

Covid 19 – impact on those severely affected by mental illness

Written evidence from Rethink Mental Illness | September 2020

We're Rethink Mental Illness, a leading charity provider of mental health services in England. We support tens of thousands of people through our groups, services and advice and information. We train employees, employers and members of the public on how best to support someone affected by mental illness. All of this work guides our campaigning for the rights of people with mental illness and their carers. No matter how bad things are, we can help people severely affected by mental illness to improve their lives.

Our evidence

Rethink Mental Illness undertook an online survey aimed at people with lived experience of mental illness in April and May 2020. The carers of people with mental illness were also invited to take part, answering questions in relation to those they care for.

We received 1,434 responses to the survey. Of these respondents, around 8% had been in inpatient care and 50% under the care of Community Mental Health Teams in the last 12 months. Most had been supported through prescription psychiatric medication (80%) or by their GP (65%). We have also gathered evidence from our own services operating on the frontline during the same time period.

Although much of this evidence was gathered during the first lockdown period in April and May, subsequent engagement with those living with severe mental illness indicates that many of the issues described continue to persist even as lockdown eases throughout the majority of England. Any future second wave of COVID-19 and related local or national lockdowns carry the risk of entrenching the issues that emerged for those living with severe mental illness during the first lockdown period.

Introduction

It will be no surprise to most of us that the pandemic is having an effect on mental health. But we were still shocked that 79% said that coronavirus and the measures to contain it have made their mental health worse or much worse.

Those who responded to the survey are a group of people with existing, often severe, mental health problems as opposed to people who have developed symptoms of mild to moderate mental illness since the pandemic started. They have also been chronically under served by the system, suffering from decades of stigma and underfunding of services. The NHS Long Term plan, with its focus on improving core community services for most severely affected by mental illness, had at last begun to change this but this pandemic threatens to set the clock back.

A later survey we conducted in July on the easing of lockdown measures was completed by 659 people. 63% of people said their mental health had gotten worse as a result. 58% were worried that the risk of them contracting Covid-19 had increased, 49% did not feel safe to go out, and 33% were frustrated that they still couldn't get the support they needed from mental health services.

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Impact on normal activities

In our major survey conducted in April and May the most common reasons that people gave for their mental health getting worse included not being able to do normal activities, not being able to see family or friends and worrying that their loved ones would catch the virus. These will be difficulties we can all relate to, yet the impact will be very different for those who are already experiencing severe mental illness. For some, regular visits from friends or family, the ability to exercise or access to outdoor space can be the difference between staying well and becoming seriously ill. The way that people are affected by the changes to daily life depends a lot on their condition and their circumstances. Some people with eating disorders, for example, struggled to find the “safe” foods they need – sadly people told us that they had been in recovery from anorexia but have now relapsed. Those with compulsive behaviours told us that they found the constant public health messaging – and genuine existential threat it represents- was making their symptoms worse.

One person who had been well for years told us that their PTSD had returned, saying *“I am experiencing flashing terror and I haven't any tools to talk to a terror that is not, in fact, in any way irrational or disproportionate.”* Similarly, it can be terrifying for someone who has paranoid delusions to be visited by healthcare professionals in full PPE.

We found that a significant number of respondents (29%) were shielding either following guidance from the NHS (9%) or had decided to shield believing they should have been requested to via the guidance (20%).

Commonly, those in both groups were less likely to be in full time employment, and more likely to receive support from social care services, to be not employed or seeking work, and to be claiming benefits for a reason related to their mental illness. They were also significantly more likely than others to say their mental health was ‘much worse’ as a result of the pandemic, often driven by fear of catching the virus. 61% of these respondents told us they would continue to shield even when Government made its initial changes to related guidance.

Impact of changes to mental health services

One strong theme to emerge from the survey was the extent to which changes to mental health services were affecting those who were normally supported by them.

58% say that that support had become “worse” or “much worse” since the UK was affected by coronavirus and 42% said that their mental health had become worse because they were receiving less support than they used to. There was considerable variation in the frequency of support received, if they were receiving support at all. The context for this is that even before this crisis hit, many people with severe mental illness were not getting the support they needed. A common theme in the survey was that services had been completely withdrawn in the wake of coronavirus:

“I feel on my own with no support when I had just managed to access support after 2 years of fighting for it”

The survey found that while people understood why services had to move online, for example, it did not change the fact that many people find online appointments less helpful, and some found them impossible to engage with. This left many feeling abandoned. And it was not just clinical appointments that were affected. Community services which are vital in supporting people’s recovery such as gardening groups, peer support groups and crisis

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cafes, stopped meeting. Many of those who are entitled to social care because of their mental illness are also found that visits were being replaced by phone calls, or not at all. We heard from our own services that many Care Act assessments simply weren't happening.

We also heard from these services of instances of people being detained under the Mental Health Act as a result of their mental health problems escalating due to a lack of preventative support.

You don't need to be a specialist to understand how important face to face contact can be in mental healthcare. And we have real concerns that those patients still needed to be seeing their psychiatrist or nurse face to face might have been missed.

"No face to face contact despite having been intubated and ventilated for 5 days in March before being able to breathe again due to an overdose. I live alone and have no support network and just phone contact has not been enough".

NHS England/Improvement must encourage local NHS Mental Health Trusts ensure that digital and telephone consultations are provided as an **enhancement of options** for service users who prefer this method, not instead of face to face.

Physical health

Our survey also highlighted worrying trends that suggest that the physical health of people living with mental illness was being negatively affected. People with severe mental illnesses typically die 15 to 20 years earlier than the general population. So it is particularly concerning that around half of our respondents said that they exercised less than usual and ate less healthily during lockdown. Almost a quarter drank more alcohol and one in 6 smoked more cigarettes as a result of the crisis.

And there are specific concerns around how some psychiatric medications, with physical health side effects, are now being managed. One carer told us how her son's blood test related to the fact he took the anti-psychotic clozapine which was cancelled without notice because staff were self isolating, despite the fact that it was crucial for his health. A test was booked thanks to her pushing, but (for the first time in 12 years) the lab then lost the sample – presumably because of the pressure they are under. 8% of respondents to our survey being unable to access the medication they needed for their mental health had made their mental health worse.

Examples of best practice

- In Somerset, an alliance of the NHS Trust and ten voluntary and community sector organisations, including Rethink Mental Illness, 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.

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- 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. Over 3000 people have registered since early April and there were 3,476 actions across across the site's Live Chat, Forums, Mood Tracker and Live Q&As in August alone. 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.
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Priorities for future action

- Rethink Mental Illness were one of 50 voluntary and social sector organisations to call for a Mental Health Renewal Plan as part of a cross government approach in a report on a new social contract.¹ This should be given by a new approach to mental health that both prevents and responds to damage caused by Covid 19. We urge this approach to be adopted by Government as a priority.
- Signs of increase demand for mental health services and a decline in the nation's mental health are emerging all the time. Government funding that identifies and meets increased mental health need as a result of the pandemic in the short and long term is required. This must be in addition to Long Term Plan funding in the NHS and must support local authorities and the community sector to meet new demand.

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¹ A New Social Contract for a mentally healthier society, June 2020

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