



# Carer Framework

October 2017

 neami  
national  
Improving Mental Health  
and Wellbeing

 Me  
Well

## Acknowledgements

Thank you to the Neami Carer Consultant and Carer Framework Steering Group members who contributed their time, expertise and insights to clarify the value the Neami Group places on carers in the recovery process.

Many thanks to consumers, carers, carer site champions and senior leadership teams across the country for their contribution to the final framework.

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# Foreword

Carer Inclusive Practice has become considerably more of a focus over time both internally for the Neami Group and broadly within the mental health sector, particularly since research has extended in this area to reflect how actively including carers and families in practice has a positive impact on consumer/customer outcomes. Over time as our organisational experience has matured, the focus of service provision has expanded, as has workforce understanding and practice within an inclusive recovery framework. The external context also continues to shift rapidly, particularly within the continued evolving environment of the NDIS. Within and outside of this context, opportunities continue to arise for the Neami Group to continue to build upon practices surrounding the inclusion of carers in order to achieve increased positive recovery outcomes and as such, indirectly influence the selection of Neami/Me Well as a preferred provider for service delivery.

As with any framework, the challenge is to capture the present and future aspirations of the organisation and provide structure whilst also promoting flexibility to adapt and evolve dynamically. Thank you to all of the contributors to this process over time, including carers, consumers, management and staff as well as the Carer Framework Steering Group members and Carer Framework Project Officer who led the consultation processes.

I commend this framework to you and look forward to seeing its continued evolution over time.



Arthur Papakotsias  
Chief Executive Officer

# Introduction

## Purpose

The aim of the Carer Framework is to inform and guide the Neami Group\* practice for effectively engaging with carers, families and friends in support of achieving positive recovery outcomes for individuals accessing services.

The aim of the Framework is also to outline and strengthen practices related to carer inclusivity within the delivery of all Neami services and contexts.

Neami is implementing the framework to achieve:

- Consistent understanding of Carer Inclusive Practice across Neami contexts in all States.
- An ability to benchmark and innovate, in line with continuous improvement practice.
- The maintenance of a partnership approach with carers and other relevant stakeholders in order to achieve better recovery outcomes for individuals accessing services.
- Relevance within a fee-for-service environment, with close consideration of the role that carers play in the customer's choice of an NDIS provider.
- Consistency in understanding the legislative obligations/operations within services within the legislative requirements of various Acts.

The framework will do the following:

**Define** carers consistently across Neami's diverse service contexts.

**Promote** Carer Inclusive Practice through understanding principles and practice models and what legislative requirements govern carer inclusive practice.

**Describe** a range of strategies and processes to strengthen existing practice.

**Enable** Neami to set well considered priorities in cultivating Carer Inclusive Practice.



Diagram 1. Carer Inclusive Practice at Neami (summarised). Carer Inclusive Practice will be promoted throughout the organisation through an understanding of guiding principles, practice models and legislative requirements.

\*The Neami Group refers to Neami National, Me Well and all other associated services/programs. Hereforth 'Neami' will be used to encompass all Neami Group activities.

## Definitions

The following key terms are defined as follows:

- **Carer** refers to people who have an interest in an individual's wellbeing, who are impacted by their illness and provide support to them at times of need.
- **Carer inclusion and family engagement** refer to a range of interactions that lead to proactively seeking the family/friend/carer's contribution of their skills and knowledge of the history, context, strengths, hobbies, personality, likes and dislikes of the service user. This is also relevant within an NDIS context, as this is particularly useful in the development of an NDIS plan and throughout the planning process.
- In this document the term 'family' is used interchangeably with the word 'carer'. Both refer to significant relationships in an individual's life that provide emotional, financial, or in-kind support in the recovery journey. These relationships are not assumed to be biological and may include any person who the individual chooses to relate with, including but not limited to parents, children, siblings, spouses, friends and neighbours.

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"It's a life commitment. It's not something that you take on for a week, a month; it's a commitment. But you do it out of love"

- Carer Comment



# Context

## Service User Outcomes

While recognising that consumer/customer choice and self-determination are an important part of the recovery process, research is clear that outcomes for service users are better when carers are engaged<sup>1</sup>. Neami National has long been providing supports that have been inclusive of carers and families. From carer information evenings and carer support groups, to joint care planning meetings and the introduction of Family and Carer Support Prompt, different service sites have adopted different approaches in supporting better outcomes for service users.

## Diverse and Inclusive Practice

Neami has long been committed to providing equity of access and seeking to ensure services are welcoming and respectful of diversity, supported by our National Diversity and Inclusion Framework. This commitment also extends to carers and families supporting individuals who access our services. One example of this may include caring duties provided by several family members, e.g. in Aboriginal and Torres Strait Islander communities. In such cases, it is essential that the needs of multiple carers or those from diverse backgrounds are acknowledged and supported in order to best meet the needs of the consumer/customer.

## External Context

The introduction of the National Disability Insurance Scheme (NDIS) led to the creation of Me Well, our purpose-built NDIS service. Where in effect, the NDIS presents a fundamental shift from block-funded systems to a market-driven environment. As such, customers and their families will select organisations based on their individual needs, requirements and preferences. The involvement of carers within the NDIS environment will support customer recovery by contributing further context to the initial assessment and better inform plans (Carers Australia Ltd., 2017).

Simultaneously, Neami National services are going through a period of unprecedented change. This includes the expansion of service types and the diversification of support roles, therefore, a framework to support carer inclusive service delivery is necessary.

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<sup>1</sup>Outcomes such as decreased symptoms, reduced relapses and rehospitalisation, increased self-care and decreased social withdrawal are obtained by engaging the family as well as the consumer (for example, Giron et al 2010; Chien, Phil & Wong 2007; Pitschel-Walz, et al., 2001; Magliano, Fiorelli, Malangone, De Rosa & Maj, 2006).

## Legislative Environment

A framework supports Neami to adhere to Legislative requirements under six existing Carer/s Recognition Acts<sup>2</sup> and supports Quality Improvement Requirements under accreditation (Appendix A outlines obligations in more detail).

Each State and Federal government has developed Carer Recognition Legislation outlining requirements of organisations to recognise and engage carers:

- *Carer Recognition Act 2010* (CTH)
- *Carers Recognition Act 2004* (WA)
- *Carers Recognition Act 2005* (SA)
- *Carers (Recognition) Act 2008* (Qld)
- *Carers (Recognition) Act 2012* (Vic)
- *Carers (Recognition) Act 2010* (NSW)

Neami has a minimum obligation to develop a Carer Inclusive Practice Framework under some of the various Acts. As such, the Carer Framework will support us in meeting our legislative requirements.

All State and Federal mental health legislation encourages the delivery of services in a partnership manner. In addition, the adoption of the National Recovery Framework (2013), National Practice Standards for the Mental Health Workforce (2013) and accreditation processes require organisations to work in collaboration with families and carers in the delivery of services. In contexts related to the NDIS, relevant aspects of the National Disability Insurance Scheme Act 2013 (CTH) s3(3)(c)(ii) are as follows:

- In giving effect to the objects of the Act, regard is to be had to: the Carer Recognition Act 2010 (CTH). General principles guiding actions under this Act (s4) include: S 4(12), "the role of carers is acknowledged and respected".
- With regards to the NDIS and participants' plans, the NDIS Act states that "where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and where possible, strengthen and build capacity for families and carers to support participants who are children; and if the participant and the participant's carers agree – strengthen and build the capacity of families and carers to support the participant in adult life".
- With regards to reasonable and necessary supports in participant's plans and funding: "the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide".

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<sup>2</sup>In addition, NSW, VIC and SA require organisations to prepare and produce reports regarding compliance and non-compliance with obligations under the Acts. Western Australia has a prescriptive requirement to prepare a report for the Carers Advisory Council using their template. Victoria requires that the service user and their carer understand the Care Relationship Principles.

# Guiding Principles

The following summarises the principles underpinning Carer Inclusive Practice within Neami operations. These have been drawn from current literature, consultation with carers and practice examples provided by consumers and staff of Neami National services:

- Contextual Support
- Equal Partnerships
- Inclusion
- Relational Wellbeing
- Mutuality and Respect

## CONTEXTUAL SUPPORT - Recovery within context of informal supports

Service users are seen in context; the majority of their recovery occurs when they are with friends, family, colleagues and others in their community (Price-Robertson, et al., 2016). The worker will have access to a greater depth of information that will increase their ability to support the service user. The claim that a service user has no supports needs to be seen as an aberration and questioned.

### NEAMI PRACTICE EXAMPLES

**Carer perspective:** "It's a life commitment. It's not something that you take on for a week, a month; it's a commitment. But you do it out of love".

**Service user perspective:** "it would be really helpful if Neami could work with my partner to help him reach out to other people who could help me to extend this circle of support during those times of crisis".

**Staff perspective:** "even if they're not well there's a relationship there and instead of discounting that, recognising and validating that and helping people to maintain their relationships".

## RELATIONAL WELLBEING - Recovery is an individual and familial process

The principles of individual recovery can be applied to the process that families engage in when a member becomes unwell (Wyder and Bland, 2014; Spaniol, 2010). Service users and their families may need support to return to their primary relationship (i.e. mother and son, partnerships, siblings or friendships) rather than a carer/care-recipient relationship.

### NEAMI PRACTICE EXAMPLES

**Carer perspective:** "I suppose every step we took was a recovery because it was a gain. So, you know, we'd start our journey, say, from here. After, say, a couple of months we got to here. So we did recover."

"I don't do the things that I do because I am his carer. I do them because I love him and want him to be safe, happy, loved, secured. He wants me to be the same."

**Staff perspective:** "the potential challenges and struggles that people have already been through before they even get to Neami-how we can support them in that journey but also support the whole family as people are all on a different sort of recovery trajectory".

## EQUAL PARTNERSHIPS - A strong support network facilitates recovery

Including families in recovery conversations and plans and allowing them to contribute and question will mean that they understand the process and can support the work that is occurring between the service user and their worker.

### NEAMI PRACTICE EXAMPLES

**Carer perspective:** "it was good to know that you had the support of professional people around you that you could call on for advice or if you had a problem, if I feel he's slipping backwards".

**Service user perspective:** "it's kind of a good idea to have that advanced care plan".

**Staff perspective:** "supporting carers and that their role in the recovery process is crucial".

"It's important to support positive natural relationships so that consumers don't feel they are being 'cared for' but it's a two-way interaction."

## MUTUALITY AND RESPECT - Carers bring their own expertise

Family have an understanding of the service user when they are well and unwell, whereas professionals usually only have interactions when the person is unwell. The carer may have witnessed many interventions with varying effects and is able to bring that knowledge to the care team.

### NEAMI PRACTICE EXAMPLES

**Carer perspective:** "I know him better than they do, and some things perhaps don't suit him that would suit another person".

**Service user perspective:** "when I'm unwell the understanding (from family) is still there, I just need it more".

**Staff perspective:** "I'd really love to see more meaningful carer consultation at all levels of the organisation directing how we work so that it's based on lived experience, not just our assumptions of what carers need or want"

## INCLUSION - Carers have the right to be included

Just as other service providers are assumed to be collaborators in the recovery process, so the assumption of family partnership needs to be the norm. The work that occurs between a staff member and the individual will impact the life of their family; therefore it is only just that they be included.

### NEAMI PRACTICE EXAMPLES

**Carer perspective:** "I do actually listen and have an input into some of the things with (consumer) and his workers. I just have an easy relationship with Neami".

**Service user perspective:** "the biggest problem is getting people together so people actually, you know, you don't have to keep running around and no one knows what's going on".

**Staff perspective:** "We also have an expectation that we need to work with the broader system because it needs to change too. We're funded to do both".

"that they're part of that team as would be obviously the client, any clinical partners, any other community or health provider".

# The Carer Framework

The guiding principles resulting from theoretical models<sup>3</sup> and consultation process are depicted in the diagram below, as are the interplays between the individual accessing the service, carer/s and staff member. This diagram encapsulates the guiding principles which are both essential and discrete to relationships, and defines what Carer Inclusive Practice consists of in a service context. At the core lies **mutual, respectful, inclusive** and **equal** partnerships between all individuals.

The principle of **Relational Wellbeing**, which exists between the individual and their carer/s, highlights the parallel process of recovery for carers when an individual becomes unwell and also provides a context in which recovery is possible for the individual. Recovery Principles are explored when the individual accesses support, with the aim of re-defining what a meaningful life looks like and planning steps to achieve this. **Carer Inclusive Practice** involves the staff member proactively seeking context, feedback and expertise from the carer/s to support recovery of the individual which is achieved through assessment, resourcing the carer/s, involving them in service delivery, planning and in seeking feedback throughout the process. In return, the carer offers further **contextual** knowledge, feedback and contribution to service planning as well as their own expertise regarding experiences with the individual in varying contexts.

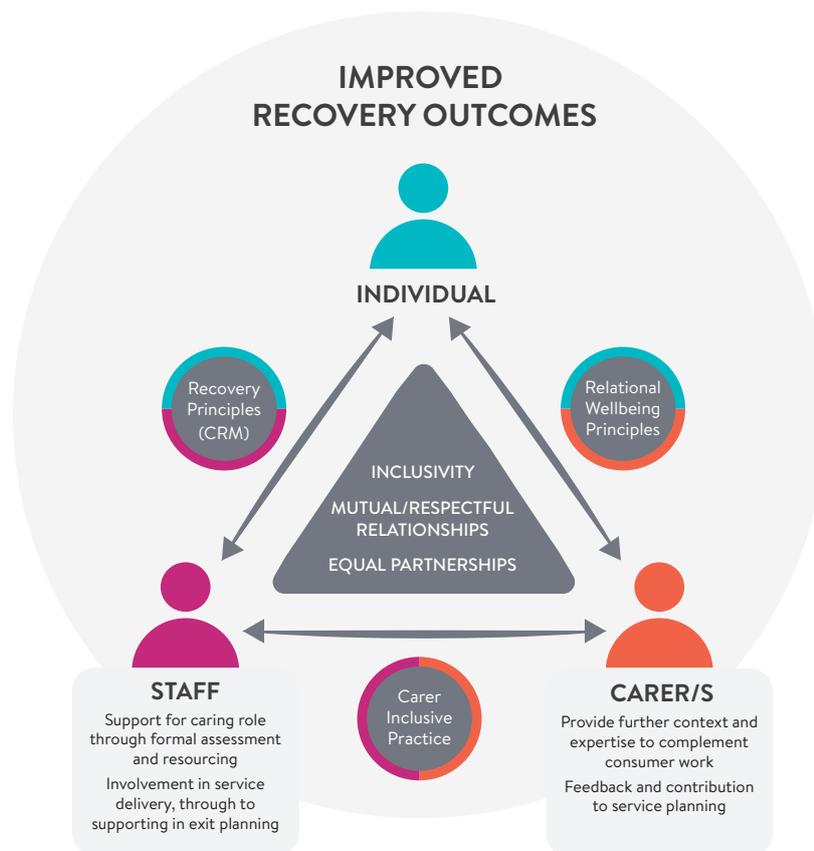


Diagram 2. Summary of the Neami Group Carer Framework

<sup>3</sup> Theoretical models considered in the development of this framework include the 'Triangle of Care' (Worthington et al., 2010) and the 'Pyramid of Family Care' (Mottaghypour & Bickerton, 2005). A link to a document explaining each theoretical model has been provided in the 'More Information' section.

# Performance Capabilities

The following four capability areas have been identified in order to achieve the vision of the framework and encompass all areas of Neami service operations and governance. This is to ensure that an organisational vision for Carer Inclusive Practice is enabled through an integrated and systematic approach.

The capabilities and subsequent standards were derived from an analysis of the evidence and from consultations held with key stakeholders:

1. Organisational capacity to innovate and progress with Carer Inclusive Practice.
2. Carers and service users have clarity on service type, roles and expectations.
3. Satisfied, informed and engaged carers.
4. A confident, capable and supported workforce.

## Capability 1 - Organisational capacity to innovate and progress with Carer Inclusive Practice

### Standards

- |   |   |
|---|---|
| 1 | Recovery definitions are broadened in scope to include a focus on relational wellbeing.             |
| 2 | Performance is measured on a regular basis to support benchmarking for ongoing service development. |
| 3 | Clear policies and procedures drive practice.   |

## Capability 2 - Carers and service users have clarity on service type, roles and expectations

### Standards

- |   |  |
|---|--|
| 1 | Carer Inclusive Practice throughout recovery journey with Neami as a minimum attainment.         |
| 2 | Carers are clear on what they can ask for, expect and their level of involvement.                |
| 3 | Carers are able to obtain information through multiple communication modes/points of connection. |

## Capability 3 - Satisfied, informed and engaged carers

### Standards

- |   |   |
|---|---|
| 1 | Feedback from carers is encouraged and promoted throughout the organisation.                              |
| 2 | Carers have an equal level of opportunity to engage with the service regardless of geographical location. |
| 3 | Carer experience is respected and utilised across different levels within the organisation.               |

## Capability 4 - A confident, capable and supported workforce

### Standards

- |   |   |
|---|---|
| 1 | Expectations of staff practice in relation to carer inclusivity are well defined across service contexts. |
| 2 | Carer inclusive training and professional development is accessible, effective and relevant.              |
| 3 | Principles of Carer Inclusive Practice are implemented by staff at all levels.                            |
| 4 | Staff in caring roles are recognised and feel supported by the organisation.                              |

# Implementation and Sustainability

## Implementation

A flexible and adaptive implementation plan will be developed annually. The implementation plan is founded upon each of the priority areas and standards to allow for measuring, evaluating and monitoring. Outcomes and achieved actions will then be reported back to the National Leadership Team on a biannual basis through an established Carer Inclusivity working group (with oversight from Innovation & Projects). The working group will adapt and amend the implementation plan when needed and maintain accountability for the process of evaluating the implementation of the framework over time. The implementation will require the consideration of diverse population groups including Aboriginal and Torres Strait Islander carers, younger carers, older carers, LGBTIQ carers, Culturally and Linguistically Diverse carers, carers living with disability and carers who have a mental illness.

## Evaluation

Measuring and evaluating the success of the framework will focus on two areas, implementation progress and increased carer inclusive activity measured through results of an audit conducted annually. The auditing process will be led by operational managers assessing level of carer involvement within their service context. The Neami Group will seek feedback from service users and carers as part of exit from the service in order to complement each service's level of understanding with regards to how they are progressing with Carer Inclusive Practice. Responsible staff will feed back themes generated from both methods to the State Leadership Teams. This allows for States to continue progressing with plans related to improving upon this practice.



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## About Neami National

Neami National is a community mental health service supporting people to improve their health, live independently and pursue a life based on their own strengths, values and goals.

### **Our vision**

Full citizenship for all people living with a mental illness in Australian society

### **Our mission**

Improving mental health and wellbeing in local communities

[www.neaminational.org.au](http://www.neaminational.org.au)

We acknowledge the Aboriginal and Torres Strait Islander people as the traditional owners of the land we work on and pay our respects to their elders past and present.

We welcome and appreciate diversity in all its forms, including staff and consumers and believe diversity makes our teams, services and organisation stronger.



## More information

For more information, contact the Service Development Team on (03) 8691 5300.

More information on the project, consultations that informed the framework and supporting documents can be found in the following documents:

- Carer Framework Key Messages
- Carer Framework Project Report June 2017
- Audit Tool – Six Practice Standards
- Theoretical Models Underpinning the Neami Group Carer Framework

# Appendix A

As of July 2016

State, Act and guiding principles	Obligation to ensure employees are aware of Act and guiding principles	Obligation to ensure that service delivery complies with guiding principles	Obligation to educate service user and carer	Reporting obligations
Western Australia Carers Recognition Act 2004; The WA Carers Charter	✓	✓		✓
New South Wales Carers (Recognition) Act 2010; NSW Carers Charter	✓	✓		✓
South Australia Carers Recognition Act 2005; SA Carers Charter	✓	✓		✓
Queensland Carers (Recognition) Act 2008; The Queensland carers charter	<p>“To provide for the interests of carers to be considered in decisions about the provision of services that impact on the roles of carers.”</p> <p>Funded organisations are encouraged to understand the provisions of the <i>Carers (Recognition) Act 2008</i>, particularly ‘The Queensland carers charter’, and to reflect the principles in the delivery of services:</p> <p>“A public authority must ensure the authority and its officers and employees have an awareness and understanding of the carer’s charter and take action to reflect the principles of the charter in providing services of the authority which affect carers and the persons they care for.”</p>			
Victoria Carers Recognition Act 2012; Care Relationship Principles	✓	✓	✓	✓

## Carer Recognition Act 2010 (CTH); The Statement for Australia’s Carers

Obligations	Quality Improvement Suggestions
<p><i>Ensure that officers, employees and agents have an awareness and understanding of the Statement for Australia’s Carers</i></p>	<ul style="list-style-type: none"> <li>• Conduct training sessions to raise awareness and educate staff about the Carer Recognition Act 2010 and its implications for program and service delivery</li> <li>• Develop material, distributed in various formats and modes to promote understanding and awareness of carers for staff</li> </ul>
<p><i>Ensure that officers, employees and agents take action to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports</i></p>	<ul style="list-style-type: none"> <li>• Develop processes that require staff to consider the impact of policies, programs and services on carers and the person they provide service to</li> <li>• Develop a policy whereby the needs of specific vulnerable groups are considered, including women, men, young carers, older carers, Indigenous carers, carers in rural and remote locations and culturally and linguistically diverse carers</li> </ul>