**Designing the new Integrated Carer Support Service: Submission from Interchange Illawarra Inc.**

1. **About Interchange Illawarra Inc.**

Interchange Illawarra is a not for profit, community based organisation that is funded by the Commonwealth and State governments. Interchange provides quality respite services to many hundreds of people with disabilities, their families and carers throughout the Wollongong, Shellharbour and Kiama LGAs and has done since 1981. We provide a range of supports including flexible respite options, peer support, social and community inclusion support, brokered respite, overnight respite and parent/carer support.

1. **Key Recommendations**

**Recommendation 1:** The Department should adopt a local carer organisation model to provide support to all carers, regardless of who they care for, on a region by region basis.These organisations could be sourced through a competitive tender process.

**Recommendation 2:** These local carer organisations should be funded to undergo the following activities at a minimum; awareness projects in the local community, carer support coordination, information, education, peer support, socialisation and respite for carers.

**Recommendation 3:** Carer support should include funding to support peer support groups at a local level in a face to face setting as well as online, with funding allowing for payment of a facilitator to coordinate the group.

**Recommendation 4:** Peer support groups should be informal places for carers to meet other carers. Peer support should therefore be a service which can be accessed without pre-conditions or structure processes.

**Recommendation 5:** Respite models such as the Family Managed Allocation (FMA) which facilitate the use of and strengthen personal support networks should be recognized as an important service type within carer support reform.

**Recommendation 6:** Respite options (and indeed other service options) should be driven by carers and their needs.

**Recommendation 7:** Carer budgets should be funded on a spectrum to support the most number of carers nationally. The lowest tier could be $1200 PA (the current FMA amount) and the highest at CDC-R budget amounts (allowing for indexation). The carer assessment used by local respite coordination groups in NSW could be used nationally to determine who receives a carer budget region by region and these budgets could be allocated by the local carer organisation and/or Commonwealth Carer Respite Centre.

**Recommendation 8:** Respite options, including FMA, should be seen as an early intervention strategy and adequately funded and supported. The Department should liaise with the NDIS to ensure that innovative respite options such as the FMA model are part of NDIS roll-out as well as carer support reform.

**Recommendation 9:** A national trial should be conducted to test the risks, advantages and disadvantages of paying resident and non-resident family members to support people with a disability, mental illness or frailty from age.

1. **General response to the paper**

It is Interchange Illawarra’s experience that the most effective means of supporting carers is through **connecting carers with local community organisations who can maintain personal relationships**. This is supported by conversations we have with carers on our books and beyond, other organisations who support carers, by Commonwealth Respite and Carelink Centres and by the research that the Department has done with carers and carer interest groups.

This is because though initial identification of a carer may occur through the health and/or education system (for example through local GPs, hospitals or schools), a light touch information and linkage approach is not enough to support a carer as they work through complex emotions regarding the caring role and can experience poor physical and emotional health, social isolation, financial disadvantage and reduced ability to participate in the workforce. Carers want to talk to other carers and have local support when they need it. They want to know that when they have had time to process a new stage of their caring journey, there is someone local who can help them in the next stage of their journey.

Interchange Illawarra is aware of a small provider in the Sutherland Shire which provides peer, telephone and face to face support; socialisation, education and “time out” to carers, regardless of who they care for, on a regular basis for under 500k per annum.[[1]](#footnote-1) This model could be replicated at a national scale, particularly in metro and regional areas. The Department would need to do further research on the best ways to reach carers in rural and remote areas, including considering funding larger providers to provide carer support outreach to areas where there are thin markets. In some areas this may be the Commonwealth Respite and Carelink Centre.

Interchange Illawarra acknowledges that currently a carer support service system largely doesn’t exist beyond Carers Australia and its state peaks and Commonwealth Respite and Carelink Centres. Carer support is predominantly a value add to supports[[2]](#footnote-2) provided through the service system the person cared for accesses (ie disability, aged care, mental health service systems) or is crisis driven (as in the case of emergency respite and chronic illness, a large area of carer unmet need). We also acknowledge that carers are not a homogenous group. Carers have different needs depending on who they care for, where they live and what their backgrounds are.

Additionally, though the NDIS has made some limited[[3]](#footnote-3) commitment to working with carers and funding providers to work with carers where doing so supports outcomes for the person with disability (through ILC), the same reforms have not occurred in aged care and mental health while ongoing support for people with chronic illness is currently not funded within any service system.

Therefore, if the Department is committed to carer support reform which aims to improve the health and wellbeing of all of Australia’s carers, reducing crisis driven response to carer need, the following principles must be adopted;

1. Carer support should not be a one size fits all approach
2. Carer support should be provided to carers in their own right, regardless of who they care for and what the person they care for has access to
3. Carer support should be provided locally and involve a combination of online, telephone and face to face support as desired by the carer
4. Carer support should be provided in partnership with the community. This is especially important for rural and remote areas where there are thin markets
5. Commonwealth Respite and Carelink Centres should continue to receive funding to support carers in emergencies and with information and referrals
6. Carers should have access to goals based planning and a carer budget in their own right on the basis of need

Interchange Illawarra makes the following recommendations on the basis of these principles:

**Recommendation 1:** The Department should adopt a local carer organisation model to provide support to all carers, regardless of who they care for, on a region by region basis.These organisations could be sourced through a competitive tender process.

**Recommendation 2:** These local carer organisations should be funded to undergo the following activities at a minimum; awareness projects in the local community, carer support coordination, information, education, peer support, socialisation and respite for carers.

We make more detailed recommendations on peer support and multi-component support below.

1. **Peer support initiatives**

Interchange Illawarra operates two local peer support groups. My Time and Our Place are local support groups for parents and carers of young children with a disability or chronic medical condition and we run these in partnership with TAFE, Illawarra Children’s Service and Big Fat Smile. Not only do carers come to socialise with other carers at these informal groups. They also;

* Meet others in similar circumstances
* Find out about available community support
* Get extra parenting information and skills development
* Make time for themselves while children play, supported by a play helper

These forms of peer support are an important support for carers of young children, particularly as they come to terms with a newly given diagnosis. We strongly support multiple other submissions which have reminded the Department that it is not reasonable to assume that unpaid facilitation of peer support groups is sustainable. These groups simply cannot function without funding to pay for a carer facilitator to coordinate and ensure that discussion is moderated and safe for all attendees. Experience, training and support is required and this is best provided in a professional, paid context.

**Recommendation 3:** Carer support includes funding to support peer support groups at a local level in a face to face setting as well as online, with funding allowing for payment of a facilitator to coordinate the group.

**Recommendation 4:** Peer support groups should be informal places for carers to meet other carers. Peer support should therefore be a service which can be accessed without pre-conditions or structure processes.

1. **Needs Identification and Planning**

Given the implementation of the NDIS and aged care reform, it is reasonable to align carer support with these initiatives and ensure that the Integrated Carer Support Model adopts consumer directed principles.

Funding a carer support organisation locally to offer a carer the choice of undergoing goals based assessment and planning supports may have merit even if there are limited allocations of individualised carer budgets.

Interchange Illawarra believes in a holistic approach to working with people in our community, focussing on capacity building to reduce reliance on paid supports. Goals assessment and planning is one way to support carers to identify natural supports and forms of respite in their life as well as strategies to achieve goals.

1. **Multi-component support (including respite)**

We note that the department is proposing a multi-component support stream of the new model. This would involve financial support, carer mentoring and respite support to create a package similar to carer budgets in the UK. As a flexible respite provider with significant experience in harnessing large numbers of volunteers and cashing out to families to allow reimbursement to friends and family in exchange for respite hours, we strongly welcome the Department’s consideration of this approach. On the basis of our own experience in the respite field, Interchange Illawarra strongly supports Alzheimer’s Australia 2013 flexible respite review which recommended a cashing out trial for respite to allow carers to reimburse their own friends and family (mentioned on pg 36 of the DSS paper. We also welcome the Department’s acknowledgement that carers using direct payments require support to build capacity to utilize their budget.

Interchange Illawarra offers a mixed model of respite support to people with disability and their carers. We offer a number of flexible respite options characterised by a desire to move beyond formalized paid worker arrangements. Instead, we;

* Harness a number of registered volunteers to provide respite support
* Offer family managed allocations (FMAs) to a number of families

For the purposes of Integrated Carer Support, this paper discusses the FMA model of respite support (a form of cashing out).

*The Family Managed Allocation Model*

The family managed allocation model of support was trialled by Interchange in the early 1990s. It is an allocation deposited into a carer’s nominated bank account of about $300 quarterly with most families using this allocation to reimburse personal support networks for respite support.

In 2011, Interchange conducted a study with Shellharbour TAFE to analysis the impacts of the family managed allocation model and make recommendations to relevant government bodies and peaks on growing the model across the country. The research found that, ‘the FMA model provides a strong fit between facilitating a person’s right to choose and building the capacity and resilience of families through their connection with a service provider… while reimbursement takes many forms, from a present, a dinner, petrol costs, it is both the capacity to recognise, if only in small ways, the respite support that a family member or friend offers and the subsequent strengthening of these informal systems of support over time that this model facilitates.’[[4]](#footnote-4)

In addition, the study with 335 families in the Illawarra found that the family managed allocation was important not just because of the above opportunities. Carers also valued ‘access to reliable and timely information and education, a sense of belonging and community and a base from which to navigate the complex word of the service system.’[[5]](#footnote-5) This supports the Department’s research in this area which affirms the need to **fund support coordination** **or carer mentoring** to ensure carer’s are able to use their budgets.

Interchange believes that funding models such as the FMA through Integrated Carer Support just makes sense. The model;

* Was initiated by carers and has evolved in response to local carer need
* Stretches valuable tax dollars further
* Supports carers to build their own capacity to work through issues and problem solve
* Supports carers to draw on and build upon natural support networks
* Will assist the Department to address the significant unmet respite need outlined in the DSS paper

If the Department was to consider funding planned respite in Integrated Carer Support, we believe innovative models such as FMA should be part of the spectrum of respite support.

On this basis, Interchange makes the following recommendations;

**Recommendation 5:** Respite models such as the Family Managed Allocation (FMA) which facilitate the use of and strengthen personal support networks should be recognized as an important service type within carer support reform.

**Recommendation 6:** Respite options (and indeed other service options) should be driven by carers and their needs.

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1. Sutherland Shire Carer Support Service Inc. [↑](#footnote-ref-1)
2. Though given aged care and disability reform, much of this add-on carer support will not continue with the loss of block funding to many community not for profits. [↑](#footnote-ref-2)
3. ILC must fund multiple priorities in addition to carer capacity building and has limited funds to administer all of its programs nationally. [↑](#footnote-ref-3)
4. Interchange Illawarra and Shellharbour Tafe, ‘Families steering their way to a better future,’ Community Services Diploma Class 2011, Pg 4. [↑](#footnote-ref-4)
5. Interchange Illawarra and Shellharbour Tafe, ‘Families steering their way to a better future,’ Community Services Diploma Class 2011, pg. 5. [↑](#footnote-ref-5)