Being

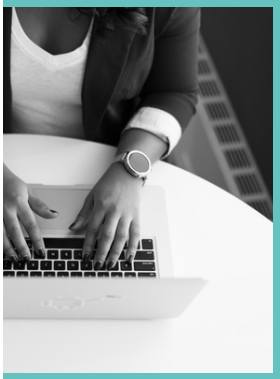
Many Voices, Many Needs

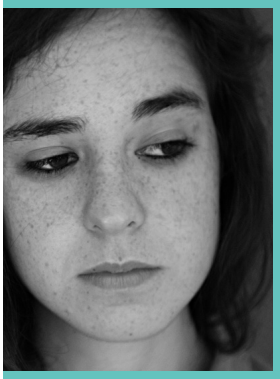
Consultations with people living with mental health issues at the onset of the COVID-19 crisis

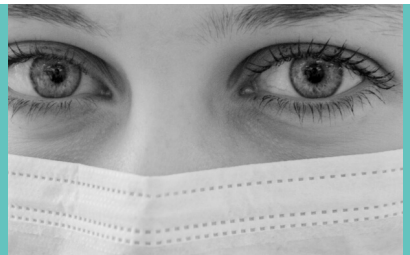
April 2020





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BEING would like to take this opportunity to thank all of our members and allies who provided feedback through participation in our survey, Zoom meetings, or via online platforms. The staff at BEING would not have been able to compile such a report without the vital voices, perspectives, and views of our members and our broader consumer community. Our heartfelt thanks go out to you.

Introduction

As the COVID-19 crisis has developed, BEING has carried out an online survey and a series of Zoom meetings with consumers, as well as a Zoom consultation with peer workers in NSW, to better understand their needs and challenges in the face of the pandemic and to keep them updated about new mental health developments. We heard from 71 consumers via our online survey, 35 consumers via the two Zoom consultations which we held and 20 peer workers who also participated in a Zoom consultation.

Consumers made clear that there is desire both for services to fill gaps that have been lost as face-to-face support has been withdrawn, as well as for new services that help to address needs that result from the COVID-19 pandemic and the public health measures that are currently being enforced. Regular Zoom meetings, teleconferencing, digital peer supports, social media groups and even peer-based text message-based call back services were some of the suggestions made for alternative services that could contribute to filling in these gaps.

There were also calls for technical support services to be provided to assist those who have access to technology, but whose technological literacy levels are low. It is vital to ensure that we do not forget the many people who fall on the less privileged side of the digital divide. Just as some Australian states have implemented measures to ensure that all students can access onlineeducation if it is needed, it is also vital in the mental health sector that we adopt an approach that can ensure that everyone who would like to participate in online alternatives to face-to- face service provision is able to.

In relation to peer workers, there is a risk that their skills and knowledge will not be utilised as effectively as they could be in this situation. We have heard from peer workers that many of them would like to continue providing support to their clients. However, in some cases they require support and additional professional development strategies to develop technology skills and support with expanding the toolkit of interpersonal skills which they use to include online support as well. We were saddened to hear some peer workers express frustration and uncertainty at the possibility of their hours being cut as a consequence of the state-wide focus on biomedical and clinical services during COVID-19.

With the radically altered workplace and personal challenges which peer workers are now confronting, there is also a need for support services for peer workers themselves, such as peer supervision and mentoring.

In line with two of the key requests made by peer workers involved in the consultation, BEING is already progressing work to develop a model of individual and group peer supervision for NSW peer workers, as well as an online forum that will allow peer workers in NSW to share learnings and provide mutual support.

Recently the NSW Parliament also assented to the *COVID-19 Legislation Amendment (Emergency Measures) Act 2020 No 1.* BEING sought comment from our members and the broader consumer community about the short-term amendments that have been made to the NSW *Mental Health Act 2007 No 8.* We carried out a series of Zoom consultations around this topic. As well as helping us understand how people with lived experience felt about the amendments and the process followed to develop them, it also allowed us to add to the information we had already collected about people's needs and fears more generally at this difficult time.

While this last section of the report refers to NSW legislation, we feel some of what it says has weight in all states. In particular, the importance of ensuring that consumers, or at the very least key consumer representative bodies, such as BEING, are consulted when such changes are to be made. It is not adequate to simply make such changes without processes of co-design, consumer participation and engagement, or at the very least (and not the desired outcome) to advise consumers of the changes as they take place.

This report is broken into three sections to reflect this information gathering process. The first of these covers the consumer survey and is broken down into the key questions which we asked people with lived experience to address. The second section provides an overview of the key insights collected in our discussions with peer workers in NSW. Finally, the third section addresses issues raised around NSW Mental Health Act amendments.

The recommendations below address some of the key needs and concerns raised in these discussions.

Recommendations

1. Consumer survey recommendations

- A clear mental health plan for NSW to cover both current COVID-19 environment, as well post COVID-19.
- Lifting of restrictions for people to move and exercise during COVID-19. This includes an acknowledgement that the enjoyment of outdoor activities, including walking, running and swimming are pivotal to people's mental health and wellbeing. The inclusion of outdoor activities to the list of 'Essential activities' should be specified for people living with mental health issues.
- Clear messaging through a central portal or website identifying new mental health services that have been established due to COVID-19.
- Provisions made for people in inpatient units to access leave, visitors, and activities focused on wellbeing and skill building strategies.
- Consistency of service provision and messaging across NSW mental health facilities during COVID-19.
- Reasons for leaving home during enforced measures should include 'for self-care purposes'.
- Establishment of online and telephone peer support services and increase in peer run and support services.
- Non-pathologising normal human emotions during such abnormal situations and times.
- Alternative measures to replace face-to-face support groups during COVID-19.
- Technical support for the less technologically literate individuals to ensure that lack of familiarity with technology does not exclude them from online social support opportunities.
- Provision of funds to purchase hardware and connectivity for people living with mental health issues who are not currently able to afford them.
- Ensure that all government language and messaging are clear and consistent.
- Provision of accessible services to help people manage negative, or self-destructive coping strategies, such as increased consumption of drugs, alcohol, and tobacco during the pandemic.
- Provision of funding for a national peer run mental health peer support warmline and online peer support service.

2. Peer worker recommendations

- Clearer parameters for scope of work for peer workers during COVID-19, particularly for NSW Health peer workers.

- Provision of individual and group support for peer workers delivered by appropriately qualified peer supervisors.
- A firm understanding of the intrinsic value of peer work by key stakeholders. That is to say that peer workers have historical experience of building resilience and hope during challenging times and as part of their recovery. They have the ability to support others in difficult and distressing times.
- Upskilling of peer workers to adapt to the needs of warmline and online peer support provision.
- Development of a targeted Facebook group/online forum that is not connected to NSW Health or their individual organisations for the purposes of mutual support and connection.
- Provision of clear and timely information for peer workers to reduce information overload and improve their capacity to assist clients.
- Provision of Zoom, or other web conferenced meetings in the workplace to allow for mutual support and shared problem solving (some identified they do not have such provisions).
- Provision of self-care information that targets the specific needs of peer workers.

Consumer Survey Results

Through the survey questions listed below, BEING was able to collate valuable information of the impact that the COVID -19 pandemic is having on people who live with mental health issues in NSW.

1. Since the COVID-19 crisis escalated how has your mental health been affected?

People had a range of different responses to this question, however increased anxiety and depression levels were common, as well as increased feelings of suicidality and desires to self-harm. A small number of participants noted that they had attempted suicide in this period and others noted an increase in suicidal ideation, as well as an increase of unhealthy coping strategies.

Increased levels of stress were also noted. One person noted that there was now more to cope with as a result of having children at home and having to deal with constant uncertainty, saying "It's hard having kids at home, no matter if they are young ones and parents try to adapt, or older ones who come back home after creating lives of their own". Another person said that it was harder to manage stress when their usual stress management activities were no longer allowed.

Another participant with a diagnosis of Obsessive-Compulsive Disorder (OCD) said that over this time their OCD symptoms had worsened. "My handwashing, showering when coming inside has increased and I am wiping down and washing all supermarket food". One person mentioned the need to throw their clothes away each time they returned home from a shopping trip.

Some people said that the loss of visits from support workers had impacted their mental health more than worry about the coronavirus itself. Some have also found that aggressive and rude behaviour resulting from panic buying in supermarkets made it very challenging to go out and shop. In the current situation it has become necessary to manage not only one's own emotions, but also one's responses to the extreme emotions many people are currently feeling.

For some people, the combined effect of drought, fires, floods and now the COVID-19 outbreak, has really left them struggling. It has been more challenging for people to apply their usual strategies for managing difficult and overwhelming emotions in the face of the sheer volume of distress produced by these events and their rapid succession. It is vitally important to remember that in Australia we are experiencing not a single crisis, but a string of crises, which has unfortunately culminated with the COVID-19 outbreak.

2. What types of mental health supports and tools do you need at the moment?

An overarching theme of the consultations included the enforced restrictions during COVID-19. Many reiterated how the isolation and social distancing measures exasperated their mental health conditions and compromised their wellbeing. Participants were respectful that these are challenging times and some restrictions are needed, however many became distressed during such restrictions. Many participants requested for exemptions to be made for people living with mental health issues to be able to participate in activities which contribute to their recovery journey and their personal wellbeing. Specifically mentioned, the need for people to continue to visit outdoor spaces such as beaches and national parks, and sacred spiritual spaces such as churches and mosques, although some mentioned national parks as being their 'sacred spaces'. One person was noted as saying "the only thing that keeps me well is running. I run every day. Now I can't run. I am starting to feel suicidal again. If only they would let me run, I know I would be fine again", and another "walking is my life. Take my walking away, and you take my life away. But do they really care about me, if I live or die?" It is important to acknowledge that different people have different ways of caring for their mental health. For some it is their pets, for others it is exercise and for others it is important to have opportunities to be in nature.

Quite a few respondents said that it would be very helpful to have increased access to therapy services via tele-health. This included both talk therapy and psychiatry. Some of the changes that people were hoping for may already have been achieved with the Federal Government's sweeping changes to tele-health bulk billing. However, it is still vital to ensure that everyone who needs to know does know about these services. With such rapid changes occurring it is especially hard for people living with psychosocial disabilities to stay up to date.

In addition, there were many requests from participants and survey respondents for lower intensity online support or opportunities for social connection, such as peer support telephone and online programs. Peer support call back services were noted by people as being an essential need, with one person saying "It's essential to me. I wish I could have a peer support worker ring me and check on me, even just for a chat. I wouldn't need hospitalisation then". A small number of people mentioned that they like not having face-to-face contact with others, with one person noting "I like being away from others but find it hard to". This demonstrates that it is important to remember that for some people living with mental health issues non-contact or non face-to-face methods of connection are preferred modes of interaction.

There were suggestions that various designated services be made available which target people who are developing mental health issues as a result of our current difficult circumstances. These included peer support services to learn breathing and meditation techniques to assist with stress and anxiety management. Peer support was mentioned here to ensure social connections.

Some people also said that they found it very helpful to have someone to talk to that was not just a family member. Many recognised that they are isolated from family and friends and expressed it was hard to talk about their feelings and emotions at this time. Many also mentioned that they did not want to contact clinical services for fear of being hospitalised. A proportion of participants and survey respondents expressed feelings of self harm and suicidal ideation during this time. A small number of people identified that they had attempted suicide since the social distancing and enforced restrictions took effect. Many again reiterated the importance and tremendous value of having peer support services as an alternative to traditional mental health services during such times of distress. It was noted that participants and survey respondents believe that peer support workers share hopes, dreams and aspirations with their clients, demonstrating resilience and positive coping strategies during times of stress and strain. One participant was noted as saying "my peer support worker is my role model, if she can do it then so can I. If she can get through tough times, and there have been a lot from what she told me, then I can get through COVID-19 with her help".

Another very important suggestion made by one respondent was provision of parenting guidance and support. A number of people said that they were worried about supporting their children through this difficult time, but also felt that additional support would be a great help to ensure that not just their own, but also their family's mental health and wellbeing was supported as much as possible. A few people referred to having adult children at home, with one person saying, "they moved out nearly 3 years ago, now they are back, it's just constant fighting and I can't cope".

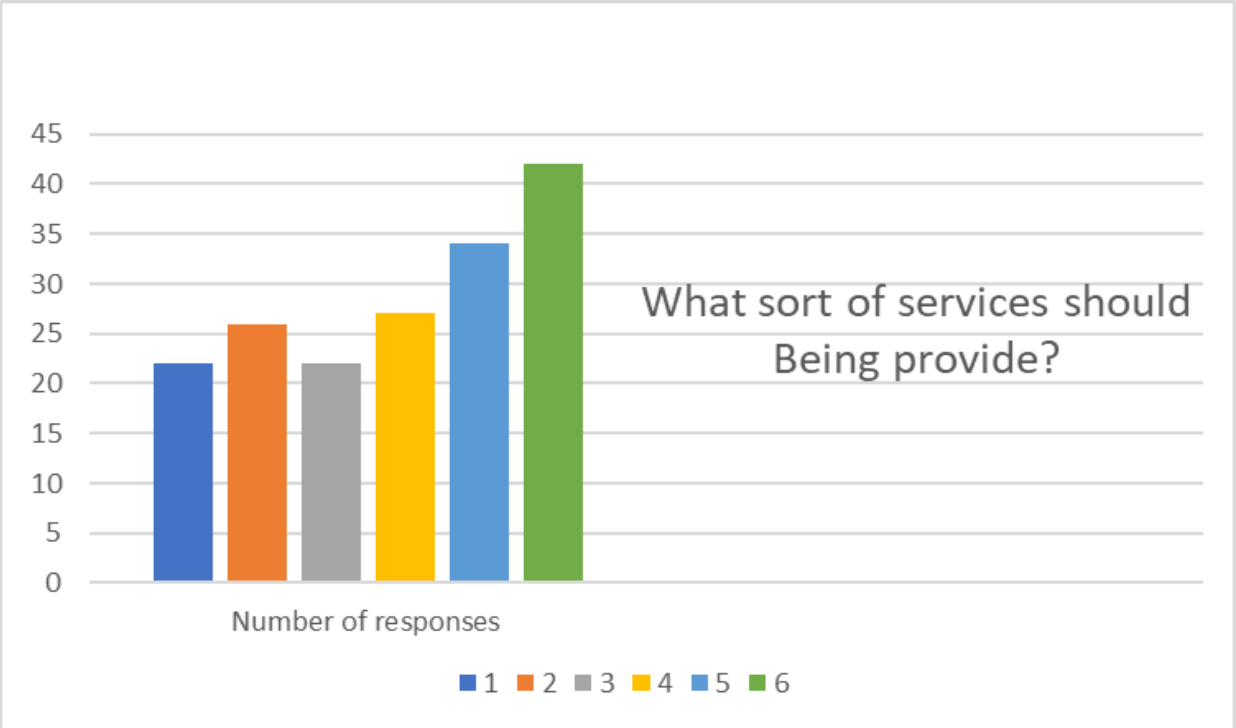
Some participants raised concerns with inpatient unit stays during COVID-19. Many shared that they feared being 'locked up' without visitors or leave. Several people expressed that there already exists a lack of activities in inpatient units, and people asked if it would be possible to increase activities during this time, particularly those which were meaningful. One participant is noted as saying "I hope they look at the activity programs. My recent stay only had reading newspapers and talking about the news of the day. We also played bingo. How is that meaningful, stimulating? How's it going to help me when I'm out of here?"

The topic of leave in inpatient units was once again explored, with many stating that they would only access traditional mental health services if they could be assured that they could have leave as needed. Participants clearly expressed that they would avoid inpatient units at all costs if they were not guaranteed leave prior to admission. One participant was noted as saying, "I've been locked up with no leave and it was hell. Why would I put myself in that situation again?" Another participant mentioned "I'm not going near the place. I'd rather be outside and free rather than being locked up and them throwing away the key".

3. How can BEING – as the peak organisation for people with lived/living experience of mental health issues – better support you during this time? [1]

Key to chart and numerical data

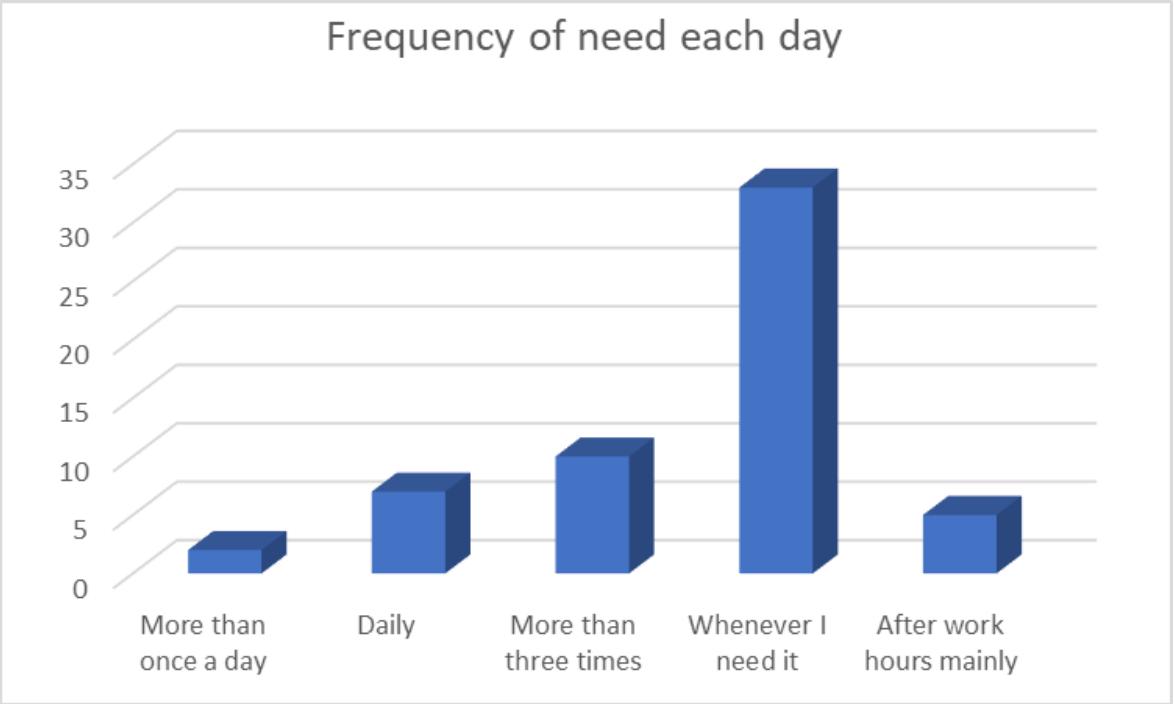
	Service	Number of responses	Percentage
1	By operating a 9am to 5pm phone service	22	38.6%
2	By operating an after-hours phone line	26	45.61%
3	By operating a 9am to 5pm call-back service	22	38.6%
4	By operating an after-hours call-back phone service	27	47.37%
5	By operating a Facebook support group for people with lived experience of mental health issues	34	56.65%
6	By running regular online meetings using video/audio platforms for people with lived/living experience of mental health	42	73.68%
Total Respondents		57	



[1] Note that the total number of respondents for this question is different to the total number of respondents overall as not all respondents answered this question.

4. How often would you anticipate accessing some or all of the health support services mentioned in question 3? [2]

Frequency of need each day	Number	Percentage
More than once a day	2	3.51%
Daily	7	12.28%
More than three times a week	10	17.54%
Whenever I need it	33	57.89%
After hours mainly	5	8.77%
Total respondents	57	



[2] Note that the total number of respondents for this question is different to the total number of respondents overall as not all respondents answered this question.

5. What impacts and tensions do you anticipate might result in your life from forced isolation?

Respondents to the survey shared a wide range of concerns in response to this question. The list of concerns raised included: overeating, smoking too much, relationship issues and balancing supporting children with study and work from home commitments. Importantly, these concerns are a mix of psychosocial and non-mental health issues. It will be important to provide holistic support for people living with mental health issues, to ensure that physical health issues are also addressed during this time in a coordinated way and that cross overs between physical and mental health are kept in mind when support is provided.

One person was concerned that isolation would create more time for rumination and leave them in a situation where they had decreased levels of structure and routine. In line with this concern another person suggested that assistance with establishing a new routine would be helpful at this time as a service offering, or component of a service offering. While having a routine is helpful for most people, not everyone finds it easy to establish a routine and this can be especially true for those living with mental health issues.

One person was worried about a sibling who works in health care and many were concerned about elderly relatives. People with mental health issues share some of the same concerns which many other people in NSW have about the health of their loved ones. Others said that they worried about how they would cope with supporting children who also felt isolated and more stressed than usual. A number of respondents noted difficulties with children or partners who have a diagnosis of Autism Spectrum Disorder (ASD) and the challenges with the many changes at this time. Similarly, another person was concerned about the challenges of explaining the current situation to her mother, who is living with dementia.

Some people expressed fears about whether or not their relatives with physical and psychosocial disabilities would have the supports that they have previously come to rely on during this time. Given the reductions in levels of service that have already been experienced by some people living with psychosocial disability, it's clear that some services are already not running as a result of the impact of COVID-19. Thought needs to be given to providing some social and support services that can replace services that are not running as usual at this time. It would also be helpful to review which social care services have now been closed as a result of COVID-19 related concerns, and ensure that this information is relayed to people who use these services in a sensitive manner.

Other fears and worries people had were relating to finances, housing and access to essential everyday items such as food and toilet paper. It seems clear from these concerns that it is important to provide more information to people who live with mental health issues around these areas. Although housing security in the private rental market is being addressed by the federal government, it is not clear how that issue is being managed in NSW public housing. Manypeople who live with debilitating mental health issues also live in public housing. More information is needed about the potential impact on people living in public housing.

Fears about medication security could also be allayed with more information. Recent panic buying in pharmacies around key items, such as Ventolin inhalers is sure to leave some people feeling anxious about the ongoing availability of medications which they and their relatives

rely on to maintain their health and wellbeing. Some people indicated that they were unable to purchase psychotropic medications and specific autoimmune medication as components of such medications were being used to treat COVID-19 positive patients.

Unemployment was a significant issue for many, with a number of people noting that being suddenly unemployed and at home with family led to more arguments with both parents and partner, and to an increase in domestic violence and suicidal ideation. One person noted "I am with my family day and night now; it's just too much being locked away with them. We fight all the time".

Others raised concerns with exacerbation of conditions such as anxiety and depression, with some specifically noting that their agoraphobia had become worse than pre COVID-19. On the flip side, a small cross section of people who identified with a diagnosis of agoraphobia said that they were used to being housebound and therefore social distancing enforcements and social isolation did not affect them.

Some people also expressed concerns that they would not be able to get adequate support from family members, or would feel reticent about sharing, because the people who are normally able to offer them support are also struggling emotionally at this time.

Overall, most expressed concerns with social distancing enforcements and the inability to go out. Many expressed that natural places, such as beaches and national parks, contributed, and in many cases were integral to their mental health and wellbeing. Some went on to identify that the social distancing and restrictions to staying at home had led to increased feelings of self-harm and suicidal ideation as the confinement and being at home for long periods of time raised issues of hopelessness, isolation and loneliness.

Many suggested that the government should take a greater focus on mental health and wellbeing when making such restrictions and allowing people space to be outdoors and exercise. Apart from the health benefits, people express greater feeling of hope when being outdoors. One person shared with BEING "I was contemplating taking my life over the Easter weekend, but then I connected with someone on Facebook. They told me bugger it go outdoors and exercise if that's what it will take to stop you thinking that way. I did go for a walk. I came back and thought about all of the things I had to live for".

6. What supports and services do you think you would need to maintain good mental health if you were advised not to leave your home?

In response to the question, many people expressed a distaste for accessing mental health services during COVID-19. The unanimous rationale was due to two key factors including concerns with contracting COVID-19, and concerns with being assessed and placed in a mental health facility for possibly longer than usual due to COVID-19. Many expressed the need for immediate measures be put in place for alternatives to public mental health facilities, including emergency departments, community mental health, and inpatient units. One person was noted as saying "I'm not going into any services as I know I won't get out. If only there was an alternative to the current system".

One person who already had a relationship with the local mental health crisis team, said that they had concerns about whether their worker would be able to provide crisis support over this period, as in previous situations where support was required they felt that the mental health crisis team did not live up to expectations. Given that mental health crisis teams are also likely to have additional demands placed on them at this time it is vital to consider how these services can be expanded or supported.

Many people identified the importance of having peer support workers to work with during this time. People mentioned the critical role peer workers play in the context of isolation, loneliness, and connection, and in supporting people who self-harm and have suicidal ideation. One participant mentioned "I had access to a peer worker when I was admitted to the hospital, and it made such a difference. It's because of them that I got better. Every time I want to self-harm, I think of them and their words of encouragement. I don't go there now".

One person shared that they would need their pets at this time. Pets will be an important source of comfort for many people during this time, especially for people who already struggled with social isolation prior to the COVID-19 pandemic. This is especially true in Australia where so many of us have pets and consider them an integral part of our family.

A very important point raised by an older aged respondent was the importance of providing technical support to those who are not familiar with videoconferencing and other web-based communications technologies. It is important at this time to ensure that everyone who would like to use these technologies to manage loneliness and isolation is supported to do so.

In line with the above, is not forgetting that some people do not have access to the hardware required for videoconferencing, or even access to the internet at home. There is still a digital divide in NSW and more broadly in Australia.

Peer Worker Consultation

1. Job uncertainty

Peer workers raised several valuable issues with BEING in the Zoom consultation. Of significance to the workforce was the expression of concerns of job security, with several peer workers identifying that their hours had been cut or their jobs were in jeopardy due to COVID-19. Such concerns were across the board of both public health and community managed workers. This is particularly so in the Community Managed Organisation (CMO) sector, where funding may have been compromised in some organisations, and the public mental health sector, which is focused on the biomedical and clinical model. Some peer workers identified that they have adapted to current restrictions by moving towards telephone check ins with clients, but it is evident that not everyone has been able to do so. It is integral that services ensure to maintain this vital workforce, and the supports needed for their security and sustainability.

It is important to note that the concerns raised were simultaneous – for the peer workers themselves and their own livelihood, whilst also for the clients they serve who will have limited access to their current peer worker or no access should the peer worker lose their job.

2. Adapting to new technology

A significant proportion of peer workers expressed a level of difficulty with the move to telephone and online support. Whilst most peer workers are trained to provide face to face support, many are unsure of how to provide such support through technological methods. Similarly, some peer workers identified that their services were not equipped to provide peer support through digital platforms, leaving many peer workers unable to work in ways other than contact by phone.

Further, a number of peer workers were being called on to provide tech support to some of their clients as an added service, despite not feeling comfortable themselves with technology. Some also expressed that they found it difficult to juggle the work of looking after their clients' mental health whilst also providing skills developed in the IT area. Peer workers suggested that some peer workers would benefit from additional IT education themselves if they are expected to provide technical support and/or assist their clients to establish digital and online platforms.

3. Not being able to provide person-to-person support

This is an area that peer workers are finding particularly challenging when trying to support their clients in relation to accessing services to meet their clients' needs, such as Centrelink, safe housing, and shopping. These kinds of supports are particularly important at a time when so many changes are occurring so rapidly and peer workers felt it important for them to be considered in the same vein as essential clinical services.

4. Challenges accessing accurate information about COVID-19

Peer workers expressed difficulty in receiving accurate and up to date information that pertains to their work practices as peer workers. Many mentioned a lack of direction, particularly by NSW Health, to consistent messaging of how peer workers will practice during COVID-19. Many raised concerns with the diversity of working approaches, with some peer workers allowed to work on inpatient units, whilst others have been withdrawn from inpatient unit work. This lack of consistency was questioned with a request for clarity at a systems level.

Peer workers also identified concerns with the lack of information being translated to their clients and the broader consumer community. This was particularly so with the recent amendments to the Mental Health Act in the COVID-19 Legislation Amendment (Emergency Measures Bill). None of the peer workers who attended the consultations knew about the amendments, and therefore were not able to relay this information to their clients. None of the

peer workers who attended the meeting knew about the amendments recently made to the NSW Mental Health Act before BEING advised them of the changes. Many commented on a discontent of not being able to provide accurate information to their clients.

5. Peer worker stress and isolation as a result of working from home

Peer workers described that they themselves experienced increased feelings of anxiety and depression as a consequence of social distancing measures, job uncertainty, lack of role clarification and personal isolation during this time. Working from home and using the telephone all day means that the kind of work they are doing has rapidly transformed from providing face to face support in a variety of different contexts to providing phone support from home. Peer workers noted that no longer having the diversity of locations and tasks that they may previously have had during a normal working day, had led to their own feelings of isolation and loneliness.

6. Clients' fears

Some peer workers' clients are now fearful about leaving home because they fear either COVID-19 transmission, or police attention. Given the lack of clarity around the recent extensions of police powers it would be helpful to provide peer workers with definitive updates in relation to this when required.

Many peer workers noted that they were uncertain as to how to work with their clients in relaying positive messages of hope during such 'hopeless' times. Many of these same peer workers said that they could benefit from positive and hopeful messages from BEING and other consumer run initiatives.

7. Consumer access to technology

Where social groups are moving online, peer workers have experienced challenges because some consumers do not have access to technology, and many peer workers are not trained in such ways of working. Perhaps in some cases, consumers could be subsidised to access technology that would allow them to maintain some level of social interaction during the COVID-19 pandemic. Recommendations for subsidised phones and plans, as well as equipment and internet plans were highly recommended.

8. Overdiagnosis

Peer workers worried that consumers' normal reactions to the high stress levels generated by the COVID-19 crisis would be over-diagnosed as symptoms of mental health issues, rather than simply being understood as normal human reactions to very difficult circumstances.

Peer workers remained keen to ensure that over pathologising of normal human reactions did not become core business of clinicians and mental health services.

9. Increased demands

Some peer workers working in hospital settings have resigned due to concerns with contracting COVID-19 from their clients. This also placed additional demands on peer worker teams and other service staff to fill the gaps. Some peer workers have chosen not to work in the mental health system during this time and this has left others with far more responsibility than they had at an already very stressful time.

10. Different/unclear transition of care processes adding to consumer stress

With all the current uncertainties which are being managed, not only in the health care system, but in the lives of people with lived experience of mental health issues, it is more important than ever to ensure that discharge planning is carried out as early as possible to ensure transparency and thoroughness.

Many peer workers expressed concerns with a lack of discharge planning taking place for their clients, and about people being discharged with uncertainty of available services.

11. Consumers and peer workers feeling less attached over the phone

The changeover to telephone support has made it harder for peer workers to develop robust and trusting relationships with new clients, leaving uncertainty in the mutual relationship.

Many peer workers expressed concerns with the lack of interface for connection work and the transition to telephone support work, for which they were ill equipped.

12. Social media exhaustion for both peer workers and consumers, missing the opportunity to just 'have a yarn'

Like many of us, some peer workers are experiencing news overload at the same time as not having any clear opportunities to share and discuss their feelings and responses with others. Respondents to the survey indicated that they are attempting to remove themselves from social media as a way of ensuring they are not overloaded with the scurry of inconsistent messages and attempted to rely on reliable sources.

13. Clarity about what peer workers are qualified to do – concerns with limited clinical staff that peer workers may be asked to do a medical assessment or medication management

It is important in the current circumstances, where additional demands are being placed on clinical staff, that peer workers are not placed in situations where they are expected to diagnose clients or manage medication compliance. We must ensure the integrity of peer worker roles during this time to ensure role clarity and distinction between clinical and peer worker roles.

Some peer workers expressed that they are being asked to uptake some aspects of clinical work, with many expressing a difficulty in challenging the very system they work in to advocate that such processes are not part of their role. Such lack of clarity from services is causing distress for many peer workers.

14. Peer workers not being included in management decisions, 'being forgotten' in processes

Unfortunately, in the rush to respond to the COVID-19 crisis, in many cases peer workers have not been included in decision making processes that impact them, or their clients.

Many peer workers expressed disappointment in services diminishing co-design and consultative processes, particularly during a time where it is greatly needed.

COVID-19 Legislation Amendment (Emergency Measures) Act 2020 No. 1 Consultation

BEING sought comment from consumers regarding the emergency legislative amendments to the *Mental Health Act 2007 No 8,* which parliament assented to on the 25th of March 2020. These amendments refer specifically to processes to be followed by the Mental Health Review Tribunal (MHRT) about mental health inquiries and Community Treatment Orders (CTOS). The feedback we received from the Zoom meetings is reflected below.

1. Lack of consultation

A key concern relating to the way in which the amendments were drafted and put before parliament, is the lack of consultation with peak bodies and the broader consumer community. Neither BEING, nor other peak bodies were consulted in the drafting of the bill that brought in these legislative changes. As a result of the lack of consultation, consumers in NSW did not have an opportunity to contribute to the formulation of legislative amendments which could

have a significant direct impact on them and their freedoms, if they find themselves in a NSW inpatient unit in the unforeseeable future.

People attending expressed frustration of not having a voice, nor being engaged or consulted on the amended measures. Many addressed gratitude to BEING for releasing their statement shortly after the amendments were passed in parliament and bringing the issues to people's attention.

Further to these consultations, BEING received information from a number of members relating to the Public Health Order and asked for their feedback to be included in this report.

Some of the concerns people raised were as follows:

- Exemptions and exclusions as enforced by the police should include access to natural spaces, such as beaches and national parks, if it is seen to be in the person's best interest for their mental health and wellbeing.
- People noted that the enforced restrictive measures lead to an increase in distress and mental health issues, with many people expressing an increase of self-harm.

Importantly, many acknowledged the disability slogan of 'Nothing about us without us', noting its importance at such times.

2. Adjournment of mental health inquiries

In section 2.13, subsection 202, clause 3 of the *COVID-19 Legislation Amendment (Emergency Measures) Act 2020 No. 1* (the Act), it is noted that the MHRT will be able to adjourn mental health inquiries for up to 28 days. Some participants in our consultations were concerned that this would lead to situations where people living with mental health issues would remain needlessly hospitalised at a time when they felt being in hospital could leave them at higher risk of infection by COVID-19. Many also expressed concerns that personal recovery is best suited to being in community and in their own home environments rather than the inpatient unit environment, whilst some highlighted the lack of activities and mental stimulation of such environments.

Most expressed that COVID-19 introduces a new level of complexities to the situation, however, all participants felt that the parameters of the amendments being due to COVID-19 are unclear. One person asked 'How is keeping people in hospital longer contributing to their wellbeing or in the best interest or meet their human rights'. Another person mentioned "I won't go near the place; I don't want to catch COVID".

Whilst we don't doubt the adequacy of the infectious disease management protocols which will be applied if someone in an inpatient unit is found to have a COVID-19 infection, these comments suggest that it would be useful to inform consumers about the steps that will be taken to balance physical health care with mental health care needs.

If people fear COVID-19 infection, they may not seek the help which they need. As an aid to this it will also be important to ensure that key workers, including peer support workers, are

made aware of the changes. As already noted above, peer workers have informed us that they do not feel adequately informed at this stage.

3. Extension of Community Treatment Orders (CTO)

The amendments also allow for potential extensions of CTOs by up to 3 months, even if this may extend the length of the order beyond the usual 12-month period (Section 2.13, Subsection 202, clause 3, the Act).

Whilst 2 people identified as having positive experiences with community treatment orders and did not feel that the extension was problematic, most participants expressed significant concerns with this approach.

As identified through the consultations, people questioned if consumers would be informed of the new process prior to their hearings or if the first place of notification for the consumer would be at the MHRT itself. If so, many believed that this process was not acceptable and that it breached the consumer's human right to have information prior to hearings, to ensure an informed decision was made prior to the hearing.

Participants from rural and remote areas raised concerns with the new processes for people in their areas. One person from a rural area in NSW expressed concerns that the new CTO measures might lead to people enduring negative medication side effects for longer than needed, noting "I live in a rural and remote area, I get to see my doctor every three months with my CTO. I had negative side effects to my meds and my doctor changed them. So if I am given a 12 monther does that mean that I will be on meds longer? That's not for me."

Consistently, people mentioned that the notion of having a 12 month CTO makes them feel less hopeful of leading meaningful and contributing lives away from public mental health services, many feeling a sense of a longer duration of connectivity to the service, which was not their choice.

4. Lack of clarity about appropriate grounds for applying the amendments

There was concern about the lack of clarity around the grounds for adjournments inquiries and extensions to CTOs. Rather than providing clear criteria which should be applied in making these decisions, the legislative amendments allow the Tribunal to make its own decisions on thebasis that circumstances resulting from the COVID-19 pandemic require such an adjournment (Section 2.13, subsection 202, clause 5 of the Act).

Participants raised concerns with this approach, stating that it is contrary to the actual Mental Health Act itself to provide safe and effective care and treatment in the least restrictive manor, and breached the human rights lens of the Mental Health Act itself. Many felt that the amendments leave processes wide open for services to take advantage and for the Tribunal to mandate services to process 12 month CTOs.

BEING has since heard from a number of people who whilst at their hearing noted a 12 month order being requested with no clear reason other than "may as well, it's all because of COVID" one person said.

It is hoped that the government will consult further with consumers and peak bodies in establishing the criteria to be applied when making such decisions.

5. The need for as much transparency as possible

Given the wide scope of the decision-making powers now granted to the MHRT, it is also more important than ever, that full transparency be maintained when decisions are made under these new powers. The reasons for decisions must be made available to consumers in an accessible and timely way, and in a way which acknowledges the services' legal obligations to provide safe and effective treatment and care in the least restrictive manner.

6. Suggestions about ways to manage tribunals with only one member

BEING raised concerns with the MHRT in relation to the Tribunal moving to one panel member in the event that COVID-19 impacted Tribunal members. We also expressed concerns that in such cases, only the legal member would be present. Further we raised concerns with hearings progressing without a mental health professional (psychiatrist) to discuss key medical issues with the service, and the Other Suitably Qualified person to bring the external lens to the hearing.

The MHRT requested that in BEING's discussions with consumers, we also ask what consumers felt would be the best way to manage situations where there is only a single Tribunal member available for a hearing, in particular if that member only has a legal background. One participant in our consultations had previously experienced such a situation where there was only a legally qualified member available for the hearing. Although the individual found that the overall outcome was satisfactory, they felt that they were not treated with the same level of compassion and understanding that they have experienced previously when dealing with members who have a deeper understanding of mental health issues, such as psychiatrist members, nor with the presence of the Other Suitably Qualified members, who in their case brought a friendly and compassionate encounter to the hearing.

Another person suggested that in a situation where this became necessary it would be appropriate for the Tribunal member to seek external advice from an appropriately qualified professional. It may be appropriate for consideration to be given to finding appropriately qualified people to carry out this role, in urgent situations. The broader medical system is currently enlisting the help of final year students and retired medical practitioners. Creativity is required to ensure that the Tribunal can fully serve the mental health as well as the legal needs of consumers in this situation.

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