

Consumer and Carer Engagement Framework

1. Why do we need a Consumer and Carer Engagement Framework?

Helping Hand recognises that participation and engagement of consumers and carers in the activities of an organisation at all levels is:

- an ethical and democratic right
- integral to improving the quality, responsiveness, safety and accountability of our services
- improves lifestyle and health outcomes.¹

This recognition is reflected in Policy 14 – Consumer Engagement and Feedback and the Carer’s Recognition Position Statement. In addition, the principles underpinning everything Helping Hand does include:

- We are committed to older people **choosing** what care they receive and how it is delivered.
- We believe in older people having a sense of purpose and **contribution** wherever they choose to live.
- **Consumer participation will be fundamental** to service development and delivery, including collaboration with other aged care stakeholders and non-traditional partners.²

The Consumer and Carer Engagement Framework provides guidance to consumers, carers and Helping Hand staff on how to support and facilitate consumer and carer participation in and engagement with key areas of Helping Hand’s business – policy, planning, delivery, research and evaluation. It complements and supports other Helping Hand frameworks, including the Care Governance Framework and the Quality System Framework.

2. Definitions

2.1 Consumers and Carers

The following definitions have been adopted to clarify what is meant by the terms *consumers* and *carers*:

- *Consumers* are people who are potential, current or previous users of Helping Hand’s services
- *Carers* are any people who provide unpaid support to someone who needs this kind of help as a consequence of disability, a medical condition (including a terminal or chronic illness) or mental illness. This broad definition is not restricted by age, gender or relationship to the person who needs assistance.³

Consumers may be carers and vice versa. At times, a person may be both. It is important, though, to identify both separately in the framework in recognition of the fact that consumers

¹ Based on ACHS EQUIP 4 Guide, Part 1 – Accreditation, Standards, Guidelines, 2006, Sydney; Helping Hand Aged Care Policy 14 – Consumer Engagement and Feedback

² <http://www.helpinghand.org.au/about-us/#principles> accessed 15/03/2012 5.00pm

³ <http://www.helpinghand.org.au/wp-content/uploads/2012/07/Positioning-Statement-Carers-Recognition2.pdf> accessed 11/05/2012 10.59am



and carers have different issues and perspectives on issues. It is important that these are identified and included in Helping Hand's services.

The definition of *who is a consumer* and *who is a carer* can vary depending on the issue being considered and/or the type of engagement required. For example:

- When planning services, *consumers* and *carers* includes people who are potential, current or previous users of Helping Hand's services and the people who care for them.
- When seeking feedback on services or conducting evaluations, *consumers* and *carers* are people who are currently using services or who have used them in the past, and their carers.

Consumers and carers may be represented by an advocate, that is, "a person or body appointed by the consumer or carer who represents their interest and may communicate on their behalf"⁴. Advocates will play an important role in ensuring participation and engagement by those who are most vulnerable.

2.2 Participation and Engagement

The terms *participation* and *engagement* are often used interchangeably. Generally, *participation* refers to the process of sharing in the activities of a group or sharing in common with others, (as fellows or partners) leading to *engagement* or commitment to the cause/issue/outcome.⁵

In this framework:

- *participation* refers to the process of involving consumers and carers in the planning, development, implementation and review of policies, services and practices which affect them as users of aged care services, both from Helping Hand and across the broader aged care sector
- *engagement* refers to the outcome achieved through participation, that is, that consumers and carers have a sense of ownership of the services they receive

3. Principles of Consumer and Carer Engagement

The Consumer and Care Engagement Framework will be implemented in line with the following principles:

Consumer and Carer Voice – everyone who may be affected by a decision must have opportunities to be involved in the decision making process at some level.

Access and Equity – at a minimum, people affected by decision must be informed of the decision making process; have access to information about the matter under discussion and be provided with the means to participate.

Trust and Respect – there will be mutual agreement about the process and assessment of the issues under consideration. All participants will show consideration and value each other as equal contributors to the engagement process.

⁴ Helping Hand procedure QAL001P Consumer Feedback (DRAFT - RiskMan) - Definitions

⁵ Based on definition of "participation" from <http://www.thefreedictionary.com/participation>, accessed 14/03/2012, 1.56 pm

Timeliness – consumers and carers must be involved at the beginning, not towards the end of the decision making process.

Transparency – the type of participation and engagement must be made clear from the outset. Non-negotiables will be explicit, including stating where there are options and choices to be made and where there are not.

Diverse and Flexible – multiple strategies are essential and must vary depending on the needs of the consumers and carers being engaged.

Balancing Impact and Input – participation and engagement activities must balance the likely impact of the process for individuals with the capacity and availability of consumers and carers to participate. This means ensuring that the necessary people are involved, the appropriate engagement mechanisms are used and the right amount of time is allocated for involvement.

Support and Capacity Building – participation and engagement must be resourced so that it is meaningful to consumers and carers. This includes resources to:

- build staff capacity to implement the framework
- build consumer and carer capacity to participate (including access to advocates)
- cover the costs, both to Helping Hand and to individuals, resulting from participation.⁶

4. Helping Hand's Consumer and Carer Participation and Engagement Spectrum

Helping Hand's Consumer and Carer Participation and Engagement Spectrum (see Table 1) is based on the International Association for Public Participation's "Public Participation Spectrum".⁷ The Spectrum provides Helping Hand staff, consumers, carers and other stakeholders with a common language to talk about participation and engagement. It also is a key tool for supporting decision making about the level of participation/engagement required for different activities and decisions.

⁶ Based on principles in *WA Consumer, Carer and Community Engagement Framework*, WA Health Consumer, Carer and Community Engagement (2007) and *Consumer and Community Participation Guidelines*, SA Health (2009)

⁷ <http://www.iap2.org.au/sitebuilder/resources/knowledge/asset/files/36/iap2spectrum.pdf> accessed 14/03/2012 2.15 pm

Table 1: Helping Hand's Consumer and Carer Participation and Engagement Spectrum

INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
<i>Consumer and Carer Participation & Engagement goal</i>	<i>Consumer and Carer Participation & Engagement goal</i>	<i>Consumer and Carer Participation & Engagement goal</i>	<i>Consumer and Carer Participation & Engagement goal</i>	<i>Consumer and Carer Participation & Engagement goal</i>
To provide consumers and carers with balanced and objective information to assist them in understanding the opportunities solutions, problems, and/or alternatives	To obtain consumer and carer feedback on analysis, alternatives and/or decisions	To work directly with consumers and carers throughout the process to ensure that their concerns and aspirations are consistently understood and considered	To partner with consumers and carers in each aspect of the decision including the development of alternatives and the identification of the preferred solution	To place final decision-making in the hands of consumers and carers
<i>Helping Hand's commitment to consumers & carers</i>	<i>Helping Hand's commitment to consumers & carers</i>	<i>Helping Hand's commitment to consumers & carers</i>	<i>Helping Hand's commitment to consumers & carers</i>	<i>Helping Hand's commitment to consumers & carers</i>
We will keep you informed	We will keep you informed, listen to and acknowledge concerns and provide feedback on how consumers and carers influenced the decision	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how consumer and carer input influenced the decision	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible	We will implement your decision

5. Putting the Framework into Practice

Consumer and carer engagement will be sought and supported in the areas of:

- Policy
- Planning
- Service delivery
- Research
- Evaluation

The spectrum provides guidance on what level of participation and engagement is expected.

5.1 Policy

Policy in this framework refers to the guidance documents which direct all aspects of Helping Hand's operations. There will be different levels of engagement with different types of documents, as some are very operational in nature around things which do not directly impact on consumers and carers. Table 2 summarises the types of documents and the level of participation and engagement required.

Table 2: Policy Participation and Engagement

Guidance documents	Description	Level of Participation and Engagement
Policy	High level organisational statements which incorporate Helping Hand's principles and industry regulatory obligations and standards	Involve or Collaborate
Position Statement	Statements which help to clarify Helping Hand's approach to emerging issues for the organisation and its communities of interest	Involve or Collaborate
Procedures	Outline expectations regarding the management of a matter including the key requirements or a detailed description of all essential processes	Up to Consult, depending on the issues covered in the procedure
Guidelines	Developed to support and guide staff to achieve the expectations outlined in a procedures or policy and offer additional detail and context	Up to Consult, depending on the issues covered in the guidelines
Work Tool	All other forms such as work instructions, assessment tools, forms, flow charts, checklists, operating procedures etc. They may have local or organisational application.	Up to Consult, depending on the issues covered in the work tool

5.2 Planning

Planning refers to the processes Helping Hand undertakes to set future directions and priorities at organisational level; the business planning processes at divisional and site /service/corporate unit levels to implement the strategic objectives; and project planning around specific activities. Table 3 summarises the different levels of planning and the level of participation and engagement required.

Table 3: Planning Participation and Engagement

Planning Activity	Description	Level of Participation and Engagement
Strategic Planning	1. The Organisational Plan is a six year strategic plan reflecting Helping Hand's aspirations. The plan is developed by the Board and Executive. 2. Mid year plan reviews occur to ensure that the plan remains relevant over time. The review is undertaken by the Board.	Consult, Involve or Collaborate Consult, Involve or Collaborate
Implementation Planning	The Implementation Plan is the work program for the first three years of the Organisational Plan and it is developed and owned by the Executive Group. Each strategy is assigned to a member of Executive or Key Manager who is responsible for leading the strategy and providing a progress report to Executive. The Implementation Plan is reviewed annually by Executive with subsequent adjustments undertaken if required.	Consult, Involve or Collaborate, depending on the specific strategy. Responsible members must identify and justify the appropriate Participation & Engagement Level to be implemented as part of their reports to Executive.
Business Planning	Annual Business Plans for departments, services and programs will identify the key projects, activities or tasks required to be undertaken to deliver the work identified in the implementation plan. They will include specific timelines related to the year of operation.	Up to Collaborate, depending on the specific project, activity or task. Responsible members must identify and justify the appropriate Participation & Engagement Level to be implemented as part of the regular reporting arrangements.
Project Design and Planning	Projects within Helping Hand vary greatly in size, resource commitment, risk and strategic value. Projects need to align with functional and service business planning, as much as aligning with the strategic focus within organisational planning. Preparation, review, monitoring and reporting will be contained within the project plan and will vary from project to project.	Up to Empower, depending on the specific project. Responsible managers must identify and justify the appropriate Participation & Engagement Level to be implemented and include participation and engagement as part of the regular reporting arrangements.
Planning activity	Description	Level of Participation and Engagement
Ongoing Management	At the local service or site level, structures and processes will exist which engage consumers and carers in hearing about and, as appropriate, participating in decisions about local site and service issues. Examples include local Consumer and Carer Committees.	Up to Empower. Responsible managers must identify and justify the appropriate Participation & Engagement Level to be implemented and include participation and engagement as part of the regular reporting arrangements.

5.3 Service Delivery

Service Delivery refers to all matters relating to the way services are provided at the individual level and seeking and responding to feedback on service quality and performance to support continuous improvement activities. Table 4 summarises the different levels of planning and the level of participation and engagement required.

Table 4: Service Delivery Participation and Engagement

Service Delivery Activity	Description	Level of Participation and Engagement
Individual level service delivery	This includes all interactions involved in delivery of services to individuals. We aim to achieve maximum consumer and carer choice and control of the services they receive, within resource and funding constraints, including in areas such as assessment; planning; coordination; delivery; review; changes; individual budget management.	All service approaches should aim to engage at the Empower level. Responsible managers must identify and justify when alternative Engagement Levels are implemented and include participation and engagement as part of the regular reporting arrangements.
Quality improvement	Investigating service quality Measuring service satisfaction Implementing quality improvement initiatives	Up to Collaborate Responsible managers must identify and justify the appropriate Participation and Engagement Level to be implemented and include participation and engagement as part of the regular reporting arrangements.

5.4 Research

Research refers to specific investigations to answer questions which contribute to our knowledge of subject or to generate or test a theory. Helping Hand undertakes research to ensure our services are relevant and effective and to improve and influence the future direction of aged care. We are committed to including the views of older people and carers in identifying research topics and participating in research, including as researchers. All research proposals must be approved through Helping Hand's Research Ethics Approval Process. The Consumer Reference Group provides a forum for advice and direction on research ideas.

5.5 Evaluation

Evaluation refers to the systematic collection of information about activities, characteristics and outcomes of programs to make judgments about the programs, improve program effectiveness, and/or inform decisions about future programming. It differs from research in terms of intent, purpose and intended audiences. Nevertheless research and evaluation use many similar techniques and methods so the principles and practices around consumer and carer participation and engagement are similar.

Helping Hand evaluates programs and services from time to time and regularly participates in externally mandated evaluations to ensure that our services are continuing to meet the needs of consumers and carers and to test new models of service. Evaluation requires

participation and engagement with relevant stakeholders, particularly consumers and carers, and will involve a variety of mechanisms. As with research, we will seek to engage consumers and carers as evaluators where possible, will conduct all research in line with Helping Hand's Research Ethics procedures and will, as appropriate, refer matters to the Consumer Reference Group for consideration.

6. Processes for Consumer Participation and Engagement

To support the implementation of this framework, Helping Hand will put the following processes in place.

6.1 Consumer and Carer Engagement Committee

The Consumer and Carer Engagement Committee reports to the Helping Hand's Executive and is responsible for facilitating engagement with consumers and carers at both a strategic and operational level across Helping Hand. Terms of Reference and the Business Plan for 2012/2013 are in Appendix A.

6.2 Consumer Reference Group

A Consumer Reference Group will be established with the purpose to

- provide consumers and carers with a platform to hear and respond to Helping Hand initiatives
- propose new initiatives or changes
- be available as a resource to "keep us on track"
- be the "go to" people when Helping Hand wants advice from consumers and carers
- provide a consumer and carer voice in decision making at Helping Hand
- support the implementation of the Consumer and Carer Engagement Framework

An Executive Officer will be appointed to provide support to the Consumer Reference Group and to facilitate discussions with other committees or groups in Helping Hand, including the Board and Executive.

6.3 Evaluation of the Consumer and Carer Engagement Framework

Helping Hand will conduct an evaluation of the implementation and impact of the Consumer and Carer Engagement Framework after two years of operation. This evaluation will be overseen by the Consumer and Carer Engagement Committee in collaboration with the Consumer Reference Group.

6.4 Support to Implement the Framework

Helping Hand has allocated resources from within the Research & Development Unit to provide support to both the Consumer and Carer Engagement Committee and the Consumer Advisory Group. Specific strategies within each domain will be incorporated into Helping Hand's ongoing operations.

Helping Hand recognises that staff, consumers and carers may require support to participate in many of the strategies arising from the implementation of the framework, for example, capacity building (eg training, peer support) for consumers, carers and staff to participate fully. Accordingly, all strategies and actions arising from the framework will be required to consider whether capacity building is required as part of their planning.