**Submission to the Department of Social Services (DSS)
on Delivering an Integrated Carer Support Service**

December 2016

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

For information contact:

Ms Ara Cresswell

Chief Executive Officer

Carers Australia

Unit 1, 16 Napier Close

DEAKIN ACT 2600

Telephone: 02 6122 9900

Facsimile: 02 6122 9999

Email: acresswell@carersaustralia.com.au

Website: www.carersaustralia.com.au

Introduction

This Carers Australia submission has been prepared with input from our National Network of Carers Associations ('the Network') which is made up of Carers Australia and the state and territory Carers Associations. The Network works collaboratively to lead change and action for carers across Australia. Our shared vision is an Australia that values and supports all family and friend carers.

The comments below reflect the input of all members of the Network which, in turn, reflects broader consultation with stakeholders.

Some general comments

On balance, most members of the Network were generally positive about the model, citing its comprehensiveness and its potential to reach more carers with more equitable service offerings across the board. However all Associations in our Network also identified a number of areas requiring greater clarification and thought, apparent service gaps and evident risks. Others had concerns about the extent to which it would reduce and "bureaucratise" carer engagement and the extent to which it could cater for different carer journeys.

One thing we would like to stress is that, no matter how appealing the model might be in theory, its success or failure will depend on the adequacy of funding (including for transition arrangements), the reach of the regional hubs, and the continuation of services not covered by the ICSS. These issues, along with others, are explored in more detail below.

We have already had the opportunity to comment on the service model in our response to the first Discussion Paper on the *Draft Service Concept*[1] and through our engagement with the Carer Gateway Advisory Group and the Subject Matter Expert Group (SME) on the Integrated Carer Support Services Project. We are pleased that many of our concerns and recommendations have been incorporated into this Discussion Paper.

Rather than working systematically through each section of the paper and providing commentary on each issue or proposal, we have chosen to structure this response around the following headings:

- Service architecture and delivery
- Quality Framework

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[1] Carers Australia, Submission to the Department of Social Services Draft Service Concept 'Designing the new integrated carer support service', May 2016, http://www.carersaustralia.com.au/storage/carers-australia-response-to-integrated-carer-support-design-concept-discussion-paper.pdf

- Ambiguities in relation to some services
- Apparent gaps in service delivery
- Uncertainties and risks to be addressed

There are some unavoidable overlaps between these themes, but we have tried to minimise them to the extent possible, sometimes through cross-referencing.

Where we have no difficulties with the Discussion Paper we have not provided comment.

Where comments are in answer to specific questions identified in the Discussion Paper, they have been highlighted in blue in the text.

1. Service Architecture and Delivery

The Discussion Paper poses the following questions:

In relation to the program overview, do you believe that the objectives, outcomes and delivery principles are appropriate for the services required to be delivered under each program? Do you believe that the services proposed to be delivered at the national, regional and local level are targeted appropriately?

Objectives

The Discussion Paper outlines the objectives of the integrated carer support service model as follows:
- proactively support carers earlier, and build their capacity to sustain their caring role;
- provide support where carers are in, or at risk of a crisis, which might adversely affect their caring role;
- provide support for carers to improve their long term social and financial outcomes; and
- support carers to participate in everyday activities such as education and the workforce.

The Carers Network is of the opinion that throughout the Discussion Paper there is too much emphasis on the sustainability of the care relationship and not enough on outcomes for carers to support them in their own right regardless of the sustainability of that relationship. Outcomes which deserve more attention include wellness and re-ablement and the recognition that services such as counselling, respite, coaching and mentoring, and peer support may well result in carers choosing not to continue in their caring role. If this is the

outcome of these services in some cases, the intervention should not be regarded as a failure.

Service Architecture

National Level

Comments in relation to services delivered at the national level of service provision include:

- A strong emphasis on the need to link the national infrastructure through to the new Digital Mental Health Gateway, the NDIS Myplace Participant Portal and My Aged Care, as well as to the Department of Human Services in relation to social welfare inquiries.

- With the carer's permission, there is an opportunity for the creation of digital carer accounts to be maximised by linking them into myGov, My Aged Care and the NDIS portal.

- There are concerns about many carers' ability to access digital services. These concerns and supporting evidence are dealt with in Section 5 (*Uncertainties and Risks to be Addressed*).

- With respect to the provision of the self-assessment and support tools (e.g. available through an app or mobile website), Carers Australia can see benefits for some carers, especially for those who are not at a stage where they want to contact service providers. However, there are some risks to self-assessment which we explore under Section 5 below (*Uncertainties and Risks to be Addressed*).

Regional Hubs

The number and composition of regional hubs

While we have no particular problems with the range of activities and services designated to the regional hubs, a key issue which is not dealt with in the Discussion Paper is the number and geographical coverage of these hubs and their resourcing. Our continuing support for the regional hub concept will be largely dependent on whether we believe the delineation of hubs and the resources available to them is fit-for-purpose and will address the objectives of improved and equitable service delivery for carers across Australia.

In this context, we will be taking into account the number and diversity of carers to be serviced through each hub, the distances covered and population dispersal within each hub,

and the very long list of activities they will be required to undertake within the funding package available to them. The funding of Regional Hubs is explored further below in Section 5 *Uncertainties and Risks to be Addressed*.

With respect to the number of hubs required, Associations have identified some merit in aligning them with other regional centres which have some responsibility for services to carers and the people they care for. This would include consideration of the following:

- Aged care planning regions
- NDIS regions
- PHN regions

However, we are certainly not suggesting that the ICSS regional hubs completely mirror any of these other regional divisions, bearing in mind that the customer base for aged care, NDIS and PHNs is larger than for carer services and that there are currently 63 NDIS regions identified and 73 aged care planning regions.

Staffing of Regional Hubs

In relation to staffing, the Discussion Paper notes that support services are most effective when teams include staff from different backgrounds. It is also suggested that staff with basic qualifications (e.g. Certificate III in Disability, Community Care, etc.) and relevant experience should be recruited to the hubs and that each hub should have a clinically trained staff member, such as a counsellor or social worker, to provide a clinical skillset which can be drawn on (pp. 30-31).

Feedback from our Associations includes the following:

- Staff at Certificate III level typically have factual, technical and procedural knowledge of a specific area of work and the skill level to complete routine activities and provide solutions to predictable problems.[2] . Given the diversity of service activities (including building connections to other services and communities) to be undertaken by hub, and given the diversity and complexity of both the problems and needs that many carers engaging with the hubs will present with, many staff will need higher levels of training and qualifications than that provided by a Certificate III.

- Feedback from carers to the Discussion Paper on the *Draft Service Concept* indicated a strong preference to engage staff with lived experience of caring. Carers Australia supports this preference, while acknowledging that in some cases it may be difficult to recruit staff with lived experience in relation to some jobs which require particular

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[2]Australian Qualifications Framework, AQF specification for the
Certificate II, http://www.aqf.edu.au/wp-content/uploads/2013/05/5AQF_Certificate-III.pdf

qualifications and experience. Having said that, all Associations in the Carers Network employ a large number of current carers and previous carers, ranging from 40% to just under 80% of staff.

- The inclusion of <u>one</u> clinically trained staff member in each hub was thought to be puzzling and somewhat random.

Local Level

The delivery of services at the local level is of real concern, particularly to the extent that a number of these services are not funded under the integrated carer support service delivery model. These include:

- Information and advice (which is to be provided by "existing", unspecified services);
- Some counselling services
- Face-to-face education and training; and
- Planned respite to be provided through aged care and the NDIS.

Our concerns are around:

- The extent to which these existing services funded by other unidentified government programs (both state and national) actually do exist in many localities, particularly in regional and remote areas of Australia, is highly variable.

- Many of the services provided at the local level are currently provided by CRCCs and other carer service organisations which are to a large extent dependent on continuing funding from national carer programs which, under the new model, will be used to fund the regional hubs. In many localities these organisations will have to close their doors if the integrated carer support services model is introduced.

- With respect to planned respite, access to respite through aged care and the NDIS is highly problematic and not available at all to carers of people who are not eligible for the replacement care opportunities available through these two systems. Further explanation and discussion of these concerns can be found below under Section 4 *Apparent gaps in service delivery*.

Comments on the delivery of specific services and activities identified in the Discussion Paper

<u>Education and Training</u>

The objectives, outcomes and principles of this initiative to build carer capacity, skills and resilience to maintain their caring role seem well considered. Educational provision should include: programs for navigating service systems, self-care such as managing stress and anxiety, and practical skills such as medication and wound management. It should also expand to include education on:

- care succession/life-stage planning (for example, future housing and support for the person receiving care)
- carers and the law (for example, support for decision making, Powers of Attorney, administration and guardianship, wills and what to do after the death of the person you care for)
- carers and their rights (including such rights as sexual/reproductive health rights, residential tenancy rights, consumer rights and making complaints)
- financial/money management skills.

These education programs should be developed in partnership with state and territory service providers. Consideration should be given to providing sufficient resources in the model to achieve and maintain Registered Training Organisation (RTO) status nationally in order to deliver nationally accredited units of competency.

One concern is that the only specified workforce linkages under this program are in a care-related field. While some current and former carers may wish to work in a care-related field, many carers will have experience, aspirations and skills that align with other occupational fields. Carers should be supported to gain qualifications in a field of their choosing, whether this is a care-related occupation or not.

These services should be adequately resourced, and any fee-for-service arrangements should ensure no carers are disadvantaged in gaining access to education services due to incapacity to pay.

Other comments in relation to education and training include:

- The need to exercise quality control in relation to the online catalogue of programs available.
- The Young Carer Bursary Program should continue to be delivered on a national basis to support young carers most in need, regardless of where they live.

<u>Peer Support</u>

The range of options and opportunities for peer support at all levels is welcome. With respect to peer support funding through the regional hubs, it needs to be recognised that this is not just a matter of providing some funding for local level peer support and moving on. Peer support activities need start-up funding, facilitator/leader training, advice and information, monitoring for effectiveness and sustainability, and re-establishment where they have discontinued. Peer support should not be regarded as a minimal investment activity.

<u>Counselling</u>

We are pleased to note that this Discussion Paper appears to be responsive to criticisms of the initial *Draft Service Concept* Discussion Paper, which focused on Cognitive Behavioural Therapy (CBT) in the counselling space. In this Discussion Paper different models of counselling are encompassed by the general term "therapeutic counselling" (including family and group therapeutic counselling). The inclusion of practical advice and problem solving counselling support as well as motivational counselling is also welcome.

We are also pleased to note that both online and face-to-face counselling will be available under the model, although there is some concern and confusion about how face-to-face counselling will be accessed and paid for at the local level (see Section 3 below on *Ambiguities in relation to some services*)

Where concerns about counselling have been expressed they relate to:

- The need to provide adequate funding for the different types of counselling services and that any fee-for-service arrangements should ensure no carers are disadvantaged in their access to counselling services due to incapacity to pay (noting that both free and fee-for service counselling are mentioned in the Discussion Paper).

- Where carers are referred to non-carer specific counselling services there is concern that those providing these services will have an insufficient understanding of the consequences of caring and specific issues facing carers.

<u>Needs Assessment and Planning</u>

Our understanding is that a common needs assessment and planning tool will be developed by the Department for across-the-board application. Experience with the aged care Regional Assessment Services (RAS) and NDIS participant planning highlights that this tool and the way in which it is delivered will need to be honed to be user-friendly and sensitive to some

groups of carers including Aboriginal and Torres Strait Islanders, CALD communities, LGBTIQ people, carers with poor literacy, and carers with disabilities relating to communications and decision-making capacity. Importantly, translation services needed to undertake these activities need to be funded.

Coaching and Mentoring

Exactly what coaching and mentoring involves, the expertise and training of those who deliver it, and how it might relate to advocacy is confusing. Consequently this service is discussed under Section 3 (*Ambiguities in relation to some services*).

Outcomes measurement through Regional Hubs

The Discussion Paper poses the following questions in relation to Outcomes Measurement:

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?

Carers Australia received a range of inputs from the Network in relation to outcomes measurement.

Key points are:

- As opposed to collecting outcomes data from the entire group of carers accessing services, targeted, representative client panels can be selected from among willing participants to assess the effectiveness of interventions. This would counter 'feedback fatigue' and would also substantially increase the quality of data. It would also assist in refining interventions based on the results. Approaches to such outcomes measurement can be sourced from a number of peer reviewed models. For example, one of these evidence-based outcome measurements is the Australian Wellbeing Index that has identified lasting improvements in wellbeing among carers who access carer-focused counselling.[3] Other evidence-based tools include the UK Adult Social Care Outcomes Framework (ASCOF)[4] which measures how well care and support services achieve the outcomes that matter most to people. This framework and toolkit includes measurement of specific outcomes for carers and for members of diverse communities. Another model is the Scottish Talking Points Framework

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[3] Cummins, Robert A., Campbell, Peter, Rechner, Ruth and Hammond, Thomas 2011, Carers counselling intervention study Deakin University, Geelong, Vic. http://dro.deakin.edu.au/view/DU:30042969

[4] https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016

which includes quality of life outcomes, process outcomes and change outcomes. Further information on the use of these models in the carer space can be found in a 2016 report by La Trobe University on HACC Active Service Model Client and Carer Outcomes and Measurement Tools. In considering whether to use these tools in the context of responses from a selected panel, there may be some legitimate concerns around the bias of volunteer representatives and how large these panels would have to be to be representative. However data generated through a validated tool, regardless of whether this is collected through select panels or wider-based client surveys, is an excellent approach to outcome evaluations.

- In evaluating outcomes of services, it is important to note that the best interests of carers should be fundamental to the desired outcomes, even where this may mean relinquishing the caring role.

Service mapping through Regional Hubs

The Discussion Paper poses the following questions:

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 service mapping[5] for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?

Service mapping of both carer specific support and other services of benefit to carers will obviously be an important role of the regional hubs.

We would suggest using a multi-pronged approach to local service mapping which would include using:
- Local service provider networks
- Employing local staff who know the region well
- Conducting a significant local awareness raising campaign using a range of approaches.

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[5] Service mapping refers to an analysis of available services within a given region, including the types of services available, their coverage areas and eligible persons.

The example from Victoria, demonstrates that Carer Associations are aware of how critically important it is to understand the types of services and eligibility criteria for them in their states and territories. However, the definition of service mapping is too narrow in the draft service concept. The regional hubs should also be required to develop comprehensive understanding of the demographic make-up of carers in their region, to highlight high risk cohorts that are not presently engaged with services. This will better equip services to identify carers not presently receiving services and encouraging them to seek support and services earlier in their caring journey, rather than engaging at a point of crisis.

There is a wealth of existing demographic data from various sources which can be broken down by Local Government Areas (LGAs) which regional hubs can use to identify carers in their catchment areas, by age, gender, carers born overseas, Aboriginal and Torres Strait

Islander background, condition of the care receiver and in receipt of social welfare. This includes Australian Bureau of Statistics data from the Survey of Disability, Ageing and Carers, and the Census. The Department of Human Services (DHS) also provides a range of demographic data by a range of geographical locations which can be interrogated to obtain a profile of carers in particular hubs. To the best of our knowledge, there is not a similarly comprehensive national data-base currently available for people in same-sex relationships

Mapping of these demographics will help to highlight those groups who require targeting because they do not identify themselves as carers, or they are not engaged in current services because available services are insufficiently culturally sensitive.

We suggest that minimum data collection standards will need to be developed as a part of service agreements. Where the Australian government is not a party to the service agreement, collaboration should be sought from other State or Territory governments or other parties to ensure consistent minimum data standards.

2. Quality Framework

The Discussion Paper poses the following questions in relation to a quality framework:
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?

As a starting point, the Statement for Australia's Carers contained in the *Carer Recognition Act 2010*[6] provides excellent guidance on best practice in carer support.

Essential components of a future quality framework should emphasise the rights of carers as the consumers of integrated carer support services and consider existing quality and accreditation standards. For example, the South Australian Department for Communities and Social Inclusion's Australian Service Excellence Standards (ASES) is an internationally accredited quality improvement program aimed at supporting non-government organisations (NGOs) in the Community Services Sector across Australia.

We also recommend Carers Australia's *National Network of Carers Associations Good Practice Guide* (2012)[7] which covers:
- Carer centred service delivery
- Rights and participation of carers as clients
- Working with specific carer populations

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[6] Commonwealth Carers Recognition Act 2010, Part 2, http://www.austlii.edu.au/au/legis/cth/num_act/cra2010179/

[7] Available from Carers Australia

- Community influence and service system change
- Leadership and governance
- Organisation management.

A national quality framework must include consideration of different state and territory laws; for example, legislation to protect vulnerable children, occupational health and safety and Powers of Attorney and Guardianship are different in different jurisdictions. Other important features of a quality framework include:

- Safety (for example, family violence, OH&S)
- Key operational requirements of regional hubs
- Monitoring of the shared carer record
- Complaints monitoring
- Review processes
- Evaluation of interventions
- Collaboration across local, state and federal governments as well as other sectors
- Access to respite, quality of respite
- Clinical governance for counselling

With respect to complaints, the Discussion Paper notes that: "Carers would also be able to submit complaints about any service, either directly to a national provider, a regional hub or DSS (p.34)." Some Associations have highlighted the need for an external independent mechanism for unresolved complaints. For example, NDIS complaints can be referred to the Administrative Appeals Tribunal (AAT).

3. Ambiguities in relation to some services

<u>Coaching and Mentors</u>

In the glossary to the Discussion Paper, coaching is described as: "A one-on-one support program, where a coach assists a carer to achieve specific goals through the provision of advice and education" (p.40). It is also noted regional hubs will provide governance of the carer coaching workforce. We would also assume that training of coaches and mentors would be a responsibility of the regional hubs. It is proposed that carers will be entitled to 6-10 week in-home or phone coaching and mentoring.

It is not clear:
- exactly what forms coaching and mentoring would take;

- the basis on which repeat coaching and mentoring services will be available to carers over time according to changing needs.

In particular, it is unclear the extent to which such coaching and mentoring is a replacement for the individual advocacy activities currently provided by carer service organisations through the Counselling, Support, Information and Advocacy (CSIA) Program or other sources of funding. According to the Department of Social Services website, CSIA services are currently provided by 54 government, non-government and community organisations.[8]

Current advocacy activities go beyond providing advice and education, which is the role identified for coaches and mentors. They may involve contacting and engaging with other organisations on behalf of a carer who is having difficulty engaging by themselves, or accompanying carers to meetings and forums where they need support and assistance. This type of advocacy support may be required on a one-off basis or a continuing but intermittent basis. It does not fit neatly into a 6-10 week program.

Targeted financial support (trial)

A very welcome element of the model is the trial of targeted financial support to assist carers to stay in education or enter the workforce. However the lack of detail in the Discussion Paper raises a number of issues and questions.

In particular, there are questions around the extent to which packages will be rationed on a somewhat arbitrary basis (as is the case in aged care Home Care Packages) and the degree to which the assessment of carer needs will be linked in any way to the level of funding available or whether all 'packages' will be of the same dollar value.

Associations also recommend consideration of targeted financial support to assist carers experiencing a financial crisis as a result of unexpected expenses associated with their caring role. An example of such a scheme is the Victorian Mental Health Carer Support Fund for reimbursement of costs incurred by the carer on behalf of the person for whom they care when they are unwell. These costs cannot be claimed through Department of Health concessions or other funding sources for carers. Currently only carers of people using public mental health services are eligible to apply.

It will be important that additional financial support provided to carers seeking employment and training does not impact on their entitlements to the Carer Payment, Carer Allowance and Carer Supplement. The support will need to be provided in such a way that it does not

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[8] Department of Social Services (DSS), www.dss.gov.au/disability-and-carers/programmes-services/for-carers/counselling-support-information-and-advocacy-carer-support-services

factor into means testing or be regarded as income for the purposes of tapering payments. In circumstances where carers are seeking educational and employment opportunities, the 25 hour rule for the Carer Payment which prevents a recipient from participating in employment, education and volunteering for more than 25 hours in any one week (including travel time) needs to be revisited by the Department of Social Services.

4. Apparent gaps in service delivery

The problem with respite

There is strong support across the Network for continued access by carers to emergency and short term respite and planned respite.

The importance of respite for carers was acknowledged in the DSS Discussion Paper on *Designing the New Integrated Carer Support Service*[9] and in responses to that consultation.

More recently the importance of respite to those who want and need it has also been explored in Carers NSW 2016 *National survey of carers respite needs.*[10]

However relying on access to planned respite through the NDIS and aged care residential care and home support evades the issue that neither of the NDIS or aged care, taken separately or together, provides a satisfactory or equitable level of opportunity for carers to access respite.

Many carers miss out on the opportunity to access planned respite because the person they care for is not eligible for aged care or NDIS support. Aged care provides access to respite support for consumers (as opposed to their carers) over the age of 65. The NDIS provides services to package participants (as opposed to their carers) under the age of 65. Even when the NDIS is fully rolled out, only about 430,000 people with disability will receive packages, leaving a great many people with significant impairments or disabilities who do not meet the eligibility criteria.

Even carers of NDIS package holders face barriers to accessing respite to meet their own needs in their own right. The rules covering NDIS operations make it clear carers are not participants within the NDIS. As the Plain English Guide to *Supports for Families and Carers under the NDIS* puts it, if carers and families have need of supports and services in their own

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[9] Department of Social Services,' Designing the new integrated carer support service' Discussion Paper, May 2016
[10] Carers NSW, National survey of carers respite needs, 2016,
http://www.carersnsw.org.au/Assets/Files/Respite%20Survey%20Report.pdf

right they are directed to find them through "other government programs".[11] A recent Carers ACT NDIS and Carers Survey analysis indicates that 80% of respondents were not offered services to support their caring roles, 57% indicated the participant's NDIS package did not include services that provided a break from caring, and only 18% indicated they had more time for themselves because of the participant's NDIS package.[12]

Meanwhile funding for respite services is being gradually transitioned to fund the NDIS. This includes the Mental Health Respite: Carer Support (MHR:CS) (which in 2014-15 supported some 40,644 carers), and the direct respite component of the Young Carers Respite and Information Services Program (YCRIS). Once the funding for these supports is transitioned into the NDIS, the supports they provide to carers will no longer be available either through the NDIS or outside the NDIS.

With respect to aged care, under the Commonwealth Home Support Program (CHSP) the consumer (care recipient) is referred to services through Regional Assessment Services (RAS). The National Screening and Assessment Form (NSAF) does include some fairly summary questions in relation to carers' needs which might result in a referral to carer services through an 1800 number. However, only a minority of carers are involved in RAS assessments[13]. Respite service providers also report very low numbers of referrals for flexible respite, centre-based respite and cottage respite from RAS, which affects their occupancy and meeting of performance targets. Respite in aged care facilities (both planned and emergency respite) is also becoming increasingly difficult to access, reportedly because providers are using short-term care placements for other purposes.[14]

The vexed issue of planned respite for carers is continually being deflected -from aged care and the NDIS to the proposed integrated carer support services initiative. The provision for respite in the ICSS Delivery Discussion Paper deflects it right back to NDIS and aged care.

Individual advocacy

As noted above, while coaches and mentors are included in the model, it is unclear that their role and the circumstances under which carers can access such supports encompasses the one-on-one advocacy support currently available to carers. If it doesn't, then the provision of individual advocacy is a gap in the proposed model. In this context it is important to note that carers have limited ability to access such advocacy through other systems in which they are likely to be engaged. The National Aged Care Advocacy Program (NACAP) and the

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[11] NDIA, Plain English Guide to Supports for Families and Carers under the NDIS, https://www.ndis.gov.au/families-carers/information-families-and-carers.html
[12] Survey findings not yet published
[13] AMR and Healthdirect Australia My Aged Care Stage Two Wave 1 Research Summary of Findings https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/10_2016/amr_my_aged_care_evaluation_summary_of_findings.pdf
[14] Carers Australia Submission to the Aged Care Legislated Review, 2 December 2016, http://www.carersaustralia.com.au/storage/carers-australia-submission-to-the-aged-care-legisled-review.pdf

National Disability Advocacy Program (NDAP) both have limited advocacy access by carers to take action on behalf of the people they care for and provide no advocacy support for carers to meet their own needs.

5. Uncertainties and Risks to be addressed

Funding

The Discussion Paper creates the impression that the only funding available to support the ICSS, with the exception of the National Infrastructure Program, is that which is currently available from existing DSS service programs for carers.

Even with savings which may come from streamlining the number of funded service providers through moving from CRCCs to a smaller number of regional hubs, it is hard to contemplate how existing funds (minus all the existing funding from Mental Health Respite: Carer Support Program and the direct respite component of the Young Carers Respite and Information Services Program) could be sufficient to adequately support the new model. Considerations include:

- If the Carer Gateway and the integrated carer support service model underneath it achieve their objectives of raising carer awareness of carer status and the services available to carers, it would be expected that there would be a significant increase in the demand for services.

- Regional hubs are charged with undertaking a large number of new activities, including new administrative and business modelling activities, and extra services have been added to the menu.

- It is important that funding of regional hubs takes into account factors such as remoteness of the location of carers as well as sustainability of services. Carers in outer regional and remote areas may need more flexible individual funding, greater dollars per head and distribution of block funding for outreach services. Interpretation costs should also be taken into consideration when considering funding allocation to regions with high concentrations of CALD residents.

- Funding will be required to help existing organisations and their clients to transition to the new model.

The impact of the ICSS on state and territory services

The model identifies that a number of services at the local level, will be provided by "other government programs". This broad assumption does not appear to be based on any mapping of what state and territory services are currently available to carers at the local level and where, let alone whether, such services would continue to be funded once the nationally funded ICSS was in place.

A number of local services such as information and advice and education and training are provided by nationally funded carer organisation, many of which will not be funded under the new model.

Nor can it be assumed that state and territory governments will step in or even maintain the carer services they are currently funding. Experience with both the NDIS and the aged care reforms have demonstrated that there is a tendency for states to withdraw from service delivery once a nationally funded reform has been introduced. Indeed, there are already signals that some cash-strapped state governments have identified that the introduction of ICSS will provide the potential for state budget savings.

The move toward more online delivery of services

Carers Australia and most of our Associations agree that there is scope for more "modernisation" of service delivery including greater scope for online engagement. Having said that, there is across-the-board concern that the model as it is proposed to be implemented may assume too high a level of digital access, knowledge and usage.

The Australian Digital Inclusion Index[15] shows that poorer people, older people, Indigenous people and people with a disability have levels of digital exclusion that is significantly above the national average. Surveys undertaken by state and territory carer associations reinforce the broad findings of this report in relation to carers. The Tasmanian Council of the Ageing's recent research project found that only 40% of the over 600 people surveyed used websites to access information. This decreased with age, with only 12% of 60 -74 year olds and 6% of 75 – 84 olds using websites. Problems survey participants raised were limited access to the internet, lack of familiarity, and problems with online instructions and forms. Such evidence needs due consideration in future planning of service delivery.[16] A 2015 Carers South

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[15] http://digitalinclusionindex.org.au/
[16] Council of the Ageing Tasmania (2015) *Finding Out – Supporting older people to access the right information at the right time*

Australia survey found that only 21% of respondents used websites specifically designed for carers and 77% of carers for the elderly had not used My Age Care.[17]

Given the large number of carers who are in the digitally disadvantaged cohorts identified in the Australian Digital Inclusion Index, the integrated carer support service must not have the impact of creating additional barriers to information and service access.

We note that in the Frequently Asked Questions section of the Discussion Paper which deals with digital service delivery, it is stated that:

> "[N]ot all carers will want to utilise digital support services. Alternate methods of contact and access will be provided for people where digital channels are not preferred or cannot be utilised" (p. 32).

While this proviso is welcome, we cannot emphasise strongly enough that the access issues identified for people using the My Aged Care and NDIS Myplace portals must not be repeated in integrated carer support services. We would like to see more emphasis on the 'no wrong door' principle, face to face contact and on the need for outreach to hidden groups of carers.

Carer Self-Assessment

As noted in our response to the first Discussion Paper on the *Draft Service Concept[18]*, self-assessment won't be appropriate for all carers including those who are new to the caring role and especially those who are in crisis. This group of carers may not have sufficient self-awareness or knowledge of potential supports. Another risk is that carers may underestimate the impact of the caring role on their life and may play down their own needs. An experienced assessor will be able to draw out a carer's true need for assistance.

Similarly, access to a multi-component intervention should not be through self-assessment, but a comprehensive needs assessment.

For these reasons, when carers first access the self-assessment tool it should be made clear to them that they may achieve a better outcome by seeking professional guidance (through a regional hub) and support in assessing their levels of stress, their needs and the means of addressing these in their particular situation.

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[17] Carers South Australia, Our Carers Our World, 2015, http://carers-sa.asn.au/Assets/Files/Carers%20SA%20Carers%20Survey%202015%20Summary%20Oct%202015.pdf

[18] Carers Australia, Submission to the Department of Social Services Draft Service Concept 'Designing the new integrated carer support service', May 2016, http://www.carersaustralia.com.au/storage/carers-australia-response-to-integrated-carer-support-design-concept-discussion-paper.pdf

It will also be important that the range of information available to carers is not limited to the types of services available for both the person they care for and themselves, but that it also covers how to navigate the various service systems. This may include information about the service responsibilities of different departments (e.g. health, disability, social security) or information on what services are offered by a range of service providers and how to gain access (for example, when a formal assessment is required). Information of this nature can help to build the capacity and confidence of carers in accessing supports.