**Response Submission to Department Social Services**

**Integrated Carers Support Services**

**A Shared Response from across Providers in Northern Sydney**

**June 2016**

Submitted by the following organisations:

Northside Community Forum (author)

NBI

North Ryde Community Aid

Hunters Hill Ryde Community Services

About Us:

**Northside Community Forum** (Northside) Northside is a network of innovative local community based organisations offering carers, people with a disability, people living with mental illness and older people with services to live their best life. side partners with a range of specialist and high quality services which gives you greater choice and enhances your independence and wellbeing.
Our range of services and offers include;
♣ Domestic Assistance for people over 65 years
♣ Social activities and events for people with disability and older people
♣ Transport to events and medical appointments
♣ Education and support for people caring for someone with a disability, mental illness, older people or someone who is chronically ill
♣ Dementia education for carers
♣ Education and respite for young people
♣ Emergency, in home or overnight respite
♣ Care coordination for people with disability, older people, people with mental illness and the people who care for them.
♣ Care coordination for people with caring responsibility who are at work or returning to work Our range of services include;

* Education and support for people caring for someone with a disability, mental illness, older people or someone who is chronically ill
* Dementia education for carers
* Education and respite for young people
* Emergency, in home or overnight respite
* Domestic Assistance for people over 65 years
* Social activities and events for people with disability and older people
* Transport to events and medical appointments
* Care coordination for people with caring responsibility who are at work or returning to work

**NBI** (Northern Beaches Interchange) provides respite, recreation, community access, disability support and carer support to families throughout the Manly, Warringah, Pittwater Mosman and Kuringai Local Government Areas. We provide support to all disabilities including (but not limited to) Angelman Syndrome, Autism, Cerebral Palsy, Developmental Delay, Down Syndrome and Intellectual Disability.

**North Ryde Community Aid** was established in 1979 by members of the North Ryde Uniting Church, now North Ryde Community Church.

In direct response to the identified social and economic needs of the residents within the local area.  An office was established in the front room of a local house and soon a regular Thursday social group started to gather. An event that continues to be enjoyed today.  Over time other groups and programs were introduced and ultimately developed into the support and services offered today.

Our community work is co-ordinated by a culturally diverse team of staff, ably assisted by a team of volunteers drawn from our local community.

North Ryde Community Aid always strives to build upon the concept of a caring community, where people know and respect one another, assist one another and contribute to the common good.

**Hunters Hill, Ryde Community Services** is a not for profit organisation providing Home and Community Care Programs.

We would like to thank the Department of Social Services for the opportunity to provide a response to the strategy. Overall, our review of the service model was positive and we acknowledge the considerable consultative and research work that the Department has already undertaken in which to derive a solid concept.

Our collaborative response focuses on areas that we believe would add value to carers offer them as recommendations to consider.

**General Comments:**

1. *Carer as a person first.*

As you are aware, there is much discourse on the definition of carer. In our view, the term carer redefines the individual role as a person first to carer first and foremost. As is the case with disability where the person as a whole is seen first and their impairment recognised as a part of the person, we believe that it is critical that carers also be identified this way. This change in definition could therefore lend itself to greater self-identification of needs by people who have caring responsibility. Such a change in perspective could result in what the discussion is calling for; greater proactive implementation of support services/systems for people caring for a family or loved one. This is mainly achieved if the model and service system do not see caring as a separate thing, rather a whole family or whole person response.

1. *Positive promotion of people with caring responsibility.*

In the same way that we are proposing a person first philosophy, the group also felt strongly that the model should focus on supporting and promoting the best parts of being a carer and not be built around carers as a homogenous group. Needs identified through the model still relied heavily on deficit thinking and as such plans will focus on filling gaps rather than supporting the whole person and the person that they care for. It was discussed amongst the group that often a carer’s need is not always about solving a problem, rather it is about providing a support, usually emotional for the individual at a point/s in time.

1. *Beware the linear service model.*

The model overall is positive giving carers many touch points and a leaner approach to accessing services without compromising the need for local services to address the needs. A floor in the proposition is that the solution appears linear in access and therefore assumes that the carer is more likely to access services well ahead of need where a preventative plan will be developed instead of at point of crises. It was our view that services for the unexpected cannot be left off the model as crises despite best intentions will always eventuate for a proportion of carers. Similarly, during such large scale reform in disability and aged care, the likelihood of crises is expected to peak as both carers and care recipients learn to navigate a new service system.

1. *Alignment with other major reforms.*

The impacts of reforms on carers cannot be underestimated as services bed down their offering at a time that participants, older people and carers learn to navigate a new service systems. Carers who fall into the “sandwich generation” will be faced with navigating a changed My Aged Care and NDIS system at or around the same time of reform to carer services. It is important that three separate reform agenda’s mirror each other in a way that carers are not forced to become familiar with three new and potentially incongruent services. Integrating and aligning in some capacity will be important so that Carers are not forced to sit on lengthy call wait times, attend multiple assessment appointments and be forced to somehow understand and align plans for each of their family members including their own needs. There must be consideration of the additional time and burden that these reforms will initially have on carers – people who already have stretched resources.

1. *Caring and employment.*

An area that was not given great attention and is recommended to be further explored is the impact of caring and sustaining employment. It is recommended that further analysis is given to economic participation of carers in so far as promoting, educating and supporting employers and businesses to create an open and flexible workplace for people with caring responsibility. This could be promoted much in the same way as parental leave and flexible workplace policies for carers. Our soft intelligence tells us that many carers resign from their paid roles as they do not believe that their workplace can support both work and personal demands. This therefore can lead to lengthy periods of unemployment or periods of deskilling in a very fast moving labour market. Carers therefore are risk of becoming one of the many 800,000 people seeking work in a competitive labour market.

In reviewing the paper, discussion moved to suggestions that could enhance the model and provide value to carers. Below is an outline of recommendations for the Department to consider.

1. *Quarantined Services:*

A suggestion that has been raised is that some funding be quarantined for counseling support. A model suggested is similar to EAP allowing for preferred counseling providers in local areas to provide phone and/or face to face counseling for carers. This would provide short term supports to carers at times of need, which can often be unpredictable and as a result of significant disruption or change to the care recipients circumstances such as change to diagnosis/prognosis, changing house or severe deterioration in health. This EAP style approach could provide a short term continuity of emotional support.

1. *Support when the caring role ends.*

It is recommended that the model have greater consideration for carers when their caring role ends. Our collective experience with carers informs us that this significant life transition is just as impactful on the carers wellbeing as the caring role itself. The model in our view did not give enough attention to this stage of life and therefore would fall short of the opportunity of being an integrated and end to end support system. It is suggested that in the same way that the NDIS model provides a support for assistance in coordinating or managing transitions, the integrated carer model could also deliver such an approach. This could focus on aspects such as;

* Managing change to identity as caring role ends
* Support regarding employment whether it be returning to full time work or seeking employment
* Assistance in managing relocation
* Re-establishing social supports and connections where the caring role has isolated the carer.

The above is not a total list, rather gives insight into what carers face when such a change occurs in their life.

1. *Value the lived carer experience:*

It is acknowledged that any person may become a carer at any time. Often the initial realisation of such a change to life’s plan is met with uncertainty, confusion and grief and loss. The value of support from people who have a lived caring experience cannot be underestimated. Our experience tells us that the caring experience sits on a spectrum from beginner to expert, with the more experienced carers being best suited to share their knowledge and experience.

1. *Valuing Care Coordination.*

Recognising that Integrated Carer Support Model has been designed to deliver proactive and preventative services, it cannot be underestimated that crises will occur. As such, it is recommended that some level of care coordination be considered as part of the model so as to enable the carer to be adequately be connected to services when needed without placing additional burden on carers to coordinate their own services whilst under varying levels of stress.

**Conclusion**

In all, the service concept offered is well considered, well researched and inclusive. The idea that a model can be proactive and preventative is a positive step in acknowledging the role of carers and their value to the broader community. There is risk, however that the execution of multiple reform agenda’s simultaneously can negatively impact the principle and value of such a model. Further work should be undertaken to understand this risk and work with services affected across all reform agenda’s to best manage it.