Mental health carers have experienced unique challenges during COVID, with adaptation to new technologies and reduced services, increased responsibilities, isolation and being confined. Mental Health Carers NSW has released findings of a survey taken during these times with extensive comments and recommendations from carers. MHCN is now embarking on a project to empower carers with advocacy skills. Here MHCN CEO Jonathan Harms discusses the survey and the advocacy project with MHCC.

**Mental Health Services During COVID**

There are obvious concerns in terms of reduced access to mental health services and reduced desire to engage with mental health services through emergency departments, because of fear of infection. It has made many people more reluctant to get help.

A number of carers have had to expand their caring role, looking after people who are perhaps a bit sicker, particularly when anxiety is heightened by the pandemic.

That has meant a lot of people have either been admitted to hospital and not released, because going back and forth increases infection risk, or they’ve been discharged and not readmitted.

People have been separated from family for long periods. The regime around visitors has been much stricter, because the Chief Psychiatrist issued recommendations early on that we shouldn’t have visitors, because of risk of infection, and LHD services were conservative about interpreting and relaxing that recommendation. Discharge to families too early has been bad for some.

**The Digital Divide, Privacy and Safety**

Then when it comes to getting assistance at home, beyond standard medication and if people need counselling therapy, there are additional difficulties due to the digital divide. A lot of consumers don’t have access to devices or accounts, or can’t afford it.

If we are going to deliver more services remotely, we need to think about how to do that. Those discussions need to be in the privacy of home. We’ve always told carers ‘you’re not entitled to hear what goes on between your loved one and their counsellor’, but now they are in the same room. This creates concerns around safety and domestic violence issues have to be faced. Statistics around DV show 80% have some element of mental health issues or substance abuse, so a carer may not be able to express their concerns, because the person is in next room.

However, digital access to counselling and talk therapies means we can deliver services to some people who have never before been able to access them. Some monthly support groups have gone weekly: Carers love that. We’ve seen scope for case conferencing that clinicians are supposed to do, making collaboration and conferring far more feasible. This presents an obvious way of engaging consumers and carers in their own care plan. But we need to make sure it is legally acceptable to discuss a person’s health record. This has not been resolved.

**Family Focused Therapy a Priority**

Where people are locked in together, families can contribute to recovery OR perpetuate conditions that have made a person unwell:Not on purpose, but they may not know what to do.We need a therapeutic conversation that looks at a carer’s own needs as well as interactions with the person**.** More family focused therapy has become a priority.

**Technical Competence**

There’s a technical competence issue: How do we develop capacity around that? We need to resource libraries to teach people how to use technology and it needs to be available.

**Tele Assessment**

One win has been tele-assessment in regional areas, so police don’t have to drive someone four hours to get an assessment then drive them back – or leave the person to make their own way back. We’d like to see data on tele-assessment to see rates on people being recommended for further treatment.

**Online Counselling**

Although there is some satisfaction with online counselling, some appreciate in-person contact. If someone has had a traumatising experience, it’s more difficult to comfort someone remotely. The availability of face-to-face contact is important - very important for consumers resistant to support or who find it difficult to focus.

**Safety and Succession**

We’d like to see data around engagement of carers in assessments, tribunal processes, around carers’ feelings of safety. If carers have safety concerns and if they are over 80, that’s really serious. Often a loved one is not set up if they pass away: “What happens if I die” is one of the most common questions.

**Historic Wins for Carers**

Back in 2007 was the first carer recognition in the Mental Health Act. Designated carers are nominated by the consumers and there is now a role of principle care provider, that can receive the same info as a designated carer under the Act. There are provisions where a person makes an inappropriate nomination – like the barmaid of a tavern by position, not name!

The Living Well strategic plan for mental health had great vision for the future of the NSW mental health system, in part advancing rights of consumers, carers and peer workers and under the psychosocial model as opposed to the medico-legal model. The NDIS has been a great boon for people deemed eligible. There are elements that obviously we would like to see improved – a system that looks at supporting people with less than permanent disability. At least there is some service around housing and Community Living Supports, the setting up of the Quality & Safeguards Commission and the advancement of carer and consumer Peer Worker roles

**Effective Change**

The advancement of principles of co-design can’t be overlooked; the breadth and diversity on consumer/carer opinion - co-design brings out the breadth of that.

There is an element of the NDIS around support facilitation not built yet: There is nothing to stop community orgs delivering other peer roles, eg, Recovery Coach roles, to help people navigate the NDIS. Without assistance in navigating, the NDIS becomes just another market, equally open to exploitation.

**Current Projects**

Under the NSW Mental Health Commission Lived Experience Framework, we are setting up a national framework for lived experience carers in reforming and delivering mental health services. To facilitate that we’re setting up a register, inviting mental health carers to join to be a conduit for information, to tell carers of opportunities for participation and capacity development to become better carers. We’ve designed training for storytelling and participating in co-design activities, writing reports, power point presentations and social media campaigning, not only attending to the Lived Experience Framework but building capacity for carers to engage in public dialogue and campaigns that focus on mental health carer reforms.

As a network across all LHDs, we are setting up hubs in each LHD with a senior care advocate – with no cost barriers to access.