Delivering an Integrated Carer Support Service

A submission to Department of Social Services (DSS)

Prepared by Anglicare Sydney

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1.   Introduction

a)   Anglicare Diocese of Sydney ('Anglicare Sydney') is a Christian organisation operating a wide range of aged care facilities and community services across the Sydney Metropolitan and Illawarra regions of NSW; it embodies the Christian commitment to care for all people in need, as comes from Jesus' command to love your neighbour as yourself.[1]

b)   Our range of services includes: carer support programs; aged care both through nursing homes and community services; retirement villages; counselling and family support services; community education for families; youth services; foster care and adoption services; mental health recovery services; emergency relief for people in crisis; migrant and refugee services including English as a second language classes; opportunity shops providing low-cost clothing; emergency management services in times of disaster; and chaplains in hospitals, prisons, mental health facilities and juvenile justice institutions.

c)   Anglicare Sydney has a long history of involvement in providing support services for carers of people with a disability. These services include:

- Support Coordination for parent carers aged over 65 years, caring for an adult child with a disability;

- Respite Option Program, providing flexible respite services for carers of people with a disability, aged 0-64 years;

- Commonwealth Respite & Carelink Centres (CRCC's) in South West Sydney and Nepean regions.

2.   Purpose of this submission

d)   The Department of Social Services has released a discussion paper entitled *Delivering an Integrated Carer Support Service. A draft model for the delivery of carer support services.* The following submission addresses issues raised in the Department's discussion paper, including the discussion questions raised on pages 15 and 28.

3.   General observations

e)   **Local supports:** Anglicare Sydney is encouraged by the Department's plans for local service involvement, as the third tier of carer support. Local supports are particularly important for older carers who may not be proficient in the use of computers or the internet 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 local service providers. Some carers will have existing contacts and relationships with local services. This is also of high importance for carers from Culturally and Linguistically Diverse (CALD) backgrounds as they are more likely to trust cultural-specific services.

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

f) **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 ICSS 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.

g) **Importance of effective transitioning and outreach:** Anglicare Sydney believes that the success or failure of the ICSS 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.

h) **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.

i) **Different service approaches are required to address the needs of different carer cohorts:** Anglicare Sydney is concerned that the ICSS 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. For instance, consideration of the needs of Aboriginal and Torres Strait Islander, Culturally and Linguistically Diverse (CALD) and Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) carers is acknowledged as a delivery principle in the Discussion Paper.[2] However there is no detail as to how this might make a difference to the way that services are delivered to each of these groups.

j) For example, it is important that multi-lingual support is available and that advisors receive cultural awareness training in dealing with CALD and Aboriginal and Torres Strait Islander carers. Some Aboriginal people may observe 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 personally 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 as carers of people with intellectual disabilities or mental illnesses). Targeted outreach will be required to firstly identify and then properly support such carers.

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[2] Discussion Paper, p 38

k) **Accessibility issues:** Accessibility is a key issue in the design of the ICSS. Many carers are aged over 55 years and may not be skilled with computers, the internet or social media. Such carers will depend on hard copy written information and telephone contact. This has implications for many aspects of the proposed ICSS, which relies on carers accessing the internet to access national level and some regional level resources.

l) **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 Carer Gateway or Regional Hub 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.

4. Response to DSS Discussion Paper

4.1 Draft Service Delivery Model

4.1.1 National Level Services

m) According to the Discussion Paper, national level services will largely be delivered on-line, with some information advice and counselling being available via phone.[3] Access will involve creating an on-line account and carer record, with carers navigating on-line to support teams, discussions and learning materials.

n) Such an approach means that many older carers will simply be unable to use national level services. According to the Discussion Paper, most 45-54 year olds (95%) access the internet. However what is not acknowledged is that internet usage declines precipitously among older age groups. According to the Australian Bureau of Statistics, only half (51%) of people aged over 65 years use the internet.[4]

o) People aged between 55 and 74 years are more likely to be providing care to a person with a disability, frail aged or chronic illness than people in other age groups. Some of these carers are unskilled with computers, the internet or social media, and instead depend on hardcopy information and telephone contact. Anglicare's view is that it will be essential for the Department to provide alternative forms of access to the range of resources available via national platforms, through the Regional Hubs and at the local level.

p) Even where on-line access is available to older carers, Anglicare's view is that many older carers will struggle with it or find it less than helpful. Our observation is that older carers often prefer meeting and sharing with other carers *in person*. Carers value a structured approach to peer support, facilitated by a professional with knowledge of the condition of the care recipient and thus the stresses experienced by the carer. More structured

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[3] Discussion Paper, p 11
[4] Australian Bureau of Statistics *Household Use of information Technology, Australia, 2014-15*. Cat no. 8146.0

processes including eligibility criteria and accountability are already required for block-funded programs.

q) In addition, cohorts such as Aboriginal and CALD carers are more likely to struggle in an on-line service provision environment due to literacy issues, or cultural norms and expectations.

4.1.2   Regional Hubs

r) The Discussion Paper proposes the establishment of Regional Hubs to promote services and assist carers to access and engage with support services. This role includes facilitating carer access to local services, which will be coordinated regionally.[5]

s) The Discussion Paper outlines that the Regional Hubs would play a vital role for individual carers including:

- encouraging carers to seek support and services earlier in their caring journey (page 8);

- needs and eligibility assessments to coordinate access to respite and targeted financial support (page 8);

- via interaction with other service systems, to become aware of individual carers experiencing high levels of strain or changes in care recipient circumstances leading to increased carer burden (page 10).

t) Anglicare Sydney's understanding is that the number of Regional Hubs has not yet been determined by the Department. The Discussion Paper mentions that the Department is currently undertaking analysis to determine how many Regional Hubs will be provided.[6] In the absence of a firm proposal at this stage, Anglicare is concerned that the degree of individual attention and care promised in the Discussion Paper will simply not be able to be delivered directly or coordinated properly by a regional entity. Depending upon the scale of each Regional Hub, these could be quite remote from the individual carers, with high client loads depending upon the actual size and population of the region being serviced.

u) Furthermore, a large scale Regional Hub could also be too remote from the local services that it is meant to coordinate. Local services may find themselves needing to pick up unfunded tasks which should be handled at the regional level, while the regional service will be unable to develop a sufficiently detailed understanding of or partnership with large numbers of local services and community organisations, a role that is foreshadowed in the Discussion Paper.[7] For carers of people with a disability who do not qualify as an NDIS participant, the Regional Hub will serve as their primary source of information and advice for local supports available to them. It is essential that information, links and advice provided by the Regional Hubs is extensive and up-to-date for the carer's local geographic area.

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[5] Discussion Paper, pp 8-9
[6] Discussion Paper, p 31
[7] Discussion Paper, p 8

v) At present there are 54 Commonwealth Respite & Carelink Centres (CRCC's) which operate at a regional level across Australia.[8] Anglicare Sydney would be concerned about the ability of Regional Hubs to deliver what has been outlined in the Discussion Paper should an even smaller number of such hubs be established. Such concerns are heightened when the need to connect with Aboriginal and CALD carer groups is considered, as well as carers who have traditionally been difficult to reach, such as ageing parent carers of people with a disability.

w) The Discussion Paper also envisages that supports such as emergency and short term respite would *leverage existing community care relationships and infrastructure.*[9] The service delivery model appears to rely upon maximising the use of existing local services and minimising the commencement of new local services. However it is not acknowledged in the Discussion Paper that many such carer support services will disappear as part of the withdrawal of program funding under the NDIS and consolidation of carer supports as part of the Carer Gateway, including CRCC's.[10] Therefore it is difficult for Anglicare Sydney to comment on how realistic this aspect of the service delivery model is likely to be in view of the changing service landscape at the local level.

4.2 Additional Service Requirements

4.2.1   Carer Access to an Independent Carer Support Coordinator

x) The draft service delivery model for the ICSS includes a wide range of proposed carer supports, such as access to information, education, peer support and mentoring. However Anglicare's observation is that carers often need a dedicated support worker who can assume the role of coordinating the various supports that a carer may need. The current ICSS design is largely built on the premise that the carer will assume the coordination role and understand how and where to access all the required supports after receiving information. That will indeed be the case for some carers accessing the service, but not for all those carrying out a primary caring role.

y) Anglicare's previous Support Coordination Program for ageing parent carers aged over 65 years caring for a person with a disability, utilised support workers to provide one-on-one, holistic assistance to carers. Support workers assisted carers by making them aware of services they may not have considered and by providing assistance to evaluate options and make decisions. A 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.

z) By comparison, Anglicare is concerned that the ICSS places the onus much more on carers to seek and arrange their own support. The Discussion Paper envisages that the Regional Hub will provide carers with *short term assistance to navigate, coordinate and access other supports,* by phone or on-line.[11] Anglicare's view is that this level of support will prove to be inadequate, especially for those carers under considerable strain or caring for a person

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[8] https://www.google.com/maps/d/viewer?mid=1IousbOO_6LlnOhd3r92qvj1R388&hl=en&ll=-36.46842594980774%2C146.4356306171876&z=6
[9] Discussion Paper, p 9
[10] https://www.dss.gov.au/our-responsibilities/disability-and-carers/overview/frequently-asked-questions-national-carer-gateway
[11] Discussion Paper, p 11

with complex needs. Carers are often so emotionally and physically impacted by the caring role that they are unable to research or make contact with service providers when they cannot navigate the path easily. Furthermore, some CALD carers have English as a second language and may have low levels of literacy or internet skills; some indeed have a disability themselves which makes independent coordination a challenge.

aa) There is a great risk that carers will be left behind unless the new integrated system provides the option of one-on-one, holistic support. A Support Coordinator would be expected to:

- Assess needs and identify, manage and coordinate supports;

- Build trusting relationships;

- Provide individualised supports as required.

bb) **Assess needs and identify, manage and coordinate supports:** Anglicare has observed that carers have a tendency to underestimate the time, nature and intensity of their caregiving role. The Coordinator is able to provide an objective assessment of the carer's duties and supports needed to assist them to carry out their role. Some carers would have more insight into their care needs than others, and be adequately assisted by self-identification of needs through a tool such as the Carer Support Needs Assessment Tool (CSNAT). 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.

cc) **Build trusting relationships:** Anglicare has observed the importance of support workers building trusting relationships with long-term carers, who were sometimes reluctant to allow support staff into the caring context after being the primary or one of the main caregivers over decades. In such circumstances, it may be difficult for carers to connect with and access services that have not been fostered through a Support Co-ordinator who has built the relationship and trust with the caregiver, care recipient and family. Wherever possible, carers should have ongoing access to the same support worker to facilitate the development of an open and trusting relationship.

dd) **Provide individualised supports as required:** Supports should include transition planning, crisis and emergency planning, goal setting and life administration (eg will preparation). The proposed range of supports in the ICSS is not as detailed as those currently included in block-funded carer support programs. 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 NDIS.

ee) Anglicare recommends that carers have access to and an option to appoint an Independent Carer Support Coordinator as part of the services available through the ICSS. Carers should be informed of this option when accessing the Carer Gateway and other supports in the ICSS.

4.2.2   Carer Access to Respite Services

ff) The draft service model refers to three kinds of respite: emergency, short-term and planned. Emergency respite can be activated by calling the Regional Hub, following a predetermined emergency care plan where possible. Short-term respite is provided to permit involvement in ICSS education sessions, coaching and mentoring, or a peer support event.[12] Planned respite is currently funded through programs outside the carer programs delivered by the Department. It is assumed under the service model that these funding arrangements would remain unchanged in the future.[13]

gg) Data obtained from clients accessing Anglicare carer programs indicates a significant improvement in subjective wellbeing scores, a finding which is supported by current national and international literature on the benefits of respite.[14] Anglicare's experience has been that carers consistently report that appropriately delivered and timed respite helps them carry on their caregiving role.

hh) Anglicare Sydney is concerned with the limited scope of respite provision under the proposed ICSS. As mentioned above, respite through the ICSS will be limited to emergencies and to allow time off for carers to attend ICSS programs. This approach ignores the fact that respite helps carers by relieving their caring burden and supporting them to continue in their role, thus compromising the effectiveness of other supports that will be available to carers under the scheme. Anglicare Sydney's view is that the ICSS does not adequately acknowledge the benefits that respite provides for carers.

ii) Carers of NDIS participants have varying experiences of respite supports in the package.[15] The NDIS aims to consider the health and wellbeing of the carer in the planning of supports, and views the participant's plan directly and indirectly benefitting the carer through the provision of services for the person with a disability.[16] While the provision of an NDIS plan for the person with a disability may provide a respite effect for carers, the approach towards carers under the NDIS is a significant change, since the carer will no longer be able to have a say in when and where the respite takes place, resulting in a loss of choice for the carer.

jj) Anglicare Sydney has particular concerns for carers and care recipients in the following cohorts:

- Complex or dual diagnoses requiring specialised support - where carers may have had negative experiences of respite;
- Mental health disorders and high functioning autism - where the participant views the carer's role differently to that of the carer, resulting in planned supports that do not accurately reflect the caregiving role and necessary respite;

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[12] Discussion paper, p27
[13] Discussion Paper, p 15
[14] Kemp, B, King, S, Paleologos, Z, Bellamy, J & Mollenhauer, J, 2016, *Carers: Doing It Tough, Doing It Well*, Anglicare Sydney: Baulkham Hills, 2016, pp 37-39.
[15] Kemp, et al , pp 40-41.
[16] NDIS 2016, *Information for Families and Carers* https://www.ndis.gov.au/families-carers/information-families-and-carers.html

- People with a disability who do not qualify for an NDIS package and the carer does not receive the benefits of any formal supports for the person with a disability; and
- Cases where the carer and care recipient hold different views on the nature and intensity of the caregiving role, resulting in planned supports that do not accurately reflect the caregiving role and necessary respite.

kk) Anglicare recommends that carers have access to and options to take up flexible respite services as part of the services available through the Integrated Carer Support Service. Respite services should be:

- Available as a stand-alone service as well as part of a multi-component service;
- Responsive and easily adaptable to individual and changing circumstances;
- Available in the home and for extended periods out-of-home;
- Available at planned and regular occasions as well as in emergency situations;
- Promoted to carers when they access the Carer Gateway and other supports in the Integrated Carer Support Service, such as the education and information streams; and
- Promoted as beneficial for carers' wellbeing and capacity to sustain the caregiving role.

4.2.3   Carer Access to Funded Social Supports

ll) The proposed ICSS will include peer support to assist carers to connect with other carers at the local level. An on-line peer support group finder will be available at the national level.[17]

mm) Anglicare has observed that social support and help to increase social contacts have formed an important part of its carer programs, providing both carers and care recipients with opportunities to connect with others through a variety of social activities. Various studies have documented the isolating effects of prolonged caring. Hayes and colleagues found the group of carers that they studied to be ten times more likely to be socially isolated than the general population.[18] Other studies point to decreased levels of social support and social participation with increasing hours per week of caring duties.[19] These findings point to the significance of social programs in contributing to the wellbeing of carers.

nn) Anglicare's programs conducted activities that benefited both the carer and the care recipient, as respite care or activities were often provided for the person with a disability whilst the carer engaged with other carers in a social setting. The programs offered specific activities for carers such as friendship and hobby groups (eg. gardening or craft), regular carer support groups (eg. meeting for a coffee every fortnight), and weekend retreats. The weekend or short getaways were particularly useful for carers, as they had an opportunity

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[17] Discussion Paper, p19

[18] Hayes, L, Hawthorne, G, Farhall, J, O'Hanlon, B & Harvey, C, 2016, 'Quality of life and social isolation among caregivers of adults with schizophrenia: policy and outcomes' *Community Mental Health Journal,* 51, 591-597.

[19] Rodger, D, O'Neill, M & Nugent, L, 2015, 'Informal carers' experiences of caring for older adults at home: a phenomenological study', *British Journal of Community Nursing,* 20(6), 280-285 and Carers NSW, Carer Survey: Main Report,
http://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202014%20Carer%20Survey%20Main%20Report.pdf

for respite, connecting with other carers and relationship building, relaxation, as well as education and information sessions on issues such as transition planning and financial matters.

oo) Anglicare support workers reported that events such as these provided them with an informal opportunity to help build trust and relationship with carers outside of the more formal context of carer services. Staff also highlighted the importance of these events for 'hidden carers' in building relationships and trust with case managers and other carers, who had been in their caring role for decades prior to being connected with formal support and meeting other carers.

pp) Anglicare is concerned that there will be a significant loss of the social and peer support provided for carers when funding for these block-funded carer programs ceases. It is anticipated that the ICSS Peer Support service may facilitate some of these activities, however there is little detail as to the depth of these activities and how these supports will be offered and organised.

qq) For carers in an intensive caring role with minimal familial and social supports already in place, the social supports provided through Anglicare's programs were organised and made possible for carers, at the very least as an initial event. The logistics of organising, say, a weekend retreat may be too burdensome for a primary carer to consider undertaking. Similarly, anecdotal reports from staff revealed that carers were interested and willing to meet up regularly with other carers as part of social support groups, but usually need at least the initial organisation and connections facilitated by staff. In addition some ageing parent carers had no access to private or public transport and Anglicare staff arranged for transport for them to attend regular social support groups with other ageing parent carers.

rr) Anglicare recommends that the Integrated Carer Support Service provide funding for appropriately qualified and experienced organisations to run social support programs specifically designed to support carers in their caregiving role.

4.2.4 Carer Access to Emergency and Crisis Funding

ss) The proposed ICSS provides for carers to set up an emergency care plan on the website, so that the Regional Hub can look after the care recipient in the event that something happens to the carer.[20] This option 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. As part of registration, the Gateway could record the details of emergency contacts and send out information to inform them of the Carer Gateway and their role as an emergency contact. However, the process of planning an emergency or crisis contingency may involve a guided and holistic consideration of several factors which could be facilitated by an Independent Carer Support Coordinator, as recommended above.

tt) Some carers may only instigate contact with the Carer Gateway at the time of an emergency, and may have no prior plans or contingencies. Historically, the NSW Government's Ageing, Disability and Home Care Services (ADHC) provided a last port of call or safety net in such circumstances. With the devolution of ADHC and outsourcing of

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[20] Discussion Paper, p27

its services, there is a significant gap in the provision of a safety net for carers and people with a disability when one of them is in crisis and in particular when the carer cannot carry out their caring role for a short period of time or indefinitely. There is a lack of a safety net for carers and people with a disability when one of them is in crisis.

uu) 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.

vv) Anglicare is concerned that carers may not be professionally guided and assisted in the preparation of an emergency plan, understand their need for such a plan, and then encounter difficulties accessing emergency assistance in a crisis situation. The ICSS should cover: the supports required for the understanding and awareness of emergency plans; registration of plans; and the timely co-ordination of and delivery of the supports required to carry out the emergency plan (including respite, accommodation etc).

ww) Anglicare recommends that carers have access to and options to take up support with emergency planning, registration and reasonable and necessary services required to implement the plan.

4.2.5   Carer Involvement in Planning

xx) It remains essential that the person with the disability be given the choice and control in the planning of their NDIS package. Anglicare Sydney has concerns about some carers not having appropriate input into the participant's planning process (where the participant chooses to have their carer included). Where differences exist between the carer and care recipient in the nature and intensity of the caring role, unintended deficiencies may arise in the participant's plan that adversely impact both the care recipient and the carer. For example, a care recipient may include their carer in the planning process, but not raise in the discussions the magnitude of the caring role given their perspective of their needs and the nature of the familial relationship. In such circumstances, the needs of the person with a disability may not be properly assessed and addressed. It is therefore essential that Local Area Coordinators and those advising carers appropriately include the voice and experience of the carer in the process, whilst prioritising the desires of the participant.

yy) Anglicare recommends that the education, information and awareness components of the ICSS and the Local Area Coordinators in the NDIS include accessible information for carers regarding their involvement in the participant's planning and their opportunity to provide a Carer's Statement.

4.3 Responses to Discussion Questions

zz) The Discussion Paper included a small set of discussion questions at pages 15 and 28. Responses to some of these questions are included in the body of this submission. Responses to additional questions are covered below.

4.3.1 Gap Analysis

aaa) The Discussion Paper asked: *A key factor in the effectiveness of regional hubs will rely upon their ability to understand the local service landscape and identify service gaps. If you were operating a regional hub, how would you undertake the service mapping for your region?*

bbb) Gap analysis requires an understanding of both the demand for a service and the supply of that service. In terms of demand, a primary source of data would be regional and local demographic statistics obtained from the Australian Bureau of Statistics, to establish likely levels of demand for carer services as well as the presence of special groups (eg. CALD groups, Aboriginal and Torres Strait Islanders). State and Local Government strategic and regional plans would point to the need for additional services in areas of new land release or higher density residential development.

ccc) In terms of supply, service directories, network meetings and Local Government directory information would assist in establishing the existence of various services. Public Health Network and Local Health District statistics and service directories, to determine client and carer numbers.

ddd) The Discussion paper asked: *How would you ensure that you have captured a complete view of the available supports for carers in your region?*

eee) Beyond the sources already named would require consultation with local services. Apart from service-by-service contact, this could be achieved through network meetings, surveys and feedback forms.

4.3.2 Outcomes Measurement

fff) The Discussion paper asked: *It has been identified that outcomes measurement will be essential for a future model. Outcomes measurement involves identifying how effective services are in achieving a particular objective. This commonly takes the form of a questionnaire which helps to assess aspects of the carer's role. However, there will be a careful balance in measuring outcomes, whilst not placing undue burden on a carer to answer multiple questionnaires, particularly where they may be accessing more than one service. What are some ways that outcomes could be measured and these issues addressed?*

ggg) A first step is in defining short, medium and long-term carer outcomes to which the ICSS would hope to make a contribution through the range of services deployed. Such outcomes will vary depending upon the cohort of carers under consideration (eg. young carers, ageing parent carers). A helpful tool in outcomes identification is the Program Logic Model, which also includes identification of theories of change which underpin the various

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services being offered. The participation of carers is essential in the design of the evaluation including outcomes identification.

hhh)The issue of carer burden is clearly in view in the discussion question. However the potentially large numbers of carers using the ICSS lends itself to the drawing of scientific samples of carers, leading to the creation of panels of carers. Carers in the panel may be asked to fill in an entry survey at the commencement of the service, then further evaluation surveys in subsequent years. Surveys would include the use of reliable and valid scales to measure aspects such as subjective wellbeing, independence, health and mobility and social participation. The creation of matched samples of carers would provide robust data in seeking to evaluate the contribution of various parts of the ICSS to overall carer well-being. Anglicare Sydney used a similar approach in evaluating its carer programs.[21] Our experience was that carers are prepared to assist in completing survey forms where they understand the purpose to be in evaluating and improving the service itself.

iii) Other methods that require the direct involvement of some carers in providing information include:

- National sample surveys of carers. Again these involve a scientifically drawn sample. It would be expected that such surveys would provide limited information on carer outcomes, but a broader range of measures of carer satisfaction with and perceived impact of the ICSS;

- Focus groups and interviews covering specific issues around ICSS processes and exploration of the carer role.

jjj) There are also a range of opportunities for gathering information through ICSS administrative processes, which do not involve further carer participation. These include:

- Peer support worker feedback;
- Setting KPI's;
- Service delivery Logs;
- Complaints registers;
- Care Plan reviews – measuring uptake or re-entry into the service;
- Organisation statistics that measure, type and times of service provision;
- Service turnaround times;
- Levels of carers retaining employment or returning to employment due to intervention;
- Government reporting systems (eg: DSS Data Exchange).

4.3.3   Quality Framework

kkk)The Discussion paper asked: *While this model will seek to help more carers, it will be important to ensure that quality services are being delivered. What would you view as the essential components of a future quality framework?*

lll) Essential components of a future quality framework would include:

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[21] Kemp, et al, 2016, pp 17-39

- **Development of a Program Logic Model** (PLM), with well-defined client outcomes.
- **Development of Operational Guidelines**, which are clear and concise, and are tightly aligned with the National Standards for Disability Services, or AACQA Home Care Standards, if possible.
- **Development of a Quality Model** (QM), defining a comprehensive suite of client outcomes indicators and service performance metrics, derived from the PLM, from the Operational Guidelines, and from existing elements of the DSS Data Exchange Framework. Ideally this would include an 'opt-in' extension to DSS DEX that captures elements of client experience that relate to the QM, as an improvement to the existing generic questions about client satisfaction.
- **Continuous monitoring of client demographics, client need and service outputs**, as per existing DSS Data Exchange Framework "priority requirements".
- **Continuous monitoring of generic client outcomes**, as per existing DSS Data Exchange Framework partnerships approach "extended data requirements".
- **Continuous monitoring of specific performance metrics**, as defined in the QM, especially including measures of client experience, to be included in the "extended data requirements".
- **Evaluation of services**, with a focus on validating client outcomes and theory of change, as per the Program Logic Model, with secondary consideration to fidelity of process/ implementation. This could be undertaken by a peak body in affiliation with a university. Ideally at the end of the first year of ICSS implementation, with 3-yearly follow-up.
- **Establishment of Client and Community Reference Groups**, around Regional Hubs, with a yearly review mechanism in place to ensure that services are appropriate and adequate for the needs of local community.
- **Development of an audit mechanism** to ensure consistent and faithful implementation of the service model across all providers, and to exercise appropriate governance.

5. Conclusion

mmm) Anglicare Sydney appreciates the opportunity of participating in this consultation process and trusts that this submission will be of assistance in shaping the final ICSS service model and suite of service provision.

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