



National Mental Health
Development Unit

Listening to Service Users

Developing Service User Focused Outcomes in Dual Diagnosis: A Practical Tool

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Foreword

Substance misuse and mental illness both exert a heavy impact on people's lives. They can affect physical health, social status, relationships, self-image...in fact most aspects of a person's life can be affected. For people who experience both mental ill health and addiction, the problem more than doubles. Both issues become entwined and impact on one another and the rest of our lives can fall to pieces as a result.

This document reflects many of these difficulties. Spurned by the mental health community for substance misuse and derided by the drug and alcohol teams for being chaotic, all too often the support we receive does not bridge the gap between fields, and rejection by services perpetuates low self-esteem.

More optimistically, this outcomes tool also reflects positive experiences and makes practical recommendations for improving services. As experts in the experience of substance misuse and mental ill health (dual diagnosis), people who have used services have a wealth of knowledge to contribute. Different services and professionals impact on our lives, and provide a map through services and into Recovery, showing the opportunities and pitfalls along the way. Such support is crucial, but it is the user, who is the driving force of Recovery.

This user focused outcomes tool is a welcome development for those of us engaged with services or seeking to help those who are struggling with mental illness, substance misuse and other issues. It highlights the struggle many face and also paves the way for a better, more coordinated and cohesive approach to address not only one issue, but the many issues involved in an individual's unique experience towards Recovery.

Through people who have used services informing the commissioning process, we can help to ensure that the real issues and real priorities are brought to the fore. The shared goal is to commission effective and accessible services which support Recovery – not just for abstinence – but for life.

Service user

Introduction

Purpose

One of the key recommendations of the Autumn Assessment Dual Diagnosis Themed Review Report (DH 2007) highlighted the need to improve effective recording of user defined outcomes. The purpose of this outcomes tool is to support the delivery of quality services for people with co-existing mental health and substance misuse difficulties (dual diagnosis), through a better understanding of service user perspectives. It is designed to:

- Provide a starting point for a dialogue with service users about what they see as important outcomes for them when they are in touch with services
- Guide commissioners regarding co-operative practice when tendering, procuring and monitoring services
- Inform providers delivering services
- Promote involvement with local service users and service user groups.

It is recommended that this should be used as a practical tool to stimulate ongoing discussion and development in improving services for people with a dual diagnosis. The accompanying workshop material will help to identify and prioritise what is important regionally and locally, based on the principles and outcomes outlined in this document.

Structure

The information is structured around a treatment pathway, (influenced by Osher and Kofoed's model¹). Each section contains:

¹ Osher F & Kofoed L, *Treatment of patients with psychiatric and psychoactive substance abuse disorders, Hospital Community Psychiatry, Vol 40, October 1989*

- Quotes and direct feedback from people using services
- Outcomes which service users would like to see
- Some commissioning principles which underpin the outcomes
- Links with current national policy guidance and best practice examples.

Methodology

Feedback was received from commissioners, practitioners and over 60 former and current service users from across the country, between August 2009 and March 2010. This included responses from in-patient, prison and community settings. Information was gathered via face-to-face meetings and discussion groups, by post, telephone and email. Participation was voluntary and any reasonable expenses paid in line with recommended guidelines (see *Find out more*, page 43). This was not a formal research project, and did not require ethical approval under the National Research Ethics Service (NRES) guidelines.

Acknowledgements

This report provides a positive example of collaboration and could not have been written without the help of people with experience of mental health and substance misuse difficulties. We appreciate their honesty, enthusiasm and constructive suggestions. We are very grateful to all individuals and several groups around the country, including:

- Addaction Substance Misuse/Relapse Prevention Group, Blackpool
- The Afiya Trust
- Derbyshire Voice

- Dual Diagnosis Support Group, Blackpool
- The Friday Group, London
- Nottingham Dual Diagnosis Forum
- St Helen's Dual Diagnosis Group
- Stockport Dual Diagnosis Forum
- Service users from Trafford Community Drug Team and Access 2 the Edge, Manchester
- Service users from Leicestershire
- Turning Point Support Link, Hertfordshire.

We would also like to thank the commissioners and practitioners for their helpful contributions and in particular the group of dual diagnosis practitioners PROGRESS (see *Find out more*, page 43).

Summary of Key Messages and Outcomes

Although the views reflected in this report are diverse, some key messages and outcomes emerged, as summarised below.

Key messages

- People with a dual diagnosis form a high proportion of those using mental health and drug and alcohol services. It is in everyone's interest to ensure that services are effective, appropriate and inclusive
- Opinions may vary about the nature and shape of a care pathway, but many of the outcomes which service users, commissioners and practitioners wish to achieve are similar.
- Many of the outcomes, for example, the need to include both mental health and drug and alcohol use in assessments are not new, but remain a priority for service users.
- Significant improvements can be made through collaborative working and innovative approaches, even when resources are limited, such as being listened to and being treated with respect.

Key outcomes areas

Commissioning, service delivery and design

Key elements of best practice from service users include:

- Collaboration and co-ordination of services to enable proactive planning rather than reactive responses.

- Clear care pathways which fully involve the service user at each stage of their journey.
- Continuity of care wherever possible and practical, i.e. one service/worker dealing with an individual's treatment, with help and support from other agencies as required.
- Staff who are approachable, professional, competent and well-informed.

Engagement

- The attitudes and values of staff have a significant impact at every stage of the treatment journey and are a high priority both from a service user and a strategic perspective.
- Being listened to and being treated with respect is especially important.
- Practical priorities, such as providing straightforward information, clear pathways and supportive signposting, make a big difference.

Assessment

- Assessments should cover both mental health and alcohol and/or drug use. Ideally there should be one assessment, involving relevant mental health and substance misuse practitioners.
- Physical health should also be addressed as part of a holistic assessment. This should include issues such as emotional health, child and family concerns, housing and employment.
- Workers should avoid assumptions based on diagnoses and listen to service user views.

Treatment

- Empowerment is an essential part of Recovery. Service users would like to have choices and be supported throughout this process. Mutual respect, honesty and a partnership approach to goal setting is key to achieving this.
- Within the constraints of national targets, treatment programmes for people with a dual diagnosis should be more flexible, to reflect the range and complexity of an individual's needs.
- Many service users would like to have some or increased support during treatment, outside formal appointments, for example through a telephone helpline or a support group.

Recovery and relapse prevention

- Many commissioners, practitioners and people using services share a common goal: to maximise treatment gains, however often lack of after-care provision and poor discharge planning can hamper progress.
- Service users want clear, integrated care pathways which continue beyond the completion of treatment episodes and form part of a wider Recovery programme and plan.
- Social isolation, lack of activity and unstable housing continue to be the biggest barriers to Recovery. Engagement and partnership working with non-clinical services promoting suitable housing, positive social networks, community involvement, employment, education and training are vital.
- Many service users are keen to be involved in delivering training as well as accessing training themselves. This improves their self-esteem and staff gain greater insight into the complex nature of dual diagnosis treatment and Recovery.

The Treatment Journey

Service users identified some key features which contribute to delivering positive outcomes across the whole treatment journey. The following reflects a structure that prioritises areas for consideration by the people questioned during this project. This may not necessarily be the same in other localities where the exercise is repeated, but is presented here to reflect issues that were universally significant.

Collaboration and communication: Timely communication between services helps to prevent problems from escalating and service users feel better supported. 'The mental health and substance misuse services are communicating through me, but not with each other.'

*"Should substance misuse services have links with the police?
Of course they should...but not when it's all too late."*

GOOD PRACTICE EXAMPLE: Joint Working

Blackpool Advocacy and Blackpool Dual Diagnosis Support Group are both small organisations with few staff. They share many of the same clients, who find it difficult to engage with services. Where appropriate, they do visits together, which is welcomed by clients and clients report that this approach is more effective than working alone.

Contacts: admin@blackpooladvocacy.co.uk or
dd-blackpool@hotmail.co.uk

Care Pathways: Care pathways should be clear, integrated and fully involve the service user. They should be flexible enough to allow for re-entry to a service, or referral to other services as the treatment journey progresses or changes. A care pathway should be an ongoing route to Recovery, not a 'dead end'.

"I waited weeks for rehab and relapsed. Really I needed to go straight from detox in to the rehab so that I had a chance..."

Better discharge planning: Co-ordination between services enables different agencies to plan proactively, not reactively.

"Mental health services have been good at explaining my position to other agencies like the courts and the benefits agency."

Continuity of care: Some change of services and staff is inevitable, but disruption can be minimised, for example by using three-way handovers and clear referral notes.

"I've never hidden my alcohol dependency from any psychiatrist, but they usually change every 6 months."

Competent, empathetic staff: Service users consistently attributed the biggest difference to their care to an individual who was empathetic, motivated and knowledgeable. Often, however, staff lack basic knowledge of either mental health or drug and alcohol use.

"I see a drugs and alcohol worker with no mental health background and a psychotherapist with no training in substance misuse. I'm saying the same things to two different people..."

The co-existence of mental health and drug/and/or alcohol use 'is sufficiently common for dual diagnosis skills to be essential in all frontline services'.

At a more strategic commissioning level, some common problems which can block progress along a care pathway include:

Different treatment philosophies: these can lead to confusion for both service users and practitioners from different agencies.

"Treatment philosophies need to be for everyone, the messages can be so muddled and contradictory."

Variations in treatment availability and eligibility criteria: Differences within and between boroughs inevitably can discourage engagement with treatment and disrupt Recovery.

"When services can't help or they turn you away, it's like giving you a meal ticket and then not giving you the dinner."

Variations in provision can be particularly pronounced between hospital and secure settings and the wider community.

"There's no difference between them and us (people in hospital and people in the community), we're all members of the public. We all need the same services, but they don't seem to be there (in the community)."

Service Users Clarifying Outcomes

- Mental health, drug and alcohol and other services communicate well and are co-ordinated. (See box below)
- Care pathways are clear, with a central access point.
- Service users are allocated a specific individual to help them navigate through the system.
- There is good liaison between primary and secondary care – GPs and specialist services.
- There is continuity of care, particularly when keyworkers change. Keyworkers read previous case notes.

Services could work better together through:

- Clear referral notes
- Link workers
- Joint working
- A common assessment tool
- Cross training
- Practitioner events to disseminate information to support workers.

At a strategic level:

- High quality services are available. People get the right services, in the right place, at the right time.
- There is equitable service provision across local areas and counties.
- Criteria for accessing services are clear and consistent.
- If not eligible, people are supported to access other services.
- There is access to a range of services including complementary therapy, education and training, employment, benefits and debt advice.
- Services are stable and service users are not continuously passed between them.
- Staff have up to date training in mental health and drug and alcohol (mis)use.

Commissioning Principles that impact directly on Service Users

Positive ethos and best practice

- Commissioners and providers foster a positive ethos and are open to innovation which may mean doing things differently – if this would improve services and benefit service users.
- Standards and principles of best practice in dual diagnosis provision should be agreed and reflected in service specifications and contracts.

Service provision and design

- Commissioning reflects a commitment to mainstreaming provision for everyone on the dual diagnosis spectrum including those with 'milder' as well as more complex needs.
- Service mapping identifies gaps and helps to ensure equitable provision of high quality services.
- Eligibility criteria are clear and consistently applied across boroughs and counties.
- Providers can demonstrate how they support people to access other relevant services during and after treatment.
- Restructuring of services and staff changes are kept to a minimum. This can be difficult, but is important to service users.

Staff training

- Ongoing and sufficient resources are available to train staff appropriately at all levels
- Providers are given adequate time for training, reflective practice, and continuing professional development (see Capable Dual Diagnosis Practitioner resources: www.nmhdu.org.uk/silo/files/developing-capable-practitioners-to-improve-services.pdf).

Stage 1: Engagement

This is the first stage of a care pathway, when a person has first contact with services, or is seeking help. Most people are anxious about taking the first step and can be easily deterred. In order to maximise the opportunity, it is vital that both staff attitudes and the practical organisation of services promote engagement.

Tackling Stigma: Values and Attitudes

What values are important to you? *My own.*

The subject of values and attitudes is not distinct to people with a dual diagnosis. However, as people with co-existing mental health, alcohol and/or drug misuse difficulties often feel let down and marginalised, it is particularly relevant. Some service users stressed the urgent need to address racism through Delivering Race Equality and other initiatives.

“Stigma plagues people who use, in their communities whilst in treatment, from providers of housing and social services, the police, ambulance staff, GPs and their staff, when trying to gain employment, at work, in education, from friends and family members, as well as from other drug and alcohol users. In fact the list is endless, people tend to view addiction as something you have done to yourself, after all no one was forcing you to drink or do drugs”²

Service user quote

2 *Stamp out Stigma Nottinghamshire NHS Healthcare Trust & Substance Misuse Service.*

No health without mental health, the coalition government mental health strategy, has a one of its key shared objectives “fewer people will experience stigma and discrimination”.

The key outcome will be that the public understanding of will improve and as a result, negative attitudes and behaviours to people with mental health problems will reduce.

Addressing outcomes in relation to values and attitudes may appear less important than clinical interventions for example. However, this area has a significant impact on the treatment experience, outcomes and long-term Recovery and is therefore a high priority from both a service user and strategic perspective.

Negative or unhelpful attitudes deter people from seeking help or discourage them in treatment and perpetuate stigma and low self-esteem.

“It’s hard to ask for help when you feel people are looking down on you”

“My experience in a secure hospital was traumatic, difficult, complex, amazingly deflating and pressurized. I felt alone and alienated. I felt that staff didn’t want us there.”

Conversely, a friendly welcome, active listening, a positive outlook and a non-judgmental attitude encourages people to engage or re-engage with services and move forward in their treatment. These are key to intervening early and preventing the effects of mental ill-health from escalating.

“This woman actually does care. She gave me her assurance that I would not be passed around.”

Feedback from people using services shows that attitudes and values of staff should not be a 'poor relation' in regard to commissioning, but they can be neglected. This may be due to a number of factors: a presumption that helpful values develop automatically, a belief that organisational ethos is the realm of providers, not commissioners and that this area does not require any financial or human resource.

There can be resource implications – such as increasing time for staff supervisions and reflective practice. However, achieving better outcomes in terms of listening and treating people as individuals with respect and dignity, should be at the centre of everything we do.

Outcomes

- Workers listen and show respect
- Workers are empathetic, approachable and friendly
- Workers are professional
- Workers are not judgmental and do not look down on people.

Measuring and Monitoring Outcomes

- Local discussions are needed to agree the best ways to know if the above are happening.
- There may be existing data sets that collect this information, or processes through which both qualitative and quantitative information is collected.
- Opportunities to involve people who use services, their carers and families can be explored.

Commissioning Principles

- Staff listen and are respectful to service users
- Training on values, dignity and respect should be encouraged within in mental health and drug and alcohol training programmes. Wherever possible, service users should be involved in the delivery of training.
- Demonstrating respect and good listening skills are reviewed in staff supervision and are part of appraisals and assessing professional competencies.

GOOD PRACTICE EXAMPLE: Stamp Out Stigma Campaign

The Stamp Out Stigma Campaign was commissioned by Nottinghamshire Healthcare Trust Substance Misuse Services. It shares a common goal with the wider mental health Anti-Stigma Campaign run within the Trust. Its focus is on:

- Tackling stigma in the key areas identified by service users: emergency departments, pharmacies and substance misuse services
- Providing service user and carer mentors for senior managers in services
- Providing anti-stigma training
- Inspiring services to focus on Recovery.

It sums up RESPECT in the mnemonic:

Remember **E**very **S**ingle **P**erson **E**xpects **C**aring **T**reatment

Practical ways to promote engagement

Reducing waiting lists is a key priority to enable people to get help and support when they need it. Other suggestions to increase levels of engagement centred around awareness and information, location and environment. A long, complicated and expensive journey understandably deters people from contacting services or attending appointments.

"I had very little income and had to cross 3 boroughs to get to appointments and how many off-licences and drug dealers do you pass on the way?"

People reported that finding out information about services, particularly when 'outside the system' was difficult. Without accurate information, people may be misinformed or unaware of relevant services at a crucial time when they are motivated to seek help.

"I found out about services through leg-work, asking other service users and then self-referring."

Consideration may also be given to commissioning services outside clinical settings, such as those provided by the voluntary sector. Signposting should be supportive and in the service user's best interest. Information should be straightforward and relevant. Being given a standard list of contact numbers, without any advice can be confusing, especially for people experiencing mental health and alcohol and/or drug misuse difficulties.

Outcomes

- There should be timely access to services.
- Services should be available locally, be easily accessible and where possible, offer more flexibility in opening times.
- People with a dual diagnosis know what services are available and how to access them. Services are well publicised e.g. in libraries, community and leisure centres, GP surgeries etc.
- There is a central access point, e.g. a telephone helpline.
- Services operate in a welcoming and pleasant environment.
- Some services are located outside hospital environments where appropriate.
- Services are physically accessible for people with mobility and other disabilities.
- Workers are well-informed about local services.
- If they are not able to help, workers signpost on and provide relevant information, so that a person is not left without any support.

Commissioning Principles

Availability

- Services are available locally or are easily accessible by public transport, with costs reimbursed.
- Waiting times are kept to a minimum, with any delays explained.

Fairness

- The criteria for accessing services are clearly explained and consistently applied, but dual diagnosis is not used as a reason to exclude.³

Information & Support

- Service users are given clear, straightforward information in a format appropriate to them e.g. verbal, pictorial, written.
- Staff are well-informed and can provide up to date information about local services.
- Signposting extends beyond merely giving information and is proactive and supportive.

Location

- Where appropriate, consideration is given to alternatives to hospital environments e.g. using voluntary sector and community premises and GP surgeries.
- Services comply with the Disability Discrimination Act and can provide an alternative service if required. (For more information see: www.dwp.gov.uk/employer/disability-discrimination-act/)

³ Bradley Review p108

Stage 2: Assessment

After initial contact, a person is assessed by services. Assessment may involve several stages, but should be comprehensive.

“I wish drugs services had asked about my mental wellbeing. I suffered depression from an early age (13) and have seen my GP due to it at several points of my life. I started self-medicating with drugs and entered treatment due to my heroin misuse. Not once did they ask me about my mental health. If they had, I believe I would have progressed through treatment and Recovery much quicker.”

‘If only they had asked’ was a recurring theme. Although a number of participants said that at assessment, they were willing to discuss their mental health, substance misuse or physical health concerns, too often only one aspect is assessed. This is a missed opportunity.

“I wasn’t asked about alcohol problems until I was sectioned.”

“When I was in hospital (for my mental health), they never asked me why I drank. I got caught a few times but nothing was said or asked.”

People with mental illness are likely to have poorer physical health, particularly in relation to cardiovascular disease, diabetes and obesity – Drug and/or alcohol use brings even further risks and complications. However, many people have difficulty in accessing the health interventions they need and the Dual Diagnosis Themed Review⁴ urged that physical health be given higher priority.

“My physical health issues were not really addressed until 2 years had elapsed in to my treatment although information was readily available from my GP.”

⁴ Dual Diagnosis Themed Review Report Executive Summary p4

No health without mental health identifies effective health services providing care that addresses both physical and psychological needs by improving outcomes for people with mental health problems through high quality services that are equally accessible to all.

Choosing Health: *Supporting the physical health needs of people with severe mental illness.* (DH 2006) is a commissioning framework to help PCTs plan for, design, commission and monitor services to deliver improved health and well-being. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138212

Some service users highlighted how support with other issues such as family problems, past domestic violence or unstable housing had helped to keep them stable and away from drugs. Often, however, these areas are not explored.

The overwhelming majority of participants welcomed a holistic assessment to get a picture of the whole situation and an understanding their priorities.

"If it's important to the individual, it's important."

"I have never been looked upon as a mother, apart from by my daughter."

When an assessment is person-centred, better outcomes are likely to be achieved. Many service user recommendations mirror those stipulated in the guidance on the refocused Care Programme Approach (CPA) and can also be followed for those outside CPA.

Ideally, one person should be able to conduct a comprehensive assessment. This should cover mental health and drug and alcohol use and the inter-relationship between them, as well as physical health and other factors. If suitably qualified staff are not available, joint assessments should be conducted. Asking questions about other areas of a person's life does not mean that one agency is expected to provide all the necessary support. Solutions can be found through effective partnership working.

Service users felt that a good assessment involves:

- Asking a range of appropriate questions
- Actively listening to the answers
- Avoiding assumptions based on stereotypes or diagnoses
- Assessing the suitability of interventions and treatment options.

“Never go in with any preconceived ideas. Every person is unique and will have a unique set of experiences and circumstances. You have to understand the person.”

Service users highlighted significant variations in the scope of assessments and in the different threshold levels required to access treatment.

The Department of Health's social care reform proposals include individual needs assessments and portability of assessments across local authority boundaries and agencies.

Outcomes

- Workers do not make assumptions, but keep an open-mind and listen to what is important to service users
- An assessment includes mental health and drug and/or alcohol use
- An assessment is holistic, with opportunity to discuss physical and emotional health, family and childhood issues and social care issues e.g. housing, benefits
- Assessments are comprehensive to minimise repetition of information
- Assessments follow a structured approach, covering all pertinent areas.

Measuring & Monitoring Outcomes

- Evidence from CPA documentation (where appropriate)
- Specific tools and measures that may already be in use locally.

Commissioning Principles

Comprehensive Assessments

- Assessments include mental health and drug and alcohol use at a minimum, and should also include physical health and social care issues. The guidance on CPA should be adopted as good practice for all dual diagnosis clients
- Wherever possible, one person should conduct a comprehensive assessment. Where assessments are separate, a joint approach to dual diagnosis should be adopted.

Training

- Staff receive training to increase awareness of mental health and drug and alcohol use to enable them to feel more competent to conduct comprehensive assessments.
- There are opportunities for training and sharing experience in the general skills required to conduct assessments e.g. listening skills, in supervision and in team meetings.

Screening Tools

- The locality should agree a set of screening tools that are evidence-based, and agreed across services. This would help to create a common language and a basis for joint working between mental health, drug and alcohol services and GPs. It would help signpost people more effectively to services that they would benefit from at this point in their pathway.

The refocused **Care Programme Approach** (CPA) is an important tool for achieving better outcomes for people with a dual diagnosis and its principles remain relevant for those outside its criteria. For example, it recommends more multi-disciplinary, joint assessments, reduced documentation and a care plan which follows a service user through a variety of settings. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083647

Stage 3: Treatment

At this stage, a person has started using services. This section covers two aspects of treatment: empowerment and suggested ways to increase treatment effectiveness and training from a service user perspective.

The focus is on treatment delivery rather than specific interventions. People with a dual diagnosis have a range of overlapping and complex needs, but an emphasis on integrated care pathways helps to determine and maintain effective collaborative treatment.

Empowerment

Commissioners, practitioners and service users alike acknowledge that dual diagnosis presents many challenges. However, it's vital that an individual is seen as a whole person, not purely as a set of problems, and that encouragement is given along the way.

“They see how everything links together to affect me and they can help me see how making changes in one area of my life can make lots of things better.”

*“We need empowerment and confidence.
There's not enough encouragement from services.”*

“Give me opportunities to develop and grow and help me to recognize why I behave as I do and then to alter my behaviour and therefore change.”

No mental health without mental health identifies: Personalisation is also about recognising the strengths and aspirations of individuals and understanding their backgrounds and contexts, including family, employment and roles in the community.

It can only be achieved by the public, private and third sectors working with individuals and communities
www.dh.gov.uk/mentalhealthstrategy.

A significant number of service users felt that the situation had improved and that they were partners in their treatment. They identified several factors including:

- Mutual respect and honesty
- Being actively involved in goal setting and having some choices
- ‘Self-help’ in the sense of being supported, but not being spoon-fed.
- Treatment being a shared journey in which both parties are involved.

“In the past I have been treated negatively... but now, my workers show me that I have choices and that I can move forward. They provide me with options but don't force me to do anything.”

“We work together, I feel as if I have a choice and that I can help myself.”

Others spoke of professional barriers, lack of understanding and being forced into the available treatment options.

Increasing treatment effectiveness

Pace of treatment

A clear theme is that the pace of treatment is often inappropriate for the individual, with service users feeling under pressure to meet targets within a set time-frame. This can result in a reluctance to be totally honest with service providers about the true state of their mental health and drug and/or alcohol use. This can be counter-productive, both in human and financial terms and could make relapse more likely.

"You speak to different people but they don't know you... you can lie and say that you are feeling better than you are. You need to be able to trust people, especially if you have children."

"I feel pressurized for speaking my mind and expressing how I am really feeling. They are trying to get me off services, but if they are listening properly, they must be prepared to hear what they don't want to hear."

Support outside treatment sessions

Support outside treatment sessions is highly valued, but is often patchy:

"The support outside treatment sessions is good. I like the direct contact number for mental health team support."

Complementary therapies and physical health

Service users also called for increased access to complementary therapies and ongoing attention to physical health. They suggested that one way of achieving this is for Primary Care and community based staff to periodically visit support groups, to give advice on subjects such as weight management and healthy lifestyles.

Commissioning, care planning and reviews

More flexibility in commissioning would help to take account of the multiple needs of many people with a dual diagnosis and the possibility of relapse. Good care planning and regular reviews are also key factors in successful treatment. Many people who have concurrent but lower levels of need fall outside the Care Programme Approach criteria, but effective care planning for them is just as vital. The care co-ordinator can sometimes dominate the process, particularly as systems become increasingly computerised. It is important that service users participate fully in the production of their care plans.

Training

Service users again stressed the need for adequate and ongoing training of staff (See *The Treatment Journey* page 8).

Outcomes

Key treatment outcomes for service users relate to partnership, pace and content/review.

- There is trust, honesty and respect between workers and service users.
- Service users are treated as equals: no 'them and us.'
- Goals are set in partnership and reflect what is important to the person. Goals are clear, realistic and positive.
- Goals may include: reducing drug and/or alcohol use or being abstinent, reducing medication, feeling stable, well and able to cope, not feeling stigmatized, and being able to 'get on with life in real terms rather than as a user.'

- A care plan is put together by both the service user and worker, and the service user has a copy.
- There is support outside treatment sessions.
- The pace of treatment is appropriate to the person.
- Attention to physical health is ongoing and complementary therapies are available.

Commissioning Principles

Empowerment and partnership with service users

- Staff demonstrate that they treat service users with honesty respect and as equal partners in their care.
- Providers/staff can evidence service user involvement in treatment and plans and goals are positive, realistic and appropriate to individuals.
- Service users understand and have a copy of their care plan.

Treatment provision

- There is support available for service users during their treatment programme, for example through a telephone helpline.
- Access to complementary therapies and on-going physical healthcare is available.

Care planning and commissioning

- The commissioning of treatment services reflects that people with a dual diagnosis have multiple and changing needs.
- Care plans are regularly reviewed.

GOOD PRACTICE EXAMPLE: Alcohol Treatment Pathways

Alcohol treatment pathways (ATPs) are locally agreed templates which map out the local help available for alcohol-related problems at various stages of a treatment journey and give attention to service user experience.

ATPs are especially helpful for people with a dual diagnosis, who may experience difficulties or delays in accessing to treatment because they have complex needs. The process of developing ATPs is often at least as important as the final product. This requires effective communication between all agencies and consensus on inclusion criteria, on the agreed roles and responsibilities, on the optimal means of inter- and cross-agency working and on best practice. These all contribute to an effective final tool that supports more explicit and effective delivery of care. More complex ATPs such as for people with a dual diagnosis will require a clear lead coordinator, with support from a core multi-agency team.

Further information on Local Routes Guidance for Developing Alcohol Treatment Pathways: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110423

Stage 4: Recovery and Relapse Prevention

In this section, service users reflect on what has helped them most on their (ongoing) journey of Recovery including some practical suggestions.

"I now sit on the same committee as my psychiatrist. It's lovely to know he's there when I need him...but I don't."

A key finding from this report is the extent of common ground between commissioners, practitioners and people using services. Although expressed in different ways, there is a shared aim to maximise treatment gains such as reducing drug/alcohol use or achieving more stability, or not using services at all. However, people with co-existing mental health and substance misuse difficulties typically require support over longer periods. There also needs to be stronger links and smoother transition between 'specialist' provision and mainstream services and community facilities.

"(I would like services) to become background support services, helping me to make my own choices."

Many service users recounted a precarious and lonely onward journey, when the end of a treatment programme felt like 'being discharged to nowhere.

"It's OK being abstinent and stabilising your mental health, but what's next? After rehab, there's nothing for you to come out to. There's a no-man's land between sobriety and using."

"For me the darkest periods in my life started when I stopped using."

Where services are available, they should be well-publicised and accessible.

Service users strongly advocated the need for after-care support immediately after discharge, whether from prison, hospital or community treatment. This may be short-term or ongoing and can take different forms, depending on personal preference and needs. Suggestions included being allocated a social worker or a, community support worker. Support, Time and Recovery Workers can be very helpful, but accessing them (through mental health services) can be difficult. Several people also highlighted the valuable role of Occupational Therapists.

“What helps me to progress is continuing support, at different levels, at different times of my life.”

“Just by knowing that support (of my practitioner) is there should I relapse...increases my confidence and makes me want to continue in my life-progressions.”

Discharge planning

Service users suggested that effective discharge planning includes:

- Planning ahead
- Discussion with service users about their priorities
- Maintaining links with community agencies whilst in hospital/secure settings
- Well-informed workers who know about local service provision and have links with other agencies
- Visiting or making contact with relevant community agencies in advance
- Follow-up by the discharging agency to check that arrangements are working smoothly.

As people have a range of needs, they may face a bewildering array of appointments and some form of advocacy or moral support is highly valued.

“A friend from the Support Group, took me to the CAB and stayed with me. There was a 20 minute wait, if I'd been there on my own, I would have walked out.”

It is clear from the comments received that 'non-clinical' services make a huge difference in the lives of people with a dual diagnosis and should be a part of the overall commissioning picture if treatment progress is to be sustained. This requires strong partnerships, innovative approaches and use of a wide variety of funding streams. For example, this could include using Personal Budgets to enable people to design the type of support that works for them in meeting *outcomes*. For more information see: www.dhcarenetworks.org.uk/personalisation/

Recovery is as individual and varied as the people using services, but four key areas emerged from service user feedback

Social networks

A top priority is more initiatives to combat isolation and support to build appropriate social networks, which are not formed around drinking or drug use. Some participants suggested matching up a service user with a person who shares similar interests and values and is more like a friend rather than a support worker. Care is needed to 'match' people appropriately, but this type of informal approach may offer greater potential to facilitate Recovery than more formal models where the power imbalance can be more apparent.

Service users also highlighted the need for activities in the evenings and weekends as alternatives to socialising around the pub/club scene.

“When I left my friends who used, I was alone and relatively socially isolated.”

Community involvement

Many people valued voluntary or paid work. Among the varied roles mentioned were: being a sessional interviewer, setting up a social club, running a football team, working with young people and volunteering with the Cats Protection League. Clearly, community involvement builds skills, self-esteem and friendships and is a constructive use of time.

"The biggest help (outside treatment services) was volunteering for a charity that worked with young people."

GOOD PRACTICE EXAMPLE: The Friday Group

The Friday Group is a facilitated weekly self-help group in Redbridge, part of the North East London NHS Foundation Trust, for people with past or current experience of mental health and substance misuse issues. It offers social and recreational activities, a shared meal and a discussion group. Members particularly value the respect shown to everyone and the mix of peer support, social networking and therapeutic help if required, available through a mental health nurse and a substance misuse worker. The benefits include better mental health, reduced substance use and improvements in housing stability, involvement in social and vocational activities and engagement with other services.

Housing

'Housing and feeling safe' was a recurring priority among participants.

'I did not get any other support, e.g. on complementary therapy, training, housing or education, I did it by myself.'

No Health without Mental Health recognises that housing and mental health are closely inter-related. Although stable housing is critical to achieving stable outcomes in health, employment and other areas, it is often a sorely neglected part of a comprehensive dual diagnosis strategy.

Employment, education and training

A high proportion of service users identified education and training as playing a major part in their ongoing Recovery and a stepping stone towards employment. There was a huge variety in the studies undertaken, from an introductory IT course to a degree in mental health nursing and a post-graduate diploma personality disorder.

"Training and education have been invaluable to me. I've been through detox, day treatment and now been 6 years' abstinent, but it's the training courses that have helped to keep me away from mental health issues."

"Since I have been using dual diagnosis services I have a qualification in health and social care which helps me be more confident in finding paid work."

People using services should have to the opportunity to give training as well as receive it. Several participants were actively involved in giving training to health professionals such as through making DVDs or in face-to-face sessions. Service users must be properly supported as part of an ongoing programme.

"Involving people in treatment and treatment delivery helps promotes Recovery through building confidence and skills and self-esteem."

Employment, education and training are high priorities nationally.

The Perkins Review states that employment should be viewed as an important outcome in the treatment of mental illness and recommends that health and social services and DWP routinely monitor employment outcomes.⁵

In response, the Government supports a Recovery model and is working to the core principle that 'work is good for mental health: it aids Recovery and has a therapeutic value, even for those with the most severe mental health conditions.'⁶ www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/realising-ambitions/

No Health without Mental Health recognises that the need is accentuated, not diminished in times of economic difficulty if already vulnerable people not to be marginalised further.

Mental health, alcohol and/or drug use have a substantial impact on other areas of people's lives. Similarly, factors such as housing, benefits, social networks and use of leisure time, have a significant influence on treatment outcomes and long-term Recovery. Clinical outcomes for people with a dual diagnosis cannot be considered in isolation.

Indeed, people using services often 'measure' their treatment progress in relation to other areas of their lives.

With regard to Recovery and relapse prevention, the outcomes that service users would like to see fell into two distinct, but associated categories. Section 4:1 relates to mental health and drug/alcohol services and Section 4.2 relates to a range of other agencies.

⁵ Perkins Review Executive Summary: *Realising ambitions: Better employment support for people with mental health conditions*, P13

⁶ Cabinet Office (2009) *Work, Recovery and Inclusion*

How mental health and substance misuse services can contribute to Recovery

Outcomes

- There is encouragement and belief in a person's Recovery, for example through running 'feel-good' workshops.
- Goals are forward-looking, progressing towards not using services.
- Continuing support is available as appropriate. It is easy to access services again.
- There is out of hours support, especially at weekends.
- Appropriate aftercare provision is in place. 'Follow-up' community support is low key but integrated – for example, the Friday Group – see box on page 35.
- There is good co-ordination with other agencies.
- Service user involvement is taken seriously and acted upon.

The DREEM (Developing Recovery Enhancing Environments Measure) <http://pb.rcpsych.org/cgi/content/full/31/4/124> is one approach to measure outcomes. It is a user-led structure which enables services to measure their commitment to, and effectiveness in, providing Recovery-based care.

Commissioning Principles

Focus on Recovery

- Services are positive and forward-looking (i.e. the care plan includes a focus on exiting the service when appropriate).
- Recovery and community integration are considered early on in a treatment programme, by drug and alcohol and mental health services including access to Support Time and Recovery workers and other appropriate provision.
- Service users are supported to use self-help tools such as a Wellness Recovery Action Plan.

Aftercare & ongoing care pathways

- There is some level of follow-up support for every discharged person.
- Care pathways do not stop when treatment ends: relevant options including follow-up, ongoing and/or out of hours support and re-entry to services are considered.
- A service can demonstrate commitment to working in partnership and that it has active links with other agencies.

Service user involvement

- Services can demonstrate that service user involvement is taken seriously and acted upon, at all levels of the organisation.

As one service user group said, *'services that involve clients do better.'*

Service user involvement must be properly resourced, organised and supported. Service user participation is vital at all levels of an organisation, but it does not always involve formal meetings and lots of paperwork. The shape and scope of service user involvement can be much wider and could include:

- Being featured in a training DVD for staff
- Writing a life-story, poetry or producing music to help others understand
- Being 'interviewed' during staff training sessions
- Presenting and delivering formal training
- Being a sessional interviewer for an organisation as part of their quality programme
- Participating in service user forums and/or regular audits
- Belonging to a diversity group
- Participating in one-off focus groups.

How other services can contribute to Recovery

Outcomes

Outcomes which contribute to Recovery and help to prevent relapse, as identified by service users include:

- Building supportive relationships and a social network to combat isolation.

- Community involvement
- Stable housing
- Access to training and education
- Opportunities to provide training to workers
- Volunteering and mentoring
- Paid employment.

Commissioning Principles

- Commissioners maximise opportunities to take a 'whole systems' approach – in both funding (joint and pooled budgets) and organisation of service delivery and training.
- There is an ethos and practice of joint/multi-agency working established through collaborative protocols.
- There are clear referral routes to other appropriate agencies.

Conclusion

Dual diagnosis involves the interplay of mental health, drug and/or alcohol use and many other factors. Solutions to these challenges will be many and varied. However, commissioners, providers, practitioners and people using services share a common task: to achieve outcomes which are realistic, effective and relevant. Commissioning plays a critical role in this process and service users have much to contribute.

We hope that this guidance tool will help to foster closer working relationships between all stakeholders, and to sustain progress along the whole treatment journey from initial engagement to long-term Recovery.

What to do next

Providing high-quality user-focused dual diagnosis services requires a strategic approach involving different people. Accompanying this report, you will find a ready-prepared power-point presentation and facilitator's notes, as the basis for a workshop to bring together service users, commissioners, providers and other key stakeholders.

The workshop can be completed in half a day and will help to build on best practice and implement solutions to challenges. The overall aim is to take forward the outcomes and commissioning principles and apply them to your local context.

Find out more

Progress Group

Progress is a consortium of Consultant Nurses in dual diagnosis and substance use who work in partnership with other national experts in dual diagnosis. Its aim is to improve the support and treatment for individuals who have co-existing mental health and alcohol and drug difficulties. Its website provides information for individuals who have a dual diagnosis, their families and carers, and health and social care workers providing support and treatment.

www.dualdiagnosis.co.uk

National Mental Health Development Unit

NMHDU consists of a small central team and a range of programmes funded by both the Department of Health and the NHS to provide national support for implementing mental health policy by advising on national and international best practice to improve mental health and mental health services.

www.nmhdu.org.uk

National Treatment Agency

The National Treatment Agency for Substance Misuse (NTA) is a special health authority within the NHS, established by Government in 2001 to improve the availability, capacity and effectiveness of treatment for drug misuse in England.

www.nta.nhs.uk

Payments

There are a number of places that people can look for guidance about paying people for their involvement in activities, for example the Department of Health's 'Reward and Recognition' guidance (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138523)

Appendix 1

Dual Diagnosis in Context

Dual diagnosis can have a high cost both to the individuals affected and to the wider health and social care communities.

- 80% of people receiving treatment for alcohol misuse experience anxiety and depression.
- Up to half of the people with mental health problems may misuse alcohol or drugs.
- A recent study of prison mental health services suggests that dual diagnosis is the norm rather than the exception.⁷

People with co-existing mental health and substance misuse difficulties also form a significant proportion of those using primary care, housing, social services and criminal justice services. They do not constitute a 'new' client group within treatment systems.

With the renewed emphasis on personalisation, quality, partnership working and cost-efficiency, it makes sense to be better informed about the priorities of people using services. This helps to ensure the most effective use of available resources, both financial and human, to deliver outcomes which are value for money and valued by service users.

Key policy and practice guidance is highlighted in Appendix 2

⁷ Shaw J et al, 2008, *A national evaluation of prison mental health in-reach services*

Dual Diagnosis Good Practice Guide (DH 2002)

This national policy guidance advocates that mental health services should take a lead in providing care for those with more serious mental health and drug/alcohol problems, promoting the approach of 'mainstreaming.' This means encouraging all parts of the care system to work with people with dual diagnosis, in preference to relying on 'specialist teams'.

Models of Care for Treatment of Adult Drug Misusers Update (DH 2006) and Models of Care for Alcohol Misusers (DH 2006)

These frameworks recognise dual diagnosis as a significant issue. The latter emphasises the direct link between mental health problems and alcohol misuse.

NHS Mental Health Contracts

(www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111203)

The perspective of service users is highlighted in the new NHS Mental Health Contracts where:

- Monitoring of care should be focused on outcomes for the individual wherever possible.
- Providers will be expected to carry out service user and carer experience surveys.

Bradley Report (DH 2009)

This review of people with mental health problems or learning disabilities in the criminal justice system concludes that tackling dual diagnosis is vital. It suggests that no approach to diverting offenders with mental health problems from prison and/or the criminal justice system will be effective unless it addresses drug and alcohol misuse.

Quality, Innovation, Productivity and Prevention (QIPP)

(www.dh.gov.uk/en/Healthcare/Highqualitycareforall/Qualityandproductivity/index.htm)

The demand for healthcare from a growing and ageing population, new technology and ever higher patient expectations mean there is increasing pressure on the NHS budget. Mental Health provision will need to demonstrate efficiency savings, whilst improving the quality of patient experience, safety and outcomes.

Dual diagnosis and the criminal justice system

Dual diagnosis is an important issue within the criminal justice and prison services, as a high proportion of prisoners have mental health and drug and/or alcohol difficulties.

Key outcomes put forward by people in contact with the criminal justice system include:

- Person-centred services
- Comprehensive assessments which include mental health and drug and alcohol use
- Easier access to treatment

- Better liaison between services, and more co-ordination between mental health and drug and alcohol services within prisons
- Greater continuity – both in terms of individual key workers and follow-up on release.

Many of these outcomes apply to all settings and have been incorporated throughout this report. These themes are also echoed in the Bradley Report⁸. www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098698.pdf

This calls for greater integration of services and ‘appropriate, flexible care to those dually diagnosed’, rather than using dual diagnosis as criteria for exclusion. It also underlines the vital role of the Care Programme Approach (CPA)⁹. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_083647

Recommendations include:

- Urgent development of improved services for prisoners with a dual diagnosis.
- Joint care planning between mental health services and drug and alcohol services on release.

⁸ *The Bradley Report: Lord Bradley's Review of people with mental health problems or learning disabilities in the criminal justice system. (2009)*

⁹ *Refocusing the Care Programme Approach: Policy & Positive Practice Guidance (DH 2008).*

Appendix 2



