

16 June 2016

Department of Social Services  
Disability, Carers Policy and Access Branch  
GPO Box 9820  
Canberra ACT 2601

***Designing the new integrated carer support service discussion paper and draft service concept***

Carers NSW welcomes the release of the discussion paper and draft service concept, *Designing the new integrated carer support service*. Amidst extensive national reform across the disability, aged care, mental health and health sectors, the development of an Integrated Carer Support Service (ICSS) comes at a critical time for carers and the organisations that support them.

Carers NSW is pleased to have the opportunity to contribute to the development of the new national carer support system. Better integrated carer supports that sit alongside other service systems and build on existing best practice to meet the needs of more carers will be critical in ensuring that carers can continue to care and maintain their own wellbeing.

As part of the National Network of Carer Associations we have contributed to and strongly endorse the submission developed by Carers Australia. We also wish to provide some additional comments which reflect a NSW perspective. This submission focuses on the importance of evaluation, integration and innovation, drawing on our experience as a peak organisation and service provider supporting carers across NSW.

Thank you for accepting our submission. Please do not hesitate to contact me on (02) 9280 4744 or at [elenak@carersnsw.org.au](mailto:elenak@carersnsw.org.au) should you have any questions regarding our response.

Yours sincerely,



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## **Carers NSW submission to the Department of Social Services discussion paper and draft service concept, *Designing the new integrated carer support service***

### **Background**

Carers NSW is the peak organisation for carers in NSW and a member of the National Network of Carer Associations. We receive funding from the NSW and Australian governments to deliver a range of services and programs. Support types that Carers NSW delivers include, but are not limited to: information, advice and referral; carer counselling; education and training; peer support; support coordination; and systemic advocacy.

Our vision is an Australia that values and supports all carers. Our goals are to work with carers to improve their health, wellbeing, resilience and financial security and to have caring recognised as a shared responsibility of family, community and government. Carers NSW believes the new Integrated Carer Support Service (ICSS) has the potential to maintain and increase the support received by many carers already engaged with the carer support system, and to extend support to hidden carers that either do not self-identify as carers or are not currently accessing formal support.

In order for these outcomes to be achieved, we believe that the ICSS must embed thorough evaluation, promote genuine and comprehensive integration and build upon innovative service approaches. This submission outlines key points and examples in relation to these themes drawn from our experience as a peak organisation and service provider for carers in NSW.

### **General comments**

*Designing the new integrated carer support service* discussion paper and draft service concept (the paper) is a clear overview of the need to better support all carers, the existing carer supports available to Australian carers, and the broader context in which carer support is delivered.

We were pleased to see the paper articulate dual goals of sustaining the caring role *and* addressing carers' wellbeing in their own right (pp. 4 and 10), as the latter goal is not often prioritised in the current service landscape. However, this second goal is not reiterated throughout the paper, or in the Service Concept diagram on page 22, which states:

“The objective of the new integrated carer support service system will be to help carers continue their caring role by delivering supports and services proven to reduce caregiver strain and improve their wellbeing, by refocussing carer support as an early intervention service.”

We strongly believe, and regularly advocate for, carers' own wellbeing to be considered as great a priority as sustaining their caring role, and for all carers to have a choice about whether or not they continue caring. We therefore recommend that the importance of carers' wellbeing, and carers' ability to make choices in their caring role, consistently inform the further development of the ICSS.

### **Evaluation**

As the paper identifies, the success of the ICSS for carers will depend on evidence based decision making. Carers NSW commends the comprehensive research reflected in the paper and the Government's commitment to funding only effective supports that are appropriately targeted. However, we have identified some gaps with regard to evaluation that are outlined below.

### *Greater transparency*

Carers NSW would have liked more detail about the research process and findings to be included in the paper or a subsequent public document, including information on methodology, recruitment and sample groups for the survey and interviews, as well as general data about the demographic spread of participants and the recruitment process involved in appointing the carer committee.

### *Further research*

The paper refers to the limited reliable evidence on the effectiveness of various carer support types. Carers NSW acknowledges this, but urges the Department of Social Services (DSS) not to assume that limited evidence is equivalent to ineffectiveness. For example, the paper notes that existing models of respite have not been shown to be particularly effective or in high demand. However, our experience working with carers, and the experience of many other organisations who have submitted to this consultation, indicates that respite is a critical support to many of the carers who access it.

Reasons for the cited low uptake and low prioritisation of respite by carers should be further explored to establish the impact of factors such as respite availability, appropriateness and eligibility criteria, as well as carer self-identification and awareness of, and experience with, respite-type services.

We recommend that further research and evaluation be commissioned as a matter of priority to establish the effectiveness of existing carer support types such as respite in the Australian context before progressing with the development of the ICSS. It would be devastating for programs that make a genuine difference to carers' lives, but which have not been thoroughly evaluated, to be overlooked in the design of the new system. Evaluation should also consider the self-reported value and impact of supports for users, not simply objective or quantitative measures of success.

### **Integration**

Carers NSW believes that properly achieving integration will be critical to the success of the ICSS, and encourages DSS to clearly identify the scope and nature of this integration. In the NSW health sector, considerable work has been undertaken to define and implement integration, and the concept of integrated care has been developed to work towards this goal. The NSW Agency for Clinical Innovation defines integrated care as:

“the provision of seamless, effective and efficient care that responds to all of a person’s needs, across physical and mental health, in partnership with the individual, their carers and family.”<sup>i</sup>

Carers NSW has been a strong proponent of integrated care, and believes that similar principles of integration, centred around the needs of the carer, should be advanced through the design of the ICSS. This concept of integration must recognise the need to deliver holistic support to carers which addresses their support needs whilst also linking to the support delivered to the care recipient, ensuring that family and community networks are strengthened.

### *Integrating new and existing carer supports*

The design of an integrated service system for carers must begin by acknowledging that many effective carer support programs already exist and should not be dismantled, replaced or duplicated unnecessarily. Carers NSW envisions an ICSS that integrates new and emerging programs and pilots with the good work already being done, extending support to more carers and building on existing expertise.

For example, Carers NSW already delivers a number of support types that fit within the scope of the paper. Our Young Carer program, funded by both the NSW and Australian governments, reaches out to young carers within schools and universities by educating teachers, counsellors and students through training and guest lectures. The program has also provided training to staff of local health districts to help them identify and support young carers within the health system. Although these programs have been consistently well received, the success of these initiatives has been limited. This is not because of a lack of initiative or interest, but rather is a result of inadequate funding and resources that would be needed to enable widespread, systematic implementation.

The paper also refers to the importance of tailored information and advice that suits carers' immediate needs and circumstances. Through the Australian Government funded Carer Information and Support Service (CISS) funding stream, Carers NSW already delivers high quality, tailored information and advice to carers across NSW over the Carer Line. Our experience dictates that timely, tailored information is best delivered on an individual basis by trained staff with the skills and knowledge to provide holistic and relevant information and referral, accompanied by emotional support, addressing an individual's needs at the point of contact.

### *Cross-jurisdictional integration*

One of the key challenges in designing and delivering a truly integrated national system is the division of governance and funding between Australian, State and Territory and local governments. Carers NSW views the development of the ICSS as an opportunity to build on the expertise and infrastructure developed across these jurisdictions and facilitate greater coordination, cooperation and sharing of information – without blame shifting, postcode lotteries or reinventing the wheel, all of which happen far too often in the carer support sector.

Carers NSW believes the Council of Australian Governments (COAG) Disability Reform Council has shown leadership in this area, regularly bringing together State and Territory disability ministers with their Commonwealth counterparts to discuss, negotiate and make binding decisions. Similar coordinated leadership will be important in ensuring that localised carer needs and programs are valued and supported in a national system.

### *Cross-sectoral integration*

The patchwork of carer support that currently exists not only spans multiple jurisdictions, but also multiple service sectors, especially health, mental health, disability and aged care. While the ICSS is underpinned by the idea that carers should be able to access support regardless of who they care for and that person's engagement with relevant service systems, this commitment must be supported by adequate resources to meet the needs of all carers.

In this period of massive sector reform, it cannot be assumed that the support currently accessed by carers will continue to be available to them. Carers supporting a care recipient who is eligible for the National Disability Insurance Scheme (NDIS) or a Home Care Package are often experiencing reduced support for themselves once the person they care for transitions to the new arrangements. Further, many care recipients are not, or no longer, eligible for funded support in the aged care, disability and mental health sectors due to the funding changes.

It also cannot be assumed that the need for planned respite will be predominantly met through the NDIS and Commonwealth Home Support Program (CHSP). While there is some capacity within these programs to accommodate respite and respite-like supports, they do not serve the carer as the primary client. The extent to which respite – whether planned or emergency respite, traditional or flexible – will be included in the ICSS needs to be clarified, as many carers and carer organisations are concerned that respite resources prioritising carers' needs for a break will be seriously diminished as a result of the current reforms.

Providing a robust and equitable system of carer-specific supports should not be the only goal of an integrated support system. The ICSS should also seek to integrate with service systems that do not focus on carers and care recipients only, such as the health system, to improve carers' access to these services as clients in their own right, and increase their inclusion and engagement in the health care of those they care for. For example, Alzheimer's Australia have recently advocated for review of Medicare items to allow doctors to consult and include carers in terms of dementia management.<sup>ii</sup>

The Ability Links program in NSW has provided a good example of how carers can be individually supported to navigate both specialist and mainstream service systems, as well as community-based supports, according to their immediate needs.

### *Integration with the community*

Local, cultural, religious and other communities can provide a rich network of formal and informal supports to carers which may, with innovative engagement and resourcing, more effectively reach and support carers than formalised programs. The ICSS must harness these networks, rather than seek to recreate them, in order to foster a diverse range of tailored, grass-roots opportunities for carers to gain support in their caring role.

For example, the *together* program delivered by Carers NSW and funded by NSW Family and Community Services registers, links, informs, resources and supports carer support groups for carers of people with disability across NSW, whether they are convened by community members or service providers, and whatever form they may take. Carers NSW has witnessed the significant impact that a relatively small amount of seed funding and educational input can have for self-organised community groups, and has been astounded at the creative and individual expressions of support that communities have explored.

The Carers Craft Studio in Coffs Harbour is a great example of how seed funding can enable innovation in carer peer support that meets a local need, establishes best practice and inspires carers across NSW. The Carers Craft Studio is a weekly craft meeting intended to provide a positive respite experience for carers, drawing on the mental health benefits of craft that a Carers NSW staff

member and carer had personally experienced.<sup>iii</sup> Demand to recreate the Carers Craft Studio in other localities has indicated the importance of resourcing these kinds of grass-roots initiatives.

### *Multiple entry points*

Finally, a truly integrated system must have multiple entry points and a ‘no wrong door’ approach. The creation of the National Carer Gateway, which has great potential to streamline access to carer supports, has also resulted in yet another 1800 number being promoted to carers. Carers NSW wishes to highlight the importance of carers being able to access direct support through as many means as possible, when they need it. Warm transfers and multiple options for how and where to receive assessment and support, such as through a local GP, are some examples of this.

### **Innovation**

While Carers NSW has emphasised the importance of retaining and building on best practice elements of the existing carer support system, we also recognise the critical importance of innovation. The development of the ICSS and ongoing reforms in other service systems provides the ideal setting for real change and experimentation. There are examples of innovative practice occurring across Australia and internationally, and we encourage DSS to seek inspiration from these practices.

### *New ways of reaching carers*

The design of the ICSS provides a valuable opportunity to review the current methods by which carer supports are promoted and try new ways of reaching hidden carers. Dissemination of carer-related information must extend beyond the disability, aged care, mental health and health sectors and seek to engage carers within their local communities and everyday lives.

The use of language that is recognisable and attractive to members of the general community should also be used increasingly, with great efforts made to surpass the sector jargon that so often takes over. For example, the term ‘carer’ means nothing to many hidden carers, and a simple tag such as “do you help look after someone?” can expand the reach of carer support opportunities.

In particular, a more ambitious use of mainstream media and social media platforms is well overdue. These modes of communication have proven effective in NSW for raising awareness of carers in the community, but they remain a relatively untapped resource with great potential. It should be noted, however, that use of new and emerging technologies must always be balanced with the need of many carers for more traditional forms of communication, such as hard copies, phone contact and face-to-face information delivery.

An additional context in which carers can be engaged, informed and supported is the workplace. For example, Carers NSW works with employers to develop tailored strategies to support carers balancing paid employment and unpaid care. This includes corporate education, employee support and employer services. Further, public and community spaces such as shopping centres, libraries, public transport, parks and cultural festivals could be more innovatively used as tools for raising carer awareness and linking carers with support.

### *Innovative systems*

Carers NSW was surprised at the lack of exploration within the paper of the UK approach to carer assessment and support, given that the UK has been a leader in establishing carer rights and individualising carer support. In the UK, carers have a legislated right to a needs assessment that must be taken into account in the delivery of services to the care recipient. The *Care Act 2014* further entitles carers to receive an assessment independent of the person with care needs' right to assessment.

Local authorities are legally required to meet identified support needs, at no charge for carers below a certain financial threshold. If a carer meets the eligibility criteria, the relevant authority must work in partnership with carers to prepare a 'support plan', which determines how the carer's needs will be met and if they will be eligible for a direct payment.

In Australia, examples of individualised funding for carers have been limited. However, a number of small programs in NSW have proven effective in providing individual support plans, funding packages and ongoing support coordination to carers in their own right. For example, Carers NSW delivers the NSW Government funded Older Parent Carer Support Coordination Program and My Plan My Choice program, both of which provide valuable support to carers.

### *Innovative Programs*

There are a range of innovative programs already in existence in Australia that reflect the importance of flexible funding and a focus on peer support. One example is the Commonwealth funded Mental Health Respite: Carer Support (MHR:CS) program, delivered by Carers NSW in Randwick, Botany Bay, Newcastle, Maitland, Cessnock and Port Stephens local government areas.

As Carers NSW delivers it, MHR:CS provides one-to-one support and advocacy, access to counselling, delivery of education and training, support from carer peer workers, opportunities for carers to have break, pursue their interests and further their training. The program facilitates skills development which assists carers in their caring role, such as mental health first aid training, but also allows carers opportunities outside the caring role which improve their health and wellbeing, connection to community and/or their employment opportunities.

In 2011 an independent wide-ranging evaluation found that MHR:CS program is providing essential services to carers who access it.<sup>iv</sup> Our own evaluation has highlighted the value that the program offers to carers, with 95% stating that their caring role had improved due to the support from the MHR:CS program, and carers consistently indicating that knowing someone is there for them is critical to their own ability to cope.<sup>v</sup>

This innovative and successful program already puts into practice many of the principles explored in the paper, such as the importance of multicomponent intervention, and the potential of combining education, peer support, advocacy and respite. It also provides another example of individualised planning and funded provided to carers as the primary client. Carers NSW has found that one of the most positive features of the programme is that it has sufficient flexibility in use of brokerage funding to deliver respite opportunities which are truly driven by the needs of the carer.

Unfortunately, the funding for MHR:CS is in scope for the NDIS, even though the NDIS does not serve carers as its primary client, and as such cannot by definition replicate the support currently being provided to carers. The expertise and positive outcomes within this program are therefore at risk of disappearing and must be sustained or replicated in the development of the ICSS.

## Conclusion

Carers NSW thanks DSS for the opportunity to contribute to the design of the new Integrated Carer Support Service. We encourage DSS to further explore and build on existing best practice in Australia and overseas when developing the ICSS and ensure that genuine and meaningful integration and innovation are achieved in the new system.

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<sup>i</sup> Agency for Clinical Innovation (2016) 'ACI Integrated Care', available online at: <https://www.aci.health.nsw.gov.au/resources/integrated-care/aci/integrated-care>, accessed 16 June 2016.

<sup>ii</sup> Alzheimer's Australia (2015) 'Alzheimer's Australia Submission to MBS Review', available online at: <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Submission-MBS-Review.pdf>, accessed 16 June 2016.

<sup>iii</sup> Gritschneider, Y. (2015) 'Let the craft revolution begin: Carers craft studio', *The Country Web*, Issue 62, Spring 2015, Rural Women's Network.

<sup>iv</sup> Mental Health Council of Australia (2012) *Mental Health Respite: Carer Support Consultation Report* Prepared for the Department of Social Services (formerly Families, Housing and Community Services and Indigenous Affairs)

<sup>v</sup> Carers NSW (2015) *Carers NSW Mental Health Respite: Carer Support Evaluation 2015*, Sydney, available at [https://www.carersnsw.org.au/Assets/Files/MHRCS\\_Evaluation\\_Report\\_2015.pdf](https://www.carersnsw.org.au/Assets/Files/MHRCS_Evaluation_Report_2015.pdf).