Champions for change

REPORT

Working together with families, carers and friends as partners in mental health recovery

Supported by:

Brisbane South PHN is the lead agency for the Partners in Recovery program supported by the Australian Government
Champions for Change

Working together with families and carers as partners in mental health recovery

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October 2015
Acknowledgements

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Contents

Acknowledgements ....................................................................................................................................... 4
Executive summary ..................................................................................................................................... 6
1. Introduction and background .................................................................................................................. 9
   1.1 Purpose, background, key milestones, objectives ............................................................................. 9
   1.2 Report structure ................................................................................................................................. 9
   1.3 Methodology .................................................................................................................................... 9
2. Family and carer involvement in recovery: A framework ...................................................................... 10
3. Forum results .......................................................................................................................................... 11
   1.3 Priority ideas (see Appendices 7.1 for detailed ideas) .................................................................... 11
4. Discussion and conclusions .................................................................................................................. 12
5. Recommendations .................................................................................................................................. 14
6. References ............................................................................................................................................. 18
7. Appendices ........................................................................................................................................... 18
   7.1 Issues and ideas – in detail ................................................................................................................ 18
   7.1 Forum program ................................................................................................................................ 22

Figures
Figure 1: Family Engagement and Support Framework key domains....................................................... 7

Tables
Table 1: FESF’s four key domains ............................................................................................................. 10
Table 2: Priority ideas from forum groups ............................................................................................... 11
Executive summary

The March 2015 Partners in Recovery Family and Carers Forum (‘the Forum’) was unique in its engagement of over 70 family members and carers in the process of crafting detailed practice, service system and implementation advice for mental health care system stakeholders, including clinicians.

The project generated detailed advice and also distilled clear, concise, key messages that are powerfully presented as families and carers declare their best ideas for a better future.

While many of the messages highlight the challenges involved in being a family member or carer, and of interacting with complex mental health systems, the overriding message is one of hope for the future.

An overwhelming message was that families and carers are committed to being a ‘family’ and to being connected. This significantly contributes to recovery outcomes, health and wellbeing. They want to be actively included in recovery planning and the implementation of those plans and to be acknowledged as primary stakeholders with much to offer and lots to gain in terms of the sustainability of their role.

The experiences of families and carers can involve numerous challenges which unfold over many years and even a lifetime. Families and carers are often the first to know when treatment is needed and play a critical role in how people living with a mental health difficulty are included in community and family life.

This report reveals a key message that recovery is more likely if families and carers are involved as partners in the process. It is built around an understanding that life for a person living with a mental health difficulty is better if relationships and ties with families, friends and carers are as strong and healthy as possible.

In addition to the 70 family members and carers who were the focus of the event, the Forum was also attended by 30 healthcare providers. The focus was on working together towards change in Brisbane South mental health services and towards better recognition of families and carers as partners in recovery.

This work has emerged because while families and carers play a critical role in supporting the recovery and wellbeing of people living with mental health difficulties, there is growing recognition of the considerable challenges faced by people in a caring, supporting role and that ‘carers need support in their own right to maintain and develop their resilience and wellbeing’\(^1\). Even more important is the evidence that recovery is most likely when families and carers are involved as equal partners.

This report details the results of the Forum which arose from an earlier study documenting a Family Engagement and Support Framework\(^2\) (the Framework). Stakeholders were engaged in a robust workshop process which asked a number of insightful questions relating to each of the four domains identified as part of the Framework, refer to Figure 1.

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2 Ibid.
This report identifies a range of themes which are presented through the lens of the four key domains identified within the Framework. Some key issues and suggestions include:

- the need to actively include families and carers as partners in service delivery and recovery and to respect and value the role of carers and families in the wellbeing of a person living with a mental health difficulty
- the need to provide education and information to carers and families as well as to key parts of the service system (including GPs, emergency services, primary care providers) and the broader community
- the need for a consistent approach to identifying and addressing the needs of carers and families at all points of contact with the service system. This requires protocols and an active, overt and consistent approach to support plans for carers
- the need for infrastructure to support the role of carers and families including carers hubs where services and support can be consolidated as a base from which to meet diverse needs
- the important role of peer-to-peer support delivered in a range of ways
- the need for an approach to service delivery that recognises and acts on opportunities for early intervention, reduces the escalation of a crisis, and actively preserves the wellbeing, resources and long-term involvement of carers and families
- the need to address system gaps such as lack of housing and supported accommodation as part of a broader strategy for transition towards greater independence.

Principles of service delivery which emerged are highly consistent with the framework overview developed by Harper and Thomas and provided in Figure 1. These include:

- **respect** for and understanding of the role of families and carers in a person’s wellbeing and recovery, as well as their role in continuity of care
- the **rights** of families and carers to information, involvement, collaborative planning, support and recognition in various practical manifestations of how services are provided
- services to be provided in a warm, consistent and **caring** way
- carers and families want to be **connected** with each other, with support and with the broader community
- services spanning acute, clinical and community based care need to be actively **coordinated and integrated** and for this to include the role of carers and families.

A full list of recommendations is tabled on pp 14-17. Although some recommendations may require workforce capacity building, they would be supported by the incremental change process underway via the structural and governance arrangements already in place through the Greater South Joint Mental Health Collaborative.
1. Introduction and background

1.1 Purpose, background, key milestones, objectives

This report captures ideas generated at the March 2015 Partners in Recovery Families and Carers Forum by families, friends and natural support networks of people living with mental health difficulties. The Forum was attended by over 100 people including 70 family members and carers.

The Forum focussed on working together towards change in Brisbane South mental health services and towards better recognition of families and carers as partners in recovery. There is growing recognition of the considerable challenges faced by people in a caring, supporting role and that ‘carers need support in their own right to maintain and develop their resilience and wellbeing’\(^3\). Even more important is the evidence that recovery is most likely when families and carers are involved as equal partners.

The Forum was structured and guided by an earlier study documenting a Family Engagement and Support Framework\(^4\) (FESF or ‘the Framework’) which included four key domains acknowledged as the key concerns of families supporting people living with mental health difficulties:

1. Improving access to services
2. Families and carers as partners in supporting recovery
3. Access to information and education
4. Family health and wellbeing.

The earlier report was based on a substantial literature review and consultation with people with lived experience of mental health difficulties, family members, young carers, GPs and service providers (including specialist agencies working with specific target groups such as young people, those from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples, and refugees).

1.2 Report structure

This report identifies key suggestions through the lens of these four key domains and offers implementation advice and recommendations to key stakeholders involved in mental health care. It includes:

- An overview of the Family Engagement and Support Framework
- An overview of the broader context of recovery and the important role that families and carers play
- Outcomes of the Family and Carer Forum
- Discussion, conclusions and recommendations.

1.3 Methodology

The Forum:

- Harnessed the findings of an engagement and research project documented in the Family Engagement and Support Framework for the Southside Mental Health Collaborative report
- Presented the framework as a basis for working in small groups plus a plenary session to address each of the four domains. Key messages are captured in this report and in a companion booklet, Champions for Change

The Forum produced photographs; the Champions for Change booklet, which is for use by families and carers as they navigate the healthcare system; and this report, which provides advice for improved systems, service delivery and practice as well as key recommendations linked to the four domains from the FESF.

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\(^4\) Ibid.
2. **Family and carer involvement in recovery: A framework**

The creation of The Forum recognises the critically important role of families and carers in the recovery process, and the significant financial, emotional, social and physical challenges of supporting someone living with mental health difficulty.

The Forum results are described and analysed according to the FESF’s four key domains:

**Table 1: FESF’s four key domains**

<table>
<thead>
<tr>
<th>Domain 1: Access to services and supports for the person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gaining access to services for the person with mental health difficulties when required is a critical concern for families and carers. Consultations revealed that families and carers are feeling the constriction of services and many feel frustrated and abandoned. Families and carers identified difficulty in gaining support for their loved ones especially when the person’s distress is escalating.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 2: Partners and service delivery and recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families and carers frequently feel disrespected and excluded from the care, support and treatment decisions of their loved one. Too often, they feel that their contribution to the care and support of the family member is not acknowledged and their wisdom and understanding of the family member is not valued. People can even feel belittled and that their knowledge is seen as less important.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 3: Access to information and education to enhance the families and carers’ capacity to support the person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many families are poorly equipped to support the person with mental health issues and find it difficult to gain information and education that is accessible and targeted to their needs. Many recounted stories of struggling to get basic information about a range of topics both mental health specific and practical.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 4: Support to sustain the health and wellbeing of family and carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>The wellbeing of family and natural support network members who are supporting a person with mental health difficulties may be highly compromised. Families must be recognized as being at significant risk of entering the mental health system in their own right unless there is adequate attention to their needs. Some groups are likely to be at an even higher risk including ATSI, refugee, young family members and those with multiple caring roles.</td>
</tr>
</tbody>
</table>

*Source: Adapted from Harper and Thomas, 2014:5*
3. Forum results

1.3 Priority ideas (see Appendices 7.1 for detailed ideas)

Each group identified high-priority ideas in line with the four domains:

<table>
<thead>
<tr>
<th>Table 2: Priority ideas from forum groups</th>
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<tbody>
<tr>
<td><strong>Priority ideas</strong></td>
</tr>
<tr>
<td><strong>Service access for the person</strong></td>
</tr>
<tr>
<td>• More active and warm referral processes</td>
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<tr>
<td>• Improved access to clinical services</td>
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<tr>
<td>• More accessible clinical services and fewer ongoing costs such as parking</td>
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<tr>
<td>• Better responses to the costs of caring (such as parking)</td>
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<tr>
<td>• Outreach, in-home services</td>
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<tr>
<td>• Flexible, after-hours support</td>
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<tr>
<td>• More funding for support programs</td>
</tr>
<tr>
<td>• Active service facilitation, coordination and integration</td>
</tr>
<tr>
<td>• Carer hubs and space for carers in acute facilities</td>
</tr>
<tr>
<td>• Address service system gaps such as lack of housing and supported accommodation, acute care options, e.g. for people aged under 25</td>
</tr>
<tr>
<td>• Culturally responsive service delivery</td>
</tr>
<tr>
<td><strong>Partners in supporting recovery</strong></td>
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<tr>
<td>• Respect for and valuing of family and carer roles. Recognition of families/carers as important and being included in a person’s care</td>
</tr>
<tr>
<td>• Promote a framework of carers’ rights with practical responses, e.g. robust and collaborative care, discharge planning and a role in support planning</td>
</tr>
<tr>
<td>• Improved communication and specific carer-communication strategies</td>
</tr>
<tr>
<td>• Collaborative, robust discharge plan</td>
</tr>
<tr>
<td>• Approachable, experienced and warm staff</td>
</tr>
<tr>
<td>• Joint family/carer meetings</td>
</tr>
<tr>
<td><strong>Information and education</strong></td>
</tr>
<tr>
<td>• Better access to information in key locations such as general practice, allied health, schools, Centrelink, police. This could include a directory of services</td>
</tr>
<tr>
<td>• Educate service providers including GPs and first responders about family/carer needs and roles</td>
</tr>
<tr>
<td>• Community and school education to help reduce stigma and isolation</td>
</tr>
<tr>
<td>• Family and carer education programs to explain causes, symptoms, early warning signs, treatments, etc.</td>
</tr>
<tr>
<td>• Innovative approaches to managing confidentiality and privacy with respect for the role of carers in ongoing support</td>
</tr>
<tr>
<td><strong>Family health and wellbeing</strong></td>
</tr>
<tr>
<td>• Prevention and early intervention approaches to avert crises</td>
</tr>
<tr>
<td>• Family and carer support programs including tailored responses to people under 18 years</td>
</tr>
<tr>
<td>• Peer support programs</td>
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<tr>
<td>• Routinely link families and carers to support services</td>
</tr>
<tr>
<td>• Develop family/carer support strategy/plan (which might be at the service level and the individual level)</td>
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</tbody>
</table>
4. Discussion and conclusions

The Forum collected significant amounts of material which broadly spanned:

- **principles** to guide service delivery and overall responses to the needs of carers and families
- **issues** identified and experienced (including some service system gaps)
- **responses** to those issues.

There was a high degree of consistency across groups on issues such as:

- the need to actively include families and carers as partners in service delivery and recovery and to respect and value the role of carers and families in the wellbeing of a person living with a mental health difficulty
- the need to provide education and information to carers and families as well as to key parts of the service system (including GPs, first responders) and broader community
- the need for a consistent approach to identifying and addressing the needs of carers and families at all points of contact with the service system. This requires protocols and an active, overt and consistent approach to support plans for carers
- the need for infrastructure to support the role of carers and families including the often-mentioned idea of carers’ hubs where services and support can be consolidated as a base from which to meet diverse needs
- the important role of peer-to-peer support delivered in a range of ways
- the need for an approach to service delivery which recognises and acts on opportunities for early intervention which reduces the escalation of a crisis and actively preserves the wellbeing, resources and long-term involvement of carers and families
- the need to address service system gaps such as lack of housing and supported accommodation as part of a broader strategy for transition towards greater independence.

Principles of service delivery which emerged are highly consistent with the framework overview developed by Harper and Thomas and provided in Figure 1. These principles include:

- **respect** for and understanding of the role of carers and families in a person’s wellbeing and recovery, as well as continuity of care
- the **rights** of families and carers to information, involvement, collaborative planning, support and recognition in various practical manifestations of how services are provided
- services to be provided in a warm, consistent and caring way
- carers and families want to be **connected** with each other, with support and with the broader community
- services spanning acute, clinical and community-based care need to be actively coordinated and integrated and for this to include the role of carers and families.

The Forum highlighted that sharing of information is sometimes in conflict with concepts such as confidentiality and privacy. Carers felt it was important to work on a new approach to confidentiality and privacy which takes into account the central role of carers and families in the person’s future and in the capacity for implementation of support towards greater independence.

The Forum has generated ideas about and support for a number of very practical initiatives. This includes strengthening and continuing some existing strategies and actions as well as some new approaches to supporting the role of carers and families. A key challenge and opportunity is to maintain the Forum’s momentum, and the preceding work to develop the Framework, and provide the capacity for successful implementation of key ideas in the future.

Many of the ideas focussed on improved practices which will rely on more and improved training, mentoring and cultural change processes. This is an important distinction from factors such as system features and a
lack of resources. Many of the ideas generated present real opportunities for change that do not necessarily generate additional costs.

The Forum does, however, raise the question of what structural arrangements are in place to drive improvements at the practice and systems level and how people living with a mental health difficulty, their families and carers are involved and engaged in those structural arrangements.

Additional and continued engagement with families and carers was mentioned several times. This Forum and the ongoing work of the Family and Carer Working Group of the Greater South Joint Mental Health Collaborative are important foundations for a well-structured approach to planning and implementation of changes which address the needs, issues and ideas raised by carers and families as part of this project.
5. Recommendations

The following recommendations are structured to reflect those ideas focussed on changes to:
(1) MENTAL HEALTH SYSTEMS, (2) SERVICE DELIVERY and (3) PRACTICE.

<table>
<thead>
<tr>
<th>1</th>
<th>Recommendations for change to the MENTAL HEALTH SYSTEM</th>
<th>Link to Family Engagement and Support Framework Domains</th>
</tr>
</thead>
</table>
| 1.1 | Ensure a ‘no wrong door’ approach to families and carers so they can access:  
• consistent information  
• active approaches to referral  
• links with peer support  
• links with education programs to assist them in their role  
• collaborative planning for their own needs and role in a recovery action plan. | • Access to services  
• Access to information and education  
• Support to sustain health and wellbeing |
| 1.2 | Develop a workforce capacity building strategy to ensure leading practices develop and consolidate, including family-inclusive practice, warm referrals, culturally-competent practice and service delivery models. | • Access to services  
• Partners in service delivery and recovery  
• Support to sustain health and wellbeing |
| 1.3 | Address system gaps impacting on families and carers, including the need for improved housing options and supported accommodation options to assist with succession and transition planning. Work collaboratively with housing systems to generate appropriate housing and supported accommodation responses enabling families and carers to transition in their roles. | • Access to services |
| 1.4 | Work to strengthen information-sharing protocols and practices so that families and carers do not have to repeat their story as often and that the role of particular families and carers is documented and understood by successive care providers. | • Access to services  
• Access to information and education  
• Partners in service delivery and recovery  
• Partners in service delivery and recovery |
| 1.5 | Develop a system-wide procedure for assessing family and carer needs, and developing a family/carer support plan as part of overall treatment and recovery. | • Support to sustain health and wellbeing |
| 1.6 | Develop a framework of family and carer rights which manifests in practical responses such as robust and collaborative care, including discharge planning and involvement in support planning. Undertake a program of mental health care services adopting this framework of rights. | • Partners in recovery  
• Support to sustain health and wellbeing |
<p>| 1.7 | Locate key services in accessible locations including access to public transport, reduction in parking costs and other barriers. | • Access to services |
| 1.8 | Maintain regional structural arrangements with capacity for planning and implementation of initiatives that actively engage families and carers and address their needs. | • Partners in service delivery and recovery |
| 1.9 | Provide better access to information in key locations such as general practice, allied health, schools, Centrelink, police. This could include a directory of services. | • Access to services • Partners in service delivery and recovery • Access to information and education • Support to sustain health and wellbeing |
| 1.10 | Educate service providers including GPs and first responders about family and carer needs and roles. Include training programs in competencies related to working effectively with natural helping systems | • Information and education • Support to sustain health and wellbeing |
| 1.11 | Provide community and school education programs integrated with curriculum to help reduce stigma and therefore isolation. | • Information and education |
| 1.12 | Expand and routinely offer family and carer education programs to explain causes, symptoms, early-warning signs, treatments, coping strategies and an understanding of the caring role in recovery (such as WellWays). | • Information and education • Support to sustain health and wellbeing |
| 1.13 | Develop innovative approaches to managing confidentiality and privacy with respect for the role of families and carers in ongoing support | • Access to services |
| 1.14 | Support and implement specialised family and carer support programs including tailored responses to people under 18 years. | • Access to services • Support to sustain health and wellbeing |
| 1.15 | Resource roles which actively help to facilitate, coordinate and integrate responses to the needs of families and carers. This could include system navigators for families and carers. | • Access to services |
| 1.16 | Ensure specialist Indigenous and culturally and linguistically diverse services and roles can be accessed. | • Access to services • Access to information and education |</p>
<table>
<thead>
<tr>
<th></th>
<th>Recommendation for changes to SERVICE DELIVERY</th>
<th>Link to family engagement and support framework domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Design service delivery models to include the option of outreach/in-home consultations providing family support and involving family members and other carers.</td>
<td>• Access to services</td>
</tr>
<tr>
<td>2.2</td>
<td>Design service delivery models to reflect a flexible approach to after-hours support.</td>
<td>• Access to services</td>
</tr>
<tr>
<td>2.3</td>
<td>Ensure comprehensive, coordinated and collaborative discharge planning ensures a seamless transition between hospital and the community and involves families and carers as important partners. This includes developing and implementing a robust, holistic discharge plan and engaging families and carers in this process.</td>
<td>• Partners in service delivery and recovery</td>
</tr>
<tr>
<td>2.4</td>
<td>Pilot a carers’ hub as a basis for providing consolidated and diverse services, supports and activities. Ensure there is space for gathering and for the provision of a range of peer-to-peer support services.</td>
<td>• Support to sustain health and wellbeing • Access to information and education</td>
</tr>
<tr>
<td>2.5</td>
<td>Support and expand peer-to-peer support programs.</td>
<td>• Support to sustain health and wellbeing</td>
</tr>
<tr>
<td>2.6</td>
<td>Work with families and carers to develop transition and succession plans towards greater independence.</td>
<td>• Support to sustain health and wellbeing • Partners in service delivery and recovery</td>
</tr>
<tr>
<td>2.7</td>
<td>Develop collaborative recovery action plans involving families and carers.</td>
<td>• Partner in Recovery</td>
</tr>
<tr>
<td>2.8</td>
<td>Offer joint family/carer meetings to share information, ideas and perspectives with other care givers.</td>
<td>• Access to information and education • Partners in service delivery and recovery</td>
</tr>
<tr>
<td>2.9</td>
<td>Develop individual service level responses to hardship and financial disadvantaged experienced by families and carers including keeping the cost of activities low, providing parking, etc.</td>
<td>• Support to sustain health and wellbeing</td>
</tr>
<tr>
<td>2.10</td>
<td>Develop a family/carer support strategy/plan (which might be at the service level and the individual level). This could include an individual family/carer support plan as well as an organisational level family and carer support plan. This will require the routine assessment of family and carer needs as part of a holistic intervention and recovery action plan.</td>
<td>• Support to sustain health and wellbeing</td>
</tr>
<tr>
<td>2.11</td>
<td>Provide timely information to families and carers at their first point of contact. Continue to offer access to information and referrals at all points of contact.</td>
<td>• Access to information and education</td>
</tr>
</tbody>
</table>
### Recommendation for changes to SERVICE DELIVERY

| 2.12 | Define and embed early intervention approaches to interventions which fully assess how well natural helping systems are coping and implement strategies to address needs identified. | Support to sustain health and wellbeing |

### Recommendations for improvements to PRACTICES

| 3.1 | Routinely offer to link families and carers to peer support programs | Support to sustain health and wellbeing |
| 3.2 | Routinely and actively link families and carers to support services depending on their assessed needs. | Support to sustain health and wellbeing |
| 3.3 | Use warm and active referral processes when linking families and carers to other resources and services. | Access to services |
| 3.4 | Provide flexible options for strengthening family relationships and communication. | Partners in recovery, Support to sustain health and wellbeing |
| 3.5 | Embrace and develop family responsive practice within individual practice frameworks and service delivery models. | Access to services, Support to sustain health and wellbeing |
6. References


7. Appendices

7.1 Issues and ideas – in detail

**Respect for families and carers**
- Clinicians should be respectful of carers and ensure a partnership approach in designing and implementing recovery plans.
- Carers make a significant contribution to the life of a person living with a mental health difficulty and should be acknowledged for this important role.
- Carers are an important source of knowledge and information and they should be recognised as experts worthy of inclusion in a person’s care and in future planning.
- Their key role must be embedded more deeply in practice and factored into the overall approach to clinical care, e.g. carers should be involved in meetings with the person, their clinicians and other professionals.
- Some participants view the role of carers within a framework of rights such as:
  - including carers in treatment and discharge planning
  - involving carers in support planning with non-government organisations
  - validating and respecting the experiences of carers.
- Spirituality is helpful to some carers and should be respected as part of an holistic approach to their needs.

**Contact with clinicians**
- Carers want clinicians to share information about available services and participate in family consultations to create a shared implementation plan.
- The carer/clinician relationship is particularly important if the person living with a mental health difficulty does not want to engage or thinks nothing is wrong.
- Carers need to understand the information being given to the person living with a mental health difficulty to enable follow up plans, support and clinical intervention.
- Families want to be part of a team with clinicians. Coordinated contact between health services is also valuable, including communication between emergency wards, mental health units and community-based mental health care.
- Some carers are shy and vulnerable and find it hard to assert their views, share ideas, ask for help, be assertive in clinical settings, or ensure access to essential community based services.
- Carers need access to flexible and responsive clinical services that cater to the needs of families trying to deal with episodic mental health difficulties.
• Strong support from GPs is very important, as is access to 24/7 telephone access to the hospital.

**Practical ways to involve carers as partners in service delivery and recovery**
- Joint meetings with carers and the person living with a mental health difficulty helps increase knowledge and the desire for recovery.
- Increased access to in-home services enables the whole family to engage in a recovery plan.
- Support for families and carers provides time for them to do other things, e.g. young children need access to outings and other recreational opportunities.
- Consider the implications of cultural differences and the expectations on women in certain cultures to care for others.
- Enable the entire family to access information and increase their understanding. Even if a person doesn’t want their carer involved, it is sometimes helpful if services work to engage families regardless, i.e. services need to proactively offer help to carers, not wait until there is a crisis.

**Active referrals to support and service**
- Carers need better access to active and warm referral processes to supports, services and resources.
- This approach actively facilitates contact between a service and the person seeking help.

**Carer support plans and recovery action plans**
- Develop carer support plans as part of overall treatment and recovery.
- These could include partnership approaches to recovery, links to supports and services for carers, and how information will be shared over time.
- Wellbeing Recovery Action Plans (WRAP) are one way to achieve better information and education involving carers.
- Collaborative, inclusive recovery action plans that address the role of families and carers can help clarify roles and the best ways to help.

**'No wrong door'**
The forum raised the need for a ‘no wrong door’ approach to accessing services. For carers already experiencing the impacts of supporting someone, the process of knocking on multiple doors, telling and retelling your story and struggling to make progress all contribute long-term to stress. Where these challenging persist, it may even be a risk that the caring role is unsustainable.

**When carers first make contact with services**
- It is important for information to be clear and concise and for service providers to provide timely follow-up.
- Post-discharge plans must be clear and referrals should be made early so that the transition from hospital care is seamless.
- It is helpful when clinicians hear a carer’s side of the story and about how their friend or relative is coping.
- Good, consistent information is vital, wherever the first point of contact is made. This includes GPs, hospitals and emergency services.

**Discharge from hospital is a vulnerable time**
- Families and carers are often unaware that a person may still be unwell at discharge.
- Discharge planning must be collaborative: Clear communication with families and carers can make considerable difference to how a discharge plan is implemented.
- It is crucial families and carers have access to information and are included as a valued part of a support system for the person.
- Transition planning and facilitation needs improvement: ‘When our loved one leaves hospital we need to be told how we can help, a list of resources, and to be linked to community services and supports.’
System navigation and integration
- Carers report that the system can be very hard to navigate.
- Individual support navigating community and clinical services is needed to improve coordination and integration between in-patient and community-based care as these services have diverse but often complementary roles.
- It would be helpful to have designated roles designed to help families, carers, and people living with mental health difficulties at an individual level.
- A directory of services including information about where carers can get help for themselves would be useful.

Confidentiality and privacy
- Better confidentiality and privacy policies relating to individual health information are required.
- Confidentiality and privacy policies can exclude family and carers from being partners in recovery.
- Carers are seeking a more collaborative approach with the clinical team involved in the care of their relative or friend and confidentiality sometimes conflicts with this.

Contributing to continuity of care
- Continuity of care significantly impacts the wellbeing of a person living with a mental health difficulty, and families and carers play a very significant role in providing this.
- Carers and families are seeking a more central and collaborative role in the care team.

Outreach and after hours support
- A carer’s role extends beyond usual business hours, and flexible support and after-hours assistance is crucial.
- After hours support services require approachable staff with skills and capacities beyond qualifications.
- Crisis support is a critical element as carers often need a great deal of assistance because a situation may have deteriorated or become unmanageable.
- This type of service will require considerable further engagement with carers and people living with a mental health difficulty.
- Generally, more in-home care was seen as important for a range of reasons including as a way to involve the whole family.

The cost of accessing services and financial hardship
- Clear pathways for access are essential as families and carers can waste money taking ‘wrong turns’.
- The financial hardship experienced by some carers must be acknowledged and addressed by the mental health care system.
- Parking and travel can be a significant cost for supportive carers or family members.

Caring for carers: Early intervention and prevention contributes to longevity
- Early intervention and prevention for carers is vital and must be individualised.
- It invests in the sustainability of their role and benefits people living with a mental health difficulty.
- Resources and services must be in place long before a crisis arises.
- Families and carers needed perseverance and the service system must not push them beyond their capacity to cope.

Information, education and reducing stigma
- Information about the needs of families and carers should be available in general practice, allied health services, schools, hospitals, Centrelink, and emergency services.
• Families and carers need better and more frequent access to information and education about mental health difficulties, causes, treatments, resources and how best to help. This will also help them feel effective and supported.
• A communication and education strategy is needed to ensure information is presented in plain language and delivered via multiple platforms, e.g. online and offline via social media, groups, carer-to-carer.
• People only get information if they know where to look.
• Misinformation and confusion at a community level contributes to stigma and isolation experienced by carers and strategies to address this could improve community inclusion and general wellbeing.
• Community education programs were recommended, including positive, good news stories. Mental health services could possibly link in better with mainstream events.
• Mental health first aid could be expanded at the community level, e.g. in workplaces, schools.

Peer-to-peer support and training
• Peer and carer groups provide support and improve access to information at varying times and in flexible ways.
• People living with mental health difficulties and their carers need support to understand mental health difficulties and their causes, triggers and early warning signs.
• WellWays 12 week program, led by people with a lived experience of caring for someone, was cited as an excellent support program.
• Services (clinical and community based) could actively offer carers information about support networks and ways in which they can care for themselves, e.g. ask carers how they are going and respond with individualised ideas about supports, resources and ways of making connections with others.

Carer hubs: one stop shops
• Carer hubs and one-stop-shop approaches to the delivery of services are important.
• They develop a collaborative approach to harnessing services and resources by helping carers and families access referrals, engage with government, advocate for improvements, and exchange vital information.
• It would be helpful to provide space or a room for families in acute facilities.

Transitioning to independence
• Preparing for and achieving a transition to greater independence for the person living with a mental health difficulty is a source of considerable anxiety for carers, particularly ageing parents.
• Significant work is required to establish new and better ways for systems to work together.

Housing and accommodation
• Some supports and service system elements were seen as weak or missing from the options available to families and carers, e.g. accommodation, housing options.
• More supported housing is needed as this plays an important role in future planning, transition towards sustainability and towards the sustainability of the caring role.

Cultural responsiveness
• Culture plays a significant role in defining caring roles, particularly for female caregivers.
• Cultural responsiveness is important in service system design, service delivery models, and at the practice level.

A response to siblings
• Siblings can be impacted by the mental health difficulty of a family member.
• Active, tailored support is needed for people under-18 years, including someone to speak with, provide information and, if appropriate, involve them in care.
Funding stability and program responsiveness

- Stable, flexible and responsive funding is needed to ensure services are consistent and embedded in the communities and lives of carers.
- Participants were keen to explore expanded funding options including more government support, innovations in social enterprises, and the role of private enterprise in addressing the needs of people living with a mental health condition and their natural support networks.

7.1 Forum program

### Agenda

**Wednesday, 25 March 2015**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>8:30-9:00am</td>
<td>Registrations</td>
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<tr>
<td>9:00-9:15am</td>
<td>Welcome to country: Adrian Bugguburra</td>
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<td>9:15-9:30am</td>
<td>Donna Bowman: Chair of the Greater South Joint Mental Health Collaborative</td>
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<tr>
<td>9:30-10:00am</td>
<td>Yvonne Donnan: Chair Family and Carer Working Group - Framework for Change</td>
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<td>Kim Thirkettle: Presenting a carer perspective</td>
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<td>10:00-10:30am</td>
<td>Morning tea</td>
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<tr>
<td>10:30-11:30am</td>
<td>Round table discussions: Family engagement and support framework – Domains for change</td>
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<tr>
<td></td>
<td>DOMAIN ONE Service access for the person experiencing mental health difficulties</td>
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<td></td>
<td>DOMAIN THREE Education and information to enhance capacity to support recovery</td>
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<tr>
<td>11:30am-12:30pm</td>
<td>DOMAIN TWO Partners in supporting recovery</td>
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<tr>
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<td>DOMAIN FOUR Support for family health and wellbeing</td>
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<tr>
<td>12:30-1:15pm</td>
<td>Buffet lunch and networking</td>
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<tr>
<td>1:15-1:30pm</td>
<td>MnB Entertainment dance performance</td>
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<tr>
<td>1:30-2:30pm</td>
<td>Feedback from sessions</td>
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<tr>
<td>2:30-3:00pm</td>
<td>Where to from here and closing messages</td>
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THANK YOU TO WONDERFUL CLINICIANS WHO LISTENED and provided timely SUPPORT. YOU ARE STARS!