharge planning, including planning for potential relapses so that the
 person knows which service to contact and the service has the
 information needed to provide the right ongoing support. (See also
 NICE's guideline on transition between inpatient hospital settings and
 community or care home settings for adults with social care needs.)

Making services inclusive

- 12 1.4.5 Ensure existing services are adapted so that they can better engage and meet the needs of young people and adults with dual diagnosis.
- 14 1.4.6 Involve young people and adults with dual diagnosis, their family or carers
 15 in improving the design and delivery of existing services to provide a good
 16 standard of care (see section 1.2). This may include developing
 17 interventions and training, taking part in steering meetings and giving
 18 feedback on services.
- 19 1.4.7 Provide local services in places that are easily accessible, safe and
 20 discreet. Bear in mind any perceived stigma involved in being seen to use
 21 the service. Consider flexible opening times, drop-in sessions, or meeting
 22 people in their preferred locations.
- 23 1.4.8 Ensure people with dual diagnosis, their family or carers are given
 24 accurate information about relevant local services (for example,
 25 community groups or family support groups). This could include
 26 information on how to access services, ways to contact the service,
 27 opening hours and how long the waiting list may be.

1	Support	for staff
2	1.4.9	Ensure the care coordinator in secondary care mental health services is
3		supported to provide or coordinate flexible, personalised care based on a
4		range of existing services (see section 1.5).
5	1.4.10	Recognise that different attitudes towards mental health and drug- or
6		alcohol-related problems may exist between agencies and that this may
7		present a barrier to delivering services. To overcome this:
8		challenge negative attitudes or preconceptions about working with
9		people with dual diagnosis
10		 develop leadership skills so staff can challenge attitudes and
11		preconceptions (for example see dual diagnosis capability framework).
12	1.4.11	Ensure practitioners have the resilience and tolerance to help people with
13		dual diagnosis through relapse or crisis so that they are not discharged
14		before they are fully equipped to cope or consequently excluded from
15		services.
16	1.5	Encouraging people to stay in contact with services
17	These re	ecommendations are for all services and providers.
18	Building	g relationships
19	1.5.1	Recognise that building a relationship with people who have a dual
20		diagnosis, may take time and involves:
21		showing empathy and using a non-judgemental approach to listen,
22		identify and be responsive to the person's needs and goals
23		 providing consistent services, for example, where possible keeping the
24		same staff member as their point of contact and the same lead for
25		organising care
26		 staying in contact by using the person's chosen method of
27		communication (for example, by letter, phone, text, emails or outreach

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work, where possible).

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1	1.5.2	Explore and discuss with the person if there any reasons why they may be
2		unwilling to use services to improve their physical health, or to receive
3		social care support. This may include:
4		the way services are organised
5		 inability to attend services, because they are not convenient (for
6		example, services are not local, transport links are poor, or do not
7		provide childcare)
8		 fear of stigma, prejudice or of being labelled as having both mental
9		health and substance misuse problems
10		• feeling coerced into using treatments or services that do not reflect their
11		preferences or their readiness to change
12		 previous poor relationships with practitioners
13		• other personal, cultural, social, environmental or economic reasons.
14	1.5.3	Help those with dual diagnosis who may find it difficult to engage with
15		services to get into and stay connected with services by initiating and
16		maintaining contact using proactive and flexible approaches (see
17		recommendation 1.2.6).
18	1.5.4	Recognise that people with dual diagnosis are at higher risk of not using
19		or losing contact with services, including for example:
20		people who are homeless
21		people who have experienced or witnessed abuse or violence
22		people who are young
23		• men
24		people who are parents or carers who may fear the consequences of
25		contact with statutory services.
26	Non-atte	endance
27	1.5.5	Ensure non-attendance at an appointment is viewed by all practitioners as
28		a matter of concern. Discuss and agree what follow-up actions should be
29		taken with key practitioners in secondary care mental health services

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involved in the person's care plan. This could include:

1	 contacting the person's care coordinator within mental health services
2	in the community immediately (particularly if there is a risk of self-harm
3	or suicide) or at least within 24 hours, if there are existing concerns
4	 visiting the person at home, contacting any other practitioners involved
5	in the person's care (identified in the person's care plan; see
6	recommendation 1.2.1), or contacting family members
7	 ensuring the person is not automatically discharged without a
8	discussion with the person's care coordinator and with all the
9	practitioners involved in the person's care.
10	Putting this guideline into practice
11	NICE has produced tools and resources [link to tools and resources tab at
12	publication to help you put this guideline into practice.
13	Putting a guideline fully into practice can take time. How long may vary from
14	guideline to guideline, and depends on how much change in practice or services is
15	needed. Implementing change is most effective when aligned with local priorities.
16	Changes should be implemented as soon as possible, unless there is a good reason
17	for not doing so (for example, if it would be better value for money if a package of
18	recommendations were all implemented at once).
19	Different organisations may need different approaches to implementation, depending
20	on their size and function. Sometimes individual practitioners may be able to respond
21	to recommendations to improve their practice more quickly than large organisations.
22	Here are some pointers to help put NICE guidelines into practice:
23	1. Raise awareness through routine communication channels, such as email or
24	newsletters, regular meetings, internal staff briefings and other communications with
25	all relevant partner organisations. Identify things staff can include in their own
26	practice straight away.
27	2. Identify a lead with an interest in the topic to champion the guideline and motivate
28	others to support its use and make service changes, and to find out any significant

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issues locally.

- 1 3. Carry out a baseline assessment against the recommendations to find out
- whether there are gaps in current service provision.
- 4. Think about what data you need to measure improvement and plan how you
- 4 will collect it. You may need to work with other health and social care organisations
- 5 and specialist groups to compare current practice with the recommendations. This
- 6 may also help identify local issues that will slow or prevent implementation.
- 5. **Develop an action plan** with the steps needed to put the guideline into practice,
- 8 and make sure it is ready as soon as possible. Big, complex changes may take
- 9 longer to implement, but some may be guick and easy to do. An action plan will help
- in both cases.
- 11 6. **For very big changes** include milestones and a business case, which will set out
- additional costs, savings and possible areas for disinvestment. A small project group
- could develop the action plan. The group might include the guideline champion, a
- senior organisational sponsor, staff involved in the associated services, finance and
- information professionals.
- 16 7. **Implement the action plan** with oversight from the lead and the project group.
- 17 Big projects may also need project management support.
- 18 8. **Review and monitor** how well the guideline is being implemented through the
- 19 project group. Share progress with those involved in making improvements, as well
- as relevant boards and local partners.
- 21 NICE provides a comprehensive programme of support and resources to maximise
- 22 uptake and use of evidence and guidance. See our into practice pages for more
- 23 information.
- 24 Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care –
- 25 practical experience from NICE. Chichester: Wiley.

Context

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- 27 Adults and young people who have a severe mental illness and misuse substances
- 28 (defined as having a dual diagnosis in this guideline) have some of the worst health,

- wellbeing and social outcomes (Relationship between dual diagnosis: substance
- 2 <u>misuse and dealing with mental health issues</u> Social Care Institute for Excellence).
- 3 It is not clear how many people in the UK have a dual diagnosis because of several
- 4 factors, including the fact that some people in this group do not use services or get
- 5 relevant care.
- 6 The Department of Health's Refocusing the Care Programme Approach identifies
- 7 people with dual diagnosis as one of the groups in need of an enhanced Care
- 8 Programme Approach because they are not being identified consistently and
- 9 services are sometimes failing to provide the support they need. The policy
- highlights the need for a whole systems approach to their care, involving a range of
- services and organisations working together. This guideline aims to address this
- 12 need.
- Groups covered in this guideline include: young people (aged 14–25) and adults who
- have been diagnosed as having a severe mental illness and who misuse substances
- and 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 usually start at age 14.
- 18 In this guideline, severe mental illness includes a clinical diagnosis of:
- schizophrenia, schizotypal and delusional disorders, or
- bipolar affective disorder, or
- severe depressive episode(s) with or without psychotic episodes.
- 22 Substance misuse refers to the use of legal or illicit drugs, including alcohol and
- 23 medicine, in a way that causes mental or physical damage.

24 **More information**

To find out what NICE has said on topics related to this guideline, see our web pages on <u>alcohol</u> or <u>drug misuse</u> and <u>mental health and behavioural conditions</u>. For specific recommendations on monitoring and promoting recovery of physical health see our guidelines on <u>psychosis and coexisting substance misuse</u>, <u>psychosis and schizophrenia in adults</u>, <u>psychosis and schizophrenia in children</u>, <u>bipolar disorder</u>

and alcohol use disorders.

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The committee's discussion

- 3 Evidence statement numbers are given in square brackets. For an explanation of the
- 4 evidence statement numbering, see the evidence reviews section.

Section 1.1 First contact

- 6 The discussion below explains how we made recommendations 1.1.1–1.1.4.
- 7 The committee noted that people with dual diagnosis are a vulnerable group, who
- 8 often have poor physical health, are unemployed, homeless or are at a risk of other
- 9 people taking advantage of them. The committee was aware from the evidence
- 10 (review 1) and their experience that people with dual diagnosis may present in
- different settings, so recommended that all staff coming into contact with them
- should be able to understand their needs and help them access services. The
- committee members were aware from their experience that people may present in
- crisis (for example at A&E) but they may be also be found opportunistically in other
- 15 settings and identified as needing immediate assistance with a range of needs,
- including their mental or physical health, substance misuse or social care needs.
- 17 They noted that the physical health and social care needs of people with dual
- diagnosis are often overlooked because of the challenging nature of dealing with
- both mental health and substance misuse issues. They also noted that people with
- 20 dual diagnosis are often excluded from services because no one wants to take
- responsibility for them and that they need help to access a wide range of services.
- The committee members were aware that criminal justice system settings were not
- included in the scope. However, they felt it was important to highlight this setting in
- recommendation 1.1.1 because it is a potential route for people with dual diagnosis
- to come into contact with healthcare services. This was also reflected in the expert
- testimony the committee heard on primary care services for homeless people (EP4).
- 27 The committee noted that wherever people with dual diagnosis present a similar
- approach to helping them access care is needed. The committee advised that
- 29 secondary care mental health services needs to be the lead organisation responsible

- 1 for delivery of services and therefore made a recommendation to refer people with
- 2 dual diagnosis to secondary care mental health services.
- The committee heard from an expert [EP4] on the physical health issues that can
- 4 affect people with dual diagnosis. They noted that although the expertise was from a
- 5 perspective of primary care services for homeless people, it was felt that the range of
- 6 health needs identified could be transferable to the wider dual diagnosis population.
- 7 The committee noted the evidence from 1 low quality [-] UK qualitative study which
- 8 highlighted commissioners' views that the health and wellbeing of people with dual
- 9 diagnosis are not being met [ES2.1.2] and also reflected on the gap in the evidence
- 10 [ES1.1.8] on the prevalence of coexisting physical health problems. The committee
- agreed to make a research recommendation in this area.
- 12 The committee noted that because of the complexity of their needs, people with dual
- diagnosis are at increased risk of poor self-care, losing contact with family and
- friends, social isolation or living in poor housing or having their homes abused by
- others as venues for substance misuse or drug dealing.
- From moderate to strong evidence from 4 cohort and 6 case-control studies, the
- committee members were aware of the range of social care needs of people with
- dual diagnosis in the UK [ES1.1.9]. They were also aware from expert testimony
- 19 [EP2] and their own experience of working with people with dual diagnosis of the
- 20 detrimental effects poor or unmet needs (such as social isolation or poor housing)
- can have on person's health and recovery process. This was supported by evidence
- from 1 high quality and 1 moderate quality study [ES2.2.1]. They noted that unmet
- 23 needs could lead to relapse, using substances, deterioration in mental health,
- offending behaviour or could also affect physical health.

Section 1.2 Care planning

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The discussion below explains how we made recommendations 1.2.1–1.2.21.

On admission to secondary care mental health services

- 28 The committee agreed that secondary care mental health services need to take the
- 29 lead in coordinating services. The committee noted that care planning is usually led
- 30 by a care coordinator because this is part of the Care Programme Approach.

- 1 However, they noted that care coordinators are part of a multidisciplinary team
- 2 subject to supervision and responsibility would lie with a consultant.
- 3 Based on their experience, the committee members advised that a care coordinator
- 4 within mental health services in the community is assigned once a person has been
- 5 referred into secondary care mental health services. The committee was also aware
- 6 from evidence review 2 that having a continuity of contact with a key contact
- 7 encourages people to keep in touch with services. Based on their expertise the
- 8 committee made a recommendation that a care coordinator can take the key role in
- 9 developing and reviewing a person's care plan. The committee noted that the care
- 10 coordinator would be responsible for organising delivery of range of needs including
- mental health, substance misuse, access to health or social care services with the
- support of a wider team and with supervision.
- 13 The committee noted from 1 moderate quality study and 1 low quality UK study
- 14 [ES2.1.1] and their own experience that timely assessments can help people with
- dual diagnosis to access services and maintain engagement with their care plan.
- 16 The committee agreed with the recommendations in NICE's guideline on psychosis
- 17 with co-existing substance misuse on the principles of recognition and assessment
- and felt it would be appropriate to link with this guideline. They recognised that the
- 19 psychosis guideline has a narrower focus than this dual diagnosis guideline.
- 20 The committee members were aware from their practice and evidence [ES2.1.10]
- 21 that services often fail to take responsibility for people with dual diagnosis. The
- 22 effects of this failure can be far-reaching for example, causing the person to relapse,
- have physical health problems because of poor housing, or become unwilling to
- 24 engage with services [ES2.2.1, ES2.2.2, ES2.2.4]. The committee was mindful that
- there could be cases where a person may have issues with both poor housing and
- 26 physical health and that this may not always be a 'cause–effect' relationship.
- 27 The committee was aware from their experience of the importance of highlighting
- 28 safeguarding issues for this vulnerable population. The committee was also aware of
- 29 current legislation (Care Act 2014) that entitled carers to have an assessment of their
- needs and they were aware from the evidence this may be particularly be the case if
- the carers are children [ES2.1.9; 1 UK study of low quality]. The committee therefore

- developed a recommendation based on their expert knowledge to highlight young
- 2 and adult carers' needs and ways to support carers for this specific population.

3 Involving people in care planning

- 4 The committee took into account qualitative evidence from 2 moderate quality
- 5 studies and 1 low quality UK study [ES2.2.9] which highlighted that an approach that
- 6 encouraged the person to be involved in their care plan decisions and respected
- 7 their preferences can help the person adhere to the care plan. The committee was
- 8 mindful that changes to behaviour may be a lengthy process and advised that
- 9 NICE's <u>behaviour change: individual approaches</u> guideline may provide useful
- 10 strategies.
- 11 The committee reflected on their experience and noted that providers need to
- understand what is having an effect on the person each time they see them so that
- they can provide the right level of support to the person at each time point. The
- committee reflected on their experience and noted that people can recover. The
- committee members also noted that in people with dual diagnosis the notion of
- recovery may not necessarily be about reducing their substance use but about
- leading a productive life. They were aware from the evidence [ES2.1.4] and their
- 18 experience that the nature of relationships between a health or social care
- 19 professional and a person with dual diagnosis can impact on a person's willingness
- to engage, their response to care and approach to recovery. They felt that although
- 21 recovery may take time, all interactions providers need to convey a sense of hope
- and optimism that it is possible.
- 23 The committee members were aware from their experience the importance of a
- 24 person-centred approach. This was reinforced by the review on views and
- 25 experiences of providers, commissioners, people with dual diagnosis, family and
- carers [review 2] and their experience. The committee was also aware of
- 27 recommendation 1.1.1 in NICE's guideline on <u>psychosis with co-existing substance</u>
- 28 misuse which outlines adopting a non-judgemental and empathetic approach built on
- 29 trust and respect. The committee felt it was important to take a person-centred
- approach when developing and reviewing the care plan [ES2.1.4, ES2.2.4, ES2.2.7]
- and recommended involving people in their care planning.

- 1 The committee recommended practical strategies that may help improve uptake of
- 2 services and prevent relapse. This was based on evidence from 1 moderate quality
- 3 study which noted self-care skills helped with daily living [ES2.2.3], expert testimony
- 4 [EP2] and the committee's expertise.
- 5 Liaising with other organisations to meet physical health, social care, housing
- 6 or support needs
- 7 The committee noted from the evidence [ES2.1.7] from 1 high, 2 moderate and 3 low
- 8 quality qualitative studies (4 in the UK) that a lack of a shared approach could act as
- 9 a barrier to providing health and social care services. The committee heard from an
- expert on local partnership working [EP1] and experts working with people with dual
- diagnosis who are homeless [EP2]. The experts highlighted factors that could help
- with a coordinated approach. Based on the evidence, the expert testimonies [EP1,
- EP2] and their own experience, the committee was in agreement that important
- 14 factors in providing a coordinated approach included a shared vision, joint
- 15 responsibilities and regular communication.
- 16 The committee members also highlighted the importance of prompt access in this
- 17 recommendation based on their own experience and findings from qualitative
- 18 evidence from 1 low quality UK study [ES2.2.8]. The committee members felt that
- direct referrals may be useful way to ensure timely response to the needs of this
- 20 group. They noted that direct access to services may be beneficial (compared to for
- 21 example, open access drop-in clinics) because this would give the person a sense of
- continuity of care which in turn may also enhance feelings of trust [ES2.2.4].
- 23 The committee developed recommendations to highlight the range of agencies or
- 24 providers people in secondary care mental health services (for example, a care
- 25 coordinator) would need to work with to ensure people with dual diagnosis receive
- care for their wider health or social care needs. The committee also highlighted in
- 27 the recommendations physical health and social care needs that need to be taken in
- consideration as part of developing and reviewing a care plan.
- 29 The committee reflected on the expert testimony [EP4], their knowledge and
- 30 experience to highlight how a person's physical health could be improved and
- 31 provided examples of how this may be achieved. This includes improving health

- behaviours (such as diet, smoking or physical activity) and minimising risky
- behaviours (such as unprotected sex, sharing needles). It was mindful this is not an
- 3 exhaustive list and recognised other behaviours may need to be addressed in the
- 4 care plan.
- 5 The committee also noted the importance of encouraging involvement in activities to
- 6 improve physical wellbeing (for example football activities or walking groups) but
- 7 were aware the risk of widening inequalities if activities only reach people who
- 8 already use services. The committee agreed that potential inequalities could be
- 9 addressed by recommending providing inclusive services and strategies to access
- services to improve engagement with services.
- In relation to social care, living or housing-related needs, the committee developed a
- list of social care, housing and support needs (in line with the <u>Care Act 2014</u>).
- 13 The committee reflected on the evidence [ES1.1.9, ES2.2.1, ES2.2.2, ES3.1], expert
- testimony [EP2] and their own experience to inform their recommendations on social
- care, housing or support needs. The committee noted from the evidence [ES3.1] and
- members' experience that a modest improvement in outcomes could be made in
- areas such as in housing, employment or social functioning. In relation to housing
- needs, the committee members noted there was strong evidence [ES1.1.9] from a
- meta-analysis of 3 cohort and case-control UK studies (2 high quality; 1 low quality)
- that people with dual diagnosis (compared with those with severe mental illness
- only) had increased probability of a history of homelessness or housing problems.
- 22 There was also evidence from 1 high quality UK case-control study that people with
- 23 dual diagnosis (compared with severe mental illness only) had an increased
- 24 probability of living in the most deprived areas. The committee noted there was
- 25 moderate evidence from 3 high quality UK cohort studies that showed a greater
- 26 number of people with dual diagnosis are unemployed compared to those with
- 27 severe mental illness only. The committee also noted the evidence for social
- 28 functioning outcomes was mixed. A meta-analysis of 2 UK case-control studies (1
- 29 high and 1 moderate quality) showed no difference in social functioning between a
- group with dual diagnosis and severe mental illness only. However, 1 high quality UK
- 31 cohort study showed poor social functioning in people with dual diagnosis compared
- to those with substance misuse. It was noted the evidence was mainly from people

- 1 in contact with secondary care mental health services and may not adequately
- 2 reflect the needs in the wider dual diagnosis population. They also were aware that
- 3 unmet needs (such as housing) can also have a detrimental impact on a person's
- 4 health and recovery process [ES2.2.1].
- 5 Recommendations on approaches to encourage use of services and the suitability of
- 6 the type of support were based on committee's expertise and EP2. The committee
- 7 was aware that people with dual diagnosis are particularly at risk of being taken
- 8 advantage of and highlighted the importance of safeguarding in relation to housing
- 9 needs.

10

Review

- 11 The committee members were aware from their experience and evidence from 1
- high quality, 6 moderate quality, and 2 low quality UK qualitative studies of the
- benefits of an integrated approach to care [ES2.2.6]. They noted that this could
- increase engagement and result in positive change in health, functioning and
- wellbeing. The committee also took into account the evidence from 3 moderate
- quality qualitative studies and 1 recent UK study (of low quality) in a voluntary sector
- organisation [ES2.1.7], members' experience, and expert testimony [EP2]. The
- 18 committee noted the importance of different disciplines working collaboratively, and
- 19 taking part in case review meetings. Although the UK studies set in voluntary sector
- services (included in ES2.1.7 and ES2.2.6) were low quality, the committee felt the
- 21 findings were relevant as they reflect views of providers in or users within this
- 22 setting.
- 23 The committee noted that the frequency of case review meetings would vary and
- 24 would involve multidisciplinary team members to make sure a person's care plan is
- 25 up to date and relevant. The recommendation to review annually was based on the
- 26 Care Programme Approach, but the committee recognised that review of care plan is
- indicated by the person's level of need and circumstances.
- 28 The committee noted the importance of regular monitoring of physical health (based
- on EP4), including for adverse effects of medications. The committee was aware
- there was strong evidence from 3 UK case control and cohort studies [ES1.1.8] to
- 31 show that people with dual diagnosis (compared with those with severe mental

- illness-only) are less likely to adhere to medications. The committee heard in expert
- 2 testimony [EP4] about side effects of medication and were aware from their
- 3 experience that this includes effects such as weight gain or adverse effects. They felt
- 4 this could be a barrier to adhering to treatment and could have a negative impact on
- 5 a person's mental or physical health. The committee's recommendation on frequency
- 6 of monitoring was based on their expertise.
- 7 The committee members acknowledged that the findings from the evidence on
- 8 working collaboratively and the views expressed in the expert testimony [EP4]
- 9 reflected their experiences of working with people with dual diagnosis. They noted
- that changes in circumstances need to be taken into account in a person's care plan
- and physical health or social care, support or housing needs revised accordingly.

Discharge or transfer

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- 13 The committee members noted that transfer or discharge are key points when a
- person can lose touch with services. They noted from the evidence [ES2.2.1] on
- challenges people can face when transitioning between services and felt this was
- applicable to other transitional contexts, for example, when people transition from
- inpatient care to community settings. Therefore they felt that handover of care upon
- discharge or when a person transfers to another service (in consultation with other
- 19 providers) were important points to be included in the recommendation.
- 20 The committee heard from an expert in early intervention services [EP3] and noted
- 21 the importance of making sure referral for transition to adult services for young
- 22 people was identified in the guideline.

Section 1.3 Partnership working

- 24 The discussion below explains how we made recommendations 1.3.1–1.3.8.
- 25 The committee decided to recommend partnership working because provision of
- health and social care services for people with dual diagnosis is often fragmented
- 27 and inconsistent. This was based on their experience and the evidence from 7
- studies (2 high quality, 3 moderate quality and 2 UK studies of low quality) [ES2.2.4].
- 29 The committee advised that from April 2013 there have been separate funding
- 30 streams for mental health and substance misuse services, with mental health

- services funded by clinical commissioning groups and substance misuse services by
- 2 local authorities. The committee felt this reflected a long standing division between
- 3 the mental health and substance misuse and has led to 2 different sets of organising
- 4 paradigms for commissioners which does not serve people with dual diagnosis. They
- 5 also noted an additional challenge for addiction services is that although funding is
- 6 from local authority budgets they are subject to commissioning and competitive
- 7 tendering.
- 8 The committee reflected on current practice. The committee noted that although the
- 9 Department of Health's 2002 policy guide had set the vision for how services and
- care for people with dual diagnosis could be delivered, implementation was lacking.
- 11 The committee was aware of Public Health England guidance on Co-existing alcohol
- 12 and drug misuse with mental health issues: guidance to support local commissioning
- 13 and delivery of care [to be published June 2016] which has set out the importance of
- 14 joint working.
- 15 The committee noted from the qualitative evidence including 3 UK studies (1 high
- and 2 low quality studies) in a range of settings [ES2.1.7] that different disciplines
- working together, with a shared approach in their dealings with people with dual
- diagnosis and shared responsibilities, could facilitate the delivery and improve the
- 19 quality of health and social care services. This could this be done by using a shared
- 20 approach, co-management of cases, and regular communication. The committee
- 21 also heard from an expert in local partnership working [EP1] who described a
- 22 framework designed to help local areas design and deliver flexible and coordinated
- 23 services for people experiencing multiple needs.
- 24 The committee noted that there needs to be a strategic framework for dual diagnosis
- work to operate within, with buy-in from providers and commissioners, for services to
- collaborate locally. Based on the evidence, the expert testimony [EP1] and their own
- 27 experience, the committee members were in agreement that a cross-sector
- 28 partnership, with a shared understanding of the problem (based on assessment of
- local needs), and a shared vision for the future were important factors. Based on
- their expertise and expert testimony, they developed a recommendation on how
- 31 services need to work together. They noted the lack of evidence from review 1.2 on
- 32 existing care pathways and felt this is an area for research recommendation.

- 1 The committee was aware of evidence from review 2 that a lack of policy on referrals
- 2 has an effect on the organisation and continuity of care. Evidence from 4 qualitative
- 3 studies conducted in different settings (including 1 UK study set in voluntary sector)
- 4 noted uncertainty on who should make referrals can also have an impact [ES2.1.11].
- 5 The committee members noted that the evidence from qualitative studies [ES2.1.10,
- 6 ES2.1.11] was consistent with their experience. The evidence noted that pathways
- 7 were deemed to be inadequately planned and supported and that movement across
- 8 a care pathway was often restricted because of failure in services to take
- 9 responsibility. They also noted that continuity of care can be interrupted because of
- 10 changes in the commissioning process or cycle. For example, they noted retendering
- for services can lead to disruption and the need to build new care pathways.
- One UK low quality qualitative study exploring views of commissioners [ES2.1.11]
- 13 noted that good links between statutory and voluntary sector improved outcomes,
- such as reduced waiting times and delivery of care. This could also help with
- organisation and continuity of care. The committee was also aware of evidence from
- the study that highlighted that existing resources were stretched [ES2.1.5] and that
- lack of funding was affecting provision in non-voluntary sectors [ES2.1.6]. The
- committee noted that this study was published in 2002. It noted service provision for
- addiction services has changed considerably in the past 10 years, the demography
- of the individuals, the treatment and the types of substances used will all have
- 21 changed markedly since 2002.
- 22 The committee reflected on their experience and acknowledged the importance of
- 23 including the needs of people with dual diagnosis in the joint strategic needs
- 24 assessment and in a local strategy (for example, housing, alcohol or drug services,
- or crime prevention). The committee noted that referral processes and pathways
- 26 need to be in place to ensure this happens. This would help with a joined up
- 27 approach to meet the needs of people with dual diagnosis who often fall between the
- 28 gaps in services. The committee noted from the evidence that currently there isn't a
- 29 service configuration that is in place nationally (review question 1.2).

Information sharing

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- 31 The committee made recommendations to highlight the importance of information
- 32 sharing. The committee noted an expert testimony [EP2] highlighted that a barrier

- the voluntary sector often faces is that confidentially is often used as an excuse not
- 2 to share information. The committee also noted the importance of services having
- 3 knowledge of other local services and being able to tell people with dual diagnosis
- 4 about them [ES2.2.3, ES2.2.10]. For example, one UK low-quality study set in the
- 5 voluntary sector noted GPs were unaware of local community groups which people
- 6 with dual diagnosis could access [ES2.2.3]. The committee was also aware from its
- 7 experience that as part of providing inclusive services staff need to be equipped with
- 8 skills. For example, skills to deal with challenging nature of working with people who
- 9 may be intoxicated.

10

Section 1.4 Improving service delivery

- 11 The discussion below explains how we made recommendations 1.4.1–1.4.11.
- 12 The committee decided to recommend improving delivery of existing services that
- are inclusive because the needs of people with dual diagnosis are often not taken
- into account and they face the risk of being excluded from mainstream services.

15 Adapting existing services

- 16 The committee agreed that the recommendations needed to focus on improving
- 17 existing services instead of creating a specialist dual diagnosis service. They felt that
- the standard care delivered in the UK could be improved by increasing engagement
- with existing services and that existing capacity and resources could be used to
- deliver these in the system. The committee adopted this approach for the design of a
- service delivery model and developed the content of the service model based on the
- 22 evidence, economic model (see economic considerations), expert testimony and
- their expertise.
- 24 The committee considered the evidence for the effectiveness and efficiency of
- 25 service delivery models [ES3.1, ES3.2, ES3.3, ES3.4, ES3.5, ES3.6, ES3.7, ES3.8,
- 26 ES3.9, ES3.10], which included randomised controlled trials and observational
- 27 studies. The evidence covered a range of service delivery interventions, showing
- some positive outcomes and there was value in what the models were aiming to
- 29 achieve. However, the members agreed that there was no overwhelming evidence of
- 30 benefit to indicate a particular model should be recommended (please see below for
- committee's interpretation of the evidence on the effectiveness, cost effectiveness

1 and efficiency of service delivery models). The committee members were also aware 2 of moderate evidence from 12 UK studies [ES1.2.1] that there are inconsistencies in 3 the configuration of dual diagnosis services within NHS trusts across the UK. These 4 inconsistencies lie in a number of areas including sources of funding, structure of 5 services, type of staff members, services delivered and coordination of care. The 6 committee also considered the evidence on current configuration of services 7 [ES1.2.1] and observed there were few specialist services for adults. They were also 8 aware of evidence from 1 low quality UK study that described mixed views amongst 9 staff in a specialist dual diagnosis service on whether dual diagnosis services should be separate or integrated with mental health or substance misuse service 10 [ES2.1.13]. The committee also noted that there was evidence from the same study 11 indicating that most commissioners felt that integrating services would be essential 12 for the effective and efficient delivery of care for people with complex needs. 13 14 Additionally, some commissioners noted that relationships between different services 15 could be expected to improve if they were required to share budgets and resources. The committee felt this finding should be treated with caution because the funding 16 17 landscape has changed considerably since 2002 and their experience suggests that 18 a third tier of provision may not necessarily meet the needs of people with dual diagnosis. Based on their experience, the committee members noted that 19 20 'integration' should be about joint working and coordinated care and did not feel a 21 specialist service was the way forward for this group. 22 The committee also noted that there was limited description of the comparator arms 23 (often described as 'treatment as usual') in the studies included in review 3 and that most of the studies were conducted in the US. The committee's view was that 'usual 24 25 care' in the US is likely to differ from that provided in the UK and the level of 'usual 26 care' delivered in the UK was considered to be of a better standard. The committee's 27 expert knowledge and the evidence was used to develop a recommendation on 28 aspects that could be included in a service. This includes interventions that have 29 shown to be effective in NICE guidelines for either severe mental illness or substance misuse. The committee was aware of the Wenze (2015)² study included

² Wenze SJ, Gaudiano BA, Weinstock LM et al. (2015) Adjunctive psychosocial intervention following Hospital discharge for Patients with bipolar disorder and comorbid substance use: A pilot randomized controlled trial. Psychiatry research. 228(3):516-25.

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- in the economic model. Members reflected on the components of the 'treatment-
- 2 engagement' sessions in the Wenze (2015) study as well as their own experience to
- 3 develop a recommendation on ways to improve engagement. The committee noted
- 4 that any recommendation on improving service delivery needs to take into account
- 5 the needs of those who reach crisis and those who relapse after discharge. This
- 6 recommendation was based on their expertise. The committee was aware from the
- 7 evidence and their experience that people experience fragmented care [ES2.2.4]
- 8 and that plans need to be in place to allow people to move back into the system. It
- 9 was noted that the Department of Health's Mental Health Crisis Care Concordat
- would have information on developing an action plan to deal with people in a crisis.
- 11 The committee heard from an expert on the service delivery model in early
- intervention services [EP3]. The committee noted that these services are able to
- offer consistent and coordinated service because the staff working in these services
- have lower caseloads and so are able have more contact with the people they work
- with and provide stability.

16

Making services inclusive

- 17 The committee members were aware from their own experience, the evidence
- [review 1] and expert testimonies [EP1, EP2] of the benefits of supporting people
- with dual diagnosis to participate in improving services. The committee also noted
- from the evidence [ES2.2.9, ES2.2.10] the importance of involving people with dual
- 21 diagnosis, and their family or carers and providing them with the information and
- support. The ways in which people with dual diagnosis, their family or carers could
- be involved in design and delivery of services was based on the findings from the
- review on epidemiology and current configuration [review 1].
- The committee also observed that there appears to be an inequity in the way that
- people with dual diagnosis are treated by services compared with other groups. The
- 27 committee's experience and the evidence from the review of views and experiences
- of providers and commissioners and people with dual diagnosis [ES2.1.3, ES2.2.5]
- 29 showed that this may be because of negative attitudes or stereotyping. A pessimistic
- attitude on the likelihood of the person staying in the service was also considered to
- 31 be a contributor to this inequity.

- 1 The committee was aware from the evidence review on epidemiology that the
- 2 prevalence of dual diagnosis varied across regions. Semi-rural areas seem to have
- 3 the highest need yet specialist services are mostly in urban areas [ES1.1.2] and
- 4 expert testimony showed high incidence of early psychosis in rural areas [EP3]. The
- 5 committee agreed to not make a recommendation specifying content or configuration
- of service delivery by geographical settings, instead they felt that the most important
- 7 message was to ensure that any services needed are delivered locally.
- 8 Although evidence on co-location of services (for example, services based in the
- 9 same facility) was mixed [ES2.1.12], the committee members took into account the
- role of stigma in accessing services. The committee members were aware from their
- experience and from expert testimony [EP1; EP2] that people with dual diagnosis
- may be at risk of exploitation (for example, forced to become sex workers) or may
- have experienced trauma (for example, women may have experienced rape). The
- committee felt that was important that a recommendation was included in the
- guideline to highlight the importance of locating services in places that are safe and
- where there is minimal stigma attached to attending. The committee also considered
- the services highlighted in the evidence review (review question 1.2) on current
- configuration of services and developed a recommendation highlighting the
- importance of safety of location, low stigma and flexibility in opening times as factors
- that can help make services more accessible. The committee members were also
- 21 aware from the evidence [review 2] that where people knew about services, barriers
- 22 to access included difficulty in accessing services outside hours, long waiting lists
- and service not being local.

Support for staff

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- 25 The committee noted the importance of support and supervision from their
- experience and the evidence from 2 high quality, 1 moderate quality and 2 low
- 27 quality qualitative studies [ES2.1.15; 3 set in the UK]. Because of the complexity of
- the care coordinator's role the committee felt it was important to highlight in the
- 29 recommendation the importance of a support structure for this role. The committee
- members were also aware from the evidence and their experience that addressing
- gaps in practitioners' knowledge can help with establishing links with other services
- and delivery of services [ES2.1.16].

- 1 Evidence from 1 high, 3 moderate, and 1 low quality qualitative studies [ES2.1.14; 2 2 set in the UK] found consistent views amongst providers and commissioners in a 3 variety of settings that a barrier to service delivery or partnerships between services 4 is different perceptions of drug and alcohol problems depending on the focus of the 5 service. Services failing to take responsibility for people with dual diagnosis and the potential impact of this on meeting wider health, social care or support needs were 6 7 highlighted in providers' views across 6 qualitative studies [ES2.1.10]. Of these, 3 of 8 the studies were set in the UK, 1 was of moderate and 2 were low quality. The 9 committee noted although 1 of the UK studies was of low quality it was a recently published study and reflected the voluntary sector providers' views. The committee 10 11 drew on the evidence and their own expertise and noted that helping overcome 12 negative attitudes in staff will help make sure people with dual diagnosis are not 13 excluded from services. 14 The committee members were aware from the evidence [ES2.1.4] on the importance
- 15 of establishing good relationships between practitioners and people with dual 16 diagnosis. They noted there was high quality UK evidence from 1 study to show that 17 practitioners perceived that behaviours such as misusing drugs could impact on 18 relationships and act as a barrier to delivery of care. The committee reflected on the 19 evidence and their experience and therefore recommended that there needs to be 20 tolerance and resilience in services to work with people through relapse, poor 21 attendance or a crisis as these can often lead the person being inappropriately 22 discharged.

Committee's interpretation of the evidence on effectiveness, cost

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24 effectiveness and efficiency of service delivery models (reviews 3 and 4):

The committee agreed that there was limited evidence of effect for assertive

community treatment and integrated treatment interventions [ES3.1, ES3.2; ES3.3]

in relation to mental health and substance misuse outcomes. The committee noted

28 that fidelity to delivery of interventions (whether the intervention was delivered as

designed) in the service models was reported for only 5 studies and where reported

30 the fidelity was considered to be good. There was weak evidence for assertive

community treatment based on 5 US RCTs, moderate evidence from 6 RCTs and 1

observational study (3 studies based in the UK) for integrated treatment interventions

- 1 compared to treatment as usual. There was weak evidence from 1 RCT for
- 2 integrated treatment intervention compared to enhanced assessment and
- monitoring. The RCTs did not all show a clear evidence of benefit. There was some
- 4 improvement noted in service use outcomes but members noted that it was
- 5 debatable whether this was necessarily an evidence of benefit. There was some
- 6 evidence of effect on social care outcomes such as housing, employment and social
- 7 functioning. The committee noted that the assertive community treatment
- 8 intervention model was no longer used in the US. The committee felt that although
- 9 the follow-up in these studies ranged from 24 weeks to 3 years, the length of time
- needed to observe small improvements can sometimes take 5 to 10 years.
- 11 The committee considered the other service delivery interventions identified in
- evidence review 3 (9 studies) including case management, contingency
- management, staff training, or supportive housing [ES3.4, ES3.5, ES3.6, ES3.7,
- 14 ES3.8, ES3.9, ES3.10]. They noted that there was mainly weak evidence from small
- studies, with short follow-up (ranging from 16 weeks to 78 weeks) and with the
- exception of 3 studies (based in UK and Ireland) the remaining were mainly from US.
- 17 It was noted that fidelity to delivery of the intervention was reported in only 2 studies
- 18 (reported as low and high fidelity). The members discussed the potential value of
- 19 service models incorporating contingency management, peer support (delivered as
- 20 part of a care coordination intervention in 1 US study) or text messaging [ES3.5,
- 21 ES3.6, ES3.10] and considered these further under research recommendations.
- The committee agreed that there was weak evidence for a staff training intervention
- considered in the review of effectiveness of service delivery models [ES3.8] and
- 24 agreed not make a recommendation on this area. The committee noted that the 2
- 25 UK RCTs were of low quality, the evidence was inconsistent and did not appear to
- show an overall benefit. In addition, a committee member reflected on their own
- involvement in delivery of the intervention in one of the studies. It was noted there
- were challenges in the delivery of a staff training intervention, particularly because of
- 29 staff moving between services, high turnover of staff and low fidelity to delivery of the
- 30 intervention.
- 31 The committee agreed there were several gaps in the evidence from review 3
- 32 including:

- population (limited evidence on young people and vulnerable groups)
- interventions or measures (for example measures looking at improving
- 3 accessibility and availability of services)
- outcomes (no evidence on physical health outcomes)
- efficiency of service delivery models for example outcomes on accessibility of
- 6 services (waiting times).
- 7 The committee discussed the evidence from the cost-effectiveness studies ES4.1,
- 8 ES4.2, ES4.3, ES4.4, ES4.5 and the economic modelling [ES4.6] (see Economic
- 9 considerations) when developing the recommendation on providing services.

10 Section 1.5 Encouraging people to stay in contact with services

- 11 The discussion below outlines how we made recommendations 1.5.1–1.5.5.
- 12 The committee members decided to make recommendations on encouraging people
- to stay in contact with services and making services accessible because they were
- 14 aware from the evidence and their own experience that people with dual diagnosis
- may find it hard to initiate or maintain contact with services. Also, their physical
- health, social care, housing or support needs are not being met.

17 **Building relationships**

- 18 The committee noted from their experience that it is important to take a long-term
- and realistic view when working with people with dual diagnosis in relation to
- 20 involving the person in their care plan and coordinating their care, particularly in light
- of the challenging nature of working with this group [ES2.1.8]. The committee
- 22 members were aware from the evidence, their own experience, and expert testimony
- of the importance of continuity and flexibility in approaches to help people. The
- 24 committee heard from experts working with people who are homeless [EP2] and
- 25 reflected on their experience of range of methods that could be used to engage and
- stay in touch with a person. The committee considered the evidence from 4
- 27 qualitative studies (1 high; 1 moderate; 2 low quality), of which 2 were UK studies
- 28 [ES2.2.4]. The evidence highlighted that a lack of continuity of care along with
- 29 changes in staff can result in a lack of trust or an unwillingness to engage with
- 30 services and good after-care was an important aspect of preventing relapse.

- 1 The members reflected on their experience and the evidence from 8 qualitative
- 2 studies of mixed quality (2 high quality, 3 moderate and 3 low quality), with 3 of the
- 3 studies (low quality) set in the UK. The studies examined the importance of
- 4 relationships with healthcare professionals [ES2.2.7] and the committee agreed that
- 5 a non-judgemental empathetic approach was needed when encouraging a person
- 6 with dual diagnosis to stay in contact.
- 7 The committee noted that the evidence from views and experiences of people with
- 8 dual diagnosis, their family or carers highlighted barriers to access or uptake of
- 9 social care or physical health services [ES2.1.3, ES2.2.1, ES2.2.2, ES2.2.5,
- 10 ES2.1.12]. Barriers included lack of support during a transitional period (for those
- who have previously had criminal convictions), failure to recognise cultural
- differences and mistrust of healthcare professionals or poor links to services.
- Negative connotations of being labelled as having problems with both mental health
- and substance misuse [ES2.2.5], negative attitudes, stereotyping or stigma about
- mental health diagnoses in substance misuse settings or about substance misuse in
- mental health settings [ES2.1.3, ES2.2.5] were also considered to be barriers to
- 17 accessing services or receiving care.
- 18 The committee was aware from evidence review 2 and their experience that having
- continuity of contact encourages people to keep in touch with services. The
- 20 committee recommended range of approaches based on their experience and
- 21 expertise [EP2; EP4].
- 22 The committee recognised that all people with dual diagnosis face difficulties in
- receiving care [ES2.1.10] but wanted to highlight that some groups are particularly
- vulnerable. The committee noted there was moderate to strong evidence [ES1.1.5]
- 25 that dual diagnosis is associated with those who were of younger age and male
- gender. The committee was mindful that homelessness is a frequent outcome for
- 27 people with dual diagnosis. Factors contributing to this include people with dual
- diagnosis not being able get, or stay in contact with, the services they need. The
- 29 committee reflected on their experience and also noted that a trauma history is
- almost always present in people with dual diagnosis, which can lead to disruptive
- 31 attachments and associated challenging behaviour. The committee extensively
- 32 discussed other groups but noted there were limitations in the evidence. They noted

- that the evidence linking ethnicity with dual diagnosis was inconsistent [ES1.1.5].
- 2 The committee noted that apart from age, gender and ethnicity, there was a lack of
- 3 evidence for particular groups identified in the equity impact assessment who are
- 4 more likely to have a dual diagnosis. This includes, for example, people with a
- 5 learning disability, teenage parents, Gypsies and Travellers, asylum seekers or
- 6 refugees, lesbian, gay, bisexual, transsexual or transgender people, and sex workers
- 7 [ES1.1.5]. The committee was aware from their experience that people with dual
- 8 diagnosis have a range of social care needs, but noted that the evidence did not
- 9 identify social care needs for particular groups identified in the equity impact
- assessment. For example, those who are socially isolated, on low income, have a
- history of being 'looked after' or are adopted or have a history of experiencing or
- witnessing domestic violence and abuse [ES1.1.9].
- 13 Although there was no evidence identified, the committee was aware from their
- experience that other groups may be reluctant to engage with or may encounter
- difficulties when engaging with services for people with dual diagnosis. These groups
- include for example people who are recent migrants, have language difficulties or
- 17 are from specific religious communities.
- Although it is not an exhaustive list, the committee highlighted the groups identified
- in recommendation 1.5.4 based on the evidence [ES1.1.5; review 2], their expertise
- and expert testimony [EP2].
- The committee reflected on the evidence from review 2 and noted although the
- review provided insight to barriers and facilitators to delivery of care they felt there
- was research needed to understand the experience of people at different stages of
- 24 recovery.

25

Non attendance

- The committee members were aware from the evidence [ES2.2.7] and their
- 27 experience that lack of emotional support and empathy can be a contributing factor
- to non-attendance. The committee were aware from their experience and the
- 29 evidence [review 2] that non-attendance can often lead to discharge. Based on their
- 30 expertise, they developed a recommendation that highlighted actions services can

- take in collaboration with secondary care mental health services to ensure non-
- 2 attendance is treated as a matter of concern.
- 3 The committee reflected on their experience and expert testimony [EP2] and noted
- 4 the importance of maintaining contact and reaching out to people to help them
- 5 remain engaged with services. They reflected on their experience to suggest follow-
- 6 up actions in the recommendations to address non-attendance.

7

8

Economic considerations

- 9 An economic analysis was undertaken which comprised a review of existing cost
- 10 effectiveness studies and a bespoke economic model.
- 11 The findings from the review of evidence (from 1 UK and 7 US studies) were
- inconsistent [ES4.1, ES4.2, ES4.3, ES4.4, ES4.5]. The US studies found that
- integrated treatment leads to minor cost savings but the UK study found that the
- intervention resulted in an increase in public sector costs. In all studies integrated
- treatment appears to result in improvement in some outcomes; however economic
- analyses used different outcome measures reported as changes on various scales
- making comparisons challenging. Three studies adopted before-after design, studies
- used different perspectives and time horizons, only 1 included economic study was
- 19 judged to be directly applicable, 3 studies were judged to be characterised by minor
- 20 limitations [++], 4 studies by potentially serious limitations [+], and 1 study by very
- 21 serious limitations [-]. Overall, there is little evidence to support one service delivery
- 22 model over another, based on existing economic evidence.
- 23 The model was based on 3 studies. The first study, conducted in the US, comprised
- 24 a treatment engagement intervention (using resources more intensively compared
- with standard care) for people with bipolar disorder and substance misuse. It was a
- small study whose health outcome was inconclusive, but yielded resource use data.
- 27 The remaining 2 studies, both from the UK, were used to estimate baseline
- admissions rates for people with dual diagnosis.
- 29 The model's time-horizon was 1 year only. Consequently, increases in life
- 30 expectancy that might have occurred as a result of an intervention were not included

- as benefits in the model. Because of the lack of data a further conservative
- 2 assumption was that wider costs, particularly those falling on the criminal justice
- 3 system, were not included. Further, the model's measured outcome might not have
- 4 measured all of the health outcome benefits.
- 5 The model showed that an intervention which combined enhanced engagement with
- 6 standard care would need to reduce relapses by about 12% for the intervention to
- 7 become cost saving. However, the committee members had different views about
- 8 whether UK standard care is better than that reported in the US studies. Assuming
- 9 standard care in the UK is equivalent to the enhanced intervention modelled, it would
- be offering better outcomes at the same cost. By definition, that would be a cost
- effective approach. However, assuming standard care in the UK would need to be
- enhanced and therefore need additional resources, at a cost of £226 per individual
- and assuming an effect size of 10% the intervention would need to result in a small
- 14 QALY gain of 0.002 (equivalent to 0.73 days in full health) for an ICER to be below
- the lower NICE cost-effectiveness threshold of £20,000 [ES4.6].
- Given the results that were obtained even though a number of potential benefits
- were not considered because of the lack of data (for example on a person's life
- 18 expectancy, improvement in the substance misuse problem, improvement in the
- mental health of service users the reduction in health and social care and the
- 20 criminal justice system costs) the treatment engagement intervention is very likely to
- 21 be a cost-effective option.

Other points the committee discussed

- 23 The committee discussed the exclusion criteria in the scope and noted that exclusion
- of mental health disorders such as eating disorders was a major gap. The committee
- 25 noted the criminal justice system settings were excluded from the scope but were
- 26 aware of NICE guidelines currently in development that included this setting (mental
- 27 <u>health</u> of adults in contact with criminal justice system and <u>physical health</u> of people
- in prison).

22

- 29 The committee considered a range of expertise that would be helpful to inform the
- development of the guideline and invited expert testimony in early intervention
- services, primary care, homeless, and local partnership working. The committee also

- acknowledged other groups (refugees, veterans) but recognised that there were
- 2 general set of needs which would subsume the specific needs of particular
- 3 populations. The committee recognised criminal justice system settings were out of
- 4 scope but noted that young people and adults with dual diagnosis who need a safe
- 5 place to stay may come into contact with people within this setting, for example the
- 6 police. However the committee noted that resources for helping the police to support
- 7 people with vulnerabilities are available at <u>Crisis Care Concordant</u>.
- 8 The committee considered all the evidence available in developing this guideline.
- 9 However some evidence statements provided background information and could not
- be explicitly linked to recommendations [ES1.1.1, ES1.1.3, ES1.1.4, ES1.1.6,
- ES1.1.7]. The committee heard from an expert in early intervention services [EP5]
- who described a study on contingency management (CIRCLE) which provided
- background information and was not linked to a specific recommendation.
- 14 The committee discussed the various forms of support groups or mechanisms for
- peer support. It was aware of mutual aid organisations including Alcoholics
- 16 Anonymous (AA), Narcotics Anonymous (NA) and SMART recovery and discussed
- the merit of adding a reference to such forms of support as examples in the guideline
- 18 recommendations. It was also aware of the Public Health England guidance (A
- 19 briefing on the evidence-based drug and alcohol treatment guidance
- 20 recommendations on mutual aid) but noted it was not aware of evidence establishing
- use of mutual aid in people with dual diagnosis. In addition because peer support
- 22 was an area identified for research recommendation, the committee did not
- recommend specifying examples of mutual aid groups within the guideline
- 24 recommendations.
- 25 The committee also noted that there may be a stigma attached to the term
- substance 'misuse' but recognised that this term is used in other NICE guidelines.

Evidence reviews

- Details of the evidence discussed are in evidence reviews, reports and papers from
- 29 experts in the area.

27

- 1 The evidence statements are short summaries of evidence. Each statement has a
- 2 short code indicating which document the evidence has come from.
- 3 Evidence statement (ES) number 1.1.1 indicates that the linked statement is
- 4 numbered 1 in review question 1.1 of review 1. **ES1.2.1** indicates that the linked
- 5 statement is numbered 1 in review question 1.2 of review 1. **ES2.1.1** indicates that
- the linked statement is numbered 1 in review question 2.1 of review 2. **ES2.2.1**
- 7 indicates that the linked statement is numbered 1 in review question 2.2. of review 2.
- 8 **ES3.1** indicates the linked statement is numbered 1 in review 3 and **ES4.1** indicates
- 9 the linked statement is numbered 1 in review 4. **EP1** indicates that expert paper 1:
- 10 'Local partnership working: examples drawn from the work of the Making Every Adult
- 11 Matter coalition' is linked to a recommendation. **EP2** indicates that expert paper 2:
- 12 'St Mungo's: people who have a dual diagnosis and are homeless' is linked to a
- recommendation. **EP3** indicates that expert paper 3: 'Early Intervention in Psychosis
- services' is linked to a recommendation. **EP4** indicates that expert paper 4: 'Dual
- 15 Diagnosis among homeless people: primary care perspective' is linked to a
- 16 recommendation.
- 17 If a recommendation is not directly taken from the evidence statements, but is
- inferred from the evidence, this is indicated by **IDE** (inference derived from the
- 19 evidence).
- 20 **Section 1.1:** ES1.1.8, ES1.1.9, ES2.1.2, ES2.2.1; EP2, EP4; IDE
- 21 **Section 1.2**: ES1.1.8, ES1.1.9, ES2.1.1, ES2.1.4, ES2.1.7, ES2.1.9, ES2.1.10,
- 22 ES2.2.1, ES2.2.2, ES2.2.3, ES2.2.4, ES2.2.6, ES2.2.7, ES2.2.8, ES2.2.9, ES3.1;
- 23 EP1, EP2, EP3, EP4; IDE
- 24 **Section 1.3**: ES2.1.5, ES2.1.6, ES2.1.7, ES2.1.10, ES2.1.11, ES2.2.3, ES2.2.4,
- 25 ES2.2.10; EP1, EP2; IDE
- 26 **Section 1.4**: ES1.1.2, ES1.2.1, ES2.1.3, ES2.1.4, ES2.1.10, ES2.1.12, ES2.1.13,
- 27 ES2.1.14, ES2.1.15, ES2.1.16, ES2.2.4, ES2.2.5, ES2.2.9, ES2.2.10, ES3.1, ES3.2,

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- 28 ES3.3, ES3.4, ES3.5, ES3.6, ES3.7, ES3.8, ES3.9. ES3.10, ES4.1, ES4.2. ES4.3,
- 29 ES4.4,ES4.5,ES4.6; EP1, EP2, EP3; IDE

- 1 **Section 1.5**: ES1.1.5, ES1.1.9, ES2.1.3, ES2.1.8, ES2.1.10, ES2.1.12, ES2.2.1,
- 2 ES2.2.2, ES2.2.4, ES2.2.5, ES2.2.7; EP2, EP4; IDE

3 Gaps in the evidence

- 4 The committee's assessment of the evidence on dual diagnosis identified a number
- 5 of gaps. These gaps are set out below.
- 6 1. Evidence on the characteristics of people with dual diagnosis in the groups
- 7 identified in the equity impact assessment. This includes for example, people with a
- 8 learning disability, teenage parents, Gypsies and Travellers, asylum seekers or
- 9 refugees, lesbian, gay, bisexual, transsexual or transgender people, and sex
- workers.
- 11 (Source review 1)
- 12 2. Social care needs of people identified in the equity impact assessment. This
- includes for example, those who are socially isolated, on low income, have a history
- of being 'looked after' or are adopted or have a history of experiencing or witnessing
- 15 domestic violence and abuse.
- 16 (Source review 1)
- 17 3. Views and experiences of:
- 18 a) commissioners
- 19 b) primary care practitioners who work with vulnerable groups
- 20 c) groups identified in the equity impact assessment (with the exception of young
- 21 people and ex-offenders).
- 22 (Source review 2)
- 4. Interventions or measures assessing efficiency of services (for example measures
- looking at improving accessibility and availability of services).
- 25 (Source review 3)

- 5. Different models of service delivery (for example, a comparison of specialist,
- 2 integrated or separate services) and efficiency of service delivery models.
- 3 (Source review 3)

4 Recommendations for research

5 The guideline committee has made the following recommendations for research.

6 1 Epidemiology

- 7 In the UK, how prevalent is a dual diagnosis and what are the physical health and
- 8 social care, housing or support needs of people with this diagnosis?

9 Why this is important

- 10 There is limited evidence on the physical health and social care needs of people with
- dual diagnosis. This includes prevalence of coexisting physical conditions such as
- cardiovascular, respiratory or infectious diseases and social care needs such as
- social isolation or poor housing. Longitudinal evidence is needed to understand
- these. This will help design coordinated evidence based services to meet the wider
- health and social care needs of people with dual diagnosis and provide a good
- standard of care. People with dual diagnosis may present in a variety of settings and
- 17 research that focuses on specific settings (for example, primary care) would be
- 18 beneficial.

24

19 **2 What works?**

- 20 In the UK, what is the effectiveness and cost effectiveness of service delivery
- interventions (peer support, contingency management or text messaging delivered in
- 22 conjunction with standard care) compared with standard care alone for young people
- and adults with dual diagnosis?

Why this is important

- 25 There is limited evidence on the optimal service delivery model to meet the needs of
- young people and adults with dual diagnosis. Evidence suggests there is increasing
- use of contingency management, peer support or text messaging as part of a service
- delivery intervention to help young people and adults with dual diagnosis access

- 1 services. Further research is therefore needed to assess their use, benefit and
- 2 whether these have a role in improving engagement with services for people with
- dual diagnosis. Research is also needed on what a good outcome for this group is,
- 4 the methodological challenges of encouraging research in people with dual
- 5 diagnosis, and appropriate methodology for engaging with this group.

3 Evidence of cost effectiveness

- 7 What is the cost effectiveness of services (or elements of standard care) for young
- 8 people and adults with dual diagnosis?

9 Why this is important

- 10 There is limited evidence on the cost effectiveness of interventions and services with
- this group. Further research is needed to investigate this and ascertain whether any
- particular services or elements of standard care provide better value for money.

13 **4 Barriers and facilitators**

- What are the barriers and facilitators for young people and adults with dual diagnosis
- to obtain an optimal service (including optimal time frame for delivering interventions)
- to meet their needs and enable their recovery?

17 Why this is important

- 18 There is limited evidence that identifies the triggers for deterioration and the turning
- 19 points for recovery for people with dual diagnosis. Although review 2 contains
- 20 evidence on the views and experiences of people with dual diagnosis, their family or
- carers, it is not always clear to which point in the care pathway the views and
- 22 experiences expressed relate to. As such, it is difficult to fully break down the
- 23 experience of care received at various intervals along the care pathway.
- 24 Understanding the experience of people who are at different stages of recovery and
- 25 how they have maintained their progress and success (1 year, 3 years, 5 years, 10
- years+) will help with designing more effective services and planning services that
- 27 deliver interventions at the right time.

1 5 Care pathway

- 2 In the UK, what is the optimal care pathway for young people and adults with dual
- 3 diagnosis?

4 Why this is important

- 5 There is a lack of published evidence on care pathways on treatment, management
- 6 and follow up of people with dual diagnosis. In the UK, service configurations,
- 7 treatment philosophies and funding streams act as barriers to coordinated provision
- 8 of care. Separate mental health and substance misuse services that are often
- 9 provided by different organisations, have different organisational and managerial
- structures, and staff within each service may often lack the knowledge and skills for
- working with people from another organisation. A review of what has worked or not
- in areas that have implemented changes to practice will help services develop
- 13 optimal care pathways.

14 Glossary

15 Contingency management

- 16 Contingency management is a set of techniques that focus on changing specific
- behaviours. For example, in drug misuse, it involves offering incentives for positive
- behaviours such as abstinence or a reduction in illicit drug use, and participation in
- 19 health-promoting interventions.
- 20 **ISBN**: