# Designing the new Integrated Carer Support Service: Design Considerations

## Awareness

- If the proposed model is to achieve a preventative focus, it will be important to identify carers early in their caring journey and connect them to potential supports. For many carers, this occurs within a healthcare setting, where the person they are looking after may be diagnosed with a condition. The challenge in doing so is that carers are commonly focussed on the needs of the care recipient, rather than how they will manage their new role. For example, a study involving the delivery of carer focussed information in a written format within a healthcare setting led to carers overlooking important information which may be of benefit to them (Grande, Austin, Ewing, O'Leary, & Roberts, 2015). This sentiment was reiterated by the Carer Working Group where carers in the group expressed that brochures were simply put in a drawer and not reviewed unless it was of benefit to them at the time. Given this, what would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?

Response:

- Regular scheduled information sessions  run at treatment facilities that are targeted at raising awareness and are endemic to the culture of treatment facilities, These sessions should  encourage carers to “look after “themselves in an effort to maintain the ability to support their loved one, not focus on the carer role per se. This requires shifting the way clinicians think from being exclusively focused on the person with illness to thinking about the sometimes less obvious impact on the family and social circle of the person with the illness, in the short term this can be achieved with a combination of training and imbedding workers who work with carers into community mental health teams.
- In the clinical settings reviewing the training of social workers, Occupational Therapists, etc. to assess if understanding of carers role is identified in core modules of their training.
- Developing relationships between GPs and NGOs to ensure carers receive follow up referrals to support programs when care recipients are discharged from hospitals/community mental health centres. We need GPs to be aware of support services so that when carers attend their practices with signs of stress, fatigue, burnout; or even just disclose they are in a caring role, GPs know where carers can access support  in addition to any medical treatment
- Employing more carer peer support workers within all health settings. Nothing can ever replace the face to face personal contact and acknowledgement of carers/families concerns.
- It is important to recognise the diversity of carers and “family” relationships which are important to the person with mental illnessand in the  early stages of the caring journey and have the capacity to respond to this diversity.
- Keeping clinical services, G.P’s and other informed is a complex task and resources will need to be committed to make sure that up to date and relevant information is available across both metropolitan, rural and remote areas.

- A key group of carers for whom awareness will need to be targeted is young carers. Young carers include unpaid carers who range from young children to teenagers (4-17 years) and young adults aged 18 to 24. Purcal and Co (2012) argue that the most desirable service goal for young carers is prevention. A primary facet of this involves identification of young carers as early as possible by health/disability services, particularly if formal services may not be adequate to negate the need for a caring responsibility to arise or become entrenched. 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? Purcal and Co

(2012) suggest that a more holistic approach to whole of family support should be taken from the outset within the health care setting. While schools are a potential point of identification, they may only identify young carers once they have become entrenched, such as where absences are observed or academic performance lowers. If this is the case, should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools?

- The better way to think about this is to consider a filtration model. While the health/disability system should be geared to identify young carers at the point of first diagnosis of the family member, the school system can then be armed to pick up on the young carers who were missed.
- The real relevance of the primary and secondary school system is in their ability to give support to a young carer. A cost effective way to approach this would be to imbed better MH and Disability knowledge into the teaching qualifications and develop training resources for teacher development sessions to increase capacity for the school system to work better with young carers
- More awareness is definitely the key – reducing the stigma attached will allow for more open communication. However taking this education away from the schools is not the answer. Peer support workers are crucial with young carers, we do need more health care workers to be able to do home visits with young carers. Transport is an issue so the more education and help we can bring to the carers homes and or schools the better.
- Schools are also now implementing 'Wellbeing Committees' which could be pathways to educate families, extended families, friends and children. Young carers may not even realise they are living with a family member with a mental health issue, let alone identify as a carer. Education needs to start with foundation of what mental health looks like (not just the stigma associated – e.g. the man in the street who talks to himself). Children need to learn that it is common and that it affects many people and what the symptoms are, so they can identify that they are young carers and there is support available and have clear guidance as to how to access support.
- Targeting schools is certainly leaving the intervention too late. Again, identification of young carers could also be made by the health care professional who is treating the consumer, by including a question in care plans about how many children do you have and how old are they. It can then be assumed that services to assist the children develop coping strategies and an understanding of the mental health issues in the family would be included in referrals.
- A preference is given to a whole of family support approach being implemented from the very first professional contact, rather than the current system of treating people in an individual or siloed manner where each family member is responsible for finding their own supports.
- Peer support groups can have a strong role in the life of young carers and programs that bring young carers together, either face to face or using technology need to resourced so they are accessible by young carers.

**Information Provision**

- Feedback from co-design participants to date has indicated that information provision must be tailored to a carer's individual situation or it is of limited value. While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?
- The issue is that most people who are the point of first contact are rarely skilled/ knowledgeable enough to determine and deliver the most relevant information; the Carer

Gateway at present also gives relatively generic outputs. Carers would prefer to have supports individualised as much as possible for them.

- Recommendations tailored to individuals would be the most valuable and least frustrating way for carers to get the information they need however, this requires *time* for someone to be able to listen to the carer, determine what their needs may be and then for that person to have enough local knowledge or access to current relevant information to give to the carer. It may be a more workable option to connect carers to a dedicated information service person.
- The ability of frontline providers to have access to up to date knowledge on local or relevant information is impacted by frequent changes in service design and delivery in response to shifts in policy and funding. Stability and sustainability of service design is important to building strong banks of information for dissemination.

## Intake

- Intake is intended solely to be a service which facilitates access to certain supports. As it involves the collection of information, it does not generally offer carers an immediate benefit in exchange for the provision of this information. Given this, are there ways to make intake a more beneficial process for carers? For example, carers and organisations assisting carers today have indicated how important having plans in place is to carers, that it provides a sense of certainty and relief. 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.

- There is a fundamental problem with the concept of mixing an intake process with service delivery of any kind, but it is a good idea to have rapid connections facilitated by an intake service especially when emergency support is needed.
- Once intake extends beyond the role of basic information gathering there needs to be a good skill level by the intake worker to connect with the carer to identify the key issues for further contact and service delivery.
- Diversity is key element both in the point of intake and service delivery. For some carers phone and on line systems can create barriers to even making the first attempt at contact for support.
- It may be overwhelming for a carer who is going through intake process to want to register their emergency plans – part of the service they go to might actually have to help them create this plan (which is a great idea for all carers to have, but may be new for majority).
- A key question to ask here would be “how many carers accessing a service for Intake would have an emergency plan?”
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- 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?

- Where possible information should be entered at initial contact and added to at further contacts, people are more likely to remain engaged if the person at the other end of the phone is able to access some information without requiring them to complete the entire process on subsequent contacts.

- A crisis line for carers – where they are given information and where the intake process could be completed (would need more thought around what information you gather for an intake in a crisis). A lot of carers feel so isolated and scared and have no idea of 'What do I do' when there is a crisis. A line they can call which will provide information and a friendly ear, who can then follow up/ link in to services could be a great way to capture carers. Education and peer support is something that could be followed up post-crisis/intake
- Intake should only ever be mandatory when a service is offering ongoing individual support, which includes working on specific goals and/or strategies, making referrals to other services, advocacy or providing psychological/counselling support. Often on intake people are then put on a waiting list to receive services. Access to education, support groups and general information should be available without waiting for the intake process to allocate support options.
- Carers may not respond well to self service contact numbers. Intake needs to be carer friendly across all ages and ability to use technology
- Intake is only as good as the person responding and also response time is often critical

**Education**

- As stated earlier, research suggests that carers may be more inclined to accessing services they report high satisfaction with such as respite. However, education programmes commonly provide longer term benefits to carers. Carers report they are commonly time poor and dedicating time to undertaking an education programme may not be perceived as helpful by carers. Given this, how can we encourage carers to access education support?

- Accessibility and availability, by having quality education available in enough places and frequently enough – online modules and videos may also be a worthwhile avenue to so Carers can access on demand, particularly when unable to attend programs as they are working carers or living in remote locations.
- Offer options for education to be tailored – one-one; online; webinars/video conferencing; teleconferencing; study groups (although informally – like coffee catch up and discussion around what has been learned)

- While online education is a cost effective and efficient way to deliver education programmes, research suggests that achieving high completion rates can be challenging. If education were to be offered online, how can we encourage carers to participate and complete an education programme?

- This is where a peer worker could be utilised, to provide ongoing encouragement, opportunity for discussion and feedback. Gives the carer some accountability that someone is checking where they are up to but also keeps it interesting as they can discuss what they have learnt and ask questions – when providing education in a somewhat remote style, you need to be 'visible' – people need to know they are not doing it on their own. A peer worker can encourage active participation, and organise study groups (social catch ups).
- Mentoring and peer support groups would also be able to provide encouragement.

- There are many organisations who run education programmes for carers funded through programmes outside of the Department's carer support funding and will continue to do so in a future model. Given this, how can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?

- Given that many carers are time poor, perhaps availability of “talking book” sessions that can be listened to when travelling in the car , with directions to a link for further questions or clarification, these consequently could be translated into various languages and avoid the issue of lack of understanding.
- When a carer is satisfied with a service and respects the people who are supporting them, encouragement from those services and support workers, to attend relevant education is well received. The support workers may also be able to assist the carer to access appropriate respite and employ other means to create the time needed to attend education programmes. Carers are inclined to attend education programs that they consider are valuable to their current situation, so timely access to relevant education is also important. Regular repeats of education programs so that carers do not have to wait long periods to attend what they are interested in, as their situation and needs change. A carer may sign up for an education workshop running next month because it is relevant to their current situation but then not attend that workshop as in that time their situation has changed.
- Many clinical settings have systems displaying services and information. Information on carer education sessions could be uploading onto these systems.
- Offer a periodic check in with the carer to track progress and answer any questions.
- All carer services and referring agencies need to be encouraged that referral to education is important.
- Details of appropriate programs should be easily collected and made accessible online with a central point for uploading made available.

### Peer Support

- What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner? Currently, some models of peer support involve use of professional facilitators or guest speakers. Implementing these models nationally may be too high in cost to sustain in the longer term. Given this, how can a peer support model be designed which encourage carers to participate and remain engaged?

- Providing training to carers to be peer support leaders could be of great value to carers. Often carers in a group setting are reluctant to take up a leadership role unless they feel confident in the role.
- Peer support training could be delivered by bringing interested carers together in a retreat setting where they could develop leadership sills but also develop relationships with other carers to form a support network in their peer support roles.
- Online forums, tele/web conferencing, skype, telephone support, monthly or bi-monthly support groups in different areas – carers have the chance to build relationships over telephone etc and meet in person occasionally.

- The evidence above suggests that peer support groups, when used as a standalone intervention, may not be particularly effective. However, peer support may provide a way for carers to connect with the Integrated Carer Support Service in a less formal way. For example, a carer may first join an online forum before deciding whether to proceed to seek more help. Peer support, when used in this way, may help encourage people to engage more using channels such as social media. Consultations to date have highlighted this may be beneficial in reaching those carers who may not have otherwise have sought formal support such as young carers and Aboriginal and/or Torres Strait Islander carers. Should peer support be a service able to be accessed without pre-conditions or structure processes?

- Yes!
- There is great potential for peer workers to have a role working with carers across a lot of different aspects (emotional support, telephone counselling, education encouragement and engagement, social engagement, assistance with managing financial packages etc), so with that in mind there may not be the need for formal pre-conditions as such, but a structured process would be required – accurate record keeping, intake and referral to a peer worker to help identify needs and best way to meet these (education etc, using financial packages). During intake, carer could be matched with peer worker who best fits their needs (and location). This is the way the NSW Family and Carer Mental Health program operates with the majority of staff having the lived experience of a carer.
- To ensure the carer is being supported and not traumatised, I believe there should be some structure to peer support. Online forums and peer support groups are a valuable resource for carers however trained facilitators need to run these so that appropriate steps can be taken to provide positive responses, timely and useful information and if necessary referral to other supports. Training carers to be a peer mentor or buddy that other carers can phone for support could be a helpful extension of support groups. Also integrating peer support workers across services, either as volunteers or by services actively seeking to employ people with lived experience would broaden carers access to peer support.
- I think peer support should be able to be freely accessed however a group will still need some structure as often they cannot find a meeting venue without an organisation backing them for insurances etc. A group also needs to be run professionally eg still needs some group guidelines etc.

### Needs Identification and Planning

  - 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?

- Goal based planning would help the service being provided bring much needed focus and direction and likely to lead to better outcomes for the carer. It gives workers (and carers where necessary) clear definitions on what needs are to be met for the carer/what skills and support they need. Can re-visit as required, but provides an avenue for accountability and gathering evidence of what you've done, and how/why you may not have.
- With consideration that when Carers are seeking support they are usually quite distressed or burnt out and initial consultation around Goals is not always suitable, it takes time to develop a relationship and determine suitable goals with a person, Whilst goal setting is an effective and useful tool, it perhaps should not always be discussed at the initial stages of engagement.
- An organization review of goal and outcomes can be tool for planning broader service delivery. Where resources are limited evidence of primary carer needs can direct resources in with efficiency.

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

- As long as the instrument is appropriate and simple to use, self-assessments should be a part of the model (it will also assist by giving carers a mechanism to step into greater self-awareness of the impact of their caring responsibilities.
- Self assessment can be a great confidence boost for a carer, or can highlight areas they may develop need to assist in their caring role.. The right form could be really beneficial.
- Self-assessment which leads to the opportunity to access resources needed can be an empowering process for carers.

**Multicomponent Intervention**

- Multi-component support seeks to amplify the effects of the supports by combining them. While all carers could benefit from these supports, funding will not extend to providing this type of support to all carers. Given that this model is seeking to apply preventative thinking, how can we ensure these supports are allocated to those carers who will benefit the most from them? What should be the criteria by which this is determined?

- Start with Young Carers!! - Preventative work done with this cohort would easily be the most economical decision in the long term.
- Some caring roles commence in later life stages and multi-component support which is developed in response to goal planning can be time limited for effective use of resources.

**Multi-component Support: Financial Support**

- In her early paper on Consumer Directed Care approaches, Howe (2003) notes that where funding allocated to individuals as part of a financial support package is not high (as opposed to some disability packages being in the tens of thousands), the overhead and administrative cost may not be worthwhile to put in place accountability measures for individuals to demonstrate how funds were spent. While some carers as part of the research undertaken have indicated they would be happy to manage a package, others in older demographics have indicated this would be yet another burden. Some carers have openly indicated that if there were no controls applied to these funds, they would have spent the funding on the person they cared for, rather than on supports to help them as a carer. How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?

- Accountability at all times for use of funds will result in better outcomes for all involved. Simple budgets are not difficult or time consuming once the initial template has been developed, however the up keep in monthly statements and ongoing monitoring can be expensive.
- The carer needs to feel that the care recipient is adequately funded to meet their needs and understand that the service provided has a benefit for them.

**Multi-component Support: Carer Mentoring**

- It is evident from our research and from consultation with carers and organisations that carers' needs vary over time. This service is intended to provide carers with goal based planning and coaching support. Coaching programmes are normally funded for a time-limited period such as the Stronger Carers Programme 10 week programme or beyondblue's New Access Coaching Service. When would a coaching programme be most effective for a carer?

- It is really difficult to specify when a good time would be for any particular carer. However, coaching is a great way for carers to move forward as it focuses on where the carer is going not their painful history. It provides the opportunity for carers to take decisive positive action. A program like this would always be applicable.

  - Some carers may not want a coaching programme which extends over time, despite the potential benefits, preferring only intermittent contact when they feel they need it. Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors should be able to determine whether the carer has the capacity to forgo coaching until another time?

- This could be part of the rapport mentors/peer workers build with carers, to help them identify when it would be suitable and also assist them engage appropriately.

**Multi-component Support: Respite support service**

  - The inclusion of respite support within a multi-component support package is consistent with recommendations arising from the literature. A number of carer organisations have reported anecdotally that more flexible responses such as brokered respite, have resulted in longer term outcomes. It is for this reason that this service is proposed to be coupled with financial support, as a form of consumer directed respite and coaching. This could mean a shift towards using respite as a complementary, not primary support. Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects? What might these be and how can they be mitigated?

  - Respite support for carers can be integral to the carer sustaining their caring role. Respite breaks where the carer has the opportunity to focus on their own needs and engage in skill building can create a great sense of wellbeing. There are currently a number of strategies in place for carers in the form of dedicated respite centres which provide multi-component support for carers. Maintaining the respite centres need dedicated funding separate to the opportunity for carers to have the funding attributed to the individual carers.

**Counselling**

  - 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.
  - 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?

- CBT has the best evidence base for getting results in shortest period of time in comparison to other established models of counselling. For a subpopulation that is time poor it is the most ideal form of counselling available especially as it shows solid efficacy via phone delivery.

- Alternatively, Behavioural therapy may be a better option as CBT can at times be too confronting for carers. This is an explanation from Beyond Blue "While behaviour therapy is a major component of cognitive behaviour therapy (CBT), unlike CBT it doesn't attempt to change beliefs and attitudes. Instead it focuses on encouraging activities that are rewarding, pleasant or give a sense of satisfaction, in an effort to reverse the patterns of avoidance and worry that make anxiety worse."
- Access to telephone counselling is a great way to go forward – where carers have a specified counsellor they can speak to or skype with on a regular or as required basis – consistent and planned, though not like the 1800/1300 numbers where they phone sporadically and speak to different people.
- Carers can be so entrenched in their caring role, that even when they want to make changes they are quite co-dependent and often subconsciously sabotage/are resistant to changes. Counselling programmes would need to be delivered with this in mind – and what is likely to have the most impact over the phone/online. When counselling face to face and can be discouraging and take years for a positive change in behaviour (due to co-dependence), so would need to be aware of this with online/telephone barriers.