Response to the Draft Service Concept for an Integrated Plan for Carer Support Services

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1. Introduction

a) Anglicare Diocese of Sydney ('Anglicare Sydney') thanks the Department of Social Services for the opportunity to respond to the Department's discussion paper '*Designing the new integrated carer support service*'. Anglicare Sydney supports efforts to better recognise the role of carers in society and to give carers the assistance they need to sustain a sense of well-being in their caring role.

b) The following submission:

- Responds to the questions raised in the Department's discussion paper, and
- Raises important issues that need to be taken into account in designing an integrated carer support service.

c) Anglicare Sydney's submission is based upon the depth of our experience in providing assistance to hundreds of carers over many years. We recognise that our observations will be particularly focussed upon issues where we have had the greatest involvement with carers. In this respect we are able to make observations about areas where service delivery could be improved by both service providers and government, complementing more holistic observations from carer groups and carers themselves.

1.1 Overview of Anglicare Sydney

d) Anglicare Sydney is a Christian organisation operating a wide range of community services and programs across the Sydney Metropolitan, Illawarra and Shoalhaven regions of NSW. Anglicare Sydney's services include aged care (both residential and community), emergency relief, children's and youth, disability, migrant and refugee, opportunity shops and counselling services. It embodies the Christian commitment to care for all people in need, as comes from Jesus' command to love your neighbour as yourself.[1]

e) Anglicare Sydney operates a number of services and programs involving carers in the Sydney metropolitan and the Illawarra regions of New South Wales, as outlined in Table 1:

[1] The Gospel of Matthew, chapter 22 verse 39

Table 1: Anglicare-provided services for carers in Sydney and the Illawarra

SERVICES FOR CHILDREN AND YOUNG PEOPLE	
Service name	**Description**
Kingsdene Respite Cottage	Short-term, planned breaks for people with additional needs during the day or overnight.
Westlink After-School Care	Provides food, music, games and activities.
Host Family Program	Regular respite care with a volunteer carer.
Peer Support:	Recreational and social activities for children and young people aged ten to 18 years with intellectual disabilities
Holiday care	Care during the school holidays for children and young people aged five to eighteen years with moderate to severe disabilities.
OTHER SERVICES INVOLVING CARERS	
Service name	**Description**
ComPacks	Short-term case management for hospital discharge
Commonwealth Respite and Carelink Centres (CRCC)	Links carers to support services and helps them to access short-term and emergency respite support.
Haven Project	Respite care provided in consortia for carers of people with a mental illness
Brokerage Interpreting Services and Allied Health	Targeting Culturally and Linguistically Diverse (CALD) people

f) The National Disability Insurance Scheme (NDIS) brings momentous change to the way Australia provides disability services. Between April and June 2016, Anglicare Sydney will be transitioning the following services and clients to other providers under the direction of the NSW Department of Family and Community Services (FACS):

Table 2: Carer services being transitioned from Anglicare to other providers

Service name	**Description**
Support Coordination for Older Carers	Case management for carers over the age of 65 years still supporting a son or daughter with a disability at home.
Respite Options	Flexible respite packages for carers who have a child with a disability
Supported Living Fund	Individualised accommodation support funding for adults with disability aged 18 to 64 years (FACS).
Life Choices	Opportunities for adults with a disability (aged 25 to 54 years) to participate in purposeful, recreational and leisure activities (FACS).
Other services	Westlink Head Injury Recreation and Leisure Service (WHIRLS), Community Options (COPS), Brokerage Options (BOPS), CALD Social Support, Counselling Support, Information and Advocacy

g) The experience in serving the community with this range of programs means that Anglicare Sydney is well placed to provide feedback to the Government's draft Service Concept. Our approach to carers is based on consultation, collaboration and flexibility in relation to differing needs – physical, familial, emotional and cultural. It is client

centred endeavouring to be responsive to changing needs and circumstances and it affirms the significant role of the primarily carer, often operating under challenging circumstances.

2. General observations

h) **Local supports:** Anglicare Sydney is encouraged by the Department's plans for local supports as outlined in the Service Concept Overview. These local supports are particularly important for older carers who may not be proficient in the use of computers and who may be wary of speaking with strangers on the phone. Directly engaging with carers through face-to-face services will allow carers to build rapport and trust with service providers. Some carers will have existing contacts and relationships with local services, so it is important for such services to be involved in facilitating intake. This is also of high importance for carers from non-English speaking backgrounds as they are more likely to trust cultural-specific services in their area.

i) **The range of supports available for carers through the Gateway:** Anglicare Sydney has observed that the listed supports to be provided through the Gateway are not as detailed or specific as those currently included in funded carer supports. It is noted that some of these supports (such as transition planning and accommodation assistance) will most likely be covered by care recipient-funded support through Community Aged Care (CAC) and the National Disability Insurance Scheme (NDIS). For people who are not covered by an NDIS package, the Local Area Coordinator stream (or equivalent new carer liaison roles) will be essential for education and advice. Local Area Coordinators need to be well trained with sufficient capacity to handle this additional task on top of their existing workloads. Advisors will require an extensive and up-to-date knowledge of the support services in carers' local geographic areas. Some carers who do not fall under the NDIS may have access to domestic assistance or personal respite through the Commonwealth Home Support Program, although they will not have access to multiple-day respite or social support.

j) **Trust and continuity of care:** Previous carer support models have utilised support workers to provide one-on-one, holistic assistance to carers. Support workers have helped carers by making them aware of services they may not have considered and by providing assistance to evaluate options and make decisions. The strength of this approach was the development of an ongoing, trusting relationship between the carer and the support worker in which the carer felt safe. Anglicare Sydney is concerned that the Carer Gateway now places the onus much more on carers to seek and arrange their own support. Carers are often so emotionally and physically impacted by the caring role that they are not able to research or make contact with service providers when they cannot navigate the path easily. There is a risk that carers will be left behind unless the new integrated system provides one-on-one, holistic support.

Wherever possible, carers should have ongoing access to the same support worker to facilitate the development of an open and trusting relationship.

k) **Importance of effective transitioning and outreach:** Anglicare Sydney believes that the success or failure of the Gateway will be predicated on the effective transitioning of existing carers to the new system, as well as finding and identifying 'hidden' carers. Existing carer support services will be a key channel for communicating with carers who are currently accessing formal support. In addition, promotional and outreach activities will be essential to identify and contact carers that are currently 'hidden' from support services.

l) **Coordination between Carer Gateway and My Aged Care:** The Carer Gateway needs to link with My Aged Care to ensure a continuum of care for people living with a disability as they reach old age. Residential respite could be helpfully added to the draft service concept to act as an important linkage between home care and permanent residential care. Older carers will also need assistance to transition into aged care services for themselves when they are unable to continue in their caring role.

m) **The need to address a variety of carer circumstances:** Anglicare Sydney is concerned that the Carer Gateway appears to be a one-size-fits-all approach to providing support to carers. There is significant variation in the circumstances of carers which requires individual responses and support. In many cases, one-to-one contact between advisors and carers will be required. It is important that multi-lingual support is also available and that advisors receive cultural awareness training (CALD and Aboriginal and Torres Strait Islander carers). For example, some Aboriginal people may recognise that a family member has trouble walking but they may not recognise this as a disability. They may see caregiving as a communal responsibility and will therefore not identify as a carer or seek support. Alternatively, some people from CALD backgrounds may not want to identify as a carer due to shame (especially carers of people with intellectual disabilities or mental illnesses). Targeted outreach will be required to identify and support such carers.

n) **Accessibility issues:** Accessibility is another key issue for the design of the Carer Gateway. Many carers are approaching old age and may not be skilled with computers or social media. Such carers will depend on hard copy written information and telephone contact. This has implications for many aspects of the proposed Service Concept because alternative communication methods will need to be available. Technical support issues are also likely to occur so it is essential that the Department allow adequate resources to provide this support.

o) **Emergency assistance procedures:** Providing care to a person with a disability is a demanding role in which crisis situations can occur. While services do seek to avoid crisis points, there are times when unanticipated events occur, such as carer breakdown or illness. For example, some older carers will contact the Gateway

because they are no longer able to provide care and they need crisis accommodation. It is vital that appropriate channels and information are provided to ensure that emergency assistance can be accessed when needed. Furthermore, the procedures for accessing emergency assistance should be communicated well to carers because they may sometimes forget key information in a crisis.

p) **Block-funded carer services:** It is likely that Government-funded carer services will need to support the Carer Gateway once CRCCs are closed. However, at this stage it is unclear to Anglicare Sydney how these supports will be funded in the future. The Productivity Commission (2011) recommended that individual carer needs be assessed and funded as part of NDIS packages. Alternatively, the Government may choose to provide funded services for carers via competitive tendering arrangements. It is also unclear whether all services will be federally funded or if the states will retain some responsibility for contributing to funding.

q) **Continuation of existing carer payments:** Anglicare Sydney notes that the eligibility and conditions for the Disability Support Pension were planned to be tightened as part of the 2014-15 budget (Buckmaster n.d.). Given the vital role of carers that has been noted in the discussion paper, it is essential that eligibility for carer payments remains unchanged.

3. Response to Questions Raised in the DSS Draft Service Concept

3.1 Awareness

The discussion paper asks:

- What are the most effective and efficient means of raising awareness of available support for individual carers early in their caring journey? (p.24)
- Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools? (p.25)

r) **Importance of awareness:** Anglicare Sydney believes that the success or failure of the Carer Gateway will be predicated on the effectiveness of awareness-raising and outreach activities. Existing carer support services will be a key channel for communicating with carers who are currently accessing formal support. In addition, promotional and outreach activities have great potential to identify and contact carers that are currently 'hidden' from support services.

s) **Young carers**: It is important that the Department work with other Commonwealth and State/Territory departments to ensure that local schools assist young carers to manage their situation. Many young carers have been providing care for their whole lives so they might not necessarily identify as carers or seek assistance. Proactive strategies would thus support early intervention for young carers. A starting point would be ensuring the provision of information for local school authorities and teachers to improve awareness of the issues faced by young carers and the support available to them. Information for young carers may also be provided via brochures or information packs displayed in school offices. More proactive outreach activities such as guest speakers in schools may help young carers identify themselves as such. Another potential outreach activity is the placement of student teachers in young carer support programs. Anglicare Sydney has previously used this strategy in partnership with Western Sydney University which resulted in young carers gaining assistance and student teachers gaining information and experience. Such a model could be replicated in other universities to promote awareness of issues affecting young carers.

t) **Older carers:** Anglicare Sydney has worked extensively with older people who provide care to an adult son or daughter with a disability. Such carers may be out of contact with support services due to a reluctance to seek help, social isolation, fatigue and/or a lack of information. A recent study of older carers in the Anglicare Support Coordination program found that only half (51%) knew where to get help if they needed it upon entry to the program (Bellamy *et. al.* 2014). One in five carers (21%) were not

in contact with any support services in the 12 months prior to getting help from Anglicare (Anglicare Sydney Support Coordination Program, unpublished data).

u) **Other hidden carers**: Hidden carers may include those of particular language or cultural groups, those living in regional and remote areas and those with limited socioeconomic resources. In addition, some carers from Aboriginal and Torres Strait Islander backgrounds will not recognise disability and caring roles because caregiving is not an individualised role. Targeted outreach will be needed to build awareness among these groups, such as promotion via community centres, Centrelink, exhibits, word of mouth and referrals from medical and allied health services (e.g. CRCCs, hospitals). When targeting doctors and health professionals, it is vital to provide straightforward referral processes and potentially incentives to refer carers to the Gateway. Universities could also be used to target new professionals entering these fields and educate them on reaching out to 'hidden' carers. Finally, advertising in mainstream media is also essential – Anglicare is pleased to have observed some radio advertising already taking place.

v) **Role of Non-Government Organisations:** Carers who are 'hidden' from support services may not know to seek assistance via the Carer Gateway. It is more likely that such carers will search for information from specialist Non-Government Organisations (NGOs) such as Carers NSW or the Cerebral Palsy Alliance. These organisations will serve as primary linkages to the Carer Gateway because carers are more likely to search for information on specific medical conditions. Existing NGOs would also have existing networks to the community and strong recognition for the delivery of good quality information and outcomes. It is essential that these NGOs are resourced in the long-term to promote awareness and handle enquiries from the public. The Carer Gateway should also provide web links to NGOs relevant to particular geographical areas and various medical conditions (and vice versa).

3.2 Information

The discussion paper asks:

- 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? (p.26)

w) **Accessible and high quality information:** Anglicare Sydney agrees that carers need quality information about support available to them and the people for whom they care. Carers are often so emotionally and physically impacted by the caring role that they are not able to undertake the tasks required to research or make contact with service providers when they cannot navigate the path easily. Therefore, individualised recommendations are important for guiding carers in the support that is available to

them without triggering 'information overload'. Information needs to be accessible, varied and tailored to suit the differing needs and circumstances of carers. It is also essential that the Carer Gateway is frequently monitored to ensure that all information is completely up-to-date.

x) In addition to appropriate access to information, carers need support to navigate between options and make decisions. Such support is an essential aspect of quality information provision and should be offered to all carers, and taken up by those who require the extra support.

y) **A variety of communication methods:** The targeted nature of information provision also needs to include communication through a variety of methods to allow for the particular skills and backgrounds of different carers. For example, upon entry to the Anglicare Support Coordination program, almost two-thirds (63%) of carers were aged 70 years or more and almost one in five (18%) were aged 80 years or more (Bellamy et. al. 2014). Such carers may not readily use online sources and will often depend on hard copy written information (with telephone contact for agencies) to be available to them at appropriate points of contact. In addition, culturally and linguistically diverse carers do not necessarily associate themselves as being in a 'carer role', and will therefore need access to culturally sensitive information through contact points that are not carer or disability specific, e.g. community, migrant or cultural centres.

z) **Fee transparency:** Up-front information should also be provided to carers outlining which Gateway services are free and which will require payment. For example, helpline and information referral services would be government funded whereas other services such as counselling might incur a cost. Information regarding government assistance for carers from low socioeconomic backgrounds should also be made publically available.

3.3 Intake

The discussion paper asks:

- Are there ways to make intake a more beneficial process for carers? (p.27)
- Another way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is necessary. […] When should intake be a mandatory process? (p.27)

aa) **Flexible yet comprehensive intake:** Anglicare believes that an effective intake tool should gather comprehensive information without subjecting carers to repetitive or time consuming processes. While intake should be mandatory (unless the carer refuses), conditional sequencing may be used to ensure carers are only asked questions that are relevant to their situation. For example, carers with basic needs

could be asked simple one-off questions related to demographics, their caring situation, their needs, linkages to other service providers and possible future directions. Carers who require a more complex or multi-stranded response might complete additional intake modules to gather more comprehensive information.

bb) **Avoiding repetition:** The main benefit of a well-planned intake system for carers is that they would not have to retell their story each time they contact the Gateway. Such a benefit would be contingent on a comprehensive database which is easily accessible to Gateway staff when receiving a call.

cc) **Data linkage with service providers:** Anglicare Sydney would like the Carer Gateway to utilise existing client information held by service providers which includes carer contact details, demographics, carer needs and the history of support given over the years. Utilisation of this rich data source would prevent current clients from 'slipping through the cracks' and facilitate individualised support sooner. As part of the current reporting requirements, CRCCs need to complete a 'transition out plan' in case they are no longer funded to provide services. Part of the plan relates to the transfer of client databases. Therefore, the submission of carer data to the Gateway could be an extension of this process, as long as the data transfer system is set up appropriately with clear instructions for workers. Prior to the closure of existing services, workers could also be utilised in outreach activities to help transition carers to the Gateway. Another area of potential data linkage would involve the sharing of carer information with support services upon referral from the Gateway. If carers go through an intake process with the Gateway, they should be asked to consent to their information being provided to referral services (e.g. intake information, assessment information, emergency plan and future care plan). This would further enhance the intake process because carers would not need to tell their story again.

dd) **Registration of emergency plans:** Providing carers with the option to register their emergency plans during the intake stage might be appropriate for some but not all carers. Some carers may not have a formal emergency plan and would require assistance to put a plan together. Other carers would rely on their extended family in an emergency. The Gateway could at least record the details of emergency contacts and send out information to inform them of the Carer Gateway and their role as an emergency contact.

3.4 Education

The discussion paper asks:

- How can carers be encouraged to access education support? (p.29)
- If education were to be offered online, how can we encourage carers to participate and complete an education programme? (p.29)
- 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? (p.29)

ee) **Linking education with other support services:** Most carers are extremely time poor and 'non-essential' or 'non-urgent' activities are the first to suffer. Thus, training and support for carers in this respect needs to be part of integrated care planning. For example, the Anglicare Support Coordination program seeks to develop educational opportunities in response to common topics of interest to their carers (such as will preparation or computer skills). In other cases, training and support requirements may be identified by exploring the reasons behind a particular service request. For example, a request for respite may relate to the challenging behaviour of a care recipient and the carer having no partner to share the load. Education and social support in a group setting may help carers to better cope with the demands of their role. Carers are more likely to accept educational help if it recommended by a support worker with whom they have a trusting relationship.

ff) **Group-based learning:** Another method for increasing the take-up of educational opportunities is the integration of skill development with support group gatherings, with the dual purpose of providing education and increasing social connections and support. Such groups create more social interactions for carers, who may benefit from improved psychological and physical health through regular meet-ups and meaningful connections (Wei et. al 2012). Pairing education with social support also accommodates carers who may not have the skills or resources to access online material. The delivery of group-based learning can also accommodate carers of a particular language group who may have insufficient English literacy for completing online training.

gg) **Flexibility from education providers:** For younger carers, training and support needs to be creatively delivered to support them through the challenges of juggling care and learning at a 'structured' institution at the same time. Educational institutions need to offer flexible and varied delivery of education to suit the young carer, for example, through online and interactive learning modules and additional online or group tutoring. Educators and institutions need increased awareness of the issues that young carers face in their role. Ongoing complex care coordination/specialised

mentoring is essential for young carers having access to education and training. They need complex care coordination to assist them in finding the right education and employment pathways to suit their individual needs while in their caring role and beyond that role when care is no longer required.

3.5 Peer Support

The discussion paper asks:

- 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? (p.30)
- How can a peer support model be designed which encourage carers to participate and remain engaged? (p.30)
- 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. Should peer support be a service able to be accessed without pre-conditions or structure processes? (p.30)

hh) **Informal online support:** Informal peer-support groups can provide a good entry-point into support systems, particularly online social media groups. For example, an online group on social media may allow carers of people with an intellectual disability to gather, share advice and ask questions. In such cases where a carer group is self-motivated, peer support may lead to the provision of information or advocacy which does not require pre-conditions or structured processes.

ii) **Facilitated peer support:** Online support may not be sufficient for all carers. In particular, older carers are still likely to depend on meeting and sharing with other carers in person. Many carers prefer a structured approach to peer support, facilitated by a professional with knowledge of the condition of the care recipient and thus the stresses for the carer. More structured processes including eligibility criteria and accountability are required for funded programs.

jj) **Role of Non-Government Organisations and community development:** In the absence of Government intervention to link carers together, civil society would need to fill the gap. For example, carers may seek assistance from NGOs or cultural or religious groups. It is recommended that such organisations are supported to work within community development models to link carers together, particularly carers who are older or from a CALD or Aboriginal/Torres Strait Islander background. NGOs would have the existing community recognition and networks needed to link carers up with informal support networks.

3.6 Needs identification and planning

The discussion paper asks:

- To what extent do you think goal based planning should be used at the assessment stage of the process? (p.32)
- 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? (p.32)
- To what extent should self-assessment form part of the future model? (p.32)

kk) **Variation between carers:** Goal-based planning should always be a component of service delivery, although the approach taken would need to accommodate differences between carers. Some carers would have substantial insight into their needs while others (particularly older carers) may be limited in their thinking to the supports they currently receive. Anglicare managers have indicated that some carers will not identify with the concept of 'goals' and will instead think in terms of what they need to provide care.

ll) **Consideration of care recipient's package:** Anglicare Sydney considers assessment to be an important step toward understanding and responding to the needs of carers and the people for whom they care. No two carers are alike which necessitates the assessment of individual needs. In some cases, carer goals will be impacted by the care recipient's plan which may include short breaks providing respite and/or the development of a transition plan for the care recipient's accommodation. Transition planning in particular is an important support for older carers. Bellamy and colleagues (2014) found that while 82% of older parent carers considered transition planning to be 'very' or 'quite' important, only 10% had received this assistance the 12 months before coming to Anglicare. The Integrated Plan for Carer Support Services should work together with NDIS packages to ensure that carers continue to benefit from important services such as transition planning.

mm) **Carer Support Needs Assessment Tool (CSNAT):** Self-assessment processes for the carer will not be automatically included in the planning process under care recipients' NDIS packages. Therefore Anglicare Sydney believes that self-assessment approaches such as the CSNAT may provide a helpful foundation for professional advice and support leading to a tailored model of care. The CSNAT may assist in identifying carers' needs and ensuring that those needs are met, although it is important that this tool is facilitated by a practitioner and ideally used in an ongoing mentoring relationship. The CSNAT Approach Summary Document states: "The CSNAT approach has a number of stages; each stage facilitated by the practitioner"

(The University of Manchester & University of Cambridge 2013:1). One such stage is the 'assessment conversation' between the carer and the practitioner which "facilitates deeper exploration of the domains highlighted as priorities by the carer" (p.2). The needs assessment should also be re-evaluated to account for changing carer priorities over time.

nn) **Importance of practitioner-facilitated assessment:** Some carers would have more insight into their care needs than others. Practitioner-facilitated assessment is particularly important for the ageing parent carer cohort as historically this group has been less likely to seek access to carer support services, given their self-reliance and longevity in caring. Importantly, only 51% of carers entering the Anglicare Support Coordination program agreed that they knew where to get help if they needed it in their role as a carer (Bellamy et. al. 2014). Therefore, Anglicare Sydney is concerned that such carers would tend to underestimate their need for support if self-assessment was the sole approach to needs identification. Practitioner-facilitated assessment would also be important for carers requiring multi-lingual support, although certain tablet devices can also be used to automatically translate online material (assuming carers are provided with the devices and trained to use them). Finally, some carers will be in crisis when they contact the Gateway and will not be able to participate in effective assessment activities. It is important that assessment occurs after crisis points have been addressed.

3.7 A Multi-Component Intervention

The discussion paper asks:

- Given that this model is seeking to apply preventative thinking, how can we ensure [multi-component] supports are allocated to those carers who will benefit the most from them? (p.34)
- What should be the criteria by which this is determined? (p.34)

oo) **Young carers:** Preventative multi-component support would probably best be applied in the early stages after the diagnosis of the care recipient's condition. This intensive support would be time-limited with a focus on promoting resilience and developing as many natural and informal supports around the carer as possible.

pp) **Other criteria:** The Gateway intake process may also be used to identify other carers who require more intensive supports. Particular criteria for intensive support may include very old carers who cannot sustain their role, carers of people with high support needs or parents of multiple children with disabilities.

3.7.1. Financial Support

The discussion paper asks:

- How can we help carers to use direct funds appropriately without large administrative burdens on carers or providers? (p.37)

qq) **Management of funds:** Accountability in the use of financial support could be achieved using a model similar to the NDIS. Funds could be distributed into a specific account where they can only be used for approved purposes. While this system would ensure accountability, it would still be labour intensive for carers and potentially providers. Support services would need to be available to help carers to manage their funds, similar to services under the NDIS for care recipients.

3.7.2. Carer Mentoring

The discussion paper asks:

- Coaching programmes are normally funded for a time-limited period. When would a coaching programme be most effective for a carer? (p.39)
- Some carers may not want a coaching program which extends over time. Given that this is indented to be part of a multi-component support model, should this be a mandatory part of the service? Should mentors be able to determine whether the carer has the capacity to forgo coaching until another time? (p.39)

rr) **Targeting:** Carer mentoring would probably be most effective during the early stages after the diagnosis of the care recipient's condition (see response under Section 3.6). Mentoring would also be effective after crisis intervention in order to prevent further crises from occurring in the future.

ss) **Accommodating carer preferences:** The decision to participate in a coaching program should ultimately be up to the carer. However some carers will not be able to make a decision about coaching due to a lack of knowledge or confidence. Other carers, particularly those from CALD or Aboriginal and Torres Strait Islander backgrounds, will not necessarily be comfortable with the concept of a 'coach/mentor'. In circumstances where the carer is undecided, the mentor can provide information and assurance to encourage the carer to take part. However the decision to take part should be up to the carer. Carers would also need to be made aware of whether the

mentoring is provided by the government or funded through their package before committing to mentoring.

tt) **Addressing crisis points first:** Unless crisis points are addressed, carers will remain burdened and unable to commit to mentoring. For example, immediate concerns such as financial stress, lost employment and emergency accommodation would first need to be resolved before a carer would be receptive to the idea of mentoring.

3.7.3. Respite Support Service

The discussion paper asks:

- Respite 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? (p.41)

uu) **Value of respite:** The Department states "there is a lack of quality evidence that respite services effectively reduce carer burden and mental and physical health problems" (p.40). However this does not reflect the experience of Anglicare Sydney. In an evaluation of Anglicare Sydney's Respite Options (RO) program, the Australian Unity Personal Wellbeing Index (PWI) was used to establish the subjective wellbeing of carers both upon entry to the program and after at least 12 months in the program. Carers were asked to rate their levels of satisfaction from 0 to 10 across seven life domains comprising the PWI. The combined score for all seven items was then converted to a score out of 100. The national average score for this index is around 75 out of 100 for the population (Cummins and Hughes 2007); carers entering the RO program scored an average of only 60. This increased significantly to 66 out of 100 after at least 12 months in the program ($p<0.01$, matched sample t-test) (Anglicare Sydney Respite Options program, unpublished data). Carers who participated in the RO program improved significantly in average scores across almost all PWI domains, including satisfaction with feeling part of their community ($p<0.01$), current achievements in life ($p<0.01$), standard of living ($p<0.05$), health ($p<0.05$), personal relationships ($p<0.05$) and future security ($p<0.05$) (Anglicare Sydney Respite Options program, unpublished data).

vv) **Consumer-directed model:** It would be important under a consumer-directed model that carers are aware of the amount of respite they are entitled to. In a similar vein to financial support (Section 3.7.1), carers may not want the burden of managing their own respite and may require assistance. Carers should be able to afford assistance in managing these services if required.

ww) **Consideration of care recipient's package:** Under the NDIS, the respite component is not allocated to the carer but to the care recipient. This ensures that it fits within the care recipient's goals and that the short breaks are suitable for both the carer and the care recipient. Some Anglicare workers expressed concern for carers who require respite support beyond the provision under the NDIS. This may occur because the care recipient is not covered by an NDIS package (e.g. people with dementia who are not covered by a relevant package or people with mental illnesses) or because the carer requires more respite than was allocated in the care recipient's plan. Under such circumstances, carers would need to pay for respite out of their own pocket which can result in financial stress and possible dependence on emergency relief services from charitable organisations. Therefore the Integrated Plan for Carer Support Services should also include a provision for additional respite in certain situations (e.g. when the carer is sick, has been hospitalised or otherwise unable to provide care - see Section 2).

3.8 Counselling

The discussion paper states:

- Utilisation of lower cost channels such as telephone or online to deliver counselling will mean more carers will be able to receive counselling. (p.43)

The discussion paper asks:

- Much of the evidence relating to effective counselling programmes for carers is focussed on Cognitive Behavioural Therapy (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? (p.43)

xx) **Appropriateness of remote counselling:** Telephone or online counselling may be appropriate for some carers. However, Anglicare Sydney does not believe that counselling will always be effective over the phone because some carers will have particular difficulties with this approach. For example, some older carers will suffer from diminished hearing and will not be able to participate well in phone counselling. In addition, some older carers may have had negative experiences with telemarketers or scams and would be more comfortable with a face-to-face counsellor. Other carers will not be comfortable with participating in telephone counselling from their home because the care recipient may be able to listen to their conversation. Multi-lingual assistance will also be necessary for phone counselling and in some instances carers may prefer to talk to someone not only of their language but also of their cultural background (e.g. Egyptian Arabic as opposed to other Arabic speakers).

yy) **A phased approach:** Anglicare Sydney understands that the Department needs to explore cost effective solutions. Therefore the Department could adopt a phased approach by adopting telephone counselling but also offering face-to-face assistance for particular carers who prefer or require it. No matter the counselling approach used, establishing a supportive relationship between the carer and their counsellor is paramount.

zz) **Counselling for grief and bereavement:** Anglicare support workers have indicated that older carers may particularly require counselling for grief and bereavement. Some older carers have never worked through the grief of having a child with a disability and may require other counselling approaches in addition to CBT. Counselling for grief may also be required for carers who transition away from their caring role due to old age.

aaa) **Financial and legal counselling:** Anglicare support workers have indicated that financial or legal issues can be an additional source of stress for carers. Some carers can be reluctant to use residential respite due to financial issues. Other carers may become overwhelmed by the burden of managing their own support package. Such carers may benefit from financial counselling services to ease burdens associated with finances. Other carers will not know how to deal with legal issues such as making Power of Attorney arrangements. Such carers may benefit from referrals to specialists in order to gain these skills.

bbb) **Other strategies:** The Government may also choose to explore counselling strategies such as mindfulness programs, narrative therapy or art/music therapy. Social and peer support programs can also serve an informal role in promoting coping mechanisms, especially for carers who are resistant to the idea of counselling (e.g. those from particular cultural backgrounds).

4. Concluding comment

ccc) Anglicare Sydney appreciates the opportunity of participating in the consultation process and trusts that this submission will be of assistance in improving carers' access to information and support.

ddd) We would be happy to meet with officers of the Department to discuss any details of our submission if that would be of assistance.

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