

# **Finding ways to stay at home**

## **Consumers' experiences of the intake, assessment and referral processes of the Home and Community Care Program in Tasmania**



**Home and Community Care  
Consumer Consultation Project Report 2006**

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# **1. Acknowledgements**

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Pauline Marsh  
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## 2. Terminology

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The following terms and abbreviations are used throughout this report:

ACAT	Aged Care Assessment Team
Assessment	The process for determining a consumer's need and eligibility for Home and Community Care (HACC) services. Also determines the level of care and resource allocation and includes ongoing monitoring and review processes and coordination and referral tasks.
Care Assistants	Formal, paid carers who provide assistance to perform tasks deemed "essential self-care" ( <i>HACC National Program Guidelines (NPG)</i> , 43).
Carer	Informal care givers, defined by the Australian Bureau of Statistics as people who provide "ongoing, informal help or supervision to persons with a disability or long term health conditions, or to persons aged sixty years and over" (ABS, 2005, 1).
Consumer	One who receives HACC services, including carers, defined as "frail elderly or younger people with severe disabilities living in the community and their carers who, in the absence of basic maintenance and support services, are at risk of premature or inappropriate long term residential care" ( <i>NPG</i> , 43).
DoHA	Commonwealth Department of Health and Ageing
DHHS	Department of Health and Human Services
GP	General Practitioner
HACC Program	Home and Community Care Program
Intake	Entry into the HACC Program; includes finding out about and making initial contact with providers.
<i>NPG</i>	<i>National Program Guidelines for the Home and Community Care Program</i> . Australian Government Department of Health and Ageing, 2002.
Referral	The process by which a HACC consumer is introduced to services.
TasCOSS	The Tasmanian Council of Social Service

### **3. Executive Summary**

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The 2005-06 Home and Community Care (HACC) consumer consultation project, *Finding ways to stay at home*, explores consumers' experiences of the HACC Program's intake, assessment and referral processes. The research sought to discover how people found out about HACC services, how they made contact and their experiences of being assessed, reassessed and referred within and beyond the HACC Program. It sought to discover the successful, and less successful, ways consumers accessed the services they needed to stay at home.

This research is important for a number of reasons. There are currently plans to make major changes to the intake and assessment process of community care services. The Way Forward strategy initiated by the Australian Government Department of Health and Ageing outlines these changes and is presently in a research and development phase which aims to develop the detail of the changes. This research project seeks to contribute to that development.

In addition, the national interest in intake and assessment is indicative of the importance of these components to the overall Program. Consumers' experiences demonstrate the relationships between the processes of locating, accessing and moving in and beyond HACC services with the effectiveness of the Program. These experiences contribute to broader discourses of the accessibility, equity and appropriateness of the HACC Program.

Consultation methods for the research included a written survey, group workshops in HACC day centres and semi-structured in-depth interviews with HACC consumers with complex needs. Consumers' experiences, both positive and negative, constitute the findings of this report. These findings are analysed and contextualised within broader concepts of community care delivery. The specific implications for the HACC Program are also discussed and recommendations are made.

### **Summary of Findings**

#### **Intake**

The research findings demonstrate that entry into the HACC Program is seldom a simple act, but is more often a process that is characterised by two phases: firstly, finding out about community care services and secondly, making contact with a service provider.

Finding out about services was generally difficult and confusing, and the lack of easily available information was raised by many participants. Information was accessed more easily by consumers who had active family members, a social network, or a close relationship with their GP. Incidences accessing services as a result of a crisis or hospital admission were also prevalent.

Those who were prepared to be assertive also reported less difficulty accessing HACC services than those who were reluctant to seek or ask for assistance, or who were socially isolated. The research identified psychological barriers to accessing services amongst consumers, such as a reluctance, or inability, to plan ahead for future needs and a perception that the receipt of services equated with a loss of independence.

Some of the difficulties expressed about making contact with service providers were related to a history of bad experiences with approaching providers. In particular, some reported experiences of contacting inappropriate organisations and of intimidating encounters with staff.

Consumers suggested ways to improve intake processes and these centred mainly on improving information availability and accessibility.

## **Assessment**

Perceptions of the effectiveness of assessment, that is, of the capacity of assessment to determine and respond appropriately to needs, varied amongst consumers. The most effective assessments were consumer-centred and holistic; considered the diverse needs and abilities of the consumer; allowed for consumer input and control in the process; facilitated independence; and matched care assistants carefully to consumers. Inadequate assessment processes resulted in a range of outcomes, for example, wasted resources, increased vulnerability and an increase in demanding and complaining behaviours amongst consumers.

Reassessment practices also varied greatly. Those reported to be effective were reassessments that were performed regularly by appropriately trained staff – specifically staff who were not involved in the daily delivery of care – and those that followed the principles of holistic assessment. Such reassessments also resulted in appropriate adjustments to service provision.

In most cases, waiting times for HACC services were reported by consumers to be minimal and were predominantly for podiatry, equipment and in-home respite. However, consumers in particular locations waited for services that were unavailable, due to a lack of resources. Most significantly, consumers reported that waits for other non-HACC services provided by Housing Tasmania and Disability Services were long and had negative impacts on their ability to live safely and comfortably at home. Thus the interdependency of HACC and other services was made evident.

### **Post-assessment referral**

The capacity and ability to refer varies greatly across HACC service provider employees. Characteristically, referrals were initiated when referrers had the capacity to recognise a consumer's changing needs and a knowledge of available resources. People who referred either assumed their own authority to act, or sought the assistance of an authorised person.

### **HACC and other services**

The interconnectedness of HACC with other services is evident in this research. Consumers use HACC services in a variety of combinations with a range of private, informal, government and non-government organisations. The need for increased recognition of this and coordination of services is demonstrated by the research.

## **Summary of the implications for the HACC Program**

The main implications of the findings relate to the HACC Program's capacity to achieve its stated aims. They are summarised as follows:

- Current inequities in the intake process result in people with particular personal and other resources gaining easier entry than others; smooth access to services is not assured for all members of the target group.
- Assessment effectiveness is compromised when the assessment process is not consumer-centred or needs-driven. Poor assessment contributes to inadequate and/or inappropriate resource and care provision.
- The inconsistency of formal reassessments impacts on the HACC Program's ability to adequately monitor and adjust service provision.
- The haphazardness of current referral processes impacts on the HACC Program's ability to provide an adequate and appropriate range of services to consumers.

- The relationships between HACC and other services are predominantly uncoordinated, and result in both gaps and duplication of service provision.

## 4. Recommendations

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Analysis of the findings of this consumer consultation research has led TasCOSS to make the following recommendations.

### Intake

#### Recommendation 1

That the Tasmanian HACC Program allocate resources to develop and implement a strategy to coordinate and facilitate the improvement of information for potential consumers and its ongoing dissemination. That the information accurately and appropriately explains the scope and services of the HACC Program and facilitates straightforward entry into the Program.

#### Recommendation 2

That the information strategy address barriers to entry by providing information that:

- uses straightforward language, with minimal jargon;
- provides a direct link to HACC entry points;
- is regionally specific;
- focuses on the promotion of independence; and
- is available in languages other than English.

#### Recommendation 3

That the information strategy address the diversity of needs and resources of the target group and the relationships between HACC and other services by providing information in a range of formats including:

a) Face to-face information sessions across the range of stakeholders:

- HACC service provider staff,
- hospital discharge planning staff,
- Carelink,
- General Practice organisations,
- consumer support groups, and
- potential consumer groups (for example, the Council of the Ageing and the 50s and Better Centre).

b) Hard copy information provided in a variety of formats:

- pamphlets,

- posters,
- fridge magnets, and
- service directories.

c) Electronic information provided in a dedicated, visible web site and linked to a range of other appropriate sites including the Aged and Disability Care Information Service.

d) Advertising material through a variety of mediums:

- organisation newsletters,
- regional newspapers (including public interest stories),
- radio stations,
- television, and
- the Yellow Pages.

#### **Recommendation 4**

That the information strategy accommodate the broad scope of the Program, the relationship between HACC and other services and the diverse ways the target group seeks information, by providing information to and through a variety of organisations including:

- Carelink
- community health centres,
- cultural community centres,
- Centrelink,
- Department of Veteran Affairs,
- Disability Services,
- GPs,
- HACC service providers,
- hospitals,
- injury and illness specific support groups,
- local government organisations,
- Mental Health Services,
- multi-purpose centres,
- Service Tasmania, and
- the Aged Care Assessment Team.

## **Assessment**

### **Recommendation 5**

That HACC assessments be conducted by specialist independent assessors to enable consumer needs and priorities to be determined with maximum efficiency and effectiveness for both the consumer and the HACC Program.

### **Recommendation 6**

That HACC assessors be suitably trained to understand the barriers to accessing services and the specific needs of the target group.

### **Recommendation 7**

That HACC assessors:

- conduct collaborative, holistic, consumer-centred assessments;
- liaise with service provider employees, GPs, case managers, ACAT and others involved in the care of the consumer; and
- act as referral agents to relevant organisations within and beyond the HACC Program.

### **Recommendation 8**

That HACC assessments be conducted face to face, in the consumer's home initially, then be followed by a face-to-face brief follow-up check one month post and a full reassessment at least 12 months after initial contact. In addition, that assessors act as contact points for consumers, enabling the consumer to initiate reassessments at additional times as needs arise.

### **Recommendation 9**

That HACC Program representatives on The Way Forward assessment working group advocate for an assessment process that:

- is consumer focused,
- is flexible and holistic,
- aims to increase consumers' capacity for independence where possible,
- ensures phone assessments are followed by a face-to-face assessment in the home of the consumer, in consultation with carers, to fully determine and respond to need,
- attempts to match consumers with appropriate workers, and
- has the capacity to measure outcomes of assessment.

**Recommendation 10**

That HACC Program representatives on The Way Forward assessment working group advocate for an assessment tool that facilitates:

- assessment of abilities as well as needs,
- assessment of resources, including personal and material, available to the consumer,
- the capacity for consumer and carer input, and
- the capacity to explain the roles of workers.

**Recommendation 11**

That HACC assessors, in consultation with consumers, refer to case managers when a consumer is receiving, or waiting for the receipt of services from other government bodies such as Housing Tasmania, Disability or Mental Health Services in order to facilitate coordination of care beyond the HACC Program.

**Recommendation 12**

That HACC service providers phone people waiting for their services to commence on a monthly basis to inform them of projected waiting times and progress toward service commencement and to confirm the consumer's need for the service.

**Referral****Recommendation 13**

That formal structures be developed and implemented in HACC services to facilitate access by consumers and care assistants to HACC assessors, case managers or other suitable staff for referrals.

**Recommendation 14**

That measures be implemented to increase the capacity of all staff involved in care provision to recognise and act on the changing needs of consumers, including:

- staff education, as part of the recommended information strategy (recommendation number 1); and
- formal workplace procedures to facilitate access by care assistants to staff who enact referrals.

**General****Recommendation 15**

That the HACC Program encourage community care delivery that is consistent with the principles of health promotion and positive ageing, in which independence and community involvement is facilitated.

## 5. Background

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### Consumer Consultation and the HACC Program

A service designed and delivered with an understanding of the views and needs of those who are to use it is more likely to effectively target these needs. It follows that involvement of consumers in health service planning, delivery, monitoring and evaluation is likely to result in services which are more accessible and appropriate to service users (Consumer Focus Collaboration, 5).

Consumer consultation in the human services sector aims to improve outcomes by drawing on the knowledge and experiences of service recipients. The Home and Community Care (HACC) consumer consultation project, delivered by TasCOSS, provides a means for consumers' voices to contribute to improving the accessibility, appropriateness and effectiveness of the HACC program. Since 2001 the HACC project has focused on a variety of issues including, respite, domestic assistance, personal care, dementia specific needs, region specific issues and issues related to people from diverse cultural and language backgrounds. In these consultations, themes of isolation, difficulty accessing particular services, financial stress and carer burdens have been raised and taken into consideration during HACC planning and prioritising processes.

### The 2005-06 focus

The focus of the 2005-06 research is on the intake, assessment and referral processes of the HACC Program. This theme was chosen for a number of reasons. Firstly, national changes have been proposed to the intake, assessment and referral processes of community care services. The Department of Health and Ageing (DoHA) strategy for community care, entitled *The Way Forward: A new strategy for community care* (2004) outlines the planned changes.<sup>1</sup> At the time of this consultation project the research and development phase of the strategy was underway.

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<sup>1</sup> The full report has not been included in this report. For the strategy document and information about the progress of the reform see [www.health.gov.au/communitycare\\_thewayforward](http://www.health.gov.au/communitycare_thewayforward)

Secondly, the focus of this research was guided by the findings from the 2004-05 HACC consumer consultation report. Difficulties with locating and accessing HACC services were raised by people from culturally and linguistically diverse backgrounds. Particular difficulties were related to low levels of knowledge and understanding of the HACC Program in general and of Carelink specifically, a lack of available information about services and the perceived ineffectiveness of brochures.

Finally, a large range of existing research literature explores issues relating to access of health and community services. The 2005-06 HACC consumer consultation research project is both informed by, and seeks to contribute to, that body of work.

## **The aims**

The consumer consultation project sought to gain an understanding of accessibility, equity and appropriateness of the intake, assessment and referral processes of the current HACC Program. Specifically, the research sought accessibility issues from stories of seeking, locating and contacting services; equity issues from experiences of exclusion and dissatisfaction with intake and assessment processes; and appropriateness issues from consumer's perceptions of the ability of assessment to meet their physical, social and emotional needs.

## 6. Project Design and Methodology

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The project design was underpinned by three primary considerations:

- the necessity to consult with a diverse range of HACC consumers;
- the health, mobility and other limitations of some HACC consumers; and
- the necessity for rigorous qualitative research practices.

Consequently, three research methodologies were chosen:

- a written survey,
- informal day-centre workshops, and
- in-depth interviews with clients with complex needs.

A written survey was selected to enable access to a broad range of consumers and was designed to obtain initial data about patterns of intake, assessment and referrals. Indications for further research emerged from the survey, highlighting the need to uncover more fully the detail and implications of consumers' experiences of intake, assessment and referral processes. The following qualitative tasks were suggested:

- determine perceived barriers to access;
  - investigate the assessment processes of clients with complex needs;
  - determine whether waiting periods were appropriate to need; and
  - explore the processes of reassessment and review.
- Workshops and in-depth interviews were then conducted to perform these tasks.

Workshops were held in existing HACC day centres because they provided a safe, non-threatening environment where the researchers could be welcomed and introduced by the day centre staff and thus assist to create an environment for open discussions. It was envisaged that informal discussions would be generated and that participants would encourage each other to contribute. The use of HACC-funded day centres also enabled consumers to participate who may not have attended a discussion group in another facility due to health and mobility difficulties. It also ensured a diverse range of consumers to participate, including carers, who brought a spectrum of needs and service use experience to the research. Day centres are well attended in Tasmania. HACC Minimum Data Set (MDS) figures for 2003-04 indicate that approximately 1433 consumers attend HACC day centres (MDS 30). In addition, day centres are attended by people who receive funding and assistance from other services, for example, the

Department of Veterans Affairs and Disability Services and thus can provide insight into variations across services.

In addition to the workshops, semi-structured, in-depth interviews were conducted one-to-one with consumers (or one-to-two in interviews involving both the carer and the care recipient) in their homes. The purpose of this methodological choice was twofold. Firstly, it enabled access to HACC consumers who were confined to their homes. Secondly, it enabled discussion about the complexities of intake, assessment and referral processes with consumers who had experience navigating through and beyond the system, in order to meet a range of care needs. The interview structure enabled a more detailed exploration of people's understandings and interpretations.

The research sought to gather and analyse HACC consumers' experiences of:

- finding out about services,
- accessing the appropriate assistance,
- undergoing need and eligibility assessments,
- waiting for services to commence,
- being reassessed, and
- post-assessment referrals.

Consumer perceptions of the accessibility, equity and effectiveness of the current intake, assessment and referral systems of the HACC Program were also sought, as were suggestions for improvements to the system.

The design of the research and the analysis of the data were informed by a series of research reports produced by the Australian Bureau of Statistics, the Consumers' Health Forum of Australia, the Australian Institute of Health and Welfare, the Australian Productivity Commission and by other academic research reports.

Consultations were conducted within inner regional, outer regional and remote areas across Tasmania. The sample group was broadly consistent with the demographic profile of HACC consumers 2003-04 (see Appendix A) with two exceptions: survey returns indicated a bias towards Northern residents in the sample and a slight under-representation in the North West and people from indigenous and culturally and linguistically diverse backgrounds were slightly over-represented in the interview and workshop sample groups.

## **6.1 Written Survey**

A written survey was conducted by Janine Combes from Community Focus, working on behalf of TasCOSS. The questionnaire was distributed to 499 HACC consumers via selected service providers across the State and a total of 269 (54%) were returned. The questions centred on experiences of finding out about services, the assessment process, waiting periods, multiple retelling of stories prior to service commencement and experiences of reassessment processes (see questionnaire, Appendix B).

The service provider organisations were selected by the consultant through a mapping process that considered type, regional location and cultural representation. A total of 19 services were involved and a copy of the draft survey was sent to the participating organisations prior to the survey being issued to ensure that those who would distribute the survey were comfortable with the content. Each organisation was asked to distribute a small number of surveys to their randomly selected consumers.

## **6.2 Day centre Workshops**

Workshops were held in 15 HACC-funded day centres in inner regional, outer regional and remote areas and a total number of 177 HACC consumers participated (see Appendix A for demographic details). Initial day centre details were obtained from the three regional day centre network coordinators and permission to conduct workshops was sought from day centre coordinators directly. Consumer participation was optional and day centre attendees were given the choice to join in the workshops, or to opt out. A written summary of HACC services was distributed at the start of each workshop to help clarify the topic (see Appendix C). The HACC research Project Officer facilitated the workshops and a scribe recorded observations and responses. Standard question and discussion prompts, although deliberately flexible, were used to elicit information about people's experiences (see Appendix D). Common themes became evident during the consultation period and information was sought to clarify and enhance understanding of these themes in subsequent workshops.

Limitations of conducting consultation in day centres include the risk that people would feel inhibited about commenting about their care if it were associated with the centre, for fear of offence or negative repercussions. In addition, the presence of carers in the

groups may also preclude frank discussions. Some participants may also be reluctant to offer personal information in a group setting.

Nevertheless, most participants were open and willing to discuss their experiences. People felt confident to talk about their own situations because others were doing so. In addition, participants were prompted by others to remember some of their own experiences, for example, "I have a girl come to do the cleaning" might prompt, "when I tried to get a cleaner..." Some day centre coordinators also prompted and encouraged people to contribute to discussions, based on their knowledge of the client's situation.

Workshop discussions were analysed using a process of thematic coding. Consumer's comments were categorised broadly under the general headings pertaining to the initial research questions, specifically intake, assessment, referral and other. Information was then categorised more specifically as common themes emerged. Relevant research was also used to further contextualise and analyse the data.

### **6.3 In-Depth Interviews**

Interviewees were from inner regional, outer regional and remote areas and included men and women with a broad range of disabilities, carers, frail aged and people from Aboriginal and CALD backgrounds (see Appendix A). The 38 participants were selected using a standard purposive qualitative sampling strategy to specifically capture consumers with complex needs who accessed a range of services (see Appendix E).

Service providers and client representative groups were asked to make initial contact with prospective interviewees, to distribute research information and to seek written consent. The research Project Officer then made phone contact and arranged to meet in the interviewee's home.<sup>2</sup> All interviews were conducted over approximately one hour and recorded on tape or digital recorder. Questions followed a similar open-ended format to those of the workshops but were used as prompts rather than as direct inquiries. The interviewer did not attempt absolute neutrality, but attempted to engage with consumers to foster a non-threatening environment in which people could talk openly.

Interviews addressed some of the limitations of group workshops by providing privacy and confidentiality for participants. Interviewees spoke openly about their experiences of

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<sup>2</sup> Five interviews were conducted in alternative locations, due to individual circumstances .

accessing services and of being assessed and referred. As anticipated, information obtained in interviews revealed a complex range of issues associated with accessing HACC services. Details about consumer's perceptions of the effectiveness of HACC processes also emerged. Interview findings were analysed using the same process as workshop findings (see page 14)

## 7. Intake

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This section presents the findings of consumers' experiences of accessing HACC services. The written survey results provide quantitative data about the types of services accessed and the ways people found out about those services. The workshop and interview findings provide the qualitative detail of consumers' experiences that highlights efficacy and equity issues of the entry process.

### 7.1 Intake Findings: What consumers said

#### 7.1.1 Written survey results: Intake

When asked which HACC services consumers had used over the last year, most indicated that they had accessed more than one service type. There were a total of 883 responses to this first question and it was answered by all of those who returned a survey.

**Q. 1 Number of services used**

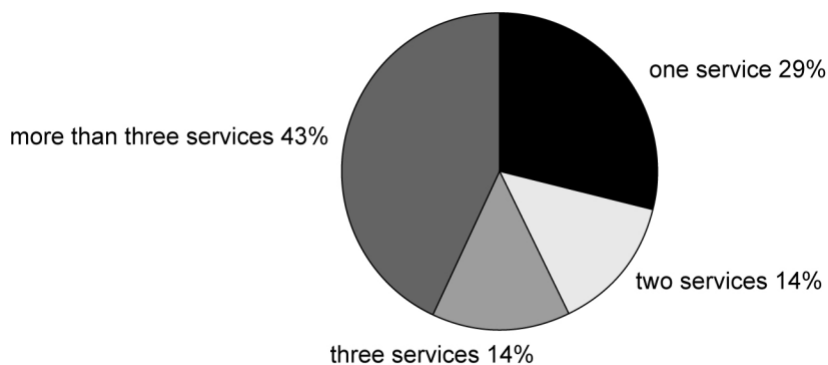


Fig 1. Service use by percentage of respondents.

The most commonly used service types were:

- Help with housework (18.8% of responses)
- Transport (12.0%)
- Personal care (11.8%)

The other services named included:

- Spring cleaning
- Window cleaning
- Ironing
- Community Options
- Hydrotherapy
- Gardening services.

When asked how consumers found out about these HACC Services the most common means cited by respondents were doctors (not specified), community health nurses, friends and family, and the Aged Care Assessment Team (ACAT).

### Q.2 Source of information about HACC services

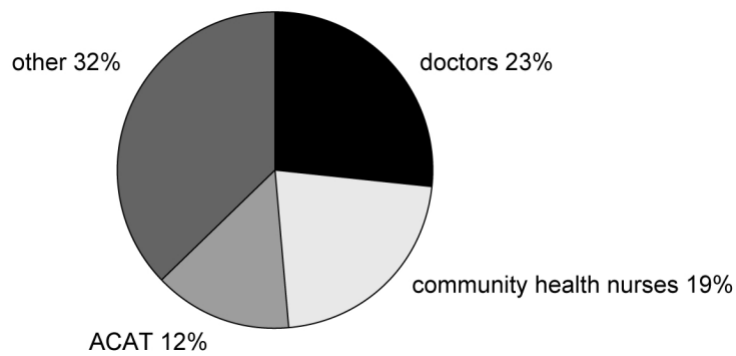


Fig. 2 Source of HACC Information Source by percentage of responses to Q.2

Other sources included:

- community group or organisation (8.1% of total responses to Q2),
- community health centre (6.0%),
- carer (4.6%),
- pamphlets/books (3.5%),
- newspaper (0.7%),
- internet (0.8%),
- Commonwealth Carelink (1.9%),
- local council (1.9%),
- hospitals (4.4%),
- teachers aid at school (0.2%),
- a volunteer (0.2%),
- the Department of Veterans Affairs (0.2%), and
- a rehabilitation provider (0.2%).

The majority of respondents (57%) indicated they found out about the HACC services from a doctor only. However, because the survey did not differentiate between types of doctors these may include GPs, specialists or hospital-based doctors.<sup>3</sup> The remaining respondents cited a number of sources of information about HACC services with some naming up to 13 sources of information (for example, doctor, community nurse, pamphlet, government department, etc).

The survey results demonstrate the range of services used by respondents and the variety of sources from which information is obtained. The workshops and interviews expand on this information and provide some detail about the factors that either aid or prevent smooth access.

### **7.1.2 Workshop and Interview Findings: Intake**

Consistent with survey respondents, workshop and interview participants reported a variety of ways in which they accessed information about HACC services. Their stories varied from relatively smooth entry experiences to difficult and stressful experiences.

## **Positive Intake Stories**

### **Hospital**

There were many stories told of finding out about services as part of a thorough discharge planning process from hospital, following an acute health-related event.

*The hospital arranged all my help: Meals on Wheels, community nurses, personal care. (Workshop participant)*

*I went to hospital when I injured my knee and had to have an operation. When I was going home they got me a seat for the bath, a walking frame that I hire, they got Meals on Wheels to come too. (Workshop participant)*

*I had a great coordinator at the rehab hospital who assisted him to get home. (Interview participant, carer)*

*After my heart attack the people at the hospital decided I should have help and they organised someone to help with the shopping, the gardening and a cleaner. (Workshop participant)*

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<sup>3</sup> For example, a total of 12 of the responses that ticked Doctor as the source of information also indicated in Q3 that they were assessed for eligibility within a hospital, suggesting the possibility that information about HACC was gained from hospital doctors during admission.

## **Diagnosis**

Participants who were diagnosed with an illness or injury that affected their ability to live at home safely and independently reported a relatively smooth entry process into the HACC system. Family carers talked about not having any idea of where to start to find information, and not even realising they were entitled to help, until a diagnosis was made.

*Once we found out more about the disease, we had an idea about what type of help we might need. (Interview participant, carer)*

Significantly, a diagnosis enables some people to join illness or injury specific support groups. Participants reported that these groups provided information about assistance in the community.

*When [my husband] was first diagnosed we went to the MS Society for help, and they came and visited us at home to see what [my husband] could do and what we needed help with. (Interview participant)*

*We went to a meeting at the MS Society and [a local service provider organisation] were there as the guest speakers...that's how we were introduced to the idea of someone coming to help. (Interview participant)*

*The specialist put us onto the Alzheimer's Association and I got a lot of information from them about what's available. (Interview participant)*

*Someone came to visit from the ... Motor Neuron Disease Group and told us a bit about things. (Interview participant)*

## **General Practitioners**

Many consumers stated they sought information from their General Practitioners (GPs) predominantly about personal care, nursing care, respite, allied health and to some extent domestic assistance.

*My GP organised the cleaner. (Workshop participant)*

*I asked my GP about respite, and she put me onto the social worker. (Interview participant)*

*The GP contacted [the service provider] for me. (Workshop participant)*

*I can ask my GP about anything I need help with. (Interview participant)*

Participants with mental health illnesses, however, reported that they sought information from their GP's about a broader range of lifestyle issues.

## **Aged Care Assessment Team**

Workshop and interview participants who were assessed by the Aged Care Assessment Team (ACAT), in many cases for respite eligibility, reported they acquired a lot of information about community care services from the assessor.

*When ACAT came to assess me for respite they told me about the day centre and about where to get the chair from. (Workshop participant)*

*When Mum came down to live with me I contacted ACAT ... and things got started from there [day centre, home help, personal care]. (Workshop participant, carer)*

*The nurse [from the hospital] sent a lady from ACAT around to assess him ... they keep an eye on him and give him suggestions for things he might need. (Workshop participant, carer)*

## **Word-of-mouth**

Many people stated they found out about HACC services from other people. That is, they entered the HACC Program via word of mouth. Informal information exchanges reportedly happened between friends in the street, during visits from neighbours, with family members, on the telephone, at church and at other social gatherings.

*It's good [the way people find out] is by word of mouth. Some people rang me the other day because they knew we received assistance and I could tell them who to ring. (Interview participant)*

*Everyone knows everyone, you've only got to ask someone for help and they'll help you. (Workshop participant)*

*It's important for people like us to let people know. (Interview participant)*

Not only did people hear about what was available, but recommendations were made and people were encouraged to make contact. Some participants denied inhibitions existed when discussing community care amongst their peers and that there was a general attitude of openness about receiving care.

*It wasn't known before, but now it's out in the open – there wasn't the help there is now, I think it's really wonderful; you're not on your own. (Workshop participant)*

## **Family**

Consistent with the survey results, workshop and interview participants reported that they had found out about HACC services because a family member took on the task of seeking help. In particular, there were many stories of daughters/daughters-in-law suggesting and arranging for home care support.

*I didn't get the help, my daughter did. I wouldn't know where she got it.*  
(Workshop participant)

*My daughter organised everything, she had to go digging. I couldn't have done it...I would never have known ... You've got to have someone there going "this is wrong, I want this and this and this".* (Workshop participant)

Family members reported they wanted the responsibility for finding assistance for those they cared for:

*I knew what he needed, I knew that he wouldn't be happy living [in an aged care residence] and I knew he wanted to be at home.* (Interview participant)

*Well, I wanted to do it, 'til death do us part and all that.* (Interview participant)

*I like looking after my Mum; she's had a pretty bad time, so ....* (Workshop participant, Carer)

## **Multi-Purpose Centres**

Consumers who had access to a multi-purpose centre, such as a community health centre or a community centre, which provided a range of community and health-related services, including HACC services, reported easy access to information. Some consumers associated HACC services with community health centres, so deliberately sought information there. Others discovered information inadvertently when they attended the centre for an unrelated purpose.

*I pick up lots of brochures and booklets from the health centre and I take them home and read them, then I ring up (I've rung about continence, advocacy, podiatry.* (Workshop participant)

*I found out about the home help from girls at the Health Centre.* (Workshop participant)

*The Community Centre arranged for the rails in my bathroom to help me get in and out of the bath, and the board that goes across the bath.* (Workshop participant)

Similarly, community centres that provide HACC and other services to specific population groups, for example, Aboriginal corporations or cultural organisations, provided a broad range of information in a culturally appropriate manner:

*We got help with the lawn-mowing and all that through here, through the centre. [The Aboriginal HACC coordinator] knows the whole community, he gets on with everyone, we have lots of laughs, we carry on a bit. I don't know what I'd do without him.* (Workshop participant)

*A few weeks ago a woman from the home help place came here [the Italian Club] and told us about the things they offer.* (Workshop participant)

## **Invitations**

Participants also reported positive responses to direct invitations to use services, in particular, day centres:

*I got onto the day centre because they sent a letter in the mail. (Workshop participant)*

*[The day centre coordinator] invited me to come here, that's why I started. (Workshop participant)*

## **Negative Intake Stories**

Many consumers spoke about the difficulties they experienced finding and accessing HACC services.

### **Poor Hospital Discharge Process**

Some participants reported they were discharged from hospital without information about assistance available at home:

*The first time I was sent home from hospital nothing was arranged and I ended up having a lot of problems. I had to go back in, then they fixed up things for me and I couldn't go home until everything was in place. (Interview participant)*

*I was sent home from hospital with a catheter and no one told me anything. I didn't know who to tell, who to ring for help. So I rang a sister at the hospital and she helped me. (Workshop participant)*

### **Lack of knowledge about HACC services**

Some consumers reported they, their families and doctors were unaware of HACC services. For example, a 75 year old woman stated she was referred to ACAT whilst in hospital because it was assumed there was no other option for her but residential care. She stated:

*I felt like I was being pushed into a nursing home when I was in hospital. When I said I didn't really want to go the doctor said, "well I want to talk to your family about it". Next thing I knew he'd arranged for a psychiatrist to come and see me, [he] thought I was mad.*

As a result, ACAT arranged for HACC services, specifically nursing care, domestic assistance, personal care, equipment loans and home modifications for this consumer as part of her discharge plan from hospital and she was able to stay at home. She stated:

*Anyway, [the doctor] got a surprise when I went for the follow-up appointment and he saw how well I was doing. (Interview participant)*

## **Confusion**

Many stories related an overwhelming sense of confusion about where and how to find help:

*There's a real lack of information, and misinformation. (Workshop participant)*

*It's a minefield ...there's no literature about what is out there. (Interview participant)*

*I hadn't had any outside help before, so who do you go to? There's not a nice list up on the wall for people to ring up and say "can you give me this, can you give me that?" ...People say, "look in the phonebook", at what? There should be a list of things, of all the different people and organisations ... but there's not, and there should be. There's other people like me, I'm not saying I'm the only one. (Interview participant)*

*There seems to be a law that says, "don't tell them, let them find out." (Workshop participant)*

*You find out in dribs and drabs, often just by chance, and often not at all. (Interview participant)*

*It's not until you're really desperate that you find out these things. (Interview participant)*

*Bit of trouble is I can't see the phone book, it's so very small. (Workshop participant)*

Some people suspected there was a deliberate withholding of information by "government" because there was not enough help to go around.

In many workshops, people contradicted each other's comments about the availability of services. For example, when one participant stated, *we can't get lawn mowing around here* another countered with, *yes you can [the home maintenance worker] does it*. Similar statements were made about Meals on Wheels and spring cleaning in a range of regions.

Many informal carers were confused about how to get help. There was particular confusion amongst carers of children with a disability during the time of transition from childhood to adulthood:

*When [my daughter] was at school she got classroom assistance and help from the government with aids ... but as soon as she left I didn't know where*

*to start. I didn't know what I was entitled to, what was available. No one came and told me anything. (Interview participant, carer)*

Confusion amongst informal carers was augmented by emotion. People reported feeling despondent and frightened when their family member was less able to look after themselves independently:

*It's very traumatic coping with an illness ... the financial side, that was very traumatic. Trying to manage your family; there's no one who can say 'do this with your bathroom' and it's hard to plan because you don't know what you're planning for. (Interview participant, carer)*

## **Practicalities**

The difficult practical aspects for carers finding assistance were also raised:

*It's pretty much impossible to work your way through the phone book and be kept on hold while your mother starts wandering about into other rooms. (Workshop participant, carer)*

Some consumers reported that family members ignored suggestions about help until it was suggested by an outside professional:

*It wasn't until the specialist suggested that going to the day centre would be a good thing that he said he'd do it. Wouldn't listen to me when I suggested it. (Interview participant, carer)*

## **Identified Access Barriers**

Consumers reported particular attitudes and circumstances that they thought prevented their smooth entry into HACC services.

## **Independence**

Some consumers stated they were reluctant to seek help because they felt they would lose their independence. Independence was highly valued amongst many participants:

*I thought I could handle it myself ...and that's what brought me down, that's what put me into hospital ... it's just I couldn't do everything myself. (Interview participant)*

*Independence is the greatest thing that anyone could give me. (Interview participant)*

*I don't get any care, I'm independent. I mow my lawns, make my dinner, shower myself. (Workshop participant)*

*Some people stated they felt a sense of failure when they had to ask for help:  
I feel like I'm a beggar. (Interview participant)*

*It's not until you're really desperate that you would actually pick up the phone and say "well what can you do to help me?" (Interview participant)*

## **Isolation**

Some consumers demonstrated that social isolation was a barrier to accessing community care. This was principally because consumers with particular mental illnesses, physical disabilities, frailty or chronic fatigue syndrome did not hear about HACC services via word of mouth.

*I don't go out a lot, only if I have to ... I go to the post office to get the mail. I don't see other people ... I don't mix with people, only if I have to get in contact with someone. I don't go visiting, I don't like to go. (Interview participant)*

*I don't like going out ...I'm a poor mixer, when I go out I can mix with people, but its getting out ...I never go over to my neighbours . (Interview participant)*

## **Assertiveness**

Consumers reported they had to be forceful and assertive in order to obtain the help they required. For those not comfortable with being assertive this was a barrier to accessing help:

*You need to be assertive, and ask for help. (Interview participant)  
I find asking very hard, very hard. (Interview participant, carer)*

*If you really need them [the service] you have to be forceful, whereas I just tend to think, I'll do it myself. (Interview participant)*

*People need a lot more than they ask for; they don't like to be a nuisance. (Workshop participant)*

Passive attitudes toward accessing community services were also a barrier, demonstrated by statements such as:

*There's plenty of people worse off than me. (Interview participant)*

*Everyone's got their own problems, they don't need to know ours. (Interview participant)*

## **Bad Past Experiences**

Another reported barrier to access was a history of bad experiences dealing with various organisations involved in community care delivery.

*I rang the council to ask them and they told me to ring the health centre. When I rang the health centre they said it wasn't their problem and that I should try the council. (Workshop participant)*

*It's just lucky if you get onto someone who knows what's going on...with so many departments and services it's a recipe for disaster. (Workshop participant, Carer)*

*I spent thirty minutes just waiting on the phone. (Workshop participant)*

*I had this feeling that they didn't want to come, I asked for help ... the staff at the hospital say you should be getting this, this and this done, but I say no; I find them too difficult to deal with. (Interview participant)*

*I had a look at a few [day centres] but I didn't like the attitude of the staff. (Workshop participant)*

*When you ring up, people should be a bit more sensitive, old people get confused. (Workshop participant)*

Some people were put off from making contact with service providers because they were given advice from peers such as:

*The books are closed [at a service provider]*  
or that services have,

*Waiting lists 'til Christmas. (Workshop participants)*

## **General Practitioners**

Access barriers specifically related to General Practitioners (GPs) were also evident. Although many felt they could ask about personal care, no consumers stated they asked their GP about maintenance, and some stated they felt their GP didn't know about day centres or equipment.

*I go to the GP about health related things, not lifestyle things. (Interview participant, carer)*

*My GP didn't know anything about the day centre, I just tell him what I'm doing. (Workshop participant)*

*The medical specialist doesn't have anything to do with all the home care stuff. (Interview participant)*

Some people stated that they didn't ask their GP for assistance; they waited to be told what they needed.

*I haven't asked my GP about [getting home help], she knows, she should tell me. (Workshop participant)*

*I only find out about things when they are offered. (Interview participant)*

In some locations people reported that access to a GP was limited and that turnover was high.

*The GP's books are closed here, you can't get in if you're new. (Workshop participant)*

*It's hard to get into a GP. (Workshop participant)*

*Some of them aren't here long enough to know what's around. (Workshop participant)*

## **Suggestions for improvement**

Consumers made suggestions for ways to improve the access to information about HACC services. Comments and examples are summarised as follows:

### **Advertising**

On television and in the Yellow Pages, advertise HACC services as you would advertise for a builder.

Use the radio, local stations could provide some information, and in community papers, particularly human interest stories.

### **Booklets and Posters**

Produce a booklet that is not a list of contacts, but a guide that is indexed by need. For example, "Need help with showering?" is followed by a range of possibilities of assistance: equipment, modifications, personal care, and includes corresponding contacts.

The name of the service needs to be clear, and what they do for you.

A corresponding poster format could be made for noticeboards and waiting rooms.

### **Education sessions**

The 'government' telling people what's available, educating people to educate themselves.

### **Email lists and clear web links**

## **Fridge magnets**

### **Inform staff**

Information should be distributed via the day centre staff, combined with face-to-face sessions from the people from HACC.

Make sure GPs know

### **Mail-outs to over 60's**

Could be done with the rates notices, or when you go for your drivers licence.

### **One Stop Shop**

An information centre, similar to Service Tasmania or the council, but particular to HACC and aged care services for carers of young and elderly, and others. It must be staffed by people who are friendly and approachable.

### **Use other community groups**

For example, Seniors Tasmania, Clubs, church groups, neighbourhood houses, hospitals.

### **1800 number**

Provide a free call number where you can ring for information.<sup>4</sup>

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<sup>4</sup> This was mentioned by a number of consumers who, when asked, stated they had not heard of Carelink.

## 7.2 Discussion of Intake Experiences

Consumers' intake experiences demonstrate that they find out about HACC services from a wide range of sources: support groups, GPs, specialist doctors, hospitals, community health centres, cultural centres, ACAT, and also through informal contact with friends, peers and family members. Characteristically, information is obtained in a haphazard manner, and driven by the necessity of circumstance rather than by a desire to forward plan. The diversity of intake experiences mirrors the diversity of the HACC Program.

Each method of entry illustrates the factors and attitudes that either assist or preclude smooth entry.

### Factors that assisted entry were as follows:

- **Easy access to appropriate information.** When information was readily available from hospitals, support groups, GPs, ACAT and via word of mouth, consumers reported smooth experiences of locating and making contact with appropriate services.
- **Assistance from family.** Many consumers entered HACC services because energetic family members pursued a search for the appropriate assistance.
- **The ability to plan ahead.** Consumers who were diagnosed with an illness, or had received a particular injury, were, to some extent, able to predict their needs. Their diagnosis eliminated some confusion and they could plan the types of assistance they required, based on their knowledge of their illness or injury. In addition, when supported by a well-funded, well-resourced support group, consumers reported smoother entry into the HACC Program.
- **A Crisis.** When a plan was not possible, an acute health event, or a worsening situation that became desperate, triggered consumers to seek assistance and access to HACC services.
- **Visible contact points.** HACC services that were housed within community health centres, multi-purpose centres and community cultural organisations were highly visible to potential consumers in the community and thus facilitated access. Visibility was enhanced because these organisations mirrored the diversity of the HACC Program; that is, multipurpose centres were associated with the same broad range of community services that HACC offer. In addition, in some areas the multi-purpose centres also contributed articles to local papers and distributed their own newsletters advertising their services. Consequently, information reached out into

the wider community. These venues also allow consumers to hear about HACC in a non-threatening environment where consumers already feel comfortable.

### **Factors that hindered entry were as follows:**

- **Lack of appropriate information.** Some people did not receive adequate or appropriate information about HACC services because of failed discharge plans from hospitals, limited roles of GPs (perceived and otherwise) and isolation from social interactions. ACAT was occasionally involved as a result of a lack of knowledge about HACC services also. This was traumatic for consumers who were led to believe they could no longer live safely and independently at home.
- **Confusion.** Consumers were generally confused about where and when to access community care assistance. In some cases, confusion was exacerbated by the trauma of caring for an ailing family member. As a result, some informal carers felt guilt, obligation and frustration.
- **Practical problems.** For people without active, energetic family members to search for services, the process of finding assistance was generally difficult. Participants stated that with no one to search for them, due to having no young family members, they weren't capable or lacked the energy to search. Informal carers reported they had little time to spend searching for appropriate care, due to the demands of their caring role. Furthermore, in locations where GPs were scarce or stayed for short periods, consumers were less inclined to seek information from them about community care services.
- **Attitudinal barriers.** Some consumers avoided seeking assistance because of the perception that receiving assistance equates with sacrificing independence, or failing to maintain self-sufficiency. Others stated that feelings of unworthiness also deterred them from seeking help. Another disincentive to contact services was a history of unpleasant contacts with organisations.

The findings indicate that entry into the HACC Program can be a complex process and is not generally a simple act of contacting an organisation.<sup>5</sup> Currently there are a range of difficulties associated with finding and making contact with HACC services for many of the target group.

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<sup>5</sup> The findings demonstrate that the ways people find out about HACC services differs from the final referral source, as recorded on HACC MDS data. For example, the survey results indicate that ACAT plays a significant role in providing information about HACC services (11.6% of respondents), but result in low numbers of direct referrals (MDS 1.7%) (HACC Minimum Data Set Annual Bulletin 2003-04).

## **7.2.1 Implications for the HACC Program: Intake**

The most significant implication of these findings is on the ability of the HACC Program to provide equitable access to services. A key objective of the HACC program is to “ensure access to home and community care services among all groups within the target population” (NPG 41). At present it is difficult for many of the HACC target group to easily access HACC assistance: information is difficult to find, people are unaware of the range of services available, entry frequently occurs as the result of crisis and people often feel they have to be assertive and demanding to secure help. This section explains these access inequalities more fully and contextualises consumers’ experiences within a broader community care framework.

### **Access inequalities and favoured situations**

Findings from the consultations demonstrate that people in particular situations have unintentional privileged access to HACC services. Those privileged are consumers who have been hospitalised; referred to ACAT; have access to a local, well-informed GP; or access to a well-funded support group. For the potential consumers who are not in these situations finding services and making contact is more difficult.

Consumers with access to particular personal resources also have unintentional privileged access to HACC services over others. In particular, consumers with supportive family or friends, energy and skills to search for services, assertiveness and a network of social relationships have advantages over those without these resources. The potential consumers without these resources are the disadvantaged members of the target group and, as a result, have more difficulty entering the HACC Program. To maximise equality, access to services must be improved for people without these personal resources.

Equitable access is further compromised when making initial contact with service providers is difficult. This report has demonstrated that, for some of the target group, making contact with providers was awkward and intimidating. Initial contact forms part of the whole process of entry and is improved by non-threatening, welcoming encounters.

Currently, hospital discharge is a significant entry point to HACC. It has been suggested that consumers who receive a minimal amount of assistance at home have lower levels of hospitalisation than those with none (see Howe, 124). This raises the possibility that improved access to information may prevent some hospital admissions. The Department

of Health and Ageing (DoHA) announced, as part of the 2006-07 federal budget, the aim to “avoid unnecessary admissions” to public hospitals (DoHA, *Promoting npg*). By minimising access inequities, the HACC Program may contribute to minimising acute hospitalisation of members of the target group.

### **Access inequities and a lack of information**

Access to information is a key principle of healthy and positive ageing. The *Tasmanian Plan for Positive Ageing*, for example, states that older people have the right to have access to information that enables them to make informed choices (9). Similarly, the *National Strategy for an Ageing Australia* associates the ability to access information, appropriate to need, with the capacity of people to remain an active part of their communities (35). The HACC program, because of its stated aim to promote independence, aligns itself with principles of positive ageing. It follows that the HACC target group requires easy access to accurate information about HACC services to facilitate their smooth entry into the Program. Currently, inadequate provision of appropriate information about HACC services limits the capacity of potential consumers to make choices, be active in the community and to maintain their independence.

Inadequate availability of information contributes to an often difficult and prolonged process of accessing providers and it potentially plays a part in avoidable hospitalisation, unnecessary involvement of ACAT and consumer and carer stress.

Accessing information is particularly problematic for the HACC target group for a number of reasons. Firstly, the target group is likely to have limited capabilities to engage in searching for community care options owing to decreased mobility, language and cultural barriers and emotional stresses.

Secondly, in general, HACC consumers and potential consumers demonstrate passive attitudes toward health care. According to Cooper, many elderly persons, used to a highly regulated system of health delivery, are likely to display a degree of passivity toward accessing health care (27). Likewise, young people with a disability or chronic condition may also assume this model of sickness, seeing themselves as “users” rather than “consumers” (Cooper 27), and it is unlikely that they will actively seek out information. Thus they rely primarily upon information that is easy to obtain.

Thirdly, the most vulnerable of the HACC target group, those who are socially and economically disadvantaged, are also among the least likely to actively search for

information about maintaining health. Although disadvantaged persons have high levels of general ill-health and are at the most risk of chronic diseases, they are the least likely to actively seek out and plan their health care (AIHW *Health Inequalities*, xii). Consequently those who would “gain the most benefit from community services” (HACC *NPG* 41) are also the most difficult to reach.

Access to information forms a key component of the ability of the HACC program to meet its objectives. The way in which information is provided to the community must take the particular needs of the target group into consideration. Thus effective HACC information dissemination must ensure that:

- access to information is not dependent on the availability of particular skills and resources, for example, assertiveness, persistence or active relatives;
- information distribution accommodates the special needs of the target group, including the socially disadvantaged and isolated;
- information is available in a range of formats that are accessible to members of the target group, including face-to-face discussions with potential consumers; and
- information is available across a range of services, reflective of the current ways people seek information about HACC services.

## **Access inequalities and entry points**

A further implication that emerges from this research is that the current ways consumers enter the HACC Program warrant consideration in the planning and implementation of future changes to entry points. The Way Forward states: “The Australian Government will work with state and territory governments to identify entry points that can be easily accessed by consumers seeking community care services, based on existing infrastructure” (action area 2.3). Currently entry occurs, not always successfully, through a variety of existing points. The limitations of these entry points require consideration, including:

- the occasional failure to implement hospital discharge processes;
- the limited knowledge of the range of services and restricted capacity of some GPs;
- the reliance on ACAT, particularly by doctors, to act as a HACC information and entry point; and
- the indications of a low use of Carelink.<sup>6</sup>

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<sup>6</sup>These findings are consistent with the Productivity Commission report’s findings which state the use of Carelink by Tasmanian residents, as at June 30, 2005, was 13 people per 1000 (12.28).

Furthermore, current entry points for the HACC system are generally difficult to find and have poor visibility, coupled with a paucity of information, impacts on potential consumers' ability to easily access assistance. The most successful entry points are indicated to be community health centres, multi-purpose centres and/or culturally specific community organisations and well-funded disease or injury-specific support groups.

In addition, when considering strategic changes to entry points there is a need to also consider the perceptual and attitudinal barriers to HACC entry. In particular, the belief that to receive community care assistance is to sacrifice independence. Such a perception has been demonstrated in other research to be widespread amongst the elderly, for example, Janlov states, "In the Western world the individual's capacity for self-sufficiency is highly valued...which may make it more difficult to accept being in need of help" (327). Her study found that "the period of asking for home help was marked by a period of emotional strain, grief and a turmoil of distressing feelings", and resulted in "the fear of losing self-determination and control over daily life and becoming increasingly helpless and vulnerable" (333). Whether actual or imagined, negative perceptions of HACC service use need to be considered when changing entry point systems, particularly the capacity of entry points to facilitate the Program's aim to support independence.

### **7.3 Recommendations: Intake**

To address the inequalities of the intake process of the HACC Program, as demonstrated by this research, TasCOSS makes the following recommendations.

#### **Recommendation 1**

That the Tasmanian HACC Program allocate resources to develop and implement a strategy to coordinate and facilitate the improvement of information for potential consumers and its ongoing dissemination. That the information accurately and appropriately explains the scope and services of the HACC Program and facilitates straightforward entry into the Program.

#### **Recommendation 2**

That the information strategy address barriers to entry by providing information that:

- uses straightforward language, with minimal jargon;

- provides a direct link to HACC entry points;
- is regionally specific;
- focuses on the promotion of independence; and
- is available in languages other than English.

### **Recommendation 3**

That the information strategy address the diversity of needs and resources of the target group and the relationships between HACC and other services by providing information in a range of formats including:

a) Face to-face information sessions across the range of stakeholders:

- HACC service provider staff,
- hospital discharge planning staff,
- Carelink,
- General Practice organisations,
- consumer support groups, and
- potential consumer groups (for example, the Council of the Ageing and the 50s and Better Centre).

b) Hard copy information provided in a variety of formats:

- pamphlets,
- posters,
- fridge magnets, and
- service directories.

c) Electronic information provided in a dedicated, visible web site and linked to appropriate sites including the Aged and Disability Care Information Service.

d) Advertising material through a variety of mediums:

- organisation newsletters,
- regional newspapers (including public interest stories),
- radio stations,
- television, and
- the Yellow Pages.

### **Recommendation 4**

That the information strategy accommodate the broad scope of the Program, the relationship between HACC and other services and the diverse ways the target

group seeks information, by providing information to and through a variety of organisations including:

- Carelink
- community health centres,
- cultural community centres,
- Centrelink,
- Department of Veteran Affairs,
- Disability Services,
- GPs,
- HACC service providers,
- hospitals,
- injury and illness specific support groups,
- local government organisations,
- Mental Health Services,
- multi-purpose centres,
- Service Tasmania, and
- the Aged Care Assessment Team.

(This recommendation also applies to section 12.3 of this report)

## 8. Assessment

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The function of assessment is threefold; to determine potential consumers eligibility for HACC services; to ensure that assistance is provided that is appropriate to the needs of the consumer; to allocate resources effectively and equitably. In addition, the full process of assessment encompasses ongoing monitoring and review processes and coordination and referral tasks, however this report will discuss these components under separate headings of reassessment and referral respectively.

This section explores consumers' experiences of assessment and their perceptions of the appropriateness and effectiveness of the process.

### 8.1 Assessment findings: What consumers said

#### 8.1.1 Written survey results: assessment

To provide an indication of the ways assessments were conducted, the survey asked people how they had been assessed. Predominantly, consumers received a home visit.

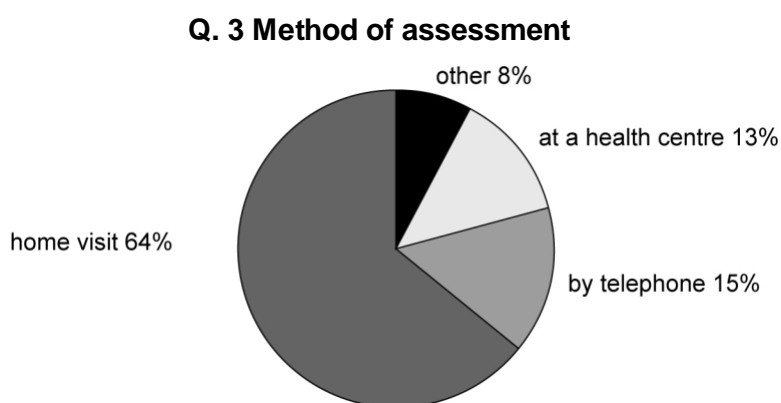


Fig 3. Methods of Assessment by percentage of responses

'Other' means of assessment were stated as:

- In hospital (prior to discharge)
- By an Aged Care Assessment Team (ACAT)

The survey also asked how many times each consumer had to explain their situation to health professionals before they received a HACC service. The majority of responses explained their situation only once before they received the service.

#### **Q. 6 The number of times consumers told their stories prior to service commencement**

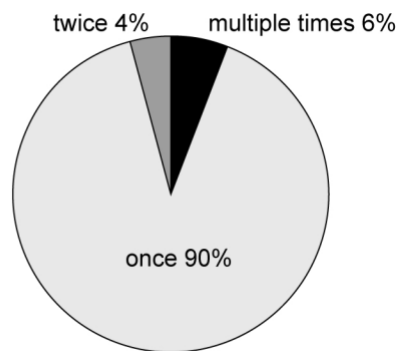


Fig 4. Number of times stories were told, prior to service commencement, by percentage of responses.

Consumers' experiences of the process and outcomes of assessment were further explored in workshops and interviews.

### **8.1.2 Workshop and interview findings: Assessment**

The workshops and interviews sought information from consumers about their perceptions and understandings of the assessment process and its relationship to their overall experiences of community care. In particular, consumer discussions explored the appropriateness and/or effectiveness of eligibility determination, need evaluation and effective provision of services.

#### **Determining eligibility**

On the whole, consumers indicated that eligibility was determined prior to a formal assessment, at the point of initial contact with a HACC service provider. A service-specific assessment then followed and either confirmed, denied or clarified the initial indication of eligibility.

For example, a couple who had been given an initial indication that they were eligible for day respite services on the phone were then deemed ineligible during a face-to-face assessment:

*They come up here ... and give us all the things that respite can do and we thought that will be great ... but when we worked it out ...we couldn't do it.*  
(Interview participant)

However, some consumers recalled instances when their assessment failed to confirm or deny eligibility. Ineligibility was determined after assistance had started. For example, one participant stated he was assessed as eligible to receive free dressings, but was later informed it had been a mistake:

*When I went home from hospital they arranged for the nurses to come and do the dressings and they said I wouldn't have to pay, because I couldn't afford it. They came three or four times and changed the dressings, then they said I did have to pay.* (Workshop participant)

His response was to immediately terminate the service:

*I told them not to bother coming back.*

In another instance a client was assessed via a home visit as eligible to attend a day centre. However, when the client went his carer discovered that staff were not trained to perform his personal care tasks and the carer stated:

*It was a total disaster and he never went back.* (Interview participant, carer)

Some participants reported being deterred from proceeding with assessments because of the methods used to determine eligibility, specifically:

*An avalanche of paperwork that you couldn't understand.* (Interview participant)

Similarly, another consumer reported she knew of people who terminated the assessment process when asked about their financial situation:

*A lot of people don't like saying what their situation is ... I know a lady, for the last 16 years whenever she is asked what her financial state is she doesn't fill it in ... so she misses out on help ... People back off, they don't want to answer those questions.* (Interview participant)

## **Evaluating and meeting needs**

Evaluating the needs of consumers is part of the process of determining the type and extent of assistance required. For consumers, the effectiveness of assessment is measured by whether assessment is followed by having their needs met.

### **Positive assessment stories**

Some consumers described assessment processes that they thought effectively evaluated their needs. Such assessments were characterised by an evaluation of what the consumer could and couldn't do around the home and of the support they had. They also featured an offer of appropriate assistance. For example,

*The first time they came to see what [my husband] could do. Help started with someone coming and working alongside him in the garden and taking [my husband] into town to help pay the bills ... it was really great. (Interview participant, carer)*

*I told [the assessor] everything, they were really good. The girls that come do cleaning ...make my sandwiches ... do my shopping for me ... they are very helpful to me. (Interview participant)*

Effective assessments evaluated not only physical need, but social needs also. For example, a social worker who was called in when there was "trouble in the family" arranged a variety of different services for the consumer, including domestic assistance, personal care, podiatry, home maintenance, home modification and Meals on Wheels:

*She arranged for someone to help me do the washing and clean the kitchen and bathroom ... She also got someone who could help me get the money from the bank ... lots of different people pop in and out. (Interview participant)*

Positive reports of assessment were also characterised by a consideration of family situations, that is, the partners, children and extended family who shared the house with the consumer.

*I needed the type of help that means I can also spend time with my daughter. (Workshop participant, carer)*

*I told her that whoever comes to help in the mornings has got to be able to fit in with the other kids using the bathroom and getting ready for school. (Interview participant, carer)*

People stated that a highly desirable component of assessment was a consideration and encouragement of individual abilities:

*If they think you can do it, they've got to let you, its very important. (Interview participant)*

*You've got to treat people like individuals, some are good at this, some are good at that. You've got to let them try. (Interview participant, carer)*

*You can't assess [my daughter] in the same way you do someone living in a city. She is completely different ... They came and wanted to see how she makes a cup of coffee, but she doesn't even drink coffee and she can't be near hot things. They wanted to start her on a program to help her dress herself, but she'll never be able to dress herself. (Interview participant, carer)*

Some participants reported that a feature of a good assessment was the capacity for choice about services offered.

*The nurse told me I should get a carer, but I don't want one, there were things I wanted to keep doing by myself. (Workshop participant)*

*They suggested respite, but we're not ready to use it yet. (Interview participant)*

*I was offered Meals on Wheels, but I can still cook for myself and my daughter helps out. (Interview participant)*

Some consumers reported successful collaborative assessment processes. For example, some consumers interviewed potential carers to determine their suitability and skills:

*I got her in, I gave her an interview, I contacted [the service provider] and arranged to get her in and have an interview ... I organised that and she came around. (Interview participant)*

*I was involved in working out who would be the best person to come and work here ..., I had a right that if the person couldn't do the job I could refuse them. (Interview participant)*

## **Negative Assessment Stories**

Consumers also reported assessments that did not fully or appropriately evaluate their needs or result in meeting their needs. The following are examples of negative assessment experiences.

Several consumers reported that home modifications and equipment were arranged without first being assessed for what they could do at home, or for the suitability of the equipment:

*When I came out of hospital they said I must have a power bed and all this sort of thing ... he was worried about me not being able to get into bed, but I can slide board from here to there, but the trouble is, [the OT] thought ...I don't know what he thought. I was really looking forward to sleeping in my own bed. (Interview participant)*

*They delivered me a wheelchair, to help me get around the house. Trouble is, it doesn't fit in the unit. It just sits there in the corner. (Interview participant)*

*Someone gave me one of those boards you put across the bath, they thought I needed it, but I don't. Its holding up my washing basket nicely though. (Workshop participant)*

Some consumers stated they were offered only the assistance that the service could provide, irrespective of their needs or abilities. For example, some consumers were

offered half an hour per fortnight to clean the bathroom and do the vacuuming, regardless of what tasks they could perform themselves.

*There seems to be a mismatch between what I need and what they offer, I can actually clean the bottom of the shower, but I can't do the high things. But they can't do that.* (Interview participant)

*I've got the services, I like the services, but it's not what I want.* (Interview participant)

*There is no system that I know of that says, let us show you what we've got, and asks 'are you getting enough [help]' I don't see it and I don't hear of it.* (Interview participant)

Similarly, gardening tasks were offered that did not reflect need or availability of family assistance:

*I had volunteers [lawn-mowing] for a short while but no more. They came once a week, but I didn't have a say how often they came ... I didn't need them that often.* (Workshop participant)

*Two hours goes nowhere. What they need to do is come and work out what your garden needs doing immediately, then what the ongoing need would be.* (Interview participant)

The impact of a resource-driven approach to assessment is summarised by one consumer's comment:

*How you live your life is determined by what's on offer.* (Interview participant)

Consumers reported instances when they believed that no effort had been made to allocate suitable staff.

*It's just that they're not the right people for [my daughter] ...they come in and they're just useless ... They don't double check on new workers, to see how they're going. The onus comes back onto me ... Because [my daughter] is so complex you've got to have the right person for her* (Interview participant , carer)

*If I had had a chance to say whether I would have chosen this particular [worker] I would have said no: what she can offer is not what I need* (Interview participant)

Some consumers expressed disappointment that assessment failed to clarify the roles and tasks of care assistants and other workers:

*Nursing is clear, but home help is confusing. They tell you a little bit, but it's not enough so that you really understand.* (Interview participant)

*Carer respite people come and sit with [the client] while [the carer] goes out shopping, but we're not sure what is ok to ask them to do and what's not. It would be good to make it clear.* (Interview participant , carer)

In some instances, information obtained during assessment was not passed onto the people delivering the assistance. For example,

*[Following the assessment] we were under the impression that someone was coming to help us with the garden, to move a rose plant, because we needed someone to do the digging. When the fellow arrived he said he didn't know anything about moving a plant and he didn't have the right gear. So he mowed the lawn, but we already had someone else who mowed the lawn.*  
(Interview participant)

Some participants stated that new staff were not informed of the information they had given at assessment.

*You feel exhausted trying to explain everything to every new staff member that comes along.* (Interview participant)

Some participants signalled that when the assessment process did not result in needs being met, they became assertive and demanding:

*I was meek and mild when I started, but you just have to be [assertive] because otherwise you just won't get nothing. You have to scream and holler, and I learnt that a long time ago. I have to, [my daughter] has very high needs ... If I want something for [my daughter] I get it, I don't care how I get it I just fight and fight until I get it, I get sick doing it, but it's the only way to get it ... it's sad.* (Interview participant, carer)

## **Telling the story multiple times**

Of the total survey responses, 10% indicated that they had to explain their situation more than once before they could obtain assistance. The workshop and interview participants provided some detail about the circumstances that resulted in the provision of multiple explanations.

Some consumers stated they were required to tell their story many times because multiple organisations were involved in their care. They stated “communication breakdowns” led to numerous phone calls from different coordinating staff about similar issues:

*Since I've had a few services involved the wheels have started falling off a bit ... there's too many people involved.* (Interview participant)

People also said they had to explain themselves numerous times to their service provider because the phone staff did not know who they were:

*You ring them up, they've got no idea who you are and you've got to explain it all to them.* (Interview participant)

Some people expressed ambivalence about providing multiple explanations to different people:

*You just put up with it, it's part of it. You know you get different things from each one, so you expect it. (Interview participant)*

*I can't remember anything that wasn't appropriate ... all of [the assessments] are valuable because things are changing all the time and they tell you about different information. (Interview participant, carer)*

However, others felt uncomfortable:

*Telling my story to lots of different people makes me feel uneasy. I prefer [the day centre coordinator] to do it for me. (Workshop participant, carer)*

## **8.2 Discussion of assessment experiences**

The findings from this research indicate that assessments that do not adequately and accurately assess the needs of consumers create inefficiencies and waste resources. Furthermore, poor assessments undermine many consumers' sense of control and independence and increase their vulnerability, thus impacting on their capacity to remain living at home.

### **Eligibility**

Ideally, eligibility for both the HACC program and for particular provider services is determined early. Eligibility necessitates discussion about financial status, for example inquiring about pension types, which can be awkward and intimidating for some of the HACC target group and may serve as a barrier to entry. However, if not established at assessment, later discoveries of ineligibility may result in a termination of services, disenchantment with community care services and reluctance to seek assistance again. These findings highlight a need for sensitivity during assessment.

### **Evaluating Need**

Evaluating need was most effective when it considered the broad range of factors that impacted on the consumer's ability to live at home independently and safely. That is, when assessment was holistic and consumer-centred. Such assessments evaluated the consumers' physical and social:

- abilities,
- needs, and

- resources.

The most effective assessments were characterised by:

- the flexibility to meet the needs of the individual consumer;
- the capacity for consumer input;
- the provision of information about employees' roles and an attempt to match care assistants with consumers; and
- an underlying aim to enable independence.

The least effective assessments were characterised by:

- inadequate evaluation of abilities or needs;
- little or no capacity for consumer input;
- inappropriate matching of consumers to care assistants;
- no follow up to assess effectiveness; and
- poor communication of assessment information to other staff.

Consumers perceived a correlation between holistic, consumer-centred assessment and the receipt of appropriate care. In instances when people felt they had not been listened to or responded to appropriately, they reported becoming assertive and demanding.

## **Multiple explanations**

Consumers most likely to experience explaining their situation multiple times were those with complex needs who accessed a wide range of services. Although not common, repeated story-telling was predominantly a result of poor communication within service provider organisations, after services had commenced.

### **8.2.1 Implications for the HACC Program: Assessment**

The findings from this research demonstrate that current assessment processes limit the ability of the HACC Program to consistently achieve the aims of assessment. Specifically, poor assessment processes impact negatively on the Program aims to assess holistically and to provide appropriate and effective resources for consumers.

#### **Assessing holistically**

The HACC Program guidelines stipulate that the assessment process should be holistic and flexible: assessment seeks to identify each individual's needs and then the services

most appropriate to meet those needs (*NPG 27*). Changes to the HACC minimum data set (MDS version 2) also encourage a thorough, holistic assessment.

Problematically, thorough assessments are not always recommended for HACC consumers. HACC guidelines state: “[t]he type or depth of assessment, whether it is a general assessment or a comprehensive assessment, depends on the complexity of care needs. This needs to be established when the client initially contacts a service provider” (27). Therefore, if a potential consumer is determined to have simple care needs during the initial phone call to a provider, they do not require a comprehensive assessment. The desire to determine care needs early is partly motivated by the HACC guideline which states: “An appropriate balance needs to be struck between over-assessing people with straightforward needs, which is both overly intensive and unnecessarily costly and failing to consider clients’ total care requirements which may lead to inappropriate services being provided” (*NPG 27*). However, although over-assessing may be costly, this research indicates that inappropriate service provision is also costly, both in the wastage of resources, and in outcomes for consumers.

The findings of this project challenge the appropriateness of establishing the complexity of care needs during initial contact for a number of reasons:

- As indicated, the initial phone call to an organisation forms part of a process of entry into HACC, and at this point the consumer may still be confused and unsure of what help is available and of what they need (see section 7.2 above).
- It is not until a full assessment is conducted that the consumer discovers the range of options open to them. For example, someone may ring asking for Meals on Wheels because that’s a service they know; however, what may be more appropriate is a service they are unaware of, such as someone to help with shopping, or modifications to their kitchen.
- Because “[d]efining and determining the level of need at an individual level ... are complex tasks” (Australian Government Productivity Commission, 12.34) they need to be performed by skilled assessors in consumer’s homes to accurately determine the level of need.

In addition, MDS version 2 collects assessment information about the functional capacity of the consumer that requires observational assessments of their abilities to perform tasks, for example, to determine if a consumer can walk without help. Furthermore, personal questions are required that necessitate a trusting relationship between

assessor and consumer, for example, “can you handle your own money?” The assessor is also asked to determine memory and behavioural characteristics of the consumer.

The nature of these additional assessment tasks, combined with the demonstrated benefits of holistic assessment and the stated aims of the Program, necessitate that the assessment process accommodate thorough assessments for potential HACC consumers.

### **Allocating resources appropriately**

The appropriate and effective allocation of resources for HACC consumers is dependent upon the assessment process maintaining a consumer-focus. Service providers need to consider the availability of their organisational resources, both material and human, and their fiscal and locality limitations. Nevertheless, prioritising the allocation of resources needs to be primarily driven by consumer need.

The HACC Program guidelines state that assessing consumers with complex needs should be “independent of service provision” and consumers should be “assessed for all their care requirements rather than a particular service” (NPG 29). Currently, when assessment is driven by resource-availability only, it fails to adequately identify needs and to provide appropriate care. It also impacts on the Programs ability to promote “more efficient and effective targeting of resources” (NPG 27)

### **Assessing consistently**

The findings also have implications for the proposed changes toward consistency of HACC assessment processes. The Way Forward aims to:

- Work with state and territory governments to develop collaboratively nationally consistent intake assessment for HACC services within the national framework that also encompasses other community care programs (Action area 2.1); and
- Work with state and territory governments to develop collaboratively the comprehensive assessment system for the Packaged Care Tier (Action area 2.2)

The identified strengths and weaknesses of current assessment practices found by this research provide valuable information for Tasmanian input into the development and implementation of nationally consistent assessment processes and tools. Specifically:

- the need to allow for consideration of consumer individuality;
- the benefits of holistic assessment practices; and

- the need to facilitate consumer input into the assessment process.

### **8.3 Recommendations: Assessment**

To facilitate holistic assessment and the provision of effective and appropriate resource allocation, TasCOSS makes the following recommendations.

#### **Recommendation 5**

That HACC assessments be conducted by specialist independent assessors to enable consumer needs and priorities to be determined with maximum efficiency and effectiveness for both the consumer and the HACC Program.

#### **Recommendation 6**

That HACC assessors be suitably trained to understand the barriers to accessing services and the specific needs of the target group.

#### **Recommendation 7**

That HACC assessors:

- conduct collaborative, holistic, consumer-centred assessments;
- liaise with service provider employees, GPs, case managers, ACAT and others involved in the care of the consumer; and
- act as referral agents to relevant organisations within and beyond the HACC Program.

(This recommendation also applies to section numbers 11.3 and 12.3)

#### **Recommendation 8**

That HACC assessments be conducted face to face, in the consumer's home initially, then be followed by a face-to-face, brief follow-up check one month post and a full reassessment at least 12 months after initial contact. In addition, that assessors act as contact points for consumers, enabling the consumer to initiate reassessments at additional times as needs arise. (This recommendation also applies to section 9.3)

#### **Recommendation 9**

That HACC Program representatives on The Way Forward assessment working group advocate for an assessment process that:

- is consumer focused,
- is flexible and holistic,

- aims to increase consumers' capacity for independence where possible,
- ensures phone assessments are followed by a face-to-face assessment in the home of the consumer, in consultation with carers, to fully determine and respond to need,
- attempts to match consumers with appropriate workers, and
- has the capacity to measure outcomes of assessment.

**Recommendation 10**

That HACC Program representatives on The Way Forward assessment working group advocate for an assessment tool that facilitates:

- assessment of abilities as well as needs,
- assessment of resources, including personal and material, available to the consumer,
- the capacity for consumer and carer input, and
- the capacity to explain the roles of workers.

## 9. Reassessment

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Reassessment forms part of the total assessment process, dealing specifically with the monitoring and review components. Consumer experiences of reassessments were varied and this section presents the findings and examines the impacts these have on the overall effectiveness of the HACC Program.

### 9.1 Reassessment findings: What consumers said

#### 9.1.1 Written survey results: Reassessment

The survey sought to determine the incidence of reassessments amongst consumers. Question seven asked if consumers had been reviewed since services had begun, either by phone or in person. A high percentage of respondents indicated they had been reassessed, although a significant percentage (20%) had not.

##### Q.7 Incidence of reassessment after start of services

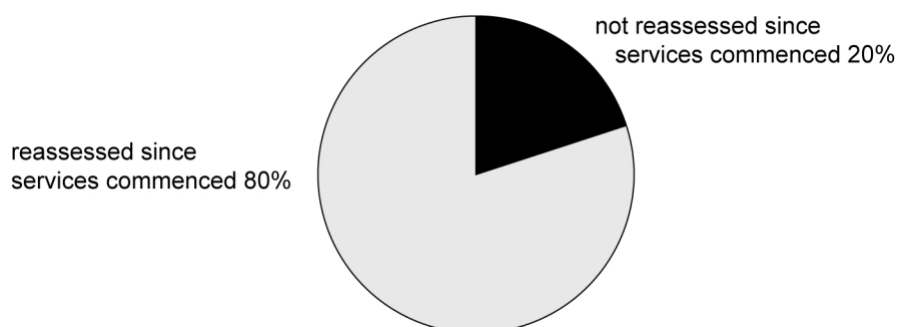


Fig 5. Number of Respondents reassessed since service commencement by percentage.

The survey also asked if the consumer's situation had changed since the service had begun, and just under half of the respondents indicated it had.

## Q.8 Changes in situation after services start

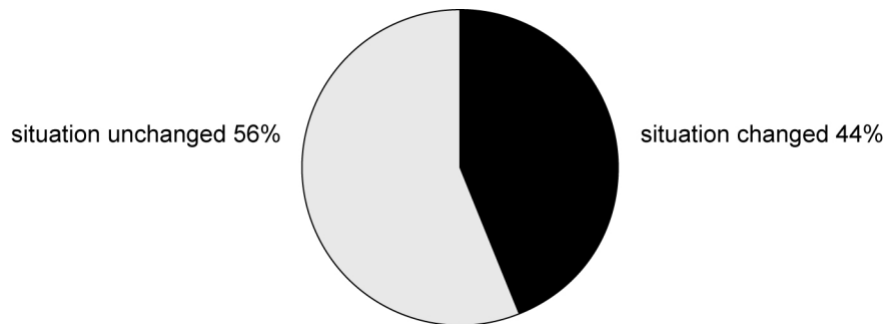


Fig 6. Changes in situation by percentage of respondents.

This question also asked how individual situations had changed and allowed for an open response. This attracted a great deal of comment in 102 responses. The type of changes noted by respondents included:

- Deteriorating health (for example, *had a stroke, have been diagnosed with cancer, severe sciatica, reduced mobility, failing eyesight, effects of multiple sclerosis*)
- Loss of family support (for example, *family moved to the mainland, become widowed*)
- Medical interventions (for example, *had a hip replacement, other operation*).

The survey did not ask how long people had been receiving services for prior to or since reassessments. Nor was information obtained regarding the relationship between reassessment processes and changes in circumstances, and perceptions of the effectiveness of reviews. Consequently, this detail was explored in workshops and interviews.

### 9.1.2 Workshop and interview findings: Reassessment

#### Types and frequency of Reassessment

The survey indicated that most respondents were reassessed and workshops and interviews revealed the large variety of reassessment format and frequency. Formats included face-to-face visits, phone calls and written forms, and frequency ranged from “never” through a range of monthly, quarterly, half-yearly and annual visits or calls.

Reassessment experiences varied greatly, from the negligible:

*I get home help once a fortnight and I've never had anyone come and see how I am. (Workshop participant)*

*Our current coordinator has been looking after [my child] for years and has never met him. We've been on the same hours for years.*  
(Interview participant)

*Someone was supposed to come and take my blood pressure, but it hasn't happened for a couple of years.* (Workshop participant)

*They used to come and do feedback.* (Workshop participant)

*They quite often just send out last year's assessment and say are things the same and I send it back.* (Interview participant)

To more regular:

*They keep in touch.* (Workshop participant)

*Someone comes once a year and sees how things are going.* (Workshop participant)

*Someone comes and does a check up regularly.* (Workshop participant)

*Once a year [the coordinator] comes out, every July, and we talk about everything that has happened in the year. She gives me ideas and tells me about new things.* (Interview participant)

Some people stated they felt that each visit from the carer or registered nurse was like a review, which they thought eliminated the need for a formal reassessment from a coordinator, case manager or independent assessor. Similarly, some felt they could ring at any time with any problems, which also negated the need for a formal review process.

## **Effectiveness of Reassessment**

Participants reported that their care delivery improved following a formal reassessment of their situation, when conducted by a person with the knowledge and skills to understand their changing needs. Reassessment also provided an opportunity to receive additional information on the availability of services.

*When [the service provider staff member] came to review me they asked if I needed extra help and I said yes, and they gave me some straight away.*  
(Workshop participant)

*When the Nurse came to check how things were I mentioned to her about how expensive the nappies were and so that's when she got us into the continence scheme.* (Interview participant, carer)

*I heard about the Spring Cleaning through [my coordinator] when she came to visit.* (Interview participant)

Some home help clients reported that gardening and Meals on Wheels were organised as a result of an annual reassessment.

Adjustments to allocated hours were also reported to occur following a thorough review, for example,

*When I had my back injury I needed more help with the cleaning. I could still do the toilet, but I needed someone to do the shower. So they changed my home help from three quarters of an hour per fortnight, to half an hour one week to do the vacuuming, then three quarters of an hour the next week so they could also do the bathroom. (Workshop participant)*

When performed by a coordinator or case manager, reassessment reportedly enabled a check on whether the consumer was experiencing any problems with care assistants, without fear of recrimination:

*I tell the head nurse in confidence if I'm having problems. I won't say a bad word to the carers, because I don't want to get a bad name amongst them. (Workshop participant)*

*I don't want to say anything directly to the carers, because you end up getting a bad name. (Workshop participant)*

Some consumers reported that checks on care assistants' performance were not conducted:

*The coordinators don't check what the carers are doing ... they just assume that the person can do the job and it's not good enough. (Interview participant)*

One consumer expressed her concern that, in the absence of a regular reassessment, the particulars of her daughter's individual needs could not be appreciated and addressed.

*Half the time the coordinator doesn't even know [my daughter] so how can they know what it's like when they haven't even met her? ... They need to see them, they're not a number, they are a person...I get very annoyed with case managers when they don't even know them. (Interview participant, carer)*

Some people stated that they felt the purpose of a reassessment was for them to prove they deserved the assistance they received.

*[The re-assessor] was not quite sensitive to the situation – she didn't understand the situation here. She told me that we were lucky to have the hours and that if the same happened now we wouldn't be so lucky. I explained to her that the doctor told me I should go for a walk and get out a bit ... She didn't quite slot into how things were here. (Interview participant, carer)*

Similarly, for many domestic assistance clients, phone calls were perceived as a check on whether or not cleaning was still needed, rather than the opportunity to re-assess changing needs.

Sometimes reassessment was thought to be unrelated to need. For example, a young person receiving weekly home help assistance for a back injury stated:

*The nursing assessment takes my blood pressure and writes down my medications, but it doesn't look at how I'm going doing the domestic chores. I'm not utilising the nursing services ... it sort of mismatches. (Interview participant)*

For some, reassessment didn't allow them to have input into service changes:

*[My coordinator's] approach was to say, 'I'm your coordinator, you are my client, deal with it.' She couldn't believe that I would know what I needed care with. (Interview participant)*

There was also evidence of the perception that those not directly involved in care delivery did not actively influence changes to care delivery. One consumer stated he didn't rely on reassessment to change his care needs, but instructed the care assistants himself.

*What I need is slowly changing ... gradually I can't do things that I used to be able to do ... I just make suggestions of what I need and take it from there, you've got to teach [the care assistants] to do what you want and how to do it...its no good telling the bosses, you never see them and they don't do nothing, so what's the good of them? (Interview participant)*

In the absence of a reassessment, consumers stated they would complain to the organisation. For example, one participant who stated he had never had a review said:

*If there was a problem with the service then we'd complain and then they'd come wouldn't they? (Workshop participant)*

Consumers also stated they were reassessed regularly by agencies other than HACC service providers. For example, ACAT, illness-specific organisations like Alzheimer's Australia and by general practice nurses.

## **9.2 Discussion of reassessment experiences**

A wide variety of assessment practices was reported by the consumers consulted. Some people felt they did not need regular reassessment because they felt they could approach the organisation at any time. Paradoxically, others felt they were forced to make contact because they were not being regularly reviewed.

Measures of the effectiveness of a review from a consumer perspective are principally derived from the association of positive outcomes with reassessment visits.

For consumers, effective reviews were those that:

- were performed regularly,
- resulted in changes to improve the appropriateness of resource allocation,
- addressed problems with carers, and
- allowed for positive and negative feedback about services in a non-threatening environment.

Reassessments that took the form of a quick phone call to ask if the consumer still needed the service failed to adequately assess changes in people's situations. Similarly, reassessments that mismatched the type of assistance currently being received were also thought to be ineffective. Regular, holistic, face-to-face reassessments lessened the need for complaints.

HACC reassessments are currently conducted independently from other community and government organisations, such as ACAT, GPs and illness and injury support groups, and make evident the need for coordination between HACC and these other services.

### **9.2.1 Implications for the HACC Program: Reassessment**

Reassessment is intended to monitor the effectiveness and efficiency of HACC services and to ascertain whether service provision is meeting the ongoing needs of consumers. Thus, the role of reassessment is to determine firstly, whether the initial assessment has been appropriately addressed, and secondly, whether the consumer's needs have changed and consequently require alterations to their services.

Currently, reassessment processes are inconsistent across the HACC program. In part this reflects the diversity of HACC services and the flexibility afforded to providers to determine the frequency of reassessments. That is, HACC guidelines state that service providers are responsible for monitoring and reviewing consumers' care needs "on a regular basis" to ensure that services continue to be appropriate (27), leaving the frequency, and format, to the discretion of each service provider. However, the loose guidelines result in an undervaluing of the importance of regular, holistic reassessment. It is evident that when regular thorough reviews are conducted by people who are not the providers of daily care tasks, consumers take the opportunity to discuss their circumstances and seek solutions to problems. Such reviews also enable a check on the appropriateness of resource allocation, decrease complaints and provide the opportunity to keep consumers informed and updated. Without regular, formal reassessments, ineffective or inappropriate care and resource allocation may go unchecked.

The value of thorough reassessments, combined with the negative consequences of poor or infrequent reassessments, indicates a need to introduce more formal arrangements around the format and regularity of reassessment practices.

### **9.3 Recommendations: Reassessment**

To address the inconsistencies of reassessment practices and to acknowledge the importance of regular, formal reviews, TasCOSS makes the following recommendation.

#### **Recommendation 8**

That HACC assessments be conducted face to face, in the consumer's home initially, then be followed by a face-to-face, brief follow-up check one month post and a full reassessment at least 12 months after initial contact. In addition, that assessors act as contact points for consumers, enabling the consumer to initiate reassessments at additional times as needs arise. (This recommendation also applies to section 8.3)

## 10. Waiting

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This research sought to determine whether consumers experienced long waiting periods for HACC services and, if so, what were the impacts of these on their ability to live safely and comfortably at home.

### 10.1 Waiting findings: What consumers said

#### 10.1.1 Written survey results: Waiting

The written survey asked consumers to indicate how long they waited to have their situation assessed. The most commonly reported waiting time was from one to four weeks.

##### Q. 4 Waiting times until assessment

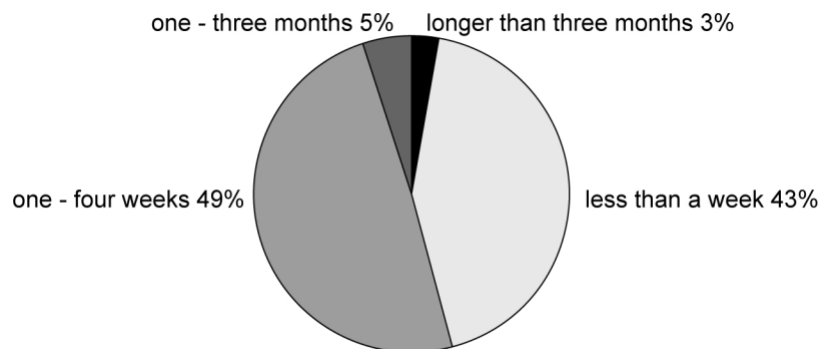


Fig 8. Waiting times from contact to assessment by percentage of responses.

Of the consumers who waited over one month for assessment, half lived in the South of Tasmania and almost half were from the North. Only one of those who waited for longer than one month was from the North West.

Of the twenty respondents who waited for longer than one month for assessment, services sought were usually a variety (for example, home help, personal care, food, allied health, respite, day centre, carer support and transport). Only three out of 20 respondents were seeking one service type only.

Once assessed, consumers were asked to indicate how long they waited for the service to begin and 60% of respondents indicated they received a service within two to four weeks.

### Q. 5 Time from assessment until service started

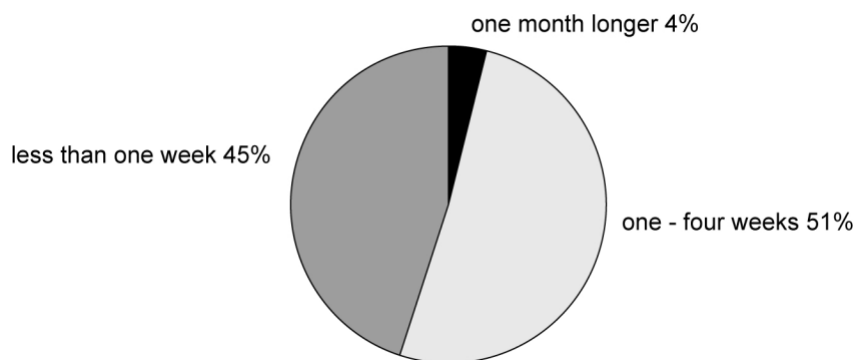


Fig 9. Time from assessment to commencement by percentage of respondents.

Of the consumers who waited longer than four weeks:

- four waited longer than three months for a service (most of these were seeking a constellation of services including home help, personal care, allied health and day centre help);
- three waited from one to three months for a service (for respite, day centre, domestic and personal care services); and
- one respondent did not indicate how long it was before they received a service.

Three of those who waited for longer than 3 months were in the North and one was in the South.

These findings indicate that, for the majority of these respondents, once assessed, services commenced within reasonable time frames. However, the survey results do not provide detail about the impact that waiting for services may have on consumers. The question arises, were the people waiting those who could least afford to wait, and were they experiencing detrimental effects as a result? Information about the types of services being waited for and the impacts on peoples conditions were sought from workshop and interview participants.

## 10.1.2 Workshop and interview findings: Waiting

Across all participants in interviews and workshops, very few people said they waited for long periods for HACC services.

*I've never had to wait for anything.* (Workshop participant)

*Everything started straight away, I don't think I had to wait at all, at least not for longer than a week or two.* (Interview participant)

When some participants initially said they didn't have to wait for anything they would then qualify their response with comments like, *well only a week or two (or three)*.

Those who did wait for HACC services waited predominantly for equipment, respite and podiatry.

*I waited two and a half months for the podiatrist.* (Workshop participant)

*I need a Podiatrist, but I have to wait a very long time. I was told to get a friend to cut my toenails* (Workshop participant)

*We had to book well in advance for respite of course.* (Interview participant)

*I've had to wait a while for my chair, but that's because they had to make a special one to suit me.* (Interview participant)

There were also stories of being put on a waiting list and "forgotten about":

*I waited twelve months for rails, then when I rang I wasn't even on a waiting list.* (Workshop participant)

Participants in outer regional and remote areas raised particular issues about waiting for services. Waiting was caused by the unavailability or limited availability of resources:

*We can't get Meals on Wheels out here.* (Workshop participant)

*There's only one fellow to do the maintenance for the whole area, you've got to wait.* (Workshop participant)

*There's not many volunteer drivers to take you to places, because they have to drive so far and they don't get paid much for it.* (Workshop participant)

*There's no lawn-mowing available around here, you just can't get it.* (Workshop participant)

*If you live out here you've got to be prepared to make sacrifices. It's not just the elderly who don't get help, it's everybody* (Workshop participant, remote area)

In contrast, one consumer stated she waited six years in an inner regional city to find a suitable day centre for her daughter, then moved to an outer regional area and found an appropriate service in the local centre. Other participants in rural areas also thought they had better access to services. One consumer stated:

*It's better out here than in the city, you can't get help like we do in the city.*  
(Workshop participant)

HACC consumers reported long waits for services provided by other organisations. In particular from Housing Tasmania:

*About two years ago [housing] were supposed to come out and do the paint job, in seven years they haven't even painted the place.* (Workshop participant)

*I waited for over six months for them to come and put a heater in, it was a bit of a battle I tell you.* (Interview participant)

*I haven't had to wait for any HACC stuff, but housing department is a different story. It took eighteen months to get my carport changed so I could fit the [wheelchair suitable] van under.* (Interview participant)

*It took me seven years to get a fence up.* (Workshop participant)

Consumers also waited for Individual Support Packages (ISPs):

*I've been on the waiting list for an ISP for a few months now, someone told me you have to reapply a few times.* (Interview participant)

## **10.2 Discussion of Waiting Experiences**

Consumers suspected to be at most risk because of having to wait for services are those with complex presentations. However, interviews with consumers with complex needs suggest that they were able to access the majority of services they needed with little waiting.

HACC services that did incur waits were predominantly podiatry, equipment and in-home respite care. In rural areas, waits for services related to the unavailability or limited availability of services in the region. Also, waits related to distance and travel difficulties.

For HACC consumers, waiting periods to access assistance from other community service and health providers were significant. Waits for Housing Tasmania services, Disability Services and dental care were long and impacted on HACC consumers' overall ability to live safely, independently and comfortably at home.

### **10.2.1 Implications for the HACC Program: Waiting**

The findings about waiting periods have two main implications for the HACC program. Firstly, the relatively short waiting times for consumers with complex needs may in part result from the success of entry into HACC via hospitals, following acute events. As discussed under “Intake”, hospitalisation in some instances may occur as a result of the inability to access assistance within the home. This underlines the need to improve access to information and entry points in order to assist people before their needs cause hospitalisation, that is, before their needs become ‘complex’.

Secondly, these findings illustrate the interconnections between HACC and other services, for example, long waits for heater installations, or bathroom modifications, impact on the health (and financial) status of HACC consumers, and thus on the extent of their need for HACC services. Waiting for Individual Support Programs, reported to be between six months to two years, mean that consumers require HACC services in the interim. A paper by Anglicare’s Social Action and Research Centre documents links between delayed access to dental services and poor health outcomes (Cameron 3).

Additionally, The Way Forward action area 1.6 indicates an intention to “better coordinate planning between the HACC Program and other relevant programs” (7). This research demonstrates that work toward improved coordination between housing services, disability and dental services would be appropriate.

### **10.3 Recommendations: Waiting**

To address the problems associated with waiting for HACC and non-HACC services, the following recommendations are made.

#### **Recommendation 11**

That HACC assessors, in consultation with consumers, refer to case managers when a consumer is receiving, or waiting for the receipt of services from other government bodies such as Housing Tasmania, Disability or Mental Health Services in order to facilitate coordination of care beyond the HACC Program.

(This recommendation also applies to section 11.3)

**Recommendation 12**

That HACC service providers phone people waiting for their services to commence on a monthly basis to inform them of projected waiting times and progress toward service commencement and to confirm the consumer's need for the service.

## **11. Post-Assessment Referral**

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The overall assessment process also involves referral of consumers to services that are best equipped to accommodate their needs. This section examines consumers' experiences of post-assessment referrals within the current system. It reveals consumers' perceptions of the problems with the referral process.

### **11.1 Post-assessment referral findings: What consumers said**

No survey information was sought specifically about referral processes, data was obtained from workshop and interview consultations only.

#### **11.1.1 Workshop and interview findings: Post-Assessment referral**

The findings from workshops and interviews indicate that referrals are initiated by many people in a variety of ways.

Referrals occurred within and beyond HACC services and were often instigated as circumstances changed, as needs become apparent, or as contact was made with a health professional and/or HACC service provider staff. The following experience demonstrates the myriad of contributing circumstances and sources of referral.

Mrs Smith<sup>7</sup> was diagnosed with Multiple Sclerosis (MS) by her GP and specialist doctor. After diagnosis, she and her husband attended a MS society meeting where they heard a local HACC service provider talk about their range of services. Following this meeting, Mrs Smith phoned the service provider who arranged for a visit by a case manager, who conducted an assessment. The case manager initially arranged for someone to help with the shopping. As Mrs Smith's condition deteriorated, she re-contacted her case manager to organise a re-assessment of her needs. As a result the case manager arranged for domestic assistance, personal care and overnight, in-home respite to

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<sup>7</sup> The consumer's real name has been changed to ensure privacy.

start. A referral to the Occupational Therapist (OT) and to ACAT was also initiated. The OT then arranged for home modifications and also referred Mrs Smith to the equipment loan scheme. ACAT arranged for out-of-home respite services. At this stage Mr Smith became Mrs Smith's carer and took on cooking, cleaning and maintenance roles. A while later, she required a surgical procedure in hospital and as part of her discharge plan, was referred to community nursing services. The community nurse then referred Mrs Smith to the continence scheme. In addition, she was informed of opportunities to privately purchase equipment. Through informal contact with peers, Mrs Smith heard about a day centre. She visited the centre and started attending. The day centre referred Mrs Smith to the community transport scheme and to the spring cleaning program. Ongoing contact with the MS society continued and as a result, a speech therapy referral was arranged. Mrs Smith also kept in contact with her GP and he arranged for podiatry services.

## **Who Refers?**

Consumers stated that a variety of people referred them to services. Many consumers reported that once they had started receiving one service they were gradually referred to others:

*The community nurse told me about the gardener. (Workshop participant)*

*The Day centre staff organised the community care for me, and that's also where I get the Podiatrist to do my toes. (Workshop participant)*

*I have a case manager and he organised the people to come and do the windows and do some work in the garden. (Workshop participant)*

*The nurse who came to see me arranged for the Occupational Therapist to come and see about a rail next to the shower, and a chair for over the toilet. (Workshop participant)*

Some people stated their care assistants sought information about services for them.

*I've had lots of different changes to staff, but every one of them will do everything they can to help ... they find the services that are available. (Interview participant)*

Others said they thought the most appropriate people to organise referrals were coordinators or case managers.

*[Coordinators] know the ins and outs of everything ... it's more formal that way. They know the best because they deal with that sort of thing all the time. (Interview participant)*

In one regional area consumers reported that they were referred to services by the Meals on Wheels delivery staff who also were volunteers in the day centre. Amongst the workshop participants there was a high reliance on day centre staff to refer because it was stated they knew about the other services in the community. There were many stories about fantastic day centre staff, care assistants and coordinators who went the extra mile and arranged for services to start.

### **Referring when the need is recognised**

Some consumers reported that referrals were arranged as a result of someone recognising a changed need.

*The community nurse noticed I was using the washing basket trolley to get around on, so she got onto an Occupational therapist who came around. (Workshop participant)*

*My coordinator came to see how I was going and she was the one that got someone from the day centre to come and visit me. (Interview participant)*

However, others reported that when they informed their care assistants or domestic assistants of a changed need the information was not acted upon:

*I asked [my carer] about help with the ironing but they said they don't do that anymore. (Interview participant)*

*I asked the girl that comes if she would be able to start helping me take the washing out. She said she has too many people to see and hasn't got any time to spare. (Interview participant)*

In some instances, when increased need was not acknowledged and referral not arranged, a crisis resulted:

*Wasn't til I was having a breakdown that I was referred to the continence scheme and got some respite. (Workshop participant, carer)*

### **Trading Control**

The principal concern raised by consumers about being referred was that they experienced a lack of control over the process. One woman stated that she needed someone to organise things because she found it very confusing, but the trade-off was her loss of control:

*I get so used to it now, I was really pissed off at the beginning because I used to be a very independent person, I used to arrange all these things for other people. When it's you it's a totally different story...I don't feel like I'm in control of my life whatsoever. Everybody else is. Everything is just taken away from me, because other people are doing it for you. (Interview participant)*

Another participant spoke of similar feelings when he was referred to another agency:

*I felt like I was a piece of meat being passed over to someone else, 'bugger him, throw him over to someone else' ... it made me feel a bit inferior, is that the word, they didn't really care ... but they have a strict budget that they have to stick to. I think it could have been done a lot better. (Interview participant)*

People were concerned that when referrals take place between providers, without their participation, it sometimes resulted in incorrect or subjective information being passed on.

*They've done the talking, but sometimes they don't do any updates and they're not in a position to give out the right information ... there is never an opportunity for input. (Interview participant)*

However, some consumers felt relieved and happy when someone took control and organised multiple services on their behalf:

*Being referred on by others is all part of the process to meet my needs, so it doesn't really bother me. (Interview participant)*

## **11.2 Discussion of post-assessment referral experiences**

Findings indicate that there are a range of methods of referral and that a variety of people are involved. Particular patterns emerged of certain providers referring to others, for example, day centres arranged transport services; occupational therapists arranged equipment and community nurses referred people to Meals on Wheels, home help, gardening and other services.

It is evident that the act of appropriate and effective referral requires key elements:

- the capacity to recognise changing needs;
- consultation with the consumer and carers;
- a knowledge of available resources; and
- authority to act, or capacity to refer to an authorised person.

Although some consumers look to their care assistants to act on their changing needs, the ability or willingness of assistants to refer varied greatly. Some consumers depended on their coordinator or case-manager to refer them to services, stating that the confusing nature of the HACC system made it too difficult to tackle on their own. Some people reported that referrals were instigated because of a crisis, in similar ways to initial experiences of finding HACC services. A trade-off for obtaining the care some consumers required was reportedly a feeling of a loss of control over their lives.

### **11.2.1 Implications for the HACC Program: Post-Assessment referral**

The principles of referral are underpinned by the HACC program's objective to "promote the provision of a comprehensive, coordinated and integrated range of HACC services" to the target group (NPG 41). This objective recognises that consumer needs may extend beyond the capacity of a single service provider and thus inter-agency referrals are required: it is a consumer-centred objective.

Referral is by necessity a needs-driven process. Therefore, successful referral processes must facilitate both need recognition and appropriate responses. This project demonstrates that, currently, consistent appropriate referrals do not occur in all instances. This can be attributed to the varied levels of skill amongst care providers to recognise a consumer's changing needs, and varied levels of knowledge about service availability. There is also confusion over whose role it is to make referrals.

It is evident that effective referral processes require the following:

- formal, regular reassessment processes;
- access to information about HACC services;
- appropriately trained and authorised referral staff; and
- easy access to trained and authorised staff by all care providers and consumers.

### **11.3 Recommendations: Referral**

To improve the occurrence of appropriate, timely referrals, TasCOSS makes the following recommendations:

**Recommendation 7**

That HACC assessors:

- conduct collaborative, holistic, consumer-centred assessments;
- liaise with service provider employees, GPs, case managers, ACAT and others involved in the care of the consumer; and
- act as referral agents to relevant organisations within and beyond the HACC Program.

(This recommendation also applies to sections 8.3 and 12.3)

**Recommendation 11**

That HACC assessors, in consultation with consumers, refer to case managers when a consumer is receiving, or waiting for the receipt of services from other government bodies such as Housing Tasmania, Disability or Mental Health Services in order to facilitate coordination of care beyond the HACC Program.

(This recommendation also applies to section 10.3)

**Recommendation 13**

That formal structures be developed and implemented in HACC services to facilitate access by consumers and care assistants to HACC assessors, case managers or other suitable staff for referrals.

**Recommendation 14**

That measures be implemented to increase the capacity of all staff involved in care provision to recognise and act on the changing needs of consumers, including:

- staff education, as part of the recommended information strategy (recommendation number 1); and
- formal workplace procedures to facilitate access by care assistants to staff who enact referrals.

## 12. Use of Other Services

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During consultations it became evident that consumers access a range of services in addition to those funded by the HACC Program. This section examines the relationships between HACC and other services.

### 12.1 Use of other services findings: What consumers said

Many people reported they used combinations of informal, private, government and non-government support services. No survey information was sought about the use of non-HACC services, data was obtained from workshop and interview consultations only.

#### 12.1.1 Workshop and Interview findings: Use of other services

The following quotes exemplify the types of services used and the variety of ways people utilised them.

##### **Informal assistance**

*Someone from the church does my shopping for me. (Workshop participant)*

*On the days the nurses couldn't come, my neighbour over the road came and helped me get dressed, it was pretty funny. (Workshop participant)*

*I have a friend come to the house a couple of hours a week, just to give me a break, so I can get out of the house and I know [Mum] is safe. (Interview participant, carer)*

##### **Private Providers**

*We have a private gardener come and do the yard once a fortnight, costs about \$45 a pop. (Workshop participant)*

*I'd get a builder out of the yellow pages if I needed a ramp put in. (Workshop participant)*

*I've got a bloke who comes once a month and mows the lawns for \$20, works out to be \$5 a week. (Workshop participant)*

*I also have a girl that I pay come in once a fortnight, she does cleaning too. I don't want to let her go. (Workshop participant, who also receives HACC domestic assistance)*

*I'm trying to save up to get a plumber to put a better shower in. (Workshop participant)*

*The man who mowed the lawns said I wouldn't get another mow for six months. I'll find someone else now, maybe through the paper. (Workshop participant)*

*I get meals twice a week from Mum's Mobile Meals. (Workshop participant)*

*I don't use the community cars; me and Mr Taxi Driver get on quite well. (Interview participant)*

## **Other government-funded services**

Respite services, funded by the Department of Health and Ageing, were used by many HACC consumers. Other government agencies were also accessed:

*The housing commission do the repairs. (Workshop participant)*

*The housing blokes come with whipper-snippers to do the garden every six months or so. (Workshop participant)*

*I get some extra respite through Mental Health Services, it's worked out really well. (Workshop participant)*

*Disability Services got involved when I got ill. (Interview participant)*

*Palliative Care have been great, they give us most of the equipment and they tell us about everything that's available, what we might need. (Interview participant)*

*I get physio as part of this GP care program, It's all covered by Medicare. (Interview participant)*

*Someone organised for people on Community Orders to come and do my garden, they came a few times. (Interview participant)*

## **Non-government support groups**

*The chair came from St Giles. (Interview participant)*

*We used St Giles for overnight respite. (Interview participant)*

*We get to use the gym, that's through the Tasmanian Acquired Brain Injury Service. (Interview participant)*

*Most of our equipment came from the Motor Neuron Association. (Interview participant)*

*They arranged for someone from the Mates program to come and visit me.*  
(Interview participant)

## **Concerns Raised**

One consumer expressed her concern about what she perceived to be a reliance on informal support to supplement HACC services:

*I wonder will wives and daughters in the future be prepared to do things like we do, or will it be down to the government to do it?* (Interview participant)

Some consumers expressed concerns about being exploited by private services:

*When you contact someone to do maintenance through the newspaper, there is no protection. They may do a bad job. I wanted some work done on my roof, but I didn't know if they were going to do a good job or not, they think old women are silly.* (Workshop participant)

Concerns about costs were also raised:

*Private gardening is very expensive ... they say they want you to stay at home but on the pension \$30 is a lot of money.* (Workshop participant)

*My tablets are very expensive, so I don't have much extra money. I spend between \$70 – 90 dollars a month on my medications. These are my expenses; pads are \$12.80, tissues for eye drops, steradents ... my toiletries, toenails \$15 every so often, this year I have to see to my hearing aids and glasses ... I get a cut in taxis and I travel by bus ... the gardener is \$16 a visit.*  
(Interview participant)

People expressed the opinion that those eligible for Department of Veterans Affairs (DVA) funding had easier access to a greater range of services.

*People on a Gold Card, they can get anything anytime they want.* (Interview participant)

Participants in workshops who were DVA eligible confirmed that they had little problems accessing assistance:

*Every month the nurse comes and checks up on me.* (Workshop participant)

*I get help with the cleaning, showering, gardening. Someone comes and takes me shopping and I've got all my equipment through DVA.* (Workshop participant)

*I've never had to wait for anything.* (Workshop participant)

*I know that DVA will pay for me to have a shower every day, so I say that's what I ask for.* (Workshop participant)

Consumers also reported that HACC providers instigated and coordinated access to other services. For example, one participant described how they organised for their bathroom modifications:

*Our coordinator [from a HACC service provider] organised for some sort of government grant, that put \$500 dollars to the renovations and we covered the rest. The people that did it came from [the HACC service]. (Interview participant)*

## **12.2 Discussion of the use of other services**

The usage of a wide range of services in varying combinations demonstrates the interconnectedness of HACC with many other services. Combinations varied, the most common was a use of Aged Care Respite, and also private gardeners, cleaners, meal delivery and transport. In some instances HACC service providers coordinated the use of other services, to complement and enhance care provision. However, some groups provided similar, but alternate, services to HACC funded groups.

There were concerns that informal services may not be as accessible in the future as young women grow older and are less inclined to be stay-at-home carers, for example daughters and daughters-in-law. Concerns about using private services were also voiced, in particular, the fear of exploitation by private operators and the high financial costs of private services.

Amongst workshop groups in particular, the differences between services provided to DVA clients and HACC clients was evident. These included the perception that DVA services were more readily available and more easily accessed by those who were eligible.

### **12.2.1 Implications for the HACC Program: Use of Other Services**

Implications for the HACC Program are threefold. Firstly, the continued use of informal assistance to complement, or meet the gaps in HACC service provision is not guaranteed. "Analysis of the likely availability of primary carers over the next few years indicates that, on the basis of demographic changes alone, the ratio of primary carers to persons with a severe or profound core activity limitation is expected to fall...despite a projected (27%) increase in the absolute number of primary carers" (AIHW, *Australian Welfare*, 158). A decrease in the availability of informal care correlates with a rise in demand for formal

care: “For people with relatively few care needs, lower availability of informal care may result in their accessing formal care services earlier than is currently the case” (AIHW, Australian Welfare 158). Consequently, an increased demand for HACC services is projected.

Secondly, HACC consumers fear exploitation by private operators. Questions arise about the HACC Program’s obligation to protect its target group from unscrupulous profiteers, and if obligated, how best to do so? In addition, the expense of private services may impact on HACC consumers’ ability to live safely at home. Addressing issues of information provision and accessibility to HACC services to improve entry into HACC may lessen the reliance on other services. Similarly, holistic assessment processes assist to protect the vulnerable by determining whether the use of private services is creating financial hardship and if their replacement by HACC services is more appropriate.

The planned expansion of private health insurance cover to include community health services, coupled with an increase in the availability of privately owned, for-profit community care providers in Australia, requires that the HACC Program consider its relationship with the private sector. For example, at a recent community care conference, care providers were asked to consider if they thought the guiding principles of care were in contradiction with those that guide the market. Furthermore, the HACC Program has a role in ensuring that members of the HACC target group who do not have the privilege of choosing a user-pays private service still receive equal quality of care.

Thirdly, community care provision by the large range of government and non-government operators is largely uncoordinated and this contributes to the general confusion amongst consumers about services. In addition, some services provide legitimate alternatives to stretched HACC services, for example, the GP Enhanced Primary Care Program. There is a need to explore options of how best to coordinate these programs to ensure resources are allocated appropriately. The Way Forward aims to “jointly identify opportunities to better coordinate planning between the HACC program and other relevant programs” (action area 1.6). This research provides an indication of which programs in Tasmania are relevant to include in efforts to improve coordination. Specifically, these are informal supports, private gardeners and cleaners, DVA, palliative care, the community orders scheme, Disability Services, Mental Health Services and injury and illness support groups.

## 12.3 Recommendations: Use of Other Services

To facilitate improved coordination between HACC and other services, TasCOSS make the following recommendations:

### Recommendation 4

That the information strategy accommodate the broad scope of the Program, the relationship between HACC and other services and the diverse ways the target group seeks information, by providing information to and through a variety of organisations including:

- Carelink
- community health centres,
- cultural community centres,
- Centrelink,
- Department of Veteran Affairs,
- Disability Services,
- GPs,
- HACC service providers,
- hospitals,
- injury and illness specific support groups,
- local government organisations,
- Mental Health Services,
- multi-purpose centres,
- Service Tasmania, and
- the Aged Care Assessment Team.

(This recommendation also applies to section 7.3)

### Recommendation 7

That HACC assessors:

- conduct collaborative, holistic, consumer-centred assessments;
- liaise with service provider employees, GPs, case managers, ACAT and others involved in the care of the consumer; and
- act as referral agents to relevant organisations within and beyond the HACC Program.

(This recommendation also applies to sections 8.3 and 11.3)

## 13. Concluding comments and indications for future research

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The HACC Program is currently utilised by a large range of people in many diverse ways. Demands on the community sector are projected to increase in response to an ageing population, declining workforce and decreasing numbers of informal carers. Owing to its key position in community care, the HACC Program is not only being called upon to accommodate these population changes, but also to respond to pressures from hospitals and residential care centres to prevent unnecessary hospitalisation and premature entry into residential care.

The themes that have emerged from this research demonstrate that improvements to intake, assessment and referral processes are not only desirable, but also achievable. The recommendations for improvements are underpinned by the principles of health promotion and positive ageing. That is, they enable the HACC Program to enhance consumer wellbeing, promote and facilitate independence and enable continued community involvement for the target group.

The data obtained in this research highlights a number of areas for further investigation. In addition, information from consumers that was not relevant to the topic, but emerged during workshops and interviews, has been considered in the formation of suggestions for future research. So too have current debates about community care service delivery.

### **Suggestions for future research**

**Vulnerability of HACC consumers.** During consultations, a number of consumers voiced concerns about experiences of poor care from a number of sources. Further research is needed to investigate HACC consumers' experiences of poor care and to explore the relationships between poor care and vulnerability and isolation. Such research could contribute to the improvement of the quality of services delivered by the HACC Program and also to the broader discourse on elder abuse in the community.

**Carers and the HACC Program.** During consultations, consumers raised issues that were specific to the experiences of carers. Further research is needed to investigate the experiences of carers within the HACC Program to reveal their particular needs and concerns.

**Coordination between HACC and other services.** Consumers indicated a high level of use of non-HACC services, in conjunction with HACC services. Further research is needed to investigate the gaps and overlaps in service delivery and to identify possible means for improving coordination between HACC and other community care services.

**Growth of for-profit, private community care providers.** Concerns raised by consumers about exploitation by private operators, coupled with a projected growth in private, for-profit service providers indicate a need for further research into the impact on HACC consumers of the privatisation and commercialisation of community care.

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## 15. Appendices

### Appendix A: Demographic data

#### Demographic Profile of Survey Participants

Variable	Category	Responses as percentage of total	MDS 2004-05 Reported Data as Percentage
Age	0-65	29.8	25.6
	65+	70.2	74.4
Gender	Male	26.8	33.2
	Female	73.2	66.8
Main language spoken at home not English	Yes	4.6	3.2
	No	95.4	96.8
Indigenous	Yes	3.8	1.6
	No	96.2	98.4

Table One. Demographic profile of survey participants in relation to MDS data

The location of survey participants was recorded as North, North West and South, of which there are no direct HACC Minimum Data Set equivalents. However, this data was matched to Tasmanian population statistics as follows:

Location	Responses by percentage of total	Tasmanian population by percentage of total
North	45.9	28.7
South	37.6	48.4
North West	16.5	22.9

Table Two. Location of survey participants in relation to overall population

#### Demographic Profile of Workshop and Interview Participants

Variable	Category	Participants by percentage of total	MDS 2004-05 Tasmanian Data as Percentage
Age	0-65	33.3	25.6
	65+	66.6	74.4
Gender	Male	37.1	33.2
	Female	62.9	66.8
Main language spoken at home not English	Yes	10	3.2
	No	90	96.8
Indigenous	Yes	6	1.6
	No	94	98.4
Location	Inner Regional	55	59.8
	Outer Regional	39	37.1
	Remote	6	2.4
	Very Remote	0	0.7

Table Three. Demographic profile of workshop and interview participants in relation to MDS data

## Appendix B

### SURVEY OF PEOPLE WHO RECEIVE HOME AND COMMUNITY CARE (HACC) SERVICES

If you are a frail older person, a person with a disability or a carer you may be receiving help from the Home and Community Care Program (HACC) with housework, bathing, transport, food delivery, home nursing, home maintenance or help with shopping.

We would like to know about your experience of receiving these HACC services. By filling out this survey you will be helping us to plan for the future.

If you could take 10 minutes to fill out this form it will help us to plan better services for the future. The information that you provide is anonymous – you do not have to put your name on it.

*Please complete this survey and place it in the envelope provided. You do not need to put a stamp on it. It will be opened and collated by an independent person who is not a service provider.*

PLEASE RETURN THE SURVEY BY November 3<sup>rd</sup> 2005

The HACC consumer survey 2005 C/- Community Focus GPO Box 2146 Hobart 7001
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#### Section one: The services you receive

1. Which of these Home and Community Care services have you used over the last year?  
*Please tick as many boxes as apply to you*

- housework help (e.g. cleaning, washing)
- personal care (e.g. help with bathing or dressing)
- transport assistance
- home maintenance/modification
- food delivery (e.g. Meals on Wheels)
- home nursing
- other health services (e.g. physiotherapy, podiatry, occupational therapy)
- help with shopping, banking, paying bills
- day centre/recreation programs
- advocacy services
- counselling or information
- respite
- help with equipment
- carer support
- Other Home and Community Care service: please describe:  
.....

.....  
.....  
2. How did you find out about these Home and Community Care Services (HACC)? *Please tick as many as apply to you*

- my family or friends
- my doctor
- my carer
- a community health nurse
- a community group/organisation
- The Aged Care Assessment Team (ACAT)
- a community health centre/multi-purpose centre
- pamphlets/booklets
- newspaper advertisements
- the Internet
- Commonwealth CareLink Service
- Local Council
- Government Department
- other method : please describe:.....  
.....  
.....

3. How was your need for a service 'assessed'?

- I talked to someone over the telephone (e.g. the people who provide my services)
- someone came to visit me at home (e.g. a community health nurse)
- I went to a service to see a health professional (e.g. doctor, community health centre)
- other: please describe:  
.....

4. How long did you wait for your situation to be 'assessed'?

- less than a week
- 1-4 weeks
- 1-3 months
- longer than 3 months

5. Once you had been told that you would get a HACC service how long did you wait for it to begin?

- less than a week
- 1-4 weeks
- 1-3 months
- longer than 3 months

6. How many times did you have to explain your situation to health professionals *before* you received a Home and Community Care Service?

- only the once
- twice
- three times or more

7. Since you have been receiving this service has anyone reviewed your situation with you by coming to visit or talking to you over the phone? *Please tick one box*

- yes
- no

8. Would you say that your situation has changed since the service began? *Please tick one box.*

- Yes
- No

If yes how has your situation changed?

.....

.....

.....

.....

**Section two: Some information about you**

We need to ask a few questions about you so we can make the best use of the results of this survey. The information is anonymous so we do not know who you are.

9. Which one of the following best describes you:

*Please tick one box*

- a frail elderly person
- an older person with a disability (e.g. over 55 years)
- a younger person with a disability (e.g. under 55 years)
- a Carer

10. What is your age group? *Please tick one box*

- under 25 years
- 25-44
- 45-54
- 55-64
- 65-74
- 75+

11. Your gender *Please tick one box*

- Male
- Female

12. Which area of the State do you live in? *Please tick one box*

- north
- south
- north-west

**13. Are you:      *Please tick one box***

- of Aboriginal or Torres Strait Islander origin?
- a person whose first language is *not* English?
- neither of the above?

**14. Do you live:      *Please tick one box***

- alone
- with family
- with other people.

THANK YOU FOR PROVIDING YOUR IDEAS. THIS WILL HELP US PLAN FOR THE FUTURE.

For further information about this survey please contact Janine Combes, Consultant, Community Focus: phone 62249579 or email [janine@communityfocus.com.au](mailto:janine@communityfocus.com.au)

## Appendix C.

### Handout of examples of HACC Services, for workshops and interviews.

Service	Examples
Domestic Assistance	Cleaning, ironing, home help, help with shopping, help paying bills.
Personal Care	showering, help with dressing, shaving, meal preparation
Nursing Care	wound care (dressings), pills, personal care.
Respite Care	Relief for carers at a centre or at home.
Allied Health	physio, podiatry, speech therapy, OT
Home Maintenance	lawn mowing, light bulbs, drippy taps.
Home Modification	Ramps, Rails.
Equipment	Loaned shower chairs etc
Case Management	COPS, to coordinate care.
Advocacy	
Meals on Wheels	
Day centres	
Transport	Not the MTT or Taxis
Continence scheme	Pads, catheters

## Appendix D.

### Workshop Prompts

How did you hear about Services?  
How did you contact them?  
What was it like to contact services?  
How were you assessed?  
When were you assessed?  
What is it like to be assessed?  
When did the service start after that?  
What was it like to wait?  
Have you been referred on to other services?  
What was it like to be referred?  
Any ideas for doing things differently?

## Appendix E.

### HACC Service Use by random selection of 15 Sample Interview Participants.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Domestic Assistance	X	X	X	X	X	X		X	X	X	X	X	X	X	X
Personal Care		X	X		X	X	X	X		X	X	X	X	X	X
Nursing Care	X	X	X		X	X			X		X		X	X	X
Day centre Respite				X	X	X	X	X		X	X			X	
Allied Health	X	X	X	X	X	X	X	X			X	X	X	X	X
Home Maintenance	X	X						X	X			X	X	X	X
Home Modification		X	X	X		X	X	X	X		X	X	X		X
Spring Cleaning	X					X									X
Equipment	X	X	X	X		X			X	X	X	X	X	X	X
Case Management		X					X			X	X		X	X	
Meals on wheels			X									X	X		
Transport					X	X		X			X		X		
Advocacy			X	X	X					X	X				X
Counselling									X						
Continence Scheme		X			X	X				X		X			X

