While we are waiting

Experiences of waiting for and receiving psychological therapies on the NHS

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This report was written by Emily Wooster, on behalf of the We Need to Talk campaign. We would like to thank everyone who took the time to respond to our questionnaire.

The We Need to Talk campaign is a campaign led by five leading mental health organisations to increase investment in and widen access to psychological therapies on the NHS.

www.weneedtotalk.org.uk

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1. Introduction

Waiting times for psychological therapies on the NHS for people with mental health problems have long been acknowledged to be too long. While no reliable figures exist for how long people have to wait for psychological therapies, waiting times of several months are known to be commonplace (MHF, 2006) and in extreme cases waits of up to two years have been recorded. This is in stark contrast to waiting times for hospital operations, which are now tightly measured and limited to 18 weeks in most cases.

The Government has now begun to take action to address this inequality in healthcare provision. The Improving Access to Psychological Therapies (IAPT) programme will, in the next three years, bring 3,600 extra therapists to half of England's primary care trusts (PCTs) with a view to improving provision and reducing how long people wait (DoH, 2008).

This could be a major step forward for people with depression and anxiety. It should see the NHS invest significantly in psychological therapies and if it is sustained it will eventually reduce waiting times across the country. This report sets out why it is vital that the IAPT programme is successful from the perspective of those whose lives may be turned around by it.

While people are stuck on waiting lists, their lives inevitably change. People get despondent with waiting for treatment, their mental health may deteriorate, relationships become problematic and may break down and people have to take time off work or interrupt schooling. We know that not getting treatment on the NHS within an acceptable timeframe is having an enormous impact on people's lives. In this report, we draw on the experiences of people who have experienced mental distress and look at the implications of having to wait for psychological therapy. We also suggest how waiting lists could be reduced.

For mental health organisations, improving access to psychological therapies has always been part of our campaigning work but with this growing interest, five major mental health charities came together to campaign on the issue. We argued that cost benefits are important, the health benefits are also overwhelmingly clear.

Talking to someone works. The National Institute for Health and Clinical Excellence (NICE) recommends a range of psychological therapies for a number of mental health diagnoses, including depression, anxiety and schizophrenia. There is also a system of regulation and training to support therapists and to protect service users. It's expected that from March 2009, the Health Professions Council will regulate applied psychologists, with regulation of other therapists, such as counsellors, to follow. When people need access to psychological therapy, they need it as soon as possible from a suitably skilled and qualified therapist. They do not need to be left on a waiting list for months or years, not knowing when they will get the help and support they need to get better.

2. Waiting times for psychological therapies

The National Institute for Health and Clinical Excellence (NICE) has recommended that a range of psychological treatments be made available on the NHS. There is persuasive evidence of their effectiveness in improving outcomes for a range of common and severe mental health problems. Despite the guidelines, people find psychological therapy difficult to access and the wait to receive it can be months or in some cases, years. A national picture of waiting times for talking therapies is difficult to gauge as primary care trusts do not necessarily have the information available. They do not have to report on it, so they do not collect it.

In a national survey from March 2006, 93 per cent of GPs said they had been forced to prescribe antidepressants instead of talking therapies owing to the unavailability of therapy. The research commissioned by *Pulse* magazine found patchy provision of services across the country. Cognitive behavioural therapy (CBT) was not even offered by a fifth of primary care organisations. Where it was, average waiting times were five months (Hairon, 2006).

Earlier this year, a freedom of information request to 100 primary care trusts, which received 33 responses, found the average time waiting to be seven months. However, for those waiting for psychotherapy and counselling, the wait was much longer – one PCT recorded waits for an assessment of more than three years. (Clegg, 2008).

Last autumn, we asked 75 people how long they waited for psychological therapies on the NHS. While the numbers involved are too small to make statistical analysis possible, the times taken to receive therapy are illustrative of people's experiences across England.

Thirty-two out of 75 respondents (42%) said they were waiting up to three months for an initial assessment but seven people (10%) had waited (or been told they would have to wait) between one and two years.

Of the 69 people who underwent assessment, 30 people (43%) said they were waiting (or had been told they would have to wait) between one and three months from assessment to treatment. However, seven people (10%) had also waited (or been told they would have to wait) between one and two years between assessment and treatment. Two people had to wait one to two years for an assessment and then a further one to two years for treatment.

Two people told us that after the assessment, they decided not to go ahead with the treatment because the waiting list was too long and 16 per cent of people told us they ended up paying privately as a consequence of having to wait for so long.

"The assessment was incredible as I felt that someone finally understood... When I was told that the wait after assessment was two years it felt like a real let down; offering a lifeline with one hand and snatching it away with the other."

"I had made a suicide attempt so they knew that I was in a crisis. I was referred as an urgent case but the therapy didn't start for over 18 months."

It's clear from asking service users and primary care trusts that there is a lottery in psychological therapy provision across the country and without a more rigorous recording of waiting times, this may always be the case, even with extra investment. Meanwhile, acute hospitals and primary care trusts are under extreme pressure to deliver on the 18-week waiting time targets for other treatments.

A good assessment process is, of course, essential in determining who needs therapy when, and what type of therapy is right for that person. But no-one should be left waiting for months or years for psychological therapy, when a need has been identified.

Recommendations

We strongly support the IAPT programme's aspiration that urgent therapy be available within three to 10 days (DoH, 2007a) and we urge PCTs to get as close to this as possible.

We call on the Government to ensure all PCTs record their waiting times and publish these annually.

3. The benefits of psychological therapy

We asked our respondents how they felt psychological therapies had benefited them and, if they had had to wait for treatment, what the consequences had been. The responses to the two questions were striking. The majority of people who had completed a course of therapy explained how therapy had a positive impact on their mental health. Waiting for therapy could sometimes have the reverse effect.

People also spoke about how therapy had benefited others (in terms of relationships and ability to study or participate in the labour market). When people waited for therapy for a long time, not surprisingly, it had consequences for relationships and work. Both 'direct' and 'indirect' benefits or consequences are important. As human beings we need to form relationships and live in a community but we also need to be happy with ourselves and have good mental health.

Direct benefits to the individual

The 'direct' benefits of psychological therapy differed depending on the therapy and the individual need. Some people described how counselling had helped deal with what has happened to them in the past. Others described how cognitive behavioural therapy gave them 'tools' to challenge their behaviours. This often led to a better understanding of their diagnosis or how to use their learning and apply it to their daily life.

"It was good to talk about the experiences that I was going through during that period of my life. It helped me to gain a certain amount of perspective on my situation and taught me methods to deal with my anxiety and panic attacks."

"To get a better understanding why I hear voices and see things, and to understand where they are coming from."

"[Therapy] enabled me to be more positive, address issues from my past, gave me an outlet to express my emotions, made me think about how I react to events and gave me techniques that enable me to cope with negative situations."

While therapy clearly improves people's mental health, our respondents told us that waiting for therapy on the NHS can lead to deterioration in their mental health, often resulting in relationship breakdowns or time off sick.

"My depression continued to worsen, contributing to the breakdown of a relationship and occasionally causing me to miss work."

"While I was waiting (for about three months) my anxiety increased as I felt I was being ignored and sidelined."

Psychological therapies and parenting

Up to one half of adults using mental health services are parents, while an estimated 28 per cent of lone parents experience depression or anxiety (Social Exclusion Unit, 2004). Many respondents told us that therapy had improved their family lives and their relationships. Not receiving therapy, or having to wait for therapy, had the reverse effect.

Mental health problems do not just affect individuals but also families and friends. There is evidence that the children of parents with mental health problems are more likely to experience mental health problems (Green et al, 2005). Providing early support to parents will enable them to support their children and can help to prevent children's longer-term mental health problems developing, as well as reducing the chances of the child going into care.

The National Service Framework for Mental Health highlights that when a parent experiences mental health problems they should be supported in their parenting role (DoH, 1999). Of course most children of parents who experience mental distress do not suffer from abuse or neglect, nor do they develop mental health problems (Hall, 2004). Nevertheless, the prevalence of neglect, educational failure, difficulties with relationships and difficulties with transition into adulthood is higher among children of parents who experience mental distress (Ahern, 2003).

When a mental health professional sees a parent they should enquire about their children to ensure they are receiving the support to meet their needs. This might involve joint working

"I am enjoying my relationship with my daughter."

"It [therapy] enables me to keep functioning. To work, support and enjoy my two foster sons."

"[Waiting for therapy] was a strain on my family who were very worried."

"All my life was affected, especially my family life. My marriage has been affected in a big way… my husband wanted a separation."

between Adult Mental Health Services and Child and Adolescent Mental Health Services. Nor should agencies assume that children can assume caring responsibilities for a parent.

In a study of the needs of mothers with a diagnosis of serious mental illness, all the women acknowledged that medication was important, but many felt that psychological interventions and social support were equally important (Slattery, 2006).

Recommendation:

psychological therapy services need to be sensitive to the needs of parents and to the ages and needs of their children. They should provide flexibility within their service to choose appointment times.

Psychological therapies and children and young people

We know that many young people have mental health problems. Statistics show that one in 10 children and young people aged between five and 16 suffer from a diagnosable mental health problem (ONS, 2004). There is some evidence to suggest that mental health problems have increased over the past 25 years (Collishaw et al, 2004). Mental health problems in adulthood often have their roots in childhood (Kim-Cohen et al, 2003).

Childhood through to adulthood is a key developmental period. If a young person is seriously mentally distressed and made to wait for a considerable period of time for psychological therapies, this can have a huge impact on the child (as well as on friends and family). Children who miss out on schooling owing to mental health problems, or who are excluded from school because of their behaviour, often experience problems in the future; for example, in entering the workforce.

Intervening early is always more effective than dealing with a chronic and enduring problem. Therapies such as counselling can be used at an early stage to help prevent severe problems developing. This might also reduce the need for the young person to take medication, which can have serious side-effects.

Recommendation:

psychological therapy services should be sensitive and accessible to the needs of children and young people. Those providing the services should be experts in children's mental health.

Psychological therapies and work

The vast majority of working age adults with depression and anxiety are in work. Indeed in any one year one worker in six will have depression or anxiety (Sainsbury Centre for Mental Health, 2007). For a significant number, however, being signed off sick with a mental health problem marks the beginning of a journey to losing their job and a life away from the labour market.

People claiming Incapacity Benefit for mental health reasons are likely to be away from the labour market for longer than those with other disabilities (Department for Work and Pensions, 2004). Roughly 40 per cent of people on Incapacity Benefit are there for mental health reasons (Layard, 2006). Lord Layard made the argument that psychological therapies could pay for themselves by reducing the number of people on Incapacity Benefit.

The relationship between prompt access to psychological therapies and getting people back into work (or helping people stay in work) has been a key driver for the Government in establishing IAPT.

In our survey, 12 people commented on the negative affects on their working lives of having to wait for psychological therapy. Although we cannot make an absolute link between receiving therapy promptly and the ability to work or study, there is clearly a relationship between the two.

"After waiting for three months the therapy seemed a little 'after the fact'. Also, by this time I had developed further anxiety symptoms. This impacted on my life to the extent that I withdrew from university for a year."

"I have been forced to take sick leave from work which has left me struggling financially."

"[I'm] currently working part time as I am unable to work full time. It's hard not knowing when or if or how long it will be before I'm even assessed... I feel like my entire life is on hold until I get the treatment that I need."

Clearly prompt access to treatment will have an impact on a person's ability to work.

For those who are in work, or seeking it, the timing of appointments can be difficult, particularly if it involves taking time off. People can be concerned about telling their employers because of the stigma attached to mental illness. They may simply be unable to take time off to attend appointments especially if they have to travel to the appointment or appointment times are scheduled at inconvenient times

Recommendation:

psychological services should be flexible, offering weekend and evening appointments for those who are working during the day.

Psychological therapies and physical health

Psychological therapies are useful for people with a range of long-term physical health conditions, including heart conditions, MS, diabetes and stroke (Dantz, 2003). One of our respondents described how talking therapies had helped with their physical health problems.

For GPs treating people with long-term physical health complaints, it can be very easy to overlook the need for mental health support. For people with mental health problems, meanwhile, GPs have been found to overlook physical health needs and dismiss them as psychosomatic (DRC, 2006).

Recommendation:

GPs should consider the relationship between physical and mental health and offer psychological therapy to those with chronic and long-term physical health conditions, where appropriate.

"Since having multiple sclerosis I cannot cope with what life throws at me. As well as that kind of physical disease my mental state reflects on my physical state. I like being able to walk, control my bladder and being independent. Counselling for me is as essential as food, breathing, water – the lot."

4. The impact of waiting

Our respondents told us about the impact of waiting for psychological therapy. Many of our respondents who were still waiting didn't know how long they would be waiting. Many felt despondent and unsure about where to go for help in the meantime. In addition to postponing the benefits of therapy, long waits can reduce the likelihood that people will attend therapy and cause them to use medication for longer, with further difficulties in withdrawing from medication.

Engagement with therapy

Waiting times affect the ability of a person to engage with the therapy when it is offered. A follow-up study of people who fail to begin counselling or terminate after one session found that 36 per cent of clients cited the long wait as the reason for failing to begin a course of counselling (Manthai, 1995). In another study, the authors found that the waiting time was the most significant factor affecting engagement (Snape et al, 2003).

Even if the waiting list is long, psychological services and GPs could do more to increase 'active waiting'. This could include: informing people that they are on a waiting list and how long they can expect to wait; legitimising returning to the GP during waiting if necessary; and increasing GP knowledge about waiting times for local services. If people cannot wait, an emergency service for immediate help should be offered (Snape et al, 2003).

Primary care trusts could also contact people regularly to enquire how things are and inform them of their current position on the waiting list. One study recommends that telephone reminders should become routine for NHS outpatient clinics. Based on a randomised control trial of respiratory outpatients, they found that those who were telephoned and reminded of their appointments were more likely to attend. Furthermore the cost of one person attending an appointment (as a consequence of the reminder) would pay for 200 telephone calls (Roberts et al, 2007). In psychological therapy services, such reminders could have a number of benefits. They would reduce people's isolation, engage people while they're waiting and reduce the number of 'no shows'.

Recommendations:

PCTs should engage people while they are on the waiting list and tell them how long they can expect to wait.

GPs should have knowledge about waiting times for their local psychological therapy services.

Medication

For many people who experience mental distress, it's not a simple either/or equation of medication or psychological therapy. They may need both, and other interventions too. Medication is by far the most prescribed treatment for mental distress (Mind, 2003). More than 31 million prescriptions for antidepressant drugs were issued in England in 2006 after an almost continuous rise over the last 10 years (BBC, 2008).

Many people are uncomfortable with taking antidepressants. Some people see medication as masking their mental health problems rather than addressing the root cause. Others are unhappy about the negative side-effects of medication. There are high rates of noncompliance with psychiatric medication for these reasons (Reed, 2005).

Some of our respondents who were unable to access prompt therapy expressed a reluctance or unhappiness with taking medication.

"Drugs don't help me and I don't want them."

"I felt I was left to cope on my own as best I could and that my life was on hold. I had to rely on medication which had very unpleasant side-effects and I wanted to get off it."

"I didn't want to take antidepressants so anxiety influenced my whole life."

It can be difficult for the GP to offer alternative solutions to medication if the only alternative is to be on a long waiting list for therapy. If someone expresses the view that medication has not worked for them or they are uncomfortable with taking it, this should be taken into account when resourcing and referring people on to psychological services.

Recommendation:

GPs should listen to patients' needs and wishes when deciding the best course of treatment.

5. Problems with therapy

Respondents to our survey discussed some of the difficulties they encountered once they started to receive psychological therapy. These need to be considered by policymakers and commissioners to ensure that speedier access to therapy is not attained at the expense of quality or choice.

The wrong therapy

Eight of our respondents said that the therapy they received was inappropriate for them and didn't fully match their needs.

"In the groups we looked at causes of anxiety and depression and were reminded of strategies for coping. This was helpful but I still feel I need individual help."

"Sessions are too superficial to sort out any problems."

Cognitive behavioural therapy has the best evidence of effectiveness for any psychological therapy and is likely to be the most widely used treatment in the IAPT programme. In CBT, people work through a structured programme and often have homework. The idea is to modify negative thoughts and improve mood and behaviour.

While the evidence base for CBT is better than other therapies; some have argued that this is because it can be 'tested' more easily according to randomised control trial conditions, which is the most respected form of clinical research in this country (MHF, 2006). Other therapies, which take longer and are less focused on changing behaviour, are harder to evaluate. The evidence base for a range of therapies is, however, expanding and the NHS needs to take into account the full range of treatments that have proven benefits.

As our survey demonstrates, giving people a choice of therapy is important. People have different needs. Some need a structured, practical way of dealing with their distress (such as CBT). Others need to explore the root causes of their distress, and some might want both.

One of our respondents who found themselves in "the wrong therapy" described their experience of being on waiting lists:

"Although I was told the waiting list was 12 months, I actually waited for over 18 months. I got four sessions and was advised that CBT would not be helpful to me. I was reassessed and waited for a further two and a half years before receiving any help."

It may be useful to try a variety of approaches. But if a therapy turns out to be ineffective people can find themselves at the back of another queue. More information should be made available about the different options and how they work before starting therapy. This would help people choose the most suitable therapy for them and could reduce the number who drop out or do not attend appointments.

Recommendations:

PCTs need to make provision for a choice of evidence-based therapies on the NHS

Practices should provide people with clear information on the different therapies available. GPs should be able to talk through different approaches in order to come to a joint decision about which approach would be suitable.

Not enough therapy

Some of our respondents said that they needed more sessions. Clearly resources have an impact, not only on the therapy that's offered (typically CBT can be a shorter number of sessions than other therapies), but also on the duration of the wait and the number of sessions that will be offered.

"[I have] had three sessions but am concerned [about] only having 10."

"They offered me eight sessions. But I felt I needed a lot more."

When it comes to numbers of sessions, different people will clearly require different amounts. NICE recommend that the number of sessions (which typically last an hour) should depend on the diagnosis and its severity (for example, six to eight sessions of CBT for those who are mildly or moderately depressed and 16 to 20 sessions for those who are severely depressed).

A shortfall in staff and budget restrictions may mean that sessions are not long enough on the NHS and some studies indicate that service users are being offered below the recommended number of sessions (Kirsch, 2002). There is evidence, however, to suggest that people benefit from even a single session of therapy (Manthei, 1995). The key is to ensure enough flexibility within the service to accommodate people who only require a small number of sessions as well as those who need much longer treatment.

A report by the Sainsbury Centre for Mental Health reported a need for 11,000 extra psychological therapists in primary care (Boardman & Parsonage, 2007). In a recent paper delivered to a Cabinet Office seminar, Layard (2006) estimated that 10,000 cognitive behavioural therapists are required to provide adequate services for anxiety and depression. Both estimates suggest that the 3,600 new

psychological therapists to be trained in the next three years will make a significant difference to the current shortfall but that further additions will be needed as training capacity grows over the next decade (DoH, 2007b).

The therapeutic relationship

The relationship between therapist and service user is a major contributor to therapeutic outcomes. In some cases it can lead people to terminate the counselling prematurely.

Many of our respondents commented on the nature of the therapeutic relationship. A few people said they felt let down because the therapist changed frequently.

"Over a period of eight months I had three practitioners."

"My therapist left part way though and sessions were never finished."

"...unfortunately the only drawback I feel is I have been let down as the therapy sessions are constantly being cancelled due to training or staff off sick... My therapist has been off sick for many weeks, but I had no sessions until I screamed and shouted."

These quotes highlight the importance of continuity within the therapeutic relationship. While it is difficult to ensure that staff are retained, staff changes should be kept to a minimum.

Many people prefer to see therapists with whom they believe they share common values or beliefs. This could be defined by sexual orientation, culture, ethnicity, religion, for example. These factors can have a significant bearing on the therapeutic relationship.

"My major concern at the moment is, how do I address problems that I have regarding my therapist? While I like her, she holds a very different moral and cultural view than me and I feel like she wants me to identify with what is right in her eyes. I don't feel like I can complain (who to?) as I waited so long – for over a year – to get this therapy."

Recommendation:

commissioners should be looking at the needs of the local population when commissioning psychological services and ensure that services are tailored to local needs.

6. Waiting – where next?

The Government has made a commitment to increase access to psychological therapies on the NHS through increased funds. This injection of new money should mean that waiting times will fall, but only in those PCT areas covered by the IAPT programme. If PCTs had to publish their waiting times, this would help to spread the benefits of IAPT more widely and encourage those not covered by it to invest in psychological therapies more quickly.

From exploring people's experiences of waiting for psychological therapy on the NHS, it is clear that long waits have a huge impact on people's lives. Waiting can contribute to a deterioration in mental health, have an impact on relationships and affect people's ability to work.

Even after starting treatment, people feel that they are not always getting what they need, either in terms of the type of therapy offered or its duration. Should a waiting time measure be applied, outcome measures such as those proposed for IAPT will be an important tool to ensure speed of access does not damage the quality of care that is offered.

The NHS needs to engage people to become true partners in their treatment by enabling them to express preferences for a particular therapeutic approach and if possible, therapist. Services should be providing information leaflets and options for appointment times, especially if work or family commitments mean certain times are problematic. A flexible psychological service should ensure that people are more engaged with the process and that they define whether it has been successful in terms of improving their health and enabling them to get on with their lives.

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