



15<sup>th</sup> December 2016

## Delivering an integrated carer support service – A draft model for the delivery of carer support services

### About the Illawarra Forum

The Illawarra Forum is the peak body working for community services and organisations in the Illawarra and the Shoalhaven. We support community organisations, promote expertise and innovation in community development, foster industry development and advocate for social justice.

For more than twenty years, the Illawarra Forum has taken a leadership role in the local community services industry and currently consists of more than 300 organisations in the Illawarra and Shoalhaven areas of New South Wales.

As part of our leadership role, we work with organisations, services and individuals engaged in supporting older people, people with a disability and their carers and engage with them to collect their opinion, expertise and recommendations.

The Illawarra Forum works closely with numerous organisations which provide support to vulnerable people across the region including:

- Home Support services;
- Residential services;
- Services for people with disability;
- Services for individuals and families with multiple layers of social and financial disadvantage;
- Support for victims of domestic violence and sexual assault ;
- Youth work programs;
- Social housing and homelessness services;
- Community health services, including mental health and drug/alcohol services;
- Community legal centre services
- Community development and community capacity building programs.

The health, aged and disability sectors are undergoing unprecedented reform, redirecting the focus to the person receiving care and supports due to aged-related frailty, disability, mental illness and or chronic illness. To some extent carers have become lost in this reform process. Therefore, Illawarra Forum welcomes the opportunity to contribute to the Department of Social Services development of a carer support model.

Illawarra Forum undertook a consultation with service providers from aged and disability services to discuss the draft service delivery model and makes the following recommendations:

- 1. Carers' health and wellbeing must be fundamental to carer support services and should at the core of the carer model.**

A truly supportive Integrated Carer Support Program (ICSP) must meet the needs of all carers and as such it should uphold the Carers Recognition Act (2010) Statements. (See appendix )

The model presented does not truly reflect the principles embedded in the Act. For example:

*“Carers should be acknowledged as individuals with their own needs within and beyond the caring role”* or adhere to the Guiding Principles<sup>1</sup> that

*“the new integrated carer support service system will ensure carers are the core of its focus”.*

As presented, the model focuses on maintaining the caring role and not on the carer as an individual in their own right. Carer health and wellbeing is just as important as sustaining their caring role.

The aims of the new integrated model are:<sup>2</sup>

- To proactively support carers to sustain a caring role and avoid a crisis that might adversely affect or end it ( e.g. information, training); and
- To provide support where carers are in, or at risk of crisis which might adversely affect or end it (e.g. emergency respite).

The enormous contribution and economic savings of carers is well documented<sup>3</sup> and should be taken into account when delivering any model of care to support them in their caring role.

## **2. Integrated carer support services must be adequately resourced to meet the needs of carers.**

As part of the current reforms, a number of carer specific services have transitioned in part or fully to the NDIS and or Commonwealth Home Support Program. These programs are not carer-focused but care-recipient focused and we are therefore concerned that financial resources provided for carers will be reduced or extinguished.

A number of the service streams in the proposed model rely on existing services, however there is no guarantee that these services will continue to be funded from July 2018. At a local level, providers have already identified reduced services on offer to carers for example, a local cottage respite provided by one organisation has been reduced from 6 respite blocks per year to just 2 per year.

## **3. Flexible Planned Respite be included as one of the service deliverables in the model.**

The lack of flexible planned respite in the draft service concept is of particular concern. Carers Australia NSW has recently published the findings from their 2016 Carer Survey - *Give us a Break* which identified three reasons why Australia’s carers still need respite;

1. It gives carers a break from their caring responsibilities
2. It gives carers a chance to look after their own health and wellbeing

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<sup>1</sup> Department of Social Services: Designing the new integrated carer support services – A draft Service Concept for the delivery of interventions to improve outcomes for carers (p 20)

<sup>2</sup> Department of Social Services: Designing the new integrated carer support services – A draft Service Concept for the delivery of interventions to improve outcomes for carers (p 19)

<sup>3</sup> Deloitte Access Economics utilised data drawn from the Australian Bureau of Statistics Series B population projections to estimate the number of informal carers.

3. It helps carers sustain their caring role<sup>4</sup>.

Flexible planned respite must remain a dedicated funding stream. There is a risk that carers' needs for respite will not be prioritised when there are competing demands on home care package funds or NDIS funding to meet the needs of the care recipient.

In the concept paper, the Department identified a lack of available research supporting the benefits of respite to carers. The new integrated carer system provides an opportunity for the department to embed research and evaluation principles into the integrated carer system for future planning and service delivery.

**Q 1A: In relation to the program overview, do you believe the objectives, outcomes and delivery principles are appropriate for the service required to be delivered under each programme?**

The Illawarra Forum welcomes objectives that focus on

- An early intervention approach,
- Seeking to help more carers,
- Providing services that will be of value to carers and
- Providing access to these services using an easier process which offers multiple entry point options.

The Illawarra Forum recommends that the model's roles and objectives should reflect outcomes that adhere to the Carer Recognition Act 2010 e.g. Carer health and wellbeing, and participation in family and community life.

Illawarra Forum supports a model that *seeks to help carers to access and receive support earlier in their caring journey and on a more proactive basis*<sup>5</sup>. Early intervention should be a key element of a new carer support model, however this philosophy is not truly reflected in the proposed Integrated Carer Support Program framework in which carers are prioritised based on level of crisis and greatest unmet need.

In the proposed model, access to counselling, respite, coaching / mentoring and financial support will be targeted and not available to all carers. The absence of planned subsidised respite further undermines early intervention strategies which would allow the carer to plan and manage their needs when and how they choose it.

**Q 1B: Do you believe that the services proposed to be delivered at the national, regional and local level are targeted appropriately?**

The Illawarra Forum supports a three-tiered approach, incorporating national, regional and local services as this is consistent with other health, disability and aged structures. However the model lacks details about some items.

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<sup>4</sup> Carers Australia NSW –Evidence That Australian Carers Still Need Respite

<sup>5</sup> Delivering an integrated carer support service – A draft model for the delivery of carer support services p7

The concept paper indicated that a national media campaign would be beneficial to reach carers<sup>6</sup> – but there is no reference to a strategy being developed. Illawarra Forum recommends that a national media campaign be delivered as part of the roll out of the new Integrated Carer Support Service.

Though many carers are familiar with computers and the internet, service providers have raised concerns that the model relies too heavily on carers' internet and IT literacy. The model needs to broaden the way it engages with carers to ensure that all carers have access to information, counselling and the self-assessment and planning tools, regardless of IT access or literacy.

Though the earlier document indicates that there are no wrong doors, face to face access is *“limited to carers who may need assistance to communicate or where there is a sensitivity e.g. young carer or person from a Cultural and Linguistically Diverse background”*. This definition is too narrow and should be expanded to include carers who are frail-aged, living in remote areas or have access difficulties.

Carer education and integrating with other funded services are two of the basic functions of the model however the Carer Gateway “Find a service” does not have a category for education therefore does not assist carers to find education programs in their local area. To find a service through the gateway, the carer must tick one of the categories to proceed with the search. We therefore recommend that education be included as a category in the service finder to ensure that other services can be accessed.

Financial support appears to be linked to remaining in the workforce, to entering the workforce or to education, which restricts access to a small number of carers. A truly national carer model should have a flexible and diverse system of financial support mechanisms for all carers.

The document is unclear regarding the number of regional hubs and the geographical area they cover. The Illawarra Forum suggests that the regional hub complement existing structures; for example, Regional Assessment Services. In addition, outreach hubs should be established for special needs populations and carers in isolated regions.

Illawarra Forum recommends government make a commitment to on-going block funding for the regional hubs and outreach programs to ensure their sustainability.

**Q 1C: 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 for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?**

The mapping of services locally and development of good relationships with other sectors will be crucial to ensure that carers get the best advice and that services are not duplicated

The Department of Social Services undertook an environmental analysis to identify organisations supporting carers. This initial mapping undertaken in stage 1 would be a useful tool to ensure that services are not duplicated.

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<sup>6</sup> Designing the new integrated carer support service –A draft Service Concept for the delivery of interventions to improve outcomes for carers p24

**Q 2A: It has been identified that outcomes measurement will be essential for a future model. Outcomes measurement involves identifying how effective services are in achieving particular objective. This commonly takes the form of a questionnaire which helps to assess whilst not placing undue burden on a carers role. However, there will be a careful balance in measuring outcomes, whilst not placing undue burden on 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?**

This is an opportunity to work with local universities to pilot studies with carers who wish to participate in a longitudinal study documenting from early in their caring journey through to their final caring role. It would have the advantage of international recognition, provide face to face interviews and targeted questionnaires. An essential objective will be the health and wellbeing of the carer and the service types /strategies that are most effective.

**Q 2 B: 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?**

Any future model needs to have good governance structures and adhere to nationally accredited system of associated standards. Services need to be provided by professional and experienced workers who understand carer issues. Carer feedback needs to be an important element in deciding quality.

Thank you for the opportunity to comment on the issues paper. For further information about this submission, please contact [nicky@illawarraforum.org.au](mailto:nicky@illawarraforum.org.au) or 02 4256 4333



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## Schedule 1—The Statement for Australia’s Carers

Note: See section 6.

- 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- 3 The valuable social and economic contribution that carers make to society should be recognised and supported.
- 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- 6 The relationship between carers and the persons for whom they care should be recognised and respected.
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- 8 Carers should be treated with dignity and respect.
- 9 Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
- 10 Support for carers should be timely, responsive, appropriate and accessible.