

waiting for change

treatment delays and the
damage to drinkers



Waiting for change: treatment delays and the damage to drinkers

Turning Point is a social care organisation working with individuals and their communities across England and Wales in the areas of drug and alcohol misuse, mental health and learning disability. We have particular expertise in working with people who have complex needs and are facing multiple social challenges.

In 2001/02 Turning Point had contact with 69,000 people with substance misuse (drug/alcohol) problems, and 28,000 became active clients. Alcohol was the primary problem for 24% of those people. Many of our clients face very complex problems – of the 13,200 of our service users who were specifically identified as having complex needs, 23% had a secondary problem with alcohol. In 2001/02, 10% of people that we saw with a primary mental health problem also had alcohol problems.

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Executive summary

Waiting for change presents a comprehensive and disturbing picture of the barriers alcohol dependent drinkers face when trying to access treatment services. It includes accounts from alcohol treatment service users about the difficulties in getting the treatment that they need and portrays the devastating effects these delays can have on them.

Alcohol is a significant problem in the United Kingdom. Over three million, or one in 13, people are dependent on alcohol – at least six times as many as the highest official estimate of people dependent on Class A drugs (Godfrey *et al* 2002).

Waiting for change shows that almost six out of every ten dependent drinkers who have sought help from alcohol services experience significant obstacles in accessing a range of treatments.

Alcohol treatment services play a major role in helping dependent drinkers to control their drinking and to rebuild their lives. However, lengthy waiting times further isolate already vulnerable drinkers, preventing them from accessing vital treatment.

Respondents in this report have revealed that waiting times and delays necessitate that dependent drinkers continue to drink alcohol, forcing many into more problematic, and potentially life-threatening, behaviour.

Dependent drinkers are also discouraged from seeking help in the knowledge that waiting lists are long. Consistently long waiting lists have been shown to erode confidence in service provision, preventing many from seeking treatment and raising further barriers to treatment.

Many dependent drinkers therefore continually experience poor mental and physical health and endure ongoing social problems as a direct consequence of not being able to access appropriate alcohol treatment services.

Waiting for change uncovers the ongoing hardship felt by dependent drinkers and highlights the urgent need to address the shortfalls in alcohol services, delays in accessing treatment and long waiting lists. The report recommends these problems be addressed as a priority in the national Alcohol Strategy.

Summary of findings

- Over half (54%) of people experienced delays in receiving assessment for future alcohol treatment.
- Waiting times for assessment ranged from four weeks to 18 months, with an average wait of nine weeks.
- Nearly six out of ten (59%) of people experienced delays in getting treatment for their alcohol problem.
- Waiting times for detoxification ranged from three weeks to 12 months with an average wait of nine and a half weeks for inpatient or community detoxification.
- Waiting times for residential rehabilitation ranged from one week to six months, with an average wait of just over eight weeks (57 days). Those entering non-residential rehabilitation had to wait even longer, with an average wait of just under four months (117 days).
- Respondents had been drinking from five to 37 years before seeking treatment, with an average drinking history of just under 14 years.
- Half of the respondents (51%) said that they had a mental health problem as well as a dependency on alcohol.

1 Introduction – alcohol dependence in context

1.1 Alcohol consumption in the general population

Over 90% of British adults drink alcohol on an occasional or regular basis (Office for National Statistics, 2000). The Royal College of Physicians has estimated that alcohol use costs the NHS up to £3 billion a year on hospital services – 12% of total NHS expenditure on hospitals (Royal College of Physicians, 2001).

It is estimated that in 1999, drinking in England and Wales costs society almost £2.3 billion, including the cost to industry in terms of sickness absence of almost £1,401 million (Department of Health, 2001).

The British Crime Survey 2001/02 found that 47% of victims of violent incidents described the assailant as being under the influence of alcohol at the time of the assault. This means that in 2001/02 an estimated 1,358,770 violent offences involved assailants thought to be under the influence of alcohol – more than two offences a minute (Flood-Page and Taylor 2003).

There is evidence that many victims of assault are likely to have been drinking prior to the incident. One review suggests that 50-80% of assault victims attending Accident and Emergency (A&E) departments had been drinking prior to the assault (George 2003).

1.2 The prevalence of alcohol dependence and its effects

It is difficult to know precisely how many people are dependent on alcohol. A recent survey estimated that 12% of men and 3% of women in Great Britain are dependent on alcohol (Coulthard *et al* 2002).

Under current population estimates, this would mean that there are approximately 3.8 million people in the England and Wales who are dependent drinkers (3 million men and 800,000 women). In other words, one person in 13 is dependent on alcohol.

A recent report by the Home Office calculated that there are between 280,000 and 500,000 problem Class A drug users in England and Wales (Godfrey *et al* 2002). Therefore, for every problematic Class A drug user, there are at least six dependent alcohol drinkers.

1.2.1 Alcohol dependence and its effects on the individual

People are said to be dependent on alcohol when it affects their physical or mental health, yet are unable to stop drinking. Dependent drinkers have a compulsion to drink and lack control over their levels of drinking. Other features include a narrowing of the drinking repertoire, increased importance of alcohol to the drinker, increased tolerance of alcohol, repeated withdrawal symptoms and drinking to avoid withdrawal symptoms (Royal College of Physicians, 2001).

'I had to get a lot, lot worse before I could start to get better. These delays resulted in huge effects on both physical and mental health.'

(MARK, 23, NOTTINGHAM)

Withdrawal symptoms will include sweating, shakiness, insomnia, nausea, anxiety and intense cravings for alcohol, when people stop drinking for any length of time. At a later stage, alcohol dependency may lead to loss of memory and judgement, paranoia, restlessness, depression and delirium tremens (DTs) if alcohol is withdrawn. If a person stops drinking abruptly and does not have medically supervised medication it can sometimes result in epileptic seizures.

Untreated alcohol dependence results in levels of drinking which substantially increases the risk of dying and diseases such as strokes, cirrhosis of the liver, several forms of cancer and damage to the brain and nervous system. Alcohol misuse is thought to be a major cause in about 3% of all cancers in England (Waller *et al* 2002) – or in over 8,000 new incidents of cancer a year.

1.2.2 Social impact of dependent alcohol use

Alcohol dependency exacts a great toll on individuals and societies. Dependence often causes considerable distress to partners, children or other family members, who may be directly or indirectly exposed to the consequences arising from compulsive alcohol consumption. Alcohol is a factor in up to 45% of cases of domestic violence (Morgan 1998) and it is thought that up to 70% of men who assault their partners are under the influence of alcohol when the assault takes place (Jacobs 1998).

Dependent drinkers are far more likely than other people to have been in trouble with the police involving a court appearance. The Office for National Statistics found that dependent drinkers are eight times more likely than non-dependent drinkers to have appeared in court (Coulthard *et al* 2002).

In 1998/99 there were 78,900 NHS hospital admissions in which mental and behavioural problems due to alcohol were mentioned as a factor (Department of Health, 2001).

1.3 Getting help for alcohol dependence

Many alcohol dependent drinkers may not contact treatment services for years. Typically, people will try to cut down or control their drinking on their own, sometimes on numerous occasions, before seeking help. But such attempts to stop drinking do not succeed for everyone. Commonly, people fail, then experience periods of repeated relapse and a return to dependence and increasingly damaging behaviours. Alcohol related health and social problems will take their toll, leading to heavy and repeated demands on emergency care services.

Heavy drinking patterns and behaviours can seriously damage a person's physical and mental health to the extent that when they finally feel motivated enough to seek help from alcohol services, their condition is often life threatening and they are in desperate need of treatment.

People who are alcohol dependent therefore often need intensive treatment and support in order to recover from their dependency and to rebuild their lives.

1.3.1 The benefits of treatment

Treatment services play a vital role in identifying and tackling a person's dependency on alcohol, reducing the harmful impact of alcohol use and helping people to overcome alcohol-related health and social problems.

It is estimated that two thirds of individuals receiving treatment show some improvement over their pre-treatment condition (Babor 1995). Treatment also reduces the cost to society of alcohol use. It is associated with lowered healthcare costs and is, therefore, a worthwhile and efficient use of financial resources.

Research from the United States shows that for every US \$10,000 invested, treatment saves over US \$30,000 in medical spending for the managed care provider (Holder *et al* 1995). It can also result in reduced criminal activity and criminal justice costs.

More research is needed regarding the benefits of different treatment settings in order to determine the most effective and efficient approach to delivering treatment.

1.3.2 Matching treatment with needs

No one form of treatment will work for everyone. There is no quick or easy option that can be universally applied. Treatment must match the needs of individuals, meet different expectations and preferences and adapt to differing social circumstances.

There is an emerging consensus that a wide range of interventions are needed to treat successfully a range of alcohol problems, whether it is occasional misuse by social drinkers or chronic misuse by individuals who are dependent on alcohol. Treatment packages are most effective when designed to suit the particular assessed needs of an individual client.

People who have severe and established alcohol problems often need more significant and intensive forms of treatment. They need greater support to help resist the pressures or cravings for alcohol, help to manage withdrawal and to develop more effective coping styles and interpersonal behaviours.

To meet people's needs, alcohol treatment services should include a range of interventions such as advice and information, detoxification, individual counselling, group work therapy, structured day programmes and more intensive community based residential rehabilitation. Treatment services should also include relapse prevention programmes and aftercare to allow people to integrate fully back into the community.¹

In addition, many people with alcohol problems also may have mental health problems or other drug problems that need to be addressed. Others may have lost their home or job. It is important therefore for specialist treatment services to be co-ordinated with a range of generic agencies, such as housing and employment services.

¹ A large clinical alcohol treatment trial concluded that the treatment types: a) motivation enhancement therapy, b) 12-step facilitation and c) cognitive behavioural coping skills performed equally well (Project MATCH, 1997).

'You may take the decision to seek help and give up which is the biggest admission you have made in your life but then wait three and half months to actually start the process. In the meantime you have to continue a certain level of your drinking as giving up independently could cause fits and damage to your organs. It is a daily torture and a reminder of the dependency that you are resolved to kick.'

(SUE, 30, LONDON)

'I waited for detox for four months after my assessment. I found that really difficult because you keep struggling on for months and yet there was nothing out there that I could go to. I was told that when there's a place, there's a place, but I was in such desperation. I was nearly dead by the end of those 4 months.'

(JULIA, 37,
MANCHESTER)

1.4 The national shortfall in treatment

There are many effective services providing much needed support and treatment for dependent drinkers across England. But the availability of existing services is far exceeded by society's alcohol problems and the demand for treatment (All Party Parliamentary Group on Alcohol, 2003).

Latest estimates indicate that £95 million per year is spent on alcohol treatment in England on a variety of interventions, though this does not cover the cost of psychiatric in-patient treatment (House of Commons Written Answers, 11 March 2003, Col. 230W). This is compared to £573 million that the Government is committed to spending on drug treatment for the UK for the period 2005/6.

The Department of Health spends 18 times more on funding research into drug treatment than on research into alcohol-harm reduction. For example, in 2002 £1,379,065 was spent on research into drug treatment compared with £73,770 in 2002/03 on research into alcohol (House of Commons Written Answers, 21 January 2003, Col. 275W).

With up to 3 million people dependent on alcohol, many with severe and established drinking patterns, large numbers are being denied help due to a major shortfall in alcohol treatment services. This is of great concern to those with alcohol problems, their family and friends and for society as a whole. The more limited the treatment options, the less likely successful outcomes become.

1.4.1 Levels of service provision

Unlike drug treatment, there are no official figures on the number of people receiving treatment for alcohol misuse. Ascertaining trends in alcohol treatment is therefore difficult.

Some research, however, shows that the number of alcohol treatment services is actually falling. Since 1997 the number of agencies providing alcohol treatment services in England fell from an estimated 517 to around 475 in 2001 (All Party Parliamentary Group on Alcohol, 2003). In comparison the number of drug treatment services has increased by over a third since 1997 (HM Government, 2002).

Alcohol services are also unevenly distributed, patchy and fragmented across the country. The patchwork provision of alcohol services has turned into a 'postcode lottery' of care – with many people unable to get any form of help simply because of where they live.

There are considerable waiting lists in some areas, particularly for structured treatment programmes, such as for in-patient detoxification and residential rehabilitation services. However, the government does not centrally collect information on waiting times for alcohol treatment.

Waiting for change therefore provides a rare insight into the extent and effect of service waiting times.

The extent of the delays and the impact on dependent drinkers was explored with those who responded to our survey.

2 Waiting for change – survey findings

The *Waiting for change* survey carried out quantitative and qualitative research into the experiences of alcohol dependent drinkers in England. The aim was to gain insight into the experiences and views of people who have contacted alcohol treatment services. The findings are based on a questionnaire that was sent to users of Turning Point's alcohol services and three focus group discussions. For more information on methodology, see the Appendix.

2.1 **Confronting the problem – personal barriers to contacting services**

'When I was ready to ask for help and finally admitted I needed it, I was desperate and expected and hoped to receive immediate help. I was ready to put myself in someone else's hands and really felt unable to struggle alone anymore. The four months that I waited for an assessment was one of the most difficult, as I was no longer struggling to pretend that I could cope and didn't have a problem. I was desperate and could not cope. If I had lived alone, I am not sure that I could have survived this time of waiting.' (Suzanne, 40, London)

Waiting for change respondents identified a considerable period between the development of their problem with alcohol and their initial attempt to contact treatment services.

Many respondents took a number of years to confront their difficulties with drinking and to recognise that they needed treatment to address their problems. Some people were drinking for a very long time, over a period of twenty years or more before they even contemplated contacting a service for advice, help or treatment. Respondents had been drinking from five to 37 years before seeking treatment, with an average of just under 14 years.

The survey revealed a number of reasons why people finally decide to take stock of their lives and feel motivated enough to contact services. A decision to seek help and treatment may be forced upon them from a crisis situation or when their lives are 'falling apart' or in 'free fall', such as the break up of close relationship and family home or the loss of a job.

A person may only begin to view their drinking as problematic if it leads to serious or damaging health problems or means having to spend a period in an A&E department or in hospital. Some people may only approach services for help when they are critically ill and feel that they may not live much longer unless they receive appropriate treatment services.

For others, there may be no crisis situation or one off event that prompts someone to contact services. Instead, a desire to seek treatment stems from the recognition of the extent to which alcohol has ruined their lives and the fact that they are no longer in control of their levels of drinking or subsequent behaviour.

'The effect of the delays caused me to drink more, causing bad depression and even contemplating suicide on several occasions. I was anxious all the time and had withdrawal symptoms.'

(IAN, 42, MERSEYSIDE)

Many users feel that there is considerable stigma and shame attached to admitting having an alcohol problem or being labelled an 'alcoholic'. One person summed up the views of many respondents to our survey, *'We're not bad people, we are people who need help. We need to break down so many barriers'*.

The stigma about having an alcohol problem was seen to be an additional disincentive to engage with services. This means that treatment services were often only viewed as a last resort, once the situation was no longer bearable for the individual.

2.2 **Falling at the first hurdle – initial barriers to assessment**

Whatever the cause, there is a cycle of recovery where people will finally contemplate getting information about treatment options. People may seek that information from a number of sources, including alcohol services in the community, their GP, hospital or social services department. It is commonly recognised by those working in the field that, irrespective of the point of entry, people will need that information promptly. Otherwise they will continue to drink and disengage from services.

Turning Point's experience in treating dependent drinkers is that it is vital for people to be assessed quickly to build on a person's motivation, so that they can be referred to and benefit from treatment as soon as possible.

2.2.1 **Getting an assessment**

The survey revealed that many people considered the referral procedures a barrier to contact with treatment services. Over half (54% of respondents) experienced delays in obtaining an assessment of their needs.

Waiting times for an assessment varied from four weeks to as much as 18 months, with an average of nine weeks.

2.2.2 **Accessing information**

To get help, people need to know what is available and where. A lack of readily available information therefore can act as an initial barrier to treatment.

Dependent drinkers need to know how to go about finding help and what alcohol treatment services are available in their area.

Respondents typically found information on services in their area non-existent, hard to find or out-of-date. Many expressed concerns that this not only created real hurdles to finding help but restricted their ability to assess their treatment options.

2.2.3 Primary care skills gap

Some respondents felt that their GP did not have the knowledge or skills to help them address their alcohol-related problems.

Respondents talked of GPs being reluctant to provide specialist help because they felt that they lacked the expertise or were unaware of what services were available locally to support people with alcohol dependency.

Moreover, some people had been to see their GP about their drinking but felt that their alcohol issue had not been taken seriously or that their doctor preferred to diagnose and treat them for depression, rather than provide support or signpost treatment services for their alcohol dependency.

'I saw a GP and she said that there is basically no help at all and she said "well why don't you just stop drinking?" at which phase I was on three litres of vodka a day which is just...I couldn't stop. I was sitting there in tears saying "help me help me" and she really didn't know what to do, so I went away and I carried on and I went to see another GP and she was a bit more understanding. She knew a bit more about it and gave me a number to contact the local alcohol team. They said we'll make the appointment in six weeks time, I said "six? I'll be dead in six weeks. I'm drinking three to four litres of vodka a day. I'm not going to—" "oh that's all we can do, we'll see you in six weeks". The wait was devastating. I lost all faith in the system.'

(Andy, 38, London)

2.2.4 Bridging the service gap

Other dependent drinkers waited a considerable period of time between being referred from their GP to receiving an assessment of their needs from their local community alcohol service or a specialist, such as clinical psychologist or psychiatrist. Many then experienced repeat appointments and further delays before being assessed for treatment.

2.2.5 Losing the will – consequences of perceived failures to assess

Delays and obstacles to assessment have an immediate effect on an individual's perception and trust in the treatment system. Many are left to feel that their attempt to seek help has been compromised. This inevitably causes people to lose confidence, feel demotivated and to fall back outside of the treatment system.

Delays also lead to a variety of personal difficulties and emotional problems. People who are putting their trust in services are left feeling badly let down, depressed and may lose what little hope they had for the future. *Waiting for change* respondents talk of feeling very anxious, frustrated and distressed during the waiting period.

'I had to wait four months just to have my needs assessed. During that time my health deteriorated and I became more depressed and did not think I was being taken seriously.' (John, 47, West Yorkshire)

Crucially, many continue to drink during this time, leading to a further deterioration in health. Lengthy waiting times also reinforced negative feelings of being alone, isolated and unsupported.

'It was frustrating and obviously debilitating as I had to keep drinking until I was assessed' (Frank, 37, Yorkshire)

'I had to wait six months to get a community assessment. It is very discouraging and disheartening. You feel that you have no option but to return to the very substance that you are desperate to address. It prolongs one's ill health and mental state of mind. It is so frustrating.' (Linda, 41, London)

'The main delay was getting professional help and waiting for an appointment which caused me even more stress. I was chronically depressed because I was drinking too much. I felt desperate to talk to someone.' (Gerald, 54, London)

'I carried on drinking through the waiting period which did me no good. I had to manage myself which was de-motivating and discouraged me to try and cut down drinking and I felt that my own problem could not be important – if it was they would have dealt with me sooner.' (Stephen, 54, West Yorkshire)

2.3 **Treading the mill – barriers to accessing treatment**

Waiting for change shows that in addition to delays in getting properly assessed, many dependent drinkers are further discouraged by serious delays in receiving treatment.

Nearly six out of ten respondents (59%) reported delays and difficulties in accessing a range of treatments. The waiting lists for those in greatest need of support were often the longest, with a typical three to four month wait to get help.

Not only can delays destroy the demand for treatment, but delayed access can also reduce overall effectiveness of treatment. Research has shown that people receiving treatment after waiting for 10 weeks improved less in comparison to those who received the same treatment without having to wait for it (Miller 1985).

2.3.1 **Delays getting into detox**

Detoxification from alcohol is the preliminary step for dependent drinkers in the treatment process. It allows people to eliminate physical dependence in a safe manner and to provide support during withdrawal. It gives people an opportunity 'to think straight' and to contemplate treatment. People with very high rates of dependence, a prior history of life endangering withdrawal complications and social instability usually need medication and support in the form of advice and nursing care. They may benefit from a period of detoxification from alcohol in an inpatient setting or specialist outpatient (non-hospital) setting.

Many respondents in our survey waited a considerable period of time for detoxification. This ranged from three weeks to 12 months with an average wait of nine and a half weeks for inpatient or community detoxification. This was attributed to a shortage of beds for inpatient detoxification and poor co-ordination of services. Because of a lack of beds, some people were inappropriately allocated a space in a psychiatric ward even though they did not have a mental illness. Many found that the environment and the lack of structured support were detrimental.

'I waited six months, had a home detox, but relapsed during the programme and when I next tried to access detox the local authorities wouldn't allow it until I had an acute episode and was admitted to a psychiatric ward. It's a question of luck.' (James, 43, Sheffield)

'I had to wait four months to get a place for detox. Having made the decision to get treatment, I became very frustrated and depressed with what seems an unnecessary long wait considering the circumstances.' (John, 55, London)

The failure to receive timely and appropriate detoxification meant that people were less likely to engage with treatment services overall. Faced with delays, some people dropped off the waiting list because their circumstances worsened; they disengaged from services and their health deteriorated considerably. Others tried to detox themselves without medical care, often with serious and harmful consequences.

As a result, it was likely that some of these people would come back at a later stage with far greater medical and social needs.

In spite of their worsening state and increasing need for help, these delays further eroded respondents' motivation to enter treatment.

'There are no beds available for inpatient detoxification. I have been waiting for six months. I worry over my health. I have had previous liver damage and nearly died but I am unable to stop drinking on my own. As tolerance levels goes up whilst you are waiting, detox becomes much, much harder.'
(Jane, 35, South Yorkshire)

2.3.2 Failures in following-up detox

Detoxification is not a treatment for alcohol dependence in itself. It is more appropriately regarded as a process that aims to achieve a safe and humane withdrawal from alcohol (Mattick and Hall 1996). It does, however, provide a unique opportunity to support clients and encourage them to take up rehabilitative services, such as counselling, community-based programmes or residential treatment.

Users in our survey highlighted the critical lack of support after detoxification. Many felt that even when detoxification was finally made available, it was offered in isolation, with no follow-up care.

This meant that the only support being offered was limited to relieving immediate medical needs rather than addressing the underlying alcohol problem through the provision of treatment.

Lengthy waits for treatment following detoxification are said to be demotivating and, once again, risk driving clients away from treatment. Intolerable waiting lists are extremely difficult to deal with for already vulnerable alcohol users in need of help and treatment.

This is a crucial time for these people who are now alcohol free for the first time in months, even years, and want to move on to achieving long-term lifestyle changes.

'The wait for inpatient detoxification is awful. My physical condition deteriorated. My legs, toes and fingers went numb. I could hardly walk. I lost so much weight. My long-term memory was affected. It drove me to the brink of despair. Surely there is a better system that this.'

(MALCOLM, 55,
LONDON)

2.3.3 Rehabilitation, counselling and community-based programmes

Dependent drinkers face serious delays across treatment services. In particular respondents identified problems entering residential care, funded by local authorities and social services. Delays ranged from one week to six months for residential rehabilitation, with an average wait of just over eight weeks (57 days). Those entering non-residential rehabilitation had to wait even longer, with an average of just under four months (117 days).

Yet again, chances to provide critical treatment interventions were missed leading to more heavy drinking and inevitable readmissions to A&E departments.

Long waiting lists also increased the risk of service provision being led by the availability of a service rather than the needs of the individual. Hospital staff informed some users in our survey that treatment would not be available because of a shortage of local treatment services. Others were told to approach alternative community-based services rather than wait for vacancies to arise for residential treatment.

'I waited over four months to get into rehabilitation and in that time I relapsed three times and spent time on a ward in a mental health hospital then waited weeks and weeks from discharge. These delays caused me more problems to my mental health and physical well-being' (Margaret, 57, London).

2.3.4 Concerns over service management

Another serious concern was the inadequate levels of staff co-ordination regarding the assessment, management and treatment of alcohol problems.

Respondents felt that the links between hospitals and non-statutory agencies were poor. Many people were referred to inpatient detoxification without specialist alcohol services first being notified. This resulted in people waiting longer than necessary for a residential placement because of delays in requesting a community care assessment.

Others on a waiting list for a place in a residential setting were left waiting without any support from services. People felt that even a minimal amount of contact with a service during the waiting period would have increased their chances of an individual following up their initial contact. This could involve allocating someone from that service or a counsellor to whom they could have spoken to during the interim period.

2.3.5 Impact of delays

Waiting for change reveals real problems with a system that makes many people wait months before they get the next phase of help. Generally, people on waiting lists for treatment for alcohol are already very ill. Where follow-up treatment is not available or subject to waiting lists there is also a higher probability of relapse.

Waiting times for alcohol treatment acts as an unsurpassable barrier to accessing services. These barriers leave often very ill people feeling isolated, demotivated, even desperate, resulting in further deterioration in their mental and physical states. Invariably, services that fail to treat dependent drinkers on time will have to pick up the pieces at a later date, or will pass them on to other services such as A&E departments or GPs.

It is clear that every day, opportunities to treat alcohol problems are being missed. In many cases, this would be avoidable if detoxification and follow-up treatment can be provided promptly and without delay.

2.4 Alcohol and mental health

Research in the United Kingdom suggests a close association between alcohol dependency and mental health problems. Alcohol dependence is associated with behavioural disorders, clinical depression and increased rates of violence and suicide.

The government inquiry into inequalities in health identified a strong association between suicide and heavy drinking, as well as deliberate self-harm (Acheson 1998).

2.4.1 Mental health problems among respondents

'Experienced medical staff have told me several times that I need to see a psychologist, but the waiting lists are so long and the help to get an appointment isn't offered.'

(Anthony, 28, Wakefield)

Findings from *Waiting for change* echo the significant overlap between alcohol misuse and mental health problems. Many people whose main problem was alcohol dependency also experienced varying degrees of mental health problems.

Just over half of the respondents in our survey (51%) said they had a mental health problem in addition to their alcohol dependency. Problems ranged from depressive disorders, including anxiety, panic attacks, depression and phobic illnesses. A minority indicated that they had a severe mental illness, including schizophrenia.

'The effect of the delays caused me to drink more, causing bad depression and even contemplating suicide on several occasions. I was anxious all the time and had withdrawal symptoms.'

(Dave, 18, Merseyside)

Users in our survey with mental health problems felt that their needs sometimes fell between mental health and alcohol services because of disagreements regarding who should be the lead agency or because both agencies were not involved at the stage when that person was assessed and referred to services.

In some areas, users reported that mental health teams would not offer support for mental health needs until after treatment for alcohol dependency had ended. In other cases, mental health teams were reluctant to offer support services in cases where an individual's mental health problems and the need for treatment only emerged

'Trying to inform people about my mental health concerns did not go as planned because people blamed it all on alcohol misuse. I received no treatment for this from health services.'

(JOHN, 21, CHESTER)

'I was referred to a specialist mental health unit, but they refused to treat me until my drinking problem is under control.'

(SHEILA, 37, KENT)

once treatment for alcohol dependency had started. People thought that this meant that their mental health needs were untreated for many years.

'My GP diagnosed me as being manic-depressive two years prior to me seeking help with my alcohol dependency. I never felt secure with this diagnosis or happy that my dosage was increased to the maximum with little consultation. I never met with a psychologist and continue to take my pills.' (Sandra, 41, London)

2.4.2 Challenges for services

Dependent drinkers with mental health problems provide particular challenges for services. The motivation for drinking, for example, may be different for someone who has a primary alcohol misuse issue as opposed to someone who has a primary mental health issue. It is important that effective access to services and care of both problems is ensured, not least because each problem may exacerbate the other.

A mental health problem adds to a person's difficulties, complicates the support that they need and may mean that a longer period for treatment is necessary. People with mental health problems also tend to relapse more often in comparison to other problem drinkers. Untreated mental health problems may make it harder to address alcohol problems and increase the risk of suicide. Treatment needs to be integrated and community based to be effective.

Dual diagnosis treatment models need to be explored from both alcohol and mental health perspectives, to evaluate the effectiveness of a truly integrated service. *The dual diagnosis good practice guide*, published by the Department of Health, stresses the importance of high quality, patient focused and integrated care for these individuals (Department of Health, 2002).

In recent years, there have been significant initiatives aimed at improving services for people with alcohol and mental health problems. The National Service Framework for Mental Health sets out how all services for people with mental health problems should be planned, monitored and delivered. It emphasises the need to consider the potential role of substance misuse for all individuals with mental health problems and the importance of meeting the needs of people with dual problems through existing mental health and drug and alcohol services.

It is essential that frameworks be applied, guidelines implemented and that services are fully resourced. Responses from those who experience mental health and alcohol problems clearly show that there remains a paucity of services equipped to meet their needs.

Service provision can take a number of forms, such as a dual diagnosis worker, trained in mental health and alcohol dependence, who can liaise with both community and specialist services. There may be a need for an assertive outreach framework for people who find it hard to engage with services and/or do not respond to traditional treatments. Whatever the shape of the service, it is important they are co-ordinated and able to link up with the specialist advice and support available from the voluntary sector. Services working across Primary Care Trusts and Drug Action Teams can benefit from joint commissioning to a pooled budget.

Mental health and alcohol services should adopt a co-ordinated and integrated shared care approach to meeting the mental health needs of people with alcohol dependency.

'With most hospital detoxes, you get dried out and then kicked out. They cost quite a lot of money. They give you a breather from your drinking, but you come out as ignorant about the issues as when you went in.'

(FOCUS GROUP)

3 Importance of relapse prevention and aftercare support

All respondents in the survey highlighted the need for treatment programmes to encompass the provision of services aimed at relapse prevention and aftercare support.

3.1 Preventing relapse

Alcohol dependence, in common with misuse of other substances, is a highly relapsing condition. The main challenge following detoxification and treatment is not only to stabilise or bring a change in drinking behaviour but also to ensure that drinking does not reoccur after treatment has ended.

Following treatment, people often feel vulnerable and additional support from treatment services is needed to prevent a relapse of their condition. Treatment gains from community based or residential treatments are more likely to be maintained when discharged patients have access to and engage with relapse prevention services.

Research has shown that with the exception of self-help groups, individuals are left largely on their own following treatment. Individual or group contact with treatment services tends not to be part of all alcohol programmes. (Ito, Donovan and Hall 1988)

Post-treatment relapse programmes should be standardised into all alcohol services.

3.2 Aftercare support

In order to encourage dependent drinkers to adopt more positive lifestyles, problems stemming from dependent drinking cannot, and should not, be tackled in isolation. Alcohol misuse is often linked to the social context in which a person lives. Many of those who have problems with alcohol also have a range of other problems, including difficulties relating to housing, employment and in some instances, offending behaviour.

Services should facilitate access to housing, employment, education and recreational pursuits for people addressing alcohol problems. There is evidence that treatment outcomes are better when all aspects of the service user's life are addressed. This requires agencies to work together to address an individual's needs and provide ongoing support and social care.

This will ensure that every support to an individual is made available in order to help them rebuild their lives and reintegrate back into the community rather than simply returning an individual to the environment, which first contributed to their alcohol dependency.

4 Conclusion – meeting the needs of dependent drinkers

Waiting for change reveals that many people with alcohol problems face difficulties in finding the right treatment. They regularly experience delays in waiting for an assessment and getting treatment – at the time when they most need it.

Waiting for assessment and treatment for alcohol dependency is potentially life threatening. It forces many to continue their dependent drinking and damages the potential for successful treatment, if it is finally received.

This needs to change. The current situation that leaves people with alcohol problems isolated and marginalised without appropriate treatment services should not be tolerated. Given the urgency of the needs of most alcohol dependent drinkers and the adverse impact that alcohol has on families, this lack of care is unacceptable.

There is not one form of treatment that will work for everyone. But ensuring dependent drinkers understand that they can benefit from treatment and that they play an active part in their own recovery is a much more humane and sensitive approach to treatment.

People want clear, up-to-date information about what is to happen at each stage of the treatment process, and when they will receive it. They want to be supported by an efficient treatment system once they have made their own choices about treatment. They must therefore be given the chance to consider the options for treatment and be able to plan treatment around their needs.

People want to be confident that services will be there when they need them, that agencies are working well together and that arrangements are person centred so that treatment decisions take into account their own circumstances and are based on their medical and social needs. Services must do all they can to minimise feelings of isolation and lapses in appropriate treatment.

Turning Point believes that the ultimate goal should be a waiting time of no more than two weeks for an assessment and that people should have a maximum two-week wait for in-patient detoxification and three weeks for all other forms of treatment.

These proposed targets for waiting times for alcohol treatment services are in line with the targets set for accessing drug treatment services (HM Government, 2002). Where patients wait longer, this should be because of their needs or their personal choice, not because of delays and inadequacies in the system of care that erode and diminish the patient's chances of success.

The government will publish a national Alcohol Strategy in summer 2003 with implementation in 2004. The Strategy will focus on tackling the harm caused by excessive drinking, crime and disorder, harmful impacts for vulnerable groups, health impacts and joining-up government activity.

Turning Point feels that a great deal more needs to be done to ensure that services are more accessible for people with alcohol dependency. Investment in alcohol treatment services must therefore be a priority for government.

5 Recommendations

- There is a need for secure, sustained and new investment in alcohol treatment services. Funding for alcohol treatment should be increased in line with resources currently allocated for drug treatment services. Funding priorities should be to increase the numbers in treatment and availability of places for in-patient detoxification, community-based services, residential based provision and after-care.
- The Alcohol Strategy should include targets to increase the participation of alcohol users in alcohol treatment programmes and increase the proportion of users successfully retained in or completing treatment programmes.
- The provision and accessibility of alcohol services should be consistent throughout England and Wales. The Alcohol Strategy should include targets for reducing waiting times to include: a) a maximum waiting time of two weeks for an assessment of needs b) a maximum waiting time of two weeks from referral to patient detoxification and three weeks from referral to other forms of treatment. The Strategy should also have specific targets to reduce the delays in accessing alcohol treatment in the 88 most deprived estates, as set out in the government's neighbourhood renewal strategy. This needs to be facilitated by joint working between Drug Action Teams, primary care, specialist mental health services, and the specialist substance misuse agencies within the voluntary sector.
- Alcohol services should be included within the remit of all Drug Action Teams to ensure that there is local co-ordination of drug and alcohol services. There should be an expectation to review the particular problems and needs of dependent drinkers and develop a strategy to meet their needs. Drug Action Teams should also develop mechanisms for contact and support while an individual is waiting for assessment or referral to services.
- The National Treatment Agency (NTA) was set up by the government to increase the availability, capacity and effectiveness of treatment for drug misuse in England. Turning Point supports calls for it to be broadened to take account of alcohol treatment. It should monitor alcohol treatment provision to identify good practice, inconsistencies and any gaps in provision. The NTA's models of care that apply to drug treatment should provide specific advice on the commissioning and implementation of alcohol treatment services.
- The remit of National Drug Treatment Monitoring System should extend fully to include alcohol. It should collect information on numbers and characteristics of people presenting for and entering alcohol treatment services, monitor existing provision and consider how best to provide services to meet the needs of alcohol dependent drinkers.
- It is not possible to separate the issues raised by misuse of alcohol and its impact on society from those created by drugs. The delay in the publication of the Alcohol Strategy and the targeting of new resources to drugs causes problems for agencies that work with the consequences of both drugs and alcohol. The Alcohol Strategy will need to be integrated with the updated drug strategy to form one substance misuse strategy.

- The Alcohol Strategy should seek to increase access to appropriate services for people who may have particular difficulties in accessing help, particularly those with multiple or complex needs. This may include people with other substance misuse or mental health problems. The Strategy should also develop ways of promoting the engagement of hard-to-engage groups in services, such as young people, women and people from black and minority ethnic communities.
- New clinical guidelines for GPs in primary care and in hospitals should be developed to give detailed guidance on undertaking assessment, management of dependence and withdrawal and the prevention of relapse and referral to other agencies. This should include a fast track system and improve referral pathways between primary care, hospitals and specialist treatment services.
- The Department of Health should fund more training in alcohol dependency for existing GPs and ensure that training in alcohol misuse is embedded in the undergraduate and post-graduate general practice curriculum.
- Information about the range of treatment services should be readily accessible to people who are alcohol dependent. They should be involved in decisions about treatment and their needs, preferences and social circumstances considered.
- Post-treatment relapse programmes, offering individual or group support and counselling should be standardised into all alcohol programmes.
- There should be greater priority on providing after care services for people when they end treatment. This means combining treatment with other measures such as access to suitable housing, employment and education to help people to rebuild their lives and reintegrate back into the community.
- More research is needed regarding the effectiveness of different forms of treatment and the benefits of different settings for treatment. Research should also examine the correlation between the effectiveness of interventions and the length, frequency and intensity of treatment. There should be additional research into the effectiveness of treatment interventions for young people.

'The delays make you feel a lot worse. It creates a vicious circle that builds up the problem. Being passed from pillar to post feeds into feelings of worthlessness. It makes you feel abandoned and isolated. Some professionals perceive your problems as self-inflicted and many lack compassion and understanding.'

(ARTHUR, 46,
MANCHESTER)

'I started drinking when I was 12, no one told me I had a problem, I kept having detox and going back to my old environment without any support. Detox on its own is a waste of time and a waste of money. There needs to be education about the condition. It's like the blind leading the blind.'

(FOCUS GROUP)

Appendix – methodology

This research report is based on quantitative and qualitative research into the experiences of alcohol dependent drinkers in England. Research was carried out between January and May 2003 across England.

The aim of the research was to gain insight into the experiences and views of people in relation to their experiences of a range of alcohol treatment services. It is based on a questionnaire that was sent to users of Turning Point's alcohol services and three focus group discussions. The groups included people from residential and community based services. In particular, the aim was to listen to people to find out what they thought of treatment services and what would turn their lives around. Comments relate to a range of alcohol treatment services experienced by users, including statutory and non-statutory services.

The questionnaire collected information about the type of treatment service sought and a person's route of referral into treatment. It specifically asked people whether they had experienced delays in receiving assessment or treatment and the effect the delays had on them.

The focus groups provided an open and supported forum for people to talk at openly about their experiences, how delays affected their lives and how they think the situation could be improved for others facing similar problems.

This report contains an analysis of 139 questionnaires. Of the 113 respondents who indicated their gender, 74 were male (53%) and 47 female (34%). The modal age-band of drinkers was 35 to 44 years (30%). Of the 119, who indicated their ethnicity, the majority described themselves as white British (87%) or white other (8%). The names of service users in the report have been changed to protect their anonymity.

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