

# Consumer Participation and Leadership Report

September 2010



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## **Acknowledgments**

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*Neami would like to acknowledge the valuable input and insights of consumers, and the time and thoughtful contributions of staff and Board members to this project*

*We also wish to thank the Health Issues Centre for their advice and kind permission to adapt the Organisational Self-Assessment and Planning Tool for Consumer and Community Participation*

*The project benefited greatly from the invaluable wisdom of the Critical Reference Group – Lei Ning; Emma Willoughby; Julie Anderson and Wanda Bennetts*

*The Consumer Consultants, Allan Pinches & Jan Hatt, would also like to acknowledge the high level of resourcing and support provided for their work by Neami as an organisation and our direct supervisors in particular. This project has been a true example of consumer participation and consumer research in action.*

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# “FOREWARD”

## ***‘Look where I started and look how far I have come!’***

### **One Consumer’s experience of Consumer Participation at NEAMI**

*‘When I referred myself to Neami I was not well at all. I was experiencing intense anxiety and my depressive moods were becoming more frequent and deeper again. Luckily for me, after being assessed, I was accepted by Neami to be a client.*

*Unfortunately though, I left contacting Neami too late and two weeks later a relapse in my mental health did take hold which saw me hospitalised for one month. However, in that most vulnerable time of leaving hospital and re-entering the community, I had the full support of Neami and my excellent worker.*

*At first I was encouraged just to ‘be’ and talk with my worker. We quickly established a very special working relationship based on trust, mutual respect, empathy, encouragement and support. I believe this relationship was crucial for re – entering the community and refocusing and returning to my recovery.*

*I became involved in the gardening group and the interaction with my peers was welcome after a period of extensive withdrawal – it made me realise once again I was not alone – something you can lose sight of when unwell.*

*Through working on my ISP I developed goals based on what was necessary to achieve for my recovery and based also on my values and strengths. I was establishing a life again that was meaningful to me. My worker always knew what I was focusing on and would inform me of anything that would foster and encourage my recovery. This ranged from psycho-education groups run at Neami including Mood and Recovery groups and community based activities such as yoga and mindfulness. I also found relevant information in the Neami newsletter.*

*With yoga, Neami organised for a group of Consumers to attend a local Neighbourhood House course with a worker for three weeks. I then continued on with the regular courses by myself. Neami provided the same opportunity for sculpture classes.*

*Throughout this time I would review and reflect with my worker how my ISP was developing and where change or further follow up was needed.*

*My mental health was much improved and my self esteem and confidence were beginning to grow. I started volunteering one day a week in the office at the Neighbourhood House I had been doing my yoga course with and continued this for two years, interacting with a lot of different people and renewing some of my old skills.*

*The work at Neami and the service it provides impressed me greatly. The focus on recovery and a strengths based approach provided much hope and opportunity. My passion for Consumer issues and work in the Mental Health sector was restored and at about the same time the opportunity to participate in CAG arose. I applied and luckily for me I was successful as this participation can be seen to be the key that opened the door and led me to where I am now.*

*During my first year on CAG, the opportunity to represent Neami at the 2008 THEMHS conference in New Zealand arose. Once again I applied and was very fortunate in being selected. Participation at THEMHS opened me up again to the great work of Consumers and the scope, possibilities and opportunities Consumer Participation and Leadership can provide all consumers with. I was fired up again!*

*My belief in my abilities continued to grow and Neami fostered this by providing me with opportunities to participate on staff selection panels and staff induction training to the extent I felt confident in my abilities to conduct this current work. The next stage in my participation at Neami involves me taking on one of the new Peer Support Worker roles.*

*In the space of two and half years, I have gone from someone who was extremely vulnerable just out of hospital and basically hiding from the world to someone who has reconnected with myself, my values, strengths and passions, my community and a life which has great meaning to me. My involvement in Consumer Participation at Neami fostered this growth in my recovery and provided many opportunities along the way.'*

This is one experience of Consumer Participation at Neami.

It should be noted that it is a very individual experience for all consumers and there is not one set pattern, approach or outcome for Consumer Participation. In fact during the audit process, it became clear, that what Consumers value in Consumer Participation are choice and opportunities to participate in ways that are meaningful to them and in turn open communication channels that provide them with the information so they know the opportunities available and they can choose. We are confident that this report is at once a practical, vision-holding and evidence-rich resource for further exploration, and detailed study, with the discussion and recommendations backed up with a “digest” of rich contextual quotations and statements from workshops, based on the actual audit tool used in the workshops.

Allan Pinches & Jan Hatt



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# EXECUTIVE SUMMARY

The Neami Consumer Participation and Leadership Project was initiated in 2009 by Neami's Board of Directors. The Project aimed to gather a sound evidence base to inform discussion and the development of a strategic approach to consumer participation and leadership in the future.

Two project workers with consumer-researcher backgrounds carried out the project in collaboration with the Service Development Team. The consultation process was closely based on the *'Organisational Self-Assessment and Planning Tool for Consumer and Community Participation – A tool for organisations involved in health policy and education'* developed by the National Resource Centre for Consumer Participation in Health (2003). The tool explored the areas of individual service planning, governance, strategic planning, policies, operations, education/training, research and evaluation.

The project brought together a rich field of data from ten audit workshops involving more than 90 participants from among consumers, members of Neami's Consumer Advisory Groups (CAGS), staff, and Board members. The audit tool was used in group sessions, carefully facilitated in a workshop discussion style and supplemented by interviews with key informants including the CEO, a State Manager, a Service Manager, VMIAC and individual consumers.

Participants in the audit workshops were asked to discuss Neami's current approach across a range of consumer participation domains; second, to talk about what they would like to see in the future; and third, to suggest some ideas for making these things happen.

A wide range of ideas for enhancing, strengthening and diversifying consumer participation at Neami were put forward by participants. A digest of some of the most compelling evidence from the audit workshops can be explored in the section at the back of this report.

It was clear that the words "consumer participation" mean many different things to different people – for some consumers the words embrace almost every interaction with Neami – ranging from group activities, meeting with individual support workers, through to more specialised notions of being in a respectful partnership with Neami on service and policy development.

While the project found that there were some very good examples of consumer participation in Neami, there is not a consistent rationale or strategic framework, resulting in ad hoc projects, some inconsistent methods and decision-making and patchy results, across a wide area.

The information gathered through the project confirms that enormous potential exists for enhancing and expanding opportunities for consumer participation within Neami and also brings to attention some areas of possible shortcomings, pointing to a need for more systematised and strategic approaches to consumer participation and leadership in Neami.

The consumer participation audit – intended as the first stage of a larger process – sets the scene for the development of a comprehensive, long term strategic plan for consumer participation and leadership in Neami.

Key areas for development identified in the project are:

- Feedback and complaints processes
- Communication strategies
- Consumer Advisory Group review

- Develop capacity for consumer collaborative projects
- Clearer consumer consultation and decision making structures at operational level
- Support for consumer initiated activities and skill-building built into budget and staffing arrangements
- Program development informed by facilitating opportunities for participation and leadership within the organisation and the broader community
- Consumers involved in both the planning and delivery of staff training, research and evaluation
- Employment of consumer consultants in projects and service development activities
- Links to external consumer participation and leadership opportunities

The next step in the process is the development of a strategic framework and action plan to support an integrated approach to consumer participation across all aspects of organisational functioning.

# 1. INTRODUCTION

The Consumer Participation & Leadership project was initiated by the Board of Neami. The broad aim was to review Neami's current approach to consumer participation and identify ways to support and extend this commitment.

Research indicates that consumers who are empowered to have a greater understanding of their mental illness and are able to direct their own care are more likely to achieve better health outcomes. The consumer movement has challenged the sector to broaden concepts of participation beyond the involvement of consumers in their own process of recovery to the broader organisational level:

*.. moving from a paradigm of service user participation to service user centredness and service user leadership, which has three critical dimensions (Gordon 2004:365).*

The involvement of consumers in service planning, development, delivery, monitoring and evaluation of mental health services has been shown to increase the likelihood of more appropriate and accessible services to consumers.

Neami has identified four levels of consumer participation and has committed to reviewing and evaluating the effectiveness of its structures and processes on a regular basis.

## Individual Level

Individual development of support plans and engagement in the recovery process with a view to active involvement in the community

## Group Level

Involvement in planning, facilitation, and evaluation of group programs

## Service Level

Engagement in planning, evaluation, policy consultation, staff selection processes and research activities

## Organisational Level

Formal organisational processes including Consumer Advisory Groups, the Neami Board, public events including the AGM, policy discussions and research

The Board was also interested to explore the role of the organisation in supporting the development of leadership capabilities which may or may not be used directly within the organisation.

The project team used a modified version of the '*Organisational Self-Assessment and Planning Tool for Consumer and Community Participation – A tool for organisations involved in health policy and education*' as developed by the National Resource Centre for Consumer Participation in Health. This tool was adapted to reflect Neami's services and the aims of the project, and was integrated into a focus group format.

Consumer consultants were employed to facilitate the focus groups with Consumer Advisory Groups, staff groups and the Board. These were supplemented by interviews with the CEO, a State Manager, a Service Manager and others with specific skills or knowledge. A Critical Reference Group provided advice on the finalisation of the focus group format and the findings and recommendations.



## 2. BACKGROUND

### NEAMI'S PROUD HISTORY OF CONSUMER PARTICIPATION

Neami was a pioneer in the Psychiatric Disability Rehabilitation and Support Services (PDRS) field. It was incorporated in 1988 after a series of community consultation meetings in Melbourne's northern suburbs, at the beginning of the Victorian psychiatric deinstitutionalisation era. Stakeholders to the discussions included clinicians at the former Ernest Jones Community Mental Health Clinic and North East Metropolitan Psychiatric Service (NEMPS), family carers, consumers/patients and other community members.

As well as providing direct services to consumers, Neami has been a key developer and proponent of the recovery paradigm in mental health, which is now largely shared ground between the consumer movement, Psychiatric Disability Rehabilitation Support Services (PDRS's), and a growing number of clinical mental health services. Crucial to say here, is that the unique knowledge and experience of consumers in Neami and other organisations, has been vital to the rise of the recovery paradigm, which has brought new hope and opportunities to many.

Enormous potential is ready to be harnessed, with the right conditions, for consumer participation to become a major enabler of innovation and change in mental health.

### FROM THE BEGINNING CONSUMERS PLAYED A ROLE

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. This report contains many key debates, a rich body of evidence, lessons from the field, and recommendations that highlight the significant service and organisational improvements that enhanced consumer participation could bring to Neami.



### 3. METHODOLOGY

The aim of this project was to review Neami's approach to consumer participation and to develop a framework to extend opportunities for participation and build leadership capacity. The project was initiated by members of the Board which was keen to review whether Neami's approach to consumer participation reflected contemporary knowledge and developments.

There are no benchmarks to assess consumer participation in mental health services, though there is evidence to suggest that participation is linked to improved outcomes for consumers. Neami therefore spent some time clarifying what it hoped to gain from the project and considering the best way to proceed.

A review of literature identified the emerging theme of leadership as worthy of further exploration. It also suggested that the project should explore all aspects of organisational functioning including non-service delivery activities.

The *“Organisational Self-Assessment and Planning Tool for Consumer and Community Participation (2003)”* and the *Primary Care Self-Assessment Tool for Community and Consumer Participation V1.0 (2002)* were identified as offering a potential framework for the project. These tools were developed by the National Resource Centre for Consumer Participation in Health, Health Issues Centre, La Trobe University. They were designed to 'assist organisations to determine their commitment and capacity regarding consumer and community participation and to identify areas of practice that could benefit from consumer participation (HIC 2003: 2)'. Each of the tools firstly identifies organisational definitions and aims for participation, then explores current activities and their intended purposes followed by identification of current and desired levels of participation using a "ladder of participation". The ratings are associated with the degree of control the consumer experiences over both process and content (See appendices). Both tools had been piloted in a range of health care settings and then refined to enhance their rigour and usability.

Neami received permission from the Health Issues Centre to adapt the tools for our use, to include a mental health perspective and a focus on leadership. The tool was adapted by members of Neami's Service Development Team and then piloted with Neami staff in a question and answer format direct from the tool. It was then determined that the best way to employ the tool would be in a workshop environment where the areas of interest were opened up to a general but specifically guided discussion with key stakeholders.

Consumer consultants were employed to finalise the tool, conduct the audit process and write the report. The consumer consultants further refined the tool to sit firmly in the Mental Health Consumer Participation perspective and the audits took place across Neami nationally over a two month period.

A Critical Reference Group was established to facilitate discussion of key findings. The Critical Reference Group was made up of four consumers who have extensive experience in working in the mental health sector and their support and advice was invaluable to the overall process.

The group contributed its expertise to the research process, analysis of the results and framing of recommendations in response to the findings of the Consumer Consultants.

Ten focus groups were held - six with consumers, one with the Board, two with staff groups and one with the project staff. In Queensland and Western Australia where there are no Consumer Advisory Groups, all consumers receiving services were invited to attend. In the other areas the groups were convened by the Consumer Advisory Groups and often involved a mix of past, current or potential CAG members. The staff audits involved a mixture of managers, SPL's and CRSW's ensuring all levels were involved. Data was collected verbatim by a scribe in the focus groups and then analysed to determine key themes and proposed directions.

In addition project staff conducted interviews based on the audit tool with the CEO, the Victorian State Manager, a service manager with expertise in cultural diversity and three CAG members unable to attend the group sessions.

Overall the project methodology was very useful in gathering information in a consistent manner across the whole organisation. The project consultants adapted the workshop format in response to the interests and knowledge of each group so whilst the areas explored differed slightly from session to session, the overall data collection provides an excellent snapshot of the views on consumer participation and leadership across the organisation.

## 4. KEY THEMES

The following sections highlight the key themes which emerged from the consultations.

### 4.1 OVERALL DIRECTION

‘Participation doesn’t sit right – something that is more action driven – could be driven or lead – Consumer Design’ (Staff)

Responses from consumers, staff and the Board during the audit process clearly indicated that there was not a shared framework for defining and supporting consumer participation within Neami. This can be seen to influence the ad hoc manner in which consumer participation takes place and can impede aspects such as communication and evaluation and feedback which are vital for good consumer participation.

‘Need to define consumer Participation at all levels, roles, skills required etc’ (staff)

Furthermore, whilst Neami has a well developed Consumer Participation Policy, there is no mention of consumer leadership in the existing policy, and there is no overall framework to support implementation.

Neami has developed excellent foundations for consumer participation and leadership to take shape for consumers. It is time now, after the period of rapid expansion in service, to concentrate on and consolidate the groundwork to build a key strategic direction with a structured and formalised plan for implementation, evaluation and quality assurance.

There is enormous scope for consumer participation and leadership opportunities through the employment of consumers within Neami. Both staff and consumers spoke about consumers designing and leading groups, training staff and becoming workers in all areas of Neami.

‘Neami service should be less driven by staff’ (Staff)

‘A completely owned process – naming, designing, running’ (Staff)

Staff pointed out it was necessary to be:

‘cautious not to build consumers to have a complete identity as a professional. Consumers can become trapped’ (Staff)

Concerns expressed by staff that greater focus on internal participation could lead to consumers being stuck in a consumer role were not shared by consumers. They clearly see participation as a pathway to skill building and social inclusion.

Staff believed it was important for future service provision to *‘be aware of what the priorities are for the organisation’* and a consumer pointed out the importance of Neami being flexible. *‘We are different day to day – don’t want to lose this with too much structure’* (Consumer)

Consumers greatly value having choice in how they participate in ways meaningful to themselves and their lives. Neami’s focus on connecting with the wider community is an important step in the recovery process. It needs to be noted however, that Neami caters for clients at different levels of wellness and stages of recovery. Neami needs to ensure its Consumer Participation and Leadership Policy provides opportunities for all consumers to participate.

Many consumers in the audit spoke of the importance of meeting and socialising with peers as a safe activity to build confidence and self esteem. This in turn was a step to moving onto the next stage of connecting with community. Participation opportunities within the organisation were seen as contributing to supporting individuals in their recovery process.


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## AREAS FOR ACTION

The results of the workshops in the Consumer Participation and Leadership Audit project point to the need for more systematised approaches to consumer participation and leadership in Neami, with some longer-term initiatives possibly including:

- The development of a consumer projects co-ordination role (or a revised version of consumer consultation) which could provide consumer-perspective collaboration and support for consumer-based research and development projects within Neami, and give consumer-perspective advice to the setup of other Neami projects
- Development of capacity in Neami for a series of strategically-targeted, consumer-collaborative research and development projects, to be carried out over time
- Strengthened decision-making roles
- A commitment to supporting all consumers to participate according to their abilities and interests

Some participants suggested that consumer consultants be employed by Neami, to assist with developing and supporting consumer participation including extending consumer participation to more marginalised groups:

- Skilled contributions from consumers in the delivery of staff training; research and evaluation; peer support in service delivery; and, consumer leadership and participation skills training
  - Linking consumer participation more strongly to Neami's decision making structures, where it can shape and influence the full suite of the organisation's activities
  - Support for consumer developed initiatives, including online peer support
- 

## 4.2 INDIVIDUAL SUPPORT WORK RELATIONSHIP

'I have found Neami as an organisation not there to tell you what to do and what not to do. They are there to help support and encourage the individual to work through their own recovery issues.' (Consumer)

Throughout the audit process it was clear that consumers have a high level of participation in their individual support relationships with their workers. Consumers value this as it provides them with a sense of control and choice and thus ownership over their recovery process and how they participate within Neami as an organisation and in the wider community.

'Healthy, trusting relationship – might be the first time for a while (you've had one) as a basis for taking you out into other relationships and the world.' (Consumer)

'When you have a good worker you have someone positive to talk to.' (Consumer)

All consumers taking part in the audit spoke in very positive terms of the relationship with their workers and how much they valued this. Consumers clearly identified the connection between this positive relationship and improvements in their mental health and advances in their recovery processes. *'Helping us grow'* (Consumer)

The relationship between workers and consumers was characterised across the audits by similar traits. Namely these were *'Respect, trust, friendliness, fairness, empathy, generosity kindness, responsibility.'*(Consumers)

The value and importance consumers place on their workers for assisting their participation and in turn their recovery processes is a credit to the individual workers and their commitment to consumers. It is also a credit to Neami as an organisation and the values it holds which permeate throughout the organisation.

Staff are aware of the significance of their roles and how they can facilitate high levels of consumer participation in the relationship.

'Ask the right questions at the right time to draw the response, asking what the Consumer wants.'(Staff)

'Just getting people there that are particularly unwell – don't make it hard or overwhelming for them – giving space.' (Staff)

'Individualised – what they want' (Staff)

The one downside highlighted by Consumers was staff turnover which leads to problems in continuity and consistency of support.

Workers were seen by consumers to provide encouragement and support in both emotional and practical ways and this is best illustrated in the words of Consumers themselves:

'Can point out strengths to help realise the strengths we have that we don't always realise.'

'Reassurance and reminding you what's important to you.'

'Help explain things in ways you understand.'

'Neami helped prevent eviction and maintain housing.'

‘Daily support from Neami worker prevented hospitalisation – I was able to ride it out.’

‘Illness can be distracting and stop you doing those (normal) things. A chat and a cup of coffee is really good.’

‘Neami has a role helping people understand the system (MH) – the roles of the various parts.’

‘Very willing to help and support participation – pushing us over the hurdles that prevent us participating.’

This support role encourages the development of confidence in the consumer to participate both within Neami and in the wider community.

The Individual Service Plan (ISP) is central to the relationship between workers and consumers and it was evident in the discussions that both staff and consumers see the value of the planning process.

‘ISP is not just paper – it leads to practical help.’(Consumer)

‘I tend to see the ISP is there to set goals and give me a sense of participation in treatment and support.’(Consumer)

‘(It is) a dynamic document to reflect where Consumer is at in terms of recovery/energy and priorities.’(Consumer)

‘(The importance of) keeping the ISP a living document.’ (Staff)

Staff viewed the ISP as a document to ‘facilitate discussion, break down barriers and break down goals into smaller components.’

When asked to rate the level of participation in the area of Individual support, most consumers rated themselves as having a high degree of control over the individual planning and support process implicit in these “key” support relationships. Most consumers rated Neami as at level 5 or 6 and identified the ideal as level 6. This was often contrasted to previous support relationships in which they had not felt the same degree of mutual respect and a non-judgmental attitude.

Also widely appreciated by a number of consumers in the audit workshops, was Neami’s conscientious efforts to honour each person’s right to self-determination in their life and recovery journey, setting their own personally-meaningful goals towards enhanced wellbeing, and being offered support to participate in communities of their choice.

“Neami as an organisation is not there to tell you what to do and what not to do. They are there to support and encourage the individual to work through their own recovery issues.”

“I can always disagree. In hospital decisions are made about me and for me without much consultation, whereas here you set your own direction and support stays with you. They trust you to identify your own directions, and help you consider options.”

*A staff comment was:* “Neami’s values of self-determination, hope, empowerment and change is what drives the work we do with people.”

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#### AREAS FOR ACTION

- Considerations of participation and leadership opportunities could be discussed in the individual service planning process.

### 4.3 CONSUMER ADVISORY GROUPS

(CAGs) Consumer Advisory Groups – need to strengthen structures and processes, especially communication

Need to create a more planned approach to consumer participation – with more inclusiveness

Leadership – need to tap into external resources

Consumers' capacity to shape and influence Neami's service delivery and strategic development

Neami's five Consumer Advisory Groups (CAGs) were often cited as being among the most important evidence of consumer participation in Neami. They were valued for some excellent work but the CAGs were also struggling in several ways.

In positive terms, the audit workshops revealed many lessons to learn in relation to the CAGs, which hopefully can inform processes for positive innovation and change across many aspects of Neami. Some of the good work already being done by CAGs includes renewing and re-designing an information kit for new consumers; commenting on a number of policy documents on emerging issues for PDRS's; helping to run community "fun days" combining consumer socialising opportunities and community de-stigmatisation education about mental health. Some CAGs also provide an opportunity to formalise skills through specific training for CAG members.

Neami CAGs were said to be having an important input to governance, strategic planning and policy development within Neami, but there were ambiguities about the CAG role, structure and function in the organisation. The lack of communication links between the CAGs and Neami's wider consumer population, most staff and service managers, and Neami's Board of management was identified as a significant issue by consumers.

A NSW CAG member said:

"The information flow is not that great. Better introduction to the CAG role is needed. Other consumers don't know what's being discussed there or who the consumer representatives are. Too driven by staff – chair role, staff attending, meetings and agenda setting."


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#### A CLOSE UP LOOK AT THE CAGS

Several aspects of the CAGs Terms of Reference have proven a source of discontentment and frustration for some CAG members – and could be viewed as discouraging to consumer participation in some ways.

Some consumers were concerned that the CAG selection process was not open and democratic. It relies on support workers promoting the role to individuals and in their view was often based on staff approaching "talented individuals" among service consumers.

CAGs within Neami overall are not authorised to set their own agenda, and generally have a focus-group type format, where the topics which are discussed are largely driven by management. Most of the CAGs are facilitated by a senior manager and most have an almost equivalent staff to consumer ratio in attendance at meetings. Some consumers expressed the view that CAGS should be facilitated by skilled consumers, while others viewed the facilitation by a manager as a benefit offering direct access to top management.



There is little interaction between the CAGs and Neami's Board, but both parties could see many benefits in remedying this. Board members expressed interest in strengthening the CAGs in various ways.

Staff said CAGs faced other information-related problems, such as:

- getting detailed reading materials only on the day;
- delays "sometimes months" in processing issues;
- lack of explanation of members' roles and responsibilities; scope and limitations for involvement; and
- lack of contact with local sites.


Some service managers and staff in workshops suggested that various barriers to consumer participation including structural problems in CAGs could have, in part, arisen from the rapid growth of Neami in recent years, and some consumer participation approaches have been "a bit hit and miss."

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## AREAS FOR ACTION

Neami is encouraged to actively work to develop, in collaboration with consumers, improved structures and processes for consumer participation and leadership, in the interests of more systematised and balanced consumer participation arrangements throughout Neami.

Thus some suggestions include:

- An improvement of structures and processes for CAGS, (Consumer Advisory Groups, or some possible future equivalent) would necessarily include improved communication pathways and information flow systems between the organisation and CAGS, and establish links with Neami's consumer population. Neami in collaboration with CAGs and other consumers would be encouraged to review the role, structure and function of CAGs. Neami is considering a project for CAGs to do a self-review process on role and function. This could be extended to include discussion of alternative structures and approaches
  - A possible move could be to seek out consumer movement advice, such as the Research and Evaluation Unit at the VMIAC, or very experienced Consumer Consultants from other services
  - To develop more inclusive ways of selecting potential candidates for consumer participation roles, including but not limited to CAG membership.
  - A review and/ or revocation of a rule that after two years of service on CAG members must retire
  - Participants also suggested that Neami explore both internal and external pathways as people complete their terms on the CAG. This might be contributing their valuable skills to Neami or other organisations. An example could be encouraging people to register with Health Issues Centre as a consumer, or linking up with consumer bodies or other leadership programs. Board membership was an option and to apply for a peer support worker role was another
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## 4.4 LEADERSHIP DEVELOPMENT

There seemed to be widespread agreement across all stakeholder groups that consumer leadership in Neami was something important to achieve -- but there was something less than consensus, in discussions so far, on how consumer leadership in Neami might be defined or what steps the organisation might need to take to get there. Further research and detailed planning is clearly needed.

Participants from the stakeholder groups were asked in the audit workshops: "How can Neami encourage consumer leadership and capacity building?"

This brought forward widespread discussion of problems, possibilities, and some practical suggestions for building consumer leadership into Neami.

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### THE NEED FOR MORE STRUCTURED AND SUPPORTED LEADERSHIP

For many consumers, staff/ service managers and Board workshop participants, it seemed clear that ideas of improvements to structures and processes for consumer participation in Neami, dealt with in other parts of this report, could also be expected to also help to strengthen consumer leadership within Neami, and to highlight and start to address some current shortcomings in this area.

Thus, a staff audit workshop participant called for: *"a more planned approach to leadership – not just driven by individual personalities."* This theme was echoed at several places in the audit process. Recommendations in this report calling for such initiatives as giving active consumer participants access to consumer-related skills training – e.g., meeting skills, public speaking/ trainer skills, evaluation and research skills, policy and sector knowledge, and more – are also relevant in the context of building consumer leadership.

A CAG member said: *"Some consumers do now play a role in training staff by telling their recovery stories...it would be good to give clients the opportunity to have training for doing this kind of work."*

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### PHILOSOPHICAL AND PRACTICAL ISSUES ABOUT CONSUMER LEADERSHIP

Suggestions elsewhere in this report about Neami needing to develop its own definitions of "consumer participation" and "consumer leadership" to pave the way for effective implementation, alongside its vision and mission statements, also hold true for leadership development.

There were also other, more open-ended philosophical discussions about the optimal nature and qualities of consumer leadership. Perhaps reflective of the complexity, uncertainty and contention around leadership and models of political power in the wider society, there was also a range of opinions about the best models for an organisation such as Neami. It seems that some people naturally love committees and policy discussions, while others do not.

Questions of consumer leadership and power balances among consumers in audit workshops, ranged from notions of strong leaders advocating for consumers to management, through to ideas drawing upon models related to ideas of participatory democracy, community development, peer-supporting groups of consumers working within Neami on organisational projects and some of their own, often with a premium on mentoring and self determination by participants. The Neami side of the equation would also need to reciprocate in a power-sharing arrangement.

While there were sometimes apparently difficult to resolve questions about the preferred role, designated duties and powers of possible consumer leaders/ workers, there was more consistency about the qualities required for such roles, including listening, empathy, caring, consumer perspective from lived experience, and more.

Questions also arose about the need for optimal settings for the range and diversity of opportunities for consumers to participate, and issues related to access, equity, social justice, and empowerment. Stakeholders' evidence across the nine workshops indicated that while Neami had some good policies and projects around consumer participation, there was a lack of a key consumer leadership presence that would be required to develop and sustain a diverse, inclusive, and effective range of consumer participation activities.

Participants in the Neami Board workshop largely agreed there was a need for more systematised consumer participation processes within Neami, including strengthening of CAGs (Consumer Advisory Groups), achieving better flows of information and communication, and opening up more opportunities for consumer participation Neami-wide.

Neami's policy to date that consumers were giving advice based on their own personal knowledge and experience rather than as "consumer representatives", was problematic for some consumers and other stakeholders.

A further issue was that the CAGs do not have two-way communication links with either consumers or to the Board. Also contentious was the fact that CAGs were not authorised to be facilitated by consumers or to set their own agendas, and were chaired by senior managers with "focus group" type questions set.

However, the audit did confirm that some good work was being done by some very high-calibre consumers on the five Neami CAGs and some valuable and meaningful input was being given on policy, strategic planning, and service delivery matters. However, there is large room for improvement and capacity building, in the interests of the consumer leadership, and consumer participation structures and processes, stakeholders have suggested.

The problems around what might be termed "succession planning" arising from the "two-year maximum term" rule for CAG members, and lack of broader articulated leadership structures, meant both a lack of pathways for these CAG "graduates" to pursue, and importantly, Neami possibly losing the wisdom and experience of these "well-briefed" consumers.

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## HOW CONSUMER LEADERS COULD CONTRIBUTE TO POSITIVE CHANGE

Participants across the workshops spoke of the need for Neami to identify the needs and aspirations of consumers and encourage consumers to join in with consumer participation in service planning, development, training, recruiting, and delivery.

A CAG member said: *"The CAG is a good place to raise issues and bring out leadership qualities..."* Another consumer suggested: *"Each site could bring consumers together to choose people to be involved in the planning of activities. Consumers leading could be a contact point, so people wouldn't just go to staff."*

A Queensland consumer proclaimed: *"Yes, we can be leaders – based on sharing our experience to help others, letting people know they have choices, becoming a [peer] support worker – training to complement the lived experience."*

A staff suggestion was: *“Different ways to engage in strategic planning based on different levels of engagement.”* Another said: *“Consumers surveyed and staff being more responsive.”* And: *“Increased consultation with consumers.”*

A significant number of Neami staff and service managers expressed a wish to help promote consumer participation and leadership, as a vision that extended from enhancing individual rehabilitation and support relationships; involving consumers at all levels of service planning and activities; and collaboratively with the organisation, setting new policies and strategic goals; through to consumers running some of their own their own services.

A service manager said: *“I would like to see a whole lot more opportunities being given to consumers...arts grants, consumer groups being purely run and driven by consumers, and forums to communicate.”* And further, *“...with the Collaborative Recovery Model coming, we will need to be much more in our thinking about things like peer mentors...”*

Similarly, a staff member said: *“Does everything have to be run by Neami? We can support consumers – for instance – by identifying funding, for them to develop programs.”*

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## WHAT MIGHT CONSUMER LEADERSHIP LOOK LIKE?

*Consumer leadership* goes directly to the question of whether Neami, or a similar organisation, embraces elements of consumer participation where, skilled, knowledgeable consumers, working from a dedicated consumer perspective, can engage in discussions with the organisation on matters of policy, planning and development -- and also use their skill sets, to consult with and engage with a wide range of consumers by facilitating consumer discussion, ensure that the consumer voice is heard, and in turn, influence positive change and development.


A reasonable number of participants across virtually the whole sweep of stakeholder audit workshops spoke in favour of Neami establishing consumer positions with dedicated responsibility to support and facilitate consumer participation and leadership – with the option of consumer workers being employed in such a capacity being affirmed a number of times.

A CAG consumer said: *“Employment of consumer consultants and project workers would be brilliant...”* Another said: *“Having an actual full time consumer consultant who could educate consumers on things like feedback and complaints, would be good.”*

One Board member said at a workshop: *“If support is not provided to consumers they can fall between the cracks, and they need to be provided with supervision and mentoring, to be consumer consultants/leaders.”*

The processes around employing highly-skilled, sector-trained/experienced, academically-qualified, and dedicated consumer perspective consumer workers/ leaders are in many ways very desirable pre-conditions for success with consumer leadership roles, such as Consumer Consultants or Consumer Project Workers.


These consumer leaders need to be well resourced and equipped for such roles; respected, recognised for their qualifications and experience; equitably remunerated; fully included in the organisation’s information loops and real decision making sites; and be regarded as full and equal staff.



With such pre-conditions for success in place, the levels and quality of consumer leadership necessary for genuine consumer participation would be well on the way to being achieved.

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#### AREAS FOR ACTION

- Amend Neami Consumer Participation Policy to include promotion of leadership development and opportunities.
  - Actively promote opportunities for consumer networking and leadership development through peak bodies, Leadership Plus (Vic), Disability Access Resource Unit (Vic), NSW CAG, the Health Issues Centre, Peer Work Project (SA), and Our Consumer Place etc.
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## 4.5 COMMUNICATION

‘(The) free exchange of information about Consumer Participation and about what levels you can avail yourself of (is important). It is the key to open the door, knowledge’ (Consumer)

Communication was one of the five most important things for encouraging and facilitating consumer participation and leadership in Neami identified by consumers, staff and the Board.

Consumers believe the more they knew about ways to participate, the more opportunities became available to them. It is important to note that consumer participation meant a wide variety of things to the different respondents. Emphasis needs to be placed on providing a range of opportunities to participate both within Neami and in the wider community. Consumers want the choice to participate in ways that are meaningful to them and this can be achieved through good communication throughout Neami.

As mentioned earlier in this report, there is a need for Neami to review, clarify and clearly define what consumer participation and leadership means to the organisation and the role of staff in supporting consumer participation and leadership in their work.

‘Define leadership (&CP) and the roles to be established’ (Staff)

All stakeholders spoke of the importance of having structured open communication channels throughout Neami which enable and encourage information flow both from management down to the ground level and back up from ground level to management.

‘Lots of opportunity to participate but not always aware of this’ (Consumer)

‘Important to involve consumers in communication process if any major changes to programs taking place’ (Consumer)

It became apparent from data collected that whilst there are some very good areas of communication within Neami, it is necessary to improve communication between all levels of the organisation.

Consumers and staff believed their one on one relationships and communication were good which in turn encourages the consumers’ participation. Communication was seen to be good at the individual level and Board level for consumer participation but not at the service site level.

At the service level staff felt the lack of clear and comprehensive communication from management hindered their work in some cases, and their abilities to inform consumers of various matters which would assist their participation. They also felt their role in decision making was diminished.

Staff also commented on how it would be good for CAG to report back to service sites so they would be more aware of consumers’ needs and issues. Both staff and consumers felt it could benefit from more structured and formalised channels of communication and information flow.

‘Middle section is missing – it is Board, AGM and individual – but what about middle – projects, groups, staff’ (Staff)

‘There are difficulties of managers filtering information through e.g.: too many emails – leads to late notice for staff’ (Staff)

Consumers felt they often missed out on information and if they did receive it was out of date so opportunities to participate were missed. In some instances consumers felt management at certain sites would make unilateral decisions with no or little consultation and consumers would find out after the event which often resulted in feelings of disappointment and dissatisfaction. As an example consumers mentioned group programs being cancelled due to funding restrictions, without consultation with consumers about exploring options for continuance.

These gaps in communication systems within Neami were necessarily seen to impede the fostering of consumer participation and leadership.

‘Communication enables consumers’ involvement in decision making, the opportunity to have input’ (Consumer)

‘Involvement in decision making (I am) listened to and suggestions are followed through. This leads to empowerment and ownership’ (Consumer).

It can be seen by the above quotes communication is highly valued by consumers within Neami and the opportunity to be involved in decision making not only encourages participation it also fosters leadership.

It was believed that more formalised systems of communication and information flow throughout Neami as an organisation are necessary to enhance Consumer Participation and Consumer Leadership in service provision.

Horizontal communication/ discussion/ and socialising opportunities for consumers with other consumers in Neami is a gap area, some consumers and staff say.

Many consumers expressed sadness and discontentment about social groups and events being stopped at various locations. This was happening in various ways because of differences in funding models; changes within the policy settings of a complex service sector; high client populations and stretched resources; many practical constraints including services’ relationships with state bureaucracies especially seen through the filter of time and extent of developments since deinstitutionalisation. However communication with consumers was poor and consumers felt excluded in the associated decision-making.


Other issues highlighted were the importance of informative and timely newsletters – not just as a communication tool, but also a vehicle for consumer participation in production. Information Booklets need to be developed for each site on Neami’s’ service and opportunities for consumer participation and leadership. It was also highlighted that meeting consumers from other sites and social interaction with your peers was greatly valued.

Practical suggestions such as these could be incorporated into an overall systematic communication strategy for Neami. The starting point however needs to be clear and accepted definitions of what Consumer Participation and Leadership are to Neami as an organisation, the service it provides and the opportunities it provides for consumers.


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## AREAS FOR ACTION

Neami is urged to work towards better communication and information flows in relation to consumer participation, to enable it to more readily “take consumers on the journey” as the organisation pursues growth, service model changes, and areas of innovation and service development.



Such improvements could help avert outbreaks of consumer discontentment and possible barriers to participation

- Review, clarify and clearly define what Consumer Participation and Leadership mean for Neami service delivery.
  - Establish clear and structured communication pathways through all levels of Neami as organisation, paying particular attention to mid level organisational communication.
  - Ensure the communication pathways encourage information flow in both directions
  - Provide Consumers with information regarding ways to participate in Neami and what Consumer Participation means.
  - Make consumers aware of Neami Consumer Participation and Leadership policies.
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## 4.6 PARTICIPATION & EQUITY

‘(There is a) need for different ways of participating for different people.’

Throughout the audit process it became very evident that there is an uneven pattern to consumer participation and leadership throughout Neami nationally. This is influenced by different funding obligations in different states determining the type of services offered, site variations, resources, communication and what was viewed as a ‘talent spotting’ approach to offering opportunities for participation.

The funding in different states determines the type of service Neami offers which in turn impacts on the level and types of consumer participation and leadership opportunities open to consumers. As highlighted in the following for example, WA receives Day to Day Living Funding which is group oriented whereas NSW is mainly funded for one on one outreach.

Whilst sites do necessarily have to take into consideration the localised population and environment, consumers spoke of the frustration of some sites providing opportunities for participation that others didn’t.

‘More consistency across sites – why can’t sites join activities’ (Consumer)

‘Groups – if not enough members open them up to other sites.

Consumers viewed changes in resourcing as being detrimental to their ability to participate.

‘Weekends cut, activities cancelled, community gardening funding cancelled halfway through project, hours have been cut’ (Consumers)

‘Neami only transports us one way now – hard to get there or get home.’(Consumer)

Consumers felt opportunities and choice to participate would increase with consistency in programs offered across sites as well as the opportunity to connect and interact with other sites.

‘Often have limited options offered rather than driven by consumers’ interests’ (Consumer)

‘Programs offered by Neami are generally decided by each sub branch of Neami and workers interested in running groups, the individual has less of a say.’

There was an overwhelming response from consumers in the audits to establishing more opportunities for social interaction amongst peers. Consumers lamented the fact that these areas of service delivery had largely disappeared with the focus now being on connecting with community. Consumers felt this was a large gap in Neami service provision and could be viewed as short-sighted. Interacting on a social level with other consumers provides a safe environment for people to reconnect with their social skills, confidence and self esteem. This in turn enabled people to move further out into the community.

Whilst there is the valid concern of creating dependency, consumers felt that service provision should not be a case of one type at the exclusion of another. To provide equity in consumer participation there is the need to provide opportunities and a service that caters to all levels of wellness and stages of recovery in its clientele.

The fact that consumers considered the lack of social interaction with their peers in Neami to be to their detriment is one which Neami needs to consider carefully in relation to developing Consumer Participation and Leadership activities for all Consumers.

Consumers in the audit process commonly referred to the need to encourage and facilitate consumer initiated and potentially consumer run activities to increase levels of participation. Consumers believed consultation on their needs and wants for the types of programs offered was not only highly desirable; it would also benefit levels of participation.

Where there are opportunities for participation, Neami provides excellent support and support and resourcing, resulting in great benefits to the consumers involved.

*Identifying Consumers who are ready for Consumer Leadership (and providing) support and fostering.’(Staff)*

The advantage to this approach is that it enables consumers to reach their full potential and provides many opportunities for consumer participation and leadership. However the perception is that these opportunities are only available to a select few and many are not afforded the opportunity. To ensure equity the focus now needs to be placed on making structural changes which will benefit all consumers. As discussed in the previous section, good communication is vital for consumer participation and leadership to occur. It also provides for equity in opportunities to participate.

Throughout the audits consumers spoke about the need for opportunities to participate in consultation, planning, feedback and evaluation of services and programs offered by Neami.


‘(Feedback) – not everyone has a say, need a form to give people – only way of giving people a voice.’(Consumer)

‘Important to involve people in planning’ (Consumer)

Neami has a wonderful opportunity to expand on what it already does well in consumer participation and leadership to incorporate a more inclusive approach for all consumers accessing its’ services.

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## AREAS FOR ACTION

- All consumer participation strategies are reviewed for the degree to which they are inclusive
  - Active promotion of consumer participation and leadership opportunities to all consumers using a range of communication modes
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## 4.7 SERVICE DEVELOPMENT

‘Consumer Participation to me means opening doors’ (Consumer)

From the information collected it is apparent that a number of service development activities and considerations are necessary within Neami to further enhance and encourage consumer participation and leadership thus providing the keys to opening doors.

Whilst it is good to have a formalised structure, providing consistency in consumer participatory practice and quality control across Neami, a certain degree of flexibility is required to cater for local environmental and demographic factors. What works particularly well at one site may not at another because local conditions and the profile of service users. Similarly, a policy of sharing what works may enhance service delivery at another site.

The fact that Neami relies on different types of funding in different states to operate its services and more importantly, that a particular type of funding determines the type of service Neami can conduct was highlighted through the audits. This has important implications for consistency of formalised structures and consumer participation and leadership within Neami. Service planning needs to consider the type of funding within the state and tailor services that facilitate and encourage consumer participation and leadership to the highest possible levels as well as having an overarching approach to the service delivery of consumer participation and leadership throughout the whole of Neami.

Service Development activities including training, research, evaluation, submission writing and policy development, need to be fully participatory at every stage of a person’s recovery and also every level of Neami. Both staff and consumers could see consumers involved in all levels of Neami.

“In all areas of Neami’s’ work- research, evaluation etc’ (Staff)

At present a consumer’s main ways to participate are on interview panels and staff induction training at an operations level and on CAG and the Board at a governance, strategic planning and policy level. Peer support work is also now an opportunity with the recent appointments of Peer Support Workers in each state.

‘Some Consumers do now play a role in training staff by telling their stories’ (Consumer)

Once again communication to all consumers of these ways to participate is vital.

Consumers and staff both stated that this involvement was *‘largely ad hoc (with) no systems in place’*

Both consumers and staff believe there is a huge potential for employing consumers within Neami in roles including training staff, working in research and policy development and health promotion. In turn service development could focus on offering training opportunities for consumers to equip them to take on work roles, not only within Neami but also into the wider community.

‘Neami should provide training to develop skills in the area of committees, being a consumer rep’ (Consumer)

‘Neami has a training section at Fairfield who could help train consumers to run groups’ (Consumer)


There is enormous scope to employ consumers with appropriate skills throughout Neami and one of the main areas could be in training new staff and implementing CRM.

'Consumer Participation can make services more relevant. Without Consumer input into service delivery people may believe they are doing the right thing but if they haven't seen the consumer perspective they don't know. It's about keeping services relevant to the Consumer base' (Consumer)

Staff also felt that increasing their skills by training opportunities both in house and out sourced would enhance their working roles. Areas identified were principles of consumer participation and leadership, consumer participation and leadership in action and consumer participation and leadership within neami as an organisation.

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#### AREAS FOR ACTION

- All service development activities are informed by a consumer perspective using the stages of participation as a guide
  - Promotion of opportunities for consumers to build their formal skills and knowledge
  - Broadening the range of roles available to consumers in service development activities e.g. co-trainer, trainer, research officer etc.
  - Professional development to build skills in facilitating consumer participation
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## 4.8 CONTINUOUS IMPROVEMENT

Inherent to service development activities is the necessity for Quality Assurance. These checks and balances will keep consumer participation and leadership at Neami focused, relevant, progressive and dynamic.

From the audit process it is apparent that stakeholders felt at present that quality assurance was *'largely an ad hoc procedure for evaluation and consultation' (Staff)*

In one instance it was stated it is *'What NEAMI wants to hear not what consumers want to say' (Staff)*

Consumers said their main way of feeding back was one to one with their worker. Some had attended planning days and program evaluations and there was the suggestions for forums and *"more days like this' (Consumer)*

Many Consumers were not aware of the complaints policy or process involved in making a complaint.

*'Consumers overall have low levels of awareness of Neami's complaints procedures' (Consumer)*

It should be noted here that consumers said that this was probably because they had not needed to use it. However, it once again highlights the importance of communication and information flow for Consumer Participation to take place.

*'Because I wouldn't expect to have the need to make a complaint' (Consumer)* *'People don't have the information – it should be in a handbook' (Consumer)*

*'It is only fair if people know about it' (Consumer)*

Further work is required to determine whether Neami's complaints policy is in line with Departmental expectations of accessibility, responsiveness and fairness.

The Board highlighted the necessity for keeping a complaints register and documentation needing to be formalised. In turn research and evaluation of complaints could then take place to inform service improvements throughout Neami.

Both consumers and staff made the suggestion of completing a feedback/evaluation form every 6 months when reviewing an ISP. This feedback/evaluation would remain separate to the ISP but would provide a regular, formalised feedback structure to sites which could then be compiled for the organisation as a whole to inform trends in service development, gaps etc. It is then important to keep that information up to date.

*'Keeping evaluation findings alive (it is) difficult to keep that information current.'* (Staff)

Because of the perceived ad hoc nature of quality assurance and evaluation by all stakeholders, a system of consumer feedback needs to be fully structured and mapped out within Neami, as do systems of quality control measures to ensure consumer participation and leadership are actively functioning throughout the organisation.

At present Neami's policy and philosophy of consumer participation is very sound however there is a gap between the theory and policy being enacted.

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### COMPLAINTS MECHANISMS: A CHANCE FOR LEARNING AND ACCOUNTABILITY

While the suggestions about the need to better promote consumer awareness about the complaints procedures at Neami, and enhance consumers' confidence to use them, are important matters that need to be acted upon soon -- the overall balance of feedback tools and types needs to be considered at the same time.

It is important too that all stakeholders are aware of the negative and corrosive effects that can occur in some services, when consumer feedback becomes too complaints-oriented. Ongoing and constructive two-way communication between consumers and managers/staff about many issues, can build more of a shared understanding on key issues, and emerging problems can be anticipated and resolved, well ahead of problems escalating.

Communication is a key element of consumer participation, and the quality and inclusiveness of the methods used to facilitate consumer partnerships with services are very important.

Complaints mechanisms are often mandated by statutory and legal requirements as well as organisational policies and procedures.

Complaints mechanisms are often somewhat daunting for service managers, staff and consumers alike, partly because of inherent difficulty of speaking about and hearing sometimes angry criticism – and problems can often creep in around issues like efficiency, transparency, confidence of consumers in the process, non-adversarial resolution, adequate solutions, and opportunities for services, workers, consumers and other stakeholders to learn from the processes.


In a workshop a Neami Board member said: *“Complaints need to be an integral part of the role [of consumer participation,] should be transparent and investigated, should go all the way to the CEO, have strong documentation, and a register with actions taken.”*

Despite the problems and challenges that can be associated with complaints mechanisms, they also carry potential rewards for all stakeholders. They do offer a firm bulwark of accountability to be available for stakeholders of a service when things go wrong – and offer many learning opportunities for organisational planning and development and new ways of articulating the partnership between consumers and organisations. Some Neami Board members suggested a de-identified complaints register to be inspected by the Board annually.

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## AREAS FOR ACTION

Neami’s complaints processes need some review, making them better publicised to consumers, better known and trusted. Consumers need to be reassured that complaints would not compromise their standing with Neami. This needs to be a guarantee Neami can stand behind as an organisation. It is suggested that Neami initiates:

- A review process - would do well to use the recent DHS document on complaints mechanisms as a guide.
  - Examine the notion supported throughout workshops, including the Board, that improvements to the complaints system would add accountability. It was suggested a de-identified complaints register be set up, to be monitored by Board, for instance, annually.
  - Develop quality control and evaluation tools to measure the success and ongoing improvements to Consumer Participation and Leadership in Neami.
  - Have formalised documentation/register of complaints and evaluate these on a regular basis as a means of quality control of Neami service delivery in Consumer Participation and Leadership.
  - Consumer Participation and Leadership policies and strategies should be ‘living documents’ open to review, refinement and change.
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## 4.9 CAPACITY TO SHAPE & INFLUENCE SERVICE DELIVERY

‘Consumer Participation to me means opening doors’ (Consumer)

Enhanced opportunities for consumer participation in Neami can be expected to increase the capacity for consumers to shape and influence service delivery and organisational strategic development.

It is important that the commitment to consumer participation is backed up by education and publicity efforts within Neami, to explain what it is about, make known opportunities to get involved, and highlight likely benefits for consumers collectively – including improved, more relevant, and more responsive service delivery. Education for staff about consumer participation is also needed.

Communication, both formal and informal, is a key enabler for consumer participation. This ranges from the interpersonal level of the support work relationship between the CRSW staff and consumers, through to more formalised meetings, forums or consumers working on tasks for Neami. While a number of consumers at the audit workshops mentioned the helpful role that newsletters at Neami sites could play in consumer participation, it seemed that the production of newsletters was somewhat patchy overall. Consumer-run newsletters were seen as a very desirable outcome, but staff information had an important place too.

It would also be helpful to make known how individuals might benefit from the consumer participation experience, in terms of personal achievement, empowerment, and being active in doing some work tasks of genuine value for a community service organisation. Sessional fees for consumer participation tasks are important, symbolically and practically, and need to be paid promptly – but it would be somewhat misguided if a culture were to develop where these modest amounts of money became the main motivation for consumer participation.

Some consumers suggested the use of modern ICT (information and communication technology) such as text message reminders for appointments, consumer-run websites and online-forums, where Neami helps get the funding and helps establish the site, and setting up consumer telephone “warm lines” (giving non-crisis peer support.)

There appears to be a lot of potential in such ideas -- with Neami’s consumer demographic groupings including increasing numbers of “tech savvy” young people -- and various expanded access methods for consumer participation, peer support, community linkages, and other recovery and support service elements, would warrant further investigation.

Questions around the “digital divide” which adversely affects disadvantaged groups, including many consumers are important and need to be addressed, but the problem and possible solutions needs to be dealt with in a later, separate exercise.

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### A RANGE OF FORUMS, METHODS, AND QUESTIONS NEEDED

For consumer participation to make an optimal contribution to practical and constructive improvements to service delivery, there needs to be a wide range of forums or methods of communication which would be listening-intensive, well-facilitated, accurately recorded and followed up with discussions with management/ staff and minutes or reports being made available for service consumers to see. Actions and outcomes would also need to be monitored.

A workshop comment from a Board member was: *“Multiple strategies need to be employed to provide successful consumer participation.”*

Some suggestions for an expanded consumer participation presence included: an AGM with more participation *“...a bit more interesting and fun,”*; and consumers being involved in community development/ education/ mental health awareness campaigns on issues such as housing needs, supports for employment access, and other aspects of social inclusion. A Victorian CAG member said enhanced consumer participation in Neami could assist consumers to *“progressively build bridges to the wider community.”*

Further possible steps arising from the audit evidence might include an exploration of the feasibility of regularly engaging consumers on a range of service delivery and quality improvement issues, through consultations/ structured surveys/ forums or other methods. Some possible methods of engagement could include Strategic Questioning, EBD (Experience-Based co-Design) or consumer satisfaction surveys (with VMIAC having compiled some generic versions).


Quite a number of consumers in the workshops expressed a liking for social events with other consumers, such as BBQs, and the peer support that could arise. (*“...sharing lessons from life”*) Many consumers also enjoyed meeting together for discussion forums, service planning meetings, or attending conferences or consultations with a Neami group. The idea of consumer-run events was mentioned frequently as an important thing, among consumer audit stakeholder workshops. Such gatherings, meetings and improved communications pathways seem to offer valuable opportunities, provide exposure and education for consumers on issues and tend to expand the pool of consumers ready and willing to participate.


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#### AREAS FOR ACTION

It is recommended that Neami review its consumer information provision policies, procedures and publications, in relation to facilitating a fuller awareness among consumers about consumer participation meaning and options, but not limited to this.

Similar improvement seems to be needed in explaining and educating consumers, from induction and when needed, information about such issues as:

- The support worker-client relationship, realistic expectations and boundaries; ISPs, and the notion of recovery
  - How Neami works and rationale for service delivery
  - The notion of one day transitioning out of Neami
  - The role of community linkages and how to make best use of them.
  - Suggestions were made that consumers should be issued with an introductory kit explaining what Neami was about, and other relevant information.
  - Part of the sometimes underspent consumer participation allocation from Neami’s budget for local services could be used for newsletter production and supplies.
  - Many consumers, particularly the under 30s, suggested the setting up of consumer internet sites, online peer support forums, or use of social networking because these were everyday life tools.
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- Strengthening of consumer groups and participation activities.
  - Building a capacity in Neami for implementing strategically-targeted Consumer Developed Initiatives.
  - Promoting consumer knowledge, and a culture of valuing consumer participation throughout Neami.
  - Reviewing complaints procedures, educating consumers about this feedback method, and consulting with consumers about whether they believe these procedures are accessible, responsive and fair.
  - Filling some of the “gap in the middle” with consumer participation opportunities – i.e., that space between consumer participation at individual support worker level and the level of becoming a CAG member, a Board member or Neami worker.
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## 5. CONCLUSION

The wealth and depth of knowledge amongst Neami consumers is a valuable resource. Neami has the opportunity to explore and develop this knowledge to enhance the future development of consumer participation and leadership as well as overall service delivery within the organisation. It is a largely untapped resource at present and the willingness exists amongst consumers to share and impart their collective wisdom.

Consumers overwhelmingly identified that the reason why consumer participation should be supported and encouraged in all its forms, is ultimately to support the development of meaningful connection. Within the organisation consumer participation provides a safe place to practice skills. Active opportunities for genuine consumer participation are an important demonstration of the key principles of Recovery – hope, empowerment, meaningful activity and responsibility.

Tokenistic approaches are just the opposite – many people have experienced the sense of being set up to fail, being patronised or ignored. It was a privilege to share and experience this knowledge base.

There is also a willingness and commitment amongst staff to consumer participation and leadership. Many staff shared ideas on how to increase this within the organisation. It was exciting to witness this enthusiasm and support of staff for consumers. When the above two factors are combined, Neami will move into a new dimension of best practice in service delivery.

The key to achieve this synthesis is formalised and open channels of communication and information flow combined with structured service development activities and a planned vision and ambition. The starting point is clearly defined definitions of consumer participation and leadership in Neami as an organisation. If we are not working from the same meaning and perspective we will lose momentum.

Neami operates from a 'values in action' perspective and the value of consumer participation and leadership is solidly grounded in self determination and participating in the community of one's choice.

By formalising systems around consumer participation and leadership and actioning them, these values come to life as will consumer participation and leadership activities in Neami. This will provide consumers with more opportunities and choice in the ways they participate, both within Neami and the wider community.

This current project provides a good example of enacting Neami's held value of consumer participation and leadership being essential and important to the organisation. This project was a great example of consumer participation. As project workers we experienced tremendous resourcing and support to conduct our role. We were fully integrated into the Service Development Team, employed for our skills with the added insight of our lived experience. There was a sharing of knowledge and synthesis of the consumer perspective and the organisational perspective.

It is an example of one way to incorporate consumer participation and leadership into Neami and that in turn expands into overall service delivery. Consumers in the audits spoke of having more opportunities like the audits to come together and share ideas and knowledge, feeding back into the organisation. Staff spoke of having Consumers involved in planning days.

Bringing all levels of Neami together with consumers creates the necessary communication channels which will optimise consumer participation and leadership in action at Neami.



## 6. DETAILED LEARNING RESOURCE

The Detailed Learning Resource section below highlights some of the key themes and compelling quotations from participants in the ten workshops in the Neami Consumer Participation and Leadership Project. It is anticipated that this section in itself will provide a “digest” for consideration, over a long period, of the wide field of information covered by the project. The responses are compiled in the workshop format.

### 6.1 SUMMARY OF WORKSHOP EVIDENCE

#### 1. WHAT DO THE WORDS “CONSUMER PARTICIPATION” MEAN TO YOU?

*“Having some level of collaboration between consumers and the service.”*

*“Allowing consumers to have some sort of control or sense of power with the services they receive and how Neami is run.”* E.g., ISP, partnership with support worker, consumer participation jobs.

*“People with mental health issues taking part in the activities Neami offers.”*

*May be “...a psycho education group on anxiety or going to an art gallery...”* May be “...activity groups, coffee, Sights and Splendour,” were some consumer responses.

*“Having choices -- options about ways to participate.”*

Self empowerment.

*“You need a strong consumer voice so people can get the services they need – to combat discrimination and get better services.”*

A Board audit workshop participant said: *“Consumer participation needs to cover the whole spectrum – engaging on an equal platform with the consumer to develop a positive relationship, and one that is directed by the consumer.”*

A consumer said: *“Participation of consumers needs to be supported and respected, have some power and views not being undervalued because of mental illness.”*

*“Joining in – discussion on ideas, feedback on planning.”*

*“A sense of belonging and trust supports participation, as well as the healing process.”*

A staff comment was: *“Consumer participation needs to be defined in ways that are genuine and not tokenistic, and meaningful for consumers.”*

*“Consumer participation can make services more relevant,”* said a consumer. *“Without consumer input into service delivery, staff may think they are doing the right thing, but if they haven’t seen the consumer perspective, they don’t know. It’s about keeping services relevant to the consumer base.”*

*Some staff comments were: “More scope for people to be actively involved in their own recovery”; “Putting the consumer in the driver’s seat in services, as well as in recovery”; and, “Participation doesn’t sit right – something that is more action driven, could be driven or lead – “Consumer Design.”*

A Victorian CAG focus group broadly agreed consumer participation in Neami would be enhanced by providing greater assistance for consumers to progressively “build bridges to the wider community” through a range of stronger community linkages.

Suggestions from consumers included:

- Consumers joining Neami in community politics/ awareness campaigns for more public housing, mental health community awareness, anti-stigma education; action for social inclusion issues affecting consumers;
- access to arts, culture, sport and recreation, or adult education and skill sharing; community service such as tree planting;
- or appropriate education options, training and work opportunities; and
- improving relationships with families (carers) and friends, and community groups.

*“Would be good to be more involved in the wider community – out of the “bubble” – meeting a wider range of people, in addition to what is already offered.”*

At the same time, across Neami, there was a widespread desire at consumer-based workshops for more opportunities for Neami consumers to meet together to socialise, support each other, and learn from shared lived experience.

*“Neami is a comfort zone – creative and communication – it is a strength, and should be maintained.”*

BBQs, Christmas parties and other social events were mentioned often as being very important for consumers – e.g., in all NSW CAGs, Adelaide, Victoria CAG and consumers in the Queensland and WA workshops -- important personally and toward building confidence for CAG roles and having an incentive to carry out consumer participation work.

A staff workshop participant said consumers would often prefer to meet at Neami locations. Some consumers said they “felt safer to relate with other consumers” they knew at a Neami site, and some had indicated they would not come to an event put into a community location due to possible stigma and privacy issues.

Queensland CP audit workshop members spoke of the need for opportunities for social interaction and for *“sharing lessons from life.”*

Need for different ways of participating for different people was also indicated in sessions.

A Vic CAG workshop observation was: *“People need opportunities to build confidence in voicing their opinions publicly/ or participating in community venues/ activities, and break down stigma barriers.”*

Adelaide CAG workshop members said they *valued opportunities to be involved with planning of events*. Included Expo “fun days” to promote resources for consumers, by consumers and activities including cooking, card making, door prizes – and each Neami site had a stall. Mental Health Resource Council was in attendance.

## 2. HOW CAN NEAMI ENCOURAGE CONSUMER LEADERSHIP AND CAPACITY BUILDING?

Participants across the workshops spoke of a need for Neami to identify needs and aspirations of consumers and encourage consumers join in with consumer participation in service planning and development.

*A staff audit workshop participant called for: “...a more planned approach to leadership – not just driven by individual personalities.”*

*Another staff comment: “More opportunities for consumers to develop consumer run and led programs beyond Collaborative Recovery Model and Flourish.”*

*“Drawing on consumer strengths, i.e., a consumer confident with public transport can provide support to other consumers.”*

*And: "Does everything have to be run by Neami? Can we support consumers – for instance, by identifying funding -- for them to develop programs?"*

Neami Board members in their workshop group were largely agreed that there was a need for more systematised consumer participation processes at Neami, including a strengthening of the CAGs operations, better flows of information and communication, and more opportunities for consumer participation to be developed Neami-wide.

One Board member said: *"If support is not provided to consumers they can fall between the cracks, and they need to be provided with supervision and mentoring, to be consumer consultants/ leaders."*

Some NSW staff delegates believed the rapid and large-scale expansion of Neami and may have caused pressures that sometimes led Neami to become "a bit haphazard" in carrying out processes for appointing and supporting members for CAGs, and similar activities.

Among the membership of the three NSW CAGs came some expressions of discontentment and frustration about changes management had made to the CAGs' terms of reference last year, which had meant the removal of any notion that members could be "representatives" for other consumers or directly advocate for them and the two-year maximum service rule on CAGs becoming a more contentious issue.

A number of NSW staff delegates at focus groups and several consumers said the "two-year" limit to CAG service should be reviewed.

Many support workers and program managers expressed enthusiasm about the whole idea of assisting with consumer participation -- as an example of why they chose to work in this field -- but felt they needed more structured approaches towards implementation. E.g., *"Different ways to engage people in strategic planning based on different styles and levels of engagement."*; *"Consumers being surveyed and staff being more responsive."* And *"Increased consultation with consumers."*

*A service manager said: "I would like to see a whole lot more opportunities being given to consumers...arts grants, consumer groups purely being run and driven by consumers, and forums to communicate." And further, with the Collaborative Recovery Model coming, we will need to be much more strategic in our thinking about things like peer mentors."*

Among several philosophical questions that arose at both the Victorian/ Adelaide staff workshop and the NSW staff workshop – and informally with executive management – was the possible unwanted consequence of people getting over-emphasised consumer identities.

A staff comment: *"We must be cautious not to build consumers to have a complete identity as a professional consumer and become trapped."*

Another worker said: *"Consumers often talk about their identities being outside illness. A lot of work is involved with trying to find other ways."*

According to a worker: *"A lot of consumers in Adelaide don't want to be taking part in groups, whether it's clinical or Neami, but would like individual support and be able to be linked into mainstream resources."*

Despite such concerns, which were also portrayed as matters of degree and personal choice, support for a wide range of service improvement and consumer rights based consumer participation was clearly evident in staff/ program managerial audit workshops.

A number of workers said it was good that Peer Support Worker jobs, coming on stream now, through the PHAMS program would provide opportunities to consumers wanting to work in Neami's service delivery.

A Board member said Neami should be *"focusing on those who are at the acute end and not just those who are well on the recovery, rehabilitation path – getting their voices heard."*

A CAG participant said: *“Maybe we should have a newsletter, so CAG is able to feed back to consumers.”*

NSW CAG members also said there had previously been consumer participation groups, but these had been stopped in some sites *“because it was felt that consumers should be in the community.”* One member said: *“We can’t even have a sausage sizzle...” for an hour once a month.”*

Socialising aspects of CAG work were seen by many consumers as valid, central, sustaining, educative, and essential for doing the consumer participation CAG role.

*“CAG members have a lot to give other consumers and the changes prevent other people being able to do this,”* a CAG member in NSW said.

A highlighted outcome of a workshop was: *“People liked the consumer participation meetings and are unhappy these were stopped by management without consultation with the consumers.”*

As several consumers and staff participants acknowledged, one constraint on organised groups and activities for consumers was the variation of funding models between sites, and in different states, which could have a major impact on the allocation of services, and some aspects of consumer participation. Different arrangements were possible under individual HACI funding in NSW, compared to group based funding in WA.

*“We’ve got to be able to apply our training. We had training [from a highly-placed consumer leader] for consumers to represent other consumers.”*

Suggestions arose from a NSW staff audit workshop about how the accumulated valuable knowledge and experience of consumers who have “graduated” from the CAGs might be put to use, including:

- A range of specific consumer-based work roles within Neami;
- Neami supporting/ providing an auspice for consumers in funding applications for consumer developed initiatives;
- Assisting and encouraging consumers to build links with consumer groups or a wide range of community work or activities; or
- Certificate IV courses in Community Mental Health to become support workers, or Training and Assessment, to become trainers, and more.

Some consumers spoke about leadership amongst/ between people, e.g.: opportunity to give a talk/presentation to other consumers about art their work and recovery.

*“Each site could bring consumers together to choose people to be involved in the planning of activities. Consumers leading could be a contact point, so people wouldn’t just go to staff.”*

*“The Consumer Advisory Group (CAG) is a good place to raise issues and bring out leadership qualities...”*

*“A lot of people don’t have the confidence to speak up – people don’t know each other well enough to speak up. A camp with organised activities could help build relationships. Groups including activities could help people socialise more confidently.”*

*“Need to get to know each other before we can build mentoring/ peer support.”*

Communication needs to be improved – monthly meetings and newsletters often delayed.

Some consumers suggested setting up consumer-run websites and online forums for people to give mutual support and discuss common issues.

Queensland CAG members said: *“Yes, we can be leaders” – “based on sharing our experience to help others, letting people know they have choices, becoming a support worker – training to complement the lived experience.”*

In the Queensland consumer workshop stated qualities of a good leader included – listening, being open, honest, and confident to talk to people, being strong within yourself – able to take criticism without falling apart – being able to listen to other ideas, shared lived experience. Similar values were expressed by the Perth consumer workshop group.

### 3. HOW WOULD YOU DESCRIBE YOUR ROLE AND THAT OF OTHER CONSUMERS WITHIN NEAMI?

#### (I) IN DEVELOPING INDIVIDUAL SERVICE PLANS

A CAG member said an Individual Service Plan (ISP) needed to be seen by consumers as not just a piece of paper, but a source of practical help.

“A dynamic document to reflect where the consumer is at in terms of recovery, energy and priorities,” was a consumer response.

*“Opportunity for me to acknowledge my own self direction – to put my hand up and say this is what’s important to me, this is what I want to focus on/ my goals, this is what support you can help me with.”*

*A CAG member said of Neami: “I can always disagree – in hospital decisions are made about me and for me without much consultation, whereas here you set your own direction and support stays with you regardless. They trust you to identify your own directions, and help you consider options.”*

Important that Neami people come to you and do normal things: *“...illness can be distracting and stop you doing those things. A chat and a cup of coffee are really good.”*

#### (II) AT AN ORGANISATIONAL LEVEL

*“It’s all about participation in my individual health outcomes. Participating in an organisation I can be a part of that direction. I want that service to be as best as it can be. Participation in the community that surrounds me leads to hope, empowerment, responsibility, and choice.”*

### 4. SMALL GROUP WORK

For each area discuss what Neami currently does, what you would like to see in the future and ideas for making it happen

#### GROUP 1.

**WHEN CONSIDERING INDIVIDUAL SUPPORT THE RANGE OF ACTIVITIES RELATED TO CONSUMER PARTICIPATION CAN INCLUDE THE FOLLOWING:**

- Participation in decisions about how, when & what services are delivered

Lack of choice of support worker, high rotation of workers in some parts of South Australia and NSW, and disruptions for services in some areas, due to chopping and changing with funding, is a source of annoyance and frustration for consumers.

*“When you do the compass and map – you can tell them how you feel about using the tools either at the time or later – give suggestions on how they could improve.”*

*"I thought joining Neami would be like going back to hospital with no decision making power. I thought I would lose some of my individuality seeing a worker each week. I have found Neami as an organisation is not there to tell you what to do and what not to do. They are there to help support and encourage the individual to work through their own recovery issues."*

Both staff audit workshops made reference to some recent service planning days involving fairly large numbers of consumers, with some including catering and socialising opportunities.

A staff member said: *"Neami's values of self-determination, hope, empowerment and change is what drives the work we do with people."*

A worker suggested that greater use could be made of aggregated consumer service data towards better planning of support work with consumers and service planning partly to get a sense of *"what things might work well."*

A consumer said

- A support work relationship based on partnership, knowledge sharing & mutual respect

*"Can talk about anything that's going on – better than I was – help through the hard times – suicidal thoughts. Talking it through with my support worker opened my eyes to the impact on others. Give it time and stick it out – you will feel better – and you do! Even when the pain feels like you can't get through the day – you can move on... the downs are not as bad as what they were."*

*"It's important to recognise the individuality of each person and individual needs."*

Regarding individual support, a consumer said *"the relationship is professional...Lost a lot of friends and social contact...Neami has filled that void with groups, giving me things to do. The staff are not my friends. It's a professional relationship which is encouraging and supportive."*

*"A healthy trusting relationship – it might be the first time for a while as the basis for taking you out into the world."*

Queensland consumer audit participants indicated the importance to them of Neami being able to support consumers throughout a range of circumstances, in cooperation with a range of other services – when consumers were in hospital or being supported to stay out, going through changing diagnoses, medication, homelessness, drug and alcohol problems, or other difficult experiences.

- Support for consumer initiated activities

Consumers in several CP audit workshops expressed a strong desire for after hours/ weekend activities and outings to be available for consumers – which had existed in some localities before, otherwise had been a popular but unfulfilled idea for a long while.

Several consumers said that weekends could be *"really boring."*

At some sites in NSW, where social activities and outings had been stopped at some sites, due to changing service models and funding issues, consumers were thinking about organising some outings for themselves.

*"Need to support people to build capacity to plan, work together as a group – helping to ensure it is a success, rather than just "if you don't do it, it won't happen."*

- Consumers are informed about the approach Neami takes in its work i.e. recovery focus

Some consumers, notably in the Adelaide consumer audit workshop, expressed dismay at continual communication problems, workers rationing services, and budgetary shortfalls leading to cuts in programs and services (e.g., weekend activities cancelled and car transport being provided going to activities, but not return -- to cut costs.)

- Strategies in place to support all consumers to participate

*“Maybe a newsletter or magazine project by consumers, for consumers could generate some employment,”* was a Sydney suggestion.

The idea of newsletters was cited often in the workshops, but very few were apparently being produced.

A number of Neami consumers suggested the establishment of consumer Internet sites, peer support websites, telephone “warm lines,” online social networking, and gatherings.

The Neami Board had reminded Neami sites of the need to actually spend the modest consumer participation organisational budget allocations.

Score for Overall Level of Participation in individual support & service delivery – now and where you would like to see it in the future – Average score: 5

## GROUP 2.

### **WHEN CONSIDERING GOVERNANCE, STRATEGIC PLANNING, AND POLICIES, THE RANGE OF ACTIVITIES RELATED TO CONSUMER PARTICIPATION CAN INCLUDE THE FOLLOWING:**

- Neami’s organisational decision-making structures that include consumer members. (For example, Board of Management, Reference Group, Advisory Committees, other structures)

*A consumer comment was: “CAG is a forum and a voice that allows individual consumers to act and make Neami aware of their own decision making processes and what impact those decisions have on consumers on a day to day basis.”*

*A consumer said: “CAG is there to put some checks and balances into the system. It gives Neami the opportunity for self reflection, and mostly it’s a voice.”*

Neami CAGs were said to be having an input to governance, strategic planning and policies within Neami, but there were ambiguities about the CAGs role, structure and function in the organisation. This was reflected in the lack of communication links with consumers, most staff, service management, and Neami’s Board.

It became clear over the audit process that the CAGs and Neami’s Board knew little about each other, and almost certainly this applied to the wider consumer population in relation to both bodies. Board members were interested in CAG members to able to later join the Board.

A Board member said: “I know we have CAGs out there somewhere, but I don’t know where they are or what they talk about. We don’t get reports about this...it is always better to get formal feedback.”

The Board's terms of reference excluded from its purview the day to day service delivery matters of Neami and thus relied on the discretion of the CEO to report on matters deemed relevant.

From a NSW CAG member: *"The information flow is not that great. Better introduction to CAG role is needed. Other consumers don't know what's being discussed there or who the consumer reps are. Too driven by staff – chair role, staff attending, meetings and agenda setting."*

The Neami Board CP audit workshop included comments that it was important not to overburden consumers with having to carry the weight of consumer participation – needed to be a shared process – "everyone's responsibility."

CAGs within Neami overall are not authorised to set their own agenda, and had a focus-group type format, whereby questions were discussed which management wanted answered. Each CAG is facilitated by a senior manager -- with some participants holding that CAGS should be facilitated by skilled consumers -- while others suggested that the facilitation by a manager could be viewed as direct access to top management.

- Participation in making key decisions at an organisational and/or project level.

At the consumer participation audit workshop with the Neami Board, there was a suggestion that "you need a consumer who is very well to participate" at a high level.

In other discussions in the study it was said that the quietest of consumers also needed to be heard, and consumers who are "quite unwell at the time" can often provide very useful feedback.

*According to a Board member: "Multiple strategies need to be employed to provide successful consumer participation."* Some examples were the Mental Illness Fellowship's 3CR consumer-run radio program, community education, pathways to employment, and a peer-run helpline.

One consumer who spoke of coming from a business background, said committees or peer group meetings were not desirable – there was just a need for clear, concise, factual communication from one leader supporting and mentoring others.

*"Consumer advocates need clear reporting/ communication structures to influence decision makers,"* a consumer said.

Some suggestion emerged that consumers tended not to regard joining the Board as moving upwards *"because it is a non-remunerated position."*

- Communication mechanisms between the different organisational decision-making structures that enable reporting on consumer participation issues. (Consider management/project/ administration levels)

Vic CAG did not report to or ask questions of consumers, nor did it make reports to the Neami Board.

*"Vic CAG does need a bit more of a consumer agenda base. It should meet more often and [in part] initiate its own agenda. Management and consumer partnership is important because it shares knowledge and skills both ways."*

From A NSW staff workshop: *"CAG was supposed to be a feed-up, feed-down thing – but when this was stopped recently, with CAG members no longer called 'consumer reps' this made them null and void."*

A number of participants, from among consumers and staff, disapproved of the rule that CAG members must retire after two years service, meaning, it was said, people with valuable experience were being lost – *“The rule should be changed.”*

- An organisational business/strategic plan that recognises and supports consumer participation.

A number of participants nominated this current project as evidence of Neami’s support for consumer participation in the organisation and wants to improve it.

One staff delegate, along with a range of audit workshop participants suggested: *“...consumer consultants attached to sites or service development.”*

- Specific Neami policies that relate to consumer participation and are developed with contributions from consumers.

(For example, consumer access to information about Neami, consumer rights and responsibilities, complaints processes, involvement of marginalised groups)

Some consumers suggested that Neami, in collaboration with consumers, should seek to play a greater advocacy/ community development role on a range of social inclusion issues of crucial importance for consumers.

Neami’s NSW CAGs said they had recently been working on introductory info kits for new consumers, giving an overview of services, methods, policies and procedures – including the complaints procedures – and many other resources.

*A CAG member said: “There is a Consumer Participation policy document, but it’s not very easy to read. I haven’t read it because it’s just too forbidding to read.”*

- Processes for reporting on consumer participation activities and achievements

*“Sixty consumers were invited to the AGM...It all gets a bit full with things it’s got to report – a bit boring and you can feel a bit shell-shocked. It needs to be a bit more interesting and fun.”*

Newsletter idea, handbook, annual report, or forums were all ideas suggested.

Score for Overall Level of Participation in governance, strategic planning and policy development - – now and where you would like to see it in the future : The average score for how it is at present was 2 (Are consulted): but consumers would like to see it move further toward Advise/influence – score 3.2

### GROUP 3

#### **WHEN CONSIDERING OPERATIONS, THE RANGE OF ACTIVITIES RELATED TO CONSUMER PARTICIPATION CAN INCLUDE THE FOLLOWING:**

- **Systems to seek and consider consumer feedback.**

A number of participants, including a Board member, suggested that Neami distribute feedback sheets to all consumers annually, to get a real sense of what people think about the services they receive from Neami, what other things they might want added to the mix, or to raise problems or concerns, etc.

Board members in their audit workshop, suggested that Neami research how satisfied consumers were with services? They mentioned several possible methodologies, including one from the Picker Institute overseas which used in-depth interviewing. A member said a high “bar” should be set for satisfaction levels.

- **Do Neami consumers have access to complaints mechanisms that are accessible, responsive and fair?**

Throughout the audit progress it became clear that Neami's complaints mechanisms need to be made more widely known and understood among consumers.

*A CAG member said: "Consumers overall have low levels of awareness of Neami's complaints procedures."*

Many consumers in CAG and consumer audit groups said they did not know about Neami's complaints procedures, and some added that this did not really matter *"because I wouldn't expect to have the need to make a complaint."*

*"People don't have the information – it should be in a handbook."*

*"It is only fair if you know about it." said another consumer.*

A CAG member, making comments similar to some others said: *"I'm sure that complaint mechanisms do exist, but I don't remember being told how to make a complaint, and don't know what it would be."*

Many workshop participants – including consumers and staff -- believed that at present many Neami consumers would be reluctant to make a complaints relating to the service, because of possible lack of confidence, or fear of damaging the relationship with a valuable service.

*According to a NSW staff audit participant: "A consumer said he had learnt from the [clinical] system: Don't buck the system."*

A Sydney manager said that a small number of serious complaints came in from time to time, which he would investigate by the book, discuss with the complainant and the subject of the complaint, and if warranted would take a range of further actions.

- **What improvements could be made to these mechanisms, if any?**

Neami Board members who attended their relevant audit workshop were for the most part unaware of the complaints procedure. A director said: *"Complaints need to be an integral part of the role [of consumer participation,] should be transparent and investigated, should go all the way to the CEO, have strong documentation, and a register with actions taken."*

Board members participating thought that a register, compiling de-identified records of complaints, should be made available to be inspected by the Board annually, so that significant lessons and trends could be considered.

A consumer from a NSW CAG said: *"We need lots of permission to have opinions, and speak up against Neami's policies and practices, if that's necessary."*

Mechanisms that inform consumers about ways to participate within Neami.

*"More education is needed among the client base about consumer participation."*

*"It totally amazes me, the consumer policy within Neami. Only through belonging to CAG have I come across the sense of depth to the Consumer Participation policy within Neami."* The informant continued to say that there would be great benefits for consumers to be informed about the operation of the CP policy, and what options it opened up for consumers.

*A CAG member said that committee meetings and policy work was clearly not for everyone: "Not many clients I know would want to have an input into that stuff...because policy and procedures language could be difficult to get their head around, or be a bit dry. Many clients don't see it as relevant to their participation in Neami. A lot of people just want to use the service to get better, or move ahead on their recovery journey."*

- Practical support to participation e.g. transport, paying people for their time or expenses, interpreters etc.)

Payment of sessional fees for consumer participation was an important issue throughout, for its practical, monetary and symbolic value.

It was very important to consumers that the payments be on time, and lateness was sometimes viewed as disrespectful.

- Recognition of the contribution of consumers to Neami and these are shared amongst consumers. (For example, recognition in annual report, conference registration/attendance supported, newsletters)

A Neami Board member said it was important to support and resource consumers to attend conferences and other relevant events.

- Allocation of sufficient resources to support consumer participation in Neami. (For example, funding to pay consumers for their involvement/ reimburse expenses/employ of consumers and community members with special expertise)

*“So many people I know want to give back to the system and be a social worker or support worker, because they have been helped so much. Things like the PHaMs system are great.”*

*“Employment of consumer consultants/ consumer project workers would be brilliant...having someone to go to if you’ve got a problem or an issue.”*

Positions with delegated responsibility to support consumer participation – the option for consumers to be employed in such a capacity was broadly affirmed at virtually the full sweep of consumer participation audit workshops.

*“Having an actual full time consumer consultant who could educate consumers on things like feedback and complaints procedures would be good.”*

- **Staff position descriptions, and/or performance appraisal, include criteria related to consumer participation in Neami.**

Consumers spoke of enjoying taking part in interview panels, and being able to bring a valuable consumer perspective to the process.

- Consumers involved in staff interviews and staff selection (For example, developing interview questions, selection panels, staff appointments)

Staff and managers said consumers often did well in this the area of staff selection if *“well briefed”* and those selected to do this consumer participation role tended to have natural ability for it.

- Key staff and consumers are identified to promote and support consumer participation within Neami (e.g. Role Models and Mentors available for other consumers to provide inspiration, motivation and demonstrate how good leadership can be achieved)

*“Peer support needs to be encouraged more.”*

A number of audit workshop participants across all stakeholder groups raised the idea of Neami employing consumer consultants, to help provide leadership and build structures for consumer participation.

- Documented guidelines and procedures that support consumer participation within Neami. (For example, Terms of Reference for committee membership, recruitment procedures for consumer representatives)

Neami has a well-written policy on Consumer Participation, but it is little known among consumers, staff or Board and much of it remains to be implemented on the ground.

- **Processes to support participation by marginalised groups (e.g. people from culturally & linguistically diverse communities).**

*“Because of the experiences many of many young people in clinical services, many young people find psych services scary. It may take some young people a long time to build a relationship of trust and partnership with a Neami support worker, but this could set the scene for further progress on the recovery journey.”*

- Partnerships with consumer groups (e.g. VMIAC)

Score for Overall Level of Participation in Operations- now and where you would like to see it in the future – the scores in this area varied widely. Currently the average was 3 (Advise/influence) but participants believed it should be at 4/5 (Plan jointly/have delegated)

#### GROUP 4

**When considering education/training and evaluation the range of activities related to consumer participation can include the following:**

- **Initial and ongoing support for members of the Board and members of Consumer Advisory Groups (CAG’S)**  
(For example, program to orientate representatives to the role, education and training by external providers, access to support from other consumers)

*“Neami should provide training to develop skills in the area of committees, being a consumer rep.”*

*“Neami has a training section in Fairfield which could help train consumers to run groups.”*

*“CAG training and support, to be honest, is a bit lacking,” said a Victorian CAG member. “Read the application for applying for CAG and it talks specifically about education and training. You are actually just tossed into the mix and it is sink or swim, and have felt at times I just could not do it – which is partly the illness.”*

- Involvement of consumer representatives in conducting educational and training activities within Neami. (For example, developing training resources and program, delivering training, evaluating training programs. Consider education and training for staff at all levels of Neami.)

*“Some consumers do now play a role in training staff by telling their recovery stories...it would be good to give clients the opportunity to have training for doing this kind of work.”*

*“I would like to see the whole process of education/ training and support to be a higher priority and to be more visible. It feels like at the moment you only get snippets of information about what is available, what you can access, and what’s out there.”*

- **Training provided to staff and consumers reflects attitudes and beliefs to promote consumer participation across Neami**

*“It might be good to get a few more consumers involved: e.g., with forums on medications, legal rights, and other guest speakers...”*

- A strategy that assists Neami to evaluate the effectiveness of its consumer participation activities. (For example, against stated aims, consumer satisfaction)

Many participants hoped the issues raised and recommendations from the present project would be a beginning for more strategic approaches to consumer participation.

- Strategies that involve consumer representatives in Neami's evaluation and accreditation activities

Some individual consumers have been involved with such roles, such as speaking to accreditation officials.

A number of audit workshop participants from all areas nominated the present project as an example of Neami's commitment to consumer participation.

- A plan for the use of evaluation results for organisational change.
- Opportunities for consumers to participate in selecting, conducting, designing and undertaking research in which Neami will participate/undertake
- Mechanisms developed to ensure Neami stays up to date with the best practice of consumer participation within PDRS service

One suggestion was to seek consumer movement advice, such as the Research and Evaluation Unit at the VMIAC, or very experienced Consumer Consultants from other services.

- How would you describe integration of consumer participation elements within Neami's organisational structure? (create organisational diagram)

**Communication** – between sites, feedback loops from CAG, newsletters, knowledge and opportunities for participation, build connection with the organisation

**CAGs** – catch up regularly with other consumers – not to represent but to discuss and consult with others

**Consumer Participation** - define roles and responsibilities; ensure consumer suggestions are responded to

**Social interaction** – more opportunities for consumers to meet others in similar situations

**Consumer initiated activities** – more support for consumer initiated activities – practical and financial in the context of skill and networking opportunities.

Score for Overall Level of Participation in Training, Education and evaluation- now and where you would like to see it in the future – the scores in this area varied widely. Currently the average was 3 (Advise/influence) but participants believed it should be at 4/5 (Plan jointly/have delegated)



# 7. APPENDICES

## 7.1 AUDIT TOOL

### CONSUMER PARTICIPATION WORKSHOP PLAN

**1. WELCOME & INTRODUCTION TO THE PROJECT** – explain this is the first stage to identify potential directions & will be followed by a more comprehensive consultation

**2. PLAN FOR THE SESSION** – run through agenda - full group to discuss the first four questions then break into small groups with each group exploring a particular area

#### 3. LARGE GROUP BRAINSTORM & DISCUSSION

1. Who would you say are:
  - i) The consumers of Neami's services
  - ii) The management of Neami's services
  - iii) The key external stakeholders of Neami's services
2. What do the words "consumer participation" mean to you?
3. How can Neami encourage consumer leadership and capacity building?
4. How would you describe your role and that of other consumers within Neami?
  - (i) In developing individual service plans
  - (ii) At an organisational level

#### 4. SMALL GROUP WORK

For each area discuss what Neami currently does, what you would like to see in the future and ideas for making it happen – (the bullet points are prompts for discussion)

##### GROUP 1

When considering individual support the range of activities related to consumer participation can include the following:

- Participation in decisions about how, when & what services are delivered
- A support work relationship based on partnership, knowledge sharing & mutual respect
- Support for consumer initiated activities
- Consumers are informed about the approach Neami takes in its work i.e. recovery focus
- Strategies in place to support all consumers to participate

Score for Overall Level of Participation in individual support & service delivery – now and where you would like to see it in the future

##### GROUP 2

When considering governance, strategic planning, and policies, the range of activities related to consumer participation can include the following:

- Neami's organisational decision-making structures that include consumer members. (For example, Board of Management, Reference Group, Advisory Committees, other structures)
- Participation in making key decisions at an organisational and/or project level.
- Communication mechanisms between the different organisational decision-making structures that enable reporting on consumer participation issues. (Consider management/project/ administration levels)
- An organisational business/strategic plan that recognises and supports consumer participation.

- Specific Neami policies that relate to consumer participation and are developed with contributions from consumers  
(For example, consumer access to information about Neami, consumer rights and responsibilities, complaints processes, involvement of marginalised groups)
- Processes for reporting on consumer participation activities and achievements

Score for Overall Level of Participation in governance, strategic planning and policy development - – now and where you would like to see it in the future

### GROUP 3

When considering operations, the range of activities related to consumer participation can include the following:

- Systems to seek and consider consumer feedback.
- Do Neami consumers have access to complaints mechanisms that are accessible, responsive and fair?
- What improvements could be made to these mechanisms, if any?
- Mechanisms that inform consumers about ways to participate within Neami.
- Practical support to participation e.g. transport, paying people for their time or expenses, interpreters etc.)
- Recognition of the contribution of consumers to Neami and these are shared amongst consumers.(For example, recognition in annual report, conference registration/attendance supported, newsletters)
- Allocation of sufficient resources to support consumer participation in Neami. (For example, funding to pay consumers for their involvement/ reimburse expenses/employ of consumers and community members with special expertise)
- Staff position descriptions, and/or performance appraisal, include criteria related to consumer participation in Neami.
- Consumers involved in staff interviews and staff selection (For example, developing interview questions, selection panels, staff appointments)
- Key staff and consumers are identified to promote and support consumer participation within Neami (e.g. Role Models and Mentors available for other consumers to provide inspiration, motivation and demonstrate how good leadership can be achieved)
- Documented guidelines and procedures that support consumer participation within Neami. (For example, Terms of Reference for committee membership, recruitment procedures for consumer representatives)
- Processes to support participation by marginalised groups (e.g. people from culturally & linguistically diverse communities).
- Partnerships with consumer groups (e.g. VMIAC)

Score for Overall Level of Participation in Operations- now and where you would like to see it in the future

### GROUP 4

When considering education/training and evaluation the range of activities related to consumer participation can include the following:

- Initial and ongoing support for members of the Board and members of Consumer Advisory Groups (CAG'S)  
(For example, program to orientate representatives to the role, education and training by external providers, access to support from other consumers)
- Involvement of consumer representatives in conducting educational and training activities within Neami.  
(For example, developing training resources and program, delivering training, evaluating training programs - Consider education and training for staff at all levels of Neami.)

- Training provided to staff and consumers reflects attitudes and beliefs to promote consumer participation across Neami
- A strategy that assists Neami to evaluate the effectiveness of its consumer participation activities. (For example, against stated aims, consumer satisfaction)
- Strategies that involve consumer representatives in Neami's evaluation and accreditation activities.)
- A plan for the use of evaluation results for organisational change.
- Opportunities for consumers to participate in selecting, conducting, designing and undertaking research in which Neami will participate/undertake
- Mechanisms developed to ensure Neami stays up to date with the best practice of consumer participation within PDRS service

Score for Overall Level of Participation in Education/Training, Research & Evaluation- **now and where you would like to see it in the future**

**5. FEEDBACK FROM SMALL GROUP WORK**

**6. BRAINSTORM – the most important 5 things Neami could do to support increased consumer participation & leadership**

**7. NEXT STEPS**

**8. EVALUATION & CLOSE**



## 7.2 LEVELS OF PARTICIPATION

Consumers and community members can participate in many different ways throughout an organisation, as illustrated in the table below. Within each area, a numeric score is attached to each level so that organisations can use this to easily describe the levels of their own activities. Higher degrees of participation do not necessarily denote more highly valued levels of participation. As consumers discussed in the audit process, differing levels of participation may apply to specific organisational functions. As an example most consumers would say that Level 6 – Having Control, is desirable in the area of Individual Support whereas Level 3-4 is desirable in the area of governance

Degree	Participant's action	Illustrative mode
6	<b>Have control</b>	Neami asks consumers to identify the problem and to make all the key decisions on goals and means. Neami's role would be to help consumers at each step to accomplish goals.
5	<b>Have delegated</b>	Neami identifies and presents a problem to consumers, defines the limits and asks consumers to make a series of decisions, which can be embodied in a plan it can accept. <i>For example: Working parties/groups</i>
4	<b>Plan jointly</b>	Neami presents tentative plan subject to change and open to change from those affected. Expects to change plan at least slightly and perhaps more subsequently. <i>For example: Steering groups</i> <i>Partnerships to develop health information</i>
3	<b>Advise/Influence</b>	Neami presents a plan and invites some feedback. Prepared to modify plan only if absolutely necessary. <i>For example: Consumer councils</i> Consumer representatives on reference groups, or consumer reference group <i>Consumer representatives on committees</i> <i>Consumer input on policy</i>
2	<b>Are consulted</b>	Neami tries to promote a plan. Seeks to develop support to facilitate acceptance of the plan. <i>For example: Evaluation surveys</i>
1	<b>Receive information</b>	Neami develops a plan and announces it. Consumers are informed. Endorsement of the plan is expected. <i>For example: Publications about how consumers can participate, patient charters, consumer-friendly administrative procedures, and the use of volunteers</i>
0	<b>None</b>	Consumers are not involved in any aspect.

Source: Modified from Brager and Specht (1973), in Consumer Focus Collaboration (2000a) Produced by the Department of Public Health, Flinders University, and the South Australia Community Health Research Unit, Commonwealth Department of Health and Aged Care, p.3

