

Home and Community Care Consumer Consultation Project

Annual Report 2004

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INTRODUCTION

This is the third annual report of the TasCOSS Home and Community Care (HACC) Consumer Consultation Project, conducted with funding made available by the Tasmanian Department of Health and Human Services.

The HACC program has, since its inception in 1985, sought to provide a range of support services that will minimise the inappropriate placement of frail aged or younger people with a disability in institutional care settings. People of any age can be eligible for HACC services, providing that they:

- live in the community
- have difficulty in performing everyday tasks without help because of a disability, and
- may require admission to long term residential care without assistance from HACC services

HACC also assists carers of the above.

The HACC Consumer Consultation Project aims to consult with HACC consumers and potential HACC consumers across the state in order to provide a vehicle for consumer input to the HACC annual planning process and add to the representation of this group in social policy development and other relevant platforms. The broader aim is to facilitate consumer participation in decisions related to community care service delivery and development, which will in turn encourage a responsive and progressive service system. The rationale underpinning the Project is that consumer participation is an ethical and democratic right that leads to more appropriate, accessible and effective health services.

The Report attempts to give voice to HACC consumers (and prospective consumers) by fully and accurately relaying their comments and concerns and by involving consumer peak organisations in the planning and oversight of the consultation process. The Report offers recommendations on how HACC services may be improved and/or better targeted. We anticipate that, as with earlier reports, these recommendations will be given appropriate consideration in the development of funding priorities for expected HACC growth funds.

It was not the intent of the project to conduct a state-wide comparative analysis of consumers' needs. No inferences should be drawn about the relative needs of any one community compared to others examined during the consultation. Rather, our goal was to highlight concerns expressed by consumers in the municipalities and areas that were consulted.

The findings of this year's Project consultations need to be assessed within a context of significant changes occurring within the community care sector,

at least prospectively. The Australian Government has signalled its intention to change important features of the broad community care sector as part of the renegotiation of the Commonwealth-State HACC Agreement. A report released in March 2003 by the then Minister for Ageing, Kevin Andrews — A New Strategy for Community Care Consultation Paper — outlined a series of proposed reforms. These primarily related to inconsistencies and complexities in the community care system, and issues of access for consumers. It is not as yet clear what specific implications this review process will have for HACC services in Tasmania.

Similarly, it is not yet apparent how the HACC target group will be affected by changes arising from the Australian Government's responses to the recent review of pricing arrangements in residential aged care (Hogan, 2004). The Hogan Report raised many issues relating to the increasing demands across the service system. It acknowledged the important role of community care within the wider aged care system, but also pointed to the ineffectiveness of what it described as a fragmented service system. The Report stated, "there appears to be a preference for older people to remain in their homes supported by formal services. In addition there are currently four in every hundred Australians who receive aged care services at home ... primarily through the HACC program." (Hogan, 2004, p23)

For Hogan, "one of the most significant issues for consideration in the delivery of aged care is the interface between Australian Government, state and local government programs — including the disability-aged care interface. The effective coordination of health and acute care services with community care, rehabilitation, palliative care and residential aged care is essential for the delivery of a quality aged care service." (Hogan, 2004, p29)

The next financial year will see the Consumer Consultation Project target those groups that were under-represented in this year's consultations — younger people with disabilities — and those who were not represented at all: culturally and linguistically diverse communities.

A rural and regional focus will remain to enable regions not previously consulted (such as the West Coast and Flinders Island) to participate in these consultations. The more specific focus of personal care service provision will be taken forward and consumer consultation strategies will be further developed.

TasCOSS is grateful for the enthusiastic participation of the HACC consumers who attended meetings and completed questionnaires, and for the efforts of HACC service-providing organisations and municipal councils who assisted in making the consultations possible. Once again, the input of peak consumer organisations involved in the Project reference group has significantly enriched the Project and we thank them for their commitment and wisdom.

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EXECUTIVE SUMMARY

The HACC Consumer Consultation Project has focused on the following areas over the past twelve months:

- Dementia
- Caring for consumers with dementia
- Kentish Municipality
- Derwent Valley Municipality
- Glamorgan/Spring Bay Municipality.

Consultations were conducted in November 2003 on the issues surrounding living with dementia in the community and caring for someone with dementia. Thirty-four consumers participated either through two focus groups in the northwest and south of the state or via a survey distributed by the Alzheimers Association.

During the months of March and April 2004, the project has focused on consulting in the three municipalities of Kentish, Derwent Valley and Glamorgan/Spring Bay.

Eight public meetings were conducted by the Project Officer and surveys distributed across each region. In total, one hundred and twenty-three consumers were consulted – seventy-three attended public meetings and fifty consumers returned surveys.

The focus of the consultations in these regions was to ascertain, from the consumer viewpoint, gaps in service provision, the quality of service provision and usage of services. These consultations were also an opportunity for consumers to voice any major concerns around the topic of living independently in their communities.

A summary of the information provided by consumers has been separated in three ways:

1. Common themes noted across the three municipalities;
2. Themes noted on an area-specific basis; and
3. Information gleaned specifically from the dementia focus groups and surveys.

All of the issues listed were considered a priority by the consumers and have not been listed according to level of importance.

In response to the issues raised, recommendations follow under the relevant headings.

Common themes across municipalities

Community Transport

A large majority of consumers raised the availability and flexibility of Community Transport as a significant issue, particularly as it is often necessary for them to access health services outside of their towns.

This applies to both the public and private sector transport for regional areas. Participants cited access to any form of appropriate transport including wheelchair accessible vehicles, a challenge, due to the absence of services or limited operating times.

In many cases the community vehicles schedule necessitated the need to spend the whole day out. This can be a barrier for many consumers who are frail or unwell. Another barrier raised by consumers was that community vehicles were often booked well in advance and this knowledge prevented consumers endeavouring to access the service. Concerns were also raised about the expectations placed on volunteer drivers and the minimal amount of support provided to these volunteers.

A Department of Infrastructure, Energy and Resources (DIER) report on the state-wide availability of wheelchair accessible vehicles across sectors is currently being completed. This report will provide the information needed for the public and private sectors to develop a collaborative action plan to address consumer need.

The recent review of Community Transport in Tasmania generated a comprehensive list of recommendations relating to the governance, strategic and operational dimensions of these services. The issues raised in the Consumer Consultation Project are consistent with the Review's conclusions, especially with respect to access, coordination and resourcing of services and the management of volunteers.

Domestic assistance

There were frequent comments from consumers indicating that the amount of domestic assistance was insufficient to meet their needs. They generally felt that once a fortnight for one hour did not cover basic tasks well and that workers had too much to do in that time. The other consistent comment was the inability of the workers to provide such assistance as pegging out of washing, and changing bed linen, due to time and work constraints.

The Home Help/Maintenance review's findings have not yet been released which limits any reference at this point in time apart from the expressed consumer need that current standards and service allocations aren't meeting their needs.

Home and garden maintenance

Access to home and garden maintenance was consistently raised as an issue. These services were considered to be of primary importance in staying independent in their own home. Consumers stated their diminishing ability to do odd jobs at home was a concern particularly anything that required physical flexibility and good balance. Although a few people at the meetings had accessed some home maintenance services many had not heard of the service. A few participants from Bicheno and Sheffield commented that response time to requests for service was lengthy (up to 5 or 6 weeks) and therefore didn't meet their immediate needs.

Spring cleaning

Most consumers considered the availability of spring-cleaning inside and outside of the home to be a priority and felt that gaining access to this service annually or biannually would promote a healthier home environment and significantly aid their independence.

As spring-cleaning is privately contracted the increased availability to consumers will come some way to addressing the limitation of tasks that current HACC funded domestic assistance programs now experience.

Information

A majority of consumers cited access to information about what services were available to them and how to access these services as a major issue.

This applied to those currently utilizing HACC services and potential HACC consumers. This lack of information or the knowledge on how to access the required information can significantly disadvantage consumers and affect any true picture forming of unmet need.

Podiatry

Consistently consumers complained of the high demand for podiatry services, which has resulted in long waiting lists in some regions. Some towns received three monthly visits by a podiatrist and others needed either to travel, be put on waiting lists or pay for a private provider where available. Generally, services were deemed to be insufficient to meet consumer needs. Podiatry services are funded by HACC, the Regional Health Scheme and the private sector, and in addition to limited resources, issues around access may be linked to the complexities created by a multitude of funding sources.

The Foot-care Assistants Program has recently been funded by HACC to address shortfalls in the availability of Podiatry services across the State. The assistants work under the supervision of a Podiatrist who screens any referrals. The assistants are then able to do basic foot-care and give advice on hygiene. In reference to the municipalities consulted, the program has recently begun in the Derwent Valley and will shortly commence in the

North West region extending into the Kentish Municipality. The program is still under consideration for the Glamorgan/Spring Bay area.

Issues/themes particular to a town or municipality

The consumers at the Wilmot meeting felt that they were particularly disadvantaged in the area of access to community nursing and any follow-up services required (either post-discharge from hospital or from medical procedures of a non-acute nature).

Home visits as a follow up service after medical procedures, particularly for the elderly, were seen as essential, affecting their ability and confidence in the home. According to those Wilmot residents attending the meeting, the lack of skilled home care has resulted in unnecessary suffering, particularly for people with terminal illnesses.

The recounting of stories of hospital discharges of the elderly at night, on Fridays and without follow-up service provision in the home is particularly concerning. This issue was raised by Wilmot residents in conjunction with the perceived lack of community nursing, however has consistently been raised by HACC service providers in their forums and as part of consultation process of the Review into Key Issues for Private and Public Hospitals during March and April 2004.

The Kentish participants also requested the availability of crisis help, for example if a consumer became ill or temporarily disabled and was unable to perform their normal activities of daily living, particularly for those without family support. This was linked to a perception that local services would respond more quickly to requests for services generally and provide a more immediate service.

Wheelchair access to community facilities in the Derwent Valley and the lack of wheelchair accessible transport was put forward as a major inhibitor of community participation for younger people with disabilities. Home modification was also cited as an issue for the frail and younger disabled to prevent falls and increase independence.

In the Glamorgan/Spring Bay Municipality participants across the region felt more could be done to provide social support to the isolated elderly from supported shopping to organized day-care and eating groups.

Consumers at the meetings raised the accessibility of Red Cross Alarms to the frail-aged that live alone. According to the consumer participants in Glamorgan/Spring Bay, the purchase and set-up fees together with on-going rental payments are considered prohibitive to many pensioners.

Centrelink has just recently recognized the need for consumers who require a Red Cross Alarm to be able to apply for long-term payments through its Centrepay program. Although this will assist consumers, a significant debt will still be incurred.

Bicheno participants in particular felt that they were unclear about service boundaries and had conflicting stories on perceived geographical service restrictions.

Dementia

There is an on-going issue with clients and their carers taking up residential and day-care respite options because of their concerns about the quality of the care and reluctance of the person with dementia to go to an unfamiliar environment.

There are many related aspects to the difficulties faced by consumers accepting respite services. One part of problem concerns the intake and assessment processes of various services. It appears that there needs to be stronger attention paid to the transition process between home and respite care, both residential and day care. The key elements to this issue are; minimizing the numbers of persons involved by eliminating multiple assessments and ensuring those key workers are appropriately trained in dementia-specific care.

Some carers reported the lack of flexibility in respite hours, for example being offered smaller periods of time by service providers rather than a full day out, limiting their ability to attend such social pursuits as lawn bowls.

The level and flexibility of respite services can significantly affect the consumers well being. If the level of respite provided is only sufficient to complete domestic duties then reducing social isolation will be difficult to achieve. Correspondingly if some services are unable to provide the flexibility of respite hours requested by carers to attend social functions then the quality of life for these consumers is reduced.

Consumers requested an increase in the provision of resources for a diversity of support workers for activities of a physical and/or outdoor nature (fishing, bushwalking, gardening), music and art therapy.

The more meaningful and creative pursuits offered to consumers will not only increase the uptake of services but by enhancing the participation of consumers in regular activities their ability to remain independently living will be significantly increased.

To support and validate the spousal relationship consumers called for an increase of community based services where partners can participate together, including residential care facilities where partners can reside with their spouse and have support on-site.

Recommendations

Community Transport

1.1 The HACC unit continue to adequately resource the implementation of the recommendations in the Community Transport Review. In particular,

1.1.1 that a full needs analysis be conducted, with such an analysis exploring alternative transport options; and

1.1.2 that a formal training package be developed for volunteers (Farley Consulting Group, 2002, pp12, 17). This would include a clarification of the role of volunteer drivers and the limitations of their tasks to ensure appropriate stakeholder expectations. To achieve this outcome, a collaboration between Volunteering Tasmania, Community Transport and the HACC unit would need to occur.

Domestic assistance/home and garden maintenance/spring cleaning

2.1 That the findings of the Home Help and Maintenance review be released to all stakeholders for their information.

2.2 That the HACC unit in conjunction with service providers consider a standard allocation of either weekly domestic assistance or ninety minutes a fortnight per consumer according to need as a minimum standard.

2.3 That the HACC unit in conjunction with service providers improve access to spring cleaning of home and garden and home maintenance to the HACC consumers in the municipalities consulted, by targeting resources and ensuring adequate service promotion.

Information and access

3.1 When planning for the Community Care Review's Early Intervention and Information Tier (Andrews, 2003, p13) occurs that the HACC unit consider an information and access service that is:

(a) Located in each municipality at a central venue, independent of service provision such as, the local council offices or Service Tasmania outlets.

(b) Staffed at least on a regular part-time basis to provide the personal contact needed to ensure that appropriate information is provided.

Podiatry

4.1 That the HACC unit consider a more flexible visiting service for government funded Podiatrists that includes visiting locations where there has been a significant assessed need.

4.2 That the foot-care assistance program is extended to the Glamorgan/Spring Bay municipality where access to service provision is limited.

4.3 The Foot-care assistants program is reviewed in twelve months time to enable an analysis of whether it has been able to reduce waiting lists and unmet need.

Town particulars

5.1 The HACC unit considers a review of funding and service delivery models to isolated regional areas to ascertain if consumer access to service provision can be improved by more appropriate and flexible funding models or other means.

5.1.1 This would include a review of the costings associated with service provision to rural areas including client assessment, travel costs, recruitment processes and the dissemination of information to clients relating to service provision.

In addition this analysis would provide a base to make decisions on which organizations are best placed to provide those services and highlight issues of concern for service development.

5.2 That the HACC unit raise with the appropriate government department the need for hospitals to have a formal discharge protocol for the frail elderly and people with disabilities.

5.2.1 This would require an adequately resourced discharge process including a discharge plan and a policy of no evening or Friday discharges for frail aged or persons with a disability who live alone.

5.3 The HACC unit to consider subsidizing the purchase of Red Cross alarms for at risk consumers who live alone.

5.4 The HACC unit to consider funding social support services for the Glamorgan/Spring Bay municipality.

5.4.1 This could include support to volunteer groups who may want to begin an Eating with Friends group in the area or similar activity.

5.5 The HACC unit to pilot an emergency-in-home support service in the Kentish municipality with a view to extending it across the region.

Dementia

6.1 The HACC unit to consider increasing funding to dementia specific organizations to further develop and facilitate a long term case management model for all consumers with dementia in the community.

6.2 The HACC unit to consider increasing funding to the Memory Support Packages which targets consumers in the early stages of dementia.

6.3 The HACC unit to ensure when targeting funding for respite care that the service providers are able to provide flexible respite options.

6.3.1 That consideration is given when the HACC unit funds respite services that there are sufficient funds to balance the consumers social and domestic needs.

6.4 That services which offer a range of outdoor pursuits, music and art therapy are considered in the next funding round by the HACC unit. This would include programs that also offer activities for couples.

3

Methodology

Project Reference Group

Currently the project has a reference group of consumer peak organizations that meet quarterly or as needed. There are representatives from Tasmanians with Disabilities, Council on the Ageing, Carers Tasmania, Advocacy Tasmania, Migrant Resource Centre, Pensioners Union, Tasmanian Community Advisory Group on Mental Health and the Consumer's Health Forum. The purpose of this group is to:

- Identify issues of concern for relevant consumer groups relating to HACC services.
- Advise project on emerging consumer needs across the state.
- Assist the project officer to target consumers for consultation in relation to identified priorities.
- Provide advice on appropriate mechanisms for eliciting current and prospective consumer views concerning HACC services.

Local area consultations

The three municipalities of Kentish, Derwent Valley and Glamorgan/Spring Bay were chosen for consultations as regional areas not previously consulted and with relatively comparable levels of service provision.

Public meetings were held in eight major towns across the three municipalities. Questionnaires were also distributed from those meetings. These questionnaires replicated the consultation questions and demographic identifiers. Transcriptions of comments offered in the meetings and summaries of the completed questionnaires can be found in Appendix B.

The questions were broad and aimed to identify

- current utilisation of HACC services among participants;
- the service gaps according to the participants' needs and priorities;
- consumer assessments of the quality/responsiveness of service provision; and
- participants' level of awareness of HACC services.

The process involved seeking assistance from local councils to identify appropriate locations and contacts. This facilitated the use of appropriately independent venues with a view to encouraging a broad range of participants, including those currently on the periphery of service provision.

Advertisements were placed in local newsletters, regional newspapers, in doctor's surgeries and via local community service providers. A 1800 number was included in those advertisements for people wishing to speak by phone or request a survey.

Prospective participants were also offered reimbursement of travel costs and respite care. Light refreshments were provided at each meeting.

Participants' comments were transcribed using white boards, butchers paper and a tape recorder, following verbal permission from the participants.

Each session began with a personal introduction, a brief description of the project and its purpose followed by an overview of HACC services (which were listed on the white board), eligibility and fees. The Project Officer then proceeded to ask the group questions which had already been pinned up across the wall (see Appendix B).

The meetings were of a ninety-minute duration with a break for refreshments at a time decided by the group. The break gave an opportunity for participants to mingle and the end of session provided a further opportunity as people completed their data sheets and asked questions on an individual basis.

Dementia Consultations

Focus groups were chosen as a preferable mode of consultation for the specific subject of dementia care.

Two existing support groups were used as the basis for consultations. The first, based in the northwest, comprised of carers of people with dementia. The second, based in the south, comprised of people with dementia.

In addition a broader coverage was sought through a questionnaire distributed via the Alzheimer's Association newsletter.

The two focus groups utilised a similar format. To introduce the session the Project Officer provided background about the project and the last annual report. An 'ice-breaking' exercise encouraged participants to introduce themselves to the group. Questions were then posed to the group, focusing on current support, the impact of dementia and supports needed to assist in daily living. Each participant was asked to complete a simple demographic sheet at the end of the session.

Limitations of the project

The project was restricted this financial year for a number of reasons:

- Change of Project Officer during the consultation period.
- Resource limitations mean that the Project Officer had limited capacity to engage in one-on-one consultations with consumers. In order to access appropriate numbers of consumers, group meetings

were consequently required in order that a substantial number of consumers are involved.

- Other limitations were the small numbers of younger people with disabilities (under 60yrs) who participated in these particular consultations as well as those from culturally and linguistically diverse groups.

It is acknowledged that these groups require diverse consultation strategies. Although an attempt was made to target questionnaire distribution to the younger persons with disabilities via service providers, the small number of returns indicates this was insufficient to significantly increase the participation levels.

Summary of participants

The following chart breaks down the number of participants from each town by the HACC target group.

	Younger persons with a disability	Frail-aged persons	Carers
Dementia participants			
Focus groups		9	8
Surveys	1	7	10
Kentish Municipality			
Wilmot	2	6	3
Sheffield	5	22	3
Railton	1	3	6
Derwent Valley Municipality			
New Norfolk	2	4	1
Maydena	2	11	3
Glamorgan/SpringBay Municipality			
Triabunna	0	17	5
Swansea	0	5	0
Bicheno	2	15	3
Total	17	99	42

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DEMENTIA CONSULTATIONS

Dementia is not a specific disease but an umbrella term used to describe a group of diseases that affect the brain and cause a progressive decline in the ability to remember, to think and to learn. Personality changes may occur. (DHHS, 1999, p5)

The prevalence of dementia is forecast to grow rapidly over the coming decades due to population ageing. In 2002, 162,000 Australians have diagnosed dementia, or 0.8% of the population. By mid-century it is estimated that 580,000 Australians or 2.3% of the population will have diagnosed dementia. (Access Economics, 2003, pp 31-32.)

There are extensive recommendations in these reports aimed at enhancing the ability of the community and aged care sector to meet the increasing burden of this disease. These include the important recognition of the carer's role reflected in flexible 'carer friendly' models of respite care in the community and residential settings and an increase of education, training and emotional support services. Service planning needs to involve all stakeholders and to consider the needs of the increasing number of people with younger onset dementia (particularly alcohol related), cultural and linguistically diverse groups and rural and remote consumers. (DHHS, 1999, p32; Access Economics, 2003, p84)

Southern focus group — Issues raised:

The information was collected from a support group of people who have dementia in the south of the state. Participants comprised nine consumers and one service-provider staff member.

- People with dementia want to be independent for as long as possible, they want to retain their dignity, and they want to be engaged in useful and meaningful activities.
- There are ongoing difficulties in relationships between partners in having to adapt to the changing need created by the progression of memory loss. There is considerable stress on carers but also feelings of guilt and anger on the part of the person with dementia.
- Dealing with feelings of guilt or frustration about adding to the burden or load that the partner has to take up when the person with dementia cannot perform the roles and decision-making that they have traditionally carried out.
- There is a need to have a support network in order for the carer and person with dementia to cope.
- There is a need for some kind of service that can provide practical independent advice on legal matters, real estate/property

evaluations/accommodation options, financial advice, and guardianship/power of attorney advice. That is, a service that is conversant with the particular needs of older people needing to make transitional decisions and don't know where to start, where to go, or who to trust in getting advice on these complex areas.

- The need for meaningful activities being available to people with dementia rather than activities that are simply filling in time.
- The need for activities that promote independence rather than doing things 'for' people.
- There are increasing numbers of younger men with memory loss but who have higher physical activity needs and the necessary support that goes along with being more active. For example, those that want to go fishing but are not able to do so safely without a support person being with them. Often the carer is not able or willing to take on this role.
- There was a general need expressed for more resources for funding of support workers and transport services to assist people in accessing a range of activities eg. Gardening, bushwalking, fishing – where people still have a strong interest in the area but need support in carrying out the activity.
- There is a need for art and music activities or therapy programs.

North-West Focus Group — Carers' Issues

The following information was collected from a carer support group in the North West region comprising 8 carers and 3 staff.

- Being socially isolated due to the role of caring taking up so much time and energy. People related that family and friends stopped coming around and that there were very few people, if anyone at all, to talk to about what was happening for them. The day centre coordinator also strongly corroborated this issue of the social isolation of carers looking after someone with dementia.
- Carers' lives are adapted to take into account the needs of the person they care for. Everything needs to be planned around safety, supervision and particular routines, rather than taking the carer's needs into account.
- The caring role and the availability of respite or services put restraints upon whether sporting interests or leisure activities could be maintained. If service providers cannot be flexible enough to meet the particular needs of a family's situation then the health and wellbeing of that carer is compromised. An example provided was where there was not a service that was available for the amount of hours on one day to care for a person with dementia so that the carer could continue to play in a lawn bowls competition. The service said they

could provide one hour/day for several days but could not provide a block of hours on one day.

- Carers expressed strong feelings of grief and anguish over using respite care for the first time, especially if the person with dementia was resistant to going to respite.
- Carers are very much caught up in the day-to-day needs of the person with dementia but they also have in the back of their minds huge concerns about what the future may hold.
- Current levels of respite mean that carers can 'catch up' on tasks that could not be done when the person they care for is present. There is very little, if any, time available for clubs, hobbies, or interests. For example, if a person with dementia does not sleep well, the carer may use a block of time simply to catch up on sleep or do things that upset the person they care for, e.g., lawn mowing and grocery shopping. This doesn't leave time for personal wellbeing pursuits. Evenings and weekends are difficult for carers as there are no services available.
- Issues around security and duty of care in day centres if clients who live within walking distance can 'escape' home. One carer spoke about the person she cared for, regularly 'returning' home unexpectedly from the day centre that was in close proximity to their home.
- Particular need for counselling services, especially face-to-face services as friends and acquaintances don't really know what it is like to be a carer of someone with dementia. In fact many say that their friends stop calling.
- An issue came up about knowing when a person with dementia is really in pain or has a significant medical issue, as opposed to attention-seeking behaviour. There were several instances where discrepancies were highlighted between the behaviours being exhibited at home and at the day centre. Generally, it appeared that the behaviours were more difficult at home, e.g., hiding things, swearing, and abusive behaviour, making considerable mess in the kitchen.
- Issues of stress and organisation when the carer needs to be hospitalised for surgery.
- It seems from this group that it can take carers many years to recommence activities (e.g., golf, gardening) that they gave up when they first began caring. One carer said she had cared for someone for eleven years before she used respite. Many carers in the group indicated that it took them years of solo caring before they used respite. This was not because everything was fine but more about wanting to be independent and not knowing if a service could possibly look after the person they cared for, who had complex needs.
- Once they find and use quality respite services and return to their interest area they cannot believe how good it feels. The carers indicated that generally they would not be able to continue without

having some personal outlet that allows them to have social interactions and conversations with non-demented people.

- Many carers stated that they first used respite when they had reached crisis point and not to prevent this happening. They also stated how helpful it would have been to have the foresight to utilise these services earlier in their caring role.

Information collected from surveys distributed by Alzheimer's Australia through their newsletter.

Issues raised:

- A need for in-home crisis and emergency respite care.
- Assistance to persuade the person being cared for to attend day-centre respite services.
- An increase in the availability of flexible residential respite.
- An increase in day-care activities that are meaningful to the consumers.
- Access to home maintenance services.
- An increase in the availability of residential services for couples with on-site support.
- An increase of activities where couples can participate together.
- The importance of maintaining a sense of humour.
- The information that services provide need to include the service provision limits to assist consumers with their requests.

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REGIONAL SUMMARIES OF CONSULTATION FINDINGS

Kentish Municipality

The Kentish Municipality has a HACC target population of 510 (Australian Bureau of Statistics, 1998, 1999 and 2002) or 9.2% of the total population in the area. According to HACC Minimum Data Set figures there are a total of 110 reported clients reported for the Kentish region in 2002/03.

In total 58 consumers participated in the Kentish consultations (32 consumers attended meetings and 26 returned questionnaires).

A conservative estimate could propose that if half of the participants were current HACC consumers then approximately one third of reported HACC consumers for this region participated in these consultations.

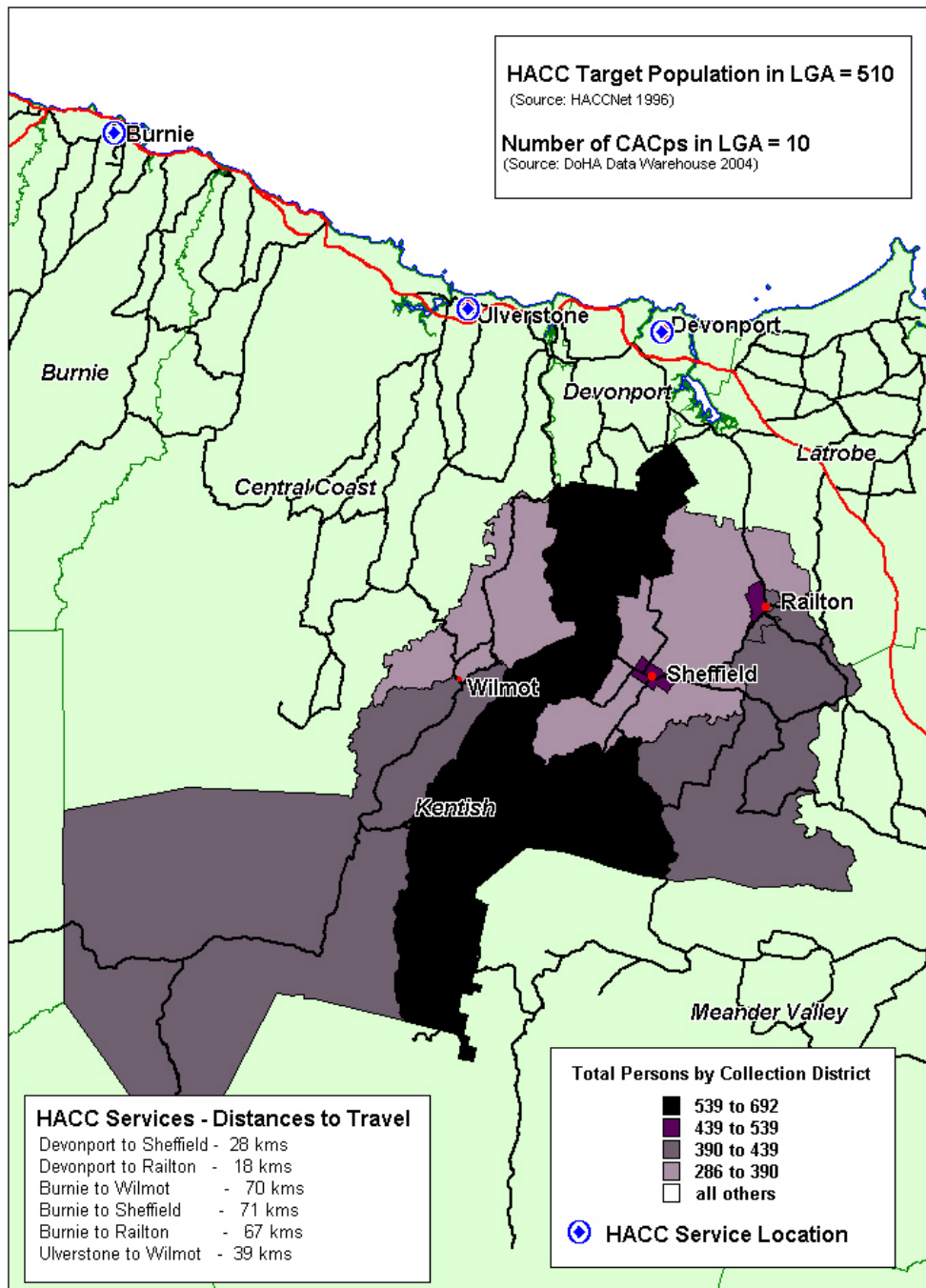
As there aren't any HACC funded services located in the Kentish Municipality the main source of the client numbers data will have been from a number of larger organizations located in Burnie, Ulverstone, or Devonport.

The Commonwealth have provided funding to Tandara Lodge which is located in Sheffield through the Regional Health Scheme, which provides 10 Community Aged Care Packages and a number of visiting allied health services as well as a community bus which travels between the Kentish towns and the relevant major towns or cities of Devonport, Ulverstone, Burnie and Latrobe.

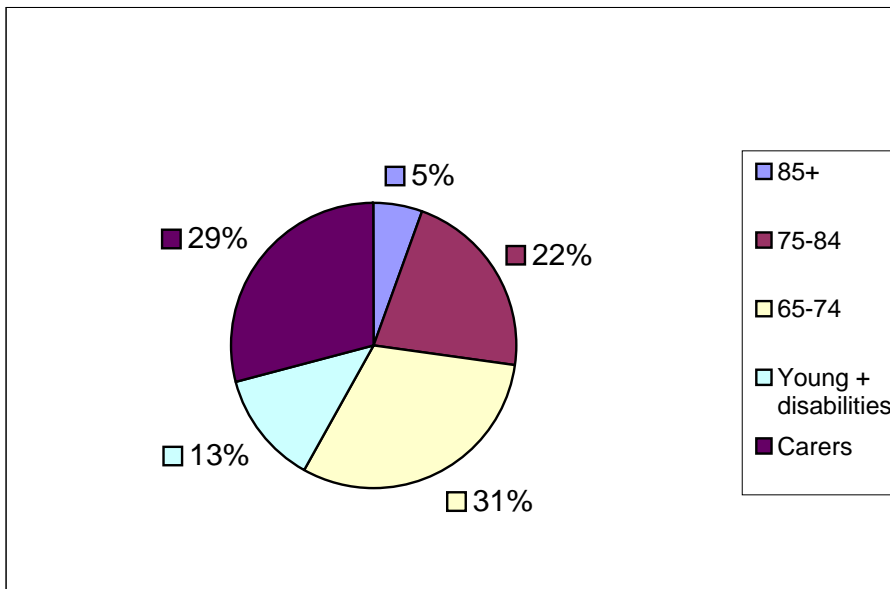
The regional map that follows provides an indication of the distances applying if consumers travel to the coastal towns or cities. For example, a Wilmot consumer may need to travel to Ulverstone for Community Health services or Burnie to have hospital treatment.

Among participants in each of the public meetings there was a general preference for locally based services. This was linked to the assumption that locally based services would decrease service response time and increase access to service provision.

Kentish

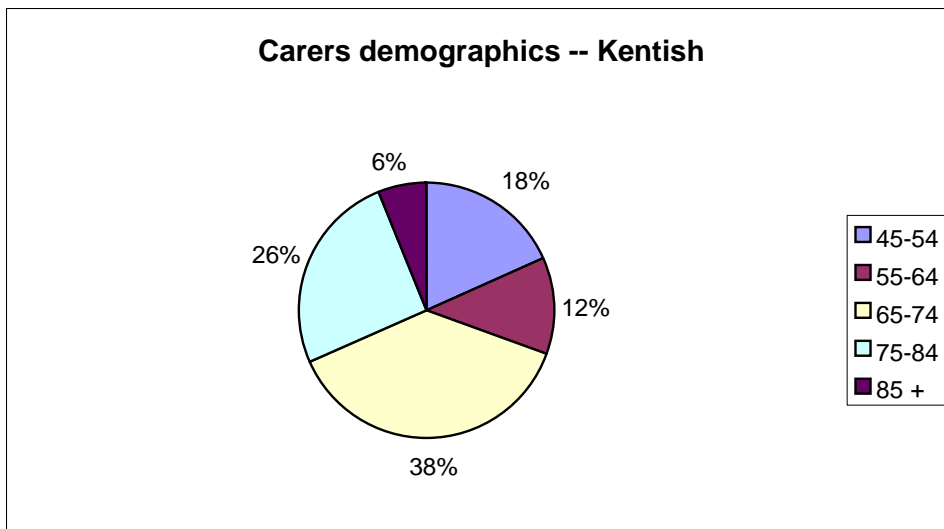


Kentish participants

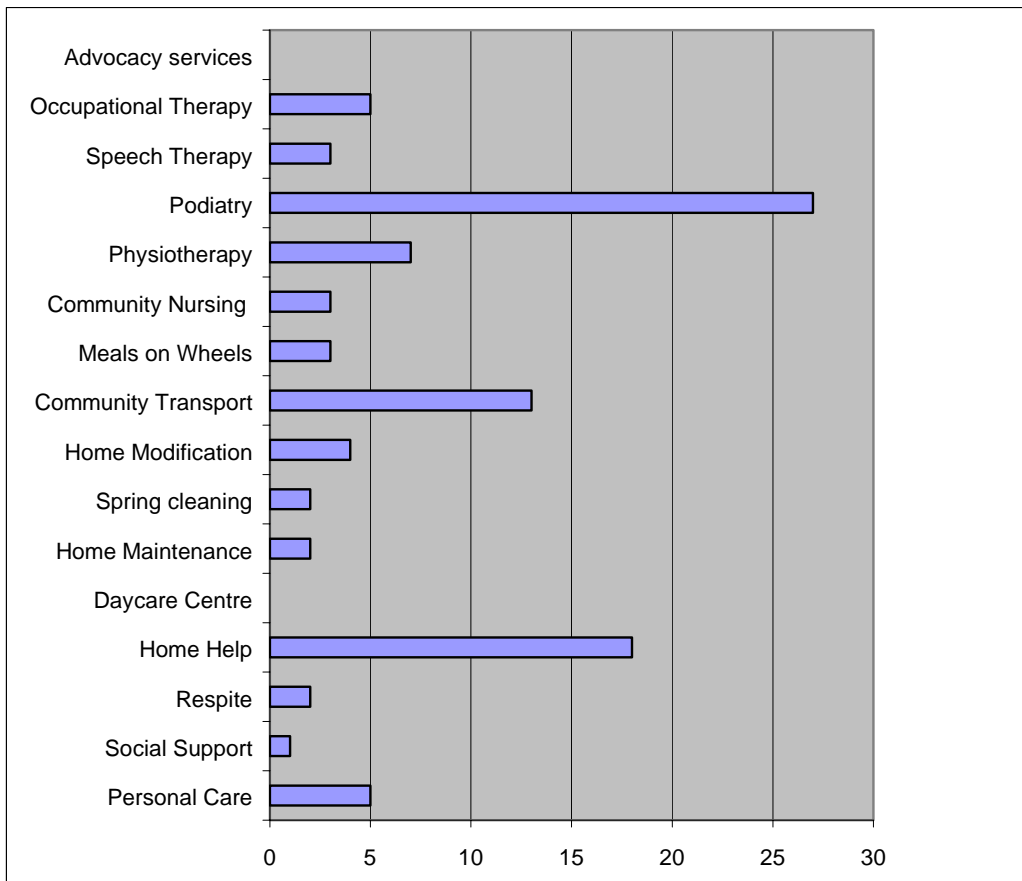


Sixty-two percent of participants over the age of 65 had a disability (excluding carers). Nineteen percent of participants were females over the age of 65 with a disability who lived alone.

Fifty percent of carers were female. Eighteen percent of carers had a disability.



Usage of HACC services by Kentish participants.



NB: Podiatry services offered by Tandara Lodge in Sheffield, also visit Wilmot and Railton and are funded through the Regional Health Service, not HACC as the chart implies.

Wilmot

Main concerns of participants:

- Increased access to Community Nursing.
- Information about the availability of services and how to access them.
- Tandara bus picks up residents in Wilmot twice a week but consumers reported this as insufficient. Consumers who don't drive haven't any other choice of transport besides the high school bus, which is considered inappropriate.
- Consumer reports of discharges from hospital of the elderly without any follow up and at night.
- People in need of palliative care at home not receiving any nursing support.
- Concern at the increasing number of interstate retirees, which may result in increased need for services.
- Consumers would like not to always have to travel to Ulverstone for service delivery.
- That the whole community be informed about availability of existing services by regular local contact from HACC funded services.
- Perceived lack of home maintenance and spring-cleaning services.
- Currently only one home-helper in the area — considered insufficient. Consumers considered the task and time restrictions prohibitive, e.g., the inability to change linen and peg out clothes.
- That three monthly Podiatry service available at Tandara doesn't meet the needs of consumers who require that service.
- Access to assistance with meal preparation or Meals on Wheels.
- Access to a chimney sweep.

Sheffield

Main Concerns:

- Although a few participants were familiar with whom to contact if they had home maintenance needs many were unaware of the availability and emphasised the importance of this service and the current difficulties they faced doing odd jobs.
- An increase in the availability of Home Help generally was discussed as well as calls for a weekly rather than fortnightly service.
- The availability of prompt help in times of crisis.
- Long waiting list for Podiatry services
- The need to attend local appointments was brought up a number of times at the meeting and in the returned surveys as an issue for those

unable to drive. A younger person with a disability cited the lack of affordability and availability of community transport to attend educational courses in major centres.

- Most of the consumers stated they were unaware of how to access services and what types of services were available.
- Response times for service provision from coastal HACC providers deemed too long (up to two weeks).

Railton

Main concerns:

- Access to community or volunteer vehicles for transport not requiring a full day out.
- Perceptions that volunteer drivers using their own vehicles gave a more flexible and appropriate service to consumers, providing they were adequately reimbursed and supported.
- Increase of home help services to weekly, as current fortnight sessions are insufficient to meet needs.
- Replacement of workers on leave.
- Access to personal care services that are able to host transfer clients.
- Access to spring and winter garden rubbish removal when it is most needed.
- Access to spring-cleaning services.
- Quality of service provision particularly in relation to assessment of home modification needs.
- Access to home maintenance services.
- Increase of Podiatry services.
- Knowledge of service availability.

Derwent Valley Municipality

The Derwent Valley municipality has a HACC target population of 893 or 9.2% of the total population for the area (Australian Bureau of Statistics, 1998, 1999 and 2002). According to the Minimum Data Set summary for 2002/03 there were a total of 189 reported clients in the Derwent Valley municipality.

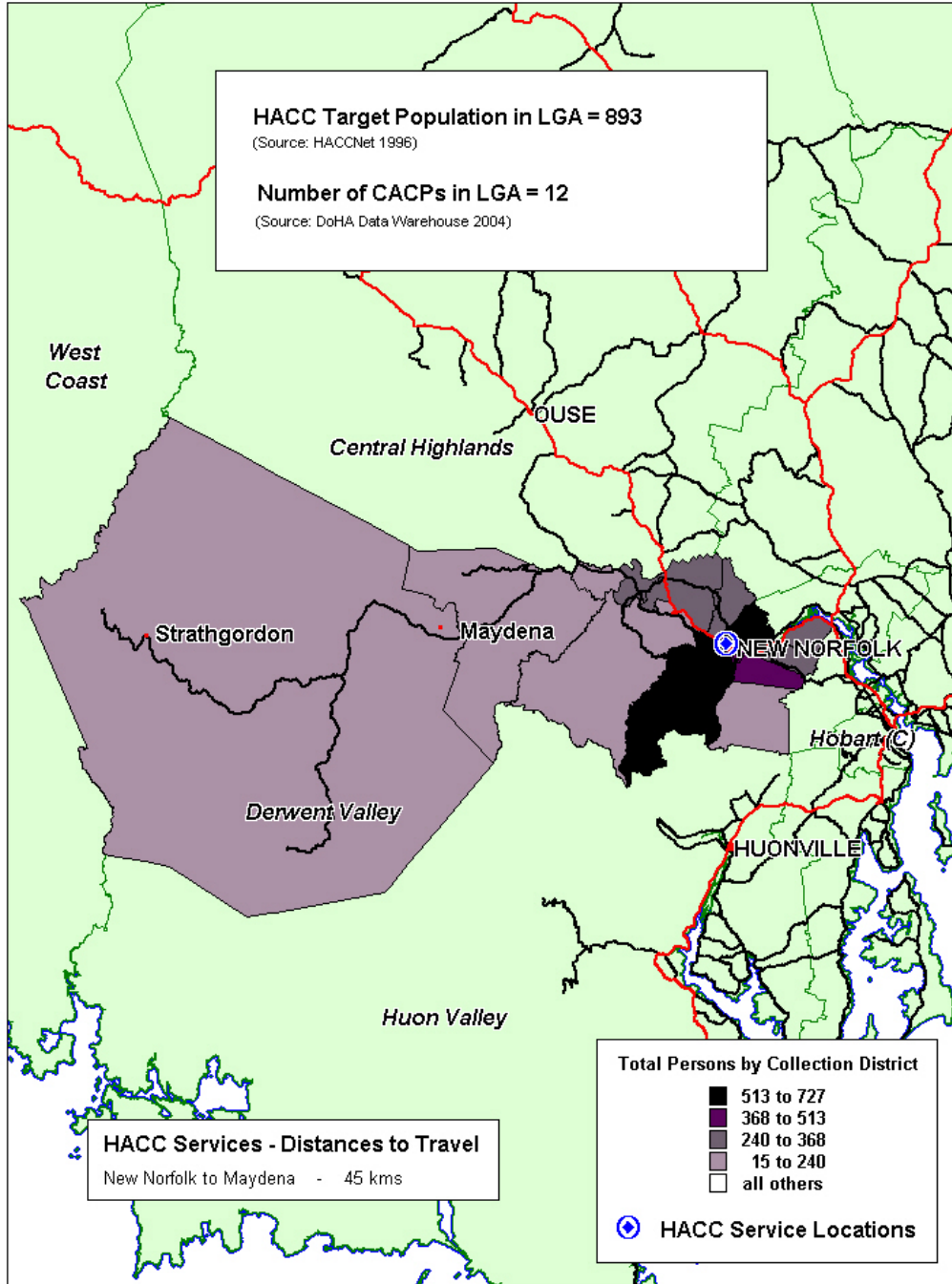
In total 27 consumers participated in the consultations (18 attending public meetings and nine returning questionnaires). Consultations were held in New Norfolk and Maydena. Although the number of participants was a lot lower than expected for New Norfolk, they were relatively high for the much smaller population centre of Maydena.

Transport was identified as a key issue for many participants. There is one community vehicle located at Maydena and otherwise there are only school bus runs to Glenora, Bushy Park and New Norfolk. There are no public transport providers operating in this municipality apart from Hobart Coaches operations between Hobart and New Norfolk. Wheelchair accessible transport is also unavailable.

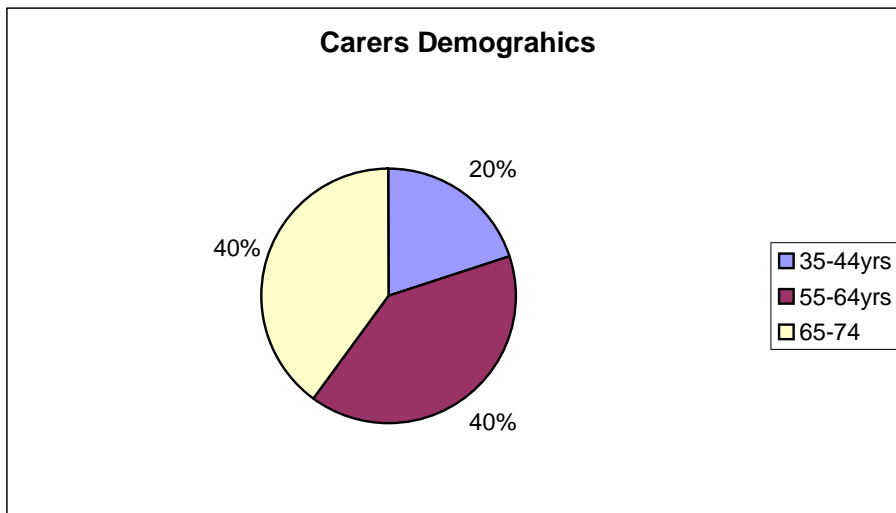
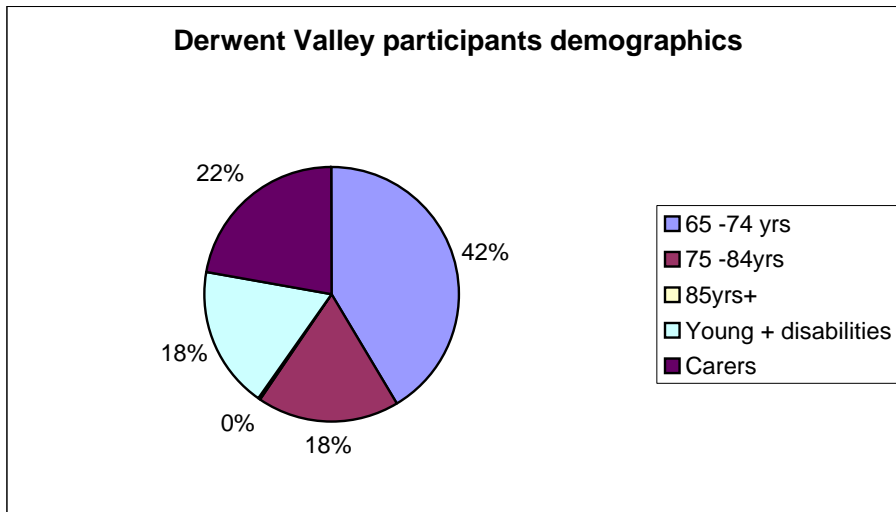
As demonstrated on the map that follows, services are located in the town of New Norfolk and coverage extends across the municipality.

There are 12 Aged Care Packages funded by the Department of Health and Ageing located in the Derwent Valley and Central Highlands. Seven of these packages are located with Corumbene Nursing Home in New Norfolk and three more at Ouse. The remainder are with Community Based Support service located in New Town. This organization extends its service provision across the southern region of Tasmania.

Derwent Valley

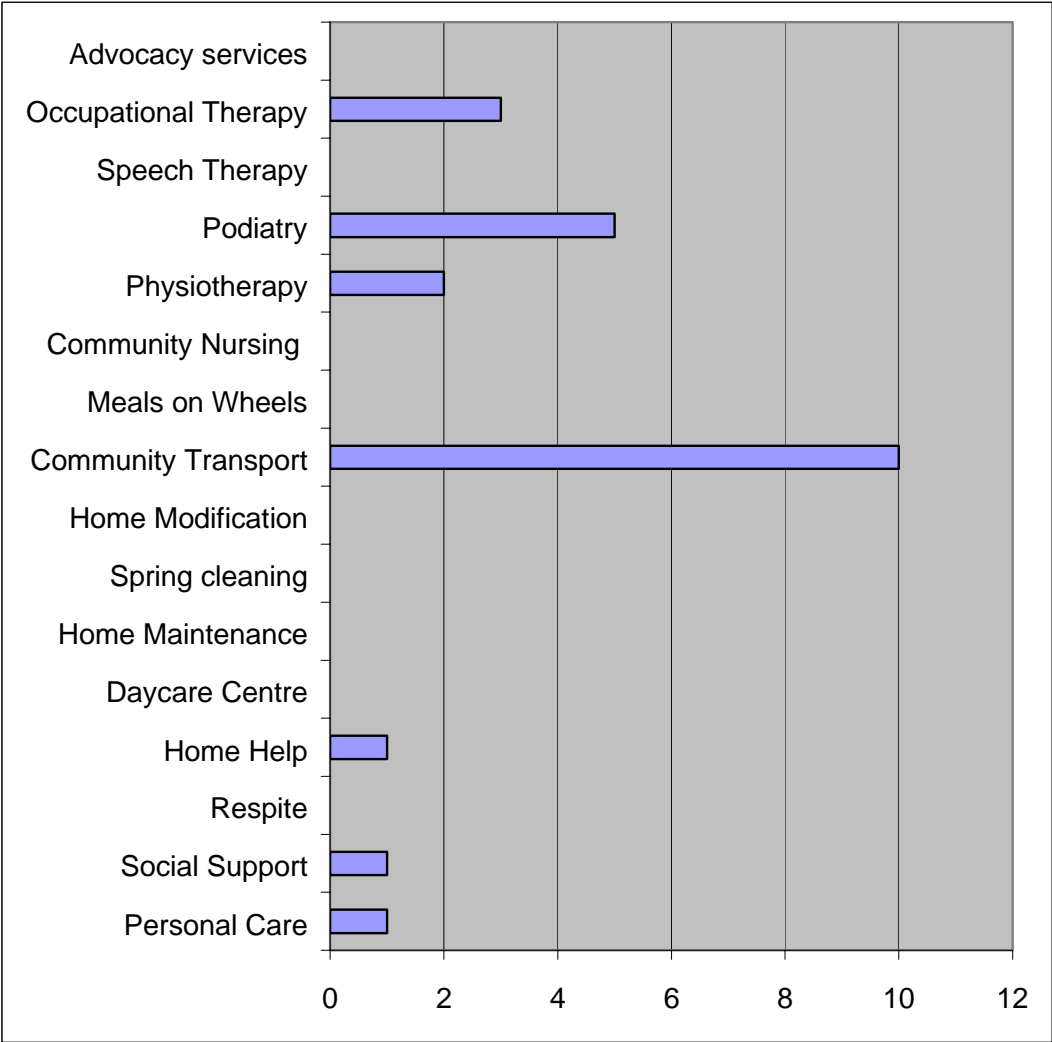


The following charts display the various pertinent aspects of the participants using the HACC target group as a descriptor.



Thirty-eight percent of participants over the age of sixty-five had a disability. (Excluding carers). Seventeen percent of participants were females aged over sixty-five with a disability who lived alone. Thirteen percent of carers had a disability.

Usage of HACC services by Derwent Valley participants.



New Norfolk

Main concerns of participants:

- Access to garden maintenance.
- Easy access to information about services, especially for consumers with literacy barriers.
- Domestic Assistance needs to increase to include changing of linen particularly for those who spend a lot of time in bed.
- Lack of resident general practitioner at local hospital means the hospital is dependent on on-call doctors who are sometimes difficult to access. For one frail-aged participant this meant a late night trip to the Royal Hobart hospital.
- Access to home modification
- Availability of community transport – currently a fortnight's notice is needed. Wheelchair accessible transport to be available to attend appointments.
- Social support needs to be considered as a priority for those who are alone and be available weekly.
- In-home crisis assistance.
- Electric wheelchair access to local shops and public toilets.

Maydena

Main concerns of participants:

- An increase in Community transport – a bus that all can access with wheelchair access would be a preferred option.
- Concerns that school buses lie idle during school hours and that this may be an opportunity to develop regular return trips to New Norfolk.
- Information about services and how to access them.
- Access to home maintenance.
- Access to home modification
- Access to spring-cleaning.
- More outreach services, e.g., a general practitioner visiting once a week would reduce community transport needs and travel time for the elderly.
- Concerns about the long days and distances some volunteer community transport drivers experienced, and about the task responsibilities of some drivers assisting high-need consumers.

Glamorgan/Spring Bay Municipality

The Glamorgan/Spring Bay municipality has a HACC target population of 435 or 10.3% of the total population (Australian Bureau of Statistics, 1988, 1999 and 2002). According to the HACC Minimum Data Set summary for 2002/03 there were 211 reported clients for the region.

In total 48 consumers participated in consultations (twenty-three attending public meetings and twenty-five returning questionnaires). Consultations were held in Triabunna, Swansea and Bicheno. A significantly larger number of participants attended the Bicheno meeting while most of the survey responses came from Triabunna, Orford and Swansea. This may be attributed to a number of factors but the inclement weather for the southern towns meetings may have contributed to the lower attendance.

There are 24 Commonwealth-funded Community Aged Care packages located at May Shaw Nursing Home in Swansea. These are for the frail-aged in need of assistance at home to stay living independently. These packages are for the entire municipality.

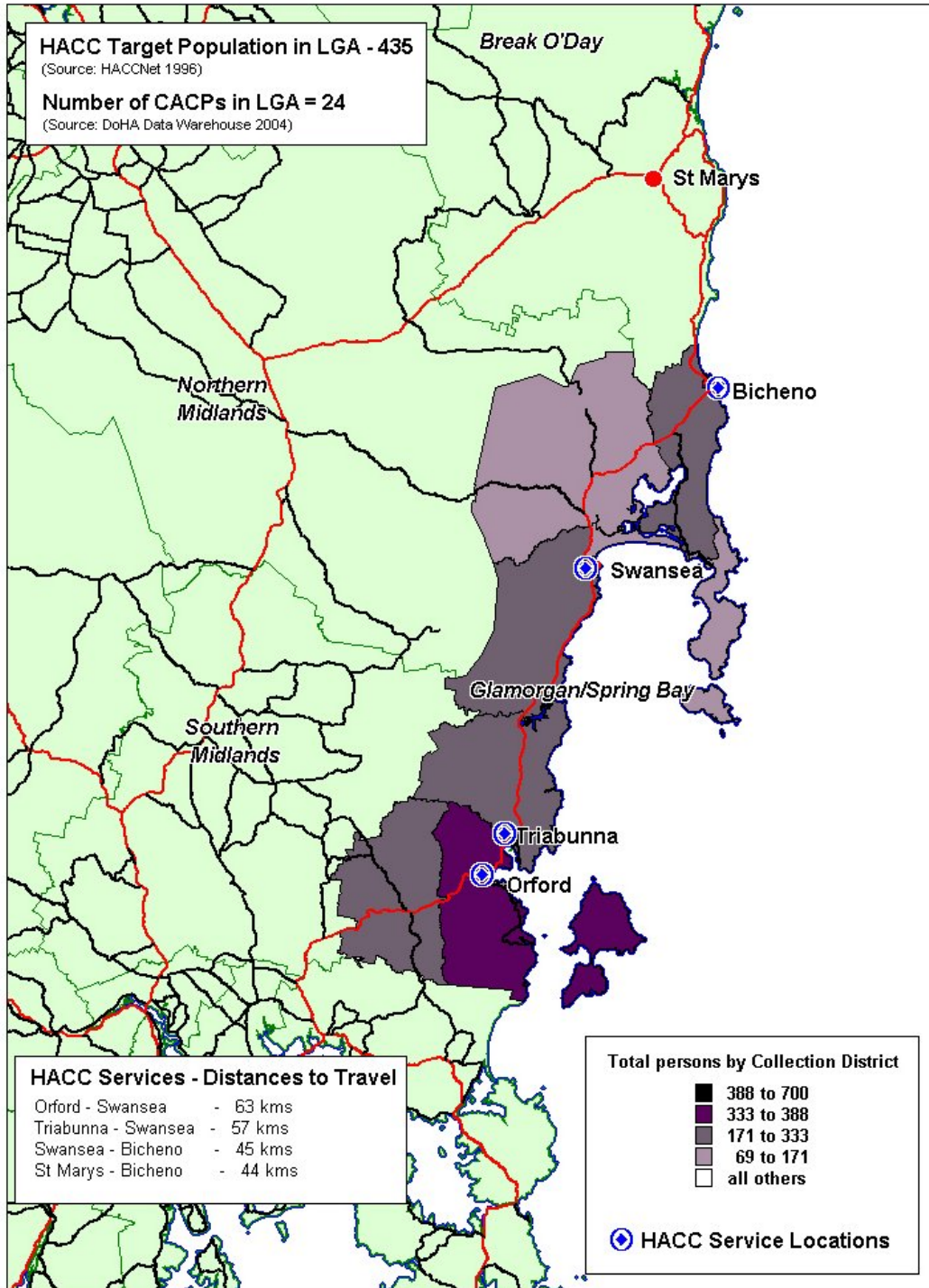
The HACC services are distributed across the region with a Day-care centre in Orford (Prosser House), which provides day respite for HACC clients as far north as Swansea. Triabunna's Community Health Centre provides a variety of HACC services locally as well as home maintenance services extending to Swansea. Swansea has a Community Health Centre located near May Shaw Nursing Home with Community Nursing and Domestic

Podiatry and physiotherapy services, which are funded under the Regional Health Scheme and HACC, are available at the centre for consumers living in Swansea and Bicheno.

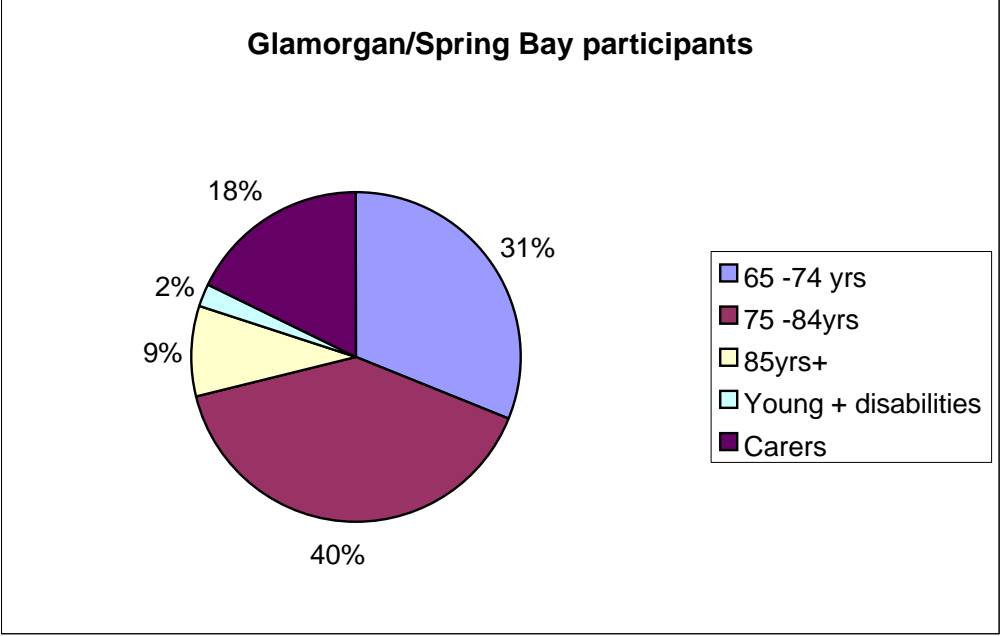
Bicheno has a Community Nurse located at the Community Health and Resource centre part-time. HACC funding is also allocated for home maintenance and domestic assistance services for consumers in Bicheno, and managed by the St.Mary's Community Health Centre.

Personal care funding for HACC consumers in Bicheno, is managed by the organization, Family Based Care who are located at Fingal.

Glamorgan/Spring Bay

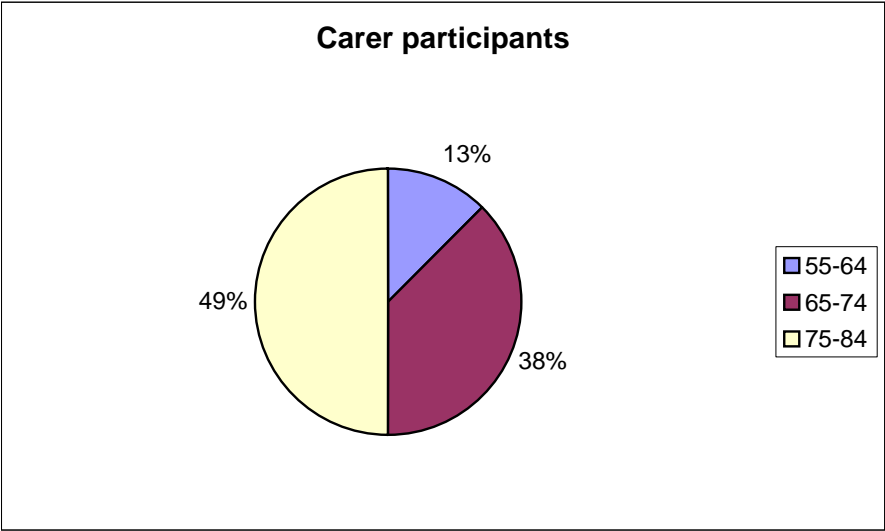


The following charts provide a breakdown of the Glamorgan/Spring Bay participants' age, whether they recorded having a disability, lived alone and/or were carers.



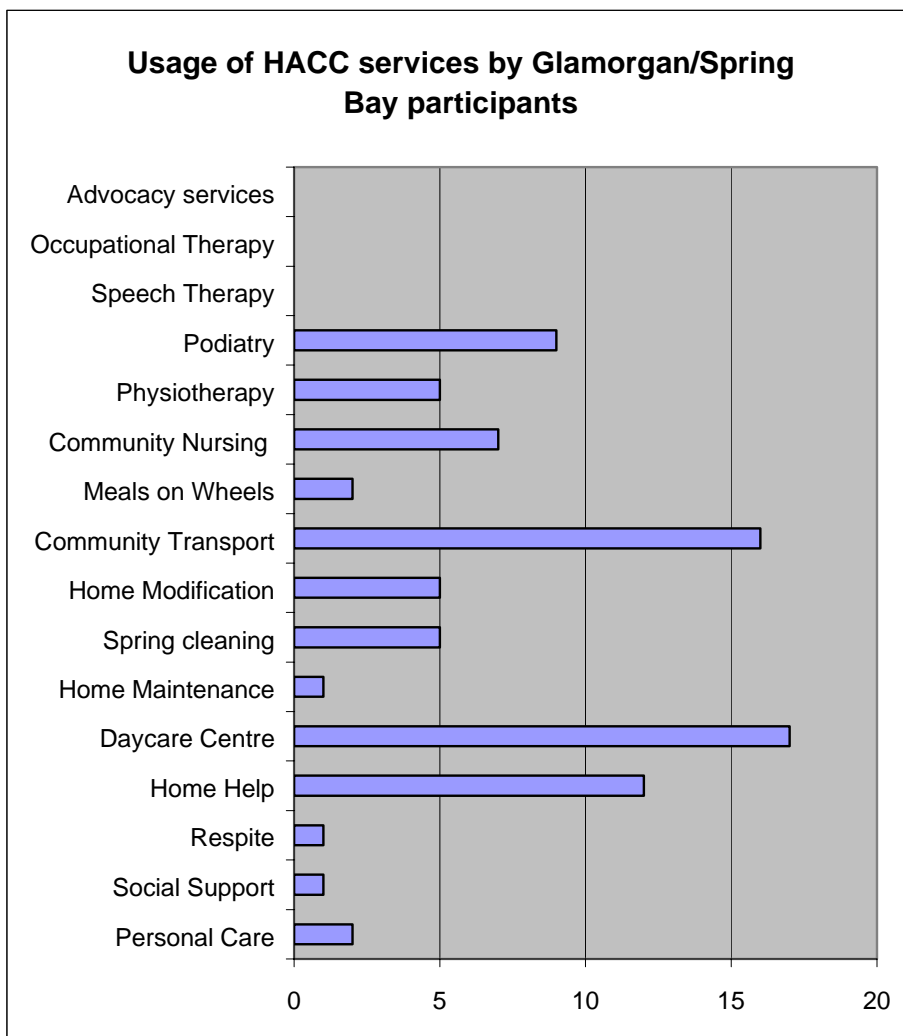
27% of participants over the age of 65 recorded having a disability (excluding carers).

14% of participants were females over the age of 65 with a disability and lived alone.



4% of carers recorded having a disability. There were an equal number of female and male carers.

The bar graph below charts the usage of HACC services by participants in the region.



The high percentage of Day-care participation recorded is reflective of the number of surveys returned by Prosser House attendees.

Triabunna

Main concerns of participants

- Access to gardening particularly garden clean-ups
- Transport to Hobart is in high demand and therefore difficult to access. The participants commented that the elderly frequently visit the Royal Hobart hospital for day surgery such a cataract removal.
- This type of surgery prevents the elderly from driving home and can cause difficulties for those unable to access support.
- The social needs of the isolated elderly. The development of social eating groups with transport support was something the participants were keen to see initiated in the region.

- The overall cost of Red Cross Alarms was considered prohibitive and subsidising pensioners was agreed by participants would be money well spent.
- Increasing home help to a weekly service without as many task restrictions was considered a more appropriate level of service provision.

Swansea

Main concerns of participants

- Accessing affordable and reliable tradesman to do odd jobs and garden maintenance.
- Knowing how to access community care.
- Access to more community nursing.
- Someone to help exercise the dog.

Bicheno

Main concerns of participants

- Participants considered access to social support services a priority.
- Access to home maintenance services that were reliable and responsive.
- The importance of the elderly being able to remain secure and safe in their homes. This was related to accessing Red Cross alarms, Occupational therapy home assessments and home modifications.
- Access to spring-cleaning.
- Access to a government funded Podiatrist. Currently there is a need to pay privately or travel to Swansea.
- An increase in the physiotherapy services available was requested due to high demand and the limited operating times of existing services.
- The participants were confused about access to services from the North or South of the state and whether there are restrictions and disadvantages due to regional boundaries. The clarification to Bicheno residents of this issue was seen to be the responsibility of government funding bodies.
- Training and support for volunteers and volunteer coordinators.
- Participants generally commented that there was a need for more local service provision given the demand for services.

6

CONCLUSION

The consultations conducted in 2003/4 provide a valuable insight from the consumer perspective as to their needs, expectations and priorities.

This information provides some detail for service providers and funding bodies to consider in current planning and can be further developed to provide an impetus for change where appropriate.

Whilst not all voices were heard there are still strong recurrent themes from consumers around access and information in the community and being able to live independently in homes that are safe and maintained to an acceptable cultural norm.

Consumers expressed consistently that they recognised the inability of community service provision to meet their every need particularly in the more isolated areas. However, they reasonably sought the resource/ knowledge/ facilitation to know how to access affordable and appropriate quality services.

In consideration of the needs of the HACC target group more importance needs to be given to linking consumers to community based supports that will facilitate these requests.

In addition the lack of dissemination of information to consumers may occur as the result of minimal communication between service providers.

A regular facilitated meeting of all community care service providers with similar regional coverage would encourage this process and:

- Promote cross referral
- Identify gaps in service provision and those best placed to provide those services
- Develop and broaden distribution of information to consumers.

The State and Commonwealth would need to support and acknowledge this process.

Further, the meetings should include consumer representatives to encourage more responsive and relevant service provision and raise particular consumer concerns.

There are a number ways to ensure cooperation between community care services. For example there could be a networking component that was included in core funding along with the necessity of reporting that time in the Minimum Data Set. Another method might be a minimal sitting fee incentive that came some way to meeting the cost of attendance as a way of

validating networking processes. A similar method was successfully used to encourage busy general practitioners to attend case conferences.

On a broader scale, the pooling of funding to community care services would also break down some of the barriers created by multiple funding bodies.

The Project has put forward a number of recommendations as to how the issues raised by consumers may be addressed. Some of these issues, such as access to home and garden maintenance, could be considered in the context of the next HACC Annual Plan. Other issues, such as hospital-community discharge planning, are more complex and necessarily involve other DHHS operations and other Tasmanian and Australian Government agencies if seamless transitions are to occur.

The HACC consumer project well into its third year will continue to utilise the information gleaned from the consultations on behalf of its target group and look for ways to further develop and improve the breadth and depth of future consultations.

It would be considered timely that although the framework within which the project operates includes on-going review that the project considers a formal evaluation process. This would provide an analysis and base on which to develop a strategic plan and add to the value and scope of the project.

7

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Appendix A

Summary of funding outcomes from 2002 and 2003 consultations

The following chart links the themes from the first two years of the Consumer Consultation Project to the priorities set out in the HACC Annual Plan and subsequent successful funding submissions. Note that funding priorities also take into account national program priorities, feedback from service providers and peak bodies. (See Appendix C for summary of HACC planning process.)

Funding can only be allocated where submissions are received in response to the annual priorities that are advertised. With a limited amount of growth funds annually, not every theme identified in the consultation process can be funded.

The chart only briefly describes the funding priorities and does not attempt to provide the detail that is needed to look at particular areas of concern within each category.

Consumer Consultation Themes 2001/02	HACC Program Priorities: 2002/03 Plan	Consumer Consultation Themes 2002/03	HACC Program Priorities: 2003/04 Plan
Personal Care & Community Nursing – Particularly North West & St.Helens	Continence	Personal Care-	Personal Care
Home & Garden Maintenance	Home Maintenance	Home Maintenance	Home & Garden Maintenance
Transport – increase access to rural areas inc. w/chair access		Transport	
Domestic Assistance Spring Cleaning	Spring Cleaning	Domestic Assistance	Domestic Assistance, Spring Cleaning
Assisted Meal preparation	Special Needs Groups	Information	Special Needs Groups
Podiatry	Podiatry	Podiatry	
Respite – flexible long day care, crisis/emergency support particularly in North West		Emergency Respite- North West-age appropriate day activities for young people	Short Term Respite for carers of young people with disabilities
Assisted shopping/Banking/paying bills.	Volunteers		Volunteers
Accessibility to Home modification			Dementia

Appendix B

Transcriptions of consumer consultations and survey results

Kentish Municipality

Meeting at Wilmot Hall (18/3/04, 10.30am –12pm Wilmot, 8 attendees)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Information on what services and how to access them.
- Community nursing – to monitor medication and pressure care (preventative), dressings and to provide assessment and information when needed.
- Home help– Ability of workers to change linen and peg out clothes, iron and-to come once a week would better suit our needs.
- Availability of spring-cleaning both inside the home and in the garden.

What services do you need but don't get?

- Community nursing to provide periodic care of the terminally ill.
- The hospital has discharged old ladies late at night and there has been no nurse to visit afterwards not necessarily in need of terminal care but some help afterwards.
- I know of two instances when terminally ill patients have been left without nursing care- sent home from hospital and their partners have had to muddle on without knowing what to do.
- Meal preparation or home delivered meals.
- Community transport is insufficient – current bus from Tandara (Sheffield) twice a week 10 – 4pm does not meet all needs – long day, restricted times.
- High school bus to Ulverstone only other choice and isn't suitable.

As to the services already here, what would you like to change about those services?

- Podiatrist only every three months at Tandara and this isn't enough.
- Access to at least another home- helper (currently only one worker).
- Access to spring cleaning and home maintenance services.

- Greater flexibility and availability of Community Transport.
- Information and access to health services available somewhere central at least on a part-time basis.
- Community Health in Ulverstone needs to spend more time around finding out people's needs like if their home needs assessing for early prevention of falls. A personal approach is needed.
- Often there is a change of GP's in the major centres and you can't develop relationships, rapport there is not time for details and important information is left out.

Can you suggest better ways to find out views on services?

- More time to be given to network through existing Progress Association.
- More advertising.

Wilmot – survey returns – 3

What three things would make a difference to you or the person you care for staying independent in your own home?

- Basic home maintenance would be great help- fixing leaking taps, replacing light globes, etc.
- Help with the garden, weeding a couple of times a year, as it is hard to get down with arthritis.
- Spring-cleaning.
- Meals on Wheels.
- Tai Chi which is suppose to be very beneficial to well being

What services do you need that you can't get?

- As above.
- Home nursing
- Physiotherapy
- Garden clean up

As to the services already here, what would you like to change about those services?

- Not applicable – what we get is at great expense to ourselves is private and of a high standard (i.e. home modification and spring cleaning).
- The service given is excellent just not enough of it.

Can you suggest better ways to find out about your views on services?

- Communication is essential with all residents of the area – perhaps a letter drop to all.

Moina – one survey respondent

What three things would make a difference to you or the person you care for staying independent in your own home?

- Community car for GP visits or associated health needs.
- Chimney sweep
- Information on HACC services (display in doctor's surgeries).

What services do you need but can't get?

- Chimney sweep
- Read-a-book service

As to the services already here, what would you like to change about those services?

- Services I have used are excellent.

Public meeting at Kentish Community Room, Sheffield (18/3/04 2-3.30pm, 7 attendees)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Home help/maintenance.
- Community transport to appointments.
- Information about services in the area.

What services do you need that you can't get?

- Crisis help due to illness
- Public dental health /Optometrist
- Local services - as response time is too long from major towns.
Currently if you become ill you have to wait for a week or more for assessment and longer for services (from Burnie or Devonport).

As to the services that are already here, what would you like to change about those services?

- Expanded time for example currently only big jobs are attended to.
- Dedicated workers- some seem very unprofessional.
- Need central point of Information about services/Carelink needs to publicize more often. For example couple living in Tandara unit were well informed of service availability and informed rest of group who didn't know about services.
- Need more medical services –GP's come and go which cause grief and worry for people.

Can you suggest better ways to find out your views on services?

- Survey in Kentish Chronicle

Survey returns for Sheffield – 12

What three things would make a difference to you or the person you care for staying independent in your own home?

- Knowing how?who?what? Services preferably via a liaison, advocate person to help access, inform me, and make enquiries one on one.
- Home maintenance- particularly anything that required the ascent of ladders. Changing of fire alarm batteries and light globes.
- Garden maintenance/lawn mowing (I am an asthmatic and have osteoporosis).
- Garden maintenance.
- Community transport to attend Latrobe hospital and medical services.
- Need local community transport for shopping and other activities and to Devonport. The cost is too much as I need to travel accompanied.
- A community car for short trips for doctors, banking and shopping in Sheffield.
- Information on services printed as well as by phone for those with a hearing impairment.
- Home help when needed – assessment takes way too long.
- Housecleaning, shopping.
- Weekly home help would much more helpful to keep up with chores and some bigger ones could be fitted in like cleaning the oven.
- More home help.
- Access to a volunteer driver to go to North West Regional Hospital as needed as my friend who drove me passed away recently.

What services do you need that you can't get?

- None at the present but believe that in a few years things will get more difficult.
- Cheaper lawn mowing – I have to pay the going rate and it's difficult on a pension.
- Assistance to attend some sort of education – I can't afford community transport and a course and as I need assistance can't access public transport. I need to stay alert and have social interaction. Perhaps home tutors could be provided.
- A local community car.
- Dialysis treatment in Sheffield. I have to travel to Burnie three days a week in a community car a distance of 80km each way is a bit of drain on the body.
- So far I'm okay. Tandara has excellent facilities for the community as well as its residents.

As to services already here what would you like to change about those services?

- Really dislike 1300 phone number to access local health provider if I need to do anything that isn't simple like make general enquiry. When you are ill you need access when you are capable of thinking and they always ring back at a time when I'm too tired to be precise which is unhelpful and frustrating for both sides. Please employ at least a part-time receptionist.
- Social/Emotional issues need to be as important as physical help. Loneliness, isolation and frustration are stressors, which undermine physical disabilities and general health to make them worse.
- It takes too long to access them i.e. Two weeks ago I hurt my knee and couldn't walk for a few days or do anything around the house and I live alone away from family. To call Burnie and wait for an assessment would take too long and by that time I could probably manage.
- I am pleased with the service I receive and have heard good reports although there are long waiting lists for some (such as Podiatry) and that is due to lack of professionals so no change is possible.
- More hours for Podiatry, etc so we don't have to wait so long between visits.

Can you suggest better ways to find out about your views on services?

- Advertisement in the Kentish Chronicle.
- Utilising a case manager or advocate to keep in touch and keep up to date on changing needs of people with disabilities. Surveys are great but personal contact would be ideal for validating our views and needs.
- Also a Community (Disability?) Information service- a coordinated collection of information to access via one channel-too many bits-services don't seem to know what other services provide so how can we?!
- I have a newspaper that is posted monthly to every household in the Kentish municipality and could include information about services (other than Tandara as that's in each edition) would come in handy

Meeting at Railton King's Hall (18/03/04, 7pm -8.30pm, seven attendees)

What three things would make a difference to you staying independent?

- Personal Care
- Garden Maintenance – Clearing rubbish from yard.
- Home help (needs to be weekly).

What services do you need that you can't get?

- Chimney cleaned once a year
- Personal care – are unable to access personal care services as she is hoist transfer so I manage myself
- Community transport on days bus is not available –currently operates from Tandara two days a week. Need volunteer locals to operate their own car or a community car – then people wouldn't need to have a full day out for one appointment.
- Hydrotherapy pool

What about existing services what would you change about them?

- Extend home help to an hour per week to really meet need and replace workers who leave or who go on leave.
- Some sort of quality control – not half done jobs when looking at falls prevention in the home for example, attention to detail as has happened ramps without rails.
- Mersey Community Care provides garden rubbish removal for small fee, which is good, but really need some help in the garden in spring and prior to winter pruning.

Can you suggest better ways to find out your views about services?

- Advertise at schools.
- Have an afternoon session.
- Visit the Sunshine Club (Social club) every 3rd Wednesday in the month.
- Advertise on the radio.
- Increase distribution of flyers.

Survey returns Railton – 7

What three things would make a difference to you or the person you care for staying independent in your own home?

- Spring cleaning of garden and home
- Spring cleaning of garden and home
- Community transport
- Podiatry at the moment my daughter does it but she when she goes away I have to wait until she gets back.
- Home maintenance- my son-in-law does what he can but I don't like to always put him out.

What services do you need that you can't get?

- As above but I also have had my community care hours cut back and my needs have increased.
- Garden help
- Vacuuming

- Spring cleaning (windows)
- Somebody who can mend my water bed

As to the services that are here what can be done to improve them?

- Very happy generally but one thing stands out – that is the avoidance of personality clashes – I used to care for my very placid, helpless spouse and he didn't need a dominating carer! – need quick change of outside help.
- Only Podiatry we do need an extra person as people have to wait so long to get to see the Podiatrist now.

Can you suggest ways to better find out your views?

- I don't really know. I didn't know you had these services. It would be nice to know about them as I have been struggling with my garden for months.

Derwent Valley Municipality

New Norfolk Library meeting room
(26.3.04, 2 –3.30pm, 3 Attendees)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Garden help – mowing of lawns, garden help – people have huge investment in their gardens time wise and emotionally.
- Access to support – information of services which needs to consider language used as some people have literacy issues, coloured pictures and in different languages would be useful, TV ads and letterbox drops, flyer in Tasmania Pensioner News.
- Home help - combined with assistance to shop and bank.

What services do you need that you can't get?

- GP's booked up more GPs needed – current GP's overworked and couldn't attend house call Sunday night so elderly lady went to New Norfolk hospital who then referred on and spent 7 hours in emergency to have tetanus injection due to dog bite.
- Public Dental services.
- Easily accessible information –more displays in Library and in GP surgeries and the outpatients at hospital but still don't reach housebound people which need letterbox drop.

As to the services that already here, what would you like to change about those services?

- Home help extended –just skim the service. Ability to change sheets especially for those who spend a lot of time in bed.

- Increase in community transport – currently you need to give a fortnight’s notice.
- Social support needs to be weekly especially for those who are alone to increase contact help access information and increase confidence.
- Flexibility of workers.

Can you suggest better ways to find out your views?

- Home visiting.
- Visit the Golden Years Club or other existing social groups like Probus.
- Advertise in chemists and banks.

Survey returns New Norfolk - 4 (Three were from areas outside New Norfolk town: Hamilton and Macquarie Plains)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Downstairs functional bathroom and bedroom
- Wheelchair accessible transport to and from appointments
- Help with maintenance around home and garden
- Spring cleaning – high fixtures, blinds and pelmets.
- Transport to and from hospital when required.
- Physiotherapy when required
- Help in emergencies
- Level Paths
- Modified kitchen
- Library facilities
- Firebreak assistance
- Lawn mowing particularly in summer and spring
- Wood splitting
- To be able to find a resolution to the water problem as the “drain” which is diverted from the Styx River is to be turned off and the New Norfolk council say it would cost too much to fix. How can a community overcome such a problem-leave your home and go into care is the only way old folk can see.

What services do you need that you can’t get?

- Information on services available – would also help answer this question better

- Accessible shopping area in New Norfolk –50% have steps and the lowered curbs are still too high for an electric chair to access.
- When I have needed to go to hospital immediately can't drive and couldn't access ambulance – big problems
- Vet affairs won't help me with small maintenance problems like fixing tap washers, changing fire alarm batteries and light globes and HACC won't either.
- I try to manage myself and haven't yet inquired about services.

As to services already here, what would you like to change about those services?

- Easier accessible public toilets for quadriplegics with electric chairs
- (Vet affairs) Services have been cut down badly of recent years- home help has been halved, handyman discontinued.
- Increase transport services to be able to react more quickly
- Increase of staff as services badly understaffed.

Can you suggest better ways to find out about your views?

- Elected councillors plus public forum in around table honest discussion
- We've had reviews, forms ad nauseum to little effect.
- I need to know about services let alone about my views.

Maydena (Attendees at meeting – 15; Two attendees live in Tyena, two in New Norfolk and one in Ellendale)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Strong willing skilled person to do home maintenance.
- Home modification – retired ambulance driver suggested toilet doors that open inwards are a common problem. And power points being raised would also be an effective part of home modification as well as traditional bathroom renovations.
- Reduced mobility stairs a risk – need government support to help reduce risks.

What service do you need that you can't get?

- Firstly we need information about services.
- Community transport and public transport to New Norfolk.
- Currently the community car is often booked – need another type to compliment or back-up roster. Last bus we had here wasn't suitable and we need one that we accommodate all (non-discriminatory).

As to the services already here what would you like to change about those services?

- Communication and information sharing between medical services for example GP's to community services.
- For services to give knowledge about self-care
- Community nurses should be able to take and carry blood.

Can you suggest better ways to find out about your views?

- Home visits- one to one interviews.

Maydena Survey returns – 4 (Three respondents live in Maydena, one in Westerway)

What three things would make a difference to you or the person you care for staying independent in your own home?

- Access to transport with a ramp and hoist to and from new Norfolk.
- Footpaths to and from local shops in Westerway
- Home maintenance indoors and in the garden.
- Home modification- I have difficulty showering over bath and getting in and out of bath.
- Access to transport
- Spring- cleaning of home and garden.

What services do you need that you can't get?

- As above
- Improved footpaths
- Bus service from Maydena to new Norfolk
- GP could visit Maydena or Westerway once a week or fortnight would save a lot of travel for the elderly, etc.

As to services already here what would you like to change about them?

- Podiatry services need to be increased to two days a week or alternate weeks, as the demand is so great.
- More Community Transport

Can you suggest better ways to find out about your views on services?

- Perhaps a questionnaire with explanations to be included in the postage of the pension card each year.

Glamorgan/Spring Bay Municipality

Triabunna – 4 Attendees

What three things would make a difference to staying independent in your own home?

- Home help
- Community nursing
- Community Transport availability

What services do you need that you can't get?

- Gardening – particularly mowing
- Spring cleaning of garden
- Transport to the city - It is in high demand and therefore difficult to access (One privately run bus every fortnight) (Community volunteer drivers in Orford and Triabunna at present use own vehicle for local and city trips)
- Social eating groups would help a great deal for lonely elderly people.
- Problem mentioned when country elderly who need day surgery in RHH in the city for cataracts for example, are unable to drive to return home due to surgery, are refused a hospital bed and there isn't HACC transport (or private often) available and therefore have to stay? overnight.

What about services here, what would you change about them to better suit your needs?

- One hour a week of Home help would better suit needs. That was able to do more such as clean windows and moving furniture.
- Weekend community services.
- Community vehicle with volunteer drivers like the bus from Prosser House to be set up in a similar way for Triabunna.
- Overall Cost of Red Cross alarms are prohibitive to pensioners -
- Money would be better spent subsidising all alarms for pensioners only charging say for rental.

Can you suggest better ways to find out about your views?

- Broader advertising
- Visits to existing groups such as Neighbourhood Watch and Probus where there is a captive audience and a variety of people

Survey returns (Triabunna 7; Orford 11)

What three things would make a difference to you staying independent?

- Home Help
- Garden maintenance
- Meals on Wheels

Swansea – 2 attendees

Neither participant is currently using HACC services but believe they will need to in the near future.

What three things would make a difference to staying independent in your own home?

- Assistance around the house - particularly vacuuming
- Garden maintenance
- Access to affordable reliable tradesmen.

How could I better find out views on services?

- Could try schools to access the young people with disabilities.

Swansea Survey returns – 5

What three things would make a difference?

- Community nursing
- Access to community care
- Keeping healthy
- Knowing help is available if I need it.
- Care of the garden
- Exercising the dog

What services do you need that you can't get?

- None
- I am quite satisfied with the services I get.

What would you change about services here?

- Nothing
- I think they are quite adequate.
- Find them fully satisfactory.
- No.
- None.

Can you suggest better ways to find out your views?

- No.

Bicheno – 17 attendees

What three things would make a difference to you staying independent in your own home?

- Assistance with shopping by helping the person and when needed going shopping for them
- Regular and reliable home maintenance (not in 6/7 weeks time from request)
- Ways to overcome loneliness need a befriender service
- Feeling secure/safe in own home i.e. set up well with ramps, etc., and Red Cross alarm.

What services do you need that you can't get?

- Community transport bus
- Rubbish removal.
- Spring cleaning would be good –especially window cleaning
- Day care to engage in social activities

What about services already here what would you like to change about them to better suit your needs?

- Podiatry (at the moment comes from Launceston every six weeks and we pay \$35.00 and I believe that this service is only temporary) – there is a free service in Swansea but if you can't drive you can't get there- It would be better if he came to Bicheno than trying to find community transport to get there. Or pay the podiatrist from Launceston to subsidise his fee so pensioners could afford to see him.
- Physiotherapy hours are stretched they leave at 2.30pm or before to drive back to Hobart (they live south of Hobart somewhere) would be better to extend hours and stay overnight to cater to demand and perhaps visit once a fortnight for two days. However, this service took a long time to get here and may finish in December. Both Podiatry and physiotherapy are services, which keep people moving and mobile and therefore important.
- Waiting time for services is too long – St. Mary's service provision for lawn mowing took up to 5/6 weeks and their attitude was that they were too busy and cut service after complaints.
- We pay for services to come from St. Mary's and back, it's a waste of funds – people could be serviced here with that money there are plenty of local blokes to do it.
- Can't get enough Community Nursing – hours need to increase.
- Services need to clarify boundaries i.e. who do we belong to so we can know what we can access, where and how.
- Comment – the Swansea GP now tries to assess everyone over 75yrs of age but we don't have that here.
- Comment – there is a community car that will be on the road soon – we had a problem with on road costs but they are being seen to which h may address some issues.
- There are respite beds in May Shaw but people in Bicheno can't access these beds unless they are receiving an Aged care package

because of the North/South carer respite differences. People from eastern shore in Hobart can access respite at May Shaw.

- Comment – that people should be able access either north or south services, people are confused by these issues.

Can you suggest better ways to find out about your views?

- Attend Community Health group

Bicheno Survey returns – 2

What three things would make a difference to you or the person you care for staying independent in your own home?

- Spring cleaning of garden and home
- Home maintenance
- Home modification (of bathroom)
- Podiatry

What services do you need that you can't get?

- Spring cleaning
- Home maintenance
- Home modification (of bathroom)
- Dental services
- Podiatry (2)

As to the services here, what would you change about them to better suit your needs?

- Coordination of volunteers and support for them as well as funds properly managed by a knowledgeable person.

Can you suggest better ways to find out about your views?

- Perhaps public meetings with a person to coordinate with government rep.

Alzheimer's Association Survey Results (Nov 03)

1 Demographics

a. Gender

Male (6)

Female (12)

b. Age range

Under 16 (0)

16 – 25 (0)

26 – 39 (0)

40 – 49 (0)

50 – 59 (2)

60 – 74 (8)

75 and over (8)

c. Do you identify as:

A member of the Aboriginal or Torres Strait Islander community? (0)

A person who has a language other than English as their first language? (0)

d. Do you receive a:

Disability pension? (1)

Age pension? (8)

Carer allowance or carer payment? (10)

Veterans Affairs pension? (7)

Other Centrelink allowance relating to age, disability, or caring.

e. I live in the:

62 telephone district (13)

63 telephone district (4)

64 telephone district (1)

f. Have you participated in HACC consumer consultations before?

Yes (5)

No (13)

2 Current Support

What support services do you currently use to enable you to care for your family member who has dementia?

- Taxi concessions
- Occasional bus trips
- Pill delivery
- Cleaning services
- Day care
- Regular phone calls
- Visits if necessary
- In care
- Age pension and carer pension
- Cleaning 1 hr/wk
- Day club once/wk
- Community & Health services North, John L. Grove Centre
- Voluntary carer
- Carers association
- Meals on Wheels
- Mum's Mobile Meals
- Alzheimer's association
- Carer respite
- HACC home help 1 ¼ hr/fortnight

- HACC gardening help 1 hr/month
- Day respite centres – Shore St, Eastside Day Care
- Home help
- Family Based Care
- Veterans Affairs Nurse
- None as yet
- Day Centre

3 Key Support People

Who are your key support people? (GP, partner, Alzheimer's & Dementia support group, minister, etc?)

- Alzheimer's & Dementia Support group x 11
- GP x9
- Family members x8
- Partner x4
- Nurses
- Minister/church x4
- Friends/neighbours x4
- Carer respite centre x2
- Home help organised by Carer Respite Centre
- Carers Association
- Day Centre staff

4 Getting New Information

Where do you go to get information about possible services that would assist you? What do you find is the best form of getting information – written information, talking to someone, using the Internet, or using the telephone?

- Talking to someone – information gathered at monthly support meetings, phone calls to A & D support organisation, and Carers Association.
- A & D Support group, written informant, talking to someone.

- From GP. Prefer written information.
- Talking to someone by far the most satisfactory.
- Written, talking to someone.
- Have got all my information from A & D support group, Memory Loss sessions, they are just a phone call away.
- Don't get any.
- Govt respite, ACAT, written information, Carers Association
- A & D staff have guided me, so its been easy to get information; also carer's staff; phone is easy & 'on the spot', written information, talking.
- A & D staff extremely helpful; talking about the problem face-to-face or by phone is best for me.
- Carer Respite Centre initially; now A & D association; telephone and talking to people.
- Current support groups provide adequate information on services available; follow up visits from A & D association, Carer Respite centre, and ACAT.
- Talking – face-to-face and phone.
- Talking to others, written information.
- Written information; talking to someone
- Talking to any of the staff at the Old Vicarage, St John's Ave, New Town.

5 The Impact of Dementia

Can you tell us about the impact the diagnosis of dementia has had on your life and that of your family?

- If I didn't belong to the A & D I would feel quite isolated at times. My family help if asked but also have their own problems. I try not to give them more than necessary.
- Very stressful. Answering questions all the time. Doing most of the work, washing, ironing, cooking, washing up, dressing, showering, cleaning, gardening, shopping, and banking.
- It is very sad to watch my mother fighting for words and often not finding the right one.
- Very scary for 2 years before I found a place in care. I'm the only relative in Australia so it was very intimidating to think of caring for her alone at home.
- It has been a complete turn around in my outlook on life and marriage.

- Have had to have much more patience and understanding, knowing that my partner's brain is not registering as it used to. Be aware of how you answer and your tone. Also have had to learn to have peace within myself as well.
- Very upsetting. Friends don't call or ring up.
- Ghastly – a nightmare of the worst kind. Great sadness. Social activity virtually 'finito'. Increased expense trying to appease appetite – buckets of bananas one week, a ton of chocolate next week. He has no idea of income. Has to be the worst sickness known.
- Quite often I feel extremely stressed and frustrated with the constant battle with my friend because it seems to me that he has no idea how much the disease has affected him. I feel he is in 'denial'. He is extremely reluctant to accept any help – he can manage and he can't!
- I find 2 of my 3 children are still largely in denial. For myself, I find I have had to assume responsibility for many things my husband has always done and supervise all the things he still does – at nearly 80 this is not easy and very tiring. However, we cope. We are still together.
- Changed priorities and living/social activities.
- As an only child it all came to me, then 56 years old and my mother 92 with memory loss. It became increasingly stressful but as always my husband coped admirably with Mum and me. Incontinence of bowel necessitated nursing home care at age 97.
- A brain tumour 1998 took its toll on my health otherwise I might have kept her in her own home.
- There has been a huge impact. Relationships harmed and break down. Alienation of friends. Social life just about non-existent. Resentment. Guilt.
- A greater need for much more patience.

6 Ongoing Support Needed

What ongoing supports would you need as a carer to maintain your health and well being? (Respite, day centre activities, crisis care, transport, etc).

What ongoing support does the person you are caring for need?

- In Home crisis care or allocated hospital care. Her care and support were adequate as she hated having 'strange people' in her home and could be quite abusive. Respite care in an aged care facility was disastrous. Expelled at 96yrs of age for verbal and physical abuse of staff. She loved her home and was happy there as it was with daily care (rostered).

- Need present assistance at this time. Who knows what in the future? Full care provided.
- Currently waiting on villa at Queen Victoria Home. Currently waiting on Day Club. Have coped without respite/crisis care up to now but could be a future need as I admit an ever increasing strain making all decisions.
- Being recognised as his carer (by the government) would be a big help! Help with transport to doctors etc in the city would be great (He's not supposed to drive beyond the local area). Respite and crisis care availability is a great comfort to know, should the need arise.
- Support is A1 but husband won't go to Day Centres – (1 day at Alz House, 1 ½ at Roy Fagan Centre). Those few hours really boosted me. I think the 'authorities' and my humble efforts have exhausted all possibilities to help my husband more.
- Respite too upsetting for her. Happy in Day Centre activities 3 days a week.
- Mainly day care activities, as he likes to be kept busy. Day trips etc are in the process of being organised.
- Needs communication with other people – he needs to be needed.
- Respite for us (carers) and daily care for Mum (caree).
- Respite at present. Already attending Day Care.
- My husband attends respite centre one day a week and this is a real help. Perhaps one more day would be great, but I'm not sure he would go.
- Respite; Day Centre activities are essential need.
- Day Centre activities are much appreciated.

7 Service Gaps

Can you list service gaps you have identified in relation to carers or for people with dementia?

- Maybe I will be able to as time goes by but at present.
- Cannot think of any. Services provided are adequate.
- There is clearly a greater need for day care type groups, entertainment, and activities in the best aged care homes. Boredom is such a great problem with decreasing ability to read, do puzzles, have conversations etc.
- Crisis care respite (My partner will not go away – afraid of being left alone). Day care – likes to share everything with me.
- Not at the moment. I am just becoming aware of all the information there is available and the help there is remarkable.

- Not really but have yet to find out about someone coming to “chat” while I went out for a “coffee”.
- I feel it is very unfair that I am denied the Carers Allowance simply because we do not live in the same house.
- Gardening is a big problem – 1 hour a month scratches the surface. Odd jobs, outside sweeping, changing globes, the odd screws, nails etc.
- No learning as I go.
- Not in this case.
- Cannot think of any. Services provided are adequate.
- Are not aware as yet of any service gaps.

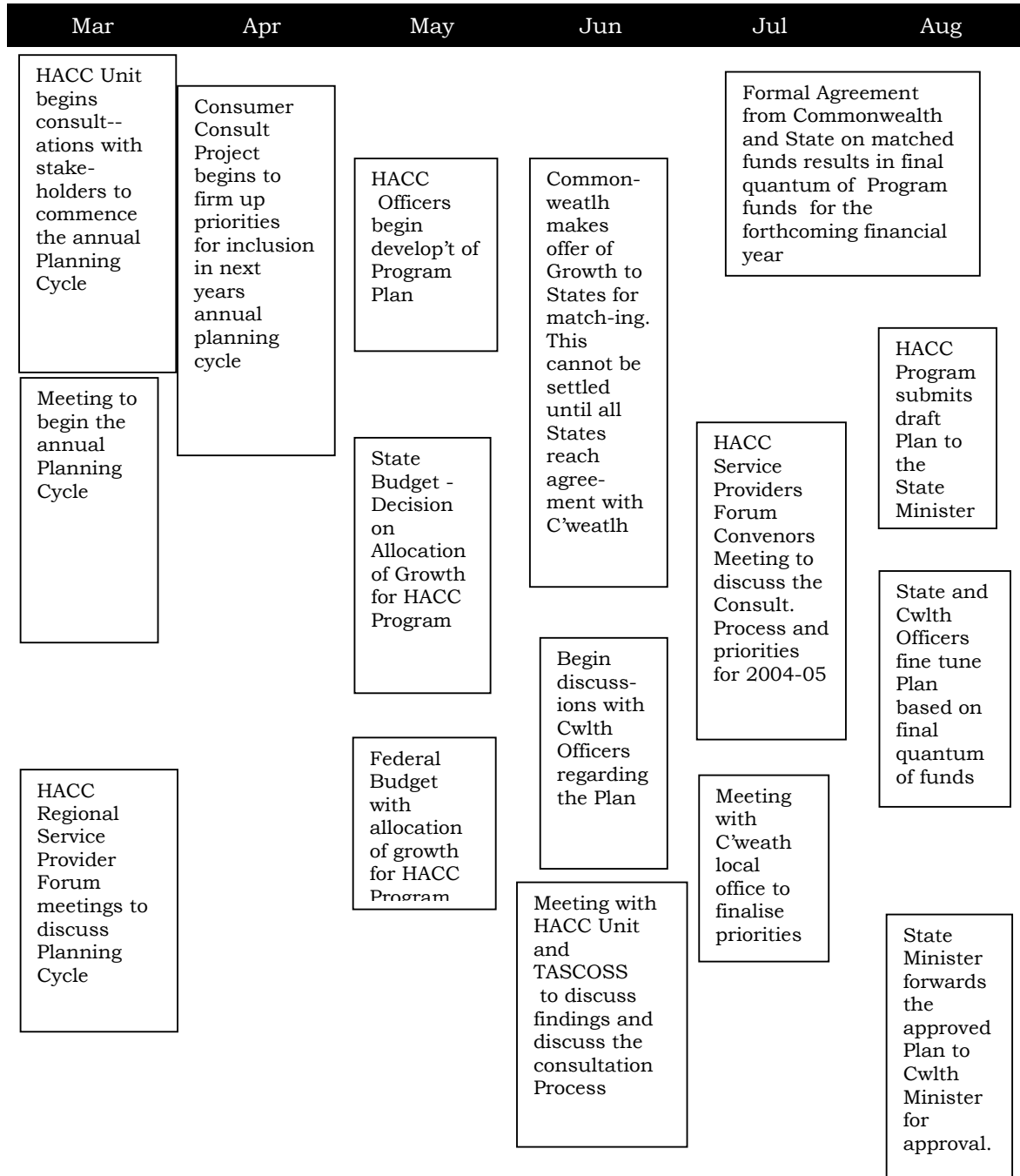
8 Other suggestions or comments

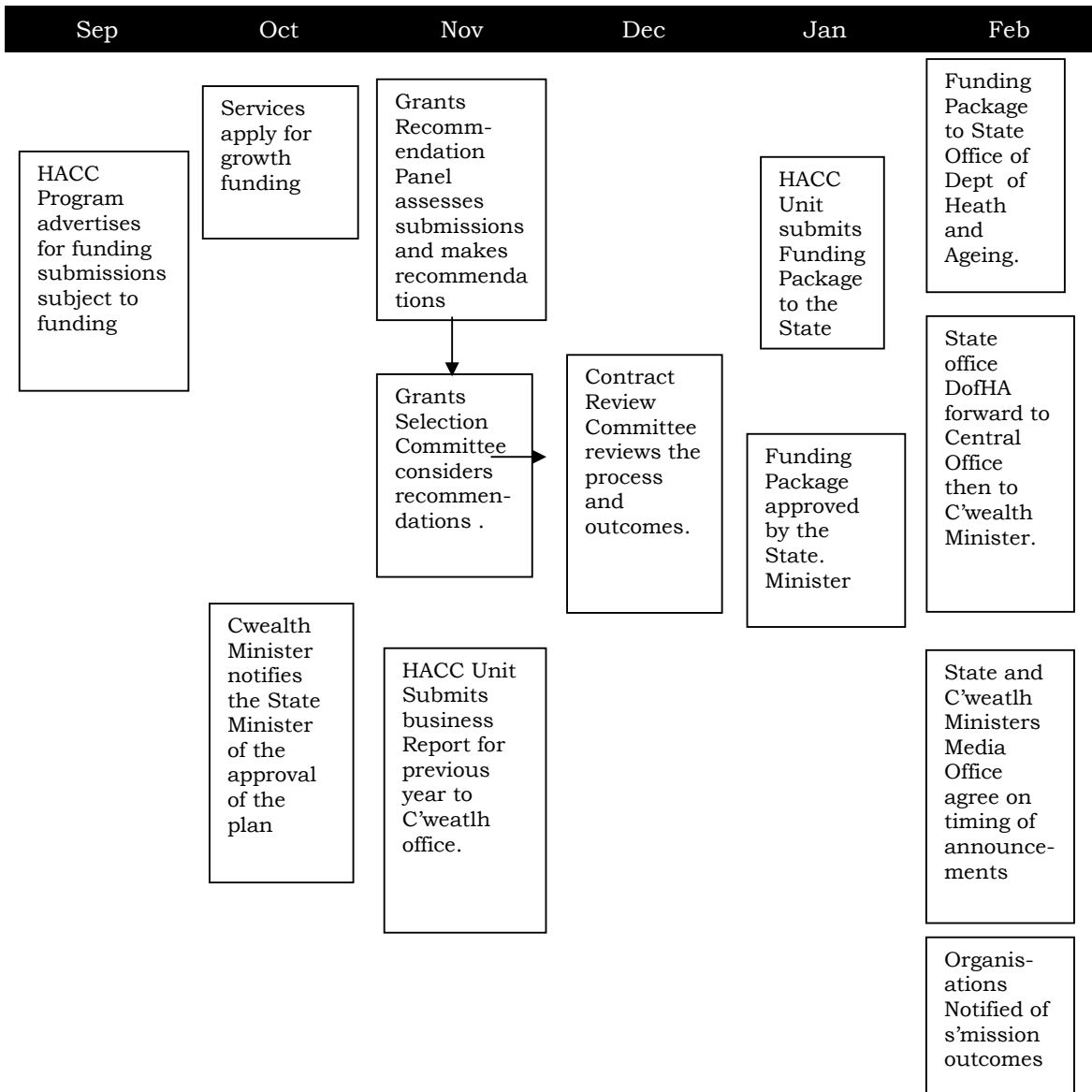
Do you have any other suggestions of the types of services you feel need to be provided for carers or for people with dementia?

- Perhaps more bus trips or picnics where both husband and wife can go together.
- There is clearly a greater need for day care type groups, entertainment, activities in the best aged care homes. Boredom is such a great problem with decreasing ability to read, do puzzles, have conversations etc. Especially “matching” sufferers with people of similar abilities.
- Going away in a group sharing problems & laughing at ourselves.
- Only if there should be some way to get the poor sick person to “play ball”, eg go to the Day Centre.
- I am deeply appreciative of the ever-willing support and encouragement provided by the Alzheimer's and Respite Care staff. They are truly beautiful people!
- Carer Respite Centre & Alzheimer's are very supportive. Do feel if more villas (such as Q.V.H) were available without such long waiting lists – partners could stay together while still having help available on the premises.
- Lots of hugs and kisses but unfortunately it is a family service. She was a loving generous and caring person and when I was diagnosed with the ‘peanut’ in my head (brain tumour) at age 60, I cried and said to my husband ‘I need my mother’. When I told her she said ‘Who told you that?’ Me – ‘The doctor’. Mum ‘He doesn’t know what he’s talking about’. NEVER lose your sense of humour!!
- Is it possible to be advised of the limit allowed on services needed in the running of sundry maintenance jobs in the home? One doesn’t like to make too many requests.

Appendix C

HACC Planning Process





Appendix D

Information Contacts

1. For information about community care services for older people in your local area call the Commonwealth Carelink centre nearest you on: 1800 052 222 (Free call).

2. Aged & Disability Care information Service (ADCIS) maintain a directory of services for the frail-aged, younger people with disabilities and their carers on their website: www.adcis.org.au This website provides information and links to community, government and health organizations state-wide.

3. Advocacy Tasmania provide a free and confidential, state-wide support service for people who are having trouble getting the help they need or would like to change something about the service they receive but don't know how. Ph: 1800 005 131 (Free call)

4. Carer Respite Centres provide information about services, make referrals and arrange short-term respite for emergencies or unplanned situations. They can support carers of frail older people, people with dementia, young people with a disability and chronically or terminally people. They can be contacted on: 1800 059 059 (Free call)

5. For general information about Home and Community Care services please contact Fran Thompson, Senior Project Officer at the Department of Health and Human Services on: (03) 6233 5056 or by email: fran.thompson@dhhs.tas.gov.au

6. For more information concerning the HACC Consumer Consultation Project please contact the Project Officer, Angela Maccallini at the Tasmanian Council of Social Service on: 1800 550 255 (Free call) or email: angela@tasccoss.org.au