

## 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 founded in 1981 and funded by the Commonwealth and State governments. Interchange provides quality respite services to over 600 families with disabilities, their families and carers throughout the Wollongong, Shellharbour and Kiama LGAs. 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 to parents and carers of people with disability.

### 2. Recommendations Summary

**Recommendation 1:** DSS creates the Integrated Carer Support Service within the framework of the *Carer Recognition Act*, the Statement for Australia's Carers and the early intervention approach DSS purports to wish to adhere to by linking carer need to tangible carer support regardless of cohort group or level of assessed carer strain. DSS does this without making incorrect assumptions about what a carer can or cannot access in the primary service system.

**Recommendation 2:** DSS defines overall program outcomes for the Integrated Carer Support Service to measure overall program success. DSS should then ensure program objectives, outcomes and delivery principles work together to meet these measurable outcomes defining program success. Overall outcomes should be created on the basis of carer health and well-being measurements which look at multiple life domains.

**Recommendation 3:** Regional hubs are funded at a truly regional level so as to cover an LGA or small sub-set of LGAs.

**Recommendation 4:** DSS develops contracts and guidelines for regional hubs which ensure conflict of interest is avoided in funding carer support at a local level. Supports should be funded to ensure diversity of support on the basis of local and trusted relationships and this needs to be clear in all DSS documentation and accounted for in the new carer support quality and safeguarding arrangements.

**Recommendation 5:** Regional hubs should undertake rigorous service mapping to fund appropriate current carer supports at a local level including programs such as My Time, peer support and carer, health and well-being programs.

**Recommendation 6:** DSS defines what short term respite is, who can access it and how.

**Recommendation 7:** DSS funds planned respite in the new national carer model for carers to access in their own right so it does not risk the success of the Integrated Carer Support Service.

**Recommendation 8:** Regional hubs should work with LACS and the RAS to give carers information and referral channels within the disability and aged care primary service systems.

**Recommendation 9:** Regional hubs should be funded to support a carer coordinator at a local level who can be a key contact for carers in the area and provide them with the information they need to find support. This is especially important for carers of people with chronic illness and mental illness who are poorly serviced by the primary service system.

### 3. General Response to the DSS Paper

Interchange Illawarra supports the underlying early intervention philosophy of the proposed Integrated Carer Support Model. In light of this early intervention approach philosophy, the paper states that the role of the integrated carer support model would be to:

- I. *Proactively support carers earlier, and build their capacity to sustain the caring role*
- II. *Provide support where carers are in, or at risk of crisis, which might adversely affect their caring role*
- III. *Provide support for carers to improve their long term social and financial outcomes*
- IV. *Support carers to participate in everyday activities such as education and the workforce<sup>1</sup>*

These broad outcomes could deliver a national program which fits within the *Carer Recognition Act 2010*. However, disappointingly the current objectives, outcomes and delivery principles outlined in the paper, as well as the supports proposed at a national, regional and local level, fail to meet the requirements of the *Carer Recognition Act 2010* (the Statement for Australia's Carers is attached to the end of this submission for DSS reference) and thus cannot possibly deliver an early intervention model in practice.

*The Carer Recognition Act Statement* outlines Australia's commitment and approach to supporting Australia's carers. It outlines how government and others in Australian society should uphold the rights of carers. Any new national carer support model should adhere to the statement principles.

Statement 4, 5 and 10 of the Statement for Australia's Carers are outlined below and Interchange puts forward that these sections have been ignored by DSS in the Integrated Carer Support Service concept paper:

*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.*

*10 Support for carers should be timely, responsive, appropriate and accessible*

It is not possible for the new reform to address section 4 of the statement in its current proposed state without funding planned respite to support carers to improve health and wellbeing and participate in family, social and community life. It is assumed by DSS that the current service system delivering supports to the person/s cared for by a carer can provide planned respite to a carer through the primary service system. This assumption is wrong and we discuss this in detail at 4iii. Without planned respite being funded by the proposed carer support reform, the early intervention approach will fail and carers will not be able to build their capacity to sustain the caring role. Further, a numbers of other supports will be gate kept by government requirement on the basis of assessed carer strain and particular at risk cohorts. These gate kept supports include counselling, peer support, coaching and mentoring, short term respite and the financial support trial. This decision prevents **all carers** from accessing appropriate support to enhance health and well-being and participate in family, social and community life.

---

<sup>1</sup> Pg 7.

It is not possible for the new reform to address section 5 of the statement in its current proposed state without linking **identified carer need to appropriate support**, regardless of who the carer is, how under strain they are or what the government dictates about when supports can be made available. In the current paper, a carer's need for a support is decided upon by the government's program guidelines and supports linked to rigid outcomes (e.g. the need for a carer to have short term respite is linked to a carer wanting outcomes in education, peer support or employment. A carer who might need short term respite to attend a birthday party still has a need for that respite, but would not meet the current paper's requirements to receive that short term respite). Carer's needs **as they identify them** should be what counts in requesting carer support.

It is not possible for the new reform to address section 10 of the statement in its current proposed state whilst the reform proposes a needs based, rationed system for carer access to carer support. A service can't be timely, responsive, appropriate and accessible if those measuring the most strain and/or identified as being in a particular cohort can access supports whilst others cannot. Further, an early intervention service would be one that puts in supports early to reduce greater need later as well as increased strain. Giving supports to carers at greatest levels of strain is at complete odds with this.

**Recommendation 1:** DSS creates the Integrated Carer Support Service within the framework of the *Carer Recognition Act*, the Statement for Australia's Carers and the early intervention approach DSS purports to wish to adhere to by linking carer need to tangible carer support regardless of cohort group or level of assessed carer strain. DSS does this without making incorrect assumptions about what a carer can or cannot access in the primary service system.

- 4. DSS Question: In relation to the program overview, do you believe that the objectives, outcomes and delivery principles are appropriate for the services required to be delivered under each program? Do you believe that the services proposed to be delivered at the national, regional and local level are targeted appropriately?**

It is unclear what the overall measurable program outcomes for the Integrated Carer Support Service are or how the program objectives, outcomes and delivery principles feed into this to measure overall program success. Interchange Illawarra believes that outcomes should be against the personal wellbeing index or another similar model which promotes carer health and well-being in multiple life domains rather than DSS focussing on partial life outcomes by linking outcomes to education, employment and capacity to continue the caring role.

**Recommendation 2:** DSS defines overall program outcomes for the Integrated Carer Support Service to measure overall program success. DSS should then ensure program objectives, outcomes and delivery principles work together to meet these measurable outcomes defining program success. Overall outcomes should be created on the basis of carer health and well-being measurements which look at multiple life domains.

In terms of DSS segmentation of reform supports to a national regional and local level, Interchange Illawarra is broadly comfortable with this segmentation, with caveats around supports missing from the reform (such as planned respite). We make specific comments on each level of proposed support below.

- i. National**

Interchange welcomes DSS attempts to create a national carer reform which acknowledges the need for greater outreach and awareness of carers both in the community and amongst carers themselves.

Many carers are unaware that they are a carer and many people in the community may not recognise that someone is a carer with diverse needs associated with their caring role. We also welcome innovative approaches to carers and technology including via use of an app. and online forums to link carers together. These national services could help carers to understand their caring role and link to supports that may assist without repeating their story, **but will only be effective or useful if supports at a regional and local level are funded adequately.**

## ii. Regional

Interchange broadly supports a regional hub approach to mapping and coordinating carer support at a local level. However, there are sections of the DSS paper which are unclear and require clarification.

Most importantly, DSS should clearly define what is meant by regional. Our understanding is that regional covers a local government or small sub-set of local government areas, rather than vast distances. Interchange does not believe that regional hubs covering vast areas will be able to fund and implement the multiple carer support programs needed at a truly local level and nor will they be accessible for carers who require face to face support at a local level.

**Recommendation 3:** Regional hubs are funded at a truly regional level so as to cover an LGA or small sub-set of LGAs.

The regional hub is key to ensuring appropriate carer support continues to be funded at a local level. Counselling, peer support and health and wellbeing programs at a local level have positive outcomes for carers which can't be replicated online or on the phone. Therefore, DSS needs to ensure that programs are funded by regional hubs on the basis of quality outcomes, rather than allowing a quality and safeguarding and funding framework which sees regional hubs fund new programs at the expense of older programs delivered by other local, quality providers.

**Recommendation 4:** DSS develops contracts and guidelines for regional hubs which ensure conflict of interest is avoided in funding carer support at a local level. Supports should be funded to ensure diversity of support on the basis of local and trusted relationships and this needs to be clear in all DSS documentation and accounted for in the new carer support quality and safeguarding arrangements.

**Recommendation 5:** Regional hubs should undertake rigorous service mapping to fund appropriate current carer supports at a local level including programs such as My Time, peer support and carer, health and well-being programs.

Finally, it is unclear how carers are deemed eligible for short term respite, what short term respite is defined as or how it will support all carers. Respite is key to ensuring carers remain caring longer and lack of clarity around short term respite as well as an assumption that planned respite does not need to be funded by the new carer support reform is worrying.

**Recommendation 6:** DSS defines what short term respite is, who can access it and how.

## iii. Local

The single biggest concern we have with the targeting of supports as proposed in the DSS paper is the absence of planned respite. Interchange supports a national carer model which supports all carers, regardless of who they care for. In early consultations and discussion papers, DSS indicated that the new national reform would support carers with adequate carer support regardless of the primary service system the care recipient was in. *The Carer Recognition Act 2010* states that a carer is 'an individual who provides personal care, support and assistance to another individual who needs it because that other individual:

- (a) has a disability; or
- (b) has a medical condition (including a terminal or chronic illness); or
- (c) has a mental illness; or
- (d) is frail and aged.'

DSS therefore needs to consider carer support, **including planned respite**, for carers of people with disability, a medical condition such as chronic or terminal illness, a mental illness or frailty from age. Though we support the government's attempts to reduce duplication of services and we support DSS' commitment to working across service systems, such as with the NDIS and the CHSP and aged care reform to better support carer and care recipient pathways to support, all carers must have access to support in their own right, including to services such as planned respite, regardless of what service system the care recipient falls under. The proposed model assumes that planned respite, a key component of any carer support model, is available to carers through the primary service system. This is simply untrue.

There is no chronic illness service system in Australia currently. The only place a carer of someone with chronic illness can go to receive respite support is the Commonwealth Carer Respite Centre for emergency respite. There is no access to planned respite for these carers in the current service system and there is no proposed future service system policy reform for chronic illness to suggest that this outlook will change.

Planned respite for carers of those people with mental illness will be dependent on whether or not the care recipient is deemed eligible for NDIS as someone with psychosocial disability, and even then the support will not be called planned respite, but rather will support goals and aspirations of the person with psychosocial disability, which may as a side effect produce a respite effect for the carer. Otherwise the carer will only be able to access emergency respite through the Commonwealth Carer Respite Centre.

The NDIS doesn't fund respite per se, though it does fund supports to sustain informal supports in limited circumstances. This is because the NDIS focusses on the goals and aspirations of the person with disability first and foremost. Though some additional supports to build capacity of carers may be funded under the Information, Linkages and Capacity Building Program (ILC), there is limited funds for the program nationally and it will not fund respite. Therefore the many carers of people with a disability who are not deemed eligible for an NDIS plan will not have access to planned respite. Though some state and territories are holding onto residual funds for disability specific supports, many including NSW will provide no disability specific support, including planned respite, by full NDIS roll-out.

The CHSP does fund planned respite for carers of people frail from age. However, those carers of people with higher support needs may not receive enough planned respite support to meet their needs, especially with aged care packages limited nationally on a needs assessment basis.

Given the context of access to planned respite in the current service systems, it is impossible to see how regional hubs will be able to link all carers to planned respite in the primary service system and the lack of funding for planned respite in the Integrated Carer Support Service is the single greatest flaw in the entire paper.

**Recommendation 7:** DSS funds planned respite in the new national carer model for carers to access in their own right so it does not risk the success of the Integrated Carer Support Service.

Finally, there is an assumption that local providers funded in the primary service system i.e. disability, mental health, aged care, chronic illness (such as it is?) will supplement the Integrated Carer Support Service by providing carers with information and advice as well as limited assistance to navigate the primary service system. This is simply not plausible to assume given the size and scope of both the NDIS and aged care reforms. Particularly in the context of the NDIS, tight cost margins will make it impossible for disability providers to support anyone who hasn't got an NDIS plan without requiring cost recovery through fee for service. Instead, DSS needs to liaise with the NDIA and CHSP reforms to ensure regional hubs link carers to the correct source of support.

**Recommendation 8:** Regional hubs should work with LACS and the RAS to give carers information and referral channels within the disability and aged care primary service systems.

**Recommendation 9:** Regional hubs should be funded to support a carer coordinator at a local level who can be a key contact for carers in the area and provide them with the information they need to find support. This is especially important for carers of people with chronic illness and mental illness who are poorly serviced by the primary service system.

**Submission Details:**

Maureen Flynn  
NDIS Transition and Support Coordinator  
Interchange Illawarra  
02 4227 1079  
[maureen@interchangeillawarra.org](mailto:maureen@interchangeillawarra.org)

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

- 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