Rethink Mental Illness COVID-19 briefings
Access to NHS mental health services for people living with severe mental illness

1. Executive summary

The spread of COVID-19 across the globe and the steps the UK Government has taken in response have had an undeniable impact on mental health services. **The pandemic has widely affected mental health, but it is important that we recognise that for some this impact is, and will continue to be, particularly acute.**

People who are severely affected by mental illnesses (SMI) such as schizophrenia or bipolar disorder, or live with severe anxiety or depression, have been hard hit by both the changes to formal mental health services and the wider implications of the lockdown, such as sharp, sudden changes to routine and the removal of coping mechanisms such as seeing friends or peer support groups. We are concerned this group is at heightened risk of relapse or crisis as a result.

This short report sets out how people with pre-existing mental illnesses have been affected by the change in access to formal NHS mental health services as a result of the pandemic, following a survey conducted by Rethink Mental Illness of 1,434 people severely affected by mental illness. Over three-quarters (79%) of people with pre-existing mental illnesses reported that their mental health had got worse or much worse as a result of the pandemic.[1] 42% said their mental health was worse because they were getting less support from mental health services.[2]

The population-wide lockdown measures and the changed nature of NHS services for people living with mental illness have happened for very good reasons. But we cannot allow this pandemic to lead to a mental health epidemic, the effects of which could last for a lifetime.

Coronavirus may be with us for many months or even years to come. **It is vital that Government and the NHS prioritise mental health to ensure services can respond to restrictions in the best possible way for users and cope with inevitable increased need.**

2. Why we need to look at severe mental illness within mental health discussions around COVID-19

Rethink Mental Illness is an organisation that exists to improve the lives of people severely affected by mental illness. Since we began as the National Schizophrenia Fellowship, we have championed the voice of people who most acutely experience the impact of mental illness.

We know that historically our beneficiaries have struggled to get the support they need – in 2018, a report by Rethink Mental Illness found that on average people severely affected by mental illness waited 14 weeks for an assessment alone and a further 19 weeks to begin treatment.[3] A report by the All-Party Parliamentary Group (APPG) on Mental Health highlighted that many people were ending up in crisis because they had been unable to access support in core community mental health services.[4]

The NHS Long Term Plan, published in January 2019, set out a bold vision for transforming community care for adults with severe mental illness. By 2023/24, at least 370,000 adults with severe mental illness would receive care from integrated primary and community mental health services – underpinned by £975m.[5] This newly redesigned model of community care would include improved access to psychological therapies for people living with severe mental illness, improved physical health care and access to support on employment, self-harm and substance misuse. Personalised and trauma-informed care would be key in all interventions and there would be a trial of a four-week waiting time to access community teams. This transformation had begun with several pilot sites beginning to test and move towards this new way of working.

[1] Online survey by Rethink Mental Illness of 1434 people with severe mental illness during April and May 2020.
[2] Online survey by Rethink Mental Illness of 1434 people with severe mental illness during April and May 2020.
[3] Rethink Mental Illness (2018) 'Right treatment, right time'.
[4] All-Party Parliamentary Group on Mental Health (2018) 'Progress of the Five Year Forward View for Mental Health: on the road to parity'
[5] NHS England/Improvement (2019) NHS Long Term Plan Mental Health Implementation Plan.
For more info, contact **Lucy.Schonegevel@rethink.org,** Head of Health Influencing at Rethink Mental Illness

3. Accessing mental health services for severe mental illness during COVID-19

Our survey of 1,434 people severely affected by mental illness and other insight from our own services across the country shows that while there are some pockets of good practice, many people have struggled to get meaningful mental health support during the pandemic – and in some cases, have not received any support at all.

42% of all respondents said their mental health had worsened during COVID-19 as a result of receiving less support from mental health services.[6] When asked to consider how support from mental health services had changed during the pandemic, 58% that support had worsened overall.[7]

3.1 Remote support

Many respondents understood the challenging nature of the current circumstances and why remote support was required. However, there were mixed views on the benefit of remote support – some people found it 'easier physically and mentally', but many others said it was harder to express themselves or be honest during virtual appointments. Some people said that they simply did not feel comfortable doing therapy remotely.

> *'I have been unable to continue with CBT because they cannot (understandably) offer face to face consultations and I do not feel comfortable with remote delivery.'*

Nearly half of respondents to the survey had been supported by a Community Mental Health Team (CMHT) in the last year. There was a general sense that the nature of support had changed from the usual therapeutic in-person intervention to a 'checking in' call.

On medication, 8% said being unable to access the medication they needed for their mental health had made their mental health worse. We are also aware of other reports about temporary shortages of Sertraline.[8] Medication issues can have potentially very serious consequences for physical and mental health. One respondent told us that it was a 'fight' to get their depot injection in their home – they have been told that home treatment will be stopped for 12 weeks, but they are understandably concerned to leave their home because of Coronavirus.

> *'Because of the virus you can't see a doctor. I had an appointment with the psychiatrists but the appointment was cancelled because the doctor was ill. I was given another appointment but it's a phone call. It's not the same.'*

Some services are continuing to see people face to face, or having staff visit their home. One Rethink Mental Illness supported housing service reported that following a number of crisis incidents related to the lockdown measures, the local NHS crisis team were very responsive – for example organising a hospital admission on a Friday night and providing regular face to face visits for one service user in the days following an overdose. Yet another supported housing service in a different location shared that even before the lockdown measures had been announced by the Government, the local NHS service had withdrawn all face to face support – and that during the lockdown, it had been difficult to get support from the crisis team when it was needed.

NHS England made clear in its guidance from March that services must balance infection control with providing services to people living with mental health issues face to face. Services were not instructed to close – but clearly many people have struggled to get the help they need. Now over two months into the national lockdown, it is vital that services re-assess that balance between infection control and worsening mental health. Services that have been able to make face to face visits must share their ways of working with other Trusts across the country to ensure that while we do not put anyone at risk of COVID-19, we are also not inadvertently putting people at increased risk of suicide, self-harm or relapse.

3.2 Frequency of support

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[6] Online survey by Rethink Mental Illness of 1434 people with severe mental illness during April and May 2020.

[7] Online survey by Rethink Mental Illness of 1434 people with severe mental illness during April and May 2020.

[8] Telegraph (2020) 'Antidepressant prices soar by more than 800pc during lockdown'

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There was huge variation in the frequency of support - some received regular calls, others had either had their support cancelled or heard nothing at all from services even when they had proactively contacted them. It's concerning that there appears to be a significant number of people who have fallen off the radar, particularly given that many appear to be feeling undeserving of help or as though they may burden the NHS.

> *'[It is] ...harder to contact mental health team, feeling as though I am a burden and not important because of everything that's happening.'*

3.3 Returning to face to face support

It's clear that people are fearful of leaving the house and contracting the virus. But there are also significant numbers of people who feel that there are others more deserving of support and that the focus on treating people with Coronavirus means that their difficulties are secondary. Some had been told that they wouldn't get support if they asked, or that GPs would not refer them. This is very concerning and goes against the need and policies set out in the widely supported NHS Long Term Plan. We welcome the NHS "Open for business" and "Help Us to Help You" campaigns and believe mental health must be a key priority within that to ensure a group that has been underserved in the past does not now feel again as though they are not deserving of help.

We know that there is likely to be a surge from pent-up demand for mental health support after the pandemic.[9] It is therefore vital that these issues around access to meaningful support are urgently addressed so that people living with existing mental illnesses and any new referrals are able to get the services they need.

It is important to note that respondents to our survey were able to access and fill in an online survey. There will be many others who are digitally excluded who could not access the survey and who we also assume are unlikely to access virtual support. Additionally, while nearly 10% had been inpatients in a mental health hospital in the past year, more research needs to be done to understand the experience of people who are in an inpatient unit currently.

4. Good practice and emerging service solutions

We are aware of a number of areas that have responded quickly to the coronavirus crisis to support their populations, including support that Rethink Mental Illness provides:

- In Somerset, an alliance of the NHS Trust and ten voluntary and community sector organisations, including Rethink Mental Illness, has brought forward implementation of a 24/7 phone line for 30 minutes' emotional support with warm transfers to local specialist interventions. This ensures that people who are able to, have a phone line to call when needed but also crucially that they are transferred on to local holistic treatment and support. This is not only helping support people during the current crisis but reaching wider groups of people severely affected by mental illness who live in rural areas who otherwise might not have had access to this specialist support.

- In Grimsby, Rethink Mental Illness, in partnership with a NHS primary care network and Navigo, a social enterprise, has recruited a COVID-19 navigator role to identify people living with mental illness who have not been in contact with local services recently to assess their clinical, social and practical needs and support them to obtain help. The aim of this is to help prevent this vulnerable group of people reaching crisis point and enable them to take ownership in addressing their needs. This role will continue, post-COVID, as a pilot with the aim of rolling out and embedding within NHS primary and community care if successful.

- With funding from Public Health England, Mental Health UK has established the Clic offer, a facilitated peer to peer online chat and support forum. 1500 people have registered since early April and 14,000 posts have been made. The feedback we have received from users so far is that people feel less isolated, have experienced improvements in mental health, and are more confident in discussing their illness. We are therefore planning to grow the forum significantly over the course of the year.

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[9] NHS Providers (2020) Spotlight on... the impact of COVID-19 on mental health trusts in the NHS

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5. Recommendations

- **Remote support:** NHS England and Department of Health and Social Care must prioritise solutions for digitally excluded people. NHS X must share its research into the extent of digital exclusion among people severely affected by mental illness and the experiences of remote mental health service delivery and during the current crisis.

- **Lifting of lockdown restrictions**: As lockdown restrictions are lifted, NHS England/Improvement must continue to provide digital and telephone consultations as an enhancement of options for service users who prefer this method. NHS England must encourage local NHS Mental Health Trusts to re-introduce face to face consultations as soon as possible for the significant proportion who respond best to support in person.

- **Co-production:** Service users must be involved in designing and delivering mental health services during and post-pandemic, both at a national (NHS England and arms-length other bodies) and local level (STPs, CCGs and Trusts) – only then will we ensure services are supporting people severely affected by mental illness effectively, particularly in the face of a future mental health epidemic.

- **The long-term:** NHS England must publish revised timelines for delivery of the Long Term Plan and provide assurance that the priorities set out in the NHS Long-term plan to redesign community provision for people severely affected by mental illness are still the priority. Government must account for the expected increase in need due to the pandemic with additional funding.