Macarthur Disability Services

response to

Designing the new Integrated Carer Support Service – draft service concept

Date: 16 June 2016

Key Messages

Macarthur Disability Services (MDS) comes from a perspective of carer focused supports that are holistic and recognise that in every relevant situation carers must be acknowledged as an integral part of the life of the person they care for. Carers should always be part of initial assessments and supported to talk frankly about the nature of their situation. In addition assessments of people with a disability, mental illness or people who are older should also incorporate the needs of the carer and documented thus ensuring their continued participation. For example, with the consent of the person they care for, a carer must be provided with information and included in discussions with service providers, including the health system. In addition, awareness of carers must the incorporated within places and situations where they may not present together, however the relationship and its responsibilities become relevant for the carer, such as school or work. MDS believes that they key to an Integrated Carer Support system must be the incorporation of flexible elements that acknowledge and relate to other components of each carer's unique circumstances and personal life, including health and wellbeing, family, being in the paid workforce, friendships and ongoing responsibilities of the caring role.

As it is also the experience of MDS that in many instances there can be more than one person as the carer, particularly within families that experience complex needs and have more than one care recipient, the system must recognise the duality of carer relationships. Furthermore, the role of 'carer' is often not clearly defined, as often the caring relationship can be interdependent between 'carer' and 'care recipient' depending on the day-to-day capacity of each person whereby roles are often swapped. A truly integrated system would be fluid enough to provide supports to ensure all aspects of caring relationships are supported.

MDS acknowledges and supports the shift to a consumer focus which is occurring in disability, mental health and aged care reforms. MDS believes these reforms offer enormous benefits through individualised funding, particularly an entitlement system that will be available to eligible people under the NDIS. MDS sees the NDIS as reducing the physical responsibilities for carers, however the following concerns are identified:

- Both reforms emphasise creating new systems, which fail to understand or incorporate the strength of the existing infrastructure and community collaborations beyond the service systems that support individualised outcomes, especially at the local level. For example, as a way of offering wrap around supports and identification of hidden carers, MDS has developed relationships with organisations that traditionally do not offer support services –

1

'touch points' such as legal, police, corrective services, neighbourhood centres, religious and community groups are integral to our carer support model.

- Neither reform places the critical relationship between individual and carer appropriately in person centred planning by allocating a component of the support package to supporting the carer as a partner in care, a situation which may jeopardise the capacity of the carer to continue their role

- The role of case management and/or care coordination has been extremely underestimated for people with chronic and complex health care needs, both in the aged care, mental health sectors

- Information about the changes has not been targeted to carers, despite their assumed role in providing 'informal care'

- Self-management of supports and/or funding under CDC and NDIS will create a new burden for carers, nor does it recognise that many carers from extremely economically, educationally and social backgrounds may not have the capacity to undertake this element

MDS agrees that unique needs of carers must also be addressed separately from those of the care recipient through an integrated carer support service. It is well known that carers tend to focus on the person rather than themselves when allocating resources (p.47), possibly resulting in difficulties of identifying evidence matching carers' request to research on outcomes, to which the paper alludes (page 18). MDS does not believe that it is acceptable to design a model which appears to leave many carers unsupported. Furthermore the reference to allocation of support based on 'highest level of need' (p.19) appears to contradict the intended outcome of early intervention and prevention. It is MDS experience that the needs of carers in any given point in time may quickly escalate unless in time intervention is available, especially at transition points (eg. declining health of care recipient, transitioning in/out of work, addition of another care recipient). This raises a concern that carers may need to move to 'high level' needs (often accompanied by crisis) before they can access support!

MDS welcomes the inclusion and recognition of individual choice and circumstances as determinants (p.7); willingness and ability have often been assumed in the past as natural products of a familial relationship. Therefore, reflecting the issues identified in the 'Statement of Need section, MDS believes that any future Carer Needs Identification process should be used, not as a rationing tool, but rather to assist carer support workers to consider and respond without judgement about carers, knowing that:

- the caring role is complex and often not static

- every relationship between carer and care recipient is different

- for some caring is a lifelong commitment

- a carer, or care recipient may opt out of the relationship at any time

- effective carer supports must be targeted to the individuals involved, with the understanding of their personality, physical and intellectual abilities, stress, levels, coping skills etc.

- individuals' need for carer support may be episodic and/or it can be coming for many years

- the interchangeable nature of informal support between 'carer' and 'care recipient, and

- flexibility in the manner (face-to-face, telephone, online etc) and timeliness (weekend, middle of the day, evening) of supports is provided

When talking to carers about these reforms, there is indication that many don't understand the potential benefits and fear they may lose the supports now in place. There is a large amount of frustration and cynicism amount carers of older people and in the caring sector overall associated with the transition to "My Aged Care" and the Carers Gateway. Carers have provided feedback to MDS staff about lack of communication strategies and delays in processing people to the point of service delivery (not just call centre wait times), and view these issues as obstacles that add to the burden of care. Many believe these reforms have been implemented to control demand as a way of reducing cost to government.

A future Integrated Carer Support system must place the carer at the centre, not focus on the system. A rigid gatekeeper model will prevent eligible carers from accessing preventative supports which has the potential to lead to carer breakdown, mounting crisis and relinquishing of care which will be costly for families and the economy. A carer and community engagement plan should be incorporated into the introduction and implementation of the Integrated Care System to mitigate negative experiences which are shared amongst community members and adding to anxiety and disinclination to engage with the system. Currently this is demonstrated by:

- if the participant cannot be contacted after three visits, they have been removed from "My Aged Care"

- if a phone assessment takes place, it is often inaccurate or not followed through; and

- clients and carers are waiting six months or more for services to commence,

- reports of Aboriginal Elders people being placed in care unnecessarily or passing away

MDS works closely with local Aboriginal Elders and has built trusting relationships. Reported difficulties with engaging with "My Aged Care" often creates generalised negative perceptions and mistrust across the whole system, including against those services that have worked hard to build positive relationships. MDS sees cultural sensitivity as a vital design element that should underpin delivery of accessible and respectful carer supports. The Integrated Carer Support ystem must incorporate learnings from the transition to both "My Aged Care". A National Carers Gateway, like "My Aged Care", should be only be one of many 'soft options' for accessing information and referral pathways for carer support, and only a small component of resource allocation.

It is MDS experience (evidenced by our feedback systems) that carer supports are most relevant and appropriate when delivered locally by familiar people. In addition, anecdotal evidence indicates that Aboriginal people and people from culturally diverse backgrounds are not accessing "My Aged Care" and providers are not receiving the volume of referrals received before the implementation of "My Aged Care" single access point. Aboriginal people prefer a personal 'yarn' (ie a face-to-face assessment) with a 'brother' or 'sister', or a worker from a trusted local organisation. For example, MDS works in partnership to facilitate and support a local group of Aboriginal Elders called the 'Yarning Circle". A trusting relationship has been built over a number of years. None of these Elders feel comfortable contacting the central point of contact for "My Aged Care", preferring to work directly with workers they know. Elders in the group are also an important link to other members of their community and encourage them to contact workers that support the 'Yarning Circle'. The Integrated Care model as described in the paper may comprise important local relationships and access solutions that have been devised over time. As a provider, MDS understands each person's individual circumstances and has built mutual trust. Often, an Aboriginal carer may be the child or grandchild of a member of the Stolen Generation, traumatised through past government policies, fearful of institutions where they spent their childhood and unlikely to disclose intake information to a stranger via an official 'gateway'. Likewise, carers of people from countries that have experienced war and oppression are also less likely to engage with the system

Responses to Discussion Paper Questions

Awareness

Preventative Focus

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

- Community education that normalises caring combined, with multiple carer supports services across communities

- Implementing a 'no wrong door' approach supported by local community protocols and cross community awareness campaigns will create greater opportunities to identify carers and for them to feel comfortable toe seek support

- One message from/about a 'one stop shop' may not succeed when carers do not recognise themselves as carers

- Not 'one-size-fits-all' but a multifaceted approach that takes into account the diversity of carers and their lives; eg. Aboriginal and CALD carers, LGBTI carers, carers of people with mental illness

- Development and support of peer support networks and workers

- Getting the message out that asking for help is not failing, but rather providing you with the 'tools of the trade' so that carers can do their job and stay well themselves

- Use of general media to start a society wide conversation about carers

- Identify all the likely 'touch' points that carers may come in contact with the system eg. GPs (with support from PHNs), hospitals, pharmacies, suppliers of aids & equipment, church groups, legal system

- Carer support to be viewed as a workforce development strategy rather than an 'add on' to disability, mental health or aged care and supports

- Build staff and volunteer understanding of the range of carer support services available and information provided to carers at initial and relevant times

- Incorporate a carer transition strategy to assist carers to understand and build capacity around transition periods such as moving in/out of the workforce, declining health of care recipient, when care recipient becomes more independent (eg. once NDIS rolls out)

Young Carers

- Schools should educate and develop strategies to recognise and assist students, parents, teachers that have caring responsibilities

- Develop resources that schools (infants, primary and high schools) can use, or a national program to increase awareness and understanding of issues

- An outreach worker to provide an education program in schools about carers and how support can be accessed in the local community

- The diversity of carers means that this group includes primary or secondary carers, for a parent, grandparent, sibling or partner/spouse; some have disabilities themselves

- Acknowledgement that younger onset dementia also affects this group of carers

- Recognition that 'young carers' are under 25 and:

  - are in after school jobs

  - may be spouses, parents

  - involved in sports and other clubs

  - attend TAFE or university

  - in the workforce, and so on

- The Community Liaison Officers from Department of Education and Training should be incorporated; processes must be developed in consultation with DET, Aboriginal Education Consultative Group (AECG), Aboriginal Education Officers (AEO), Aboriginal TAFE Coordinators and Aboriginal University Units to develop short term programs, identify young Aboriginal carers and the role they may be playing with their families

- innovative programs involving volunteers can work well with Gen-Y carers. For example Anglicare's Young Carers Program has been heavily involved with Western Sydney University (WSU), linking students with young carers to provide tutoring and peer support

Design Concept Response: Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than schools?

- People requiring care do not always have health situation; disability and ageing are not illnesses and caring occurs in all areas of life

- Resources are best allocated to a universal campaign within and via all government institutions

- Engaging of young people could be achieved via use of social media platforms in a way that is relevant to this group – use their language

- Care should be taken to not embarrass young people; it's often very hard for a young person to disclose that 'I am looking after my mother/father', so they need to ring anonymously such the Young Carers hotline through carers NSW

- Communication strategies must be presented in non-invasive ways through school and other newsletters that young people read (eg. sporting clubs), as well as word of mouth

- Sometimes young carers are deliberately 'hidden' as parents fear their children will be taken from them or the young carer does not want to ask for help and let the adult for whom they providing care thinking they cannot cope or perceived as a burden

- Young carers are a hidden cohort in Aboriginal communities, with this role often being shared by several members of the family; some young carers have come into the family unit via Out of Home Care and/or foster care and then find themselves in the caring role for their grandparents, aunts and uncles

INFORMATION PROVISION (pg. 25 – 26)

MDS believes a multi-layered approach should be used to provide information to carers. Various strategies should be used to engage carers as individual carers will access information differently, have diverse skills and education levels, vary in terms of personal resources and income, and have varying information needs during the caring role. The design and delivery of information systems should be conducted in direct consultation with carers from all walks of life and locations. The following concerns and suggestions include:

- Feedback from carers indicates that the Carer Gateway is too generic with very basic broad spectrum information being provided, many services are still not listed due to delays with departmental changes to funding programs and contracts. MDS has operated a 1800 Freecall information and referral line for 20 years. Evaluations and feedback from users indicates a high level of satisfaction with this service, with the majority of respondents indicating their appreciation of a local provider that knows the local community and can

make assisted referrals to not just the community support system, but also to social, health and recreational groups in the community. An integrated system should link to existing, successful local services and networks.

- Categories on the Carer Gateway data base and search function are not user-friendly; more needs to be done to work with carer organisations and groups to ensure the system is easy to use by conducting ongoing consultation and evaluative feedback.

- Like "My Aged Care", the Gateway does not reflect real-life questions people ask or how they need their information to be presented; carers are reporting that "My Aged Care" is not improving access to services but rather resulting in multiple assessments and delays, thus adding to carer stress and anxiety

- The Carer Gateway, like "My Aged Care" is not always an appropriate pathway for Aboriginal peoples and appears to assume that everyone has resources and tools to support access supports

- People with low levels of literacy and numeracy and lack of access to technology are not using the Carers Gateway – an Integrated Carer System will need to address this

- The Carer Gateway should also include a stronger focus on wellness and enablement

- Carers using MDS services indicate they are not using the Carer Gateway, saying it is too impersonal

- One-stop-shop models are not always suitable for certain locations and demographics; access depends on carers being proactive, and it is often difficult to tailor responses to individual needs for a central point unless it is multi-locational, connected to the community in which it is located, and staff by staff that are well trained, have exceptional communication skills, know and understand local need, are multi-skilled, multi-cultural, and so on.

- Carers report that a national call centre is frustrating as call centre staff are not familiar with the area the caller is calling from and often ask carers to spell their suburb; this leads to lack of trust towards call centre staff and the system overall

- Websites are good for carers who want to remain anonymous and/or gather information at their own speed, however should not replace direct contact; websites are particularly useful as new carers come to terms with their new situation or deciding whether to become a carer; likewise the distance and impartiality of a phone call is sometimes preferable to a face-to-face meeting or giving and email or residential address

- Be aware that internet and mobile phone access is non-existent or limited in many rural areas, therefore the use of technologically based information systems may also be limited

- Carers should be able to access information from/about local carer support services without having to commit; brochure stands in community places; local social media feeds

- Provision of resources and presence of carer support staff and other complementary services at expos are an ideal care engagement strategies and not only provide information but can immediately connect carers. For example MDS in partnership with other organisation have organised 'Carer Safaris' which comprised of a series of combined workshops, private sessions and an expo that travelled around the Macarthur and Wingecarribee regions. Feedback from attending carers indicated they were more informed and felt comfortable approaching services on the day and into the future. A variety of promotional methods were used to attract new and hidden carers.

- Existing carer support services provide information and ongoing community presence and build relationships of trust with carers; these services also offer variety of choice for carers and often work collaboratively to share resources and diversity of knowledge (ie. GUIDING PRINCIPLE: *Reuse of infrastructure*)

- A 'hub' and spokes model is recommended as an effective way of utilising existing local knowledge, skills and experience of current carer support services (*ie. GUIDING PRINCIPLE: Retaining strengths of current system*), with a hub/call centre in each state to create a consistent framework and links for promotion and initial access, when needed; the hub should immediately refer to a service provider and not spend on time intake or assessment, especially when the caller is distressed (ie. GUIDING PRINCIPLEs: *Simple & Nationally consistent, locally responsive*)

- It is insufficient to have a call centre in only one place, thereby limiting the recruitment of potential staff; the key access point for carer supports must be able to recruit appropriate bilingual and bicultural workers to meet specific communities' needs (*ie. GUIDING PRINCPLE: Equity of Access*)

- A high number of Aboriginal callers will rely on an Aboriginal provider they have developed a relationship with, not necessarily a carer support organisation, but an Aboriginal person/worker or provider that they know, one that has a cultural perspective leading to understanding of individual circumstances and can assist them; a Stolen Generation member may not want the care to disclose information to someone they do not know or trust.

- Information provided needs to be culturally appropriate, easy to read and enticing for Aboriginal people eg. use Aboriginal art and Aboriginal people promoting supports.

- some carers may use an APP for smartphones/tablets focussed on local services

Design Concept Response: Would individualised recommendations be of benefit when carers are undertaking or receiving other services (specific to situations)

- MDS agrees that with this design concept as a personalised approach to working with carers which not only enables the provision of information and knowledge building rather than simply providing a brochure and telling them to make a phone call. A personalised approach enables a worker to identify any underlying issues that may not be evident through a single point of contact to provide information. Effective information provision, particularly more

complex information, is supported by building rapport and relationships with carers in their local communities (ie. *GUIDING PRINCIPLE: Carer Focussed*)

- There are a number of carer support services that have been funded or developed to respond to specific carer circumstances (eg. carers of people with a mental illness) which other service providers rely on due to the specialist knowledge and support models (eg. Haven Project Consortium in Macarthur/Wingecarribee region)

- Local carer support services have evolved and developed to align with the specific needs of the communities in which they are situated, including language, culture, local schools' disability units, community and mental health services, Autism support networks etc.

- Individualised recommendations that hold the carer at the centre of decision should underpin any recommendations as one size does fit all, and personal circumstances various from person to person, family to family

- Aboriginal people prefer holistic approaches, therefore individual information provision must be tailored to a carer's individual need and also recognised kinship ties across the community

INTAKE (pg. 27)

Design Concept Response: are there ways to make intake a more beneficial process for carers?

- Intake processes should be as simple as possible with clear explanations about:

  - the purpose

  - likely questions to be asked

  - how information will be used

  - timeframes associated with service referral/acceptance

  - be flexible to allow carer to respond at a different time if they are unavailable at set time

  - ensure there is prompt follow up (especially if the carer indicates a problem with the process)

- Use different methods to suit varying circumstances; acknowledge that not all people feel comfortable with telephone calls. Feedback provided by carers that use MDS services indicate they value and appreciate a more personalised, face-to-face meeting. Furthermore, having a worker visit the home wherever possible lessens the stress associated with having to leave the care recipient. The latter also provides the intake worker an opportunity to observe the situation the carer is in which may not be evident via a phone call. Alternative venues could be the office, other service provider where they feel comfortable or a local café. The use of technology (eg. SKYPE) could also be explored.

- All attempt should be made to reduce the use of jargon and information provided in easy to understand language; wherever necessary the use of interpreters must be used (not family members)

- The following core skills are recommended for intake staff:

  - advanced verbal and listening skills (including the ability to identify underlying issues not articulated by the carer)

  - ability to respond to distressed carers with sensitivity

  - have in depth knowledge of service options

  - ability to understand the context of carers needs in order to respond appropriately

- Service providers need to understand and implement good customer service strategies to ensure that the carer experience is maximised

- Make use of other systems of "My Aged Care" to also connect carers

- Wherever possible (with consent of carer), include other significant people in the cares lives at intake

Design Concept Response: When should intake be a mandatory process? eg. to what extent would intake be required to facilitate access to peer support or education (ie. limit its utilisation)

- This will depend on the nature of supports to be provided. For example, arranging for an individual to receive a home visit or to attend a group will have WHS implications which needs to be discussed openly with the carer

- Intake processes can be modelled to include access to peer support and access to education, with the actual provider reporting on outcomes. Inclusion of criteria within intake that identifies a more intensive support pathway can be utilised to ensure carers with complex needs are prioritised eg. referral from health care or GPs, referral from another service provider that has identified that a carer's situation is at risk of escalating to crisis if immediate intervention is not provided

- Carers should be involved in informal choices about service design (including development of what they see as relevant outcomes). Initially, some will be happy with generic support or education , which will provide time and space to absorb the information with reassurance that it is quite okay to call back if further support is required. Others may require more intensive support from the beginning, especially if their situation is complex

- Cultural mores should be observed in any intake process, with the specific cultural expectations discussed during this phase

- Intake is also about providing carers with relevant information and options that they may wish to explore now and in the future, particularly if circumstances change

EDUCATION (pg. 28 – 29)

Design Concept Response: how can we encourage (time poor) carers to access education support?

- Carers should be encouraged and supported to view education as an important part of taking on a new job and not as failure. Provision of education places value on the carer role and assists carers to enhance their skills and knowledge.

- Education should be viewed as any other adult learning opportunity and use adult learning principles – use trained learning facilitators (especially those that also have carer experience if possible), build on existing knowledge through facilitated learning, be carer driven (models and topics) and available at transition points in the carer role

- Explore models that also promote peer learning and support

- Develop diversity of learning avenues – online of face-to-face (or a combination of both)

- Time poor carers value well organised sessions (with respite available if required), high calibre guest speakers, enjoyment, opportunities to network with other carers (and in some instances service providers) and availability of feedback processes. Access to interpreters wherever necessary.

- Technical skills training (eg. operation of equipment, personal care etc) should be delivered by experts in these fields and in the home.

- Use age appropriated education for young carers that uses language they use. Work with young carers to design the program if possible.

- Utilise existing resources already in the sector eg. Sector Support and Development Officers in NSW have already developed carer related education/training programmes which have been deemed to be beneficial and effective

- Design and implement carer education programmes that are cyclic with stand-alone sessions that don't require attendance at an earlier session. Ensure these are offered on a regular basis as many carer education programmes are often one-off in an area

- Small group programmes work best as they also offer the opportunity for discussion and connection to other carers

Design Concept Response: how can we encourage carers to participate and complete (cost effective and efficient) online education programme?

Skills development is often a necessary step to encourage and introduce carers to the online world. For example, MDS offers Basic Computer Literacy and Social Media training to carers. This very hands on, interactive programme is offered in small groups or one-one-one (usually in their own home). In many instances, accessing online carer learning opportunities is part of the training. Some of the outcomes of this programme are:

- Increased confidence to use computers of mobile devices such as smart phones or tablets

- Increased knowledge and skills which has enabled carers to access online information and training

- Increased connections to other family members or friends that can also provide additional support for the carer (eg. via Facebook or SKYPE)

- Increased direct access to other service providers

- Carers accessing this programme are given the opportunity to 'play' with devices, learn about best options for internet providers and benefits of connecting online with other people and learning. Building technical familiarity and knowledge in a fun atmosphere has proven to be beneficial. The programme takes into account differing learning styles and literacy levels and is designed according to what the carer would like to learn.

- Online access to learning should also be complemented by other methods and not be relied on as the only education method otherwise there will be a risk of isolating carers further. For carers in isolated areas, use of webinar based programmes could also be useful which can also be used to facilitate an online learning group.

- Use existing community resources such as libraries or seniors' computer groups; encourage other service providers to establish an IT hub for those carers that may not have the money to purchase devices or internet access.

Design Concept Response: 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?

- Bring training to carers in their local communities by supporting partnerships between local service providers and specialist training providers

- Provide workforce development opportunities that enable carer support workers to also train carers

- Utilise the knowledge and skills of carers to train other carers – Care Peer to Peer Training should be resourced and supported

- Involve mainstream service providers in training about carers and supports available

PEER SUPPORT (pg 30)

Design Concept Response: what are some of the tools or supports which could assist in delivering peer support to a broader base of carers?

- Peer Support can take place in many situations that don't necessarily require a dedicated formalised carer support group. Providing opportunities and supporting carers to attend and engage in other activities can create a similar outcome. Furthermore, involvement in less formal activities can build confidence for carers to try out more formalised peer support. For example, MDS, in partnership with other local services has established the Care Free Singers which is a singing group made up of both carers and some care recipients Members of the group have identified not only the benefits of singing, but also the reduction of isolation through friendships. Having a carer support worker at these sessions which are held every two weeks assists carers to have a direct connection to assistance if it is required. Once involved, the majority of these carers have sought more formalised supports and connection to other peer support opportunities

- Not all guest speakers are expensive. It is MDS experience that many offer their services for free

- Many models of carer peer support assume that carers have the time and capacity to organise and maintain carer groups and networks. These models do not acknowledge the addition demands placed on carers. Paid workers are the key to creating and sustaining a well organised group so long as carers have direct involvement in these processes (if they choose). Many carers using our services report that it is good to come along to a group where everything is organised. Having the burden of coordination and organisation enables carers to relax and engage in worthwhile peer to peer support

- Models of peer support need to take into account cultural differences around how people are supported within their culture. The concept of organised groups is an unknown concept. In many instances the peer to peer support is organic with the support of a culturally sensitive worker to provide ongoing support within the particular cultural setting

- Many carers are excellent peer educators, however ongoing supports need to be in place to enable them to take on this role

- Continuity of funding will be required to support the ongoing organisation of peer groups and networks. In many instances funding is linked to one-off time limited project grants. Once the grant period ends the support ends! Continued, recurrent funding that supports ongoing peer to peer programmes will sustain carers in the long term thus reducing the risk of them relinquishing their role and placing the care recipient into care

- The benefits and use of technology as a tool to connect carers and link them to their peers is only just beginning to be realised. A number of carers (especially younger cohorts) are utilising web based technology to raise awareness of their group, advertise events, as well as facilitate online education and chat forums. An Integrated Carer Support system should also invest in action based research to determine the advantages and outcomes of carer driven use of technology as a peer support tool. Outcomes of this area of research could engage carers in the design of effective online programs and identify best practice models.

- Web-based peer support methods include social media platforms (eg. Facebook, Twitter), carer blogs; online discussion within closed groups has proven beneficial for many carers.

Design Concept Response: how can a peer support model be designed which encourages carers to participate and remain engage?

- The design of any model of carer peer support needs to involve carers from the very beginning. It is MDS experience that carers are very resourceful and experienced at problem solving; using and acknowledging shared carer skills and knowledge promotes their valued status and supports continued engagement with peer programmes

- A combination of care led programmes is seen as beneficial, however easy access to funding will be necessary to keep carers engaged

- Peer programmes should be adequately resourced eg. access to transport (if required), respite or childcare

- Recurrent funding should be available to employ Community Development or Engagement Officers across all regions with their roles aligned with the needs of specific groups and regional demographics

- regions that experience high levels of disadvantage should be seen as a high priority and attract additional resources. It is these regions that also experience high levels of complexity due to isolation, low levels of education, low income, language barriers, exposure to torture and trauma in past lives (eg. refugees). The role of carer often adds to the disadvantage with these carers extremely difficult to engage. Using existing community capitol and services (eg. neighbourhood centres, sporting groups, church groups etc.) as a pathway to build an all-of-community approache to engaging carers could be explored

Design Concept Response: should peer support be a service able to be accessed without pre-conditions or structure processes (as a start for specific groups)?

- The evolvement of peer support groups and networks should be a fluid process; these groups are often the entry point for many carers which then link them to ongoing support; informal support groups provide the opportunity for new carers to develop confidence and trust, as well as explore other support options in a supportive environment. Access without pre-conditions or structure allows for these processes to occur.

- Informal groups are often a 'spring board' into more formal groups.

NEEDS IDENTIFICAITON AND PLANNING (pg. 31 – 32)

Design Concept Response: to what extent should goal based planning be used at the assessment stage of the process?

- The new system must include a 'soft entry' for assessment for those people that are new to the role and/or uncomfortable with providing their personal details or participating in the assessment process. In particular, young carers, people from Aboriginal or CALD background are less likely to participate in a rigid assessment process and may take time to engage with the system.

- Assessment should be an ongoing process, not one-off; a continued evaluation of needs is required to ensure quick adjustments can be made for changing needs.

- All assessments should place the carer at the centre with their health and well-being incorporated into the overall assessment

- Not all people are goal or plan orientated – assessment needs to be individual and person centred. In many instances, having a 'spotlight' placed on the carer and their needs is unfamiliar to many carers. Being asked to think about *their* goals can be daunting as many carers will place the needs of the care recipient before their own. Carers will need to support to transition to a person centred way of thinking about themselves before any goal setting or goal development can be achieved.

- The approach taken under the NDIS may also be worthwhile to use with carers, whereby the First Plan is more about putting in place 'reasonable and necessary supports' rather than immediately concentrating on goals.

Design Concept Response: would a goal based planning approach be worthwhile (if not in conjunction with a funded package of financial allocation)?

- Whilst it is acknowledged the Integrated Care Support system has an overall aim of early intervention and prevention, many carers will still come to the assessment meeting feeling overwhelmed and stressed. A requirement to contemplate future goals for someone struggling to get through each day will be a daunting task. Before movement towards, goal setting, time should be spent with carers to address initial issues that are impacting negatively on their wellbeing and lives.

- Goal planning can be introduced at different stages accompanied by adaptation to tools, communication and engagement strategies to facilitate engagement with the diversity of carers. For example the approach used for an older carer and that used for a young carer would be very different.

- 'Consumer *Directed*' is the key to this process, however carers will need to be adequately resourced and supported to 'direct' their *own* plans; any planning and individualised funding should be with the carer, not connected to the care recipient's package as both have very different needs. The focus of an integrated system should be the carer.

- Capacity building funding should be made available to assist carers to build their knowledge and understanding of the self-directed concept. Capacity building projects should be inclusive of carers and have outcomes linked to increase capacity at both the individual and community level.

Design Concept Response: to what extent should self-assessment form part of the future model?

- While there will be some carers that will have the knowledge, skills and capacity to conduct a self- assessment, there will be many that don't. Over time this capacity could be developed with certain carers, however the whole Integrated Carer Support System should not rely on this solely.

- For those carers that choose to undertake self-assessment, there is the potential for very positive outcomes, as carers are in the best position to know about themselves and what they require, however this process should also be accompanied by other evidence based methodologies. Furthermore, carers that initially engage with self- assessment should also be able to opt out if they find that they are unable to continue due to changed circumstances or additional pressures on their time.

- A self-assessment model could also be used to provide continuous evaluation of their capacity and well-being, however carers will need to be trained and supported to continuously engage with this process. Use of technology could be beneficial to self-assessment and ongoing evaluation (eg. development of an APP).

MULTI COMPONENT INTERVENTION (pg. 33 – 41)

General

Design Concept Response: how can we ensure these supports are allocated to those carers who will benefit the most from them?

- Prevention and early intervention is not a concept that all carers understand or recognise, particularly those carers that don't even identify as a carer. The benefits and links to continued overall carer well-being should form part of any carer education program and assessment processes.

- Assistance to engage in self-assessment at this stage may facilitate carer choice, however in many instances carers don't always identify as needing support. Careful engagement, relationship building and a period of intensive support/intervention could assist carers to move towards increased understanding of early intervention and prevention.

- It will be difficult to determine who will benefit most from allocated supports when carers are often hidden, not good at identifying and expressing their needs and put their needs behind the care recipient and other family members

- A multi-component intervention plan will need to be developed in direct consultation with the carer and other significant people in the carers' lives. In some case this may also involve service providers with whom carers have developed strong relationships with (with their permission of course)

Design Concept Response: what should be the criteria by which this is determined?

The Integrated Carer Support system should develop a risk analysis system based on ongoing research and evidence gather. However, over years of providing support to carers, MDS has identified the highest risk areas for carers:

- Assessment for preventative carer support must focus on risk factors likely to contribute to carer breakdown and inability to continue with the caring role. For example, high level of carer anxiety and depression, other illnesses of carer and other family members, injury, complex and multiple caring roles and insufficient formal supports for the care recipient

- Carers of people not receiving formal supports are potentially at a higher risk; the NDIS should provide some relief to carers, however the aged care system continues to provide limited supports, with the burden to fill the gap falling with the carer;

- However, with reference to the NDIS, it should not be assumed that all carers will benefit from their care recipients moving to a package. Carers of people with severe and persistent mental illness will remain vulnerable, and will require ongoing support.

- Carers living in regional and remote areas continue to experience isolation and disconnection from both formal and informal supports.

- Carers with existing disability or health conditions should also be considered as a higher priority

- Carers experiencing financial disadvantage are also at risk

1. **Multi-component Support: Financial**

Design Concept Response: how can we help carers to use these funds appropriately (for themselves) without large administrative burdens on carers or providers who may be assessing them?

- Many carers may need varying levels of support, whereas others may not be able to coordinate finances.

- Carers are already expressing high levels of anxiety associated with a push for them to manage packages under the NDIS. For many, this is an unwanted additional burden that adds to the carer load.

- Consumer Directed Care (CDC) and NDIS have provisions for others to pay invoices etc.; this is an accepted and necessary component of individualised funding, however the choice should always remain with the carer about what system (or part thereof) they wish to use.

- The complexity of individualised funding systems extensive and costly administrative processes that may be beyond some carers' capacity to manage; voucher systems may alleviate some of this, however can also be problematic to administer, especially where there are unspent funds

- Individualised funding systems should not be implemented at the expense of group supports and capacity building initiatives; if carers are required to pay for group support out of their package, this may be seen as a lessor priority leading to isolation

- A number of carers will require an individualised support package to enhance their role as a carer (including transport and education)

- A major concern is that many carers will use the funding on the care recipient rather than themselves

- Administrative fees for management of packages will need to be monitored as this varies from organisation to organisation and is also impacted on the locality of organisations. Whilst MDS acknowledges that administrative fees should not be overly expensive, there should also be recognition that associated overheads also vary and need to be recognised by a realistic benchmark based on industry evidence and knowledge

2. **Multi-component Support: Mentoring**

Design Concept Response: when would a coaching programme be most effective for a carer (ie. carers needs vary over time)?

MDS recommends the following:

- as early as possible to align with the objective of early intervention and prevention

- during times of crisis

- at transition points in the carer role (eg. paid workforce entry/exit, declining health of care recipient, when a co-carer can no longer assist)

Design Concept Response: should this be a mandatory part of the service, or should mentors be able to be determine whether the carer has the capacity to forgo coaching until another time?

- Participation in a coaching program should be voluntary; imposing mandatory requirements undervalues the capacity and knowledge that many carers have; any mandatory requirement does not align with the aim of choice and control. It can be suggested as assessment or carers can be encouraged to join a coaching programme but never forced.

- The concept of coaching/mentoring is not understood or accepted in many cultures; mandatory requirements may intimidate many of these carers, leading them to not engage with the system

- Mentors will need to be highly skilled and trained in their role; personal boundaries will need to be observed in any mentoring relationship

- The Integrated Care System assumes that supports for carers should be joined up, holistic and offer choice; for those carers that choose not to engage in a coaching program, other methods of support can be implemented (eg. an intermittent contact line; linkages to other carer networks)

3. **Multi-component Support: Respite Support Service**

Design Concept Response: will moving more to a consumer directed model, where funding is attributed to and individual carer, result in unintended effects? What might these effects be and how can they be mitigated?

- Respite assists carers to plan other activities when respite is provided; many use it to do other work (paid or unpaid) when the care recipient is receiving respite or engaged in other activities; it should not be assumed that packaged care will reduce the need for respite as carers use respite for many different reasons

- A specific allocation for respite as an add-on to NDIS or CDC/Aged Care packages would be viable; management alongside the care recipient's funding could allow the carer to plan ahead rather depend on wait lists;

- Consideration should also be given to unfunded carers – they will still require respite, if these carers are not able to access respite they may end up moving to crisis or relinquishing care

- Individualised funding should have some guidelines to ensure supports are in place for the carer; many carers will use the funding for the care recipient as they often do not see the benefit of direct support for themselves

COUNSELLING (pg. 42 – 43)

Design Concept Response: what other counselling programmes and techniques would be beneficial in reducing carer burden (vs. online or phone)?

- The benefits of have a variety of opportunities for carers to debrief and engage in both therapeutic and non-therapeutic counselling are linked to overall and continued health and well-being. A variety of options should be available.

- There already exists telephone counselling via Carers NSW, and Lifeline also offers a good service that carers also access; the Integrated Carer Support system needs to recognised and support what is already working well

- Online or phone provide an option for carers to connect and check in, however these options should also provide information around community supports and when it may be necessary to seek more intense or clinically based counselling

- Grief counselling is critical for carers that have lost the care recipient or there is a change in the carer role due to the care recipient moving into care or death.

- Linking with the local Primary Health Networks to establish counselling support accompanied by other wellness programmes may also be an option to be explored within the Integrated Carer Support system

- The delivery of any counselling programme would need to be culturally sensitive and also recognise that not all cultures readily accept this type of intervention

Design Concept Response: could these be delivered to a broader group of carers through telephone or online channels?

- These options are worth exploring (especially with younger carers or those in isolated regions), however older carers may not feel comfortable using these options; however these options should always be explored with all carers, with some older carers slowly engaging so long as they have support to learn how to use new technologies

- In some instances cost may be prohibitive, therefore options for counselling support via the Medicare or health system could be explored

- Technology can also be used to provide one-on-one support such as via SKYPE or other teleconferencing platforms (extremely beneficial for carers in isolated areas)

SPECIFIC CARERS (pg. 44 – 47)

Young Carers

- In addition to previous references to young carers, wherever possible employ younger staff members that have a lived experience of being a carer that can quickly engage with a younger care would be beneficial

- Inclusion of support for young carers within Youth Worker Training would also assist the capacity of the sector to assist young carers

CALD Carers

CALD carers feel comfortable using organisations that have embedded cultural diversity into their everyday operations. Assistance and support should be given to mainstream organisations to develop strategies to effectively engage with people from CALD background

The existing community care programme infrastructure has embedded carer support in local community organisations that are known and trusted access points for those seeking all types of assistance; this infrastructure needs to be retained

Ensure there is access to culturally appropriate case management and care coordination services

Aboriginal Carers

MDS draws on knowledge gained through supporting the "Yarning Circle", a group of Aboriginal carers that meet regularly and attend activities organised by MDS. Many members are also Aboriginal Elders.

- As noted earlier, Aboriginal communities do not necessarily seek out service models that don't account for cultural and kinship connections; the concept of a one-stop-shop does not align with this aspect of Aboriginal culture. Aboriginal carers with whom MDS has contact indicate they would feel uncomfortable, especially if the one-stop-shop was collocated with services and organisations that have been linked to the abuse and removal of Aboriginal children

- Aboriginal carers should also have choice around which services they use; whilst many will use Aboriginal specific services, many will not (citing lack of confidentiality as an issue)

- Implementation of "My Aged Care" has been problematic for Aboriginal Australians with many having negative experiences associated with a lack of cultural awareness and understanding on the part of RAS assessors

- Carers from Aboriginal background are often embarrassed or fearful of seeking support as they feel that they have let down their community. For this reason it often takes time and perseverance to engage with carers from Aboriginal background.

- Caring within Aboriginal communities is not an individualised undertaking; Aboriginal communities see the responsibility of care as being a shared responsibility across the community, including responsibilities in other geographical locations other than where they live, hence individualised interventions may not be accepted unless there is acknowledgement and allowances for an 'all of community approach'.

LGBTI Carers

LGBTI carers have the same needs and expectations as all carers and should receive a service based on need just the same as any other person. This does not necessarily mean that they should identify with an assessor their status. However, organisations that provide support to carers should ensure their operations are non-judgemental/discriminatory.

Rural and Remote Carers

Whilst MDS does not operate services in designated rural and remote areas (as per the Monash definition: http://www.med.monash.edu.au/srh/resources/echidna/geog.html), it should be acknowledged that carers living in the outer lying areas of Wollondilly and Wingecarribee LGAs also experience isolation similar to those living in areas that fall under the Monash definition due to the spread of small village communities that have limited connections to larger town centres. There is poor transport infrastructure, limited access to internet and mobile phone connections which also add to the isolation. Workers spend more time and travel resources engaging with these carers. Service delivery models in these areas should attract additional resources to address these issues.

PROVIDING INTEGRATED SUPPORT (pg. 48)

Assistance for the person they care for:

- there is a need for both the carer and care recipient to access the community together (as they have always done) to do enjoyable things together eg. carers choir, ballroom dancing for people with dementia, dementia cafes

- Aboriginal carers also like to include the care recipient in activities wherever possible, however many also enjoy time away as well. It's about choice!

- Community interaction, education and support are enhanced if there are activities for both the carer and care recipient (ie. GUIDING PRINCIPLE: Cost effective)

Support to Access Employment/Working Carers

- MDS agrees with the suggested supports identified in the paper and believe that a central hub would offer an excellent point for carers to access type of support.

- Employment agencies should also be encouraged to learn more about the demand placed on carers wishing to enter or return to the workforce and have specific strategies in place to ensure barriers to employment are addressed.

- An evaluation of the respite system and hours should be conducted as this system currently does not support working carers

- A lot more education directed at employers and their responsibility under legislated should also be incorporated into the Integrated Carer Support system

Support When Caring Changes or Ends

As identified earlier, these events in a carer's life are significant transition points; an Integrated Care Support system should be able to respond quickly at these points; furthermore support should be provided to a person for at least six months (if they require it) after the caring role ends to ensure a smooth transition by connecting them to other community supports, counselling, and exploring options for other activities that they may not have been able to attend or participate in whilst they were a carer

People caring for someone with dementia or other deteriorating condition will need continuous support; in many instances these carers do not recognise the additional workload this may present and take on more and more work before they seek assistance or move into crisis. Ongoing support, monitoring and education will be critical

Aboriginal carers may require additional support during 'Sorry Business' which may mean providing support to return an Aboriginal person to Country, supporting other family members and associated costs