



Report on findings from consumer and carer discussions
about the implementation of the Active Service Model and
consumer participation

Health Issues Centre

and

Lincoln Centre for Research on Ageing
at the Australian Institute for Primary Care

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Merle Mitchell, consumer, members Victorian Ministerial Advisory Committee
Natasha Kukanja, Aged and Community Care Victoria

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INTRODUCTION

This report was prepared by Health Issues Centre in collaboration with the Lincoln Centre for Research on Ageing at the Australian Institute for Primary Care for the Department of Human Services (DHS). The report details the methodology used for the consultation stage of the project and findings from the review of the literature and consultations with consumer and carer peak organisations and consumers and carers recipients of HACC services.

Further to the consultations stage, this project also included the development of a Consumer and Carer Participation Strategy for the Home and Community Care Program (HACC) Active Service Model (ASM). The strategy has been used by the ASM team for internal planning and implementation processes.

The Active Service Model is a quality improvement initiative that explicitly focuses on promoting capacity building and restorative care in service delivery. The core components of the Active Service Model are:

- Capacity building, restorative care and social inclusion to maintain or promote a person's capacity to live as independently and autonomously as possible.
- A holistic person- and family-centred approach to care that promotes wellness and active participation in goal setting and decisions about care.
- Timely and flexible services that respond to the person's goals and maximising their independence.
- Collaborative relationships between providers.¹

Discussions held with consumers and carers aimed at gathering their opinions and views about the ASM and about possible strategies to ensure the ongoing involvement of consumers and carers in the implementation of the ASM.

This report includes an outline of the methodology followed to conduct the consultations, a summary presentation of the main findings emerging from the review of literature and documents relevant to the ASM and its pilot implementation, as well as the findings from discussions held with consumer and carer peak groups and consumer and carer users of HACC services. The report also includes a brief discussion about the implications of these findings for the implementation of the ASM.

¹ Victorian Government Department of Human Services. 2008. Victorian HACC Active Service Model Discussion paper. Rural and Regional Health and Aged Care Services Division. Melbourne. p. 5

This section outlines the methodology used to review key literature and relevant documents and the approaches implemented to consult with consumers, carers and consumer and carer peak groups.

Review of literature and documents

A content analysis of available literature and documents about the Active Service Model (ASM) was conducted to ascertain the main principles that inform the ASM; the analysis also sought information about consumer and carer views of the ASM and strategies for seeking ongoing involvement of consumers and carers in the implementation of the ASM. The main documents reviewed were:

- DHS Active Service Model Discussion Paper (DHS 2008).²
- ASM Pilot Projects evaluations available at the time of the preparation of the literature review.³
- HACC Service Provider Consultation Final Report (AIPC 2008),⁴ which included written responses from various agencies and consumer peak groups.
- Health Issues Centre report to DHS about the consultation held with consumers and carers from Alzheimer's Australia about the Active Service Model (Health Issues Centre 2008).⁵

Findings from the review of literature and key documents were utilised to produce a summary of information and comments about the ASM and its implementation. This information was summarised in an Information Sheet developed for the initial discussion session held with consumer and peak groups. The summary—of findings from the review of literature and key documents—is listed in the findings section of this report.

Discussion sessions

A total of six discussion sessions with 41 consumers and carers who were users of HACC services were held, and eight face-to-face interviews with five carers and three consumers were conducted across Victoria. Further, two sessions were held with a total of 14 representatives of key consumer and carer peak groups' representatives.

The discussion sessions were held as an open-ended conversation based on the main lines of enquiry of the project. The purpose of the discussion sessions was to gather the views of participants about current HACC services and the ASM, and to seek their suggestions about possible strategies for ongoing consumer and carer involvement in the implementation of the ASM.

² Department of Human Services. 2008. *Active Service Model. Discussion paper*. Rural and Regional Health and Aged Care Services Division. Melbourne

³ HDG Consulting Group. HACC Active Service Models. Evaluation report. Melbourne; HDG Consulting Group. 2007. HACC Active Service Model. *Active clients, active workers project*. Melbourne; Moreland City Council. 2007. *The independent living project*. Melbourne

⁴ Australian Institute for Primary Care. 2008. Active Service Model. HACC Service Provider Consultations. La Trobe University. Melbourne

⁵ Health Issues Centre. 2008. *Report on consultations with Alzheimer's Australia*. Melbourne.

Discussion sessions with consumer and carer peak groups

Two discussion sessions were held at the beginning and end of the project with a total of 14 representatives of consumer and carer peak groups. One session was held in October and one in November 2008. Both sessions were held at DHS. The invitation list for these sessions was compiled and finalised in collaboration with DHS.

The aim of the initial session was to give participants the opportunity of having a discussion around the following points:

- What a HACC service should look like to satisfy the needs of those you advocate for
- Your views on the draft Active Service Model
- Ways in which you and your group would like to participate more in the way decisions are made with regard to the ongoing development of the Active Service Model.

Participants at the initial discussion session with consumer and carer peak groups were:

Dianne Biermann, Alzheimer's Australia Victoria
Helen Dubberley, Ethnic Communities Council of Victoria
Lesley Hall, National Disability Services
Leigh Hillman, Carers Victoria
Lena Morris, Rumbalara Aboriginal Co-operative Ltd
Jenny Murray, MS Society
Debra Parnell, Council on the Ageing Victoria.

Findings from this discussion session were documented and included in the findings section of this report.

The second session aimed to examine findings from direct discussions with consumers and carers, and the draft strategies recommended for ongoing consumer and carer participation in the development of the Active Service Model.

Participants at the second discussion session were:

Helen Dubberley, Ethnic Communities Council of Victoria
Helen Bryant, National Disability Services
Leigh Hillman, Carers Victoria
Greg Ladgrove, Rumbalara Aboriginal Co-operative Ltd
Michelle Stoter, Victorian Indigenous Committee for Aged Care and Disability
Jenny Murray, MS Society
Debra Parnell, Council on the Ageing Victoria
Fred Chuah, Consumer, Victorian Ministerial Advisory Committee
Natasha Kukanja, Aged and Community Care Victoria.

Findings from this discussion session were documented and are included in the findings section.

Discussion sessions with consumers and carers

The aim of these sessions was to seek the perspectives of consumers and carers on the way that services are being re-focused to assist people who use HACC services, such as older people and people with disabilities. The sessions also aimed to identify ways in which consumers and carers would like to participate effectively in the way decisions about HACC services are made.

Six discussion sessions were held, with a total of 41 consumers and carers between October and November 2008 in metropolitan and regional Victoria. Four of the sessions were organised with the support of the following organisations:

- Alzheimer's Australia Victoria
- Darebin Community Health Service
- Boort District Hospital
- Ballarat City Council.

Sessions were held at the following locations:

- Alzheimer's Australia Victoria with members of the Consumer Advisory Committee
- PANCH Health Service with the Italian group participating at a Planned Activity Group (PAG)
- Boort Day Centre with the *Men on the Move* group
- Ballarat Day Centre with a group of participants at a Planned Activity Group (PAG).

Two general sessions were held at DHS with consumers and carers invited through several organisations including Carers Victoria and the Council on the Ageing. One participant contacted Health Issues Centre directly to express interest in attending the sessions after seeing a note about the project in Health Issues Centre's *eNews*.

Findings from these discussion sessions were documented and are included in the findings section.

Face-to-face interviews with consumers and carers

The aim of the face-to-face interviews was to gather information from consumers and carers, who otherwise may not have been able to participate in the consultations, by visiting them in their homes. The purpose of the interviews was to learn from consumers' and carers' personal experiences and to ask them what a HACC service that satisfies their needs should look like. The interviews also aimed to gauge their views about the way services are being refocused, and to identify ways in which they would like to participate more actively in decision-making about these services.

Face-to-face interviews were held with a total of eight consumers and carers; five were carers and three were consumers. These interviews were organised with the valuable collaboration of the following organisations:

- Boort District Hospital
- Ballarat City Council
- Darebin Community Health Services
- Carers Victoria.

The three interviews with consumers were held in Boort, Ballarat and Northcote. Of the five interviews with carers, two were held in Ballarat, one in Boort, one in Hoppers Crossing and one in Watsonia. One of the carers contacted Health Issues Centre directly to express interest in contributing to the project after seeing a note about the project in Health Issues Centre's *eNews*.

Findings from the interviews with consumers and carers are included in the findings section.

Recording of sessions and interviews

Extensive notes were taken at discussion sessions and face-to-face interviews. Interviews were digitally recorded, selectively transcribed and used to present verbatim quotes in the final report.

Reimbursement

All consumers and carers who participated in the sessions and interviews were given \$25 in cash for their participation.

Analysis of the information

The transcripts of notes from sessions and interviews were analysed using content analysis. Emerging themes were coded and grouped according to the main lines of enquiry. These were: views of the current services; views about the ASM; and opinions about strategies for ongoing consumer and carer involvement in the implementation of the ASM. A further analysis was conducted to outline some implications of the findings for the ASM implementation.

SUMMARY OF FINDINGS

This section of the report contains a summary of the main findings from the literature and consultations. An extensive and detailed presentation of findings from the consultations is found later in the report.

Literature review

The literature and documents reviewed for this project included the Department of Human Services' Active Service Model Discussion Paper; Pilot Project evaluations, including Moreland City Council, Melton, Brimbank and Maribyrnong, Murrindindi, Royal District Nursing Service, Banyule City Council and Baw Baw Shire Council, as well as the Service Provider Consultation Report developed by the Australian Institute for Primary Care. The AIPC report included information about the written responses to the DHS Discussion paper from:

- Aged and Community Care Victoria
- Barwon Health
- Brotherhood of St Laurence
- Ethnic Communities' Council of Victoria
- Municipal Association of Victoria
- Multiple Sclerosis Limited
- Royal District Nursing Service
- Western District Health Service.

The documents reviewed also included the Health Issues Centre' report to DHS on a consultation session conducted with the Community Advisory Committee of Alzheimer's Australia Victoria in June 2008.

The review of the literature and documents showed that there is significant support for the ASM among service providers and some of the main consumer and carers peak groups in Victoria. The main views emerging from consultations with service providers, written submissions in response to the DHS Discussion Paper, and the available evaluation of the Pilot Projects include:

- The principles are applicable to all individuals requiring or receiving service support from health and community care sectors.
- The principles of the ASM are appropriate and consistent with initiatives being implemented in other parts of the sector, such as chronic disease self-management.
- The ASM should not be used as a cost-saving approach or to remove existing services.
- There was broad support for the implementation strategies; in particular, the development of an audit and planning tool to assist agencies;, workforce development strategies, and a communication strategy for the broader community and HACC-eligible clients.

Other relevant comments found in the literature and documents reviewed included:

- The principles and objectives of the ASM need to consider factors such as cultural sensitivity, and need to be implemented with careful consideration of the CALD and Indigenous person's readiness for supportive intervention.
- Establishing goal-setting in a way that takes into account the cognitive ability and motivation of the client.
- Shortages of allied health staff may be a barrier to achieving the aims of the ASM in some areas.
- Workforce development is needed to assist with a change in workforce culture and skill development.
- Services will need to instil the clients with confidence that they will be able to recommence services again if they are in need of them, in order to be accepting of more episodic care.
- The need for a communication strategy to overcome community and client perception of service delivery and entitlement.
- The cost of and lack of access to transport are barriers to implementing the ASM successfully, especially in assisting clients to access health promoting and socialisation activities.
- Engaging in health-promoting activities with clients promotes a more valued and meaningful relationship between workers and clients.
- Assessment processes should:
 - Be holistic and person-/family-centred and consider current roles, interests, abilities and aspirations.
 - Use a strengths-based approach and identify life areas with the potential to be strengthened or maintained.
 - Seek opportunities for capacity-building and restorative care.
 - Consider the needs of younger people in need of HACC services.
 - Take into account cultural issues, Indigenous background, disadvantage, dementia, risk of homelessness.
- Planning should consider the trajectory of the client's health and life-changing circumstances and should be documented, monitored and evaluated.
- The time and costs to achieve goal-directed plans for each individual has to be scoped and recognised, as it is likely to be greater than current time necessary to assess and implement HACC services.
- A need to reconsider the name: 'active service' has a connection with 'war time'; infers a specific prescriptive model; and can be interpreted as focusing mainly on physical activity.

Consultations

The discussion sessions held with consumer and carer peak organisations and with consumers and carers were fruitful and many suggestions were made with regard to ongoing consumer and carer involvement in the implementation of the ASM. Discussions also included interesting comments about the ASM and specific problems with current HACC services.

The main finding in relation to the ASM is that consumers and carers as well as peak groups welcome a service system that is flexible and centred on the needs of consumers and carers. Flexibility was seen as an important enabler for the ASM to work efficiently. Consumers and carers and consumer and carer peak groups believe there will need to be relatively substantial changes in the ways services are administrated and managed by service provider organisations. For example, there would need to be better assessment systems and a skilled workforce both at the administrative and at the workers' levels to enable active involvement of consumers and carers in decision-making.

Some consumers and carers and peak groups believe that the ASM will work best with consumers and carers who are able and have the physical and mental capacity to work collaboratively with service providers both at the administrative and direct care level. Some participants in these discussions suggested that the model may not be applicable to all HACC clients. This would include those clients with progressively deteriorating health conditions such as dementia, who may struggle to understand and to make appropriate adjustments to their changed abilities. It may also be difficult to work in partnership with those clients who lack mental capacity due to other psychiatric or neurological illnesses.

In terms of consumer and carer involvement in the implementation of the ASM, valuable suggestions were made about formal and informal strategies for participation at both the individual level of care and organisational/service provider level. Suggested strategies can be grouped according to the types of participation, from information delivery to partnership between service provider and clients. Some suggestions address DHS' role in ensuring effective consumer and carer involvement. Consumers and carers also provided valuable insights about barriers and enablers for this involvement to be effective and meaningful.

DISCUSSION OF FINDINGS AND IMPLICATIONS FOR THE ASM

Findings from the discussions with consumer and carer peak groups and consumers and carers have some implications for the implementation of the ASM. This section of the report presents a discussion of the findings from the literature review for the project, mainly the information available through the Australian Institute for Primary Care (AIPC) report on their consultation with service providers, and the findings from the consultations held with consumers and carers.

Discussion based on findings from literature and from conversations with consumers and carers

Some findings from the discussions with consumers and carers are similar to the findings from consultations with service providers detailed in the AIPC report, albeit with some differences in emphasis.

It is interesting to note, for example, that both service providers and consumers and carers acknowledge the need for workforce development and assessment processes that reflect the holistic needs of the person and their family. This has obvious implications for the implementation of the ASM. While service providers identified, for example, the need for more allied health staff and changes in staff culture, consumers and carers identified the need for better assessment systems implemented by skilled staff at the administrative and at direct care levels.

Consumers and carers were especially interested in better assessments and coordination of services at administrative level, so that services offered to the person are related to their needs. Examples of such services included: services during times of crisis; services provided across Council boundaries; knowledge of other services available to the person; and better communication between services. According to consumers and carers, improvements in these areas would allow for a more realistic implementation of the ASM.

Both service providers and consumers and carers agreed that the principles of the ASM should take into consideration the cognitive ability, physical capacity, motivation and readiness of the person to achieve the goals outlined in their plan. Service providers emphasised the need to be mindful of the trajectory of the client's health and life circumstances and that plans need to be reviewed and monitored over time. Consumers and carers emphasised the need for a model that takes into consideration the changing nature of their lives and needs. For example, respite needs of carers may change according to the circumstances of the person they care for, or needs of clients may change according to the progression of their condition.

Findings from the conversations with consumers and carers also referred to the needs of people affected by degenerative health conditions such as Alzheimer's disease or advanced states of Multiple Sclerosis. Consumers in wheelchairs or affected by back or muscle debilitating conditions, or suffering from sight loss or mental health conditions, were adamant that the support they receive from HACC workers is essential for them to be able to remain at home.

Discussion based on findings from conversations with consumers and carers

Most participants in the discussions were appreciative of the services they receive and some said that it is the HACC services they receive that allow them to stay at home. Many participants have received HACC services for several years. For some participants, attending social activities and sharing time with others or having time off from their caring role has been very important.

Consumers and carers emphasised the need for an ASM that is flexible and responsive to the needs and preferences of consumers and carers. This reflects the person-centred approach of the ASM as outlined in the DHS *Active Service Model Discussion Paper*. Consumers and carers expressed the need for a service model that respects people's needs and preferences and a system that is flexible enough to accommodate a process of negotiation about the number of service hours allocated and the type of services provided. Consumers and carers emphasised the need for an ASM that focuses on the decision-making capacity of the person and/or their family and the possible options laid in front of them. For example, consumers and carers would benefit from an ASM that considers their preferences in terms of timing and type of services received (e.g. day of the week and hour of the day to receive the service, or having the choice of gardening vs cleaning).

Most consumers and carers were interested in being able to negotiate and come to agreements, through a personalised assessment process, about the type of services they needed and when and how they would like to receive them. For example, starting with the person and asking them: 'What do you need?' 'What do you want?' or asking consumers, for example: 'If you have access to 90 minutes of services, what would you want done?'

Some carers also felt that maintaining a flexible, restorative focus, even in the face of progressive deterioration, would be of benefit. For instance, some carers of clients with dementia felt that it was important to continue to set physical goals and encourage exercise in their family member with dementia, as maintaining physical fitness has been shown to delay the rate of progression in some cases (e.g., to get blood pressure down and avoid further strokes).

These findings may have implications for the implementation of the ASM as they outline some of the changes needed in the provision of HACC services. For example, consumers and carers believe that staff who conduct assessments need training to be able to offer a holistic and person-/family-centred plan. Staff would need to know the whole range of services available, have a flexible approach to service provision and have well-developed personal skills.

A challenge for the implementation of the ASM is the fact that some consumers and carers were sceptical about the capacity of the HACC service providers to implement an ASM-type of model given the limitations and challenges of the current system and current culture of staff within the HACC system. They were keen to see some of the problems in the existing system fixed in the first instance. For example, they highlighted problems related to change of staff/workers, change in time scheduled for services, lack of flexibility in the delivery of services, difficulties in understanding why they were eligible for one service not another, and lack of capacity of the administrative staff to schedule or re-schedule services according to clients' needs.

Some carers found it difficult to isolate issues with the HACC system from other aspects of the aged care system (e.g. packaged care) and were concerned that the changes would only relate to a small component of the overall system.

Discussions also suggested that an ASM should be based on assessment processes that include the carer or family members and that this assessment process should be undertaken by a skilled workforce. For example, the criteria for assessment should be based on consumer and carer experiences to reflect their needs and preferences. Further, staff should have the skills necessary to deliver services that are flexible and respond to a plan developed from a partnership between clients and the service provider.

Based on experiences with 'direct payment' systems at the Commonwealth level, some carers were interested in exploring the possibility of expanding the ASM approach further towards consumer-directed models. Nevertheless, most carers, even those currently using a direct payment model, advised caution in thinking about implementing this model as it requires high-level management skills, including computer literacy and understanding of financial management.

Participation

At the individual level, consumers wanted the opportunity to provide feedback on an anonymous basis. Most had never been asked to offer their feedback about the services they have received. This may constitute a clear indication to the ASM team that ongoing consultation at the individual care level about the ASM would be a welcome initiative among consumers and carers. Among the methods for this were feedback surveys, direct conversations with consumers and carers, and letters.

At the organisational level (ASM team and service providers level), consumers and carers proposed a series of methods for participation including formal structures (such as carers' groups or forums, consumer advisory groups), committees that are subgroups of existing umbrella organisations (e.g. COTA, Carers Victoria), and critical reference groups. These groups could provide ongoing advice to the ASM team and to service providers.

Further, consumers and carers were interested in participating in the training of administrative staff and workers as they consider the consumer and carer perspective to be a crucial element in the training of staff who implement the ASM.

Consumers and carers also argued that it would be valuable to consider having an advocate/advisor with the consumers and carers at assessment time. This would be a valuable support in decision-making processes about services required.

EXTENSIVE PRESENTATION OF FINDINGS

This section of the report present a detailed account of the findings from discussions with consumer and carer peak organisations and consumers and carers users of HSACC services.

The discussion sessions with consumer and carer peak organisations and with consumers and carers users of HACC services were fruitful and many suggestions were made in terms of ongoing consumer and carer involvement in the implementation of the ASM. Discussions also included interesting comments about the ASM and main problems with current HACC services.

The main finding in relation to the ASM is that consumers and carers, as well as peak groups, welcome a service system that is flexible and centred in the consumers' and carers' needs. Flexibility was seen as an important enabler for the ASM to work efficiently. Consumers and carers and peak groups believe there will need to be relatively substantial changes in the ways services are administrated and managed by service provider organisations. There would need to be better assessment systems and a skilled workforce both at the administrative and at the workers' levels to enable active involvement of consumers and carers in decision-making.

Consumers and carers and peak groups believe that this model will not work for people with a disability or with health conditions that do not allow them to be active participants. This model will work well for consumers and carers who have the physical and mental capacity to work collaboratively with the service providers, both at the administrative and the worker level.

In terms of consumer and carer involvement in the implementation of the ASM, valuable suggestions included formal and informal strategies for participation and participation strategies at individual level of care and at the organisational/service provider level. Strategies could also be grouped according to types of participation from information delivery to partnership between service provider and clients. Some suggestions address DHS's role to ensure effective consumer and carer involvement. Consumers and carers also provided valuable insights about barriers and enablers for this involvement to be effective and meaningful.

Following is a detail account of the findings from the discussion sessions.

Findings from the initial discussion with peak groups

This summary includes findings from the initial discussion held with seven representatives of consumer and carer peak groups. The summary is presented according to the topics discussed, including views about current HACC services, views about the ASM and suggestions about ongoing consumer and carer involvement in the implementation of the ASM.

Views about current services

- We see that services are withdrawn as a person's health deteriorates.
- There is a need for more individualised funding and this requires a huge cultural change.
- For all the talk about flexibility, workers want to do it but services aren't able to be flexible.

- Funding structure doesn't facilitate creativity. There is no new growth or ongoing funding, only pilot funding. Funding is about service provision within a box.
- The PAG among ATSI communities is the one that gets people out. Being active through PAG is good. There are issues with eligibility as some participants don't meet criteria but if they don't access PAG, they have no support. The longer people remain at home, the more isolated they become. PAG is also about prevention for the younger groups.
- HACC is also about young people with a disability.
- Complex medical issues need to be addressed in the current system. For example, providing services to people with a catheter. The RDNS continence management program in Moreland is perceived to be working well. Sometimes people are denied services because of complex needs; that is, catheter, dementia.
- People are confused about services available. People are told what they can get; for example, meals. It is a reactive model and there is a lack of resources which places tight parameters on the person and their choices.
- Need for more communication between services.
- Expectations are high but limited choices are offered.

Views about the Active Service Model

Concerns about the model

- Person-centred care is about enabling people. In talking with consumers you may raise their expectations about services. Consumers may have concerns about what the model will look like in the end.
- Terminology is a big issue and clarification is needed. For example, Health Promotion principles aim to assist people to maintain an active life even within the constraints of their health condition. Health Promotion is seen as focusing on getting people back to health rather than being 'person-centred', which is about getting the person able to participate. We want people to remain active regardless of their condition.

Consumer- and carer-centred model

- A lot of people are capable of doing more around the home.
- There is a need to communicate to the consumers that the ASM is about starting with the consumer. Starting with the person and asking them: What do you need? What do you want? It is a fundamental approach to ask people what they actually need. Asking consumers, for example: If you have access to 90 minutes of services, what would you want done?
- The current system views unpaid carers as another support structure (i.e. "son to mow the lawn"). The ASM has the potential to be more enabling for carers.
- The framework needs to be complemented by a carer and family-centred approach. This means doing carer assessments and ensuring more time is dedicated to assessments. Staff conducting assessments need to acknowledge the role of carers. There is also a need to address the specific needs of young carers. The ASM model should work towards seeing people as family members.

Allocation of resources

- It is implied in the ASM that people can manage their care. Will 'direct payments' be considered? There are different ways of providing support. For example, if you are only talking about providing limited hours of service per week, could you give people \$2000 and give them the choice about the types

of services they can receive, and have them provide the receipts. This approach doesn't work for everyone. It is about the individual and the support they need and how they want them managed. What would you want done in those 1½ hours? What is possible? Could people be given the money and outsource the services; for example, meals for a month?

- The model tries to give consumers more say, but this is a sector constrained by a lack of funding and capital.

Assessment issues and coordination of services

- The model needs to include adequate assessment; this is especially the case when there is a crisis or illness because this is where problems arise.
- Carers and respite: services need to be able to do a comprehensive holistic assessment, this requires CREATIVITY.
- There need to be consistency across councils with assessment approaches. You need advisors to have good knowledge about where to go for activities and they need to have links with Council. Services need to be provided outside Council boundary areas. For example, if people move between LGA, consumers should not have to have another assessment. Assessments should include thinking creatively and having knowledge about what's out there; for example, other services, swimming.
- Need for more communication between services. Services need to be able to offer other services. The assessing agency doesn't need to see itself as the end point for decision-making. Instead, living at home assessment is meant to provide a more holistic service. People will mostly ask for what they know is available, but this means they are not accessing the range of services and activities available to them.

Workforce

- Workers need to be appropriately paid and trained to offer clients a holistic model of care. There is a need to enhance the skills of workers in participation and facilitation.

Current practice

- Some service providers run HACC programs in gyms.
- One of the participants describes how they, as a peak group, conduct their assessments: *We sit with them and discuss their needs and we offer advice about the services that are available.*
- Another participant said: *We let them tell us what they want; we look at family and we look at supporting the family as well as the older person.*

Other comments

- Suggested name: 'Active Australia'; 'consumer directed model'.
- Keen to see it work.
- Should we add 'communities' to the 5th point of the five main principles?

Strategies for ongoing consumer and carer involvement

General comments

- Use not one strategy but a range of strategies.
- Build consumer and carer involvement at the start.
- Seek more than feedback on the services consumers and carers receive. It was recommended that DHS develops an evaluation plan and this includes talking to more people receiving services and asking them the question: is it meeting needs?

- Consider that consumers may say that you have to fix the existing issues before they provide more input.
- Ensure that change occurs from feedback. DHS has to commit to reform and provide feedback about progress and changes.
- Establish independently managed consultation processes.
- Ensure that each organisation has its own feedback and complaints process. But be mindful that “people don’t bite the hand that feeds them”.
- Ensure consumers receive support to participate; support would enable people to be informed and to make contributions; there also need to be a commitment to advocacy.
- Conduct regional consultations. Need to have a mix of rural and metropolitan perspectives.
- Acknowledge that this is a changing client group; there is a risk of missing input from clients.
- Seek feedback from past carer, former users.
- Consult with non users of HACC; for example, Rotary, Probus.

Involvement strategies

- Hold community meetings.
- Provide clear communication about what services are available; for example, transition from hospital to home, one-stop-shop for information.
- Hold broad consultations not just at peak body level.
- Consider consumers as collaborators and partners.
- Establish a commitment to advocacy; provide funding for an advocacy mechanism.
- Conduct HACC customer satisfaction surveys; need to develop well-defined consultation process.
- Consider approaches that enable people to talk about their experiences. This is much more effective for quality improvement than measures of satisfaction; use a variety of methods to capture experience rather than satisfaction surveys.
- Write to the ATSI organisations to inform them that a consultation will take place.
- Carers suffer from form ‘fatigue’; they fill in so many forms so it needs to be a CONVERSATION. Peaks can organise it and people may be more upfront.
- Consider that committees are very different roads to go down, often they can be tokenistic.
- Conduct annual evaluations; they are better than committees.
- Call for written submissions.
- Consultations through peak bodies.
- Consult ATSI communities through key organisations.
- Establish a consumer and carer advisory group. The risk may be regarding representation.
- Use qualitative techniques such as interviews and life stories.

Findings from discussions with consumers and carers

This summary includes findings from the six discussion sessions with a total of 41 consumers and carers and eight interviews with consumers and carers. The findings are presented according to the topics discussed, including views about current services, views about the ASM and suggestions for the ongoing involvement of consumers and carers in the implementation of the ASM.

At interviews and at discussion group sessions extensive written notes were taken and they have been used to paraphrase the consumer and carer views in this

section. When appropriate, verbatim quotations (in italics) from transcripts of digitally recorded interviews with consumers and carers have been inserted to exemplify the findings.

Views about current services

- Participants are generally content with the services and have been receiving them for a number of years.

The reason we want this help is because X [wife] is nearly 88 and I am 90 years old, and she is not a chicken any longer, so this help is absolutely wonderful.
(Consumer)

The assistance we get is 100 per cent and the people are excellent. All has been done very well, and each person that comes does their work very well. (Carer)

I think that I have to be involved and by being X's carer and I'm more than capable to manage and all falls into place. (Carer)

We only have to ring... we have a wonderful service here. They do it willingly and exceptionally well.
(Consumer)

There have been times when it is absolutely wonderful. Like over the school holiday period when one of the girls takes my girl to the movies or do something and there may be a bit of travelling but all runs very smoothly. (Carer)

- Home care and personal care are valuable services that have allowed some participants to stay at home.

Keeping my wife at home is important for me and for her; the environment is more friendly than in the hospital. (Carer)

We can't help getting older and sometimes... and this applies to X [wife]... sometimes she wants to do this and that, but sometimes she can't and we need to bear in mind, we think that we can but we trip up because we are not really capable to do it. That's why we are so grateful of the help that comes in. We try to do as much as we can. (Consumer)

- Attending PAG helps people to be involved and socialise with others.

[Tuesdays at Day Centre] it's my only outing. On Tuesdays I go to day centre, we have a talk and lunch and I feel happy. (Consumer)

- Outings once a month are very special for some consumers as they enjoy the trips and visits to other places and share lunch with a small group of people.

- Respite care allows carers to have time off from their caring role.

So I go down to my shed; it's relaxing. (Carer)

- Some of the more frequent complaints about current services included:
 - Lack of services

They don't give you an incentive to stay at home. I am upset when I see the lawn not mowed. That's why people go to the nursing home when they can't cope anymore. We are not getting the help that we should be getting. (Consumer)

- Changes of staff/workers. This affects the carer's capacity to organise the change-over to the new person; some participants would prefer to know in advance when the current worker is not available so they are able to explain the routine to the new person; services should consider the effects that the change of worker may have on the consumer and the carer.

I have very positive things with my respite services and also very negative things. Up until Monday I had no respite because the girls I had were not available to me and when I call to get respite they had nobody, so they said that they will introduce someone new for you, which I always find very difficult because my daughter is autistic and is also disabled and my son has learning difficulties as well, therefore I don't leave my children with anybody and I like to meet the person before I feel safe enough to leave them. So I have to go through the process again!... I have one of the girls for five years and the other girl for four years which was fabulous but they have given me no warning. (Carer)

- Changes in time schedule for services; carers would like to know in advance when and why changes occur. Changes on service delivery time (e.g. personal care) and delays may affect their routine or doctors' appointments.

It was more trouble than it was worth it. You could never guarantee on anyone arriving on time and of course when you have someone with ABI [they] need a regimented routine and when someone says that they are going to be here at 9.00 o'clock, my God, better be here within 10 minutes either side, not 45 minutes later!! (Carer)

The time they provide the services change; for example, personal care, is sometimes at 8.15 or at 9.30 am and I have to prepare my wife for those different times, [it] gets confusing. The only complaint is the timing of the services, better roster system is needed; someone with the skills at rostering. Schedule more in tune with the client's needs. It would suit me better if the services happen at the same time each time. (Carer)

[Council services] you seem to have a new lady every second week; she didn't know what was going on and you have to run through it again. And when you call they didn't seem to know what was going on, where their own staff were, what the timing was. (Carer)

- o Lack of flexibility in the delivery of services (e.g. respite hours)

It needs to be flexible. Flexible. I was locked in; there was no consultation [about hours of care]. (Carer)

- o Some consumers complained about assessments processes.

Recently I have X and it was wonderful but in the past I had a lady from the Council, [she] come to my home and sat at the table with her and all what I said was I'm happy with what I am receiving, can I keep receiving what I'm getting now; I don't want anything more or anything less. And she ploughed into me and she said that in the school holidays I may get something extra each week but [...] that I was being unreasonable because there were many other families out there that desperately need the services and that I needed to look at other services myself. I am very aware of other families' needs but you are in my home looking into the needs of my family, my situation and me personally and you are telling me that I need to cut back!! Since then I have been re-assessed and the other lady came and she was lovely and she said that she didn't see that what I asked for was an issue. (Carer)

[ASM implementation] it would take a whole revision of the HACCC services. I understand that there are always more people requesting the services than services available. [HACC services] came in, it didn't matter what your needs were; 'these is what we are going to give you' and it was basically 'take it or leave it because we have other people to give it if you don't like it'. (Carer)

- o Quality of the meals on wheels; some thought they were plain and always the same, while others were happy with the meals provided.

I had meals on wheels when I have the shoulder operation because I couldn't move, I had my arm on a sling for six weeks; I couldn't cook. Some were quite good, some I couldn't eat. But you got to accept that you are not going to get restaurant-style meals. As far I am concerned meals on wheels are a real emergency-type thing and I was in that situation. When the arm was out of the sling, and I could move it, I went back to doing the cooking. (Consumer)

Complaints system:

- Some participants said that people don't complain about services they receive because it is not their attitude to complain, but may express their issues directly to the worker. Some participants said that people don't want to complain about services for fear of losing hours allocated.

You can't give them feedback because you can't, because you would be considered a malcontent person. (Consumer)

The feedback question is difficult because many people feel nervous about giving any feedback. (Consumer)

There is a fear amongst carers that if you speak much you are going to be penalised. There is a genuine fear. You will find that ninety 90 per cent of carers are very appreciative of the services they have got and [...] once you got it you don't want to lose it. So you tend to hold your tongue. I cannot emphasise strong enough that it has to be an independent third party. (Carer)

- Some consumers said that they fear requesting a re-assessment (even though their needs may have changed over time) for fear to losing their allocated hours.

Fear of assessment should not exist: why should parents feel frightened for what they receive? (which is already very little compared with their needs). (Carer)

I tell the Council when I'm not happy but they tell me that there are lots of other people who need services. (Consumer)

- Complaints system should be available for clients that are not as articulate, are old, or from CALD backgrounds.

Support with paper work

- One carer said how he would benefit from help with the paperwork associated with his wife having been diagnosed with Alzheimer's two years ago and then having to organise home and personal care. Most recently he has more paperwork associated with Medicare and doctors' appointments because his wife has been diagnosed with breast cancer and has been admitted to hospital on a few occasions.

Councils

- Some consumers and carers have noticed differences in what some councils offer compared with others. There are strict council boundaries that affect their eligibility and also differences in the frequency of the services.

The girls that I have had over the years have been exceptional, they are perfect, I never had any problems. But it always seems [that the problem is] the organisations... because when I had to move houses, they told me that I couldn't have my respite because I

moved into a new zone... there are Council boundaries.
(Carer)

- There was some concern about how councils cope and plan for demand of services with the increase in the ageing population in certain geographic locations.

Information about services available

- Participants want to receive more information about services available and eligibility criteria. There is an issue that some consumers may lack the capacity to understand this information and some people may need support on this.

Changes of administration of services to the federal government

- Several questions were posed regarding the possible change-over to federal administration of HACC services: Would this change affect services? Would consumers and carers receive services still from the same councils? Can clients choose other providers (e.g. meals on wheels)?

Administration and workforce

- Some participants referred to the need for better administration and management of workers' shifts.
- Some participants referred to the need to have better skilled assessment personnel; there is a need for better trained workers and assessment teams; assessment may be an emotional issue for some consumers and carers and the process should be managed with good personal skills.

It's the administration side of things, you are dealing with parents that are under immense pressures and they are in such a difficult situation. The person you speak with is your care manager: they need to have some understanding. But from my personal experience, lots of the time you find that you are an inconvenience, that you are ringing and that you are just a number. You are ringing because you need a couple of hours and you are giving them something of you, [by telling them about] the difficult times you are having and how distressed you are or that you are going through something, but you are not getting anything [from them]. They don't suppose to be psychiatrist or anything and they are there to run a service but they need to have a bit more empathy with the person they are speaking to because when you ring all what you want to know if it's possible. (Carer)

- Some participants suggested that allocation of hours should be more flexible to account for the changing needs of clients, especially carers as their needs for respite services may change over time or on occasions. For example, if the person they care for is admitted to hospital, they do not need the services, but other times, they need more as they themselves may be sick or other members of the family may be ill.

- Some participants referred to the strict Occupational Health and Safety regulations that hinder the standards of services (e.g. workers are not allowed to move furniture).

Because my wife and I were in different bedroom, they would come and do the bedroom, the shower, the toilet and the floor but they wouldn't do the basin and I asked them why... they said: it's OH and S... OH and S was the excuse for everything and anything, in fact it was an excuse not to do anything! (Carer)

- Some participants referred to the quality of services (e.g. poor cleaning standards). Others accept that there is a diverse range of standards of cleanliness in the community.
- Some participants said that on occasions it is the worker who advocates on behalf of a client because they know the situation in their homes.
- Some participants identified the issue of the low rates of pay for workers and asked if they pay for their own transport?
- Others identified the issue of change of workers. It was suggested that this change-over of staff may have to do with the fear from services that clients 'get too close' to the worker and may be liable to been exploited. Is 'getting too close' an issue for clients? Is it really a problem for the worker?

Views about the Active Service Model

- Some consumers and carers suggested what the ASM should be like:

I think that it comes down to being approachable; you should be able to approach and feel comfortable ringing and not feel afraid that you are like you are ringing at the wrong time. (Carer)

It would be lovely if it really made people feel that this is our service and we are part of it as it's enjoyable to us and no,: 'Oh my God my normal person isn't coming today!, Who am I going to open the door to today?' or 'what will that person be like and would they be grumpy?!'... (Consumer)

- Some participants reacted strongly to the idea that they could be more involved and active, especially participants in wheel chairs or with disabilities or with health conditions that make them sick or weak.

If we were active enough to do it ourselves, we wouldn't need support. (Consumer)

It's not fair, if you pay for something you shouldn't expect to have to do more work. (Consumer)

We receive what we require! (Carer)

It would depend of course on the degree of their disability and the reason why they are getting this care.
(Carer)

Consumers offered several ideas that could be considered in the implementation of the ASM:

- Do more social activities. For example, go ten-pin bowling, play darts. Good idea to take people shopping together but people like to go to different shops and need a skilled worker to manage a group.
- Have a change-over system for new workers, especially for disability services, so the client gets to know the new worker and is more involved in the worker's role.

There should have been a change-over process where one of the girls was in my home and the new one came as well. Respite is not just like house cleaning, is not that you just walk in and understand and just know, because you are learning all the time [about the child].
(Carer)

- There should be flexibility in service provision and clients should be able to share in the decision-making about where the available money goes (e.g. hours allocated for what purpose). For example:
 - It should be possible for a client to forego hours of cleaning a week for hours of lawn mowing or cleaning the gutters.
 - Clients should be able to pay a private service and then charge it to the government.
 - Have aged care packages that give users the choice to have a say in what types of services they want and when they want them.

Administration and workforce

- The model will need to be more flexible and transparent and accountable with efficient administration systems and skilled workers; including skills on how to treat people with respect and dignity.
- ASM would require transparency and good coordination of services and relationships with other departments; for example, education, DHS, local government.
- Home care, disability, aged care services are divided in silos and these need to be broken down.
- System will need to be able to manage demand and waiting lists.
- If direct payment was to be considered, the person managing the funds needs to be honest, well-educated, computer literate and know how to design a care package and its management.
- Example of direct payment could involve allocating \$5,000 to the consumer or carer who can spend on any services they require; for example, \$25 per hour

or \$35 per hour and manage what they really want, when they want it and when they need it.

- Professional organisations and services should recognise and acknowledge the experience of carers who have been looking after a person for a long time. New carers also contribute new perspectives and may ask key questions (e.g. young people that are carers).
- The ASM could have a component for 'emergency services' (such as a call centre similar to the Commonwealth Carers Service—but better and localised) to address the needs of clients that need occasional services sometimes but not always and not on a regular basis.
- One consumer asked: *Would the workers get paid the same if the clients do some of the work?*

Information

- A better model will require more information about what is available and the criteria for eligibility. It's not only for the aged and frail; it's also for young people with disabilities.

Assessments

- Decision-making has to be better implemented with more flexible assessment processes and skilled staff and the carer should be part of this process as well.

What Council does not understand is that you may have a family that's going through a difficult time for a short amount of time (it may be a three months, things that happen in the household, it may be an operation) when they need double the amount but then they may get back to normal, but I think that it should be flexible enough to allow for that to happen. (Carer)

[Involving the carer]... that's has always been a point of contention with any carer. I think that [the problem of] dealing with any organisation is that 'hey don't ask the carer' what services do you want?' and 'why do you want them?' and 'how is it going to help you?' They come and tell you this is what we are going to do and you can say 'yes' but I cannot say 'I can cope with that OK but I can't cope with that'... but it's not the mindset. (Carer)

- System should eliminate unfairness; for example, clients with severe conditions should get more services according to their needs; assessments should reflect their real needs and acknowledge that in some cases the client is NOT going to get better (e.g. MS, epilepsy).
- Criteria for assessment should be based on consumer and carer experiences. For example, a carer looking after a person with a severe condition should ask: *'if I didn't do this, the person I look after would be dead'.*

- Forms for assessment should reflect real needs and a better and more efficient process for assessment is needed, with special consideration for CALD clients, older and non-literate clients.
- Assessment should provide the basis for priority setting; for example, including questions about how to distribute the scarce resources available.

Some consumers and carers provided examples of instances where the ASM could have worked but didn't:

- A carer would have liked having more physical activity for a dementia client but the worker had to be persuaded to do this
- A client receives meals on wheels weekly but asked if she could get them fortnightly and start cooking her own meals as she was better, but her services were not able to accommodate this request
- A client was happy to do some cleaning but worker did not show flexibility.

Participants also said that some active sharing is already happening. For example, some participants said that they do the dusting (as workers cannot because of occupational safety reasons—one suggestion was that they use a mask) while the worker does the vacuuming.

I clean the top of the fridge and the worker does the lower parts.

I keep active because I have diabetes and walk after each meal.

Terminology and use of language

- Professionals use jargon that clients do not understand.
- The ASM should have the word "partnership" in it.
- Proposed name: PAP = Positive Ageing Program.
- "Consumer and carer/ service provider working together".

Examples from Commonwealth packages and 'direct payment'

- Some consumers and carers referred to their Commonwealth-funded direct payment programs and the pilot of the 'individual payment' system for disability services at DHS. They manage funds either allocated directly to them via a commercial bank or through an organisation which manages and allocates the funding in collaboration with the client.
- These consumers and carers said that the system is very demanding in terms of administration skills and that they have had to develop their own management systems to keep track of hours allocated, workers' attendance and shifts, etc. However, they suggested that the system allows them to manage the fund with flexibility.
- Some consumers and carers recommended caution about implementing a system of direct payment as there are not many people that could manage complex funding arrangements and the associated paperwork. One carer mentioned the risk of other family members intervening in the management of these funds. The person managing a direct payment system would need to be honest, be computer literate and be well-educated.
- Direct payment would be difficult for some clients. Carers need to manage finances and they are already overwhelmed.

[Direct payment]... oh... look I could, but there are lots of people that couldn't. There are all sorts of issues, the family dipping their fingers in, lots of things. It would cost an organisation to oversee it all, costing as much again... I don't agree with that. It's horses for courses with people and I would have great reservations about it. Some of the carers are not much better than the people they are caring for and I just wouldn't trust them to be able to manage payments for services, unless it was so simple, but is never going to be that simple. Some of these ladies, who are caring for their husbands, never have had to do any of the financial [arrangements] in the house and all of the sudden to ask them not only to be caring but to be managing the finances when they haven't for the last 50 years, I think that's too much to ask. (Carer)

Strategies for ongoing consumer and carer involvement

Establish formal structures for participation

- Face-to-face meetings twice a year with existing consumer groups (not only peak groups) hold monthly discussion at day centres.
- Consumer and carer advisory group/ panel/ parents' board with representation from all sectors/users and peak groups.

Council should have a parents' board and they should not be allowed to hand-pick anyone. I think that it should be done by another service, a disability service, perhaps XX (advocacy service) that have a knowledge of parents... have quite a broad [representation] of people with disability, cerebral palsy or perhaps Down's Syndrome. You need a broad range of parents. And perhaps you will need some people from the aged care, people with dementia to make up a panel. [...] They can invite you and the information comes with one of your bills, an expression of interest, 'would you be interested in...?' I don't think that you would get a hundred people, I think that you would be lucky to get 30 or 20 and by the time they turn up, you will get the right number of people, and you definitely will get that. (Carer)

- A group meeting of consumers and carers, then they can submit a form to the Council about their needs and views.
We can be involved with other people and let the government know how we are going and how we are... meet each quarter. Or if it's organised with letters, they can put them in the letterbox and collect them which can be easy for each household to do. (Carer)
- Establish a subcommittee of umbrella peak groups such as Carers Vic. and others.
It probably has to be through an organisation like Carers Victoria or Carers Australia. (Carer)

- Establish a group of consumers and carers that represent the broader issues but also the issues affecting people with specific conditions and special needs. They should be paid for their work. Service providers should be invited to meetings, including organisations such as the Municipal Association of Victoria.
- Establish a critical reference group, a group of people who are capable of having a say.

Have a critical reference group. Participants develop their own research and the information is provided to the services. (Consumer)

Consultation

- Talk directly with consumers and carers (interviews)

It may be a face-to-face rather than a written form; in fact a face-to-face would be very good and perhaps purely with the carer and not with the cared-for person being present, or perhaps something that could possibly be done over the phone. (Carer)

- Feedback surveys, collected and managed by an independent organisation but ensure that the information collected is used in an effective way and is processed to effect change.

You may have an on-off day for feedback and if there were sheets at that meeting where you can feel the positive things that have happened and maybe negative... in a service like this you need to have both sides. I think they should be able to hear the negatives and if there are many negatives all pointing in the same direction, that's an area that they need to look into a little bit more. This form can be sent to the panel and they put it together with others. (Carer)

I think [they can have] surveys. I don't think that there's enough surveys, I had a couple and sent them back. I think that I had a survey once in the last 18 months if that; whereas I think that it should be at least every year. The government should put in place... you know like XX (advocacy services) or if they want DHS or someone that high up or from the sector. They can have a person that analyses it or running the occasional once-a-month meeting. (Carer)

When the survey is being conducted it should be made quite clear that it is not a witch hunt and that they want positive feedback and recommendations about how can they improve, or maybe areas that they are not addressing and how they can take those up. (Carer)

- Encourage people to write letter to the services
- Provide feedback after a consultation takes place
- Use local and community radio. Talk-back for opinions

Provide information

- Provide information; brochures about services
- Use local papers, newsletters and websites to provide information
- Have a system to support people who cannot “digest” information about services available

Complaints systems

- Develop better complaint mechanisms; complaints process should be managed outside the providers’ system (e.g. advocacy organisation to handle and manage complaints); have telephone number to call but the person answering needs skills.

It should be a way to do it [lodge a complaint] without you looking like you have been difficult, when you are not. (Carer)

A survey would be good but it has to be run by an independent body, an outside body. (Consumer)

You may have a person at XX (advocacy service) that someone can ring and complain to them and have someone that could deal with the situation. I know in the past, they have done this. It has to be independent. (Carer)

Have a telephone number to call and the person answering has to be probably a person that has a background in disabilities and probably certified so some professional that has empathy and understand the situation. (Carer)

- People who are running the programs need to be supported to recognise that the purpose of feedback is for improvements.

It has to be done in such a way that the people in the program aren’t terrified by it either. That’s the other side of it: that the people who are running it may think that if there is a complaint their jobs would be on the line, so that needs to be protected as well. (Carer)

Training workforce

- Include consumers and carers in training of workers and administrative staff
- Have a system by which the administrative staff attend the home where the worker delivers the service to become familiar with what is the real situation

Use advocacy mechanisms

- Have an advocate/advisor from the consumer perspective at assessment time so they can support the consumer/carer with the assessment process.

I have told them that I would not have an assessment unless I have a person from XX (advocacy service)... this is a facility for early intervention or disabled and you can have a worker to come when the person from the Council comes. (Carer)