

Right treatment, right time



Rethink  
Mental  
Illness.

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## Foreword

Rethink Mental Illness was first established a generation ago by parents who were worried about their children with severe mental illnesses, such as schizophrenia.

The care they needed just wasn't available. Since then, Rethink Mental Illness has grown into a charity that delivers services across England, runs groups around the country for people severely affected by mental illness and campaigns for change.

We have come a long way since then. Developments like the early intervention in psychosis services and the availability of talking therapies such as cognitive behavioural therapy through the NHS are huge steps forward. Yet, no-one doubts that much more needs doing. That's why the Prime Minister has made a bold commitment to 'parity of esteem' for both physical and mental health - a commitment which has been taken up by the opposition as well. We have the chance, in this generation, to make life better for people severely affected by mental illness.

This report puts forward the voices of over 1,600 people who have used NHS mental health services, and shows a system under huge pressure. It follows the recent report of the All-Party Parliamentary Group on Mental Health in showing the urgent need for resources in the core mental health services such as community mental health teams and other secondary care services.

We publish these voices ahead of the new long-term plan for the NHS. There are truly encouraging signs in the new long-term plan indicating that severe mental illness will get attention and resources. Building on the progress of the Five Year Forward View for Mental Health, we live in hope that we can one day see the end of people saying: "These answers were on behalf of my husband who sadly took his own life six weeks ago. There was inadequate support and too long a wait for therapy."

We will continue to report on the progress to parity of esteem for people living with mental illnesses. Following the long-term plan, we will work to establish a realistic target date and a measure progress towards it each year - and listen to the voices of those affected. We will do this until everyone has access to the right treatment, at the right time.



**Brian Dow**  
Deputy Chief Executive of  
Rethink Mental Illness

We are a group of over 150 individuals who rely on mental health services, for ourselves and the people we care for. We are some of those who Rethink Mental Illness surveyed during summer 2018 to capture our experiences of mental health services. That evidence forms the basis of this report.

Although awareness of mental health and public perceptions of mental illness have come a long way over the last decade, this report echoes what we know about how far mental health services still have to go to ensure that people receive the right treatment at the right time.

As people who use mental health services, we know how devastating it can be to wait over six months for treatment to begin, with your illness worsening in the meantime. Far too many of us have struggled to access treatment at all, after being told we are "too ill" to access IAPT services yet "not ill enough" for specialist support. We know the fear of having to reach crisis point

before we are eligible to access services

And as carers, we have felt the powerlessness of doing everything we can to get help for someone who desperately needs it, only to realise that it's just not possible.

This survey of over 1,600 people shows that the extreme challenges we have experienced as individuals and families are part of a bigger problem. The findings speak for themselves: people are waiting over three months for an assessment alone and over six

months for treatment to begin.

### **This cannot go on.**

It is an injustice that people who are the most unwell are waiting the longest and frequently receiving poor quality care and treatment.

Fundamentally, core mental health services, such as community mental health teams cannot cope with demand, leaving many people with mental health problems to fall through the gaps.

We welcome the Prime Minister's firm commitments on mental

health and the new funding plan, due to be published soon. The recent budget made new commitments on crisis care and promised better services for young people, but there is much further to go.

We ask those in power to listen to our experiences and to act. It is not too much to ask that everyone affected by mental illness should get the right treatment, at the right time.

### **Co-signed by the following 150 people with lived experience**

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## Executive summary

For the first time, this report sets out a clear picture of the significant gap in access to health services for people severely affected by mental illness.

A survey conducted by Rethink Mental Illness of over 1,600 people on their experiences of care and treatment shows that people severely affected by mental illness are often waiting the longest for treatment and then receiving inadequate care.

**“My problems were not taken seriously and I ended up as an inpatient last year, which would have been completely avoidable with appropriate community support. I often feel completely alone with my illness, despite the fact that on paper it looks like I have support because I am under the care of the community mental health team. I thought that I was going to be dead before I got to the top of the waiting list.”**  
**Service user**

Behind each of these numbers is a real person whose life and family is being devastated. Due to a lack of quality services, more people are likely to reach crisis point and lives are unacceptably being put at risk.

With the right care, people who are severely affected by mental illness can live long and fulfilling lives. We need to see the government and NHS England, alongside local health and social care decision makers, prioritise funding for timely and high-quality mental health support. Support which is close to home and put in place as soon as a person first asks for help.

### Key findings:

#### 14 weeks



Average wait time for an assessment

On average people are waiting 14 weeks for an assessment alone, with one in 10 (9.4%) waiting six months. One in twenty (4%) said they had waited a year or more. These are individuals living with complex and severe mental illnesses such as schizophrenia, bipolar disorder, personality disorder and eating disorders facing extreme distress which, in-turn, is likely to exacerbate their mental illness.

#### More than half



Not receiving treatment in adequate time

More than half of people surveyed (56%) believed they are not receiving treatment in adequate time, with one in six people (16%) waiting six months or more to receive treatment. On average people are waiting 19 weeks.

#### One in three



Asked for a service that was unavailable

One in three people (30%) asked for a service that they were told was unavailable. Nearly 200 people named these services, many of which are core, evidence-based services, including access to a psychologist, family therapy or dialectical behavioural therapy.

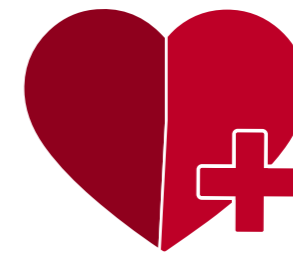
#### Over a quarter



Not referred by GP to an appropriate service

Over a quarter (28%) of people felt they were not referred by their GP to an appropriate service to support their mental health.

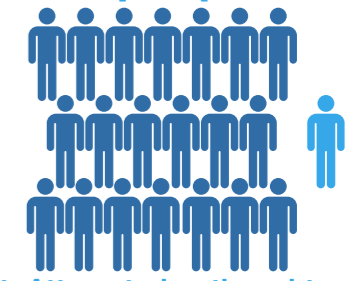
#### Just over half



Felt they receive support for a sufficient and appropriate time

Where people were able to access a secondary care practitioner, for example a psychiatrist, care coordinator, psychiatric nurse or occupational therapist, just over half (51%) felt that they received this support for a sufficient and appropriate time.

#### 20+ people



Attempted or thought about suicide due to lack of services

Over 450 people told us about their experience of waiting for extremely long periods to receive support and the poor quality of services they endured. At least 20 people talked about having attempted or thought about suicide due to lack of services.

**“These answers were on behalf of my husband, who sadly took his own life six weeks ago. There was inadequate support and too long a wait for crucial therapy. He was originally under a home treatment team after a suicide attempt, then transferred to the mental health team after a few weeks. The level of care and support under this service was appalling, despite my husband constantly expressing his suicidal thoughts. I truly believe that, if he had received talking therapy sooner, he would still be here.”** Carer

## Progress to parity?

It is well documented that there have been welcome improvements for people living with poor mental health in recent years.

Awareness campaigns including Time to Change, have led to improved attitudes to stigma for people facing anxiety and depression. The Five Year Forward View, which set out the NHS' plans for improving and expanding mental health care between 2014-2019, has taken steps to address long-standing, unacceptable inequalities between accessing services for mental and physical health. In particular, there has been significant investment and improvements in the improving access to psychological therapies (IAPT) programme, early intervention in psychosis (EIP) services and perinatal services.

However, in most cases, as is set out in this report, those who are most ill, including people living with psychoses, schizophrenia, bipolar disorder and personality disorder, who rely on secondary, community care under a mental health trust, are still not receiving the care they need.

Gaps in these services have a knock-on impact effect on wider services, for example people transitioning from child and adolescent mental health services to adult services facing a cliff edge, or not enough community support for people ready to leave hospital leading to expensive delayed discharges and out-of-area placements.

### What is parity of esteem?

The Fair funding for mental health: putting parity into practice report (2018) from the Institute for Public Policy Research (IPPR), defines parity as 'people living with a mental health condition must have an equal chance of a long and fulfilling life as those with a physical health condition'.

There is general consensus, through reports published within the last few months from the Care Quality Commission<sup>1</sup>, the All-Party Parliamentary Group for Mental Health<sup>2</sup> and the Institute for Public Policy Research (IPPR)<sup>3</sup>, that while there have been steps to parity of esteem between physical and mental health services, there is a significant way to go – predominantly for those most severely affected by mental illness.

### Mark Champion

Service Manager for our early intervention in psychosis services – sees the benefits of early intervention:

**“If we can intervene early and treat young people with dignity and respect, then it increases the chances of them being able to maintain control over their lives and continue along a path they choose. However, if this support is to cease as a young person reaches adulthood, then the hard work up to that point is almost redundant.”**

## The policy context: reasons for hope

There have been welcome, ambitious commitments from the Prime Minister, about the need to “tackle the burning injustice of mental illness” to achieve parity of esteem.

Most recently in October 2018, The Prime Minister stated that “record investment in the NHS will mean record investment in mental health... For the first time ever, the NHS will work towards standards for accessing mental health services that are just as ambitious as those for physical health.”<sup>4</sup> This is a position which has taken from the opposition, with shadow Secretary of State for Health and Social Care Jon Ashworth MP stating that “we need a major change, not just in people’s attitudes, but in the focus delivered by ministers too...delivering top-quality mental health services will be a top priority”.<sup>5</sup>

Similar sentiments have been repeated by Simon Stevens, Chief Executive of NHS England, who said core services for those with long-term and severe mental health needs “do not get the resources they need.”<sup>6</sup>

In summer 2018, the government announced a budget increase for the NHS of 3.4% every year for the next five years. NHS England is now drafting a long-



term plan, which will set out how this funding will be allocated across healthcare. With mental health marked out as a priority ‘workstream’, there has never been a greater opportunity to deliver on the commitments that have been made for mental health.

It is vital that much-needed extra funding is given to core community services for people severely affected by mental illness which can underpin the whole mental health system.

However, the NHS long-term plan is only part of the picture. With the planned government spending review in 2019 and the upcoming green paper on social care, it is essential to address wider funding for prevention and social care services to enable services to take early action to prevent mental health problems, support people to live independently and save lives. Without this, any extra funding for the NHS is undermined.

1. Care Quality Commission, State of care report, 2018.

2. All-Party Parliamentary Group for Mental Health (APPGMH), Progress of the Five Year Forward View for Mental Health: On the road to parity, 2018.

3. IPPR, 2018. Fair funding for mental health: putting parity into practice. [Online] Available from: [https://www.ippr.org/files/2018-10/1540372212\\_fair-funding-for-mental-health-october18.pdf](https://www.ippr.org/files/2018-10/1540372212_fair-funding-for-mental-health-october18.pdf).

4. May, T. 2018. World Mental Health Day reception speech. [Online] 10 October, Downing Street. Available from: <https://www.gov.uk/government/speeches/pms-words-at-world-mental-health-day-reception-10-october-2018>.

5. Ashworth, J. 2018. There still isn't parity of esteem between mental and physical health. The Labour List. [Online] Available from: <https://labourlist.org/2018/07/jon-ashworth-there-still-isnt-parity-of-esteem-between-physical-and-mental-health>.

6. Thomas, R. 2018. Mental Health Matters: Mind the gaps. [Online] 22 October 2018. Available from: <https://www.hsj.co.uk/policy-and-regulation/health-to-become-accountable-to-nhs-improvement/7023640.article>.

## The problem: The people who are the most ill are waiting the longest for treatment

Rethink Mental Illness surveyed over 1,600 people and found evidence that those who are most ill are not receiving the care they need.

### Gaps in how mental health services are provided

Over a quarter (28%) of people taking part in our survey felt they were not referred to an appropriate mental health service by their GP. The All-Party Parliamentary Group for Mental Health report Progress of the Five Year Forward View for Mental Health: On the road to parity (2018) highlighted the case of someone with complex psychosis whose GP told them that if they wanted to access psychological therapy quickly, they should lie to IAPT staff – a service for people with common mental health conditions – to avoid being rejected from the service and thereby preventing them from receiving support.

We also know that some people aren't referred at all due to gaps in service provision. Nearly a third of people (30%) asked for a service that they were told was unavailable. Nearly 200 people named services, many of which are core National Institute for Health and Care Excellence (NICE) approved treatments that people should expect the NHS to provide to meet their needs. These services included access to a psychologist, family therapy or dialectical behavioural therapy. Even talking therapies and early intervention in psychosis services were mentioned – cornerstone services of the Five Year Forward View.



**“I’ve been in recovery since 2013 - I’m now tired and suicidal. I want counselling, someone to talk to without judgement, but I was told that counsellors don’t like to take on people with my diagnosis (borderline personality disorder). I’m struggling with rejection and loneliness as it is... this in itself makes me more suicidal and dead inside.” Service user**

Many people also spoke about how their applications for support such as art therapy and exercise prescriptions were rejected. These ‘social prescriptions’, where health professionals can refer patients to non-clinical services, increasingly demonstrate evidence of positive outcomes for patients, as well as cost-savings for the NHS.<sup>7</sup> The benefits of social prescribing have been recognised by the government, with the Secretary of State for Health and Social Care pledging a further £4.5m. This funding is welcome, however it must translate into enabling people to access social prescribing services at the right time.

### What sort of treatments should people with severe and complex mental illnesses be receiving?

When someone is diagnosed with a complex or severe mental illness they are usually referred for assessment and have access to a community mental health team (CMHT) based in secondary care under a mental health trust – 90% of respondents to our survey who received support from secondary care were supported by a CMHT. From here, people should be able to access evidence-based therapies based on their diagnosis and/or needs. These can include, but are not limited, to:

- Cognitive behavioural therapy for psychosis, bipolar disorder or eating disorders.
- Dialectical behavioural therapy for borderline personality disorder
- Family therapy
- Cognitive analytical therapy for borderline personality and eating disorders
- Psychodynamic therapy
- Psychotherapy
- Group therapy

Findings from our survey add to the wider picture developed from the Adult Psychiatric Morbidity Survey (2016), which found that unmet treatment requests were about seven times more likely among people with a psychotic disorder than in the rest of the population (12.2% of people with psychotic disorders, compared with 1.8% of those without).<sup>8</sup> The National Clinical Audit of Psychosis (2018) report found that only 26% of patients with psychosis had been offered a treatment of cognitive behavioural therapy for psychosis and only 12% of patients in touch with their families were offered a family intervention<sup>9</sup>, despite these being recommended by NICE.

### Waiting times for treatment

Half of people surveyed (56%) feel they are not receiving treatment in adequate time.

The average time people are waiting to be assessed, with no support in the meantime, is 14 weeks. Almost one in 10 people (9.4%) are waiting six months or more. It is unacceptable for people experiencing the effects of serious mental illnesses such as paranoia, hallucinations and suicidal thoughts to wait this long without help.



### Laura Peters

Advice Service Manager, who oversees Rethink Mental Illness’ advice service said:

**“Our advice service is overwhelmed by phone calls from people living with complex, severe mental illness who are struggling to access crucial NHS services like dialectical behavioural therapy for people with borderline personality disorder. We have to do what we can to signpost them to what help there is out there, such as a Rethink Mental Illness peer support group, but fundamentally we need to see a significant increase in NHS service provision.”**

7. The King’s Fund. 2017. What is Social Prescribing? [Online] 2 February. Available from: <https://www.kingsfund.org.uk/publications/social-prescribing>.

8. McManus S, Bebbington P, Jenkins R, Brugha T. 2016. Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. [Online] Available from: [https://files.digital.nhs.uk/pdf/q/3/mental\\_health\\_and\\_wellbeing\\_in\\_england\\_full\\_report.pdf](https://files.digital.nhs.uk/pdf/q/3/mental_health_and_wellbeing_in_england_full_report.pdf).

9. Royal College of Psychiatrists. 2018. National Clinical Audit of Psychosis. [Online] Available from: <https://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/nationalauditofpsychosis/coreaudittoolsandreports.aspx>.

“There always felt as if there was never enough time for me. Everything was on a deadline and they didn’t hide the fact they were under pressure to discharge people. I was left for months at a time with no contact from my community psychiatric nurse. Following a suicide attempt, I did not hear from them for a month (despite me making many phone calls). The therapy I was then offered I was told from the beginning it was limited to 12 weeks, and if I was still struggling I wouldn’t be offered anymore. There were no specialist therapies available such as dialectical behavioural therapy.”  
**Service user**



The average time people are waiting to then receive therapy is 19 weeks.<sup>10</sup> One in six people (16%) are waiting six months or more. These people are likely to be sitting in a CMHT being monitored but without treatment.

#### Length of treatment

Where people were able to access a secondary care practitioner, for example a psychiatrist, care coordinator, psychiatric nurse or occupational therapist, half of the people surveyed (51%) did not receive support in a timely manner.

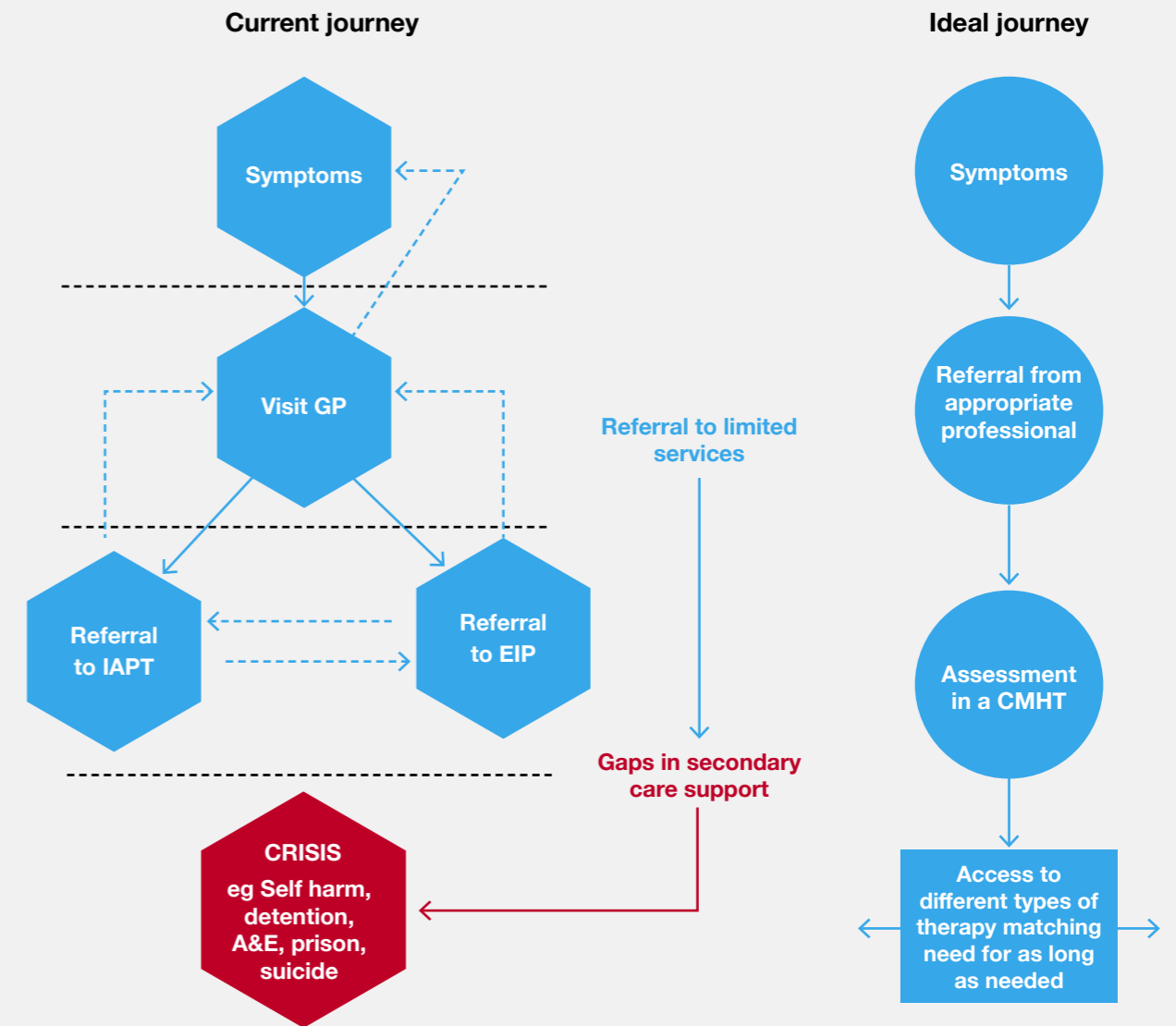
We frequently hear from people about the huge benefits of early intervention in psychosis services (EIP). EIP has received significant focus and investment since the Five Year Forward View, and is a NICE-approved package of treatment for people experiencing their first episode of psychosis.

Within the service, people receive access to psychological therapy and medication, physical health care and support, family interventions and wider support for well-being, education and employment. However, treatment in this service is limited to a maximum of three years – even if you’re still unwell. Many people are referred to community teams as soon as the three years are up and face the cliff edge of lack of support.

#### Real versus ideal service provision

There is a stark contrast between the services available for mental health care and physical health secondary care services, such as those for people living with cancer. In physical health services there are clear waiting time standards and pathways so people know what services they can expect and when, choice about which service

### People’s current journey through mental health services versus what the ideal experience should be



and treatment to receive. Their secondary care will undoubtedly last for as long as is needed – quite rightly, as it would be unacceptable for people with physical illnesses to be told they can only receive treatment for a limited period of time even if they had not recovered – however this is not always the case for many people living with severe mental illnesses.

10. The ‘mean’ average was calculated by adding up the amount of weeks that respondents said they had waited and then dividing by the total number of respondents.

## How is this impacting people?

Rethink Mental Illness hears from people through our support line and services every day about how lives are being devastated due to a lack of secondary care community services.

If people living with complex, severe mental illnesses are not able to access the right care when they need it, they are in limbo in CMHTs being monitored but not receiving treatment. In addition, insufficient contact with busy health professionals means their physical health is impacted due to lack of support to stop smoking, or being given little or no information about the physical side effects of their medication. This results in one of the most shocking inequalities of our age – that those with a severe mental illness are more likely to die 15-20 years earlier than the general population.<sup>11</sup>

In the worst cases, people are reaching a point where they could become a risk to themselves through self-harm, attempted suicide, or even a risk to others. Only a quarter of people surveyed (27%) received a timely and compassionate response from a trained professional during a mental health emergency. This is leading to an inappropriate intervention from A&E or the police, followed by detention under the Mental Health Act.

It is a devastating reality that in the very worst cases people will take their own lives. At least 20 people told us they had attempted to take their own life or had suicidal thoughts, due to lack of mental health services.

The impact of a lack of services on families, friends and carers is very evident. We hear all too often through our own services and support groups from carers who are struggling to cope with supporting their loved one to access the treatment they desperately need. Our survey showed how little support there is for carers to help them look after themselves, as well as their loved one.

Only one in four carers (23%) felt they were well-informed and respected as a partner in care and only one in four people (24%) received a carer's assessment. One carer heartbreakingly described their current position as "desperate, alone, hopeless" another simply wrote "I'm all alone".



### Eileen Murphy

Head of Involvement, who oversees Rethink Mental Illness' peer support groups said:

**“Caring for someone with a mental illness can take its toll emotionally and practically. Due to squeezed public finances there are too few services, available to carers to address their own practical and emotional needs. Rethink Mental Illness began setting up peer support groups in 1970s. We now have 52 groups for carers where they get to meet and support one another on a regular basis. These groups are vital to help ensure that carers of people severely affected by mental illness get the recognition and help they deserve.”**

The impact of the lack of mental health services on a person severely affected by mental illness:



**“I was at a point where I felt that it was a choice between something changing and me killing myself. Yet the CMHT chose to discharge me without offering any treatment because I was ‘not ready for change’.”**  
Service user

**“I was told my own mental health had to deteriorate before social care would get involved.”**  
Carer

11. Royal College of Psychiatrists. 2013. Whole-person care – from rhetoric to reality: Achieving parity between mental and physical health. [Online] Occasional paper OP88. Available from: <https://www.rcpsych.ac.uk/files/pdfversion/OP88xx.pdf>.



## Impact on the NHS and other public services

A report by the All-Party Parliamentary Group on Mental Health<sup>12</sup> highlights how recent investment in crucial but specialist services such as IAPT, EIP and perinatal care have received funding, resources and workforce but core services have not.



While the Five Year Forward View has taken steps towards parity of esteem, we also need core services to be up to scratch to prevent people from falling through the gaps.

Severe mental illnesses are long-term, potentially lifelong, conditions. It is insufficient to continue to look at services in isolation, whether it's specialist services such as EIP or a children and young people's service. When a person has completed three years in EIP, or reaches their 18th birthday, the progress they have made can be undone if there is no community support to continue monitoring their treatment.

Without this ongoing support, people can experience a mental health crisis and suddenly need expensive inpatient beds or beds in secure care hospitals, having an immediate impact on NHS finances. The IPPR's recent

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**“Due to delays in my referral to a third mental health provider, my condition deteriorated to the point I was hospitalised for two months.”**  
**Service user**

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report<sup>13</sup> demonstrated that if NHS England invests in services across primary and secondary community care, it could result in a reduction of inpatient admissions and detentions under the Mental Health Act - a key ambition for the current government and an aspiration more generally for a modern society.

In addition, the lifelong implications of being hospitalised or detained can significantly impact an individual's life chances with regards to housing, training and employment, as well as an increased likelihood of them being a victim of crime.<sup>14</sup> The annual cost of severe mental illness to the NHS and social care is estimated to be £36,000 per patient (at 2011 prices), a figure that excludes the costs linked to caring and unemployment.<sup>15</sup>

Of course, there is also an urgent need to look at the wider finances of local authorities and their funding for prevention and social care support. Any investment and improvements in secondary care community services can be significantly undermined if funding for supported housing, social workers, employment support, carers services and other crucial support continues to be eroded.<sup>16</sup> For example, our survey found that three quarters of people said they needed appropriate supported housing, yet less than half of people received it.



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### Mark Yates

Director of Operations who oversees Rethink Mental Illness' services said:

**“We run a range of services funded by local authorities including supported housing and advocacy. In recent years, we've seen real pressure on local authorities and their squeezed budgets. We're therefore being creative in finding other ways to provide vital support to people. For example, we're piloting a navigator post in Sheffield to help identify people's holistic needs and get them the right help at the right time, whether it's support to fill out benefits forms, or helping them access the treatment they need.”**

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12. All-Party Parliamentary Group for Mental Health (APPGMH). 2018. Progress of the Five Year Forward View for Mental Health: On the road to parity. [Online] Available from: <https://www.rethink.org/media/3563402/on-the-road-to-parity-final-report.pdf>.

13. IPPR. 2018. Fair funding for mental health: putting parity into practice. [Online] Available from: [https://www.ippr.org/files/2018-10/1540372212\\_fair-funding-for-mental-health-october18.pdf](https://www.ippr.org/files/2018-10/1540372212_fair-funding-for-mental-health-october18.pdf).

14. Young, N. 2018. How nurses can improve care for people with severe mental illness. Nursing Times [Online]; 114: 9, 34-36. Available from: <https://www.nursingtimes.net/roles/mental-health-nurses/how-nurses-can-improve-care-for-people-with-severe-mental-illness/7025579.article>.

15. Schizophrenia Commission. 2012. The abandoned illness. [Online] Available from: [https://www.rethink.org/media/514093/TSC\\_main\\_report\\_14\\_nov.pdf](https://www.rethink.org/media/514093/TSC_main_report_14_nov.pdf).

16. Campbell, D. 2018. Social care cuts to continue in spite of £1bn boost. The Guardian [Online] 27 June. Available from: <https://www.theguardian.com/society/2017/jun/28/social-care-cuts-to-continue-in-spite-of-1bn-boost-english-councils-say>.

## Why are services insufficient?

There have been welcome commitments from the government and NHS England about the need to improve mental health services.

So why is this not translating into improving enough people's experiences of the support they receive when they are unwell? Rethink Mental Illness believes this is due to the following reasons:

- No clear care pathways with waiting time standards – the Five Year Forward View recommended that pathways with clear access standards and waiting times be set out for severe mental illness such as bipolar disorder, personality disorder and eating disorders – including those with a dual diagnosis. These are yet to be developed, but without them how can people know what care to expect and when?
- Funding for services – there is simply not enough funding, as highlighted by the IPPR report, and where there is funding, it is focussed on specific services.
- An insufficient workforce – Health Education England's workforce strategy set out the need for 19,000 more mental health professionals and yet there has currently only been an increase of 915 in one year compared to March 2017.<sup>17</sup>

Of the workforce we do have, we need to use them better, for example the All-Party Parliamentary Group for Mental Health set out the need to look at an improved career pathway for the peer support workforce.<sup>18</sup>

- There is insufficient data to hold commissioners and providers to account – NHS England's dashboard is welcome, but where there is high-quality data, it predominantly focuses on priority specialist areas such as IAPT and EIP waiting times.
- Local commissioners do not involve people with lived experience in their decisions sufficiently – Rethink Mental Illness' report, Progress through partnerships (2017) found that only 1% of Clinical Commissioning Groups (CCGs) co-produce their services. Decisions about complex care need to involve the people using them.

**“I have battled for mental health help for my very disturbed 21-year-old son and basically have got nowhere. I have taken him to hospital in severe distress as he can't see any point in living the way he does, in a fearful and anxious state, happy one minute and suicidal the next. He doesn't wash or eat and I fear the phone ringing telling me he is dead. I work 80 hours, seven days a week to pay for somewhere for him to live... as he was homeless and could not get help. Finally he gets an appointment for the community team and all they offer him is to look up a leaflet on the internet... I was beside myself.”**  
Carer

## The solution: our recommendations

The NHS long-term plan is a once-in-a-generation opportunity to now get this right. Rethink Mental Illness is calling for:

1. NHS England to develop clear pathways for people with severe mental illnesses including:

- Access standards, for example everyone with psychosis should receive NICE-approved treatment.
- Waiting times, for example everyone with psychosis should receive treatment within two weeks.
- No time limit on care – people should receive treatment for as long as is necessary.
- Expectations on choices about what treatment to receive, including therapies and social prescriptions.

2. A concerted approach from the Department of Health and Social Care, NHS England and Health Education England to develop and implement a strategic workforce programme with clear leadership and tangible, measurable deliverables that address the supply and skill mix of the workforce.

3. A funded cross-government mental health strategy to identify and fund improvements to public health and social care services, including supported housing and carers services frameworks by April 2020.

4. NHS England to increase funding for mental health services by at least 5% over the next five years and 5.5% for the following five years, as set out in the IPPR's recent report.

5. All arms-length bodies, commissioners and providers to embed co-production principles in the design and monitoring delivery of services with people with lived experience. This will require a culture change with leadership from the Minister along with the introduction of incentives and monitoring in assurance frameworks by April 2020.

6. NHS England to work with NHS Improvement and NHS Digital to develop the dashboard further to include operational performance data for people treated in secondary, community care under a mental health trust; long-term outcome data and service user and carer experience.

It is only if these recommendations are put into practice that we will see people severely affected by mental illness receiving the care and support they need to have an equal chance of a life as long and fulfilling as the lives of those with physical health conditions.

17. The government gave details regarding how many of the additional 19,000 mental health staff to be recruited by 2020 were employed by July 2018 (HC Deb 13 Sept 2018 171694 W).

18. All-Party Parliamentary Group for Mental Health (APPGMH). 2018. Progress of the Five Year Forward View for Mental Health: On the road to parity. [Online] Available from: <https://www.rethink.org/media/3563402/on-the-road-to-parity-final-report.pdf>.

## Methodology

The statistics in this report are based on a survey of 1,602 people which ran during August and September 2018.

There were 41 questions in the survey and it was promoted on social media and through our e-campaign mailing list.

The survey asked about people's experiences of primary care, secondary inpatient and community care, crisis care, carers services, as well as asking about demographics. We asked for experiences of services in the last two years, reflecting the fact that we have seen investment and improvement of certain services following the Five Year Forward View.

We asked people how long they waited to receive an assessment and treatment for their mental health condition. We then compared this waiting time data with NHS England data for people receiving IAPT treatment with mild and moderate depression and anxiety. 89% of people are receiving an assessment and beginning IAPT treatment within 6 weeks and 99% within 18 weeks<sup>19</sup>.

NHS England does not collect official data on how long people should wait to be seen in secondary care, meaning this report gives us the best insight to the experience of people severely affected by mental illness waiting for treatment and identifies that those who are most ill are waiting the longest.

Of the 1,602 who responded, the number of people from English regions who had experience of services within the last two years was 1,272 people. Respondents were well-balanced across ages and English regions, however the majority of respondents were white women with only 10% of respondents non-white and 11% men.

## Glossary

### All-Party Parliamentary Group for Mental Health (APPMH)

The All-Party Parliamentary Group (APPG) on Mental Health is a group of MPs and Peers from all political parties who are interested in mental health.

### Art Therapy

Art therapy is a form of psychotherapy that uses art media as its primary mode of expression and communication. Within this context, art is not used as diagnostic tool, but as a medium to address emotional issues which may be confusing and distressing.

### Bipolar Disorder

Bipolar disorder, formerly known as manic depression, is a condition that affects your moods, which can swing from one extreme to another.

### Care Coordinator

A care coordinator job is often the single most important role involved in the care of any individual patient. Supervising interdisciplinary care by bringing together the different specialists whose help the patient may need, the coordinator is also responsible for monitoring and evaluating the care delivered.

### Child and Adolescent Mental Health Services (CAMHS)

Child and adolescent mental health services are the NHS services that assesses and treat young people with emotional, behavioral or mental health difficulties.

### Care Quality Commission (CQC)

The Care Quality Commission is the independent regulator of all health and social care services in England.

### Cognitive Analytical Therapy (CAT)

Cognitive analytical therapy is a form of psychological therapy looking at the way a person thinks, feels and acts, and the events and relationships that underlie these experiences (often from childhood or earlier in life).

### Cognitive Behavioural Therapy (CBT)

Cognitive behavioral therapy is a talking therapy that can help you manage your problems by changing the way you think and behave. It's most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems.

### Community Care

Community and social care supports those in the community who need extra care and assistance with everyday activities.

### Community Mental Health Team (CMHT)

Community mental health teams (CMHTs) support people living in the community who have complex or serious mental health problems. Different mental health professionals work in a CMHT.

### Dialectical Behavioural Therapy (DBT)

Dialectical behavior therapy (DBT) is a type of talking treatment. It's based on cognitive behavioral therapy (CBT), but has been adapted to help people who experience emotions very intensely. It's mainly used to treat problems associated with borderline personality disorder (BPD), but it has also been used more recently to treat a number of other different types of mental health problems.

### Early Intervention in Psychosis (EIP)

Early intervention in psychosis services are multidisciplinary community mental health teams that assess and treat people with a first episode of psychosis without delay (within two weeks). They aim to provide a full range of pharmacological, psychological, social, occupation and educational interventions for people with psychosis.

### Eating Disorder

An eating disorder is when you have an unhealthy attitude to food, which can take over your life and make you ill. It can involve eating too much or too little or becoming obsessed with your weight and body shape. But there are treatments that can help, and you can recover from an eating disorder. Men and women of any age can get an eating disorder.

### Exercise Prescriptions

Exercise prescriptions commonly refer to the specific plan of fitness-related activities that are designed for a specified purpose, which is often developed by a fitness or rehabilitation specialist for the client or patient.

### Family Therapy

Family therapy – or to give it its full title, family and systemic psychotherapy – helps people in a close relationship help each other. It enables family members, couples and others who care about each other to express and explore difficult thoughts and emotions safely, to understand each other's experiences and views, appreciate each other's needs, build on strengths and make useful changes in their relationships and their lives.

### Five Year Forward View for Mental Health (FYFVMH)

The Five Year Forward View for Mental Health set out the NHS' plans for improving and expanding mental health care between 2014-2019.

### Group Therapy

Group therapy is a useful way for people who share a common problem to get support and advice from each other. In group therapy up to eight people meet with a therapist. Group therapy uses psychoanalytic psychotherapy. This type of therapy is concerned with how things are here and now.

### Health Education England

Health Education England is the national leadership organisation for education, training and workforce development in the health sector. It exists to support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place.

### Improving Access to Psychological Therapies (IAPT)

Improving access to psychological therapies services provide evidence-based psychological therapies to people with anxiety disorders and depression.

### Institute for Public Policy Research (IPPR)

The IPPR is a registered charity and a progressive think tank.

### Mental Health Trust

Mental health trusts provide health and care services for people with mental health problems. There are 60 mental health trusts. They are commissioned and funded by clinical commissioning groups.

### National Institute for Health and Care Excellence (NICE)

The National Institute for Health and Care Excellence provides national guidance and advice to improve health and social care.

### NHS England

NHS England leads the National Health Service (NHS) in England. It sets the priorities and direction of the NHS and encourages and informs the national debate to improve health and care.

### NHS Improvement

NHS Improvement is responsible for overseeing foundation trusts and NHS trusts, as well as independent providers that provide NHS-funded care. They offer the support these providers need to give patients consistently safe, high-quality, compassionate care within local health systems that are financially sustainable. By holding providers to account and, where necessary, intervening, they help the NHS to meet its short-term challenges and secure its future.

19. NHS England. 2018 Mental Health Five Year Forward View Dashboard. [Online] Available from: <https://www.england.nhs.uk/publication/mental-health-five-year-forward-view-dashboard/>].

# Glossary

## NHS Digital

NHS Digital is the national information and technology partner to the health and social care system using digital technology to transform the NHS and social care.

## The NHS Long-Term plan

The NHS long-term plan sets out the NHS' plans for improving and expanding care for the next ten years.

## Occupational Therapist

Occupational therapists treat injured, ill, or disabled patients through the therapeutic use of everyday activities. They help these patients develop, recover, improve, as well as maintain the skills needed for daily living and working.

## Parity of Esteem

Parity of esteem is defined as 'valuing mental health equally with physical health'.

## Perinatal Services

The perinatal period is usually defined as the time between conceiving a baby until the end of the first post-natal year. 20% of women (or one in every five women) experience mental health problems during this time, making this a relatively common experience. Services provide specialist assessment, treatment and support for women with current or previous moderate to severe mental illness who are pregnant or have given birth within the past year.

## Psychiatric Nurse

A psychiatric nurse is a nurse that specializes in mental health and cares for people of all ages experiencing mental illnesses or distress.

## Psychosis

Psychosis is a mental health problem that causes people to perceive or interpret things differently from those around them. This might involve hallucinations or delusions.

## Psychodynamic Therapy

Psychoanalytic or psychodynamic psychotherapy draws on theories and practices of analytical psychology and psychoanalysis. It is a therapeutic process which helps patients understand and resolve their problems by increasing awareness of their inner world and its influence over relationships both past and present.

## Psychotherapy

Psychotherapy and psychotherapeutic counselling are talking therapies. They are used to treat emotional problems and mental health issues. As well as talking, the therapy could use a range of methods including art, music, drama and movement.

## Personality Disorder

A person with a personality disorder thinks, feels, behaves or relates to others very differently from the average person. There are several different types of personality disorder.

## Schizophrenia

Schizophrenia is a severe long-term mental health condition. It causes a range of different psychological symptoms. Doctors often describe schizophrenia as a type of psychosis. This means the person may not always be able to distinguish their own thoughts and ideas from reality.

## Severely Affected by Mental Illness

Someone severely affected by mental illness would include people with a diagnosis that typically involves psychosis (losing touch with reality or experiencing delusions) requiring high levels of care and possibly hospital treatment.

## Talking Therapies

Talking therapies are treatments which involve talking to a trained professional about your thoughts, feelings and behaviour. There are many different types of talking therapy.

## Time to Change

Time to Change is England's most ambitious programme to end the stigma and discrimination experienced by people with mental health problems. It's led by Rethink Mental Illness, in partnership with Mind.



**Leading the way to a better  
quality of life for everyone  
affected by severe mental illness.**

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