Approach to designing an Integrated Carer Support Service System in Australia

Submission to Department of Social Services: Discussion Paper

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Designing an Integrated Carer Support Service System

The Mental Health Coordinating Council (MHCC) is the peak body representing community managed organisations (CMOs) in NSW. Our members deliver a range of psychosocial disability support programs and services including housing, employment and social inclusion activities, as well as clinical and peer supported services with a focus on recovery oriented practice. MHCC members also include organisations that provide advocacy, education, training and professional development and information services.

We work in partnership with both State and Commonwealth governments, and the public, community and private sectors in order to effect systemic change. MHCC also manage and conduct collaborative research and sector development projects on behalf of the sector and is a registered training organisation (MHCC Learning & Development) delivering nationally accredited mental health training and professional development. MHCC is a founding member of Community Mental Health Australia (CMHA) the alliance of all eight state and territory community sector mental health peak bodies. Together we represent more than 800 CMOs delivering mental health and related services nationally.

Background

The Designing an Integrated Carer Support Service System: Discussion Paper (DP) outlines the draft design of a new service concept - an integrated carer support service system. This second phase of the design sets out to define the process to be undertaken in three parts.

1. Definition of a Service Concept, which will identify the high level services aimed at providing improved outcomes for carers.

2. Definition of a Service Delivery Model, which will define the services in more detail, the mechanisms by which they will be delivered (e.g. face to face, mobile device, telephone, etc.), participants who will deliver these services and the technology which will support this.

3. Definition of a national carer needs identification tool, which will articulate a design of a nationally consistent needs identification tool.

The purpose of a new service is to deliver supports that reduce "caregiver strain" (based on a model of social, psychological, physical and financial outcomes) with the twofold objective of increasing a carer's well-being and reducing the risk of burn-out or the caring role ending. The ultimate design of the new service will form the basis of a proposal to Government, for consideration on how to proceed with operationalising the service. The Service Concept articulates what services are going to be delivered and why this will assist carers, and represents the first component of the design of the new integrated carer support service system in draft form for discussion.[i]

In the context of the wider design, the Service Concept articulates what services are going to be delivered and why this will assist carers. It identifies a set of carer-specific supports (that could be delivered by the service) that improve carer outcomes. It will ultimately form the foundation for the design of the Integrated Carer Support Service, by articulating how the needs of carers will be met by the services described. It is intended to provide a high level framework for more detailed design.

MHCC welcomes the recognition of the important part carers play in supporting people living with mental illness and psychosocial difficulties and thanks the DSS for providing us with the opportunity to comment on the second stage development of the Plan by way of a submission to the Discussion Paper (DP).

Nevertheless, we are concerned that poor awareness across the mental health sector about this DP and its submission deadline, means that many stakeholders were unable to provide their own submission. MHCC suggest that in future consultative processes that state peaks across mental health and other human services are better informed as to the Commonwealth's activities in this important space.

General comment

Whilst accepting that this discussion paper does not attempt to provide details for implementation that encompasses the specific needs of the various carer stakeholder groups identified, MHCC has determined to identify issues particular to carers of people with mental health issues. We do this so that the DSS may consider these matters when progressing to the next stage of program development and implementation.

Within a very limited time frame, MHCC has consulted with the mental health sector and is providing comment based on the expertise and lived experience of these carers and senior carer advocates in NSW, some of whom belong to MHCC member organisations. We thank them for providing input at very short notice.

In the first place MHCC and those consulted support the philosophical framework in the DP highlighting that:

- Carers need timely, early and responsive support rather than a reaction to breakdown;
- That carers are impacted and face a number of health, psychological, social and economic and require support in their own right to build capacity and maximise their quality of life, and hence the quality of life of those they care for;
- That a well-planned population health-based approach, with timely and well thought out interventions will assist in early identification of family members and carers, and increase access to hidden carers;
- That specialist interventions that support awareness, information, education, peer support, counselling and integrated respite supports are necessary additions to gateway models and will ensure support to carers in the extended life-course of caring.

MHCC support the strategic purpose and intent of the draft Service Concept for designing a 'new' integrated carer support service. We agree that the literature cited provides some of the evidence and rationale for a model that will deliver interventions that can better support and improve outcomes for carers. However, MHCC emphasise that there are many issues that carers of people living with mental illness experience that require specific consideration.

During consultation with carers, one of the issues highlighted relates to the impact of the legislation on rights and obligations in the context of involuntary care and treatment under the *Mental Health Act 2007*(NSW). Likewise the consequences of other pieces of legislation such as the *Privacy Act 1988* (Cth) and the *Anti-Discrimination Act 1977* (NSW) and how these instruments operate on the ground deserves consideration in the planning and implementation process in terms of providing information, education and integrated service supports. Whilst legislation across a variety of areas affects all carers and the person they are supporting, in our view, there is no area so affected by

stigma and discrimination as mental illness. Therefore, we emphasise the need to support carers and the person affected to understand how they can navigate a complex service system, learn about their rights, and find where they can access support, information and guidance for themselves or those that they care for.

MHCC acknowledge that the design concept is a high-level document that provides the guiding principles (p.20) that seek to enable measurement of progress and outcomes against stated objectives. However, in the context of an integrated carer support system for carers of people living with a diversity of mental health and coexisting conditions, we note the absence of a clear interface between Commonwealth and existing state programs.

As we understand it, the environmental analysis (in the DP) has only sought to identify Commonwealth programs. MHCC propose that in NSW for example: the Family and Carer Mental Health Program (FCMHP)based on the Carer's Compass (developed by the King's Fund, UK) which offers education and training and individual support services to families and carers of people with mental illness, is utilised to inform the design of this 'new' integrated carer support service system. The FCMHP is a program that whilst underfunded, has been highly successful in bringing together many of the elements identified by carers of people with mental health conditions as critical to building capacity (see Appendix 1).

A report was undertaken by ARTD Consultants that provided data summaries and discussion of data collection and reporting issues during a period in 2013 on behalf of the NSW Ministry of Health, Mental Health Drug and Alcohol Office. The FCMHSP monitoring system is designed so that it is possible to not only provide snapshots of clients and services, but to follow service patterns and outcomes for individual clients. It does this by linking data collected on the different forms through unique client IDs. The data provides useful information concerning those people accessing the service. [ii]

We support the philosophical underpinning in the DP that sets out to establish a service concept that is a preventative rather than a reactive coordinated system response that meets carers' needs early on; supports them as their needs fluctuate and builds capacity to fulfil and sustain their caring role over the lifespan.

Carers consulted have emphasised the need to review existing programs and build on learnings and evidence of best practice, carer evaluation and outcomes. Additionally carers highlight the need to enhance existing programs in numerous ways both in terms of information, accessibility and co-design opportunities, resources and workforce and carer training in addition to respite as well as clinical and psychosocial support. Some carers have commented that early experiences of the Carers Gateway has been disappointing, and that an understanding of carer access to the internet is often limited.

Approach to the design of the new integrated carer support service system

MHCC raise a number of questions and comments arising from the draft concept DP:

- Firstly "the department has undertaken three research activities to design an effective, sustainable Integrated Carer Support Service, it is necessary to gather information about and analyse the current ways, in which carers receive support." One of these is an environmental analysis (Current State Report) to identify the organisations currently supporting carers and understand their processes, types of staff and technology.

MHCC ask how this analysis will capture the service gaps? For example, we are aware of the many 'hidden' carers whose needs are not being met due to them not accessing services for a variety of reasons; geographic; cultural; or as a consequence of a reluctance to seek support due to potential or perceived repercussions. Young carers, CALD and First Nations People as well as carers of people with a mental health condition or AOD difficulties may be reluctant to seek support because of for example: potential legal ramifications, relationship breakdown, fear of violence, stigma and discrimination.

- Secondly, the department is undertaking market research (Carer Service Development Research) to understand the needs of carers in relation to a carer information and support service.

  MHCC ask how this process will capture information about informal supports? This additional information could lead to very different ideas as to how the system might deliver and fund support for carers. We ask also what might be the barriers to access and participation and how those issues might be brought to light?

- Thirdly, the department will conduct an analysis of meta-reviews of international evidence on the effectiveness of supports in achieving good outcomes for carers.

  MHCC ask that such reviews take into account the cultural and geographic context in Australia, since many such reviews in other contexts assume broad-based similarities across 'western cultures' without taking into account the varied cultural, geographic and social service environment in which supports operate.

- The co-design activities and the development of the draft Service Concept in the draft Service Concept has been developed through an iterative process involving carers, organisations who support carers today and the Carer Gateway Advisory Group (CGAG). Using the findings from the analysis of the current state of the carer service system, the Carer Service Development Research, and a review of the clinical evidence, the Department engaged in co-design workshops with the CGAG, a Subject Matter Expert (SME) Working Group and a Carer Working Group.

  We ask how the needs of those not supported by carer organisations or other supports may be represented? We also ask that in going forward that the department make clear how the SME Working Group will be comprised in order to appropriately represent the great diversity of interests across carer stakeholder groups.

- MHCC highlight the need (when developing a "new" integrated service system) to use language that speaks to the various stakeholder groups. For example in mental health 'Recovery' principles and a recovery practice orientation is key to service delivery at every level.

  Whilst appreciating that the DP is expressing a broad-based statement of need, from our perspective the language used relates more to a traditional disability/aged care focus. We interpret the focus to be on the importance of carers supporting people so that they do not require expensive residential care, rather than emphasising a focus on carers supporting people to live in and participate in the community of choice. This is a key objective in the mental health space. Neither does the "language of need" speak to the experiences of young carers and adolescents under 18 still living at home.

- The DP acknowledges the contribution carers make to our society, stating that the Australian Government provides a range of supports specifically for them. However, these services are accessed through pathways across disability, community mental health, and aged care sectors.

  It is important that in future development that these pathways acknowledge all the potential conduits such as AOD, children's services/ out of home care and foster care need to be recognised as areas requiring support.

- The DP reports that according to the ABS the most common reasons reported by primary carers for taking on the caring role were family responsibility/obligation (26%), the carer feeling that they could provide a better quality of care than others (19%) and emotional obligation (16%) likely driven by the relationship between the carer and person being cared for.

  Carers consulted commented that in their experience this is actually driven by societal norms and cultural expectations not the relationship itself.

- In identifying the "stressful challenges" (p.8) that carers experience MHCC highlight two areas that we propose need more thought:

  - grief where activities or hobbies are no longer possible due to caring responsibilities (AMR Australia, 2015); and

  - a greater propensity for financial hardship.

  The grief experienced by carers is much bigger than loss of activities or hobbies. This ignores the profound effects of the loss of dreams and expectations for themselves and for the person they care for, as well as the loss of the relationship they had or expected to have, or loss of the person (if their condition results in changes to personality or functionality). In the context of mental illness there is a great deal of research that highlights carer loss and grief.

  Likewise, the term financial hardship does not express to degree to which poverty or risk of poverty is experienced by carers. The limitations on their own careers and cost of multiple losses and their own potential health issues need to be fully recognised in service planning support needs.

- In discussing the difficulties carers experience in navigating the service system, the DP acknowledges that "carer support organisations face complexity associated with the current funding arrangements, with a need to define which of the carer programmes a carer is eligible for. Complexity is inherent where carers need to be classified in relation to the person they are caring for, particularly where they are caring for more than one person" (p.16).

  Some programs require that the carer be a 'primary carer'. This does not recognise the complex and variable dynamics of families (including family of choice). One example provided is the difficulty accessing young carer supports for more than one child in the same family. In this example, one young person receives supports as the 'primary carer' (as the older child) and younger siblings are ineligible. Similarly, where a parent is identified as the 'primary carer' there is difficulty accessing supports for a child also be supporting their parent. There is a need for services to be flexible to accommodate the needs of the whole family or support network.

- In the DP the example states that someone caring for two people, one who is aged and one who has a mental health condition, is eligible for multiple programmes and in providing support, carer organisations are required to draw down on and manage multiple funding streams.

  Those consulted suggest that it is absurd to have to identify the 'primary' disability to identify which funding they are eligible for. An example given was where a young carer of a parent who uses a wheelchair who also had depression. Asking the carer which aspect was more challenging, the physical care or the emotional care, the young person said 'emotional' without hesitation. Whilst the 'primary' condition is paraplegia due to spinal cord injury the greater need identified by the carer was emotional support.

- The DP states that "under current arrangements, carers are commonly required to provide information about themselves, and the person they care for, to multiple organisations across the service system. This is related to a lack of automated information sharing in place. This is both in relation to the needs of the person they care for and their own needs" (Department of Social Services, 2015).

  Carers report that this requirement is often re-traumatising for both the carer and consumer. Having to tell their story/ies over and over really must be acknowledged as traumatic. In this context MHCC urge that service designing must ensure the principles of trauma-informed care and practice are embedded in assessment processes and program development.

  It also needs to be recognised that having to provide information about the consumer, and have this information shared between organisations can be a significant barrier for carers. We ask that consideration be given to

  - How a consumer provides informed consent to have their personal information shared?

  - What if a consumer refuses consent and this then prevents a carer accessing supports? (MHCC note that In the Family and Carer Mental Health Program this was a significant ethical and access issue that required consistent lobbying as the funders wanted to be able to tie carer support to consumer outcome.

- The DP recognises that there is limited standardisation of practices across the country, and carers have quite different experiences in accessing supports. A number of organisations raised examples where carers who had moved into their region and had different expectations of the supports they could request and the way in which they could be accessed. This leads to an unequal experience in accessing support across the country. In addition, the current brokerage model utilised in some carer support programmes means there is significant differences in the level of support provided from one carer to the next (Department of Social Services, 2015).

  MHCC note here that different geographic and socio-economic regions often present with different needs, both social and cultural. The carer support program needs to be able to flexibly respond to need in order to provide support in culturally appropriate ways.

- In discussing the fact that locating and accessing respite services is often challenging (p.17) the DP defines "respite as a form of support where a carer is relieved by an individual who provides substitute supervision and assistance to their care recipient… etc."

MHCC stress that this is a problematic definition when it comes to mental health respite. Sometimes what is needed is not 'substitute supervision' but for the carer to be able to have a break away without cost or at a minimal cost (as carers are often in the lowest percentile re income (ABS, Carer health and wellbeing report, 2011).[iii] Sometimes what is required is support that addresses barriers to participation and respite. The example provided concerned one carer reliant on the care recipient (her husband) to drive her and her children. Neither she nor her husband were employed due to his mental health condition. As a consequence of her parenting and caring roles she could not work. Since they live in a semi-rural area with poor public transport this meant she and the children missed opportunities to participate in school and community when her husband was unwell. The carers support worker was able to negotiate for her to receive some driving lessons as a way of addressing a barrier to respite. This had a positive effect on the wellbeing of all members of the household.

Sometimes what is also required is for carer and care recipient to have a break together as a first step towards increasing trust of services and openness to respite for either consumer or carer or both. This is particularly important when past negative experiences of respite have been experienced by either the carer or consumer or both.

- The DP states that "as planned respite is funded under the main service systems targeted for care recipients (e.g. CHSP), carers face increasing difficulty in seeking this type of support, particularly where they are caring for more than one person" (p.17).

This is particularly so for carers of a person with a mental illness. The episodic nature of some people's experience makes it difficult to plan ahead. Or they may have planned but then the consumer is too unwell for respite and not unwell enough to be admitted to hospital so the carer has to cancel their break in order to care of the person (or people).

- The DP states that "given that an objective of the future model is to assist as many carers as possible, it will be necessary to identify those carers who will require a higher level of support so as to target Government assistance for those most in need" (p.19).

MHCC suggest that this contradicts the aim of supporting carers to sustain a role and avoid a crisis. Carers report this as a difficulty with current supports in that carers need to demonstrate high need in order to access supports. Without the necessary support due to assessed level of need, the chances are that they will present later with higher needs. This is less than cost effective in the long-term and represents a massive human cost on families and consumers.

- With regards to Section B, outlining the Draft Service Concept in a chart (p.21) MHCC suggest that an omission here is the partnering and collaboration with other services. This is particularly important for example in supporting COPMI as the needs of a parent will impact on the child or young person.

Many carers services eligibility excludes children under 16 due to issues around legal consent and need to work with the parent/grandparent or other legal guardian. If carer services are to reach children and young people, they will need to work in an integrated way with other family services and services that support the care recipient and/ or work with the care recipient to increase their capacity to support their children.

- In returning to considerations about language utilisation in developing the design concept, the DP talks about "Awareness" (p.24)."The objective of awareness is to find carers; particularly hidden carers, through outreach, partnerships and co-located services, and encourage their use of available interventions. This task is made more challenging by the fact that the majority

(79%) of carers do not necessarily see caring as their primary responsibility (AMR Australia, 2015)".

Carers report that they often do not identify with the term 'carer'. MHCC has be told by carers that the term has negative connotations for carers of people with a mental illness. They suggest the term 'caring' is patronising. Carers of people with mental health and AOD issues suggest the term 'carer' may have connotations of enabling or co-dependency.

For someone who does not see caring as their primary responsibility, they should not need to identify as such in order to be able to access carer supports. This may lead to exclusion of working carers and people who see their primary role as something other than the support they provide to a care recipient. For example a parent may see their primary responsibility as parenting rather than as a carer for a family member or friend.

- The DP reports improved awareness within the broader health sector echoed in co-design workshops. Participants of the Carer Working Group indicated they would have liked more direction on what they could expect, at the time at which their caring role commenced. This was commonly within the context of medical setting, necessitated by either an unexpected event or a medical diagnosis. The DP goes on to suggest that hospitals also create an environment where carers would be most receptive to the service. Mass media (radio and TV) would also be beneficial; ensuring a broad group of carers could be reached as carers spend a significant amount of time in the home.

  Our consultations suggested that schools and tertiary education providers are consistently identified as most appropriate places for awareness raising of the needs and supports available especially for children and young people who are carers.

- MHCC provide some additional comment to the Design Considerations listed commencing on page 25.

  o It is important not to assume that the preventative focus is the same for adults as young carers. A primary aspect of this involves identification of young carers as early as possible through health/disability services, and through schools/education sector and child and family services.

  o In order to raise awareness of young carers, adults in their lives need to understand the needs and supports available for families and young carers. Therefore a preventative focus on awareness for young carers will need to look very different and be age appropriate.

  o Schools need awareness raising to understand the needs and be able to offer reasonable adjustments to assist young carers to participate in education and extra-curricular activities.

  o The most effective and efficient means of raising awareness for individual carers early in the caring journey is through engagement with Peer support workers - carers who have been there and can offer information, empathy and hope.

  o The DP identified that in co-design workshops, preferences among carer participants were split, with some carers indicating they would prefer to self-manage intake processes, for example through an online channel. Other carers highlighted they would seek to do this via telephone or other human interaction. This would need to factor in

age considerations also. Older carers are more likely to want to talk on the phone or in person.

Intake for young carers would need additional consideration. Young people and their parents may minimise the impact of caring for many reasons: fear of removal; fear of repercussions on the parents; lack of understanding about what is 'normal' (needs are different to other children who are not carers); parents unawareness of the impact on their children (often siblings' needs are missed); etc.

o   The DP asks if there are ways to make intake a more beneficial process for carers? A carer peer support worker can offer validation, empathy, information about what services are available, information about the mental illness and recovery, understanding of the 'intake' process.

o   The DP suggests that in undertaking intake (either through phone or self-service online) carers could opt to register their emergency plans with the service so that in the event of an emergency, information can be readily accessed to deliver respite support.

Emergency care plans for carers of someone with a mental illness are complex and require some time to work through due to issues of safety, and the need to educate carers about appropriate avenues for support, and the need to involve the consumer(s) in discussions or do this in tandem with consumer crisis care plans.

o   The DP suggests that another way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is necessary. For example, to what extent would intake be required to facilitate access to peer support or education? While it will be important as part of the future service to measure outcomes of the interventions developed so as to build upon and improve their delivery, this additional administrative burden may represent a barrier to people otherwise accessing these services. Given this, when should intake be a mandatory process?

MHCC suggest that there is also a need to consider trauma-informed principles in the intake processes. Carers may be trauma survivors (including indirect and vicarious trauma). Intake has the potential to re-traumatise in a number of ways. There is also need to consider consumer privacy in this intake process.

o   In discussing education as an intervention (p.29) the DP states that carers view their individual situations as complex, unique and very different to other carers. Carers are concerned (as reported in the Carer Service Development Research (2015) that the service would not offer anything specific to their situation. The challenge will be delivering education and counselling interventions specific to the needs of the carer cohorts - without the interventions becoming over specialised and too varied to support economies of scale.

This is where skilled facilitators, especially those with lived experience can bridge the gap – drawing on common experiences of isolation, worry, grief to build a sense of mutuality. This can draw out individual ways of coping which others are free to explore for themselves, adapt or dismiss as irrelevant. Psycho-education which draws on peer support principles gives a mix of information and emotional support which are experienced by carers as helpful and supportive. Individuals with unique needs also should have ready access to one-on-one supports where the group is not sufficient to completely meet their needs.

o   In responding to design considerations (p.30) regarding encouraging access to education supports. Carer support workers suggest that building a relationship over time and introducing people to those who have benefited from education is beneficial. It may take several years before a carer will attend a face to face program.

Offering telephone groups (tele-group counselling or talk link) is one cost-effective and time efficient support. It enables people to access the service from anywhere they have phone reception. It is important to target people more likely to be comfortable with and desire online supports, e.g. young carers.

Local partnerships and networks are important. Ensuring the Carer Gateway is able to be regularly and quickly updated and that services are encourage to regularly update their information.

o   The DP reports that strong feedback has been received through the co-design workshops and through the Current State Analysis that peer support should be included in a future support model. Co design workshop participants reported that peer support assisted carers by broadening their informal support network, providing an opportunity for social interaction and in some cases, a period of respite.

A Peer support model which will encourage carers to participate and remain engaged can be fostered by utilising peer support workers employed in other parts of the program (e.g., education/respite/information/intake/needs identification and planning etc.) as group facilitators or co-facilitators. Also by supporting infrastructure for support groups: venues, insurance, peer support for facilitators/leaders.

Support for bilingual group leaders such as those employed by Transcultural Mental Health and ethno-specific organisations should also be encouraged.

Peer support should be a service accessible without pre-conditions or complex structural processes.

o   With regards to Needs Identification and Planning (p.32), the objective of this service is to assist carers by identifying unmet needs and providing aid in planning informal and formal supports. A good example of this is was the ADHC funded older parent carer program where funding for planning for the future and discretionary funds to pay for immediate needs that would lead to a longer term benefit was possible.

o   Planning was reported by co-design workshop participants as being highly important for carers and something they were seeking assistance with, particularly early in their caring journey. This is particularly problematic for carers of someone with a mental health condition, as long-term prognosis is by no means certain. Likewise, the episodic nature of some people's condition means planning ahead can be difficult.

Needs identification should not only rely on provision of physical care needs but also emotional support, prompting, coaching, supervision and monitoring of wellness, insecurity of supports for the consumer and other caring tasks that are less tangible but have an impact on carers stress and emotional wellbeing.

o   An approach of empowering carers to identify their own needs is consistent with consumer directed care models. The DP asks to what extent do you think goal based planning should be used at the assessment stage of the process?

Goal based assessment and planning approaches are common to Consumer Directed Care principles, usually in conjunction with a funded package or financial allocation of some form. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?

Carers consulted propose that this be done in conjunction with goal based planning for the consumer (hence partnerships being important). This is potentially useful for longer term carers, especially for carers of people with a mental health problem early on in the caring journey. Carers in the early days often "don't know what they need, they don't know what's available and are focussed on the consumer's needs and not their own, or the rest of the family."

Goal based assessment and planning tools tend to be individualistic. Holistic assessment and planning for the whole family or support network is more culturally appropriate for carers who come from cultures where the focus is on the whole family or community rather than on individuals.

Needs of other family members need to be taken into account as these can undermine carers' efforts to make changes that will enable them to increase their own well-being.

o The DP refers to the review of the UK direct payment scheme. Carers UK found more than half of those carers questioned reported their overall experience of the scheme was positive, with almost three quarters stating that the care they are able to purchase is better at meeting their family's needs than the previous service. The discussion here assumes that carers are managing consumers' funding packages.

It is important to consider the impact on carers where consumers are self-managing their funding or where a guardian is doing so. Dealing with issues due to consumers' poor financial management can be a significant source of worry and stress for carers. Particularly young carers, older parents and spouses.

o In discussing Multi-component Support: Carer Mentoring (p.39) the paper suggests that "while the term 'mentor' suggests a peer led programme, the intention for this service is to provide a coaching-style service delivered by qualified support staff". "Qualified support staff' and peer led are not mutually exclusive. Peer support workers are qualified support staff who are also able to coach and mentor by drawing on lived experience. This could be a significant role for carers to assist them to return to the workforce (easing economic burden on them and the tax payer) whilst utilising the skills they have gained from their experience as a carer.

A coaching programme will be most effective for a carer when it is most valued by the carer. Some will feel this is early on, others will feel this is when they feel "stuck".

o Making the service mandatory is to ignore the principle of autonomy as well as to negate people's lived experience. It is considered that making a service mandatary is patronising and controlling and not in keeping with strength- based and collaborative practice. A coaching/mentoring service is unlikely to be effective when a person feels coerced into receiving it. They will likely do/say whatever they need to in order to receive the parts of the service they need. At best it's time-wasting and at worst disempowering.

o The DP suggests that there are low levels of uptake for respite services. Despite the high levels of satisfaction, uptake (by carers) is low with only 10.7% of primary carers reported as using respite services (Australian Bureau of Statistics, 2012). Those consulted suggest that this is mainly due to the unsuitability of current respite options or consumer reluctance or resistance to respite and lack of flexibility.

o In relation to the utilisation of respite services in an emergency, the DP reports that co-design workshop participants felt this needed to be a standalone service for these instances. While the service remains the same, it is acknowledged there will need to be a direct pathway for emergency respite support which is not immediately paired with a multi-component intervention. Carers suggest that this doesn't impact on planned respite. Having limited occasions of respite per year, carers can be reluctant to plan respite in case it is needed for emergency respite in the future and vice versa.

o The objective of the counselling intervention (p.43) is to improve a carer's psychological outcomes through delivery of traditional psychotherapy individual and/or group sessions, such as the Cognitive Behavioural Therapy (CBT). Some carers expressed that they had thought accessing services such as counselling was tantamount to 'admitting defeat' and a failure to provide adequate care.

Carers reported to MHCC that they found peer support an effective way of addressing this concern. Self-disclosure about the effectiveness of counselling and how counselling can help overcome the stigma of accessing counselling, and can also dispel the myths people have about counselling.

Carer peer support workers, while not providing counselling, do provide many of the core components of person-centred humanistic models of counselling (unconditional positive regard, empathy, validation, empowering people to come up with their own answers)

o While counselling has been shown to be highly effective at reducing 'carer strain' delivery of counselling to large numbers of carers is challenging due to the resources involved. Similar challenges are being faced in the mental health sector where many people who would benefit from counselling are unable to access the service due to long waiting lists and high costs. Comparative research of delivery modalities (i.e. telephone counselling versus online programmes) has demonstrated that digital and telephone counselling are as effective as face to face counselling. Utilisation of lower cost channels such as telephone or online to deliver counselling will mean more carers will be able to receive counselling.

Design considerations should consider group counselling programs and structured therapeutic groups. It can also be cost-effective and utilise peer support as well as the counsellor as a resource.

o The DP asks that since much of the evidence relating to effective counselling programmes for carers is focussed on CBT, what other counselling programmes and techniques would be beneficial in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?

There is some evidence of mindfulness based programs such as ACT and MiCBT (Carers Tasmania) are helpful to carers.

Another carer reported that "quality counselling from a community family counsellor has been a wonderful help to me and through the flow-on effect to my son." She also reported wonderful benefits to her son when he received some counselling sessions.

A suggestion was made in relation to cost of counselling as to whether SKYPE might be a way to deliver counselling in rural areas, or where transport is an issue.

o The DP recognises need to support young carers to sustain their caring role and continue to develop and progress in their own right. Young carers are at risk of negative impacts from their caring role. These include difficulties in school attendance and attainment which has longer term impacts in terms of young carers' opportunities for further education, training and employment. We also highlight here the long-term financial implications including loss of earning potential and risks of poverty and hardship.

Commonly low income household circumstances affect young carers' social lives, including their friendships and social and recreational activities. MHCC highlight that some of the experiences that young carers are more likely to experience are shown to be detrimental to future physical and mental wellbeing (The Adverse Childhood Experiences Study ACEs).[iv] This includes implications for brain development, and research into trauma and its impacts would be of much value here. MHCC note that due to ethical considerations there are few children involved in research studies, they are rarely identified as a high needs group and therefore their needs are likely to be underestimated. This is where prevention and early intervention programs need to work alongside young carer supports.

There is a need for age appropriate supports alongside supports that realise that young carers may have knowledge and skills beyond their developmental stage. Young carers express frustration at patronising and paternalistic attitudes of services which fail to recognise and value their knowledge and expertise. Tension between helping young carers to 'be a kid' and realising their life experience, means in some ways they are not like other children. This is where peer support activities such as camps and other social activities can be so valuable as young carers feel like they 'fit in' and can also get access to information and referral to other supports that build relationships of trust etc.

o The DP highlights the research by AMR Australia (2015) identifying that carers from culturally and linguistically diverse communities face significant challenges in accessing support for their caring role. Capacity building approaches including partnerships are vital to ensure that ethno-specific organisations are able to support carers rather than trying to fit people into a service that doesn't understand them or their needs.

o Similarly, Aboriginal and Torres Strait Islander carers report significant barriers in accessing support services, attributed to the numerous pathways and cultural difficulties (AMR Australia, 2015). The DP reports that co-design participants highlighted that carers in this cohort are reluctant to access funded services due to their mistrust of government. MHCC has identified that other issues include poor life expectancy; that the caring role may impact on health of carers, as does caring for multiple people with complex needs. The impact of trauma and intergenerational trauma must also be considered as an issue that has implications in every aspect of a carer's experience.

In mainstream services carers experience a lack of cultural appropriateness together with a poor understanding of the different role expectations and family structures. These differences affect eligibility criteria. A 'primary carer' is a concept that does not match cultural norms where different family members may be expected to fulfil different roles. Organisations need to take a whole of family/whole of community approach. Carer supports need to be community led, community driven and community run. There is a vital need to take a long-term approach and strive to build trust. Relationships are built with individual workers not services, and this is particularly problematic with short-term funding and high staff turnover.

o The DP acknowledges that carers in regional, rural and remote settings face significant challenges in their caring role. While the difficulties faced by carers in these areas are similar to those in metropolitan areas, the problems are intensified in these settings. In addition to those challenges list in the DP (p.47), MHCC raise a number of related issues:

- The impact of dual relationships – the carer might be accessing support from a counsellor/ worker already known to them in another capacity (e.g., through school, business or community activities). Small communities increase the likelihood that a carer will have past or current connection to the service provider or that the person they care for does. This is challenging for reasons of privacy, bias, stigma, past negative experiences etc.

- Geographic distances are a barrier for service providers and for carers. There is need for multi-modal supports e.g., carers can access respite and accommodation that enables them to attend face to face peer support/psychoeducation programs.

- Mobile phone reception is a challenge in remote areas for service providers travelling to locations and for carers participating in phone based services or programs.

- A good way of reaching numbers of carers is the use of free online resources was mentioned. A free course Caring for People with Psychosis and Schizophrenia can be accessed with FutureLearn, based at Kings College, University London.

- Service providers who are not familiar with the local community are limited in their capacity to empathise with and be able to realistically offer support and information. Reliance on large central databases (e.g., the Carer Gateway) means that rural carers and service providers can easily be left with the perspective that there are no local services for carers - which may or may not be true.

- There is a greater need for community capacity building approaches to support carers and raise awareness. Service providers who are well respected tend to be very busy.

- Access and equity issues need to be considered separately in each section considering design implication, whether this is older carers, young carers, Aboriginal or CALD carers. The needs of LGBTI carers are grouped together like this is a homogenous group with similar needs and this is not the case.

o In considering elements of providing integrated support (p.48) the DP reports that "feedback from co-design participants has highlighted that carers often seek support for the person they care for ahead of enquiring about support for their own needs. Therefore, to ensure the service offers value for carers and can assist in connecting them to supports, the service must have connections with organisations who provide support for the person they care for." The listed examples should also include community managed mental health programs, community mental health, mental health inpatient services, AOD services, housing and supported employment etc., as well as consumer-led initiatives.

o Balancing employment whilst caring for someone, or returning to the workforce after a caring role has ended has been identified as a key challenge for carers. MHCC also raise the issue of entering the workforce for women after raising children or for young carers entering the workforce for the first time as important to include as considerations.

As mentioned earlier in this submission, it is vital that carers have access to Information and advice about rights, particularly to request flexible work arrangements and about other implications arising from disability discrimination legislation. For example what can you do if you suspect your employer is discriminating against you or you suspect you were unsuccessful in securing a job because of your caring role? MHCC comment here that they provide from their website an online resource that offers information on mental health rights and related matters in NSW.[v]

For carers who are returning to the workforce after the end of their caring role, in addition to those supports identified, the Integrated Carer Support Service must also employ carers as mentors and peer support workers to support other carers.

o It is recognised caring can, for many carers, become a primary focus of their day to day lives. With the responsibility that comes with caring, many carers are concerned largely with the needs of the person they care for, rather than planning for their own future. The DP suggest that there are two primary ways caring can transform; the person being cared for may move into residential care; or they may pass away. MHCC adds to these issues that the person being cared for may be in recovery and need less support, or the carer leaves home (young carers) or the caring role is shared by a greater number of people. Sometimes the carer may decide they no longer wish to support the person to the extent they have in the past or they have separated from the person they were caring for. There are many, many, ways caring can change over time and all may involve a sense of loss (even if the role changes for positive reasons).

Where the person being cared for passes away, understandably, carers experience grief and stress. During both of these times, carers may need support, particularly emotional forms of support. However, there will need to be a balance in supporting past carers to transition from their caring role, and the need to assist current carers. This is also the case for carers whose role changes due to less support needs of the person they care for (when in recovery or remission).

Design Progression

Lastly, MHCC comment briefly on the design of the new integrated carer support service system which has two primary phases:

1.	formulate an understanding of the current state; and

2.	the design of the new integrated carer support service system.

The purpose of the first phase is to understand a number of identified areas of concern. In this last part of the DP MHCC comment on the following issues:

- MHCC suggest that in attempting to understand the weaknesses in the system, MHCC propose that to understand this well carers who are not recognised or supported by current systems need to be able to input into the discussion.

There are a number of core objectives of the second phase, to design the new integrated carer support service system:

- identify the design principles;

- define the objectives and philosophy of the service, and the supports to achieve this;

- design and validate the way in which these supports will be delivered; and

- design and validate the way in which carers needs will be assessed, and the information which will be collected at key points.

- MHCC propose that in considering all of the above it will be necessary to embed action evaluation to allow for modification to improve the systems as issues and gaps are identified.
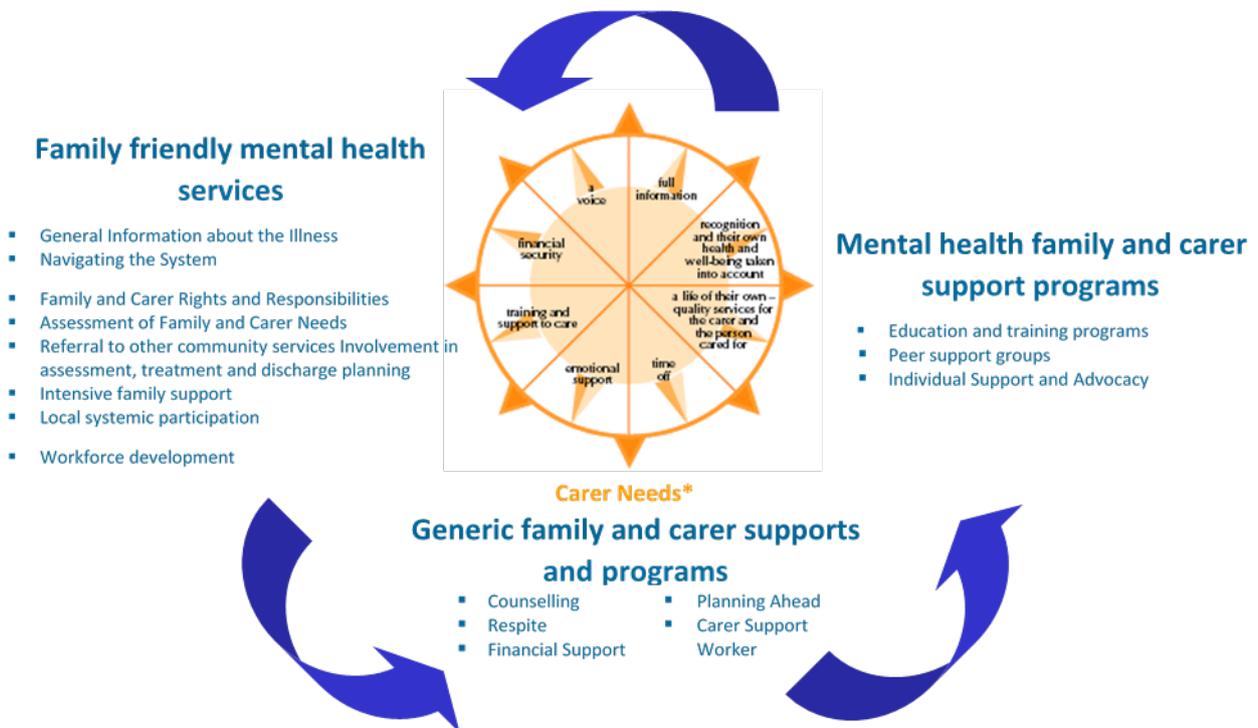

MHCC express their willingness to engage in further discussion concerning the design of the new integrated carer support service system, and would welcome involvement in future consultation processes.

16 June 2016

Family and Carer Mental Health Program
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Family friendly mental health services

- General Information about the Illness
- Navigating the System

- Family and Carer Rights and Responsibilities
- Assessment of Family and Carer Needs
- Referral to other community services Involvement in assessment, treatment and discharge planning
- Intensive family support
- Local systemic participation

- Workforce development

Carer Needs*

a voice
full information
recognition and their own health and well-being taken into account
a life of their own – quality services for the carer and the person cared for
time off
emotional support
training and support to care
financial security

Mental health family and carer support programs

- Education and training programs
- Peer support groups
- Individual Support and Advocacy

Generic family and carer supports and programs

- Counselling
- Respite
- Financial Support
- Planning Ahead
- Carer Support Worker

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[i] Australian Government 2016, 'Designing the new integrated carer support service: A draft Service Concept for the delivery of interventions to improve outcomes for carers, DSS, Available: https://engage.dss.gov.au/wp-content/uploads/2016/04/Draft-Service-Concept-3.pdf [Accessed June 2016].

[ii] ARTD Consultants 2013, Family and Carers mental Health Program, Monitoring period: July - September, 2013, Data summaries and discussion of data collection and reporting issues, MHDAO, 2013.

[iii] Available: http://www.abs.gov.au/AUSSTATS/abs@.nsf/DSSbyCollectionid/4926CFF764B65A25CA256BD000288447?opendocument

[iv] Available: https://www.cdc.gov/violenceprevention/acestudy/

[v] MHCC 2015, 'The Mental Health Rights Manual: An online guide to the legal and human rights of people navigating the mental health and human service systems in NSW' (4th Edition) 2015, Available: http://mhrm.mhcc.org.au/home/