Mental Health Respite: Carer Support

Consultation Report

Prepared for the Department of Families, Housing,
Community Services and Indigenous Affairs

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Acronyms and Abbreviations

ARAFMI   Association of Relatives And Friends of the Mentally Ill

CALD   Culturally & Linguistically Diverse

CRCC   Commonwealth Respite and Carelink Centre

DoHA   Department of Health and Ageing

FaHCSIA   Department of Families, Housing, Community Services and Indigenous Affairs

PHaMs   Personal Helpers & Mentors (FaHCSIA)

FMHSS   Family Mental Health Support Service (FaHCSIA)

LGBTI   Lesbian, Gay, Bisexual, Transgender & Intersex people

MHCA   Mental Health Council of Australia

MHR:CS   Mental Health Respite: Carer Support Program (FaHCSIA)

MIFSA   Mental Illness Fellowship South Australia

TCC   Targeted Community Care Program (FaHCSIA)

UPA   United Protestant Association

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Introduction

About the Mental Health Respite: Carer Support Program

As part of the National Mental Health Reforms announced in the 2011–12 Budget, the Australian Government allocated $54.3 million over five years to expand mental health respite and carer support services to give around 1,100 families and carers of people with mental illness greater access to flexible respite and support services.

Under the Mental Health Respite: Carer Support (MHR:CS) program, expanded and new services will provide carers of people with a mental illness a range of supports including respite care and activities such as peer support and education that assist them in their caring role.

Research has demonstrated that carers often experience poor physical health, financial difficulties, isolation and their own mental health issues as a direct result of their caring responsibilities. The carers of people with mental illness have different respite and support needs to other carers, due in part to the unpredictability and episodic nature of mental illness.

The aim of MHR:CS is to provide flexible and responsive services that enable carers and families of people with mental illness, intellectual disability or autism to better cope with their caring roles, improve their relationships with the people they support, and balance their caring roles with other parts of their lives. The program has evolved since the first services were funded in 2007 to respond better to the diverse needs of carers.

MHR:CS is delivered nationally in each Home and Community Care (HACC) region. In addition to the network of 55 Commonwealth Respite and Carelink Centres (CRCCs), 79 organisations are funded to provide respite and other forms of carer support in a further 135 sites (for more information see the FaHCSIA website MentalHealthRespite).

MHR:CS providers offer a range of services, including:

- Respite
- Brokerage (procuring support and respite services on behalf of targeted carers)
- Educational programs
- Counselling
- Peer support
- Advocacy services
- Information and referral
- Social and recreational activities.

From 2007 to December 2011, MHR: CS provided assistance to over 100,000 carers of people with severe mental illness and intellectual disability through 190 funded services located in metropolitan, rural and remote areas, with services located in all HACC regions.

In 2011 a wide-ranging evaluation of the three initiatives under the Targeted Community Care Mental Health Program (PHaMs, FMHSS, and MHR: CS) found that MHR:CS is providing essential services to carers who access it, but in many areas it is not reaching adequate numbers of carers or providing the full spectrum of care required. The review found that the MHR:CS program would benefit from simplification, changes to eligibility and changes to the service delivery system so that more coherent approaches to care can be supported.

The new allocation of $54.3 million over five years is in addition to current funding levels, and will be used to expand the current mental health carer support program rather than create a new carer support program. It is therefore timely that carers and respite service providers gather to consider options to inform the expansion of the MHR:CS service delivery model going forward.

About the consultations

During July 2012, the Mental Health Council of Australia (MHCA) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) hosted two workshops with key mental health carer stakeholder representatives to seek their input into the expansion of FaHCSIA's Mental Health Respite: Carer Support Program (MHR:CS).

More than 90 mental health carers and respite services from across Australia attended workshops on 2 July (mental health carers) and 9 July (MHR:CS services) to discuss and inform decisions about how the key strengths of the current mental health respite and carer support program can be carried forward into new and expanded services.

To further develop the MHR:CS model, FaHCSIA was particularly interested in information which could be gathered from the workshops to help answer the following questions:

1. What principles should guide the future expansion of MHR:CS services?
2. What are the best features of the MHR:CS and what should it do more or less of?
3. Are there gaps in current MHR:CS services and/or in the capacity of service providers and how could these be addressed?

This summary report is based on presentations and discussion among stakeholder participants as well as further analysis and commentary by MHCA and FaHCSIA staff. Valuable and wide ranging perspectives were captured from both carers and respite service providers, including insights directly relevant to the expansion of the MHR:CS program as well as more general issues.

In order to faithfully represent the views expressed at the workshops, this report incorporates the broad range of comments that were made, even if they were at times contradictory.

Findings

Reflections on the current program

Across both workshops, carers and respite service providers were positive about the current program. It should be noted that many of the key issues identified by service providers as success factors align closely with those identified by carers themselves. Both groups argued that services should be able to provide flexible, creative, peer-led services which are developed collaboratively with carers in direct response to their expressed needs.

Nevertheless, there are divergent expectations around the application of the in-built flexibility of the MHR:CS program, including how additional resources should be allocated to meet growing demand. In particular, mental health carers and service providers find the application of the brokerage component of MHR:CS confusing and at times arbitrary.

Definitions and understandings of 'respite' and broader notions of care need further discussion and clarification in program guidelines and the application of eligibility criteria appears to vary across services, with carers and service providers sometimes confused about who is able to access particular services.

Carers expressed a strong need for a more comprehensive suite of support services, which remain adaptable to a broader set of individuals' needs. Service providers find it difficult to plan and allocate resources within such potentially undefined parameters. Both groups acknowledged that there is inequity in the availability of services between urban, regional and remote areas of Australia. While this variability is an ongoing feature of the broader service system across Australia, there are innovative examples of improved access to healthcare in regional areas from which lessons can be drawn.

Case management and coordination is an area of particular concern for both carers and service providers. It is perhaps a feature of both growing carer expectations and the sector as a whole that the range of programs funded at the outset of the original Mental Health Respite Initiative may no longer meet the full range of complex needs identified by mental health carers.

There are few standalone mental health carer support services in operation and most mental health carer support is provided by programs which are managed through Commonwealth Respite and Carelink Centres or by a range of non-government providers who also deliver programs across a range of client groups. As the complexity of and demand for services grows, it may be appropriate to revisit the availability of more 'one-stop shop' services, particularly in locations where there is high demand for support. A more centralised service model would also assist mental health carers to overcome access barriers associated with fragmented and difficult to find service information.

In addition, the implementation of 'no wrong door' protocols across MHR:CS funded services would contribute to a more cohesive experience of support by mental health carers over time. The implementation of such protocols could necessitate a rationalisation of respite and support information resources in order to provide more effective referral pathways and support for carers.

While uniformity across services may not be a primary goal of the MHR:CS program, the use of common assessment tools and guidance on the use of brokerage funds would assist to bring a more standardised approach to service delivery.

Hidden carers, particularly Indigenous, CALD, LGBTI and young carers, are not well serviced at present. MHR:CS may need to weight funding applications to redirect resources to meet unmet need, including towards work with hidden carers and filling geographic service gaps.

While there is a great deal of information in the community for mental health carers, many are struggling to locate this information and remain unaware of the range of support services and entitlements available to them.

When asked, almost half of service providers attending on 9 July reported having some form of carer representation within their service structures. At the same time, it was apparent that services are struggling to move to more fully integrated carer peer support initiatives.

Transparency, accountability and more effectively targeted service provision would be well served by actively encouraging services funded under the MHR:CS to formalise the inclusion of carer representatives in governance and decision making mechanisms within services and programs, with protections put in place to avoid conflict of interest by carers as program users.

Sector-wide capacity issues were highlighted by service providers. Key amongst these issues is the difficulty in managing project funds at the service level without corresponding resources to implement broader sector level improvements. The ability to undertake research within the sector, as well as establish pilot projects to help drive innovation in service delivery and design, were seen as valuable ways to improve sector capacity.

Relationship building between carers and their support workers and between support workers and other agencies is seen as a primary success factor leading to positive outcomes for mental health carers. At present, these skills appear to be limited to individual workers, rather than a feature of the sector as a whole; this reflects the pressing workforce and training issues faced by the sector.

During opening presentations at both workshops, there was a question raised by a couple of participants about the validity of MHR:CS program statistics quoting numbers of carers serviced and overall satisfaction ratings. Data is collected and reported from providers as a way to ensure transparency. An analysis of this data contributes to the evidence base in relation to the effectiveness of investment in mental health carer support initiatives over time.

The issue of flexibility drew strong and divergent responses during the workshops and will require further consideration. While both carers and service providers agree that flexibility is a feature which must be maintained within MHR:CS, there are strong views about the appropriate application of that flexibility on the ground.

Carers are seeking complete flexibility to suit their individual circumstances and meet their individual needs. They want the providers to consult closely with them, and deliver services that cater to their specific needs, regardless of whether the services form part of their standard suite. Some providers reported that they are already providing this flexibility for carers.

Service providers agree that flexibility is important, but some feel that it can be achieved economically and efficiently by increasing the range of support options offered to all carers, rather than the option menu being open-ended.

Reasons which may account for the variability in approaches to flexible service provision include:

- pressure on services to deliver outputs, rather than successful carer outcomes
- lack of appropriate local services
- changing mental health carer perceptions and expectations
- conflicting requirements across funding sources at the state/territory and national levels and across funding streams
- the nature and orientation of services which focus exclusively on mental health carers as opposed to larger organisations offering multiple programs to multiple target groups
- services developing their own guidelines in the absence of more prescriptive criteria in the overarching MHR:CS program.

There is currently a high degree of flexibility within MHR:CS (particularly within the brokerage component), however, it appears that service providers are interpreting guidelines in different ways and not always reflecting carers' expectations.

Providers and carers would like clearer guidance in relation to flexibility for services funded under the existing and expanded MHR:CS program. Service providers are seeking guidance on balancing a potentially open-ended set of needs with their ability to plan and deliver cost-effective services. Carers are seeking assurances that when they engage with services, they will not have to adapt their personal circumstances to fit with those forms of support on offer.

Implications for the expansion of the MHR:CS program

Program Design

1. Clarify definitions of respite and parameters of carer support services which can be provided under MHR:CS funding.

2. Establish clearer parameters to guide the allocation of brokerage funds within MHR:CS.

3. Implement uniform and transparent performance indicators over time.

4. Develop standardised, easy to use needs assessment and outcome measure tools for use by service providers.

5. Expand the availability of case management services delivered under MHR:CS.

6. Weight funding applications to redirect resources to satisfy unmet need, particularly towards hidden carers (CALD, Indigenous, LGBTI and young carers) and to address gaps in geographic availability of services.

Service Provision

7. Develop national mental health carer eligibility assessment tools for use by services which align with criteria used by DoHA.

8. Implement 'no wrong door' protocols for mental health carers across services funded under MHR:CS.

9. Establish 'one stop shop' services for mental health carers in areas of high demand.

Sector Capacity

10. Establish unified information resources for use by services and carers and ensure broad dissemination of these materials.

11. Increase availability of carer peer support initiatives, noting that the Centre of Excellence in Peer Support's *Charter of Peer Support*[1] may be a useful component in a suite of materials to assist service providers in establishing such programs.

12. Set aside a component of the MHR:CS funding pool to enable commissioning of research within the sector, as well as to establish pilot projects to help drive innovation in service delivery and design.

13. Support the development of networking, relationship building and case coordination skills among workers in the sector.

Governance

14. Formalise the inclusion of carer representatives in governance and decision making mechanisms within services and programs, with protections put in place to avoid conflict of interest by carers as program users. This includes enabling the participation of carer representatives in assessment of funding bids at the national level.

    For service providers, the National Mental Health Consumer and Carer Forum booklet, "*Consumer and Carer Participation Policy: a framework for the mental health sector*", may assist services in their transition to more inclusive service-based governance processes.

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[1] 2011, Centre of Excellence in Peer Support, available at www.peersupportvic.org

Elements of an ideal model of service

At the conclusion of both workshops, a 'wish list' of elements which an expanded MHR:CS program model should encompass was discussed.

It should be noted that both groups put forward very similar components of an ideal model and key elements from both mental health carers' and service providers' perspectives have been summarised into a single list.

Key elements of an ideal model are that it should:

1. Provide a one-stop shop service delivery model which includes outreach services
2. Offer client centred services, focussing on the individual needs of carers
3. Strengthen collaborative and shared care practice
4. Offer portability of support across services and geographic locations
5. Include carer peer workers
6. Offer a whole of family recovery focus
7. Be culturally, age and gender appropriate
8. Be available in urban, regional and remote communities
9. Incorporate carer directed approaches to care
10. Deliver comprehensive carer information for carers and mental health workers
11. Address carers' physical & emotional health needs
12. Move away from the language of 'respite'
13. Embrace evidence based planning

Broader Implications

A number of issues were raised by participants during the workshops which may or may not be within scope of the MHR:CS expansion. These issues may require consideration and/or discussion with a range of other Australian Government agencies and non-government organisations.

Those issues include:

- Calls for a national mental health carer public awareness campaign
- Review and assess best practice nationally with a view to developing a 10 point plan for carer advocacy and support
- Establish a national peak body for mental health carers
- National mapping with a view to developing a register of community services relevant to mental health carers
- Conduct a pilot study to determine the feasibility of a carer self-management funding and service model
- Publicly report on MHR:CS outcomes and accountability measures and use this data to determine next steps
- Develop KPIs, determined by both mental health carers and non-government service providers as partners
- Initiate a process of cultural change across the mental health workforce on the importance of carers
- Redesign models of service delivery to clearly reflect broader notions of social inclusion, including cultural competency (CALD, Indigenous, youth, older people, LGBTI people) and the importance of what is valuable and meaningful to carers, family and communities
- Establish local national and local level steering committees to review and monitor carer support programs under MHR:CS, inclusive of mental health carers and clinicians
- Establish local level tender review panels to recommend tenders for national selection
- Redevelop MHR:CS guidelines so that they align with National Mental Health Standards, the National Mental Health Plan and relevant carer legislation
- Establish a preferred panel of providers with adequate training and minimum pre-requisites for qualified staff
- Initiate regular, transparent MHR:CS review and budget monitoring at the local level.

Stakeholder Perspectives

During the course of both workshops with carers and respite service providers, a number of speakers gave their perspectives on current trends in carers' needs and how services were responding to those needs. Carer representatives and respite support services expressed support for many elements of the current program, and outlined a number of constructive suggestions to strengthen current and future services to ensure they remain flexible and responsive to carers' needs.

Special thanks go to Eileen McDonald, Jackie Crowe, Kieran Booth, Judy Bentley, Jill Farrelly (FaHCSIA), Ian Boyson (FaHCSIA), Simon McMahon (MIFSA) and Sandie Downsborough (UPA) who shared their perspectives.

Carer advocates

While respite and carer support are essential to carers and family members, and do bring positive benefits, access to a much broader range of services is required.

Several key systems issues were identified by carer advocates during their presentations.

Many elements of current programs are working well, however there are issues which run counter to the broader range of carers' needs, including:

a) Inflexibility in current programs leads to cost shifting within the system - particularly when a lack of suitable options at some services results in diversion to alternative programs whose guidelines may be more flexible.

b) Out of date terminology - the original meaning of respite no longer fits with the original purpose of respite and is now much broader. Carers were appreciative of FaHCSIA changing the name of the former respite program to include 'carer support', however the flow-on results of the change in language may not have yet filtered out to the sector.

c) Inconsistency in interpretation of policy and program guidelines, including in relation to:
   - consistency in eligibility criteria
   - access to and delivery of services
   - distribution of funds
   - interpretation of relevant legislation.

d) Tender systems for service providers are insufficiently transparent, with concerns raised by carers about whether service staff have sufficient understanding of the unique needs of carers and consumers. The view was put that this results in services which can create winning tender bids but which have insufficient knowledge of the services to be provided. One solution proposed was to put greater weight through the tender process on demonstrated knowledge and experience.

e) A corollary to this issue is the need for greater inclusion of carers in the governance and decision making structures of services providing support to carers.

The role that families, friends and carers play in the ongoing recovery of a person with mental health issues cannot be underestimated. The involvement of carers at all points of the service delivery process is fundamentally important to the delivery of appropriate, responsive and high quality services.

There is little research into the impact and outcomes of current mental health respite programs for families and carers. Carer advocates argue that at a systems level, Australia must demonstrate that respite care is effective and improves the intended outcomes for families and carers who use respite care.

A clear call was made during the workshops for the establishment of a Mental Health Respite Accountability Framework to guide the funding of respite and carer support services into the future. (See FaHCSIA feedback on pg 15 for more information on this point.)

Carer advocates who spoke during both workshops perform caring roles within their own families, and a number of personal and family issues affecting carers were identified in conjunction to the systems issues raised above:

- Carers need recognition and acknowledgement of the individual needs of each family member and their particular family context. The 'one size fits all' nature of some services fails to acknowledge these individual needs.
- Lack of flexibility and narrow eligibility criteria mean that if a carer doesn't fit the 'pigeon hole', the service can't help.
- Among families that have separated, only one parent can access respite services.
- Mental illness is long-term and not 'fixable', yet organisations' programs are often delivered on a short-term or per-episode basis. Clearly this has an impact on relationship building with carers over time.
- Delineation between services results in a perception among carers that if they access a particular service, another provider won't offer 'gap filling' services. Competition between services for funding and referrals reinforces this perception.
- When in crisis or overwhelmed carers have no energy to call a number they don't know.
- Carers fear not being able to cope and repercussions in admitting that they're not coping.
- Many carers lack computer skills or access to the internet to search for support options and information.
- Feelings of guilt, shame and selfishness lead to a failure to ask for help.
- Knowledge of respite services is limited – carers commonly believe someone is 'more worse off than I am' and therefore they are not as entitled to existing respite services, when in fact they are.
- Carers can be treated negatively in education settings or in their workplace if they are absent to due consumer illness, particularly if they choose not to disclose details.

A particularly strong issue raised by carer advocates was that of hidden carers, often family members who consider their caring role to be a normal part of being a spouse or family member, or those who are usually not considered primary carers such as children, youth and extended family members. Community and cultural stigma around mental health issues is often responsible for further masking of caring roles, preventing groups of hidden carers from accessing available support and assistance. These issues particularly impact on young people, Indigenous carers and CALD communities.

Service capacity is a critical factor influencing outcomes for carers, particularly in relation to:

- The availability of a suitably trained workforce, including mechanisms to ensure staff continuity and career progression.
- The ability to incorporate carers as peer workers in the respite and carer support workforce.
- Inherent limitations (including time and program guidelines) which prevent staff building and maintaining relationships with other services.
- Funding models which categorise respite as an incident of service, rather than an outcome.

- The lack of a coherent and coordinated approach to information provision relevant to carers.
- Inconsistencies between service provision in metropolitan, regional and remote Australia. There are no mechanisms to ensure equity of access to service, and some responses do not address the issue adequately (e.g., 1800 and toll-free support lines which are not accessible or prohibitive for mobile phone users). Rural carers and Indigenous carers in remote communities are particularly affected by this geographic disparity of services.

In terms of service models which are most likely to result in positive outcomes for mental health carers, the following key components are suggested by carer advocates:

- A focus on recovery oriented service provision which acknowledges that a person with lived experience of mental illness as consumer and/or carer is the expert in their unique recovery journey. This should be the organising principle for service delivery.
- The concept of family recovery and the interdependence of family and consumer recovery is understood and incorporated into training for all service providers at every level.
- Programs take into account knowledge about trauma, including its impact, interpersonal dynamic, and paths to recovery.
- Services offer 'person centred' whole of person/family support that can respond flexibly to the age group, location & cultural needs of individuals and families.
- Carers must have a voice and be present at all levels of policy making & service planning, service delivery and evaluation.

Respite service providers

Presenters from both CRCC and non-CRCC services addressed the service provider workshop on 9 July, offering their perspectives on how carers' needs are currently being met as well as suggestions for improvements which could be made as part of the expansion of the MHR:CS program.

As with carers, there is strong support among service providers for a change in language, particularly the word 'respite' which can be misleading. Many services now offer a far broader range of services which are more accurately described as 'carer support'.

While most services receive funding from multiple sources, it is acknowledged that MHR:CS funding and guidelines are quite broad. Consequently, a range of differing approaches to their interpretation is driving some variation and inconsistency across services.

One feature of the sector which should be noted is that there are few standalone mental health carer support services in operation. Most support is provided by programs which are managed through Commonwealth Respite and Carelink Centres or by a range of non-government providers who also deliver programs across a range of client groups.

While some services do not deliver direct support or employ support workers, they do provide information around a range of services and play a central role in coordinating services for carers within their particular catchment area.

As raised by carers, service providers agree that each region is quite different in terms of the availability of and access to services. Services also acknowledge the short term nature of the services they provide and the need to look at building in longer term supports.

The MHR:CS program is helping to drive innovation across the sector. Examples of innovation across carer support services include:

- Providing flexibility, choice and tailored support to carers, rather than trying to fit carers into a particular service type
- Collaboration with other services to broker comprehensive support solutions for carers
- Acknowledging urgent need and maximising accessibility through 24 hour and out-of-hours services, some with immediate response times
- Not referring carers to waiting lists
- Utilising in-built flexibility in allocating funding to best meet needs e.g. when mental health funds run low, switching to other funding pools to provide seamless service
- Accepting direct referrals, often from carers themselves
- Providing an umbrella of services to carers such as drop-in support, meals, counselling support (or paying for carers to attend counselling sessions), transport, assistance in joining community/sporting/recreational groups, peer support, mentoring and domestic assistance (such as gardening, pest control).
- Offering personal development opportunities for carers including writers workshops, practical skills for carers workshops and stress management.

Access issues and service availability are acknowledged by service providers, particularly in relation to:

- out-of-home community programs
- day programs that are culturally specific
- overnight accommodation for young people
- access to subsidised transport (for both consumers and carers)
- social and recreational activities (for both consumers and carers).

Eligibility criteria across some programs, such as HACC, mean that people with mental illness can be excluded from available services. This compounds a broader problem for the sector: that the lack of access to services for mental health consumers is compounding the demand for services providing support to mental health carers (who are bearing an increasing proportion of the care needs of consumers).

Access can be further restricted to services who only take referrals through a case manager. This precludes a large proportion of mental health carers whose contact with the system is irregular and not facilitated by case management services.

Workforce issues are also acknowledged by service providers as having an impact on program delivery and carer outcomes, although these issues are not experienced uniformly across jurisdictions. There remains a shortage of suitably trained workers in some parts of the country, particularly those who are qualified or who feel experienced enough to manage complex mental health issues. Cultural competence in working with CALD and Indigenous people in a mental health context is also an acknowledged workforce gap.

There is some confusion about the guidelines as they relate to the brokerage component of MHR:CS, with many service providers unsure of the correct use of those funds. Many utilise a large component of brokerage funds for coordination and direct service delivery.

In terms of service models which are most likely to result in positive outcomes for mental health carers, the following key principles are suggested by service providers:

- continue to fund existing providers in order to build expertise and experience in the sector
- acknowledge and include peer led services, such as the model used by FaHCSIA for PHAMs services
- encourage carer-directed respite care packages
- strengthen and support engagement strategies with carers, families, carer networks and other service agencies - acknowledging that engagement can be labour-intensive and is not well supported in current program guidelines
- adjust program guidelines to encourage longer term approaches to service delivery and maximise relationship building opportunities with service users
- support flexible and collaborative service design and delivery, such as in-home assessments and integrated/coordinated care across agencies
- encourage whole of family approaches, which are of particular importance in providing support to young carers, as well as in Indigenous and CALD communities.

FaHCSIA feedback

Senior FaHCSIA staff gave the following observations and feedback to both groups based on participant input throughout the workshops:

The program needs to be much clearer about a shared understanding of what our **terminology** means, including:

- lived experience and the place of peer workers or carers in delivery of services and the importance of lived experience in all aspects of how we move forward
- the notion of families and family recovery, whatever we do going forward needs to encapsulate this. It's not about primary or secondary carers it's about families on a care recovery journey – the program needs to encourage recognition of this.

Whatever services we provide need to be **carer driven**, based around carers and their families, not around what's available or allocation or resources, but designed around the support carers and families need.

Carer led care is the carer's journey for the long haul. Carers need to be empowered, whether they are able to hold the funds, or get the services they need - support options need to be driven by carers.

The notion of **flexibility** stood out during the workshops. There are some mixed messages on this. We (FaHCSIA) think we've built a large degree of flexibility into the program but obviously there are different perceptions on how that's panning out in the delivery of services on the ground. There is a need to look at how we tie flexibility with core principles and how it will translate into and drive the outcomes we're seeking.

Maintaining flexibility in the program is a key issue, it's a fine balancing act to be flexible enough to be driven by the carer but also know what it's going to do and how to report on it.

There was robust discussion and strong points put forward regarding **accountability**. We need to keep focussing on this as we promote 'flexibility' and ensure that services are 'driven by families'. Accountability ties in strongly with achieving outcomes, which are about getting better service delivery for families and carers. We may need to provide more clarity about

what these outcomes actually mean on the ground. The Department needs to be clear about what we're delivering, and this may mean we need to limit some flexibility.

Selection of providers is a perennial challenge for government – it's always a balance between broader outcomes and accountability.

Skilling staff takes time as it is not an easy job but requires a huge range of communication skills if we want to do early intervention, education to prioritise between carers, to really listen and hear and turn it into something powerful.

Emerging priorities across both workshops include:

- increasing the use of carers as peer workers
- identifying opportunities for appropriate skilling and education
- acknowledging the value of carers as staff members and workers within services
- culture change across the sector in relation to stigma
- coordination of services across communities, between government and the services themselves
- providing clarity between levels of funding across Commonwealth and state/territory governments
- promotion more broadly of the current range of support options.

The Department needs to be careful about what we agree to. There are a range of needs and we need a common way of defining them and linking them with what we already have, such as the Department of Health and Ageing's pilot on 'consumer directed care'.

We can see that a common carer assessment would be a useful tool for providers.

FaHCSIA will take ideas from both workshops and use them in planning processes during this financial year. We're conscious it's a crowded service system and have heard complaints regularly about different levels of government funding similar things, which may be a waste. We need to harness what is working well.

FaHCSIA will keep people informed through forums such as GovDex and the FaHCSIA website. Carers and service providers will hear more as a way forward becomes clearer, in order to capitalise on the good we already have on the ground.

Appendix 1 – Group Discussions

The following tables summarise both carer and service provider views from workshops on 2nd (mental health carers) and 9th July (respite providers) when asked to consider:

1. Strengths of the current mental health respite: carer support program
2. Service gaps & barriers impacting on carers' use of respite and support services
3. Suggestions to improve mental health respite and support services
4. Organisational and capacity issues

STRENGTHS OF THE CURRENT MENTAL HEALTH RESPITE: CARER SUPPORT PROGRAM		
ISSUE	**WHAT CARERS SAID**	**WHAT SERVICE PROVIDERS SAID**
Service Innovation	Where they are available, carers are benefitting from: - Recreational activities which support social inclusion and reduce isolation. - After hours support and outreach services. - Holistic services which address both mental and physical health. - Counselling services. - Supported accommodation. Examples of best practice services include: - Share the Care, the Haven Project, day-to-day living project (Darwin): social inclusion and reducing isolation. - Sunnyfield (NSW): holistic support program similar to PHaMs There has been an increase in flexibility over the past two years. Motivated workers who go 'outside the square' to broker solutions are appreciated, especially when they: - Are flexible with brokerage funds - Enable access to non-traditional forms of respite Examples of best practice services include: - Carers Link (SA, Barossa):excellent trained and flexible staff	Early intervention approaches which incorporate prevention, health promotion and individualised care are best practice. Services which are able to provide immediate responses without resorting to waitlisting are significantly better able to meet carers' needs. There is little if any waste in the system: resources are being used 'on the ground'. When done well, the MHR:CS program can build capacity in the community to provide long-term solutions. There is capacity within organisations which provide a broad range of services to multiple target groups to link service types across programs. Holistic care which responds to both short and long-term needs are important. Services appreciate being able to offer flexibility through: - No requirement for formal diagnosis - Ability to allocate funds flexibly to address broader needs Assessment processes are important, particularly within a culture of assessment across the lifespan. It is important to use assessments to develop a support plan for carers.
Access & Information	Access to afterhours services, 1800 lines and after care counselling are improving. Examples of best practice services include: - Team Health (Darwin): after hours support - ARAFMI (NSW): outreach service in partnership with Standby - Anglicare	Helplines which are adequately resourced with trained staff (including carers as peers) are important service elements.

ISSUE	WHAT CARERS SAID	WHAT SERVICE PROVIDERS SAID
Education & experience (workers & carers)	Workers who 'get it' provide the best service i.e., those who understand the specific needs and contexts of mental health carers. The most successful workers are those who can make connections and form partnerships across multiple agencies to secure comprehensive packages of support. Matching workers to age, gender and cultural background works well. Examples of best practice services include: - Carer Safaris (NSW): multi-agency information fair day - Carer Connect 121 (ARAFMI QLD): centralised information service	It is important to build carers' skills to improve their resilience. Workshops with a creative focus are a good way to achieve this. Family education is an important strategy. Overall, levels of staff training are improving. Staff commitment to the program's goals is high across services. Examples of best practice services include: - Well Ways: holistic family education
Carer involvement & recognition of knowledge & experience	Services which acknowledge the expertise and lived experience of carers, and include carers in decision making processes, are working well.	The best support models encourage carer participation in decision making, listening to carers and mechanisms such as 'carer advisory communities'. This representation should also extend to CALD and Indigenous carers.
Networking & relationship building	Strong relationships with support workers and other carers are critical to successful carer support.	Respite coordination is crucial to successful outcomes, including through: - Guided referrals so that carers don't have to repeat their stories - Coordination with other agencies - Understanding of local service systems to help carers navigate their way Examples of best practice services include: - CRCC: partnerships and collaboration
Peer support	There are examples of carer led support groups in other carer sectors. Carers note that a large proportion of peer support is unfunded by carers operating under their own initiative.	

SERVICE GAPS & BARRIERS IMPACTING ON CARERS' USE OF RESPITE AND SUPPORT SERVICES

ISSUE	WHAT CARERS SAID	WHAT SERVICE PROVIDERS SAID
Service gaps	Service gaps include: - insufficient support to meet need, even by phone, particularly in the early stages of caring - respite houses for those who have to travel long distances to see loved ones - lack of transportation and funding for transport - toll-free 1800 numbers Geographic barriers: - in remote communities a lot of people don't have mobile phones, 1800 or other phone supports of limited use - addressing needs in regional areas is complex - a mobile unit for remote areas could increase reach of support services e.g., in the Kimberly region for Indigenous communities	Gaps which services currently unable to fill: - comprehensive wrap-around services, due to necessity to focus on immediate needs - overnight and residential respite options - distance and geography barriers - transition from acute support to community is not well supported
Workforce	Skill and competency gaps: - cultural, age & gender appropriate personnel & services - stigmatising attitudes of clinicians, service providers - lack of knowledge and information for service providers & medical staff to pass on to carers - wide variation in skills base of service staff & high turnover of staff - insufficient case management & relationship building skills and/or capacity - clinicians often have insufficient mental health training	Skill and competency gaps: - workers' ability to collate & transfer information to carers - GPs level of information & skill in dealing with mental health consumers & carers - levels of skill across sector are inconsistent - stigma is still an issue across services & professions Carers' resilience: - training for peer support & mentoring roles - physical & mental health of carers not being addressed There are challenges in the intersection of professionals' needs vs carers' needs. Workers are not well equipped to deal with challenging behaviours.

SERVICE GAPS & BARRIERS IMPACTING ON CARERS' USE OF RESPITE AND SUPPORT SERVICES (cont.)		
ISSUE	**WHAT CARERS SAID**	**WHAT SERVICE PROVIDERS SAID**
Collaboration	Lack of coordination between case management for carers and case management for consumers Siloing and competition for service funding are a disincentive for services to work together Need MOUs & service agreements in Indigenous communities	Siloing is becoming entrenched as services develop under current system Care coordination is costly and not well resourced within current arrangements Coordination across services is not a feature of current service planning Collaboration between Commonwealth and state programs needs improvement. Need to find constructive venues to broker linkages e.g., Medicare locals
Funding	Inadequate funding to meet need Annual funding instead of recurrent funding makes long term planning more difficult Inequity in distribution of state & Commonwealth funding Tender process – services forced to balance skills to respond to administration/writing tasks rather than on the ground support skills Not getting 'bang for your buck' with services that the government is funding	Inadequate funding to meet need Case coordination capacity requires more funding Annual funding instead of recurrent funding makes long term planning more difficult
Flexibility	Service & program structures are top heavy, need to focus on service level resourcing Narrow criteria in some programs Complex cases where outcomes & improvement not likely in the short term can deter services from providing support to carers Some NGOs don't identify the carer needs & lack innovation Some services and programs more rigid than others in their application of eligibility criteria and support options	Many ongoing services too prescriptive which hampers flexibility Diversity needs across communities are not being met, including: - Indigenous people - CALD - Young carers - LGBTI - Comorbidity Referral requirements which depend on having a case manager prevent access to some services HACC programs exclide people with mental health issues and their carers

SUGGESTIONS TO IMPROVE MENTAL HEALTH RESPITE AND SUPPORT SERVICES		
ISSUE	**WHAT CARERS SAID**	**WHAT SERVICE PROVIDERS SAID**
Services	More flexible services Out of hours support Locally based 'one-stop shops' Lifespan approach to respite and support Family focus and recovery based care Case management and coordination central in service provision Supported accommodation Rationalisation of information sources within and across jurisdictions, including: - Carer respite information pack (including contact & service directories) - Respite service networking nationally - Gateway services – caller navigates on behalf of client/consumer/clinician/community service Carer self-managed packages have many advantages over current fragmented services Community awareness & information campaign is required to link more people in caring roles to available support services, particularly hidden carers who do not identify as 'carers' (including Indigenous people, CALD and young carers)	Carer directed support packages would improve choice and successful outcomes Eligibility criteria need streamlining, including removal of requirement to have a case manager to accept referrals Need to develop a centralised approach to information provision (including information packs) and community awareness to attract new carers HACC services should have percentages of mental health clients built into service agreements
Governance	Carers should be involved and embedded in service planning and decision making Development of stronger accountability standards Compliance mechanisms and indicators should be built to reflect mental health standards COAG may be the appropriate place to seek agreement on uniformity of standards, expectations and principles	CALD carer representation on boards, CALD peer workers and translation of materials would enable more hidden carers to receive support Adoption of PHaMs peer guidelines would enable greater participation of carers in service planning and delivery

SUGGESTIONS TO IMPROVE MENTAL HEALTH RESPITE AND SUPPORT SERVICES (cont.)		
ISSUE	**WHAT CARERS SAID**	**WHAT SERVICE PROVIDERS SAID**
Resources	More resources targeted at research, evaluation and data collection Need to reassess the entry of US and British firms into the market, particularly with respect to local knowledge and experience – "it's not just value for money but value for experience that matters."	More resources required to expand the sector
Workforce	More resources targeted at workforce training & development Regularly updated information for staff generated at the national level Workforce needs to be expanded Protocols to promote peer (carer) worker integration into services Case management and collaboration skills require further development and investment	Need to develop workforce skills and a greater capacity for strategic partnerships across the sector

Organisational and capacity issues

Service providers were asked to consider organisational and capacity issues which will need to be addressed in the expansion of the MHR:CS program. The following key issues were put forward by services:

ORGANISATIONAL & CAPACITY ISSUES	
ISSUE	**WHAT SERVICE PROVIDERS SAID**
Workforce	Capacity to attract and retain skilled staff Inequalities in award pay rates need to be addressed Sector has insufficient person centred relationship skills required to work with mental health carers Need more staff, cannot find or service hidden carers without additional staffing Should have mandatory employment of carers as peer workers, acknowledging the resource implications in employing carer peers with additional support & training needs (also applies to CALD & Indigenous peer employment) **Note:** Service providers were asked an additional question regarding how they attract skilled workers to their services. Key responses include: - Attracting skilled workers in NSW & VIC is less of an issue following additional FaHCSIA funding for training. There is a growing number of Cert. IV trained staff to draw from. - Further mental health first aid training is essential, even for otherwise well-qualified social workers and case manager entering the sector. - Much work still needs to be done to address training of undergraduate mental health practitioners.
Education & awareness	For staff: - Accessible education/training for staff, particularly in recovery models of care - Better use of online training (e.g., mental health first aid training) - Cultural competence training so that staff understand peer worker roles For mental health sector: - Need an overarching communications & information strategy for the sector, with unified branding that carers can recognise (to avoid confusion) - Need to address stigma among clinical MH services around working with community MH services For community: - Community development focus to education - Need to make use of social media and networking to reach carers

ORGANISATIONAL & CAPACITY ISSUES (cont.)

ISSUE	WHAT SERVICE PROVIDERS SAID
Service issues & guidelines	Current broader guidelines work well, don't want the program to be prescriptive System has become complex, need to streamline MHR:CS processes to improve clarity for services. This includes development of clearer policies, KPIs and service agreements Expanded program needs to look at geographic pockets where no services currently exist. Responses to geographic issues to date (e.g., 1800 lines) aren't improving accessibility Need a national mental health carer eligibility assessment tool for the program (possibly developed with DoHA to address crossover of both agencies' programs) Brokerage guidelines are confusing and require clarification Indigenous, CALD & young carers not well serviced, MHR:CS may need to weight applications to redirect resources toward areas of unmet need The inclusion of intellectual disability and autism in eligibility criteria is diverting resources from mental health
Collaboration	Consider annual or biannual national meetings of programs funded under TCC, including CRCCs, NGO providers , PHaMs and FMHSS.
Funding	A number of issues are driving calls for increased funding by service providers, including: - Increased numbers of referrals - Increased demand for crisis & out of hours support - Demand for transport assistance - Changes associated with new award wage increases - Growing expectations for higher skilled staff - Growing demand for brokerage & case management services - Labour intensive nature of dealing with hidden carers and marginalised groups (CALD, Indigenous & young carers) - Expectations to provide a standard suite of services i.e., employ peer workers, provide counselling, advocacy & respite Consider investing in specialist mental health carer advocates The point was made that there is widespread duplication of services across the sector at present which is difficult to identify at the service level.
Reporting	Outside of program reporting, there is little robust data on mental health consumers or carers which can be used to inform program planning Changing program reporting & data collection requirements of funding bodies must be settled, both within particularly funding programs and ideally across agencies. This also applies to IT systems which host and are used to collect information. At present, greater emphasis on reporting will defer resources away from service delivery MHR:CS reporting needs to be more directive & conclusive

Measuring Success

Service providers were asked an additional question in relation to this topic: "How do you know what's working in your service?" This question was asked to determine what mechanisms are in place to measure and record delivery of support services and outcomes for mental health carers.

MEASURING SUCCESS

WHAT SERVICE PROVIDERS SAID

Services providers reported a range of measures to evaluate effectiveness under three main categories:

Direct feedback

- formal and informal feedback from carers
- consultation with service providers
- surveys
- focus groups
- observing successful outcomes for carers

Service measures

- number of urgent versus non-urgent respite requests
- number of referrals and self-referrals
- reviewing phone call outcomes
- reviewing care plans
- measuring goals against outcomes
- quality assurance processes within agencies
- complaints/compliments procedures

Reporting

- process and impact evaluation
- program reporting to funding bodies
- FaHCSIA reporting
- national evaluations e.g., Well Ways

Appendix 2 – Workshop Agendas

Mental Health Respite Carers Workshop
Old Parliament House, Canberra
10.00 am – 4.00 pm, 2 July 2012

Agenda

9.30 am – 9.45 am	*Arrive, tea & coffee*
9.45 am – 10.00 am	Introduction - Frank Quinlan, CEO of the MHCA
10.00 – 10.10 am	Welcome to Country – Matilda House
10.10 am – 10.40 am	Setting the scene for the Mental Health Respite: Carer Support Initiative:

- National Mental Health Reform Agenda;
- 2011-12 Mental Health Budget measures; and
- What we know from research and evaluations.

(Ian Boyson – FaHCSIA – Section Manager Mental Health Branch)

10.40 am – 11.00 am	Presentation – Carer Perspectives, Eileen McDonald
11.00 am – 11.15 am	*Morning Tea*
11.15 am – 12.00 pm	**Workshop** – What do respite and carer support services do well now to support carers?
12.00 pm – 12.30 pm	*Lunch*
12.30 pm – 1.00 pm	Presentation – Carer Perspectives Jackie Crowe & Keiran Booth
1.00 pm – 1.45 pm	**Workshop** – What are the service gaps and/or barriers to access that impact on carers' use of respite and carer support services? What could we do to improve respite and carer support services?
1.45 pm – 2.15 pm	**Group Discussion** - Summary of key issues
2.15 pm – 2.30 pm	*Afternoon Tea*
2.30 pm – 3.30 pm	**Workshop** – What would an 'ideal' respite and carer support service look like?
3.30 pm – 4.00 pm	**Report back and wrap-up**

Mental Health Respite Service Provider Workshop
Old Parliament House, Canberra
10.00 am – 4.00 pm, 9 July 2012

Agenda

9.30 am – 10.00 am	*Arrive, tea & coffee*
10.00 am – 10.10 am	Introduction and welcome - Frank Quinlan, CEO of the MHCA
10.10 am – 10.40 am	Setting the scene for the Mental Health Respite: Carer Support Initiative:

- National Mental Health Reform Agenda;
- 2011-12 Mental Health Budget measures; and
- What we know from research and evaluations.

Jill Farrelly, FaHCSIA, Mental Health Branch Manager

10.40 am – 11.10 am	**Panel Presentation** – Feedback from 2nd July Carers Workshop Eileen McDonald, Jackie Crowe & Judy Bentley
11.10 am – 11.30 am	*Morning Tea*
11.30 am – 12.00 pm	**Presentation** Sandie Downsborough – United Protestant Association, NSW Simon McMahon – Mental Illness Fellowship of South Australia
12.00 pm – 12.40 pm	**Workshop** – What do respite and carer support services do well now to support carers in their caring role? How do you know? Where are the gaps and what would you suggest as solutions?
12.40 pm – 1.15 pm	*Lunch*
1.15 pm – 1.55 pm	**Workshop** – Are there organisational/capacity issues or other issues which will need to be addressed in the expansion of the current program? What do we mean by flexibility? What do you do to attract skilled workers to the sector?
1.55 pm – 2.15 pm	**Group Discussion** - Summary of key issues
2.15 pm – 2.30 pm	*Afternoon Tea*
2.30 pm – 3.30 pm	**Workshop** – What would an 'ideal' respite and carer support model look like?
3.30 pm – 4.00 pm	**Report back and wrap-up**

Appendix 3 – List of Participants

2ND JULY - CARERS WORKSHOP

Alexandra Rivers, Schizophrenia Fellowship NSW
Lynette Pearce, National Register of Mental Health Consumers and Carers
Alexandra Mond, FaHCSIA
Anita Kulessa, FaHCSIA
Margo Lilley, FaHCSIA
Tony Fowke, Mental Health Carers Arafmi Australia
Jan Crossie, NSW
Phil Crossie, NSW
Patrick Hardwick, Private Mental Health Consumer Carer Network (Aust)
Doris Kordes, Carers ACT
De Backman-Hoyle, Victorian Mental Health Carers Network
Wayne Seary, FaHCSIA
Lynette Caruso, FaHCSIA
Jamie Moss
Stephanie Bassingthwaighte, Shade4Hire
Margaret Pyyvaara, Caring Choice Adelaide Hills Fleurieu Pty Ltd
Tara-Jade Brown, Adelaide Autism Adventures
Anne Barbara
Arahni Sont, Arts Access Australia
Aine Tierney, Diversity Health Network ACT
Jean Platts, NMHCCF
Yvonne Quadros, Coffs Harbour Mental Health Carers Support Group
Judy Burke, MIND
Margaret Springgay
Judy Philips, DoHA
Julie McChesney
Rose Beard
Heinrich Conrad, NT
Alec Dann, WA
Faye Dean, WA
Margaret Lewry, QLD
Tania McCurley, NSW
Margot Lilley
Keiran Booth, National Mental Health Consumer & Carer Forum **[SPEAKER]**
Judy Bentley, National Mental Health Consumer and Carer Forum **[SPEAKER]**
Jackie Crowe **[SPEAKER]**
Eileen McDonald **[SPEAKER]**
Ian Boyson, FaHCSIA **[SPEAKER]**
Jenny Moylan, FaHCSIA
MHCA: Peter Perfrement, Simon Tatz, Carolyn Conaghan, Frank Quinlan, Melanie Cantwell

9TH JULY - RESPITE SERVICES WORKSHOP

Katharine Preiss, Carers SA
Sue Sacker, Schizophrenia Fellowship NSW
Samantha Harris, Mental Illness Fellowship WA
Steve Lowe, Country North Community Services Inc
Sue Cripps, Catholic Community Services NSW/ACT
Sue Farnan, Mental Illness Fellowship Victoria
John Edwards, Aspire - Sage Hill
Tina Newman, Independent Living Centre of WA, Commonwealth Respite and Carelink
Centre, North
Rebecca Burgess, FaHCSIA
Alison Laverty, Mid North Coast Commonwealth Respite Centre
Melissa Farrance, Carers Australia
Michelle Sully, WA State Office, FaHCSIA
Gary Vogt, Carers' Link Barossa and Districts Inc.
Julie McChesney, Arafmi (WA)
Jenny Moylan, FaHCSIA
Peter Sparrow, Carer Support
Peter Campbell
Lynette Caruso
Robyn Beavis, Barwon Health
Stephen Gamble
Jean Giese, Carers ACT
Bev Hamilton, FaHCSIA NSW Office
Jane Henty, Mental Health Carers Arafmi Australia
Aimi Johnson, Commonwealth Respite and Carelink Centre - Eastern Metropolitan Region,
Victoria
Lisa Kinsey-Smith
Anita Kulessa, FaHCSIA
Julien Leith, Victorian Mental Health Carers Network
Paul Mayne, Langford Support Services Inc.
Kerry Meiers, Carer Support Services
Alexandra Mond, FaHCSIA
Sheryn O'Grady, Commonwealth Respite and Carelink Centre- Brisbane North
Judy Phillips, DoHA
Liz Veal, Mental Health Carers NT
Sandie Downsborough, UPA - North Coast Region **[SPEAKER]**
Simon McMahon, MIFSA **(SPEAKER)**
Jill Farrelly, FaHCSIA **[SPEAKER]**
Eileen McDonald **[SPEAKER]**
Jackie Crowe **[SPEAKER]**
Judy Bentley **[SPEAKER]**
Ian Boyson, FaHCSIA
MHCA: Peter Perfrement, Simon Tatz, Carolyn Conaghan, Frank Quinlan, Melanie Cantwell,
Josh Fear