



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

Supplementary Submission Two

To the

Productivity Commission Inquiry into Mental Health

Dated 5 August 2019

Introduction

This second Supplementary Submission is being forwarded specifically in relation to carers – Point 8: Issues relating to carers, family and friends and also expands upon Recommendation 13 of our original Submission Number 49 which was:

Recommendation 13.

Introduce training to staff in how to better engage with carers and families by the implementation of: The Practical Guide for Working with Carers of People with a Mental Illness.

The 2017 Mind Australia commissioned inquiry by the University of Queensland, School of Public Health into 'The economic value of informal mental health carer in Australia showed the following:

the total replacement value of \$13.2 billion is equivalent to 1.7 times the current national expenditure on all mental health-related services in Australia, including hospital, clinical outpatient and psychosocial support services. Total national expenditure on these services was estimated to be \$8.0 billion in 2013–14 [14]. These figures highlight the significant value provided by carers, in terms of providing support for people with mental illness.

A major inquiry was instigated by The House Standing Committee on Family, Community, Housing and Youth. The landmark Report of 25 May 2009 titled 'Who Cares...?'¹ Report on the Inquiry into better support for carers' detailed many issues facing carers however there has not been any significant change to the culture of carer engagement.

If this high-level inquiry and report has not changed the essence of carer engagement more broadly, then things need to change, action is required now. The Carer Guide together with all the resources developed to support implementation, provides that mechanism.

There is much research which has been undertaken over a number of years which has clearly demonstrated that the engagement and involvement of carers has had a positive influence on the physical, mental and psychosocial outcomes of consumers. Where carers have the opportunity to work in partnership with health professionals and service providers, this research also demonstrates positive outcomes for carers' health and wellbeing and the length of time they are prepared to stay involved. Policies and legislation have been developed to reflect this philosophy².

Carers also contribute to consumer safety quite frequently over three main levels of intensity: low ("contributing without concern"), moderate ("being proactive about safety"), and high ("wrestling for control"). Carers who engaged at high intensity provided the patient with greater protection, but typically experienced negative consequences for themselves. Carers' experiences of negative consequences from safety involvement need to be mitigated by practice approaches that value their contributions³.

This brief Supplementary Submission Two provides the history, resources and crucial importance of engaging carers of people with a mental illness. We believe this Submission is a once in a lifetime

¹ Who Cares...? 25 May 2009 House of Representative Committee

https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=fc/hy/carers/report/prelims.htm

² National Carer Recognition Act 2010.;

National Mental Health Policy [Commonwealth of Australia 2009];

Fourth National Mental Health Plan, An agenda for collaborative government action in mental health 2009–2014;

Royal Australian and New Zealand College of Psychiatrists (RANZCP) Guidance Notes, *Involving Families*, 2000.

³ "I'm Trying to Stop Things Before They Happen": Carers' Contributions to Patient Safety in Hospitals

[Bronwen Merner](#), [Sophie Hill](#), [Michael Taylor](#) First Published April 19, 2019 Research Article

<https://doi.org/10.1177/1049732319841021>

opportunity to change the lives of carers , enable them to contribute to the recovery journey of the consumer and to facilitate the much-needed cultural change by recommending implementation of the Practical Guide for Working with Carers of People With a Mental Illness into all organisations and services where mental health treatment and support is provided.

Recommendations

- **The phased mandatory implementation of the Carer Guide, e-learning training resources, and the App⁴ within all service settings which are/have introduced the Carer Experience of Services (CES) outcome measure.**
- **The phased uptake of the Carer Guide and accompanying resources into organisations which are commissioned by the PHNs to provide services to their consumers and carers.**
- **The phased uptake of the Carer Guide to all organisations and services in which mental health treatment and/or support is provided.**
- **The ongoing administration and hosting costs beyond 31 December 2019 be undertaken by the Australian Mental Health Outcomes and Classification Network or a lead jurisdiction, a PHN, NDIA or similar entity.**

Context

Public, private and community managed mental health services have a responsibility to identify and work with carers in all phases of a person's illness. However, much of the ongoing care for people with long term mental illness and disability was until recently provided via the Australian Government initiatives such as the Partners in Recovery, Personal Helpers and Mentors Scheme and currently the National Disability Insurance Scheme.

A large volume of literature also exists clearly describing the needs of carers⁵, however what is lacking in Australia is clearly articulated nationally consistent practical guidance for working with, engaging and supporting carers and families.

Main Aim

The **main aim** of the *Practical Guide for Working with Carers of People with a Mental Illness* (hereafter Carer Guide) provides practical guidance to assist clinicians and service providers to work with carers in a meaningful, mutually beneficial way using a partnership approach which will enhance outcomes for consumers and support carers and families in their caring role. The underpinning principle is that carers are equal partners in care.

Where implemented, the Carer Guide will enhance the capacity of mental health providers to meet the increasing number of standards which guide mental health delivery. The Carer Guide will assist in streamlining and supporting mental health provider organisations or services to meet their obligations under the National Standards for Mental Health Services, *Standard 7 – Carers* and the requirements of the Australian Commission for Safety and Quality in Healthcare, particularly *Standard 2 – Partnering with Consumers* , which also has strong implications for partnering with carers.

⁴ The App can be downloaded from the Apple Store or Google play

⁵ The economic value of informal mental health caring in Australia: summary report March 2017

https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf

The Mental Health Council of Australia in their 2011 Submission to *The Productivity Commission Inquiry into Disability Long Term Care and Support*,⁶ estimated that between 149,800 and 206,000 people have a psychosocial disability and that any long-term care and support must at the very minimum, budget for this number of people.

In July 2012, Professor Bryant Stokes delivered a report to the Western Australian Government into admission, transfer and discharge practices in public mental health services. The review known as the 'Stokes Review'⁷ had one of the recommended themes around carers and families. The edits below are from this 2012 Report, however these are still the experiences of many carers across Australia.

Page 53: The Review heard clearly that there are areas of service where carers and families believe that considerable improvements need to be made. For some, an unhesitating opinion was that the system, by virtue of not providing adequate timely and preventive care, was a major contributing factor to the patient's suicide.

While the Review received a considerable weight of negative carer and family experiences, a number did describe receiving positive and supportive care.

The prominent theme for carers and families was a concern for the safety and wellbeing of the patient and a persistent sense of powerlessness within the system. They expressed a need for information about admissions, treatment, referrals and discharge/transfer plans.

Carers were concerned about the patient's illness and said they need education to understand the illness, treatments and the course of the disease. Training is needed to implement helpful interventions, to de-escalate symptoms and to support the patients' restorative pursuits. The carers also described their exhaustion and said that the burden of care sometimes affected their own mental wellbeing.

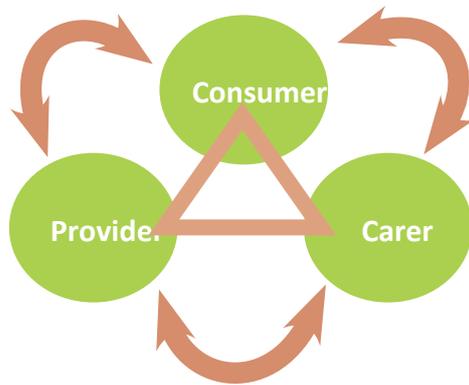
Page 58: Carers reported to the Review a number of very complex and traumatic scenarios in which the system seemed to flounder, and from the carers' perspective, the system has seriously failed the patient and their carers.

Historically, the training of professional staff and the delivery of care to people in both the acute and recovery phases of a mental illness have been focussed fundamentally as an individual treatment model. Confidentiality has been seen as being protective of the consumer and has many times become a constraining element when caring for an individual. The results in many situations are that carers are unable to contribute or receive information or to participate in the recovery process. This individual treatment model can be illustrated by the following diagram from the UK Carers Trust⁸ and shows a new paradigm in engaging with carers of people with a mental illness.

⁶ *The Productivity Commission Inquiry into Disability Long Term Care and Support*, April 2011

⁷ Stokes Review, July 2012. <https://www.mhc.wa.gov.au/media/1288/mental-health-review-report-by-professor-bryant-stokes-am-1.pdf>

⁸ ² Worthington, A, Rooney, P, Hannan, R 2013, *The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England, Second Edition, 2013*, Carers Trust, London. The Carers Trust is acknowledged as the copyright holder of the concept and the Triangle of Care model



Family members and carers have a unique role to play in the journey because they know the person, and in all probability knew them before they became unwell. They are a source of information about a consumer's life beyond their diagnosis of mental illness, including information about their interests, skills, beliefs and ambitions.

This model shows very clearly that all three are partners in care, the consumer, the carer and the service provider, all working together for the same reasons and outcomes which are to provide better support in the recovery process. This partnership improves outcomes for consumers, reduces carer anxiety and provides improvement in the ability and desire of family and other carers to remain supportive. It also improves satisfaction for staff when this partnership approach is embedded within practice.

Need for Practical Guidance

There are number of significant gaps in the engagement of carers which have been consistently articulated within many reports, inquiries, policies and procedures however the actual engagement of carers remains unactioned in many places.

It was in relation to this continuing lack of engagement that the Network formed a Consortium of key organisations to develop a guide which would provide practical assistance to clinicians and service providers, and allow for their services or organisations to self-assess against six Partnership Standards, as well as the best opportunity for clarity, accuracy, expertise and dissemination.

The Consortium believes that the Carer Guide will directly assist, guide and support providers as they engage people with chronic mental illness and psychosocial disability, their carers and families. The Carer Guide is crucial to the successful implementation and ongoing effectiveness of services, giving providers increased skills leading to greater engagement with and support for carers and better outcomes for consumers.

The development of the Carer Guide was jointly funded by MIND Australia and HelpingMinds.

Consortium member organisations

- Mental Health Carers ARAFMI WA Inc.
- MIND Australia
- Private Mental Health Consumer Carer Network (Australia) [the Network]
- Mental Health Council of Australia
- Mental Health Carers ARAFMI Australia

It was thought that the national standing of these organisations in partnership would provide the best opportunity to influence practice and drive change. Despite the best endeavours of these organisations, the uptake and implementation of the Carer Guide still remains elusive.

The Carer Guide should also have applicability to the Primary Health Networks, NDIS, and any other mental health service providers where mental health care is delivered.

Resources to support the implementation of the Carer Guide

To assist in the implementation of the Carer Guide and to support service providers and organisations the following resources have been developed, are free and available.

The resources available are:

- One online introduction module on the Carer Guide⁹ developed by the Network
- Five Online Training resources¹⁰ funded by HelpingMinds
- An App¹¹ which allows self-assessment and provides organisations/services with up to 6 Reports funded by the Commonwealth, Department of Health
- A carer specific website www.workingwithfamiliesandcarers.com.au , funded by Mind Australia which provides access to a wide range of:
 - Articles and Research
 - Fact Sheets
 - Guides
 - Professional Learning
 - Reports
 - Toolkits and Templates
 - Training Manuals
 - Videos

Benefits for staff:

- Creates a more helpful, supportive relationship with carers
- Gives carers and consumers realistic expectations
- Ensure staff have information about consumers' moods, behaviours and the best way to interact with them
- If the consumer exhibits challenging behaviour, the carer may be able to provide assistance by influencing them in a positive manner
- It can reduce admissions. Carers can often recognise the signs the consumer is becoming unwell allowing staff to act in a way that provides early intervention and offers care in the least restrictive environment.

Benefits for services and organisations:

Implementation of the Partnership Standards and use of the Guide (including self assessment tools) provides evidence to Accreditation Agencies of the organisations ability to better meet the National Safety and Quality in Healthcare Standards. The implementation of the Guide also assist in driving the national safety and quality improvements in a cost effective manner. It can also assist services to prepare for or improve their results when the Carer Experience Survey is implemented or undertaken.

The Network wishes to focus on the following in particular:

Five Online Training resources – funded by HelpingMinds

These modules provide easy access to the Partnership Standards and can be completed in a person's own time and convenience. Each module is focussed on one of the Partnership Standards. They can be viewed at: <https://helpingminds.org.au/health-professionals/>

This is a convenient way in which to upskill service providers.

⁹ Introduction module for the Carer Guide:

<http://www.pmhccn.com.au/Portals/2/PublicDocuments/ppt/intro-to-practical-guide/>

¹⁰ Online training Modules: (<https://helpingminds.org.au/health-professionals/>)

¹¹ App Store and/or Google play

An App which allows self-assessment and provides organisations/services with up to 6 Reports – funded by the Commonwealth, Department of Health

This is an amazing resource for service providers, services, organisations and jurisdictions. It was funded following an approach to the Commonwealth, Department of Health. It was developed on a very low cost basis considering the large amounts of funds which are being expended in the Reporting aspects of mental health services both nationally and at the state and territory levels.

However ongoing administration and hosting costs and oversight has been limited and will expire in 2020. Another entity other than the Network will be required to take over these costs, this could be a lead jurisdiction, Australian Mental Health Outcomes and Classification Network etc.

Ongoing costs

Currently the hosting and the administration costs of approximately \$4,000 per annum but these will require adjustment with increased usage over time.

Here is a screen shot of the App:



The image is a promotional graphic for the 'Carer Guide Self-Assessment App'. At the top, a green banner contains the text 'Carer Guide Self-Assessment App' in white. Below this, on the left, a hand holds a smartphone displaying the app's interface, which includes the text 'Carer Guide' and a green icon of three people. To the right of the phone, the text reads: '“Carer Guide” Self-assessment App now available to use to assess your practice. Organisations can link their staff self-assessments and generate reports More details from: www.carerguide.com.au'. Below the text are two buttons: 'Download on the App Store' and 'ANDROID APP ON Google play'. In the bottom right corner, there is a logo for the 'National Mental Health Commission Carer Network (Australia) Limited'.

Tools available on the App

The following shows the screen of the App once opened which shows the tools available for service provider access.

The Implementation Tools in the App work on a ‘traffic light’ system, ie Red is not met, Orange is partially met and Green is met. These terms are consistent language of the National Safety and Quality in Health Care Standards 2nd Edition used for accreditation purposes. The screen shot is below.

Implementation Tools – Practical Guide App

 Simple strategies to consider	Taken directly from the Guide
 My Assessments	Separate assessments for each organisation you work for, or your own private assessment
 My Organisations	A list of the organisations you are linked with
 Codes	Where you enter codes to connect to an organisation

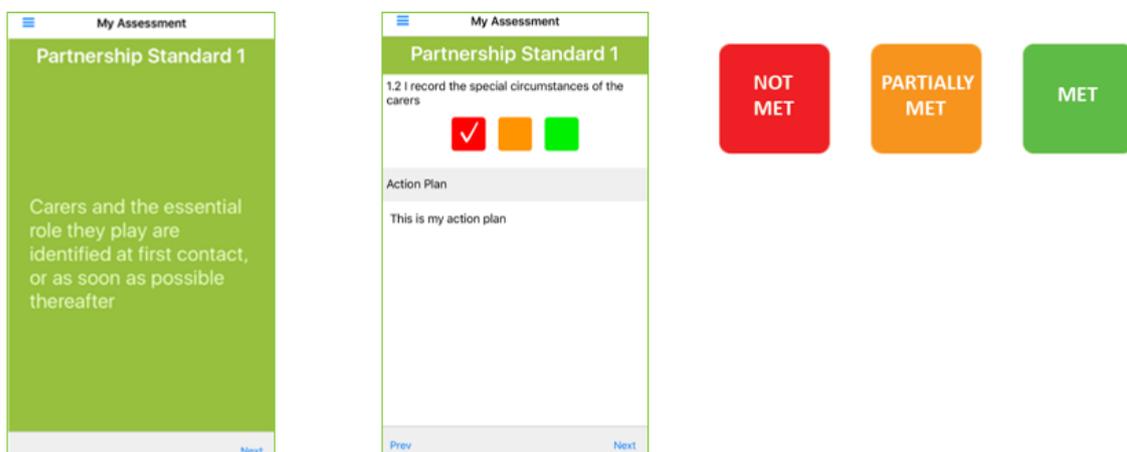
Once the Carer Guide app has been downloaded a service provider can select:

- Strategies to consider – directly taken from the guide for each partnership standard
- My assessments – has the option of doing your own individual assessment or ones for different organisations that you might be working for. There is the ability to have multiple assessments so that you can assess your practice in each different environment if you work for more than one organisation or department.
- My organisations shows you a list of the organisations you are linked with
- Codes is where you go to enter the organisation code that is generated in our administration portal to link your assessments with an organisation

Self assessments

The App enables a service provider to self assess against the criteria within the six Partnership Standards with a critical component being the ability to develop an Action Plan which is kept alive at all times, enabling the service provider to review their progress in better meeting the criteria.

Implementation Tools – Practical Guide App



- When you go into My Assessments, you can work through each activity within each partnership standard and assess your own practice against it.
- When you assess as not met or partially met, you can also include an action plan of what you might need to do or change to improve the rating.
- It is a simple process of clicking next and working through each of the partnership standards.
- As you make changes in your practice, or implement action plans you can go back into the app and change your rating e.g. from partially met to met. It keeps this information live at all times, however with the reporting functions you can do comparisons between two different points in time.

Reports

The additional exciting aspect of the App is the ability of the service, organisation or jurisdictions to access the following reports.

carer guide Organisations Codes Administrators **Reports**

Reports

This screen enables you to run reports for the organisations that you are an administrator of.

- Individual Service by Activity Report**
This report displays performance information for a specified service at the activity level at a point in time
- Individual Service by Partnership Standard Report**
This report displays performance information for a specified service at the partnership standard level at a point in time
- Individual Service Snapshot Comparison Report**
This report compares performance information for a specified service over two points in time.
- Service Comparison by Partnership Standard Report**
This report compares performance information for specified services at the partnership level at a point in time
- All Services Comparison Report**
This report compares performance information for specified services against all other services in the system at a point in time
- Action Plan Report**
This report displays action plan information for a specified service at a point in time

www.carerguide.com.au

The reports that can access are:

- Individual service by activity level - this is each activity within each partnership standard
- Individual service by partnership standard – this reports just at the partnership standard level
- Individual service snapshot comparison report – this is where you can compare your organisation’s results in two different points in time.
- Service comparison by partnership standard report – shows a comparison of multiple departments within your organisation at a set point in time
- All services comparison report – shows how your service is rating compared to all other organisations using the app – however the names of other organisations are not included to ensure confidentiality and privacy.

- Action plan report – this shows dot points of all the individual action plans that users have entered from your organisation at a particular moment in time.

As mentioned in the Introduction to this Supplementary Submission Two, the Network considers this a ‘once in a lifetime’ opportunity to make a lasting difference to the engagement of carers. It is heartening to have policies but they must be translated into practical action accompanied by training. This is what the Guide does. It is what is missing in other approaches resulting in carers not being taken seriously. Now is the time to take action!

Recommendations

- **The phased mandatory implementation of the Carer Guide, e-learning training resources, and the App within all service settings which are/have introduced the Carer Experience of Services (CES) outcome measure.**
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