



COVID-19: Recommendations for Mental Health Services

**Developed by: Mad Covid, Bethan Edwards, Andrew Grundy,
Ellie Bradford and Nell Aitch, November 2020**

#MadCovidRecommends

Introduction

Mad Covid is a UK based service user / survivor led group that began in March 2020 in response to the COVID-19 pandemic. Our aim is to create a community of solidarity, bringing together the voices of lived experience to create a historical record, and to influence change in real time. To this end we have created a series of broad recommendations for mental health services during the COVID-19 pandemic. They focus specifically on services for people with pre-existing mental health conditions who have moderate, severe or long-term needs.

Our recommendations derive primarily from the Mad Covid Symposium, held on the 28th of October 2020, which will be described in detail later. We have additionally drawn on the personal testimonies provided to Mad Covid since mid March 2020, which derive from our multiple projects, through which we've engaged with hundreds of people with lived experience. Our projects have included:

Mad Covid Diaries: An initiative to record lived experiences of the pandemic. We have received over 200 diary submissions providing personal accounts of accessing mental health services and living with a pre-existing mental health condition during COVID-19. These are published on our website [here](#).

Mad Covid Fund: We have raised over £25,000 and awarded over 175 grants to people who have pre-existing mental health conditions who have found themselves in financial need due to COVID-19. We have also provided grants to inpatient wards to enable digital contact with friends and family, as well as to provide meaningful activities. You can apply or donate to the fund [here](#).

Mad Covid Voices: We conducted 26 interviews with people who were using inpatient and community services about their experiences during the UK's first lockdown. Some of the interviews are available to view [here](#).

We have also facilitated various other user-led projects, such as #MadCovidChat, Quarantine, Pandemink!, Quarantine Quiztacular and Mad Makers. You can read more about our work [here](#) and follow us on Twitter [@MadCovid](#) and Instagram [@MadCovid](#).

Our team is entirely volunteer based. We receive no funding from the Government or the NHS for our work. Aside from our publicly sourced Hardship fund, our sole financial support has come through a small grant from the National Survivor User Network (NSUN) to purchase our Zoom account, who we thank for their support.

Context and Scope

Mental health services have been in crisis for decades. Since March 2020 we have consistently heard how existing systemic problems predating COVID-19 are continuing and are being exacerbated by the pandemic. These include, but are not limited to: chronic underfunding; poor and often harmful experiences of crisis care; a lack of inpatient beds; increased contact with emergency services including, the police in the absence of meaningful support; and 'off-rolling' (discharge) to manage caseloads.

These systemic problems must be addressed by government, policy makers, providers and the NHS as a matter of urgency. However, our recommendations relate specifically to the way mental health services are currently being designed, accessed, delivered and experienced due to COVID-19.

The Mad Covid Symposium

As outlined in our introduction, the recommendations contained in this document, are primarily based on the Mad Covid Symposium, which was held via Zoom on the 28th of October 2020. The symposium was promoted on Twitter under the hashtag #MadMeetUp and was open to survivors/service users and a limited number of allies. Overall, we sold 98 tickets and there were 67 attendees, five of whom identified as mental health professionals. The event consisted of brief presentations from a survivor/lived experience panel, followed by the opportunity for questions before finishing with an open discussion.

The aim of the symposium was threefold:

- To discuss the impact COVID-19 has had on people with pre-existing mental health conditions.
- To discuss what mental health services and others can do to support us during the impending second 'wave' and any further 'lockdowns'.
- To write a short account of the discussion, to be shared with mental health services, professionals, organisations and anyone else (which has resulted in a [blog post](#), which provides a descriptive overview of the event and this document)

The event was recorded so that it could be shared with the wider community and it can be watched back online on our [Youtube channel](#). It was chaired by MadCovid member, Bethan Edwards, who facilitated the discussion throughout. Panel members were: Tamar Jeynes, Nell H, Andrew Grundy, and Hattie Porter, all of whom are survivors/service users, and had experience of accessing mental health services during COVID-19. Two of the panel have also had inpatient experiences during this pandemic. Whilst panel members shared their experiences of services, audience members could contribute via the 'chat' function on Zoom. This showed that the experiences being shared resonated with many others in the audience. It also gave an indication as to what we as a collective felt was poor practice (e.g. comments such as "That happened to me too" or "That shouldn't have happened!"), and what was regarded as good or desired practice. After a short break, the panel members briefly shared what they felt services could do to support us, in what was then the impending second wave, before the discussion was open to the wider audience. Audience members shared further accounts of accessing, or trying to access, services. Many similar experiences were shared. Overall, there was a real feeling of validation and solidarity.

Following the symposium, the Mad Covid team reviewed the recording of the event, agreed overarching themes, and the practical recommendations arising from these. This has

resulted in 12 good-practice recommendations that we as a collective urgently want and need to see implemented. Each recommendation is largely supported by quotations from the symposium itself, but supporting evidence from our other projects has been provided. All of the individuals quoted in this document have given their permission for us to use their words.



Recommendations

**1. NOW, MORE THAN EVER BEFORE,
SERVICES MUST WORK IN A
PERSON-CENTRED WAY.**

**ONE SIZE OR BLANKET SERVICE
SOLUTIONS WILL NOT MEET ALL
NEEDS, PARTICULARLY THE MOST
DISADVANTAGED.**



Everyone's experience of COVID-19 will be different. Some people with pre-existing mental health conditions have found the pandemic a positive experience, since it has opened up wider opportunities for digital engagement. However, the majority of people who have engaged with Mad Covid have found COVID-19 and its consequences ('lockdown', limited community mental health service provision, remote contact with services, and blanket bans on visitors to inpatient wards) detrimental to their mental health.

Crucially, services must not make blanket assumptions about how their service users are coping. Based on the personal testimonies we have received to date, we would like to highlight that the following populations are likely to be left behind by a 'one size fits all' approach, and may need more support from mental health services during COVID-19:

- People living alone and people who have limited social support.
- Black and Asian people, and people from other ethnic minorities who are at increased risk of experiencing adverse outcomes if they contract COVID-19, and who already experience significant structural inequalities in accessing and receiving mental health services.
- People living in poor housing conditions, as well as those unable to pay for additional heating and electricity. Throughout the pandemic we have received applications to our hardship fund from people who live in these circumstances - some have no means of storing food or cooking it, others have no central heating and rely on expensive portable heaters. The day centres, services and local cafes,

that people once relied upon to meet their basic needs, have not always remained open during COVID-19.

- People who receive social care. The Coronavirus Act (2020) eased duties placed on Local Authorities to provide care to those who needed it under the Care Act (2014). Chloe told us how her social care was withdrawn and spoke about the impact this had on her and her friend, who tragically died by suicide in the absence of support:

"...I've used services for a very long time since I was...about 15. I'm 30 now and I'm also autistic and I have daily care, and about a week before lockdown hit we got the message that it [care] was going to be stopped dead. So I went from having 14 hours a week care and social services, to nothing. And it was deemed as being too high risk for me to stay in my flat ...so I had to go and live with my parents. And I was lucky because I had that option but I haven't lived with my parents since I was 19 and I'm 32 and there's good reasons why I wasn't at home. But one of my friends who I'd lived with, the same thing happened, and she killed herself over lockdown. There's been so much..., and i can't see it improving as we go into the second lockdown."

Chloe, Mad Covid Symposium

- People who are digitally excluded. We have repeatedly heard from people who report that they're digitally isolated, as well as physically isolated. Through our hardship fund we know that some people simply do not have access to the devices or reliable internet connection that they need to access digital services or support. We've granted numerous awards for laptops, tablets, phones and WIFI connection. Wendy, who we provided with a laptop through our hardship fund, told us:

"...I have a phone but due to anxiety am unable to make phone calls. I do use the phone for games, texts etc. but due to physical health needs am unable to use it to write more than a sentence or two, so my laptop was an essential for emails, following social media and the like. I really missed it [having a laptop] and found myself becoming even more isolated."

Wendy, Mad Covid Fund applicant

- People who have comorbid physical health conditions, including those who have to 'shield'. Again, we have received many applications to our Mad Covid Fund from people who are shielding who have experienced difficulties shopping, and increased costs associated with food delivery and taxis to medical appointments.
- People who have children and who have had to home-school, as well as new mothers / parents.

- People who are experiencing financial difficulties, which have been exacerbated by COVID19. Our hardship fund has provided us with significant insight into the financial difficulties experienced by people with pre-existing mental health conditions. As well as the difficulties highlighted above, we have provided grants to people who fall through the traditional mechanisms of support, for example asylum seekers and students.

Given the diversity of people using mental health services with moderate, severe and long-term needs, now is the time that services truly embrace person-centred working, by rejecting blanket approaches. As Andrew said at the Mad Covid symposium:

"...there's a lot of talk about person-centred services... it shouldn't be a one-size-fits-all... this is the time to actually put that into practice"

Andrew, Mad Covid Symposium

We urge that the rhetoric of 'person-centred services' is made a reality, as much as is feasibly possible, for all service users during this pandemic. More than ever before, services must be attentive to our needs and preferences at this time.



2. COMMUNITY AND INPATIENT MENTAL HEALTH SERVICES MUST REMAIN OPEN DURING COVID-19.

THEY ARE ESSENTIAL SERVICES.

Despite our best efforts since April 2020, only now is it being widely recognised that community mental health services have not remained 'open' or 'open as usual' during COVID-19. Whilst inpatient services have largely remained open, the degree to which community mental health services have remained 'open' has been variable across the UK. At the Mad Covid symposium Andrew recalled:

"...face-to-face appointments at the CMHT were cancelled in March and I did get a phone call from my CPN to let me know that the centre was closing, and that obviously meant that I no longer had that monthly check-in with her and I wasn't offered a phone call, there's not an alternative, that just completely shut down."

Andrew, Mad Covid Symposium

Sadly, Andrew is not an isolated case. We have been inundated with people reporting that their community mental health services, by cancelling routine appointments, had effectively 'shut-down' during COVID-19. Mia received a letter in April 2020 to inform her that her local Early Intervention Team were cancelling all routine appointments, with no provisions being made to deliver these remotely:

"The letter made me very concerned for OTHER service users because it does not give any patients a 'back up' plan or any decent access to appropriate medical care. All it said was that patients could "ring the EIT" if needed, and it gave the numbers for Samaritans etc. This is just not good enough."

Mia, Mad Covid Blog

Whilst we have been able to meet friends in a pub and have our hair cut, many of us have not been able to receive essential services for our mental health. Our lives depend on these services, they are essential.

3. WORKFORCE CAPACITY MUST BE INCREASED TO MEET THE NEEDS OF PEOPLE WITH SEVERE AND ENDURING MENTAL HEALTH CONDITIONS.

NO ONE SHOULD BE DISCHARGED FROM OR REFUSED ACCESS TO SERVICES DUE TO COVID-19.



Unlike the recruitment drives to meet demand and capacity in services that were responding to the physical health consequences of COVID-19, no similar attempts were made to ensure the needs of people with a mental health condition were being met during COVID-19. The redeployment of community mental health staff to inpatient services was frequently reported to us during the first lockdown. This had a detrimental impact on the ability of community services to remain 'open', and upon the mental health of those receiving community services, who were left without essential support. Nell reflected on this during the Mad Covid Symposium:

"...mental health patients were kind of canaries in the coal mine of the nhs and...I feel like lots of community mental health teams weren't prepared and understandably as well, but there were cases where community mental health teams were actually completely shut down because of redeployment and I feel like going into the second wave we can't be seen as just the kind of the bottom of the run in terms of redeployment..."

Nell, Mad Covid Symposium

In addition to closing CMHT's and cancelling appointments, we also heard testimonies from people who had been discharged from both community and inpatient mental health services, as well as waiting lists due to 'COVID-19'.

"...On the day that [lockdown] was announced I got a letter saying I was being taken off the waiting list for my community mental health team just full stop nothing else and, then when I tried to call them up and was like what's going on here do you have like a crumb of explanation and they were so aggressive and really resented the fact that I was asking for information about my

care...a huge thing at the start of COVID, is it was just sort of like I was being treated like well can you not just hold it together for a few months and stop being a bother."

Rosalind, Mad Covid Symposium

In April 2020, Mad Covid called for an end to the redeployment of community mental health staff, in addition to an increase in the mental health workforce. At our symposium, Bethan expressed concerns that additional funding is likely to prioritise people with low level needs, as opposed to people with higher and longer term needs:

"The worry is that people are going to have mental health conditions or problems or difficulties or distress, however we want to call it, or madness, as a consequence of the pandemic. That's a concern for us as a community of people with long-term, some of us with severe, mental health conditions that we had way before the pandemic, how that's going to impact on us. I think a fear of mine is that all [the] resources are going to be invested in primary care or low level interventions and support, and we're going to be forgotten about again."

Bethan, Mad Covid Symposium

We therefore, call again for increased resources, specifically for people with severe and enduring mental health conditions, at a time when demand is even higher.



4. COMMUNITY SERVICES MUST BE AVAILABLE IN PERSON AND DIGITALLY.

DIGITAL ONLY SERVICES SHOULD NOT BE PROVIDED UNLESS THIS IS REQUESTED BY THE PERSON THEMSELVES.

COVID-19 has driven forth a digital revolution in the way mental health services are delivered. Whilst this has increased the accessibility of services for some, it actively excludes others who experience digital poverty or have difficulties using digital devices due to their mental health condition, for example paranoia. We spoke about these challenges in detail during our keynote at the Royal College of Psychiatrists' Meaningful Online Care Conference in November 2020, in addition to the impact digital services can have on the effectiveness of therapy or treatment. You can watch our keynote [here](#).

Unfortunately, the lack of in person face-to-face support has had a detrimental impact on many who have engaged with our projects. During the Mad Covid Symposium, Nell spoke about the impact this loss had on her, which led to a deterioration in her mental health, sectioning, and admission to hospital:

"...I live alone and all my face-to-face support was moved online eventually and I found that quite difficult...face to face is really important for me and online definitely it doesn't have the same effect for me and it doesn't have the same feel and it all just took a toll on my mental health and I ended up being sectioned..."

Nell, Mad Covid symposium

Remote services are not a replacement for in person services. Face to face, in-person appointments must be provided to people who are digitally excluded and for those who report digital services are not helpful for them. Alternative solutions to facilitate the delivery of in person services should be given due consideration. We have heard good practice examples in some areas, where people are meeting their care coordinators outside and having moving hospital appointments for bloods to GP surgeries or at home.

5. INPATIENT SERVICES MUST ENSURE ADVOCATES AND LEGAL REPRESENTATIVES ARE AVAILABLE AND ACCESSIBLE TO ALL.

THEY MUST NOT BE EXCLUDED FROM WARD ROUNDS.



Access to advocates and legal representatives are an essential means of ensuring that our rights are protected and the law upheld when we are often at our most vulnerable. Mad Covid has heard testimony that access to advocates and legal representatives during COVID-19 has been difficult for some. We are unclear how widespread these difficulties are, but we have heard that advocates and legal representatives have been prevented from attending ward rounds in some areas in the UK. N spoke about their experiences whilst an inpatient during the first 'lockdown':

"...advocates can't come onto the wards - for example they can't be in ward round with you, nor are any external agencies, like my social worker can't come either, or even my care coordinator. So they haven't been involved in ward rounds for a month now, over a month. I haven't had a tribunal in this time, but the people who have done I think have found them quite difficult, because they're happening over the phone and they're not being told of decisions as quickly as they would normally...I just think there's already a huge power imbalance on psych wards between the staff and patients, but this had just made it so much worse because you now can't have anybody advocating for you in the ward rounds, and tribunals aren't working in the same way they normally do, and there really does seem to be a focus on just getting people out of here as soon as possible."

N, Mad Covid Voices

Nell also had a similar experience when she was an inpatient:

"You're entitled to a solicitor and an advocate and we weren't allowed to see them face to face. So in one hospital the only way I

could contact my advocate was by the patient pay phone, which was in a corridor which was really busy, and there was no privacy there. So yeah, that was quite difficult..."

Nell, Mad Covid symposium

Access to independent advocates must be facilitated on all inpatient wards. They must not be excluded from ward rounds or mental health tribunals.



6. INPATIENT SERVICES MUST ENSURE CONTACT WITH FRIENDS OR FAMILY IS OFFERED AND ACCESSIBLE TO ALL.

Blanket bans preventing visitors and leave from inpatient wards were widespread during the initial lockdown, and are still in place in some areas of the UK. In their interview, N described the impact this had on them N:

“...the biggest change I forgot to say - we’re on lockdown, so there’s no leave and no visitors and haven’t been for 4 weeks now. I dunno why I forgot that. That’s had a huge negative impact, because... I kinda just want to see my mum. Also not being able to go on leave means not being able to go for a walk, i’m sleeping a lot worse because I’m not getting any exercise, and it’s also going to be very difficult getting discharged when I haven’t been outside in 4 weeks. That’s a big change.”

N, Mad Covid Voices

In accordance with our first recommendation, blanket bans will not meet everybody’s needs. Having visitors is an essential coping mechanism for many whilst an inpatient. Again, alternative ways of facilitating in person contact must be considered, for example utilising outside space. Accessible digital contact must be enabled, particularly for those who are digitally excluded, to stay in touch with family and friends.

7. ADDITIONAL RESOURCES MUST BE MADE AVAILABLE TO INPATIENT SERVICES TO MEET INCREASED SOCIAL AND OCCUPATIONAL NEEDS.



In light of restrictions placed on in person visitors and leave, we have awarded multiple grants to inpatient wards from our Mad Covid Fund for activities to occupy, and devices to overcome digital exclusion. A Mad Covid Fund applicant wrote the following testimony:

"During COVID-19 both patients and staff have had to adapt to a new way of functioning. As our ward has a 'red zone' where patients with suspected symptoms (and mental health needs) are assessed, we noticed an increase in occupational deprivation because people can't routinely go for walks in the local area, can't just pop to the shop, can't do their normal routine. The MadCovid fund has enabled us to develop a new routine whilst following social distancing measures. This includes having yoga mats to exercise inside, a radio to listen to if self-isolating, a netball hoop and ball to exercise in the courtyard, soil and plants to make the ward garden a place everyone wants to be. Thank you MadCovid!"

Mad Covid Hardship Fund Applicant.

Additional funding was not routinely provided to inpatient wards to cater for these additional needs as a consequence of COVID-19. It is unacceptable that NHS staff had no alternative but to apply to a service user led hardship fund, crowdfunded by the public, to ensure people's basic needs were met as inpatients.



**8. NEW WAYS OF WORKING,
INCLUDING REMOTE SERVICES,
HAVE SIGNIFICANT GDPR AND
PRIVACY IMPLICATIONS, BEYOND
DIGITAL PLATFORM SECURITY.**

THESE MUST BE ADDRESSED.

Wherever or however mental health services are delivered, confidentiality and privacy is extremely important. During COVID-19, many people have found themselves stuck in extremely difficult, pressurising, and in some cases, traumatic environments - whether they have moved back in with their families, are trapped in an abusive relationship, are trying to home-school young children, or are living in chaotic student housing. Now more than ever, privacy is a rare commodity for many people and home isn't always a safe place. Having sensitive conversations about the difficulties we're experiencing can put us at risk or make living situations difficult, as Dylan mentioned in their interview:

"I live with my family which has mostly been fine, but I do worry when I'm having a video appointment that they are listening in... We don't discuss mental health, so it's draining having to keep up a facade and say I'm okay when I'm struggling."

Dylan, Mad Covid Voices

In their interview, Ali also told us:

"I find medical appointments hard if family are in the house, I feel like I need to be on my own in the house to have privacy, but that's not always possible, so I end up having to cancel."

Ali, Mad Covid Voices

We've heard from service users and professionals about the need for digital platforms to be GDPR compliant, particularly in relation to Zoom. However, little consideration is given to additional factors that compromise GDPR aside from choice of platform. For example, sessions happening in a room with the rest of the team present. In their diary, @RelapseRover wrote:

"I communicate with my Care Coordinator on the telephone or videoconference. I can hear the other people in her office talking, and once heard a pigeon falling down her chimney when she was working from home. She occasionally responds to the people in her office and last week someone brought her a cup of tea in the middle of our appointment. It would be better if she went into a private room, as she would do if I was seeing her in person. It feels less private and secure."

@RelapseRover, Mad Covid Diaries

Issues of privacy, confidentiality and sensitivity are of paramount importance when designing and implementing new ways of working with service users as a result of COVID-19.

9. CARE PLANS MUST BE COLLABORATIVELY REVIEWED REGULARLY TO ENSURE THEY REFLECT CURRENT CIRCUMSTANCES AND RESTRICTIONS.



Reviewing and amending care plans regularly during COVID-19 will help ensure that they reflect current needs in light of the impact the pandemic, and service changes, may have on someone's mental health. It will also provide an opportunity to discuss individual circumstances, as detailed in our first recommendation, to ensure no one is left behind. We have heard that lockdown and the 'new normal' have had a significant impact on the ability of many people to use or access coping strategies and support networks. These are often contained in care plans and are referred to when people are in crisis. Hattie spoke about this during the Mad Covid Symposium:

"...I think there was a lot of adjusting and trying to cope in the absence of all of the coping mechanisms that I'd learned and ...that helped - so seeing people and being able to rationalise my intrusive thoughts. I couldn't do any of that anymore so it was hard to like relearn all of those things"

Hattie, Mad Covid Symposium

As well as having a chance to discuss alternative coping strategies, care plan reviews will also provide an opportunity to discuss preferences for in person or digital contact and any support required to access services digitally. Speaking at the Mad Covid Symposium, Andrew emphasised the importance of care planning during COVID-19:

"...I think care plans should now be reviewed so that we can not only revise our own coping strategies but we can talk about how we want our care to look going forward. We need, as I said earlier, we need more emotional support at this time not less."

Andrew, Mad Covid Symposium

Person-centred care planning must be prioritised as staff navigate how to meet the specific preferences and needs of service users arising from their experience of COVID-19.



10. WORKFORCE TRAINING NEEDS RELATED TO COVID-19 MUST BE IDENTIFIED AND TRAINING PROVIDED ACCORDINGLY.

Whilst COVID-19 has been an evolving situation, it is important that mental health services recognise that additional training needs related to the pandemic have arisen, and will continue to arise. It is their responsibility to remain abreast of current guidance and evidence. Additional training needs may include the use of digital platforms and the barriers these pose for people with severe and enduring mental health conditions. It may include the risks COVID-19 poses for some people. For example, during the early stages of the pandemic information was released about the potential increased risks COVID-19 posed for people taking clozapine, which Andrew spoke about at the Mad Covid Symposium:

"...when I first heard about COVID I was quite anxious about the infection risk. I got no information I had to do all the reading myself which is fine, I'm a researcher, I can access journals and things like that, I read one paper that suggested that people on clozapine are at greater risk of pneumonia and so they were theorizing that we might be at greater risk of COVID and Rethink initially issued some guidance that suggested people on clozapine might even consider shielding so as you might imagine in the early days you know that was confusing it was worrying"

Andrew, Mad Covid Symposium

Further training may be required in relation to PPE. Whilst she was an inpatient, Nell noticed that PPE regulations were not being adhered to by all staff:

"It was a really strange feeling where COVID-19 was very visibly present in terms of staff wearing PPE, but also it wasn't present because it wasn't always taken very seriously I felt sometimes. Staff would pull their masks down sometimes to talk to you."

Nell, Mad Covid Symposium

Service providers must ensure that additional training needs related to COVID-19 concerning new ways of delivering services, in addition to the impact the pandemic itself may have on people with severe and enduring mental health conditions, are identified and training provided accordingly. Mechanisms must be in place organisationally to identify and disseminate information to staff at pace.

**11. SERVICES MUST
COMMUNICATE CLEARLY AND
CONSISTENTLY ABOUT CHANGES
ARISING DUE TO COVID-19, IN A
TIMELY MANNER.**



A widespread concern shared by those engaging with Mad Covid's projects, particularly in the early days of the pandemic, centred around the absence of timely and consistent communication about the impact COVID-19 would have on the availability of community mental health services. This was an anxious and uncertain time for many people with a mental health condition, which was compounded by a lack of information from services themselves. Phone calls made to community teams were often greeted with uncertainty and ambiguity. Some people didn't hear from their teams for weeks, and those that did often received a blanket letter instructing them to ring if they needed support.

More recently, concerns have been expressed about the discordance between what is espoused publicly by CEO's and service managers, and the experience of service users who are accessing services. Transparency about the reality on the ground is key to avoid causing greater confusion and uncertainty at a time when clarity and consistency is needed.



12. GENUINE CO-PRODUCTION MUST BE CENTRAL TO ALL SERVICE DEVELOPMENTS, INITIATIVES AND CHANGES ARISING DUE TO COVID-19.

It has been widely acknowledged that co-production, or the involvement of people using mental health services, has been poorly implemented during COVID-19. Whilst services were under pressure to act with haste early on in the pandemic, and perhaps we could forgive a lack of involvement at that point, but that lack of meaningful involvement demonstrates the absence of people with lived experience in decision making roles within services. It also clearly demonstrates the lack of infrastructure to enable involvement at pace. Underfunded and poorly valued involvement or co-production predates COVID-19, however, now more than ever it is essential. Tamar spoke about the frustration she has recently experienced as a lived-experience practitioner during COVID-19:

"To co-produce you need to have some lived experience people who are leading on that along with other people... If you're going to come up with a strategy, you need to have people with lived experience working with you on the strategy. Don't say the group's co-produced when it's all being done by non-lived experience staff."

Tamar, Mad Covid Symposium

Service users/survivors have to be at the table when decisions are being made, and must have equal influence during the decision making process, for genuine coproduction to occur.

Conclusion

On the basis of the Mad Covid Symposium and our other projects, we offer these 12 practical recommendations to improve service user experience of mental health services in this lockdown, and in any future lockdowns. These 12 recommendations sum up what many service users have said about their needs and preferences. We ask that professionals listen to, take on board, and respond to what service users themselves are saying here. We urge that services learn from past mistakes and are more proactive going forward. We ask that services urgently review how these recommendations can be quickly implemented in services in everyday practice. Our hope is that service users will get the support and help that they need, and that they deserve.



MADCOVID.COM

#MadCovidRecommends