

# Consumer Participation Framework

Service Development  
February 2014

## Acknowledgments

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Neami would like to acknowledge the members of the Expert Working Group who contributed their lived experience knowledge and time to the development of the Consumer Participation Framework:

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Many thanks to everyone who contributed.

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## Introduction

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The Consumer Participation Framework will guide the activities of Neami National to ensure genuine participation is supported in a sustainable and achievable manner. The Framework sets out the principles to guide the way that Neami engages and works together with consumers. It sets out to achieve a more structured system within Neami that builds capacity within the organisation together with contributing to the empowerment, skill development and personal growth of consumers. It describes a spectrum of types of participation with an increasing level of involvement as well as a process for initiating consumer participation activities.

## Context

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*“If we plant a seed in a desert and it fails to grow, do we ask, “What is wrong with the seed?” No. The real conspiracy lays in this: to look at the environment around the seed and to ask, “what must change in this environment such that the seed can grow?” The real conspiracy that we are participating in here today is to stop saying what’s wrong with psychiatric survivors and to start asking: “How do we create hope filled, humanised environments and relationships in which people can grow?”*

*Dr Patricia Deegan, Keynote Address, TheMHS Conference, 1996, Brisbane*

The rights and privileges due to being a citizen can be revoked for people with mental illness ranging from involuntary hospitalisation and forced treatment to homelessness, poverty, unemployment and non-treatment. Attached to this social exclusion are fear, misunderstanding, stigma and discrimination. In 2007 Australia signed up to the UN Convention on the Rights of Persons with Disabilities. Article 3 of the General principles states “The principles of the present Convention shall be...c) Full and effective participation and inclusion in society;”

Improving health services through consumer participation, A Consumer Focus Collaboration publication, (2000) states that:

*“There are four reasons why health care organisations should have a strong consumer focus and be involved in enhancing and responding to consumer participation.*

- *Participation is an ethical and democratic right.*
- *Participation improves service quality and safety and helps gain health service accreditation.*
- *Participation improves health outcomes.*
- *Participation makes services more responsive to the needs of consumers.”*

In conjunction with a rights and recovery perspective, the Australian Ministers’ Advisory Council’s National Mental Health Working Group endorsed the National Standards for Mental Health Services 1996 (NSMHS). Subsequently, these standards have been revised and are now the National Standards for Mental Health Services (2010). Standard 3 discusses Consumer Carer Participation. This Standard should not be read in isolation but gives clear direction around what a service needs to achieve.

Current recovery literature distinguishes between the experience of consumers and the programs and support provided by services. Larry Davidson, in his 2004 article “Recovery: Challenging the Paradigm”, poses the position that services offer treatment and rehabilitation interventions but consumers experience the recovery journey. Services can facilitate recovery but cannot create recovery. Consumer participation engages consumer’s experience of services to inform and promote a recovery orientation and a person centred focus.

## Background

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### Neami's vision is:

- *Full citizenship for all people living with a mental illness in Australian Society.*

Neami National has a long history of consumer participation that has been embedded from the beginning of the organisation. In 2009, the Neami Board of Directors instigated an audit of Neami's consumer participation practices. The results from this audit were compiled into *The Consumer Participation and Leadership (CPL) Report 2010*. The report recommended further investigation into consumer participation and leadership across the organisation.

### From the Beginning Consumers Played a Role

#### **(Excerpt from *The Consumer Participation and Leadership (CPL) Report 2010*.)**

*"Consumers have been actively involved in the development of Neami from the beginning, through shaping its activities, program planning, policies, and its growth and development. Consumers of Neami included many patients who had been discharged from the NEMPS Larundel/ Plenty/ Mont Park Psychiatric Hospital campus. Some of these became residents of newly opened Neami supported housing places in the community and, with others, attended the day centres that Neami ran for more than a decade.*

*The early days were very exciting times – Neami by necessity was almost inventing itself as it went along, and the still very young PDRS sector itself was also exploring more empowering ways of supporting consumers in the community in the wake of often adverse institutional pasts. The consumer movement was also growing in size and influence, following the founding of the Victorian Mental Illness Awareness Council (VMIAC) in 1982. Consumers in the new Neami day programs did voluntary office work, used computers for the first time, answered phones, and developed work routines. Neami and the VMIAC often had shared associations with a number of active consumers over the years.*

*Consumers who became strongly interested in the social policy and people issues within Neami's work in the local community, gained a considerable voice as members of the Neami Board, and some were to become active consumers and advocates in the field.*

*Neami has been and continues to be a training ground and encouraging supporter of consumers who want to make a difference in an often challenging mental health service arena; where it is often difficult for consumer needs to be fully articulated, understood, and incorporated into the policies and programs of the sector.*

*In the early days of Neami, there was a strong sense of ownership and belonging for those associated with day programs. Over time this has dissipated as the emphasis in programs has moved to embrace a social inclusion focus. The expansion of the organisation to other states and the consequent variety of funding and program arrangements has contributed to a very changed landscape. Nevertheless, the many thoughtful and stimulating interactions with consumers, staff, service managers and Board members as part of this project confirmed that the Neami community spirit remains, and offers a precious resource for the future. Clearly, however, in the light of the massive growth and change Neami is experiencing and developments more generally in the consumer movement, it is timely to reflect on a new plan, new structures, and new approaches to support consumer participation.*

*The recent period of intense growth presents great opportunities and also significant challenges for Neami, its consumers, the Board, staff, carers, and friends in the community. The changes place a premium on good communication, recognition of the problems of distance, clear definitions of working concepts, clear thinking, a shared sense of purpose, common aspirations of what can be achieved, and working together on just how to get there.*

*Consumer participation has the potential to become an important enabler of Neami's service delivery and strategic goals."*

Following on from *The Consumer Participation and Leadership (CPL) Report (2010)*, Neami has undertaken further work and made significant inroads into the development of pathways for consumer participation, including:

- The Consumer Advisory Group Review (2012)
- The integration of consumer participation in all strategic planning activities
- The identification of a range of consumer participation opportunities in State Plans
- The development and roll out of Launching Pad a consumer leadership and education program which aims to support consumers in their participation by creating a learning environment for consumers to develop skills and knowledge to engage in participation opportunities
- The implementation of the feedback process for consumers and carers
- The appointment of a Manager Consumer Participation Strategy

The Consumer Participation Framework progresses a coordinated approach that enables consumer participation to be embedded into the systems and processes of Neami.

The following section defines consumer participation, outlines the barriers and the importance of ensuring diversity.

## Consumer Participation - Definition

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***"I think it is about the transparency where we are given the opportunity to help Neami plan for the changes that are ahead ....."***

***(Comment from the Expert Working Group)***

*"...There are many different definitions of consumer participation, and there are diverse views and criticisms about the terms 'consumer' and 'participation'. It is important to be aware of these debates. Not everyone will agree with one definition or with the terms being used. In addition, for many people from culturally diverse backgrounds, terms like 'consumer' and 'participation' are often barriers. These terms are embedded in Australian policy documents and are unavoidable. However, many people come up with terms they prefer and there ought to be enough flexibility to allow for this." (Launching Pad Module 1)*

The National Mental Health Consumer and Carer Forum define consumer and carer participation as:

*"...participation by consumers and carers in formal or informal planning, delivery, implementation and evaluation of all activities associated with mental health services (voluntary or paid), as well as all processes, which effect (sic) the lives of consumers and carers, through sharing information, opinions and decision making power" (National Mental Health Consumer and Carer Forum - Advocacy Brief, 2010).*

The definition of consumer participation developed by The National Mental Health Consumer and Carer Forum aligns closely to Neami's values of respect, self-determination, empowerment and partnership as well as being developed in Australia. It fits well with a community managed mental health service such as Neami National.

## Barriers to consumer participation

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In order to engage in effective consumer participation, some barriers or challenges may be present. It is good practice to reflect on what the barriers may be and work to put strategies in place to overcome them. Some barriers to effective participation may include:

- Lack of clarity on the type and purpose of participation
- Insufficient resources available or allocated for participation
- Attitudes, understanding and competency among staff on consumer participation
- Lack of integration of consumer participation mechanisms within the formal service planning, delivery and evaluation processes
- Adequacy of consumer representation is likely to impact on effective participation and the achievement of anticipated goals
- Poor communication and non-collegial approaches between staff and consumers, including unequal power relationships
- Consumers may have support requirements that, if not supported, may prevent participation.

The consumer participation framework attempts to address these barriers and makes recommendations for Neami to implement to ensure consumer participation processes are fully supported.

## Ensuring Diversity

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Consumers are not a homogenous group and include people from different educational, cultural and employment backgrounds, gender and different mental health needs. These differences need to be taken into account when organisations embark to incorporate consumer participation. More specifically, some people or groups may require extra effort to engage. They can include people from the following groups:

- Aboriginal or Torres Strait Islanders
- Culturally and linguistically diverse backgrounds
- Lesbian, gay, bisexual, transgender, intersex
- People with a physical or intellectual disability
- Refugees or asylum seekers
- People in the forensic system
- Homeless, at risk of homelessness or in unstable or inappropriate housing
- Living in remote areas of Australia
- Diagnosed with borderline personality disorder

The following section outlines the key concepts that define and support consumer participation.

# Conceptualising Consumer Participation

Neami’s Consumer Participation Framework brings into relationship key participation concepts.

1. Levels of participation activity - “What is the sphere of influence of the participation?”
2. Spectrum of participation – “What is the type of the participation activity?”
3. Principles of consumer participation – “What are the principles that guide participation?”
4. Process of consumer participation – “How do we engage in a meaningful process?”

## 1. Spheres of Influence (Diagram 1)



A focus on consumer participation can be conceptualised as the sphere of influence of the participation activity.

*“I’m a part of the Consumer Advisory Group for Eastern Health. Next year we are running a forum for consumers and carers for dual diagnosis called “our side of the fence”. They are listening at long last”*

(Consumer comment from the Expert Working Group)

## 2. Spectrum of Participation Types

*“Makes me feel like I have a voice”* (Consumer comment from the Expert Working Group)

In Diagram 2 the spectrum of participation lists the range of types of engagement. This focuses Neami on the intentionality of the approach to consumer participation. All types of engagement may be included in a service initiative or one type may be singled out. The diagram represents a spectrum of participation types and is not meant as a linear process. Through the process of consumer participation Neami’s intention of the type of participation could change as consumers themselves may have a different perception on what their participation looks like. This transformative participation may result in outcomes that were never envisaged from the outset.

(Diagram 2)

**Spectrum of Participation Types**

**Types of Engagement**

**Inform      Consult      Involve      Collaborate      Empower**



**Increasing Level of Involvement**

**Purpose**

To provide consumers with information to help understand the issue	To obtain feedback on an issue, options or decisions	To work directly with consumers to understand and consider their concerns and aspirations	To partner with consumers in developing options and making decisions	To place final decision-making in the hands of consumers
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**Neami undertakes**

We will keep consumers informed	We will listen and acknowledge concerns and aspirations and provide feedback on how consumer participation has influenced a decision	We will work with consumers to ensure that their concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how consumer participation has influenced	We will look to consumers for advice and innovation in formulating solutions and incorporate consumer advice and recommendations into the decisions to the maximum extent possible	We will implement decisions made through consumer participation processes
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**Participation Activities**

Newsletters	Focus Groups	Workshops	Expert Advisory Groups	Board of Directors
Website	Surveys	Community Meetings	Research Committee	CRM
Annual Report Presentation	Website	Program Planning	Staff selection	Launching Pad
Media Releases	Complaints and Feedback	Paid Participation	Working Groups	Speeches & Talks
			Co Facilitation	

Adapted from IAP2 Spectrum of Public Participation

### 3. Principles of Consumer Participation

*“Empowerment is the single most important element of being involved in Neami’s operations”*  
(Comment from the Expert Working Group)

The following principles will guide consumer participation at Neami. Principles developed in consultation with an Expert Working Group comprising of consumers from all States as well as specific interest groups such as ATSI and CALD influenced the development of the principles for consumer participation.

#### **Respect:**

Neami will partner with consumers in a respectful manner and people will be actively listened to as respected partners.

#### **Empowering:**

Consumer participation activities will include knowledge skills and resources to create an authorising environment that will support conditions conducive to independent action, self-determination and autonomy for consumers.

#### **Citizenship:**

Consumer participation activities will support consumers to actively participate in the community of their choice and recognize their identity as active citizens in the community.

#### **Recovery:**

Consumer participation activities will work towards creating a recovery environment that encourages hope and optimism, connectedness, meaning, and rebuilding a sense of identity.

#### **Equality:**

Neami will give equal value to the lived experience expertise contributed by consumers as it gives to service provider knowledge in all consumer participation activities.

#### **Transparency:**

Neami will provide clear and comprehensive information and make available critical information to support meaningful participation. Neami will let people know how their participation has affected the outcome

#### **Honest:**

Consumer participation activities will be conducted in an honest and open manner.

#### **Choice:**

Neami will embed a range of consumer participation activities within the organisation as well as identifying opportunities at systems level and community level to give consumers a choice in the participation activity.

#### **Advocacy:**

Consumer Participation activities will provide a forum for consumers to advocate on issues of concern. Neami will endeavour to further these issues in a systemic approach.

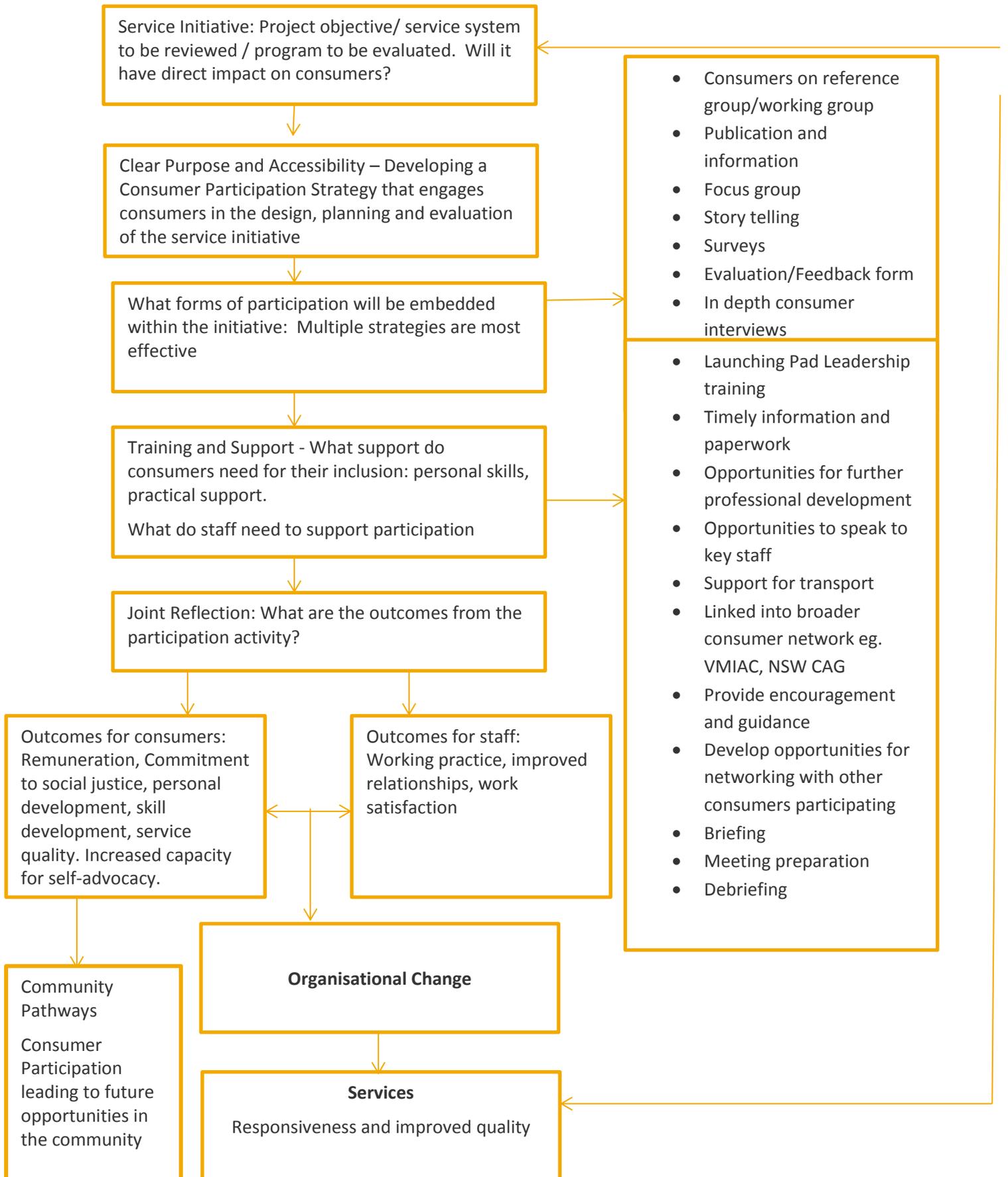
#### **Inclusive:**

Neami will work to overcome the barriers to participation by actively opposing discrimination, and valuing diversity of views. We will endeavour to engage consumers who are hard to reach, including Aboriginal and Torres Strait Islander peoples, young people and cultural and linguistically diverse communities. Remuneration will be provided to consumers in recognition of their expertise and experience.

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The following diagram 3 labelled “Consumer Participation Process Map” details a flow chart that outlines a process for considering consumer engagement, support, reflection and specific outcomes that enables organisational change. The process is required to be implemented for any service initiative.

(Diagram 3)  
Consumer Participation Process Map



The final section of the Consumer Participation Framework details key priority areas Neami can action, a process of implementation and evaluation, with concluding comments.

## Framework Priorities

To support consumer participation in a sustainable manner that builds capacity within Neami four key priority areas need to be addressed:

1. Develop a planning framework
2. Build capacity with consumers and the workforce
3. Implement a quality improvement framework
4. Dedicated resource allocation

The four priority areas identified are underpinned by recommended actions, each of which have been aligned to best practice literature. The literature highlights the importance of developing detailed plans to implement consumer participation. Developing plans that incorporate consumer participation into the planning process will meet the needs of consumers and Neami as an organisation. It is important for Neami to have an understanding of current consumer participation activities in order to identify what is in place, what is working well and opportunities to build on. The literature also highlights that in order to achieve effective consumer participation, it is important to develop consumer skills and confidence as well as prepare staff and internal processes to incorporate consumer participation. Having a dedicated resource allocation and budget for consumer participation means Neami can incorporate consumer participation into the unit costing of delivering services which promotes the importance of consumer participation activities. Increased human resources are required to embed consumer participation at the service level. The funding is to be included in the budget for consumer participation.

Key Priority Area 1 – Develop a planning framework	
Strategy	Actions
Implement a planning framework	<p>Develop a planning framework that:</p> <ul style="list-style-type: none"> <li>• Incorporates consumer participation in the planning process</li> <li>• Develops plans for consumer participation with KPI's in:                             <ul style="list-style-type: none"> <li>- Strategic planning</li> <li>- Service planning</li> <li>- Staff recruitment</li> <li>- Orientation and training</li> <li>- Service delivery</li> <li>- Service implementation</li> <li>- Service evaluation</li> <li>- Health decision making</li> <li>- Resource allocation and development</li> <li>- Community participation</li> </ul> </li> </ul>

Key Priority Area 2 – Build capacity with consumers and the workforce	
Strategy	Actions
Implement a consumer leadership and education program	<ul style="list-style-type: none"> <li>• Evaluate Launching Pad training</li> <li>• Run Launching Pad in every State annually</li> <li>• Develop self-contained professional development sessions</li> <li>• Run 2 professional development sessions annually to Launching Pad graduates</li> <li>• Develop a national register of Launching Pad graduates</li> <li>• Liaise with communications to design a newsletter template.</li> <li>• Develop a quarterly newsletter for graduates</li> <li>• Send out weekly updates to graduates on email to promote consumer participation opportunities and employment opportunities</li> <li>• Develop a scholarship program for graduates of Launching Pad to further education in mental health or related fields</li> <li>• Develop resources that will support consumers in their participation</li> </ul>
Build the capacity of Neami Workforce to incorporate consumer participation	<ul style="list-style-type: none"> <li>• Liaise with learning and development to incorporate consumer participation into orientation</li> <li>• Develop training for staff around consumer participation.</li> <li>• Provide a range of opportunities for workers across Neami to learn about consumer participation such as:                             <ul style="list-style-type: none"> <li>- Support staff to contact local consumer run organisations and subscribe to consumer orientated newsletters.</li> <li>- Joint reflection with consumers around consumer participation activities</li> </ul> </li> <li>• Evaluate training</li> <li>• Support staff to attend consumer presentations at conferences such as TheMHS and peak body conferences</li> <li>• Develop a quarterly newsletter for staff</li> <li>• Liaise with communications to develop a space on e-mi dedicated to consumer participation</li> <li>• Ensure consumer participation is a regular agenda item on all meeting agenda's</li> <li>• Incorporate consumer participation into position descriptions of staff</li> </ul>

Key Priority Area 3 - Implement a quality improvement framework	
Strategy	Actions
Benchmark consumer participation activities at Neami	<ul style="list-style-type: none"> <li>Develop and implement a self-assessment audit of consumer participation activities undertaken, for managers to do at the service sites and for head office functions</li> </ul>
To develop a Policy and Procedure Framework to support consumer participation	<ul style="list-style-type: none"> <li>Review Neami's Consumer Participation Policy to develop a paid participation policy</li> <li>Develop a set of procedures to support consumer participation</li> <li>Ensure staff are aware and educated on the consumer participation policy and set of procedures.</li> </ul>
Strengthen Quality Improvement Systems	<ul style="list-style-type: none"> <li>In partnership with consumers develop or choose an Experience of Service survey</li> <li>Develop an auditing tool against the KPI's developed in the planning framework</li> <li>Instigate an auditing cycle to implement the above tool</li> <li>Develop a system to incorporate the trends of complaints into practice change</li> </ul>

Key Priority Area 4 –Dedicated resource allocation	
Strategy	Actions
Increase financial resources	<ul style="list-style-type: none"> <li>Develop a budget for consumer participation to be include in the organisational budget</li> </ul>
Increase human resources	<ul style="list-style-type: none"> <li>Recruit consumer participation officers in each state</li> <li>Allocate consumer participation portfolio holders at each service site</li> </ul>

## Implementing Framework Priorities

A Consumer Participation Framework Implementation Committee will be formed and chaired by the National Services Manager, Jenny Hall, to oversee the implementation of the four priorities. A call for expression of interest from the National Leadership Team, Regional Managers, support workers and consumers will make up the composition of the committee and will be supported by the Manager, Consumer Participation Strategy with invited attendees as required. The committee will be tasked to develop a work plan with performance indicators and lines of responsibility for each action.

## Evaluation

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The purpose of evaluating the strategies in the four key priority areas is to assess the success of implementing a structured system within Neami that builds capacity within the organisation together with contributing to the empowerment, skill development and personal growth of consumers and to gather information that will inform future changes and growth. Consumer participation strategies as identified in the Framework will be evaluated against key performance indicators set by the Implementation Committee using a mixed method approach. Evaluation results will be used to make adjustments to the approach outlined in the Consumer Participation Framework.

## Conclusion

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Creating opportunities for dialogue with consumers is necessary but is by no means sufficient for effective participation. Much depends on the promotion of the opportunity and the supportive processes that builds capacity, nurtures voices and enables people to empower themselves. A deep participatory process engages consumers in all stages of a given activity, from identification to decision making.

Consumer participation is rarely a seamless process it can provide the spark that can lead to outcomes not envisaged and to changes of attitudes toward consumers and the nature of relationship.

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