Submission to the draft Service Concept ‘Designing the new integrated carer support services’

Feedback submitted via online submission form, 16 June 2016

Site: https://engage.dss.gov.au/designing-the-new-integrated-carer-support-service

MI Fellowship | Wellways is a not-for profit membership organisation. Changing our organisational name from MI Fellowship to Wellways reflects the hopeful directions we have for participants, families and carers. We share with them common hopes and expectations around wellbeing and wellness.

Our primary purpose is to support people with mental illness and other psychosocial disabilities, their families and their friends in order to gain inclusion into communities; to create a home, get a job and build meaningful relationships. We provide this support through recovery, education and advocacy programs.

Carers and families are an integral part of Australia’s health care system, providing unpaid personal care, support and assistance to the lived experience and recovery of people with mental health issues.

The caring role has significant impacts on a person’s health and wellbeing. Evidence shows that mental health carers experience high rates of grief, trauma, stress, depression, anxiety and poor physical health. People also experience stigma, discrimination and social isolation resulting in the breakdown of relationships and disconnection from family, friends and community.

It is absolutely essential that carers and families receive social, emotional, financial and practical supports to sustain their caring role, while maintain aspects of their life, their identity and personal journey.

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We welcome the opportunity to provide feedback on the new Integrated Carer Support Service and how it relates specifically to family carer support and mental illness related disability.

We agree with the need to support and sustain the vital role of unpaid carers. The Carer Gateway is a convenient way to provide a recognisable source of clear, consistent and reliable information to assist carers to navigate services and support. We strongly support the need for an integrated carer support service, please find following specific feedback relating to the design and implement this new initiative.

Guiding Principles for Carer Support Services

Investment in services for families and carers:

1. We recommend a central principle that families and carers have needs in their own right, which, although related, must also maintain some separation to the needs and rights of persons with disabilities. We recommend this principle because:

    - Carers of people with mental illness experience high rates of depression and anxiety, and have their own right to health and wellbeing
    - Every person has the right to privacy, and without individually separated service this can become problematic
    - Not all carers live in the same geographical area as the person with disabilities – so separation of service can be a very practical consideration
    - With the right interventions, we can increase the personal capacity of carers to sustain their valuable support roles
    - With the right interventions we can build the knowledge and skills of carers to promote recovery for the person they support
    - Very often, those carers and families most in need of support people who are not receiving any mental health services. Under current and proposed funding streams there is no capacity within individual funded packages to support these carers and families because their loves ones have not or could not engage with services.

2. We recommend a principle of providing evidence based services for families and carers

    - While generic, informal support groups for families have a role to play, strong evidence exists for the provision of evidence based support programs, peer education, and services which have been shown to improve the wellbeing and capacity of families and carers.

Design Considerations

In relation to mental health, we provide feedback on the current draft service concept, which include:

Awareness

What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?

We commend the service concept in noting the specific needs of Young Carers, Aboriginal and Torres Strait Islander communities, people from Cultural and Linguistically Diverse backgrounds, Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI) and Rural and

Remote communities. There are, however, gaps in other forms of diversity and related need, which include:

Age 65+
We note that Australia has a shortage of adequate mental health carer support services for our aging population (65+). Mental health carer support services for our aged population, for example, may co-locate with services for dementia. We note a potential gap in being able to refer people aged over 65 years to suitable support services which focus on recovery and support for carers.

Spirituality
Many people with mental health related disability, particularly those people with diagnoses of psychosis or schizophrenia, may have strong spiritual beliefs and related needs which have been discouraged. It is not uncommon for people to be told that their spiritual beliefs are in fact a symptom of psychosis, despite new Mental Health Acts (eg, Victoria 2014), and international human rights law, which protect the rights of individuals to hold and practice their personal spiritual beliefs.

Family and carers also seek spiritually specific support and we encourage the service concept to explicitly recognise the rights of people to hold and practice their spiritual beliefs, and to provide for individual and community supports/services which provide space for spiritual diversity.

Acknowledgement of trauma
Trauma-informed practice within mental health is increasingly recognised as best practice. There is a very large proportion of people with mental illness related disability who have experienced trauma as a child, adult, or both, and frequently people have not been asked about their trauma history, or been referred to appropriate support services.

Evidence shows that family and carers may experience secondary trauma, a feeling of powerlessness, feeling abused by the treatment system, experiencing guilt, feeling traumatised by when the person they support are subject to trauma, experiencing trauma themselves and chronic grief and loss.

We recommend the service concept recognise the importance of overcoming secondary trauma, the important role in acknowledging people’s experiences of trauma, and support people to disclose these experiences, and in providing referral and linkages to appropriate mainstream or peer led support services.

We agree that a preventative focus is needed to identify carers and connect them to potential supports early in their caring journey. We would also note that in the early stages of the caring role or within diverse communities people may not identify with the term ‘carer’.

Along with health promotion and printed materials, we recommend the carer support service recognise the important role that the lived experience workforce play in early engagement and support. Engagement strategies should be considered in the following environments:

- Health Services: General practitioners, hospitals, emergency departments, medical specialists, primary health networks and maternal health services
- Education: kindergartens, primary and secondary schools, further education and child care centres
- Workplaces
- Community organisations: community centres, sporting clubs, places of religion

In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner?

School staff are in a powerful position to make a significant contribution to an individual student's mental health and wellbeing. Due to their ongoing contact with students, school staff are well placed to recognise behaviours, emotions or thinking patterns of concern and support young people experiencing such difficulties to get help when needed and to remain engaged in their schooling. While a successful whole-school mental health strategy relies on the actions of individuals throughout the school, impact is maximised when that action is coordinated through a clear, simple and usable set of policies and procedures. (www.mindmatter.edu.au)

In Victoria the FaPMI Strategy (DHS, 2007) seeks to reduce the impact of parental mental illness on all family members through timely, coordinated, preventative and supportive action. One of the aims of the FaPMI strategy is to provide education, including: schools, student wellbeing & support staff and school nurses (FaPMI Strategy presentation, 2015). With the assistance of MHR:CS funding, MI Fellowship has worked in partnership with primary/secondary schools and youth services and integrated family support services to delivery mental health young carer education and prevention programs such as Champs, PATS (Paying Attention to Self) and Understanding Mental Illness for Primary School Children. These community and peer led education programs have proven to reduce young carer stress, increase a young person's understanding of mental health, positively engage families in community support and assist in the reduction of emerging mental health issues in young carers.

We strongly recommend consultation with the Department of Education to support young carer identification, education and community awareness within the school system.

Should more resources be directed towards raising awareness about young carers in the health care sector, rather than school?

We recommend a specific prevention focus on young carers, who are an often over-looked group. Young carers are at high risk of long term disadvantage as result of missed education opportunities and compromised high school performance. Daily stresses of caring for a parent/siblings, fear of being affected by a mental illness in their lifetime, coping with stigma and trying to manage ordinary stresses of being growing up. It is estimated that there are 388,800 carers under the age of 26 years in Australia, representing 17% of all carers in Australia and 18.8 of these are primary carers. It is estimated that a further 6-10% of young people under 26 years are informal carers. One quarter of young carers provide care for someone with a mental illness (Australian Bureau of Statistics, 1998). These figures probably underestimate the total number of carers in Australia as many young people are not identified as being carers (Paying Attention to Self (PATS) Programme Guide 2006 Centre of Adolescent Health).

Raising awareness initiatives for young carers should be the focus of both schools and the health care sector.

Information Provision

Feedback from co-design participants to date have indicated that information provision be tailored to a carers individual situation or it is of limited value. While

information is available through carer organisations today, as well as the Carer Gateway, would individual recommendations be of benefit when carers are undertaking or receiving other services?

We agree with the recommendation of the co-design group that tailoring information delivery to carers' specific needs is of great benefit. Peer led education programs for carers improve participants' psychological well-being and views of their relationships with their relatives with mental illness. (Wellways Evaluation).

- Manualised and evidence based education
- Peer support in a structured and supportive learning environment
- Knowledge about mental illness and recovery
  Skills and strategies to identify strengths and community resources that assists participants to deepen their understanding and sustain their caring role

Research shows that this type of peer education program results in:

- Reduced tension, worrying and distress
- Improved self-efficacy and empowerment, communication skills and empathy with their loved one.
- Fosters a sense of belonging and peer connection

Intake

Are there ways to make intake more beneficial to carers?

An intake assessment can be a powerful tool to assist carers and families to identify their needs, for many it may the first time they have articulated how they are coping in their caring role. Using a self-directed assessment tool can be an empowering process. It is also important that the carer is provided with a copy of the intake tool that they can reference and provide at further intakes or assessments, this eliminates the needs for carers to re-tell their story. An intake process should be designed to optimise someone's quality of life and wellbeing and to continue to be effective in their caring role for as long as is right for that person.

We agree with the service concept that a central intake process could be beneficial for carers to register their emergency plans with service providers.

We note that how we engage carers and families is crucial, carers should be able to identify their preferred method of communication (online, phone, SMS, email). Have the ability to access support in a crisis that should not be delayed due to the intake process or registering a client. Appropriate time must be allocated to allow for carers to provide personal information. It would be of great benefit to a carer if the intake information is centrally stored with permission, this would support carers not having to "re-tell their story" to a number of providers or organisations.

Evidence within our own programs suggested that when peer workers are involved in the engagement process carers gain a sense of universality (sense that one is not alone, that "we're all in the same boat") was perceived as the most helpful factor (Wellways evaluation).

Should intake be a mandatory process?

While we agree with intake being a mandatory process to access to services such as planned respite, education programs, counselling etc. we would strongly suggest that carers and families are able to seek basic information about the caring role and carer support services without being registered or being involved in an intake process. It is always the choice of a carer if they would like to ‘register’ with a service or organisation.

When data is recorded at intake this information will be useful tool to measure evaluation. MI Fellowship reports that collecting data at intake has led to:

- Greater understanding of individual needs of carers/family members
- A more holistic approach in working with the whole of family
- An increase in family inclusive practice
- Improved linkages and referrals with community organisations
- Clear data to report to funding bodies
- Carers ownership of self-directed assessment tools
- Assists carers and family to sustain in crisis and not be reliant of a service delivery response
- Identifies gaps in service delivery

Education

Education, employment and volunteering significantly enhances recovery, improving health and wellbeing, self-confidence, financial security and a sense of belonging in the community. Carers often face barriers to workforce participation, and gaps in or lack of opportunity to study. We believe that education and return to work programs for carers are vitally important to assist carers to regain their own identity.

How do we encourage carers to access educational support?

Our experience indicates that many carers and families are initially introduced to further education and employment opportunities in the mental health sector via peer and community education and volunteering. There are many opportunities to use the wisdom and knowledge gained from having an experience of mental illness, recovery and caring. At MI Fellowship we have supported this development through:

- A ‘speakers bureau’ of trained and supported carers and consumers to be community educators
- Delivery of community education programs called ‘Understanding Mental Illness’
- Delivery of talks and workshops at schools, community groups and business organisations that are aimed at reducing stigma and building social inclusion for people experiencing mental ill health their family and friends.
- A mental health helpline available to anyone wanting advice or information of mental ill health and supporting roles
- A weekly radio show led by consumers about mental illness called ‘Brainwaves’

We strongly recommend that:

- Education and employment is discussed as part of the intake, assessment and planning process.
- Peer support workers are utilised to explore gaps in education and employment. Share their experiences and provide practical support to move towards regaining this element of identity.

- Service delivery programs are designed to assist carers to utilise their new skills and explore an area of interest and development. For example as part of MI Fellowship's respite program we would employ carers to design and facilitate a special interest respite activity. One carer delivered a 4 week art program that focused of journaling to support carer wellbeing. This carer has since returned to the paid workforce providing this course to a number of carer support organisations.
- The provision of respite is available for carers to attend education
- Easily accessible Information and links for carers to local services and providers.

If online carer education programs were offered, how could we encourage carers to participate and complete the programs?

MI Fellowship supports the development of online training and education programs and suggest that these programs could support basic return to work skills.

The online function would allow carers to participate in their own time and hence may not require respite support. Online courses would also enable carers to choose education and training that is of interest to them at the most appropriate time.

We would suggested that online programs are short in duration and provide a certificate of completion that is recognised by '*jobactive'* providers to assist with participation requirements for the Newstart Allowance.

Peer Support

How can peer support be delivered to a broader base of carers in a cost effective manner, can these models be designed to encourage participation and remain engaged?

Our experience of recruiting and supporting Well Ways peer facilitators, has shown us that many carer peers are highly motivated to provide peer support to other carers but are not provided with the right pathways, training or support. If invited to explore the possibility of drawing on their own lived experience intentionally through participation in peer programs and training, we believe a large number of carer peers could be successfully identified, engaged and supported to provide quality carer peer support.

Working collaboratively alongside the developing consumer peer workforce by combining consumer and carer peer training, as well as supporting consumer and carer peer networks, is not only more cost effective but strengthens the knowledge and skill base of both consumer and carer peers.

Should peer support be a service that can be accessed without pre-conditions or structured processes?

In addition we acknowledge the importance of providing peer support and encourage the service concept to provide clarity about the discipline of peer work.

- Mental health carer peer work is an emerging discipline, with many different associated roles (eg., peer support work, peer education, peer speakers, peer academics, peer counselling, peer buddies, peer group facilitators, peer advocacy, peer supervision, and many more). It is important to acknowledge that peer work is a discipline rather than a specific type of support, and so can provide an important function in a variety of contexts, complexity and remunerations

- The relatively new Certificate IV in Mental Health Peer Work provides a national standard for qualifying peer workers. Model such as Meads Intentional Peer Support have also been a very successful tool in helping carers identify what a 'good or balanced life' looks like for them. The model provides a framework that support mutually transforming and supportive relationships.

- Peer work is still emerging across all parts of the mental health sector, and requires continuing investment in training and development to support the growth of the new workforce. Relatively few Australian peer workers have yet to complete the new Certificate IV. As this qualification rolls out nationally, there are even greater barriers to completion for peer workers in regional and remote areas. Investment in directly funding or incentivising peer workforce development will provide a challenge, we suggest consideration of funding scholarships to support the development of peer workers.

Needs Identification of Planning

To what extent do you think goal based planning should be used at the assessment stage of the process?

Goal based planning is an important way of supporting carers to address 'what is not working for me'. The journey of change underpins MI Fellowships needs identification and planning tool, allowing individuals to explore:

- Causes for concern
- Getting help
- Making changes
- Finding what works
- It is as good as it can be

Would a goal based planning approach be worthwhile?
The service concept indicates an alignment with principles of the carer journey in mental health, as evidence in the Carer Life Course Framework (D Pagnini, 2005). Because of this, we see potential for the integrated carer support service to have its greatest impact on elements of personal recovery and moving from the role of carer to family. These outcomes would include:

- Hope and optimism
- Connectedness with families and carers, with peers, and a sense of belonging within the broader community
- Through community capacity building, individual and peer support: Opportunities for families and carers to develop more meaningful and contributing lives through participation in society, education and employment.
- Through peer support: Opportunities for people to find their own meaning in their mental health experiences, to cope better, to be able to self-manage their health and wellbeing and caring roles and to be able to navigate service systems more easily.

This will have a significant positive impact for families and carers of people affected by mental illness. A 2004 Victorian report found that what carers most value is support with addressing the psychological and physical health effects of caring (What carers value – review of literature and practice, DHS, 2004).

Through individual support, family inclusion, education programs, peer support, linkages, respite and building natural networks, programs would allow carers to:

- maintain their own physical wellbeing and mental health
- sustain their role as carers
- access the knowledge and skills to be most effective in their role as carers and family, including:
    - Education about mental illness
    - Information about mental health and community services
    - Knowledge and skills to support recovery
    - Recognition and inclusion by mental health services
- Personal support to address loss of identity, employment, financial arrangements, change in housing arrangements, future planning, relationships (strategies for communication), trauma and grief, social, natural and peer supports
- provide a gateway for consumers to access their own support services (particularly for those consumers who have not already engaged in health or disability mental health services)

The ultimate impact of these outcomes should indeed result in decreasing the socioeconomic burden of disability, reducing demand on consumer individual funded packages, and improving the lives of individuals, families and communities.

To what extent should self-assessment form part of the future model?

We agree that self-assessment is an important element of the service concept and recognise that disability support services for people experiencing mental ill health and their carers has not focused on personal recovery. A self-assessment tool could be beneficial in exploring the balance between providing supportive services and promoting independence. We would recommend that the multi-component intervention not be accessed via self-assessment but a comprehensive goal planning and assessment tool.

We would also like to highlight that carers in crisis may overwhelmed and consumed by their caring role and unable to recognise or act on specific areas of concern such as their own emotional and physical health needs, unstable housing or environments of concern. We would recommend a mix of self-assessment and service provider assessment tools.

A Multi-component intervention

Just like with individuals, the needs of families and carers can vary greatly. Some families experience particularly significant impacts from their caring role when it is compounded with social or economic disadvantage, the development of mental illness by carers themselves, family violence, the individual affected by mental illness not seeking or accepting support services, or other barriers or forms of disadvantage. In these instances of complex need, we support the concept of multi-component support packages for some carers. Access to these packages should be focused on carers and families with the greatest need as identified in the assessment and planning process.

What should be the criteria by which packages are determined?

The multi-component intervention is a way to move from crisis driven service delivery to focus on prevention, planning and sustaining. MI Fellowship believes support should be:

- A combination of carer and service provider assessment to ensure that intervention is able to assist the carer to move towards their goals and move out of stuck places.
- Carers should be provided with a good understanding of services that are available, and an ability assess a service that is relevant and beneficial for them
- Service should be delivered in a timely manner that respects and allows for the carer to move at a self-determined pace.

- Consideration and priority should be given to carers with complex needs, multiple caring roles and diverse experiences.

Financial Support
How can we help carers use these funds appropriately without large administrative burden on carers or providers who may be assisting them?

The flexibility of carers managing their own funds and support needs can be viewed as an advantage allowing carers to identify services that are most helpful and condusive to their situation and long term suitability in their caring role. We also considered that carers managing their own funds may result in better choices that demonstrate value for money. We are concerned that this could place additional administrative burden on carers, depending on the level and process for financial accountability. We acknowledge that the service concept does point out one of the disadvantages is that extra time and effort that may be a placed on a carer who is already time poor and stressed.

Carer Mentors
When would a coaching program be most effective for a carer?

We strongly support the concept of a carer coaching program. As outlined in peer support the benefits of peer support are strongly evidenced as an effective model the supports a mutually benefit relationship that moves towards the carers outlines goals. Peer mentors provide an opportunity to normalise someone's experience and explore 'what happened to you' or 'your world view' that might have resulted in someone being in a stuck place.

We reiterate our thoughts outlined in peer support that carer mentors need appropriate training and systems of support to be successful in these roles.

The Carer Mentor model would be most appropriate to assist carers move from their uni-directional caring role to a place of family, friend or community member. These stages of the caring journey are outlined in the Carer Life Course Framework:

- Suspicion that something is wrong
- Confirmation of mental health problems – need information about service systems, rights and confidentiality. Intense feelings of denial, sorrow, grief, fear.
- Adjustment - realization that life with be different, isolation
- Management – More stability, accumulation of stressors
- Purposeful coping – purposeful coping, found meaning
- End of active caring role

At MI Fellowship our carer peer workers are trained in the Intentional Peer Support Model (Mead and Copeland, 2004) which helps someone move towards personal recovery. In addition use the CHIME Recovery Model (Leamy, Bird et al) to assist carers and families works towards their concept of a 'meaningful life'. CHIMES identifies 5 key areas outlined below:

Connectedness: Peer Support and support groups, relationships, support from others, being part of community

Hope: Belief in the possibility of recovery, motivation to change, hope-inspiring relationships, positive thinking and valuing success, having dreams and aspirations

Identity: Different aspects of self, rebuilding/redefining positive sense of identity, overcoming stigma

Meaningful Life: Making sense of mental illness experiences, spirituality, quality of life, meaningful life and social goals, rebuilding life

Empowerment: Personal responsibility, control over life, focusing on strengths

Given the multi-component intervention is time limited, should carers be able to postpone coaching sessions to a later time?

MI Fellowship recognises that mental health issues are episodic and that crisis can sometimes put a hold on carer development or recovery work. We would therefore recommend that coaching sessions are flexible so carers can determine the most effective and appropriate time for them to focus on their unique journey. Over time this model will support carers to sustain in their roles over a longer period of time and move away from a service delivery response in crisis.

Respite Support Service

We know that, as a direct result of their caring responsibilities, Australian carers are one of the most isolated population groups in the world and experience the lowest average levels of overall life satisfaction (Carers ACT). It is noted that under the NDIS, supports such as paid household assistance, assistance with transport and assistance to access the community may provide a respite effect for carers and families. Whereas flexible respite funding provides carers and families with the opportunity to target their needs which may be; connections with peers and community, explore interests to sustain their physical and emotional health and taking a break from their caring role.

We are concerned that the service concept has only identified respite as a component of the multi-component intervention and highlight that this decision would restrict much needed support for the wider caring community. Respite should be considered as a stand-alone need that for example could support people to return to education, accessing the community or peer support.

Counselling

Much as the evidence relating to effective counselling programs for carers focuses on CBT. What other counselling programs and techniques would be beneficial in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?

The caring role has significant impacts on a person’s health and wellbeing. Evidence shows that mental health carers experience high rates of grief, trauma, stress, depression, anxiety and poor physical health. People also experience stigma, discrimination and social isolation resulting in the breakdown of relationships and disconnection from family, friends and community. We recommend that a variety of counselling approaches and techniques be available in the new integrated carer support services to provide choice flexibility that meets the needs of individuals.

We would like to stress the importance of counselling services with experience, skills and resources to work effectively with disadvantaged, diverse communities and young people.

What is missing?

There is no recognition that families and carers can also be a pathway to engage with consumers

For many people affected by mental illness related disability, families and carers can provide a pathway for engaging with the person in need of support. We recommend that this type of approach be considered in how carer and family supports are provided. While it is essential that families and carers be able to access supports in their own right, it is always worthwhile to enquire about the people they care for and whether the right supports are in place for them.

An Outcomes framework

The draft service concept highlights that there is a lack of reliable evidence to support the effectiveness of some carer support programs.   We recognise that is a concept document but further consideration needs to be given to how service providers will be meeting their objectives or vision, it falls short in proposing a measurement framework for outcomes achieved. Wellways believes that the new integrated carer support services provides an opportunity to embed and improve data collection, program performance and evaluation tools.

Within mental health services there is an increasing focus on measuring individual and community outcomes, while also recognising the inherent methodological and sometimes ethical challenges involved in capturing this data.

We recommend that DSS look towards best practice in mental health outcomes, which suggest:

- Co-design and co-production of outcomes measures between service users, service providers and funders
- Collection of different data sources including (a) individual qualitative measures related to personal recovery outcomes and satisfaction, (b) high level systemic and community measures and (c) evaluation of socioeconomic impacts

We recognise the importance of measuring community objectives, however we note inherent methodological challenges of doing so.

Potential measures of meeting objectives may include:

- New people family and carers of mental illness related disability entering the system
- Individual impacts such as self-reported measures on personal recovery outcome scales, employment and educational outcomes
- Long term community outcomes: we recommend consideration of research studies of targeted community interventions.

What would be the implementation challenges?

From a mental health perspective, implementation challenges are likely to include:

1. The structure of how any new services interface with existing mainstream mental health services, including strategies for the disability sector and mental health sector to work together more effectively, and to share knowledge across sectors.

2. The scoping and maintenance of an appropriately skilled workforce to support effective delivery of carer support for mental health specific disability.

    - Evidence from other community based mental health services indicates best outcomes are achieved with:

    - Multi-disciplinary work teams, including skill mixes such as peer support, carer peer workers (certificate IV in mental health peer work or intentional peer support training), family support workers, social work, occupational therapy, psychology, counselling and other types of therapy.

    - It is generally the responsibility of service providers to develop their workforces, however DSS may wish to play a role in promoting best practice, minimum qualifications for best practice, and building a shared body of knowledge about best practice

3. Retaining a focus on personal and relational recovery with mental illness

    - Support services for family carer have often failed to deliver on personal and relational recovery, even when that has been a stated intent. Models of respite or a break from your caring role does not provide adequate support to sustain in your caring role.

    - Families are often defined by their caring role, someone ‘doing the caring’ and someone ‘being cared for’. This **dynamic relationship causes inherent tensions within family units**. The recovery approach to support people to live the lives they want and to encourage consumers to make their own decisions involves partnership. With this support care becomes supportive, flexible and temporary, support families to move beyond the role of carer and return to being a family member.

4. Retaining a focus on genuine co-design and co-production with consumers, families and carers

    - Co-design and co-production of mental health supports and services, and evaluation practices, for both individuals and communities, is without question the most effective and respectful approach to service provision within mental health.

    - Despite this, all services and structures face continual challenges in maintaining genuine co-design and co-production. It is easy for these approaches to become superficial or tokenistic, particularly when there are time and cost pressures.

    - We acknowledge strategies to ensure that co-design and co-production are embedded into the service concept and will work in practice. Are encourage the current strategies in the development of co-design and co-production principles, recruitment of consumers and carers to leadership roles, the use of well utilised, trained and supported advisory groups, and strong consumer and carer involvement in developing and measuring effectiveness.

Conclusion

The new integrated carer support service is an opportunity for carers and families to build their capacity to sustain in their caring role, as well as identifying the importance of moving from the role of ‘carer’ to family, friend or community member.

There are a number of elements that have been shown to sustain people in their caring roles: stable housing, work, strong and varied networks, a sense of belonging in community, peer support, family support and friendship. To reduce the need for people to rely on formal services and increase the likelihood that family recovery will be sustained after a period of service, supports need to be designed that will support people’s capacity to live, work and belong to their community of choice.

We note that the caring role often extends beyond a single carer, therefore the new model must support the whole of family (family of choice or family of origin) to identify their specific needs. The model must also acknowledge that the caring journey is not liner and that various levels of support will be required over time.

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