Rethink Mental Illness COVID-19 Briefings
COVID-19 and support in the community: social care, carers, and peer support

1. Executive summary

Though clinical support is a vital component of care, people severely affected by mental illness need more than this to lead healthy and fulfilling lives. This objective cannot be achieved by medical treatment alone. Our beneficiaries rely on a far wider network of services to help them stay well.[1] It is vital that these are in place to ensure that the NHS Long Term Plan[2], which prioritises services for people severely affected by mental illness for the first time, is delivered.

Some of these forms of support are dependent on statutory services, while others are reliant on the support they need from their loved ones, or the support they provide each other. This briefing covers three key topics under this umbrella: social care, carers and peer support.

Our findings reveal that in many cases it is carers who have picked up the additional burden that the pandemic has placed on their loved ones and from the difficulties people severely affected by mental illness had faced in accessing other forms of support. **They also reinforce the importance of social care and peer support to people severely affected by mental illness**, in many cases by their absence during the pandemic**.**

Overall, they show the need to expand social care and the benefits to peer support to more people severely affected by mental illness in the longer term, and to double down in our efforts to support their carers. The recommendations we make focus on improving the scrutiny, transparency and accountability of the system during and after the pandemic and on expanding the number of people severely affected by mental illness who benefit from these forms of support in future.

2. Context

The Care Act 2014 is the major piece of legislation that governs social care in England. Under it, local authorities have a duty to assess whether people have ‘eligible needs’ for support in areas such as getting out of the house, keeping safe, maintaining a clean home, managing money, preparing meals or in making a contribution to society. If a person has ‘eligible needs’, local authorities conduct a financial assessment to see whether they should charge for these services. Carers are also entitled to an assessment under the Care Act.[3]

The Coronavirus Act 2020 made several changes to the Care Act[4] known as Care Act easements. Where these are activated, local authorities no longer have to carry out detailed assessments but should are still required to respond within a timeframe that does not jeopardise a person’s human rights. Financial assessments are no longer required, but local authorities have the power to charge retrospectively. Local authorities are no longer required to prepare or review care and support plans , and the overarching ‘duty’ to meet eligible care and support needs has been downgraded to a ‘power to meet’ them.

Before the pandemic, as NHS England’s Community Mental Health Framework sets out, Care Assessments were difficult to access and ‘not having such an assessment can mean that people cannot access personalised support and advocacy, welfare advice and employment support. This in turn can risk poorer mental health’.[5]

Carers assessments were even more challenging to access. In the 2019 State of Caring report by Carers UK[6], only 27% of carers said that they had had an assessment of their needs, or a review of their existing support, within the last 12 months. We are concerned that the emergency changes to the Care Act threaten to make this status quo far worse for people severely affected by mental illness and their carers, with needs only being met at or close to the point of crisis, with potentially damaging long term implications.

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[1] Rethink Mental Illness, Building Communities that Care, June 2019.

[2] NHS England, NHS Long Term Plan, January 2019

[3] Rethink Mental Illness, Social Care Assessment Under the Care Act 2014

[4] Department for Health and Social Care, Care Act easements: guidance for local authorities, May 2020

[5] NHS England, The Community Mental Health Framework fo Adults and Older Services, September 2019

[6] Carers UK, State of Caring 2019, July 2019

Eight councils have so far notified the Government that they have activated easements to the Care Act,[7] but concerns have been expressed in confidence with Rethink Mental Illness that the number of areas not applying the Care Act to its full extent may be much higher.

The findings of our survey point to the level of support our beneficiaries receive falling since the pandemic, in many cases with a dramatic impact. Though we cannot attribute these directly to an easing of support under the Care Act, they reinforce the value of social care to people severely affected by mental illness and their carers, a need to ensure this support continues through the pandemic and to ensure it is expanded we move out of it..

3. Our findings on social care and carers

3.1 Remote support

Over the 194 people who answered our question on how the social care support they receive has changed since the UK was affected by coronavirus, 45% said it had got worse or much worse, 28% said had stayed the same, and 6% said it had gotten better or much better. The qualitative responses we received suggest that many people are receiving remote support, rather than face to face help they had previously.

'I was supposed to be assigned a personal carer, who was to visit me and take me out. This was put on ice. I only receive phone calls from a social worker'.

'I was having six hours of support workers a week to keep engaged in my mental health support and treatment but now it's a few phone calls a week'.

'I need more than a phone call. It is challenging to keep going'.

We heard of examples of staff going above and beyond, doing their best to deliver as much support as possible in difficult circumstances.

'Instead of one 2 hour session with my support worker face to face, she is ringing 4 days a week for 25 mins. Obviously, she can't help with practical things so easily, but it's helped having more regular daily input, albeit by phone. There are pros and cons'.

3.2 No support

However, when asked how their support had changed, the most striking aspect among the quantitative responses was the number of people who are currently going without any support at all, in some cases having made a proactive effort to contact services.

'My support worker has refused to see me for 2 months'.

'I haven't heard from my social care worker since lockdown was implemented'.

'I am supposed to have fortnightly contact with my social worker, but my social worker has not made proper contact with me in over three weeks'.

'I now have less care and support. I am unable to have my personal assistant working due to lockdown. I have not been assigned a new social worker and have no support from council or social care to check in on me'.

3.3 Exacerbating existing issues with access to care

Some of the responses we receive point to existing issues within the social care system that have been exacerbated by the pandemic. We heard of issues with people struggling to access support having moved house, and where assessments have either been paused, or slowed further by the pandemic.

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[7] Disability New Service, Coronavirus: concerns over councils 'rushing to free themselves' from Care Act duties, April 2020

'I was previously getting up to 3 care visits a day because of my physical needs, but also checking that I was OK mentally. I had to start again when I moved and they are now providing no support or help at all. I have not even been reassessed and can't be'.

'It hasn't changed because of the pandemic, I had it withdrawn due to the member of staff being moved to a different area and she was never replaced. I have gone downhill drastically since I lost her support'.

'I don't see my social worker but they can't do anything to improve my situation. I was supported to be getting a supported living flat but everything is on hold. I've already waited two years'.

'I am in the process of being assessed by social services. They have paused the process of the assessment so not able to get any further with this. They are so slow. I first was referred in the autumn. I was awaiting more of the assessment process from their finance team but they won't do this by phone so therefore cancelled until after the pandemic as they insist on home visit'.

3.4 Section 117 aftercare

Despite assurances we have received that Care Act easements do not apply to people in receipt of Section 117 aftercare having been detained under the Mental Health Act, one of the qualitative responses we received shows that this is not always the case.

Though only one respondent mentioned Section 117 aftercare, we did not prompt for this, and it may be that more people who took our survey are supposed to be in receipt of it. In any case we can reasonably assume that where there is one instance, there are more.

'I have Mental Health Act Section 117 aftercare in place and receive help at home with cleaning and decluttering. I haven't had it for 8 weeks'.

3.5 Impact on mental health

The reduced support that people receive is having a negative impact on their mental health. Social care clearly provides an important window into the world, practical support and helps people get out into the community.

'I don't receive any support which has left me alone with only my thoughts. I understand the virus is a physical condition and people sadly die, but mental health problems are also disabling and people will also be dying from suicide due to the isolation and loneliness'.

'None. I sleep under sofa where I feel safe'.

'I have support workers who usually administer my meds daily, they usually help me food shop and help me clean my flat but they aren't able to do anything apart from the meds call. I am doing my food shop online but it is hard to get delivery slots and I struggle with the anxiety around shopping because of my eating disorder'.

3.6 The burden on carers

The impact of the pandemic on carers of people severely affected by mental illness has been dramatic. Many of the responses we receive showed that carers are picking up the additional burden from the difficulties their loved ones face in accessing the services that they normally rely on. These cover clinical and social care services, as well as forms of community support.

'My wife is the recipient of support and treatment which has been halted since the lockdown. As a result her fragile mental health state has deteriorated impacting us every day in every way'.

'My Mother's care plan is now not really being implemented by the Care agency. As a result I'm having to do more to get Mum to eat'.

'My daughter's ability to live independently, always limited at the best of times, is now non existent. Her physical health is deteriorating, reducing her chances of resuming her former living situation, and causing extreme anxiety for all of us'.

'No day centre provision and no respite care. This has left my family very exhausted from caring and they are still expected to work from home and still provide care for me'.

'The support services my son uses are closed. His CPN only telephones him once a week with no personal visits. He has been let down and no one cares'.

'My son's mental health has dramatically deteriorated. His day centre has closed for 12 weeks, his carers have stopped attending due to shielding our son. As such he is now self-harming and extremely volatile. He thinks that it's us not allowing him to go out. This has put immense pressure on the rest of the family'.

4. Peer support

Peer support will always be a key part of helping stay well, whether they come together to support themselves or each other, using wider community resources or groups designed to help them with other issues they face in their life. Many of these services have paused or moved online.

In common with many of the other issues we asked about, some have adapted to this well, but for the majority of things are either not the same or unsuitable. The most striking findings here were the range of different types of support people severely affected by mental illness rely on and the impact their inability to access many of them during the pandemic has had.

'I am part of a peer support mental health group and we now are part of a WhatsApp group to keep in contact. We are trying to keep in contact daily now which is good'.

'My local group is for people who have been bereaved by suicide and they are in the process of going live on Zoom, so that people who are isolated can access help remotely.

'I use alcoholics anonymous and there are no groups to go to. The meetings make you feel safe. I know I can go on the computer but I do not feel comfortable talking to people in that way

'At the moment the places I would use for support are closed. We do have a weekly catch up but again it's not the same'.

'I used to attend a peer support group hosted by chaplains. It was the only weekly activity that I always attended and felt safe at. I have not left my home or seen anybody since being discharged from the medical hospital after my overdose.

'Occupational services which were trying to get me use to being in a public place with other people. Also to help deal with my anxiety with people around me'.

'I normally use a crisis cafe if I feel unsafe at home, they are running an online support on zoom but sometimes if I don't leave my house I self harm and having a safe space to go to prevents it'.

5. Conclusion

Our recommendations below centre on four central areas: improving scrutiny, transparency and accountability, expanding the number of people severely affected by mental illness and their carers who benefit from social care in the longer term and expanding the number of people who benefit from peer support.

This means ensuring that we have a full understanding of when Care Act easements are enacted, clear processes that should be followed when they are, and that the populations affected have a clear picture of what these mean. Understanding the impact of any reduction in support under the Care Act for people severely affected by mental illness will also be vital in the longer term. In the short term, it is clear that face to face social care support is vital, and we urge services to maintain face to face contact wherever and as soon as it is safe to do so, in line the recommendation we made in our previous briefing on access to mental health services.

It is also vital that people on already low incomes aren't faced with the bill for the support that they receive during the pandemic, and that longer term funding reforms focus on expanding social care to everyone who needs it, not only those with financial assets. Not doing so risks jeopardising the vision set out in the NHS Long Term Plan[8].

It is clear that in many cases it is carers who are picking up the additional burden caused by the difficultly in delivering statutory support of all kinds to people severely affected by mental illness. It is vital that we reverse this trend in future, particularly in light of the demands placed on carers over recent months.

Lastly, our findings clearly demonstrate the value of peer support to people severely affected by mental illness. Increased central funding for services provided by Mental Health UK and the launch of the online peer support service Clic[9] shows that this has been recognised. We believe this needs to go further so that more people severely affected by mental illness are signposted to the support and services they need.

6. Recommendations

- Local authorities should request permission activate Care Act easements, rather than notifying the Government once they have done so, in line with Mental Health Act safeguards. Following guidance on Care Act easements should be mandatory, strengthening the current requirement to have regard to guidance when easements are activated.
- Where easements are activated local authorities should publish clear, accessible information and advice targeted at services users and carers on what easements mean for the support on offer, in line with existing duties set out in the Care Act.
- An impact assessment of changes to Care Act should be conducted to understand what they have meant for people severely affected by mental illness and other disadvantaged groups.
- Face-to-face social care support is reinstated wherever possible as soon as it is safe to do so.
- Nobody in receipt of social security benefits as a sole source of income should be charged for the social care they receive during the pandemic. Longer term funding reforms should go beyond financial assets alone to ensure more people who don't meet this threshold also receive support.
- We ask the Government to examine why Care Act assessment for carers are so rare, how they can be expanded, and to work with carers services as part of this process.
- We repeat our call from the Building Communities that Care report for an expansion of peer supports workers to help more people severely affected by mental illness.

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[8] NHS England, NHS Long Term Plan, January 2019

[9] Mental Health UK, https://clic-uk.org/, launched April 2020

Appendix on research

Our online survey ran during April and May was completed by 134 people in receiving social care and a further 78 who do not receive support currently but have in the last 12 months, 396 carers. A further 259 use community services and support groups currently, and 185 who have used them in the last 12 months. We have sufficient permissions to recontact each of these groups and conduct further research.