

care DIGNITY
respect
change HOPE

**Submission to a draft model for the
delivery of an integrated carer
support services system.**

16 December, 2016

www.anglicare.asn.au



Anglicare Australia

PO Box 4093
Ainslie ACT 2602
T (02) 6230 1775
F (02) 6230 1704
anglicare@anglicare.asn.au
www.anglicare.asn.au

Anglicare Australia is pleased to submit a response to the draft model for the delivery of an integrated carer support services system.

Anglicare Australia

The Anglicare Australia network consists of 36 members across every Australian state and territory with a joint budget of over \$1.05 billion, and a strong workforce of 12,600 staff and 7,800 volunteers. The network caters to the specific or integrated needs of over 931,000 people and supports them to identify pathways to participate meaningfully in society.

Anglicare members are independent organisations connected to the Anglican Church. They provide social services in their respective communities and choose to come together as part of the Anglicare network to strengthen their effort in responding to the multiple and complex needs of people and families across Australia, to match local presence to national strength, and ultimately to bring positive change to Australia. Between them they contributed to more than 50 service areas in the community: including social housing, homelessness services, emergency relief, family support, out of home care, home and residential aged care, remote Aboriginal community support, alcohol and other drug management, early childhood education, financial counselling, employment services and disability services.

Anglicare member organisations work with family, kin and community carers, either because the services themselves involve carers, including aged and community care, disability care and support, mental health services and alcohol and other drug services; or because carers and the people they care for are so often caught in the lower income brackets of our society and so connect with Anglicare members through financial counselling, emergency relief, social housing and other forms of community support.

Among several of our network member organisations with a long and proud history of working with carers, Anglicare Sydney recently launched an evaluation of two substantial carer support programs, which included the impact on carers of the introduction of the NDIS and a response to this draft service model for a carer support system. *Carers-Doing it Tough, Doing it Well* makes it clear how vital accessible responsive support is to carers, and highlights some of the risks involved in shifting to a new care and support system for people with disability if it excludes – rather than includes – the carer.

Current circumstances

The design of a comprehensive integrated carers' support system demonstrates a real investigation into the complexity of life for the many people in Australia who are voluntary, mostly family, carers.

As commentary in the draft model makes clear, the proposed new system needs to draw on the connections with the ongoing reforms in aged and disability care.

We are concerned that carers are not getting the support they need, and are at risk of losing more as the NDIS and further aged care reforms roll out. The shift to a customer or client focus in both aged and disability care has resulted in some carers finding it more difficult both to be a part of the planning for the person they care for and to access support and services for themselves. We understand that the integrated support system is designed to address some of these issues and deliver a more holistic support. However the logistics of the aged care, health and disability systems generate a lot of complexity and difficulty, and are still evolving at a rapid rate. The proposed system needs to be carefully designed with that in mind.

The draft model is broad and aspirational. We make the point that a lot of detailed work in this area still needs to be done.

And so, on the one hand we are wary of too much haste, particularly given the large scale of this proposed carer support service system. On the other, circumstances are becoming more difficult for carers on a daily basis. It is important to pay attention to how people who are carers live their lives.

It is reasonable to say that for many carers life is complex, demanding and precarious. And that they cobble together the support they can get from different government and community agencies and from family and friends. We point again to the Anglicare Sydney report *Carers: Doing it Tough, Doing it Well* which found that carers' wellbeing is significantly improved if they can access case management support and a variety of respite options, despite their high likelihood of experiencing housing and financial stress. And that the benefits flow on to care recipients.

Transition

One of our fears is that in moving towards a new and comprehensive support system, the growing problems carers face, such as

- diminishing access and lack of certainty regarding respite for carers
- barriers to carer involvement in the My Aged Care System
- the sharp focus of support and services on NDIS customers at the expense of carers
- new limits on access to carers' allowance
- changes to other income supports such as the Disability Support Pension
- the public relations campaign against the growing cost of "welfare"
- the fall in the number of carers overall
- the increasing pressure that, for most carers, comes with ageing themselves

will not be addressed in the meantime.

That may appear to be a way of saving money while a new system is put together, but in fact is more likely to shift and to escalate the difficulties and the costs.

Furthermore, there are real risks that during the transition to the new carers system, the precarious patchwork of supports that so many carers rely on will fall apart, leaving them and the people they care in a more difficult situation. Too many of the valuable, accessible, community-based carer support services that have grown up over the past years - such as the block funded respite and case management programs Anglicare Sydney evaluated - will disappear altogether as they do not fit so directly into the new service models. It is important that the existing support is maintained and that planning for a new carer support system must include a well-funded transition.

There are salutary lessons to be learnt here in regards to the implementation of the NDIS and the aged care reforms.

Firstly, the need for a comprehensive *and* finely crafted communication strategy ahead of and then throughout the introduction of a new system is paramount. The problems that have arisen through lack of clarity in funding arrangement for aged care services is just one example of the cascade of confusion, and unhappiness, that follows the roll out of a scheme with an inadequate communication strategy.

Close and ongoing monitoring of the impact of the new scheme, both in the transition and on arrival, is also a necessity. There needs to be data collected from the very start on who is and isn't accessing the new systems, identification of the barriers to that access, and action built into the plan to ensure there *is* equity of both access and outcomes among the wide range of people it is intended to support.

It is fair to say that these measures have not been put in place for the NIDIS and aged care reforms, and there is great concern across Anglicare Australia network services that the people we work closest with are most likely to be taken advantage of or miss out entirely.

Funding

It is clear that this draft model of a service system does not attempt to address the issues of funding. Nonetheless, we cannot respond in good faith without emphasising the importance of adequate funding. There are short and long-term funding issues.

In reflecting on the systemic reforms in the health and social service sector of the past decade, there is a history of underfunding the transition itself. We are all familiar with government investment in industry restructuring, as has taken place in the dairy and automotive industries. Many of the difficulties consumers, service providers and carers face in health and social service transitions might be much less difficult if the reshaping and reorganisation were similarly funded.

Funding in the long term would also need to be increased if an integrated comprehensive service system as described is to be established. It will be important for government, and the Australian people, to understand the scale of the proposed new model, in terms of how much it will cost and – as a result – how much it will save and how much extra it could deliver.

Again, there are lessons to be learnt from the implementation and design of the NDIS and the aged care reforms. The Samaritans Foundation, an Anglicare Australia member, has produced a compelling case that the reasonable cost that the NDIS is prepared to pay service providers is simply inadequate, and fails to properly account for award wages, leave entitlements or unavoidable on-costs. In the aged care space, the introduction of a higher level of charges from home support services is leading many people – and their carers – to choose not to access services for which they've been assessed as eligible.

In other words, a new integrated system of support for carers cannot be put together out of existing funds, nor could we expect it to operate without the adequate long term resourcing of its central components.

Structure

The idea of regional coordination makes sense conceptually. However, it raises many practical questions.

The recently released draft Fifth National Mental Health Plan appears to be relying on the Primary Health Network's and the Local Hospital Networks to provide regional planning. The NDIS has a national agency and would seem to be rolling out through local government areas. The new aged care system has developed Regional Assessment Services that are linked to the national My Aged Care telephone and website registration and referral service.

There is a reasonable ambition to ensure these service systems work with each other efficiently but we are quite unsure as to how that might work.

There are already quite strained connections between the NDIS and the aged care systems, with many people – and their carers – finding it difficult to navigate from one to the other, or to maintain the support they could be entitled to in one setting when they find themselves in another.

As carers work with all these services and systems, it is quite a challenge to see how the regional hubs would work without resourcing them to build strong links and relationships into all of these other bodies, and fund them to develop the capacity to build on that work. There is no real emphasis in the paper of the scale of this exercise.

Anglicare Australia again draws the Department's attention to Anglicare Sydney's recent research report *Carers: Doing it Tough, Doing it Well*. Among its key recommendations are that the support system includes carer support coordinators to assist carers to access culturally and personally appropriate support and guidance in dealing with the extraordinarily complex web of systems and services referred to above.

Unacknowledged need

We come back to the accessible block funded programs that Anglicare Sydney have shown deliver such an important level of personal support to carers. While the draft service system model pays attention to the need for carers to have access to care, support and information, it could be substantially improved.

Flexible respite services are a key factor in wellbeing and sustainability for carers, across the board. The opportunity to access planned and emergency respite in number of settings is a key factor in maintaining the resilience and positivity they need to continue with their invaluable work. An integrated Carers Support System must include adequate funding for, and the promotion of, respite for carers.

We lend our support too to the recommendations in Anglicare Sydney's report for the system to fund Social Support Programs specifically designed to support carers in their caregiving role, and for a part of the carers support system to be the inclusion of carer support information and the involvement of carers in the planning of care in both the aged care and disability systems.

Conclusion

In the discussion above we mention on several occasions the relevance to this planned new system of the design and implementation of major aged care and disability reforms. We urge the government to ensure the final design of a new integrated carer support system be informed by rigorous, honest evaluation of the NDIS and Living Longer Living Better aged care reforms, paying particular regard to the equity of access and outcomes for both consumers and carers.

We do not believe a new national system of regional coordination hubs will prove effective without a concrete commitment of adequate funds. We note the recent report prepared for Carers Australia by Deloitte Access Economics that put the annual value of informal care at \$60.3 billion, and remind the department that good support for carers, on their own terms, will pay for itself.

We also drew attention to the urgent need to strengthen existing programs that are at risk now that these other reforms are being rolled out. It would both unreasonable and counter-productive to leave carers in the lurch as the new more customer focussed models of aged and disability care take shape; and during the inevitably slow and complex roll out of the integrated care support system should it be introduced.

Finally we acknowledge the involvement in carers in the design of this draft model. We urge the government to ensure that carers and their community organisations are integrally involved in the final design and the implementation planning for this new system if it is proceed.

END

Contact Person

Roland Manderson
Deputy Director
Anglicare Australia
PO Box 4093
Ainslie ACT 2602
T: 02 62301775
roland.manderson@anglicare.asn.au

References

Deloitte Access Economics, *The economic value of informal care in Australia in 2015*, Carers Australia June 2015 <http://www.carersaustralia.com.au/storage/access-economics-report-2015.pdf>

Kemp, King, Paleologos, Bellamy and Mollenhauer, *Carers: Doing it Tough, Doing it Well* Anglicare Diocese of Sydney, Social Policy and Research Unit, December 2016 https://www.anglicare.org.au/sites/default/files/Carers_Report_Digital.pdf

Samaritans Foundation, *Is the NDIS reasonable cost methodology reasonable?* Lorna Worthington, commissioned by Samaritans Foundation, June 2016.

