"Succeeding Together"

Schizophrenia Fellowship of NSW

Submission on the proposed model for the delivery of carer services

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“Succeeding Together”

About the Schizophrenia Fellowship of NSW

SF NSW is a specialist mental health recovery organisation, with a 31 year history, committed to improving access to services and the circumstances of people living with severe and complex mental illness.

SF NSW delivers trauma-informed recovery-oriented psychosocial support programs and services for carers and consumers. This includes carer respite and support groups, specialist mental health Disability Employment Services (DES), care coordination, housing, social inclusion, clinical and peer supported services. Each year, 10 000 people, across 33 sites in NSW and ACT, access our services.

The Fellowship:

- 74% of our employees and 75% of our board have lived experience as a mental health carer or consumer.
- Provides Carer Assist services- supports for carers of people with all types of mental illness
- Provides Respite Services, including recreational and educational service options to meet the needs of families and friends caring for a person with a mental illness.
- Runs the OnFire! program, an innovative program for eight to 18 year old young carers of people with a mental illness, usually a parent.
- Supports 67 support groups which hold over 800 meetings per annum, the majority of which are for carers of those living with a mental illness, CALD and speciality groups.
- As part of a commitment to holistic care and care coordination, SF NSW involves carers in all parts of our specialist mental health services for consumers of mental health care.

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To the Department of Social Services,

SF NSW appreciates the opportunity to provide comment on the proposed model for the delivery of carer services.

SF NSW seeks feedback from carer clients each year; in 2015/16, 90% of carer clients rated our service as excellent or good. As such, SF NSW is well placed to comment on and anticipate real impacts of changes in carer services and policy, including the alignment with what carers want and require for support.

SF NSW delivers services and coordinates care for people across silos of sectors, funding and policy through the building of relationships and trust with other providers, funding bodies and most importantly, individuals and the communities they operate in.

SF NSW would like to raise serious concerns with the proposed model. In particular, we are **concerned with the reliance on the existence and capability of local services** to provide the proposed programs, with no indication of how local services will be supported to do this and in an environment where funding has been stripped from these services.

Furthermore, the **dependence on technological platforms** in this model is alarming. Many of the carers that access our services have little or no access to the internet and limited capability to use smart phones and computers. The strategies in place to provide services for carers who do not use the internet at all (30% of carers) appear inadequate.

A more detailed response is provided in the subsequent pages. SF NSW would welcome the opportunity to participate in further discussions towards the development of the integrated carer services.

Kind regards,

Ellen Marks

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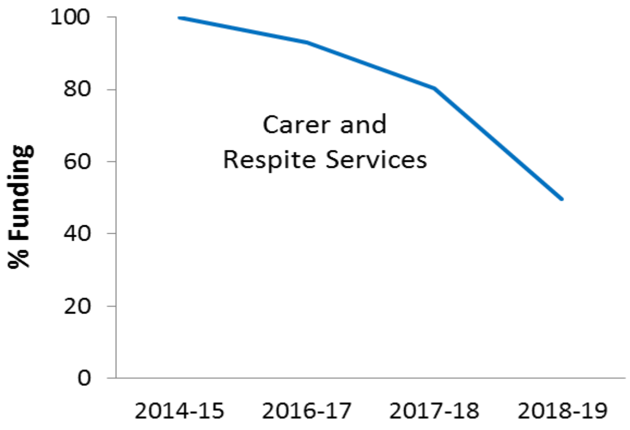
SF NSW comments and recommendations

Model is reliant on capacity of existing services that will be defunded

SF NSW is deeply concerned with the proposed model particularly the reliance on the existence of service providers, following transition of funding away from the very same services, and with no indication of the level of funding support that would be provided in its place.

As identified in the Discussion Paper, funding which has flowed to Respite Services, Mental Health Respite Carer Services, and the On Fire program aimed at young carers, will transition to into the integrated carer model. The projected loss to SF NSW's funding is displayed in the graph opposite. It is unlikely that the same level of service, and the additional services proposed in the Discussion Paper, will be offered unless additional funding replaces that which has been transitioned.



In our experience, funding transitioning into the proposed integrated carer supports, combined with the NDIS roll-out, has created a sector with great instability and market consolidation. These concerns must be addressed in order to achieve effective outcomes from the proposed model and ensure ongoing access to services.

Recommendations:

1. Further invest in carer services, whereby funding for respite services is quarantined from transition and the proposed model is seen as an additional investment.
2. Invest in additional carer services aimed at addressing socio-economic disadvantage, particularly for young carers

Concerns with the level of reliance on online technology platforms

Whilst SF NSW supports the use of innovative technology to reach those who are able to access and use the technology, SF NSW is deeply concerned with the lack of offline supports in the proposed model. The Discussion Paper rationalises this strategy with:

"The Carer Service Development Research, which surveyed 1300 carers across Australia, found that 70% of carers search for information and services using Google (AMR Australia, 2015)." [1]

However, this also means that 30% do not access the internet at all. In our experience, many of the carers who access our services do not have the financial means, infrastructure or ability to use to use the proposed technological platforms. While SF NSW supports innovative technology to support carers, it is important that robust services remain available for the larger percentage who are unlikely to access services which are based on the use of technology. In the proposed model, there are not parallel services offered for every outlined online service, and there is little detail as to how, where and when carers who cannot access the internet will be able to gain access- particularly for those who are living in rural and remote Australia.

Recommendations:

- Maintain and further develop innovative, targeted support and inclusion of carers in the mental health system.
- Ensure that the supports offered to those who do not access the internet are equally robust and detailed in the proposal as for those carers who frequently use the internet.

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[1] AMR 2015

Responses to the specific questions in the Discussion Paper

3. Program Overview

- 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?

SF NSW is deeply concerned with the lack of respite services provided under the proposed model, which indicates that the objective is only to support:

"access to planned respite through collaboration with organisations such as My Aged Care and the National Disability Insurance Agency."

SF NSW does not support respite services being provided through the NDIS. Under the NDIS, individuals with an NDIS package may be able receive funding for respite for their carer, rather than the current situation where respite is provided to the carer without the need for the consumer to elect to use their NDIS package to provide respite. This means opportunities for mental health carers to be supported in their own right are decreasing.

Some people with a psychiatric disability lack insight into their condition, including lack of insight for the need of respite for their carers. These facts must be taken into account when developing strategies for the provision of respite services for carers of those with a psychiatric disability.

Alternatively, respite is provided indirectly, through coordination of activities for the individual with the NDIS package, which indirectly provides time for the carer to undertake respite type activities at their own cost. **Indirect respite under the NDIS does not fund carer supports and requires a great deal of advocacy and coordination to ensure that respite time is achieved.**

While there is mention in the Discussion Paper of the intention to leverage existing community supports for respite services, and an indication of some level of funding support, this relies on the existence of these services in an environment likely to result in market exit of providers.

Carers experience difficulty in navigating the system, and in our experience, advocacy supports for carers is a crucial initiative. Supporting carers through advocacy appears to be lacking in the proposed model.

- 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[2] for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?

Service mapping for regions will require significant consultation with PHNs and LHDs, who are currently undertaking service mapping in their regions. Stakeholder consultation is one way to ensure that a complete view of available supports is captured.

5. About how carers might experience the model

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

For an outcome measure to be effective, the responses need to be collected in one place and, as mentioned above, carers should only be asked to respond from one service. Completing the outcome measure online where carers can be directed would be the only viable option, which will not capture the responses from those who do not access the internet (which will be a key group to receive outcome measures from due to the inadequacies in the proposed services).

Furthermore, it is not clear as to who will carry responsibility of managing the data, how data will be communicated and how the system will be monitored in order to be responsive to changes needed.

- 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?

A quality framework should follow the National Carer Strategy and Carers Recognition Act 2010.s

The organisations involved in regional hubs could form part of a quality framework, however, the feasibility of this strategy at local level is not clear.