



Outcomes for older people with chronic and complex needs

A longitudinal examination of the use of
community services following an aged care
assessment in Victoria

A study conducted by
Australian Institute for Primary Care at La Trobe University,
Brotherhood of St Laurence
and St George's and North West Aged Care Assessment Services

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Glossary

ACAP – Aged Care Assessment Program

The role of the Aged Care Assessment Program (ACAP) is to ensure that frail older people (over 70 years, and over 50 years for Indigenous people) receive services appropriate to their needs and to promote the coordination of aged care services and other health and community support services (DoHA 2002).

ACAS – Aged Care Assessment Service

Under a cooperative working arrangement the Australian Government provides funds to state and territory governments specifically to operate Aged Care Assessment Teams (ACAT), known as Aged Care Assessment Service (ACAS) in Victoria (DoHA 2006a).

ACAT – Aged Care Assessment Team

ACATs conduct a comprehensive assessment of the restorative, physical, medical, psychological, cultural and social dimensions of care, and provide information and referral to appropriate services (DoHA 2002, p 9). Service providers are not eligible for subsidies for some services, unless the client has received approval in the ACAT assessment (DoHA 2002, p.47). Thus, ACATs have a gate-keeping function for some services.

ADL – Activities of daily living

ADL is a way to describe the functional status of a person. Occupational therapists typically look at 11 categories of ADLs. These are the activities that are fundamental for self care.

Baseline

The first point of data collection in this study, between July and October 2005. Some data gathered at this point was retrospective, for example information about community service use in the previous three months.

CACP – Community Aged Care Package

A CACP is an individually tailored package of care services which helps people with multiple care needs to stay living at home by coordinating the different services. The program is funded by the Australian government.

Carer

A carer in this report refers to the primary informal carer – a person, such as a family member, friend or neighbour, who has been identified as providing care and assistance on a regular and sustained basis.

CRC – Carer Respite Centre

Carer Respite Centres provide information and linkages to respite services available in a particular location. They assist carers in planning respite, or in accessing respite in an emergency (DoHA 2005a).

Case management

Assistance of a client with complex care needs from an agency worker who has been formally designated as responsible for ensuring the coordinated and appropriate delivery of services from more than one agency.

Community services

Community services are a system for providing support to sustain and nurture the functioning of individuals, families and groups, to maximise their development and to enhance community well-being (LGCSAA 2002). HACC provides 16 different community services to eligible people. This report focuses on eight of these services described in the table below.

Home care	Assistance with domestic chores, including cleaning, dishwashing, clothes washing, ironing, shopping.
Personal care	Assistance with daily living self-care tasks, such as eating, bathing, toileting, dressing, grooming, getting in and out of bed and moving about the house.
Delivered meals	Delivery of a prepared meal (widely known as meals on wheels).
Home nursing	Professional care from a registered or enrolled nurse
Day care/planned activity group	Attendance/participation in structured group activities designed to develop, maintain or support the capacity for independent living and social interaction which are conducted in a centre-based setting.
Home maintenance	Assistance with the maintenance and repair of the person's home, garden or yard to keep it in a safe and habitable condition
Transport	Assistance with transportation by an escort (e.g. in a vehicle provided or driven by an agency worker or volunteer)
Respite	Assistance received by a carer from a substitute carer who provides supervision and assistance to their care recipient in their absence.

There is also some information on other HACC services included in the report (see Tables 12a and 12b).

EACH – Extended Aged Care at Home package

Commonwealth-funded coordinated packages of care tailored to help older Australians with complex care needs to remain living in their homes (DoHA 2006b). An EACH package substitutes for a high-care residential place (Productivity Commission 2007, p. 12.22).

HACC – Home and Community Care

Commonwealth and state-funded services including allied health and nursing care, meals and other food services, domestic assistance, personal care, home modification and maintenance, transport, respite care, counselling, support, information and advocacy and assessment (DoHA 2007), available to people with profound, severe and moderate disability and their carers. HACC aims to prevent premature or inappropriate admission to residential care. (SCRGSP 2007, p.12.22)

IADL – Instrumental Activities of Daily Living

IADL are not necessarily done everyday but are important to independent living. Activities include using a telephone, shopping, preparing food, housekeeping, doing laundry, using transport, taking medications and handling finances. An IADL scale measures competence in these functions, which are less bodily oriented than physical self-maintenance.

MDS – Minimum Data Set

The ACAS Minimum Data Set (MDS) is a collection of data about ACAS clients (such as their age, living arrangements and activity limitations) and recommendations for long-term care. The Australian and state governments use this information to help plan for the Aged Care Assessment Program (DoHA 2006a).

Post-assessment period

The nine-month period between the recruitment date and the third follow-up data collection point (T3).

Preventative / restorative HACC services

These services, including allied health care at home, home modifications, equipment (e.g. a bed-stick or raised chair), linen services, counselling, aim to assist the client to attain or retain independent living skills.

Respite

Respite supports both older people and carers by providing age appropriate care and activities for the client and rest for carers. For approved older people, the cost of respite care is partially subsidised by the Australian Government (DoHA 2005b). Respite is provided in the following ways:

- Home and community respite is provided in a client's home or in the community, such as the worker taking that person on an outing or to a local park (DHS 2003, p.3). This care can also be provided overnight.
- Planned activity groups as described above.
- Residential respite is short-term care provided in a residential aged care facility. It is targeted to older people needing additional care due to illness, or because their regular carer is unavailable because of illness or holidays (DoHA 2005b)

The respite most commonly referred to in this report is residential respite, as very few people were using in-home respite services. Planned activity groups are referred to as such, not as respite.

S&CP – Social and community participation

According to the ACAS MDS definitions and coding guidelines activities involved in social and community participation refers to assistance or supervision with shopping, banking, participating in recreational, cultural or religious activities, managing finances and writing letters.

T1, T2, T3 – Time 1, Time 2, Time 3

Respectively the first follow-up data collection point (T1) undertaken approximately three months after baseline, the second (T2) undertaken approximately six months after baseline, and the third (T3), undertaken approximately nine months after baseline. *T3 participants* refer to the forty-five who participated at baseline and at T3.

Summary

Introduction to study

This is a study of older Victorians with complex or chronic needs recommended by the Aged Care Assessment Service (ACAS) to continue living in the community with the support of a range of community services. Participants were followed up three times at approximately three-month intervals following their ACAS assessment.

The purpose of this study was to examine the extent to which community services are used by older people with significant care needs and the extent to which community service recommendations are taken up. The study also aims to identify the factors that facilitate or hinder service uptake and to explore ACAS clients' and carers' experience of the services.

The study participants were recruited by clinicians from the St George's ACAS and North West ACAS at the time (or within two weeks) of the older person's ACAS assessment in mid 2005. Participants were:

- 33 clients who were recruited with their carer
- 28 clients who were recruited without their carer
- 18 carers who participated without the involvement of the ACAS client that they cared for.

Around three-quarters of the older people participants were aged 80 years and over and were female. They were living in a variety of housing situations, with 57 per cent living alone.

A total of 79 ACAS clients were represented in the baseline data collection with 45 remaining throughout the study. Of these, around three-quarters were receiving a full pension.

Key findings

Frail older people used a combination of community services, privately purchased support services (if they could afford these) and informal support from family and others in the local community to assist them in their daily lives. As would be expected in a sample of people with complex or chronic care needs, use of community services increased over the period of the study. Nearly three-quarters of the study participants took up at least one new community service in the post-assessment period. The community service that had the lowest uptake of all recommended community services was respite.

This study found that the community care system is meeting the needs of many frail older people; however, 38 per cent of study participants reported that the older person needed more help with daily living activities. Furthermore, the study found the community care system is working best for older people who have either a case manager or assistance from family members who help them access the required services.

For some older people, the situation was less than optimal. Three risk factors associated with difficulties in accessing community services were identified: social isolation of the older person, high carer burden and the older person reporting low mood.

Social isolation

Older people who had less than weekly contact with family members were less likely to access social and community participation services (such as assistance with participating in recreational cultural or religious activities) in the post-assessment period than those with more frequent contact

with family (44% compared with 64%). Although this was not a significant association, it suggests isolation is linked with use of fewer services.

High carer burden

While informal care can be the preferred way of supporting older people in the community for some older people and their families, it can become overly burdensome for some carers. Carer burden amongst carer participants was considerable. More than 40 per cent of carers at both the first and third follow-ups rated their emotional burden/strain as high (4 or 5 on a scale 0–5). High social burden/strain was reported by around one-third of carers at both of these follow-ups.

Carer burden was significantly associated with uptake of new community services in the post-assessment period. Fifty-six per cent of those reporting medium or high carer burden took up one or more new community service, compared with 82 per cent whose carer reported low carer burden. There was also a similar tendency for older people whose carers reported medium or high carer burden to be less likely to use social and community participation services than their counterparts.

Older person reporting low self-rated mood

Older people who reported low mood were significantly less likely to be recommended assistance with social and community participation than those who reported their mood as high (40% compared with 73%).

This group was also significantly less likely to take up a new community service in the post-assessment period than those who reported their mood as high (37% compared with 100%).

A positive relationship was found between use of community services and improved well-being for older people. The data indicated a trend for those older people who used certain services post-assessment, such as respite and social and community participation services, to be more likely to have improved mood scores than those who did not. Further, use of certain community services such as Community Aged Care Package (CACP) and respite had a positive impact on carer well-being.

Barriers to uptake of community services

In addition to personal factors that put older people at risk, the study found structural barriers to service uptake. These barriers included cost, lack of information, lack of availability of services and waiting lists. The study also revealed non-structural barriers to uptake of community services including some of the attitudes and values held by the older person or their carer.

Conclusion and recommendations

The main conclusion of this study is that achieving optimal post-assessment outcomes for most older people with complex and chronic needs will involve three key directions in the future:

- identifying and supporting older people at risk of not accessing community services
- supporting the carers of frail older people living in the community
- reducing the structural barriers to accessing community care.

The study found that the most important facilitator of uptake was having a case manager or someone to link the older person to the service. This suggests that careful consideration should be given to enhancing the case management and the care coordination models of community care for frail older people who are socially isolated, experiencing low mood or whose carer is experiencing high carer burden.

There could be roles for ACAS and HACC providers in achieving optimal post-assessment outcomes. ACAS and HACC assessments could include client and carer risk assessments using standard scales for measuring carer burden and client mood. Risk assessment could be a trigger for targeted support for older people and their carers.

For clients who are assessed as at risk of not taking up recommended community services, post-assessment support could be improved by measures such as:

- increasing the availability of ACAS care coordination (care coordination conducted by ACAS until the required supports have been put in place)
- ongoing monitoring of client and carer well-being by HACC providers
- increasing the availability of case-managed care at diverse levels of need.

The authors acknowledge that the following recommendations have resource implications for both the ACAS and HACC workforces and that they cross state and federal program boundaries.

Identifying and supporting older people at risk of not accessing community services

Recommendation 1: A standardised assessment should be made of the older person's psychological well-being and social resources at the time of the ACAS assessment.

Recommendation 2: Respite-recommended people who have a carer should also be recommended to a Carer Respite Centre (and assisted to access the CRC where necessary).

Recommendation 3: There should be post-assessment follow-up and assistance with linking to services for older people at risk of not accessing community services.

Supporting the carers

Recommendation 4: The ACAS assessment should include assessing the capacity of carers to provide care.

Recommendation 5: The ACAS assessment should include assessing carers' burden.

Recommendation 6: There should be post-assessment follow-up of carers experiencing high carer burden.

Recommendation 7: The support (physical, emotional and financial, according to need) for carers of frail older people living in the community needs to be enhanced.

Reducing structural barriers to accessing community services

Recommendation 8: The policy and funding constraints that influence the cost, quality and quantity of community services for frail older people should be examined.

This study has been able to demonstrate that limitations of the present community care system put certain groups of older people and their carers at risk of not taking up recommended services. The emphasis on community care solutions to enable people to remain in their homes seems likely to continue. It is therefore highly desirable that the present system is enhanced so that needs and potential risks are both effectively identified and addressed.

1 Introduction

Are the needs of older people with complex or chronic care needs living in the community being met? What is the role of community services in supporting older people? What are the factors that facilitate or hinder uptake of community services? To address these and other questions, the study explored ACAS client and carer pre and post-assessment experiences over a period of twelve months.

1.1 Overview of the literature

Few community care services are provided to individuals with the sole and explicit goal of delaying or preventing their admission to residential care, although such outcomes are often implicit for individuals and their carers and are commonly stated and explicit program goals (Howe, Doyle & Wells unpub.). Generally shorter term goals are articulated, such as providing immediate relief from a specific need or preventing functional decline. Changing the likelihood of admission to residential care may be a long-term goal, implicit in the provision of services, but other factors that come into play in the intervening period will also influence the outcome. Community care services may have only limited power to counter the effects of some of these factors, such as health episodes with severe disabling consequences or mounting disability from progressive mental and physical health conditions.

The best evidence of a relationship between receipt of community care services and delay/avoidance of admission to residential care was provided in meta-analyses of the impact of home-based support on older people (Elkan et al. 2001). The study found that the protective effect of provision of home care services was not dependent on targeting elderly people who were at risk—it was also evident when services were provided more widely.

Overseas studies have also shown a positive relationship between receiving community services and delay/avoidance of residential care admissions (Gaugler et al. 2005b; Long et al. 2005). However, this relationship is complex, influenced by the particular characteristics of older people, carers, and the service system. Researchers have proposed that delay/avoidance of residential care admissions could be achieved by measures to expand community care, such as relaxing strict eligibility rules for services, increasing funding to enhance service coverage and widening the range of services, reducing client payments, and restricting provision of residential care beds (Applebaum, Mehdizadeh & Strake 2004; Burr, Mutchler & Warren 2005; McCann et al. 2005).

Delaying admission to residential care also depends on the timing of community services. The earlier that older people receive community care services the longer their admission to residential care can be delayed (Gaugler et al. 2005a, 2005b; Stuk et al. 2000; Desai, Lentzer & Weeks 2001). These studies showed that small amounts of service at an early stage of decline are effective in delaying functional impairment, reducing physical dependency and improving psychological and social well-being. Conversely, there is evidence that Instrumental Activities of Daily Living (IADL) dependent older people who received no services are at a higher risk of adverse consequences (e.g. dehydration) and of admission to residential care.

These research findings are reflected in Australian Government aged care policy and practice which has increasingly emphasised community options for older people, and increased funds for community care in recent Commonwealth budgets. The 2004–05 Budget provided for a doubling of places for Community Aged Care Packages (CACPs) over three years and increased funding for Home and Community Care (HACC) services by 8 per cent on the previous financial year (DoHA 2004). It should be noted, however, that funding for community care is not projected to gain on that for residential care as a percentage GDP in the future (Treasury 2007).

1.2 Aged Care Assessment Program

The role of the Aged Care Assessment Program (ACAP) is to ensure that frail older people (over the age of 70 and over the age of 50 for Indigenous people) receive services appropriate to their needs and to promote the coordination of aged care services and other health and community support services for this group (DoHA 2002).

The model is not unique to Australia; for example the Netherlands, UK and France all employ multidisciplinary teams to determine and coordinate appropriate types of care or support for older people living in the community (Leichsenring & Alaszewski 2004).

Under a cooperative working arrangement the Australian Government funds state and territory governments specifically to operate Aged Care Assessment Teams (ACATs), known as Aged Care Assessment Service (ACAS) in Victoria. Assessment teams are multi-disciplinary and may include health professionals such as medical officers, social workers, nurses, occupational therapists and physiotherapists. ACAS teams should include, or have access to, a range of disciplines, skills and expertise sufficient to make accurate and complete assessments of the person's needs (DoHA 2002).

For an older person to access Commonwealth-funded residential care, residential respite, Community Aged Care Packages (CACPs), Extended Aged Care in Home (EACH) packages or flexible care, they must first be assessed as eligible by an ACAS. In addition to assessments, ACAS is also responsible for providing information, advice and assistance to frail older people who want to remain at home with support or who are considering moving into an aged care home. Their services are provided free of charge (DoHA 2002).

The outcome of the assessment is a care plan which may include one or more of the following recommended actions:

- new or increased level of community care services
- access to mental health or disability services
- entry into residential care, respite, CACPs, EACH or flexible care¹.

Where possible, in assessing a person and developing a care plan, an ACAS should involve the person's carer, family or other nominated representative, as these are an important element in developing the most appropriate care plan (DoHA 2006a). An older person can be assessed by ACAS more than once within the same year, depending on their care needs. Approvals for residential care, respite care, CACP, EACH and flexible care must be renewed every 12 months.

Approval for a person to receive care does not mean that the person is obliged to take up the approved care. Agreement to receive delivery of service is between the person and the service provider (DoHA 2006a).

Use of community services in Victoria

The most common recommendation following an ACAS assessment is for new or increased community services (Howe, Doyle & Wells unpub.). However, little is systematically known about the outcomes of these recommendations in terms of the experience of the older person and of their carer (if a carer exists).

Recent analyses of the matched records of individual older people across the 2004–05 Home and Community Care (HACC) and the Aged Care Assessment Service (ACAS) Minimum Data Sets

¹ Because access to residential care, respite, CACPs, EACH and flexible care is subject to eligibility requirements, ACAS has a gatekeeper function.

(MDS) found that the strongest predictors of community service use were gender and dependency (Howe, Doyle & Wells unpub.). Increased dependency was associated with increased service use. Older women with ADL dependency were consistently more likely to use community services than older men. Living arrangements were also related to accessing community service. Older people living alone were more likely to be using services than those with co-resident carers. Howe, Doyle and Wells (unpub.) have suggested that co-resident carers may avoid using services for several reasons, including concern about financial costs, fear of refusal of services, perception of poor quality services and diminished self-esteem associated with loss of their role as a carer.

1.3 Purpose of the study

The purpose of this study is to examine the extent to which community services are accessed by older people with significant care needs and to determine to what extent community service recommendations are taken up. The study also aims to identify the factors that facilitate or hinder service uptake and to explore ACAS clients' and carers' experience of the services.

Research questions

The research questions are outlined below:

1 Use of community services prior to ACAS assessment

- 1.1 What community services were older people using prior to ACAS assessment?
- 1.2 What factors were related to community service use prior to the assessment?

2 ACAS recommendations

- 2.1 What proportion of older people were recommended assistance with activities?
- 2.2 Which types of community services were recommended?
- 2.3 What factors were related to recommended assistance with activities?
- 2.4 What factors were related to community services recommendations?
- 2.5 What proportion of older people took up recommendations for assistance with activity limitations?
- 2.6 To what extent were recommendations for community services taken up?

3 Post-assessment use of community services

- 3.1 What proportion of older people took up new selected community services after ACAS assessment?
- 3.2 Which community services were accessed in the post-assessment period?
- 3.3 Was there a change in the number of selected community services that older people accessed?
- 3.4 What proportion of older people received packaged care following ACAS assessment?
- 3.5 What other sources of support do frail older people in the community utilise?
- 3.6 What older person-related factors influence post-assessment receipt of community services (e.g. dependency, socio-economic status and social isolation)?
- 3.7 What carer-related factors influence post-assessment receipt of community services (e.g. presence of a carer, carer-burden, carer relationship and level of assistance available from carers)?

4 Influence of community services on older person and carer psychological well-being

- 4.1 Does receipt of community services influence older people's psychological well-being?
- 4.2 Does receipt of community services influence level of carer burden?

5 Facilitators and barriers to uptake of community services

- 5.1 What factors facilitate the uptake of community services?
- 5.2 What factors are barriers to the uptake of community services?

6 Experiences of accessing and using community services

- 6.1 How satisfied were older people and their carers with the community services that they received? (For example, were services provided in a timely fashion, were they appropriate?)
- 6.2 What is the relationship between service satisfaction and client characteristics?

2 Research method

This research was a one-year longitudinal study of care and well-being outcomes for a sample of ACAT clients recommended for long-term care in the community. The study was devised as a pilot with a possibility of a broader scale investigation informed by the findings.

2.1 The study sample

The study participants were recruited by clinicians from the St George's ACAS and North West ACAS at the time of the assessment or within two weeks of the older person's ACAS assessment. The recruitment period was 1 July 2005 to 30 October 2005. ACAS clients were recruited to the study at the end of their assessment if they met the inclusion criteria and if in the clinician's judgement the additional interview was not overly burdensome for the older person. Criteria for inclusion in the study were:

- living in the community at the time of the assessment
- assessed in the community
- recommended new or increased levels of community services by ACAS
- English-speaking
- absence of severe dementia
- informed consent given by the participant.

The recruitment process involved explaining the purpose of the study, reading the Participant Information and Consent Form with the client and conducting a 10-minute recruitment interview. Carers (primary informal carers) who were available were also interviewed at the time of the assessment. Some carers of older people who were too frail to be interviewed were recruited on their own. A total of 79 ACAS clients were represented in the baseline data collection:

- 33 clients were recruited with their carer.
- 28 clients were recruited without their carer.
- 18 carers participated without the involvement of the ACAS client that they cared for.

2.2 Data collection, analysis and reporting

Older people and carers were interviewed at baseline and at three-monthly intervals for the next nine months. The baseline and follow-up data items are outlined in the Appendix. Baseline data collection commenced in July 2005. Follow-up data collections were conducted three months (T1), six months (T2), and nine months (T3) after the baseline interview.

Ethical considerations

During the data collection period interviewers provided information regarding various services to twelve older people and nine carers presenting with needs. In a few cases where significant deterioration in the person's situation was observed, the relevant ACAS was notified. The researchers recognised the potential impact on findings, but participants' well-being took priority.

Data analysis

Survey data was processed and analysed with the assistance of SPSS. Qualitative data from interviews was analysed using thematic and content analysis.

Data items

At baseline participants were asked about their use of eight community services and a range of health services in the previous three months (see Appendix). These questions were repeated at each of the follow-up interviews. Information on the use of other community services was collected in

the last follow-up. These services were: home visitor services, excursions provided by a community service agency, assistance with paperwork, allied health at home, home modifications, equipment provision, linen service and counselling. These data items address research questions 1, 2, 3 and 5.

Information on the participants' need for assistance with daily activities, recommendations for assistance with activities and community service recommendations was accessed from the 2005–06 ACAS Minimum Data Set (MDS). In the 18 cases where the carer was recruited without the participation of the person they care for, MDS information was not accessed. These data items address research question 2.

Participants were also asked about their activity limitations, social activity and their self-rated health status and mood. These data items address research questions 3.4 and 4.

Questions specifically for carers were designed to ascertain carer burden and their help or supervision of the ACAS client they care for. These data items address research questions 3.5 and 4.2.

Additional qualitative data were recorded by interviewers at each follow-up interview. Some qualitative questions were included in the questionnaires and further qualitative information not systematically requested from participants was recorded by interviewers. These data provide context to most research questions.

Both older people and carers were also interviewed about their experiences of accessing and using community services for the older person. These data items address research question 7.

Case studies

Case studies (using pseudonyms) have also been included to provide fuller description of some of the issues experienced by people in the study.

2.3 Participation rate

Of the initial 79 participants, 45 remained in the study throughout the entire 9-month period and 34 participants (43%) withdrew prior to the final follow-up interview (T3) (see Table 1).

Table 1 Number of study participants (older persons and carers)

	Baseline	T1 3 months	T2 6 months	T3 9 months
Older person only	28	14	17	12
Carer only	18	20	23	16
Older person & carer	33	20	14	17
Total remaining	79	54	54	45
Withdrawn	0	24	24	34

Of withdrawals, 65% were due to the older person's move to residential care, poor health or death (see Table 2). Older people who entered residential care ceased to be involved in the study; however, some of those who remained in community care but withdrew from the study due to poor health continued to be represented in the study by their informal carers.

Table 2 Reason for dropping out of the study (n=34)

Reason for non-participation	Number	Percentage
Older person died	3	9
Older person entered residential care	12	35
Poor health of older person	7	21
Lack of interest (Older person and/or carer)	8	24
Unable to contact (Older person and/or carer)	4	12
Total	34	100

2.4 Characteristics of the study participants

As Table 3 shows, comparison of the characteristics of the study population with wider data from the 2005–06 Victorian ACAS Minimum Data Set showed that, like the general ACAS population, the study sample included older people with different levels of dependency and living arrangements. However, due to the selection criteria (outlined above), the sample had a lower proportion of people with symptoms or diagnosis of dementia and of non-English speaking people than the average sample of community dwelling and community recommended ACAS clients.

Table 3 Characteristics of older person study participants and general ACAS clients

	Study participants %	St Georges & North West ACAS clients %	All Victorian ACAS assessments %
	(n=61)	(n=723)	(n=6355)
Aged 80+	74	70	64
Female	75	68	64
Lives alone	57	46	42
No carer	15	20	17
Dementia diagnosis/symptoms	10	22	22
High ADL dependency	10	15	12
High IADL dependency	64	73	65

Additional information focusing on community services use and recommendations appears in Table A1 in the Appendix. This shows that the study participants' use of community services at the time of the assessment was comparable to the general ACAS population, except that due to the selection criteria the proportion using no community services was considerably lower than among the general ACAS population. The study group had higher proportions of recommendations for HACC, low-level residential care and low-level residential respite.

As Table 3a shows, participants remaining at T3 were similar to the initial larger study group with respect to socio-demographic characteristics, use of health and community services or carer burden.

Table 3a Characteristics of T3 client participants (n=45)

	Number	Percentage
Lives alone	23	51.1
Female	28	62.2
No carer	6	13.3
Daughter* as main carer	22	48.9
High IADL dependency	31	68.9
Full pension	34	75.5
Private health insurance	13	28.9

* or daughter-in-law

Forty-five older people were represented in the T3 data collection. Twenty nine older people and 33 carers were interviewed. Six older people did not have an informal carer, 20 of the carers were the older person's daughter, two were daughters-in-law, two were sons, nine were spouses and six were other relatives or friends.

Older persons' self-rated health and mood

Data on self-rated health and mood at baseline was missing for seven T3 participants. Of those for whom data were available, 45% rated their health as 'fair' or 'poor' and 34% rated their mood as low ('a bit down' or 'miserable'). However, only 20% of the participants who rated their mood as

low were recorded as having diagnoses of psychoses and depression/mood affective disorders. Another possible code that can be recorded in the MDS is symptoms and signs of 'unhappiness', but none of the older people with MDS data was recorded as having unhappiness as a symptom. See Appendix for self-rated health and mood scales.

Carer burden levels

Carer participants reported the level of burden that they experienced through a five-point scale ranging from 1='no strain' to 5='great strain'. They rated five dimensions of burden/strain: emotional, physical, financial, social and overall (Gilleard 1984).

The highest single dimension of carer burden was emotional. More than 40% of carers at T1 and T3 rated their emotional burden/strain as high (4 or 5 on the scale). This was followed by social burden/strain to which more than 30% of carers gave a high rating at these same stages. Physical burden/strain affected carers overall the least intensely.

3 Findings

3.1 Use of community services prior to ACAS assessment

3.1.1 What community services were used prior to ACAS assessment?

Information on participants' use of eight community services in the previous three months was collected at baseline and at each follow-up from the older person or their carer. These eight community services are referred to in this report as selected community services. People were only included in the study if they were recommended new or continuing community services by ACAS; as a result most older people recruited had already been using some kind of formal community service at baseline.

The most commonly used service before the ACAS assessment was home care (60%) and the least commonly used was respite (9%) (see Table 4.1).

Table 4 Pre-assessment use of selected community services (T3 older people only) (n=45)

Type of service used	Older people who used this service	
	Number	Percentage
Home care	27	60
Personal care	9	20
Delivered meals	14	31
Home nursing	7	16
Day care/planned activity group	9	20
Home maintenance	5	11
Transport	6	13
Respite	4	9

Most older people were using one to three selected community services prior to assessment (see Table 5).

Table 5 Number of selected community services used prior to assessment (T3 older people only)

Number of services used	Number	Percentage
0	6	15
1	12	29
2	12	29
3 or more	11	27
Total	41	100

Note: Data on baseline use of home care and personal care is from the ACAS MDS data. This information is missing for other four participants.

3.1.2 What factors were related to community service use prior to assessment?

The factors related to use of community services prior to assessment were statistically tested using chi-square tests. The usage of selected community services prior to ACAS assessment was related to having a carer and level of dependency. Those with no carer were significantly more likely to use three or more community services prior to assessment than those with a carer (83% compared with 15%). Those who were dependent in four IADL activities were more likely to be receiving two or more selected community services at baseline than those with lower IADL dependency (68% compared with 38%). By contrast, the number of selected community services used at baseline was not related to: gender, self-rated health, self-rated mood, carer burden at baseline, financial situation or social activity.

3.2 ACAS recommendations

MDS data were available for 36 of the 45 people who participated in the T3 interviews. Three types of ACAS recommendations were examined in this study:

- recommendations for assistance with daily activities (not recommendations for services) (see Table 6).
- recommendations for community services which are also accessible by other means. These may be for continuing use of a service (or a package of services) that the older person was already receiving prior to the assessment, for an increase in the amount of service or for a new service (see Table 7).
- recommendations for community services that require approvals. These include recommendations for respite services, CACP, EACH and flexible care.

3.2.1 What proportion of older people were recommended assistance with activities?

All older people were recommended assistance with at least one activity. The types of assistance most commonly recommended were assistance with domestic tasks (67%) and assistance with transport (53%) (see Table 6).

Table 6 ACAS recommendations for assistance with activities (n=36)

Assistance recommended with	Recommendations	
	Number	Percentage
Domestic tasks	24	67
Personal care	11	31
Meals	14	39
Health care tasks	18	50
Social and community participation	14	39
Home maintenance	10	28
Transport	19	53

3.2.2 Which types of community services were recommended?

Of the 36 participants with MDS data, HACC services were recommended to 72%; respite services were recommended to 86%; 31% were recommended aged care packages (13 for CACP, 1 for EACH) and 22% were recommended Carer Respite Centre (see Table 7).

Table 7 ACAS recommendations for community services (n=36)

Type of community service	Recommendations	
	Number	Percentage
HACC	26	72
Respite*	31	86
Carer Respite Centre	8	22
CACP or EACH **	14	36

*Residential or in-home respite

**Data on CACP recommendation was available for 39 older people.

3.2.3 What factors were related to recommended assistance with activities?

Recommended assistance with selected activities was associated with the level of carer support and the older person's self-rated mood, but not with living arrangement, type of carer or carer burden at baseline.

Level of carer support

Participants with a high level of carer support were less likely to be recommended assistance with domestic tasks (54% compared with 80%) than those with less support from a carer, but more likely to be recommended assistance with health care tasks (79% compared with 36%).

Self-rated mood

Perhaps surprisingly, older people who rated their mood as good or very good were significantly more likely to be recommended assistance with social and community participation (73% compared with 40%).

3.2.4 What factors were related to community services recommendations?

Community services recommendations were associated with gender, level of dependency, presence of carer, living arrangement and self-rated mood.

Gender

Men were more likely to be recommended for respite than women (79% compared with 53%).

Dependency

People with high IADL dependency were more likely to be recommended for respite than those with moderate or low IADL dependency (77% compared with 50%).

Self-rated mood

Participants who rated their mood as good or very good were more likely to be recommended for a CACP than those with poorer self-rated mood (50% compared with 19%).

Living alone

People living alone were more likely to be recommended for HACC services than those who lived with others (85% compared with 50%).

Presence of a carer

People with no carer were more likely to be recommended for a CACP than those with a carer (80% compared with 25%).

3.2.5 What proportion of older people recommended for assistance with activity limitations accessed relevant community services in the post-assessment period?

Of the 36 participants for whom MDS data were available, over 80% of participants who were recommended assistance with domestic tasks, personal care, meals, nursing and home maintenance received related HACC services in the post-assessment period (see Table 8, Column A).

Considerable numbers of older people accessed community services even though they did not receive an ACAS recommendation for this type of assistance. Column B (Table 8) shows older people that had used home nursing or home allied health, home maintenance or day care/home visitor/PAG community services in the post-assessment period, although they had not received a recommendation in their assessment for the service.

Table 8: Recommendations for assistance with activity limitations and actual use of selected community services (number of older people) (n=45)

Recommendations for assistance with activity limitations				Number of older people who used selected community services in post-assessment period				Number who did not use each service	
Activity	Recommended for assistance	Not recommended for assistance	MDS data not available	Service	Recommended for assistance	Not recommended for assistance	MDS data not available	Total users of this service	Did not use this service
Domestic tasks	24	12	9	Home care	21	6	4	31	14
Personal care	11	25	9	Personal care	9	3	3	15	30
Health care tasks	18	18	9	Home nursing and/or home allied health	8	8	2	18	27
Meals	14	22	9	Delivered meals	12	3	1	16	29
Home maintenance	10	26	9	Home maintenance	8	7	2	17	28
Transport	19	17	9	Transport	7	2	2	11	34
Social activity	14	22	9	Day care, home visitor, planned activity group	11	8	5		21

3.2.6 To what extent were community service recommendations taken up?

All ACAS clients used one or more HACC services in the post-assessment period (whether they were recommended for HACC or not) (see Table 9). Only seven of 31 older people recommended respite (23%) used respite services in the post-assessment period and only three of the eight older people recommended to Carer Respite Centres (38%) (see Table 9). Section 3.6.2 provides some understanding of why uptake of respite is so low amongst respite-recommended ACAS clients.

Table 9 Service recommendations and actual uptake of recommended community services

Community services	Service recommended at baseline (number)			Service used in post-assessment period (number)			
	Yes	No	Missing*	Recommended	Non-recommended	Recommendation missing	All older people
HACC/Veterans' Home Care	25	11	9	25	11	9	45
Respite (residential or in-home)	31	5	9	7	0	2	9
Carer Respite Centre	8	28	9	3	0	2	5
CACP or EACH	14	25	6	10	0	0	10

*HACC/Veterans' Home Care, respite and CRC recommendations were missing for 9 participants. CACP/EACH recommendations for 6 clients were unknown.

Some of the factors influencing uptake of recommended services are illustrated in Shirley's story on page 12.

Implications of a carer reducing their assistance: Shirley

Shirley, who is in her eighties, lives alone in her house in the inner north-west of Melbourne. She receives a full pension. She says that she is 'comfortable' financially.

Health

Shirley rated her health as 'fair', deteriorating to 'poor' by T3. She has severe osteoarthritis, fractured vertebrae, and ulcers on her legs causing limited mobility and chronic pain. By T3 she had lost the use of her right arm.

She rated her mood as 'a bit down' to 'miserable', explaining:

Especially when I can't do things for myself. You get out of bed and you want to do things but you can't. Making a cup of tea is an effort.

Supports

Shirley does not have a lot of informal support. She does not receive help from friends or neighbours. One daughter lives overseas; the other daughter used to be considered a carer but the deterioration of her and her husband's health has limited this. She freezes some meals and occasionally drives Shirley to an appointment.

Social activity

Her daughters phone every few days, but visit rarely. Once a month, Shirley meets three friends for lunch. Following an ACAS recommendation, she started going to a Senior Citizens club for which she is picked up and where she plays bingo and has a meal weekly. She is 'very satisfied' with this arrangement.

Nevertheless, Shirley rated her social activity as insufficient: 'You get depressed—you're on your own'. With her eyesight failing, she finds it difficult to watch television or read for long: 'It's hard filling in your time', she said.

Services and issues

At T1 Shirley was getting assistance only once a week from the district nurse who was coming to attend to ulcers on her leg. By T3 she was receiving twice-weekly assistance from HACC personal care. However, Shirley felt this was insufficient and it was less than the assistance others were receiving.

Shirley also receives fortnightly home care and assistance with shopping, leaving her with no fresh food in the 'off week'. She does not get meals on wheels because she 'know[s] what the meals are like'. She relies on supermarket frozen meals and says her nutrition is not as good as it could be. She used to go shopping with an escort but by T3 that clashed with a district nurse visit. This was disappointing as she would like to get out more often.

She had received Veterans' Affairs home maintenance assistance but was frustrated by the restrictions on tasks they were able to undertake. Her council does not offer this service.

Shirley had approval for residential respite but 'didn't know how to go about [organising] it'. At T3 she reported she would be taking respite her daughter arranged.

Unmet needs

Shirley recognises there is a lot she can no longer do but is not sure how to get further services. She would like some assistance with her garden—a 'desperate need'. She said 'I'm in a situation where I don't know what I want'. She had been approved for a CACP but was unaware of this and did not know whether she was on a waiting list.

3.3 Post-assessment use of community services

We examined post-assessment use of community services for all 45 participants of T3. This included the 36 participants for whom MDS data were available and nine participants for whom this data were unavailable.

For the community services for which baseline data were available we examined ‘new use’, ‘ongoing use’ and ‘no use’ in the post-assessment period (regardless of the recommendation). For other community services, where baseline information is not available, the distinction between new and ongoing use was not possible.

New use of selected community services is defined as uptake in the post-assessment period of services that study participants were not using prior to their ACAS assessment. Ongoing use is defined as use of a community service prior to assessment and continuing use of the same services after assessment.

3.3.1 What proportion of older people took up new selected community services after ACAS assessment?

Nearly three quarters (74%) of the study participants took up at least one new community service at some stage in the post-assessment period (see Table 10). In most cases they were still being used at the 9-month survey.

Table 10 Number of new selected community services taken up in the post-assessment period

Number of new selected community services	Number of older people	Percentage of sample
0	12	27
1	21	47
2 or more	12	27
Total	45	100

3.3.2 Which selected community services were accessed in the post-assessment period?

Table 11 shows selected community service use in the post-assessment period. All these community services were being used by a higher proportion of participants at the end of the study than at baseline. For example, at T3, 69% of the T3 participants were using home care compared with 60% of the same group at baseline (refer to Table 4 for selected service use at baseline).

The majority of T3 participants who used home care and delivered meals in the post-assessment period were already receiving these services before the assessment. Older people recommended assistance with home maintenance and transport had generally not received this ‘formal’ assistance prior to assessment. Despite participants indicating that home maintenance was a very difficult service to access, Table 11 shows that it was more commonly newly taken up than any other selected community service (31%). The rate of new uptake was less than 10% for meals.

The rate of uptake was also low for respite and home nursing (13%). The low rate of respite uptake requires further examination as we know that the majority of the older people who did not take up respite were recommended respite at the time of the ACAS assessment. Barriers to uptake and older persons’ experience of respite are reported in sections 3.6 and 3.7.

Table 11 Status of use of selected community services in the post-assessment period (n=45)

Post-assessment use of selected community services					
	Ongoing %	New %	Total using services %	Total using services (number)	Not using service %
Home care	53	16	69	31	31
Personal care	18	16	33	15	67
Home delivered meals	27	9	36	16	64
Home nursing	7	13	20	9	80
Day care/PAG	16	18	36	16	67
Home maintenance	7	31	38	17	62
Transport	4	20	24	11	76
Respite	7	13	20	9	80

*Total number of older people using the service in the post-assessment period (ongoing use + new uptake)

Post-assessment use of other community services

Nine months after the ACAS assessment, 55% of all T3 participants had used at least one service involved in assisting with social and community participation (S&CP) since the baseline (see Table 12a). Twenty-six (58%) of the study participants had used at least one preventative/restorative HACC service since the baseline ACAS assessment (see Table 12b). Equipment was the most commonly used service (58%) in this category.

Table 12a Post-assessment use of social and community participation services (n=45)

Social and community participation (S&CP) services	Number	Percentage
Home visitor	5	11
Planned activity group/day care	16	36
Being accompanied on excursions/trips	4	9
Assistance getting to places	11	22
Paperwork/letter writing	0	0

Table 12b Post-assessment use of preventative/restorative services (n=45)

Preventative/restorative HACC services	Number	Percentage
Allied health care at home	10	22
Home modifications	14	31
Equipment (e.g. bed-stick, raised chair)	17	38
Linen services (laundering bed linen)	1	2
Counselling	4	9

3.3.3 Was there a change in the number of selected community services that older people accessed?

The proportion of T3 participants who were using three or more of the eight selected community services increased from 27% at baseline to 42% by the end of the study (see Table 13).

Table 13 Number and proportion of study participants using 3 or more selected community services in the post-assessment period

Number of selected community services	Number of older people	Percentage of older people
None	7	15
1	9	20
2	10	22
3 or more	19	42
Total	45	100

3.3.4 What proportion of older people received packaged care following ACAS assessment?

Fourteen T3 participants were recommended for a CACP at baseline and ten of these were receiving an aged care package at the end of the study. Of the six recommended for ongoing packages, five participants continued to receive packaged care (one other had discontinued). Of the eight participants who were recommended a new CACP, five had taken up a package and three had not by the end of the study.

One participant (see case study of Katharine on page 32) had made a conscious choice to take up a CACP in order to lessen the burden on her daughter who had young children. Another participant reflected that she was relieved that services were being coordinated for her by a case manager.

3.3.5 What other sources of support do frail older people in the community utilise?

Community services are only one type of support that study participants use to assist them in their daily lives. Others include family, friends, neighbours, and privately purchased goods and services. In most cases this combination of formal and informal care was positive for participants, but in some cases, the burden on family or on equally ageing friends was problematic.

Family

Support from family was available to most of the people in the study and was provided variously by spouses, siblings, children (and children-in-law), nieces and nephews and grandchildren. In most cases, the majority of care was provided by a female relative. As well as the emotional support provided in familial bonds, practical support included: holidays and overnight stays; outings for a meal or to a social occasion such as a family wedding; and transport to appointments, or to the library or cemetery. Within the home, support was provided in: personal care (such as cutting hair and toenails), preparation of meals (or dropping off frozen meals), gardening and home maintenance, shopping, managing banking and finances (and in some cases contributing to rent, housekeeping or medication expenses), laundry and house cleaning. Family members also assisted live-in carers by sitting with their relative, so the carer could go out.

A significant role played by family is monitoring the provision of services (for example HACC) and the health and care needs of the older person. Family often instigate the seeking of additional outside support for their relative. Many family carers were greatly affected by their caring role. Qualitative data on the impact of care-giving by family members is presented in Appendix II.

Members of the local community

Older people connected to their community have a range of resources to draw on including neighbours, shopkeepers and community volunteers. Some commercial services make their business more accessible by, for example, providing home delivery, or in one case, coming out to the footpath to serve a customer whose scooter cannot mount the front step. Volunteer driver services allow older people to access health services at a low cost. Friends and neighbours help by hanging out or bringing in washing from the line, picking up shopping, preparing meals, home and garden maintenance, providing transport, phoning, or visiting to check the person is all right (in one case, every day). For one person, significant care (including getting her up out of bed and getting dressed) was provided by two neighbours, while her carer husband was in hospital. This care was highly valued and one man referred to his neighbour as 'an angel in disguise' for the support he provided. These sources of assistance also included much valued social interaction. See case study of Charles and Margaret on page 24 for an example of the value of personal networks.

Privately purchased services

Some people on higher incomes were able to privately purchase services where HACC or other subsidised services were not available or not of a standard acceptable to the older person or their carer. Services purchased included home-delivered frozen meals (to replace meals on wheels),

dental care, home modifications and home maintenance. A number of people had private gardening services, not universally available through HACC but identified as a need by several people.

3.3.6 What client-related factors influenced post-assessment use of community services?

Client-related factors found to be associated with post-assessment use of community services were receipt of a CACP service, contact with family and self-rated mood (Tables 14 to 15).

Receiving a CACP

In the post-assessment period, as would be expected, people who were receiving a CACP at T3 were more likely to use three or more selected community services, to take up new community services and to use social and community participation services than those who were not on a CACP (see Table 14). Of the 10 people receiving a CACP package, 9 (90%) were using 3 or more selected community services, compared with 13 of the 35 (37%) of those not receiving a CACP package.

Table 14 Use of services in the post-assessment period, by whether receiving a CACP

Services use	Whether receiving a CACP nine months after ACAS assessment (number of older people) (n=45)		
	Yes (n=10)	No (n=35)	Significance
Social and community participation services			
Yes	8	7	p=.002
No	2	27	
New community services*			
Yes	10	23	p=.048
No	0	12	
Three or more community services*			
Yes	9	13	p=.004
No	1	22	

Note: Community services here refers to the eight services selected as the main focus of this report (see p.X)

Social isolation

Frequency of contact with family was used as an indicator of social isolation. Respondents who had at least weekly contact with family members were more likely to access S&CP services in the post-assessment period than those with less frequent contact with family (64% compared with 44%). While this association was not statistically significant, it suggests that social isolation is linked to use of fewer services. This finding is illustrated by the case study of Elizabeth (p.18).

Self-rated mood

Participants were asked to rate their mood on a five-point scale ranging from 'very good' to 'miserable'. Those who rated their mood as high (very good or good) at baseline were significantly more likely to access new selected community services than those who reported low mood (100% compared with 37%). Those who rated their mood as high were also more likely to use S&CP services in the post-assessment period than those who reported their mood less favourably (64% compared with 48%). Self-rated mood did not influence the likelihood of using three or more selected community services or accessing respite services.

Table 15 Use of community services in the post-assessment period by self-rated mood (number of older people)

Services used in post-assessment period	Self-rated mood of older person at baseline (n=45)			Significance
	Good or very good	OK, a bit down, miserable	Missing	
S&CP services				
Yes	7	13	4	NS
No	4	14	2	
New selected community services				
Yes	11	10	2	p=.050
No	0	17	5	
Number of older people	11	27	7	

3.3.7 What carer-related factors influence post-assessment use of community services?

Carer-related factors that influenced post-assessment use of community services include the carer's relationship to the person they care for and the reported carer burden (see Tables 16 and 17). The panel on page 20 outlines some dimensions of carer burden.

Carer relationship

While ACAS recommendations for assistance with activity limitations did not vary by the relationship of the older person with their informal carer, post-assessment use of some community services did vary by the relationship with the carer. During the post-assessment period people who had a carer daughter (or daughter-in-law) were less likely to use home maintenance or transport assistance or to receive a CACP than people with no carer, a spouse carer or another informal carer. On the other hand, people with a daughter carer were somewhat more likely to take up respite services in the post-assessment period. The qualitative data presented in section 4.2 examines the relationship between the carers and use of community services in more detail. Due to the small sample size it was only possible to compare daughter/son carers with all other carer arrangements.

Table 16 Use of community services in the post-assessment period by whether older person has daughter / son carer (n=45)

Services used	Whether older person has daughter / son carer		Significance
	Yes	No	
Home maintenance			
Yes	5	12	p=.041
No	17	11	
Transport			
Yes	3	8	NS (p=.096)
No	19	15	
CACP			
Yes	2	8	p=.041
No	20	15	
Respite			
Yes	6	3	NS (p=.21)
No	16	20	
Number of older people	22	23	

Social isolation is associated with fewer services: Elizabeth

Elizabeth lives alone in her eastern suburbs flat which she bought after her husband died. She is in her late 80s, receives a full pension and has private health insurance.

Health

Elizabeth claims the 'only thing wrong with me is my limbs'. She has limited mobility and chronic pain. She was hospitalised after a fall prior to T1 and had another fall before T2. She initially rated her mood as 'good', saying 'Can't change anything so it's no good getting moody about it'. By T3, frustrated by activity restrictions, she rated it as 'ok'.

Supports

Elizabeth's main support is her friend of a similar age, Mabel. Mabel does washing, shopping and errands (including banking), and takes her to appointments. At T1, Mabel had to support her own sister after an accident. Consequently Elizabeth had less food in the house and washing that needed doing. By T2, Mabel was able to provide some support again. Elizabeth cut short a recent stay with her daughter. She said she 'couldn't get out of there fast enough', the house being crowded and busy with a teenage grandson and dogs.

Elizabeth receives daily calls from Mabel and the personal alarm system operators. She also has a twenty-year relationship with her GP who has been suggesting she go into residential care: 'He gets hopping mad' that she does not want to. She does not receive support from her neighbours, who won't sweep in front of her flat, or put her bin out.

Social activity

Along with Mabel's visits, Elizabeth has contact with family in person or by phone at least once a month, but no further social contact. She reported that her level of social activity was 'enough': 'I like my own company—I'm not vain when I say that'. She was not recommended for social and community participation activities in her assessment.

She indicated fear of falling had been an underlying reason for ceasing activities like attending the ballet and a planned activity group that she had enjoyed on one occasion:

I know it may sound a bit self-pitying, but I don't want to have any falls. I'm even a bit apprehensive going out with this [frame].

Services and issues

Elizabeth feels she gets enough services, but does not always find them satisfactory. She is 'moderately dissatisfied' with the home care service, particularly the worker activity limitations and lack of continuity of the workers. She does not enjoy her meals on wheels: 'They're all awful'. Her experience of respite was negative: the facility was not always clean, there were 'too many people around' and she was hit by another resident.

When asked if she had a CACP she remarked: 'I've had many people come and see me. Frankly I can't remember where they come from'.

Unmet needs

Elizabeth has not had her hair cut for a long time, because she cannot find a hairdresser to come to her home. She also said she 'could use [some] physio, but I'd rather not stir things up'. Unwilling to go into residential care, Elizabeth pointed out that she would have mobility difficulties in or out of care and said, 'Personally I'd rather have a few things left undone'. Elizabeth does not want to leave her home, saying: 'It's very hard, unless you're very moneyed, to get accommodation with your own amenities'.

Level of carer burden

Low carer burden was significantly associated with taking up new community services in the post-assessment period. Of the participants whose carer reported low carer burden, 82% took up one or more new selected community service compared with 56% of those whose carers reported medium or high carer burden. There was a similar trend for use of social and community participation services, with older people whose carer reported low carer burden being more likely to use such services than their counterparts (see Table 17).

Table 17 Use of new and social and community participation services in the post-assessment period by carer burden (n=29)

Services use	Carer burden at baseline		Significance
	Low	Medium or high	
New community services			
Yes	9	10	p=.032
No	2	8	
Social and community participation services			
Yes	7	4	NS (p=.074)
No	4	13	

Dimensions and impact of caring for older people

There are many dimensions and impacts of caring for older people. In this study, these mostly affected women who were the significant majority of carers.

Stress

For some carers, the stress and pressure of providing high levels of care to the aged person on a daily basis left them with few resources for seeking outside care. One carer explained that she didn't have the time to read information that had been provided about services:

I've got this much paperwork (shows bag full of services information). It's very hard to get the time to read them.

Another carer felt that the work involved in service planning and coordination was 'too much' on top of the direct care:

It all got too much and I tuned out.

For some daughter carers it was difficult to balance caring responsibilities with paid work. For example one carer described carer burden as the 'physical strain in getting everything that is expected of me in total—work, maintaining my own house, assisting dad and having some social life'. Other daughters commented that they had given up their jobs or careers to care for the parent.

Carers' multiple roles

Many daughter carers had multiple caring roles and were looking after unwell or disabled children or partners as well as caring for their parent and/or parent in-law. Some daughter carers expressed a sense of disappointment that they had just finished caring for their children and now were caring for parents rather than having an opportunity to develop other interests or skills. One carer commented:

I'd like to do some voluntary work—just to get your brain going. It gets stale, like being home with little babies.

Carers' health

Some carers also had significant health issues themselves which exacerbated the strain of caring or substantially reduced the assistance they could provide. One husband carer had found it difficult to care for his wife due to his own chronic health problems. He explained:

If you can't breathe you can't do anything. It's enough to make you depressed.

Other carers also reported limitations caused by health problems including breathing difficulties, multiple sclerosis, Meniere's disease, heart disease and chronic back pain. A case study of decreased carer support resulting from poor health can be found on page 12.

Emotional burden

Carers expressed a range of feelings associated with their caring role, including guilt, anger, frustration, depression and being unacknowledged in their role. Many of these are illustrated in the case study of Helen on page 22.

Some daughter and son carers experienced an interactive effect between their parent's mood and their own. One participant explained: 'My mood reflects Mum's mood'.

3.4 Influence of community services use on the well-being of older people and their carers

3.4.1 Does receipt of community services influence older people's psychological well-being?

Self-rated mood was used as an indicator of psychological well-being. Data on change in mood from baseline to nine months after the ACAS assessment was available for 38 older people participating in the study (see Appendix for rating scale).

While baseline mood did not influence the likelihood of accessing respite, there was a tendency for those who had used respite services in the post-assessment period to be more likely to have improved self-reported mood scores at T3 than those who had not used respite services. Five of the seven older people that accessed respite services during the post-assessment period had improved self-reported mood scores at T3 compared with 11 of the 31 participants who did not access respite (71% compared with 38%). While the association was not statistically significant, several carers suggested that respite had had a positive effect on their relatives' well-being. One carer whose mother had been experiencing depression reported that her mother enjoyed the experience because 'there were things for her to do, there were people her age she could talk to'. The carer felt that respite had made a 'big difference'.

The data also indicated a trend for those who had used social and community participation services to be more likely to have improved mood scores than those who had not accessed these services (57% compared with 33%). This finding was supported by qualitative data. Two client participants were enjoying day care so much that they were hoping to increase the number of days they attended. One carer reflected that:

Until she did it [go to the day centre] I didn't realise what it would do for her, the social interaction. I hadn't realised how lonely Mum was for interaction at her own age level.

3.4.2 Does receipt of community services influence level of carer burden?

The study did not provide conclusive evidence of the influence of community service use on carer burden. However, there is some indication that there is a positive relationship: the proportion of carers reporting high levels of overall burden decreased from 44% at T1 to 33% at T3. In addition, a number of carers' testimonies showed the positive affects of receiving case management and/or respite for carers.

Respite gave some carers the chance for a break, a trip away or social activity. One carer who had not accessed respite for his mother was aware of what it might have done for him:

In hindsight I think we should have put Mum in respite. I wish I had done it, more for me than her. If at all possible, the value of it needs to be conveyed to the carers. The penny didn't drop for me, I didn't realise just how worn out I was until after [she died].

One carer reported that non-residential respite had been 'like a great cloud that has been lifted, a great weight'.

The negative impacts of lack of service use on carers also emerged. For example, one carer whose mother would not use social and community participation services commented:

She thinks she's too old to make friends. She's quite happy to put the whole burden on to us kids.

A highly burdened carer: Helen

While Helen's carer burden was particularly acute, this case also represents aspects of the experience of several other carers in this study.

June, a pensioner, lives alone in the north-western suburbs of Melbourne. Helen, her only surviving child, is her carer. June is in fine health for her age, having recovered from a hip fracture six months prior to this study. Helen took over many caring activities at the time of June's fracture and explained that now her mother expects her to continue. Helen reported:

My mother isn't disabled, she has nothing physically wrong with her ... She's decided she's not doing anything more.

Helen reported her mother's mood as 'good' but said:

Her attitude makes me feel guilty. She's unhappy, even though she's in good health and could have a great life if she wanted to.

Carer burden

Helen's caring activities include getting prescriptions filled, providing transport, shopping, washing clothes and linen, taking June to the doctor, paying bills and cleaning the house. This is very time-consuming because Helen lives one hour's drive from her mother.

Helen experiences high carer burden but didn't rate her burden at 5 on the questionnaire because it is 'too dramatic (and it) makes it sound like I'm not coping, but I am'. She rates her mood as 'a bit down' and reports getting 'a bit weepy'. Her resentment is evident: 'My mother thinks I'm specifically put on this earth to help her'. Helen talks about retirement dreams she and her husband have relinquished because of the care she has to provide to her mother. Due to her mother's good health, she expects to be caring for her for a long time:

I'm taking it day by day: If I think about 10 years hence, I get panicky.

At T1 Helen explained that her mother was amazed at the suggestion that Helen might need a holiday. At T3 she had been to visit her daughter and grandchildren in Tasmania for a week, while her husband had remained in Melbourne to look after June. Helen feels trapped but also feels guilt about not having her mother living with her. She explains:

It would ease my guilt if one time I rang Mum and asked her what she'd done that day and she didn't say 'nothing'.

Helen has not accessed carer support services and explains that part of the emotional strain for her is that she has no-one to talk to.

Social activity

June's social activity includes visiting neighbours and being visited (about once a week) by her sister, grandchildren and friends. Helen also takes her mother out for dinner weekly.

Services and issues

Helen is thinking of cancelling her mother's 1.5 hours per fortnight of home care and getting a private service because she is frustrated about the restrictions on the workers' tasks and on the cleaning products they can use:

They don't actually clean, we have a list a foot long of things they don't do and two inches long of what they do do.

3.5 Facilitators and barriers to uptake of community services

Factors that facilitate or impede the uptake of community services will be discussed in this section with a specific focus on two service types that had the lowest uptake rates of recommended services: respite and transport.

3.5.1 What factors facilitate the uptake of community services?

From the qualitative data, the main factor facilitating the uptake of services was having a person to assist in linking the older person to the services. This happened mainly through:

- family support (advocacy)
- information shared by friends
- assisted referral (by a case manager, ACAS clinician, a GP or hospital social worker).

Family support

The study findings indicated a tendency for older people with more frequent contact with family to be more likely to take up community services. The benefits of family support also emerged from carers' statements. In one case a son was assisting his mother (the primary carer) to urge his father's doctor to refer them to access community services through the Department of Veterans Affairs.

Shared information

Some client participants had been able to access community services due to the information that friends or family had shared with them. One carer had a friend who was supporting his elderly sister and was therefore able to explain things to her. A daughter-in-law who had been through the community care system with her own parents was also able to share information on community services. Further examples of family and social support are described in the case study of Charles and Margaret on page 24.

Assisted referral

In many cases other organisations, agencies or individuals facilitated the uptake of services. The hospital social worker, for example, assisted one older person to access respite. The ACAS assessor or a CACP case manager assisted some older people and carers in becoming familiar with the community services available:

In the beginning you're just bewildered. Now I know who to ring, who to ask. I know I will try now to get results. (Carer)

A number of service providers, including an occupational therapist, a meals-on-wheels provider, a social worker, a nurse and a doctor, were all reported as having assisted people to access community services. This assistance included making phone calls on the older person's behalf, recommending them for a service assessment, accompanying them to the service or advocating on the client's behalf to have earlier access to a service. Some referrals were made as part of a hospital discharge plan and in some cases an ongoing relationship with the service providers opened up a wide range of programs and supports. One person who was recommended by ACAS for assistance with social and community participation was assisted by a visiting occupational therapist to access this assistance. This client had not previously attempted to access support services and said:

[She] said 'How are you?' and I said 'I'm not worth a cracker' and she came in here with me and called the counsellor.

Social resources are associated with uptake of services: Charles and Margaret Wilson

Charles and Margaret Wilson, a married couple aged in their 80s, both receive the full age pension. They own their own home and have private (hospital) health insurance. Charles was a minister of religion and retired completely between T2 and T3. Margaret is the client in this study; however Charles (who is her carer) has also had an Aged Care Assessment and is receiving HACC services.

Health

Margaret has limited mobility and suffers from back pain and falls. She also has short-term memory loss. Margaret rates her health as 'good' at both T2 and T3 and says: 'I'm getting old, that's all'. Margaret rated her mood as 'good' at T2 and T3 and on both occasions, added (jokingly): 'Oh I'm shocking! Shocking!' Charles added: 'We have our ups and downs, but we're placid, as well as could be expected'.

Supports

The Wilsons have a number of people who support them and they also provide ongoing support to people from their parish. Their children all live interstate but help their parents where they can. For example, their daughter-in-law, who had been through the community care system with her own parents, was able to give them information on services. Charles said they were 'lucky we've got children who can explain things'. Margaret had also recently been able to stay in Western Australia with their children, while Charles was in hospital. Their son had also taken action around his father's well-being, removing the ladder to protect him from falls. Charles reported that friends and neighbours help with home maintenance and gardening (including mowing): 'Friends come, or a neighbour. A friend sends his workmen over to help me—he took three trailers of timber to the tip'.

The Wilsons also have developed a close and valued friendship with the person who provides their home care and personal care services.

Carer burden

Charles reported low carer burden in both interviews. He said: 'I think we're very fortunate to be living in Australia where a carer can be helped to do the caring'. He has recently retired from his pastoral duties, stating that 'they have to recognise that [Mrs Wilson] is number one in my life'.

Social activity

Church is the Wilsons' main social outlet. At T3 they reported that in the past two weeks friends had visited 'just about every day'. They had also been to a restaurant, gone sightseeing and attended church. They had spoken to their children on the phone and were expecting a visit from their granddaughter the next day.

Services and issues

The Wilsons were very grateful for the services they receive:

If they say they're going to be here, they're here. If there are going to be any hitches, they always call. They're all very friendly. We're very satisfied with all the help we receive.

3.5.2 What factors are barriers to the uptake of community services?

Some 38% of study participants (older person or their carer) reported that the client needed more help with activities including domestic tasks, home maintenance, gardening, going out, personal care and company. Older people and carers were asked why they were not getting the additional assistance that they felt they needed. The many reasons that emerged from the interviews are presented below.

Affordability

Cost was a barrier to some services, particularly respite and taxis. Some respondents explained that respite costs close to the full pension which does not leave enough to continue paying rent or to pay bills. One older person commented:

They rip you off everywhere you go ... they take nearly your full pension, you still have bills to pay. I think they charge too much. If it was \$100 a week then you'd have a chance to keep your home.

Some older people had used residential respite but the cost was a barrier to future use, while others enjoyed a free month of respite per year from Veterans' Affairs.

Although the subsidised taxi service provides a 50 per cent discount for eligible pensioners, it was considered too expensive by many study participants. For example the subsidised return fare for people living half an hour away to a city hospital is \$30. Some people reported the cost of taxis stopped them from accessing medical and rehabilitation services or visiting a spouse in hospital.

Waiting lists

Waiting lists were the most commonly cited barrier to uptake of HACC services, with some participants being told of 12 month waiting lists for HACC home care. Significant delays in access to a service tended to further discourage uptake. One carer said:

She's still waiting, I haven't bothered phoning them again.

Participants trying to access respite also encountered lengthy waiting lists. One person was on a waiting list for residential respite for six to eight weeks before she was contacted to find out what she wanted. Another older person had delayed an operation because the low-level respite bed that she was waiting for would not be available immediately after the operation. One carer waiting on respite commented:

It takes so long to get someone for [in-home] respite—you get put on a waiting list and don't know what's going on.

Lack of availability

Some people resided in areas where their council did not offer some HACC services. Most commonly these were gardening and maintenance. As one older person commented:

You look at the garden and you know you can't do it and it just depresses you.

For several participants needing transport assistance, the service was not available to them from their council. One of these people was able to go shopping with her brother who drives, but he is 82 years old and 'slowing down'. She does not want to burden him, but has been unable to find other arrangements. A carer said:

I have given up asking the Council because they haven't helped enough, not because they don't want to, but they don't have the funds ... They said they could help if she was in a wheelchair.

Lack of information about services

Another barrier to uptake of services was lack of information. Often older people and carers did not know what services existed.

When you've been independent you don't know about these things and they don't advertise so you don't know what is available. (Older person)

One carer commented that after the ACAS assessment there was no further contact or information about services: 'After the assessment, that was it'.

Awareness was lowest of escort services and day care centres. One client on a CACP, who was unable to leave the house unassisted, had not heard of escort services.

Others knew about the services but felt that they were 'never given as an option', and this included some cases where the person had been recommended for that particular service at their assessment. In-home and residential respite were the services that people were most likely to know were available but did not know how to access. A striking number of older people and carers who had been recommended respite but had not previously accessed it, did not know how to go about booking a place (nor, in a couple of cases, even what respite was). Referring to respite, one carer said:

I find it difficult to find out how to get services. It's hard to find where to go to get them.

One carer indicated that the ACAS assessor 'gave me a list of respite places, but most didn't actually provide respite'.

Attitudes and values held by older people and their carers

Attitudes held by older people and their carers emerged as an important barrier to use of community services. One carer did not seek the respite recommended for her husband as she felt this would be 'leaving him'.

Independence

One prominent value was 'independence'. Some older people valued their independence highly and were resistant to offers of external help, as illustrated by the case of Frank and Evette on page 28. One frustrated carer remarked:

Getting Mum to accept help would be far more difficult than anything you could think of.

While some people uttered with pride comments such as 'everyone says I'm too independent', their carers felt quite differently:

If we could beat this stubbornness out of her, she'd have a lot less problems if she did what she was told.

'Family ethos'

Some people refused to accept external help, preferring to rely solely on familial assistance. In some cases there was an expectation that care would be provided within the family because of the family ethos. In some cases total reliance on family assistance was causing stress on carers. This is described in the high carer burden case study on page 22.

Wariness of strangers

For some older people, the refusal of services was linked with a dislike of strangers. One carer said: 'Mum's not that keen on strangers coming in'. It was often due to the highly intimate nature of personal care tasks such as assisting with showering, that people objected. Personal care provided by a carer of the opposite sex was unacceptable to some people. One carer explained that for older

people with dementia, unknown people were a source of ‘genuine’ fear. Some people were unwilling to use subsidised taxis, because they wanted someone they knew to take them to appointments, or shopping.

Misconceptions

Sometimes the refusal of a service was based on misconceptions. For example, one older person refused home maintenance because she believed the service was provided by people on community-based corrections orders.

Fear of permanent residential placement

Some older people were unwilling to access respite in fear that it would be the first step towards permanent residence in a care facility:

I'm frightened he won't come back and get me. They're trying to get me there for two weeks, but I don't need to. I'm no trouble am I?

Physical and mobility limitations

Physical and mobility limitations were a barrier for some people to accessing services. For one person, the kicking associated with Parkinson's disease prevented him from using community transport or attending a day activity centre.

Service unsuitability

Some older people felt that respite services were unsuitable for them. One main objection was client mix. Some study participants were concerned that in respite they would have no social interaction because other residents would have dementia, would be too old, or they would already know each other. Others were concerned about aggressive behaviours.

Respite was also felt to be unsuitable by one client due to lack of continuity of medical care in the respite facility and by one carer who explained that her mother was unwilling to go to respite unless staff could speak her language.

Dissatisfaction with services²

Dissatisfaction with some community services deterred some older people from continuing to use the service. Reluctance to use community services due to negative experiences was most common for Meals on Wheels and taxis.

High carer burden

Perhaps surprisingly, the study found that high carer burden was a barrier to uptake of community services. It emerged that some highly burdened carers felt unable to use the service information they had been given or unable to plan care for their relative. Factors that contributed to high levels of overall carer burden were carers' own poor health, multiple caring roles and the stress and emotional strain of caring (as described in the panel on page 20).

² Satisfaction with services is discussed in detail in section 3.6.

Negotiating the appropriate level of care: Frank and Evette

Frank, a self-funded retiree, lives alone in his home attached to his daughter's house next door. His daughter, Evette, would like Frank to stay at home for as long as they are able to care for him properly there. Frank and Evette have different perceptions of the acceptable level of autonomy for Frank. This has implications for his well-being and for their relationship.

Health

Frank and Evette both consistently rate Frank's health as very good 'for his age'. Frank states that 'for 95 I think I'm doing remarkably well'. However, Frank has difficulty getting out of bed and in and out of taxis and he has fallen in the house. His deteriorating mobility and strength is concerning to Evette because this limits his access to services and prevents him getting himself up when he has a fall (leading to numerous ambulance callouts). An occupational therapist has suggested bathroom modifications and the installation of rails, but Frank has declined. Evette reports deterioration in Frank's memory. She crosses off days on his calendar and has installed a large clock in his kitchen. Frank loses things and gets frustrated when he can't find them.

Frank rated his mood as very good at all three interviews, stating 'I'm always a happy person.' and '[I] never suffer from any sort of depression'.

Supports

Frank has recently started on a Community Aged Care Package (CACP). At T1 Evette was concerned that his care needs had been underrated and she wanted him to be reassessed. This reassessment had happened by T3 and the nurse had also assisted with bringing the package forward so that he could access services earlier. Frank took up new community services during the study period, and also receives support from Evette.

Carer burden

Evette described conflict between herself and her father regarding levels of supports and service, and his independence. She expressed concern that she 'badgers' her father about things he does that she perceived put him at risk. He refuses support and that causes conflict. Recently Evette has withdrawn support from her father, telling him that if he refuses to access outside supports (for example getting a bed stick), she will not assist by 'bailing out' as much. She commented:

Concern for achieving the appropriate level of care puts strain on the relationship with Dad.

Social activity

Frank's social activity consists of a weekly dinner at his daughter's house, fortnightly visits from his two adult grandchildren, a monthly meeting of a wine appreciation group and intermittent trips to cafés with his daughter and her friends. Frank said he didn't think he had any friends, but he didn't report being lonely. Evette stated that she wants him to make more friends and expressed frustration that he is refusing to go to day care because he thinks they play bingo, which he dislikes (but he has not checked if this is true).

Services and issues

Frank reported positively about the services he was receiving and did not believe he had any unmet care needs. Evette believed her father needs someone to be there while he showers and to help him get dressed. She also wants Frank to go to chair exercise classes to build his upper body strength (to assist with getting up after falls).

3.6 Experiences of accessing and using community services

3.6.1 How satisfied are older people and their carers with the service system?

Table 18 presents data on levels of satisfaction on the service experience scale (described in the Appendix). Where applicable, a combined service experience score was calculated for older person/carer pairs. The table shows data for the 50 cases that provided the information at T1. Approximately two-thirds of participants rated their service experience positively (68%) Approximately one-fifth rated their experience as 'neutral' (22%), and 10% were dissatisfied or highly dissatisfied.

Table 18: Level of satisfaction on the service experience scale

Service experience	Number	Percentage
Dissatisfied/highly dissatisfied	5	10
Neutral	11	22
Satisfied/highly satisfied	34	68
Total*	50	100

*Missing=4

Satisfaction with community services

Overall satisfaction with services was high. However, satisfaction was lower for home-delivered meals, personal care, home care, respite and taxis than the other services listed in Table 19.

Table 19 Satisfaction with community services 3 months after ACAS assessment

Service	Number of participants receiving service n=54	Satisfaction with community service		
		Satisfied %	Neutral %	Dissatisfied %
Home care	36	83	11	6
Personal care	18	83	17	0
Home delivered meals	14	72	29	0
Home nursing	14	93	7	0
Day care	12	91	9	0
Home maintenance	14	93	7	0
Transport (escort to shops etc)	10	90	10	0
Transport (subsidised taxi)	25	81	15	4
Respite	9	83	17	0
Ambulance	13	92	8	0
Case manager	13	92	8	0

3.6.2 What is the relationship between service satisfaction and the characteristics of older people?

Using the service experience scale (see Appendix) we found that the clients'/carers' overall rating of the service experience was associated with older person's self-rated health, as well as carer living situation.

People who rated their health as 'good or very good' were significantly less likely to be satisfied with their experience of community services than people who rated their health 'fair or poor' (42% compared with 76%; $p=.03$). Older person/carer pairs where there was non-resident carer had lower service experience scores than those where the carer was living with the older person (52%).

3.6.3 Positive experiences of community services

General features of community services that study participants appreciated were:

- quick response to need
- high quality care
- service providers regularly checking in to see that everything is working
- being able to contact the service provider at any time.

Home care and personal care

Satisfaction with HACC home care and personal care services was almost always a result of continuity of staffing. As one older person remarked, this continuity:

... gives for a better relationship. You get more comfortable with them and trust them.

Taxis

Satisfaction with taxis was related to waiting times for wheelchair-accessible taxis and how friendly and helpful the drivers were. Older people's experience of taxi drivers varied:

Some are very nice, but some couldn't care less about you.

Who could be satisfied with those drivers?

Residential respite

Nine participants (carers and older people) made specific comments about their positive experience of residential respite, such as:

She liked it because there were things for her to do, there were people her age she could talk to. (Carer)

I really enjoyed it, it made a big difference. I was in depression. (Older person)

Positive aspects of residential respite included catering for special diet, good meals, activities, other people of a similar age and helpful and attentive staff. Positive experiences of respite were an important influence on participants' willingness to use the service again:

I'd call it a 5 star hotel ... I'm going back next month ... the staff were out of this world ... It was like moving from one family to another family.

Ethno-specific services

Older people and carers from culturally and linguistically diverse (CALD) backgrounds appreciated when services were available that were staffed by people who spoke their first language.

3.6.4 Negative experiences of community services

HACC services

Comments were recorded from 18 carers and older people who complained about the restrictions on the tasks that HACC service workers are permitted to do. It was frustrating, for example, that home care workers were not permitted to perform tasks such as moving furniture, dusting, washing curtains, and cleaning windows, cupboards or the fridge. The following comments were typical:

They won't move a chair to vacuum under a chair... a chair isn't that heavy. There is something weird about home care and what they do. (Carer)

They've been neutered to such an extent – they're probably useless now. (Carer)

Some participants complained that home maintenance workers are not allowed to do any work requiring a ladder, cut grass, prune plants above their head height, move bricks or logs or do any electrical work. The frustration stems from the fact that the person (and in many cases their carer) are also unable to perform these tasks.

Meals on wheels

Sixteen participants were dissatisfied with meals on wheels. Concerns included poor taste, lack of variety and inconvenient delivery times. Some people reported losing their appetite or substituting meals, for example with ice-cream. One daughter-carer had to start cooking and deliver meals to her mother after discovering she had been throwing her meals on wheels out to the birds. Others purchased supermarket frozen meals as an alternative. Comments included:

I'd rather die of starvation. I couldn't eat their stuff. (Older person)

She won't have a bar of it. (Carer)

It was having to wait in for the meal that was difficult. (Older person)

Nothing appealing about them, I was losing weight. (Older person)

Respite

Past negative experience was a barrier to subsequent use of respite. One older person who two years before had not been satisfied with her respite experience commented:

You may as well stay in your home and carry on with what support you can get.

Despite having had a poor experience in respite, one participant planned to try another respite facility. Dissatisfaction related to a range of aspects of residential respite. Some older people were dissatisfied with the organisation of the facility, such as rules that stipulated hall lights off at 8pm or inadequate entertainment or recreation. Some were unhappy with the housekeeping services such as thin towels or the bathroom being cleaned only once a week. For some the concern was physical aspects of the facility including a shared bathroom, a small room or the location far from the shops. One person described the food as 'the pits'.

Taxis

Dissatisfaction with taxi services (which in some cases had led the person to cease using them) related to long waiting times or taxis failing to arrive at all; dirty taxis, 'rude', 'smart' or 'surly' drivers; drivers failing to listen to directions; and language barriers. A number of people felt taxi drivers didn't care about them, or would not help them, particularly in relation to getting in and out of taxis. One participant described the difficulty of using taxi vouchers when attending her art class. She had to collect her voucher at the destination, then take it back out to the driver while carrying her art materials, which is awkward due to her restricted mobility.

A positive and negative experience of a CACP: Katharine

Katharine lives alone in a rented house in the north-west suburbs of Melbourne. She receives a full pension and rent assistance. She has two adult children.

Health

Katharine rated her health consistently at the midpoint rating of 'good'. She has back and neck problems and balance issues. She has arthritis in her hands and suffers memory loss resulting from a stroke. She finds it difficult to 'see order in things' and can get easily confused. Katharine spoke of her depression and said 'I'm pretty miserable, to be honest'.

Supports

Katharine started receiving a CACP in 2005 (prior to her assessment). She took it on as she wanted to give her daughter, who had previously provided a lot of support, 'a break'. When Katharine was worried about a \$15 weekly rent increase, her son offered to cover it.

Since commencing the CACP Katharine has received many more services, which have led to improvements in her life. She particularly appreciates her weekly art classes: an art show where her pictures were sold 'was like a shot in the arm'. Katharine also enjoys her weekly gardening group for people with a disability. A scooter has proved very useful for her independence and she can now go unaided to the library or meet a friend for coffee. She was also able to change to a private meals service that provides 'lovely good-sized meals'.

Social activity

Katharine loves social interaction and rated her social activity as insufficient. She was worried she was withdrawing: 'This can happen to you if you're not having daily contact with people'. Katharine has frequent contact with her daughter, and sometimes cares for her grandchildren. At T3 she had recently enjoyed the company during a holiday with her daughter and grandchildren: 'You wish it could always be like that', she said.

Services and issues

Katharine does have a problematic relationship with her CACP case manager and escort/carer. She feels she has never had clear information as to what assistance she is entitled: 'I don't feel like I know where I'm going and what I can ask for'.

Katharine's escort/carer plays a gatekeeper role between her and her case manager. She feels that there is often no follow-up on decisions. She finds this very stressful, exacerbated by her memory loss. She also felt discouraged from accessing other assistance. At a particularly desperate point, Katharine and her case manager agreed some respite was necessary. The case manager after several weeks had not made the arrangements and phoned to say 'Do you really still want that respite?' Since this initial discouragement Katharine has not asked for respite again. The cost is also daunting for Katharine.

Katharine has also had difficulty finding more affordable rental housing. The escort would not allow her to forgo her regular shopping trip in exchange for this more pressing need.

Katharine is reluctant to take her concerns further. She would say things like 'wouldn't want to make a fuss' and 'I don't want to take away from others'.

Unmet needs

Other than respite and more affordable rental housing, Katharine says she very much needs some gardening assistance to clear her yard. When she asked her case manager she was told they 'supply that to some clients'. She did not feel this was an invitation to request it.

4 Discussion

This study found that while the community care system is meeting the needs of many frail older people, there are significant barriers to accessing services for some older people.

The system appears to be working best for people who have either a case manager or family members who have managed to navigate the aged care service system. For some older people who were socially isolated and, experiencing low mood and whose carer was suffering from high carer burden the situation was less satisfactory. The study found that these people were less likely to access community care services. Socially isolated people who are not well connected with family and/or their local community may have to contend with both the structural barriers that limit their ability to access community services and a lack of informal support to help them to overcome these barriers.

Even though ACAS provides older people with a comprehensive assessment and care plan that aims to address their holistic needs, their community service options are restricted by structural barriers such as the limited range of service types, lack of certain services in some locations and affordability. Furthermore the service system is fragmented and older people must deal with multiple agencies or facilities to access different types of support. However those who are accepted for packaged care (CACP or EACH) are referred to a 'one-stop shop' where all of their service recommendations and broader needs are managed by a case manager. The study noted several examples of flexible service procurement, with the needs of the older person as the focus.

Factors that influence recommendations and uptake of community services

The study found that increased dependency, being female, living alone and not having a carer were associated with increased recommendations for community services. These findings correspond with the analysis of ACAS and HACC matched data conducted by Howe, Doyle and Wells (unpub.). A finding that is of particular interest was the association between low self-rated mood scores and ACAS recommendations. Older people who rated their mood positively were more likely to be recommended assistance with social and community participation (S&CP) and more likely to be recommended a CACP than those with moderate or low mood scores. The lower rate of recommended assistance with S&CP among people with low mood scores may be partially explained by the lesser inclination of people in this group to seek social activity. This may in turn influence the ACAS assessor's recommendation.

With respect to uptake of community services, the study found that use of community services increased over the nine-month post-assessment period. Overall this is the expected outcome in a sample of frail older people with complex needs. The study, however, revealed that older people's ability to access community services differed significantly. Three factors placed frail older people at risk of not taking up community services

Self-rated mood

The relationship between older people's self-rated mood and use of community services emerged as a central finding in this study. People who rated their mood positively at baseline were more likely to take up new HACC services, to use three or more HACC services and to use social and community participation services in the post-assessment period. The study further found that use of both respite and S&CP services was associated with improved mood scores between the baseline and T3 interviews.

The relationship between older people's mood and use of community services appears to be complex. The need to better understand it is heightened by the fact that more than one-third of the 61 older people recruited for the study rated their mood at baseline as low ('a bit down' or 'miserable'). Yet only 20 per cent of those reporting low mood were recorded in their assessment

as having diagnoses of psychoses and depression, mood affective disorders or symptoms of unhappiness.

Moreover, the community services that could potentially have a positive influence on mood, such as respite, are the very services that older people with low baseline mood were less likely to be recommended and also less likely to take up even if they were recommended. This finding suggests that low mood may be an important barrier to accessing the type of assistance that people require to support them at home. Given the small number of participants in the study, the findings must be interpreted cautiously.

Social isolation

The study did not find a relationship between the clients' level of social activity and pre or post-assessment use of community services. For many frail older people in this study low level of social activity did not necessarily indicate social isolation. Lack of contact with family, friends and/or the community was a more likely indicator of social isolation. The case studies reveal that people who were less connected with their family and their community had most difficulty in accessing the support they needed to remain in their home. Also, respondents who had at least weekly contact with family members were more likely to access S&CP community services in the post-assessment period than those with less frequent contact. While the association was not significant this warrants further investigation to verify the extent to which socially isolated frail older people are at risk of not accessing community services.

Interaction between formal and informal care

People with a daughter carer were more likely to take up respite than those with spouse carers and other carers, but at the same time, those with daughter carers were less likely to use transport services and home maintenance services. One possible explanation is that because daughters provide some kinds of informal care for their frail parents, some formal services are not needed or perhaps not wanted by the older person. With respect to respite, it is possible that daughters are more able to manage the process of arranging respite and more willing to make the decision to take up respite than spouse carers.

Stronger advocacy on behalf of the older people and carers in this study might have helped to reduce the information barrier to community services and possibly also the affordability and waiting list barriers. For people who are unfamiliar with negotiating for themselves, stronger advocacy could help them acquire cost concessions or to progress on service waiting lists.

Carer burden

The data illustrate how informal carers are both invaluable providers of support for older people living in the community and facilitators of community care. At the same time, some of these informal carers are experiencing high carer burden, particularly in the emotional domain.

The study found a significant association between low carer burden and higher levels of uptake of community services. Carers experiencing high carer burden were less able to access services for the client for a range of reasons including their own poor health, multiple roles (e.g. work and caring for other members of the family), and emotional strain. These factors sometimes limited their ability to access information about the community services or to take the necessary steps for planning care and arranging services.

Across the period of the study, overall carer burden ratings decreased and service uptake increased. However, carers' self-rated mood did not improve and emotional burden was rated highly by almost half the carers at both the beginning and end of the study. This suggests that the nature of the services used, for example, home care may not reduce the emotional strain of caring, despite providing relief from some practical tasks.

While it cannot be assumed that the experience of caring for a person with complex or chronic care needs is only a negative one, virtually no carers volunteered positive aspects of the role. One carer reported that having had a good relationship with her aunt through her childhood had meant that caring for her aunt as she aged was very important to her.

Use of carer support services other than respite decreased during the post-assessment period. Some carers reported that they had not used the carer support phone line and that carer support groups did not sound attractive. The finding that people whose carer experienced high burden were less likely to take up community services suggests that further consideration should be given to providing practical and emotional support to carers. Do ACAS or community service providers have a larger role to play in linking carers to support services?

Use of specific community services was found to have a positive influence on carer well-being: this applied particularly to CACPs and respite. The emotional support received from the older person's case manager was something valued by some carers. It was striking, however, that respite, which may reduce carer burden by providing rest or the opportunity for social interaction, has one of the lowest uptake rates of all recommended community services.

Barriers to accessing community services

The main barriers to community service use that emerged from the study were waiting lists, lack of information about services, lack of affordability, lack of availability of services, older person/carer attitudes, unsuitable services and perceived poor quality of some community services.

Effective information provision about services and older person/carer attitudes are two issues that ACAS teams grapple with constantly. They can make recommendations as an outcome of their assessment, but the person must accept the recommendations or approvals before they can be referred for community-based services such as HACC, or waitlisted for residential care or packages. With the complexity of community services for older people, the challenge for ACAS is to provide information on available services in such a manner that they can retain it. 'Information overload' can also result in a person (either the ACAS client or their family member) not recalling what has been discussed and arranged as a result of the assessment.

Some people were unsure about the outcome of the ACAS assessment. For example, several were unsure about whether they were on a CACP, even after the interviewer had described a CACP. Some people were unclear whether they were on a waiting list, or how long the wait might be.

Respite

The study found that some carers and some older people were benefiting from respite services (mostly residential respite). For some carers respite was great support, giving them the chance for a break, a trip away or social activity. For the older person positive aspects of residential respite included catering for special diets, good meals, activities, the opportunity to interact with other people of a similar age, and helpful and attentive staff. Positive experiences of respite were an important influence on participants' willingness to use the service again.

Respite, however, was one of the least commonly used community services both before and after the ACAS assessment. Even though 86% of older people for whom MDS data were available were recommended respite (including those who had used it in the past) rates of uptake were very low: only 23% of respite recommendations were taken up at in the post-assessment period.

An important difference with respite recommendations is that uptake requires instigation by the older person or their carer as opposed to other community service recommendations where a provider will make contact.

Lack of information about the service or how to access it emerged as one of the main barriers to taking up respite. Only 22% of older people were recommended to a Carer Respite Centre and only 8% used CRCs in the post-assessment period (CRCs assist carers by providing information and linkages to local respite services). Higher levels of ACAS recommendations for CRCs could reduce the information barrier and contribute to increased uptake of respite services for older people with carers.

Older people without carers may also require greater provision of information about what respite offers, how to access it, and in some cases, actual assistance with accessing. Clearly it is important that respite is explained in the context of a long-term care plan and not portrayed as a ‘fast-drop’ to permanent residential care.

Other major barriers were the cost of respite and dissatisfaction with the service. Respite was amongst the services scoring the lowest level of satisfaction. Some people were dissatisfied with: the organisation and rules of the facility, insufficient entertainment or recreation, the housekeeping service, physical aspects of the facility and the food. Uptake of respite was also impeded by unsuitability of the service, waiting lists, lack of availability and client attitude—for example, fear that respite would lead to permanent placement in residential care.

The findings suggest a number of barriers to be addressed to ensure a greater take-up of respite. Clearly consumers’ experiences need to be taken into account, as they act as a powerful disincentive to further use.

Support to access community services

The study found clearly that for many study participants, the ACAS assessment was not enough to guarantee them the community service that they needed. Many older people and carers need extra help beyond the assessment to access the various services. The main facilitator of community service uptake was having a person to assist instigating and following up referrals for the older person. This happened mainly through families, friends and assisted referral (case manager, ACAS clinicians, GPs and hospital discharge workers). These people helped by linking the older person to community services, provided information, made direct contact or advocated with services on behalf of the client and encouraged the older person to take up services. They are especially important as ACAS is not funded to monitor whether or not people have taken up recommended services.

Experience of using community services

Two-thirds of client/carer pairs were satisfied or highly satisfied with their overall service experience. However approximately one-third were less than satisfied with their experience (22% rated their experience as ‘neutral’ and 10% were dissatisfied). Even where ratings of satisfaction with services were positive they were often accompanied by comments reflecting dissatisfaction. Nearly 30% were less than satisfied with home-delivered meals and 15–20% of client/carer pairs were less than satisfied with personal care, home care, respite and taxis.

Overall satisfaction with community care services tended to be lower in cases where the older person’s self-rated health was ‘good’ or ‘very good’ and where there was a non-resident carer. Are the frailest people receiving better quality services or are they more likely to be satisfied with getting any type of help even if it is not always optimal? The sample was too small to do a multivariate analysis of the association between self-rated health and service satisfaction. It would be useful to do this analysis for each type of community service and to control for the possible influences of socio-economic factors such as education and financial status on expectations. Further are carers who live with the client more reticent to express dissatisfaction than non-resident carers such as daughters and sons? If so, is this a generational difference?

An important impact of service dissatisfaction is the helplessness and frustration felt by some older people because they cannot remedy the situation for themselves and do not have access to informal support. Some people reported depressive feelings because their garden is not being attended; others reported loss of appetite and weight due to their dislike of meals on wheels.

An important finding was the relatively large number of study participants that were dissatisfied with the activity limitations on HACC home care and home maintenance workers and with the provision of home-delivered meals. While there is clearly a need to protect the health and safety of home and community care workers, the needs of frail older people living in the community must be met. Similarly, improvements to meals on wheels and taxi services require further investigation.

Reflections on research method

This study encountered some methodological difficulties that are commonly experienced with cohorts of frail older people. These difficulties included a low recruitment rate, a high drop out rate (43%) due to poor health or leaving community care and poor recall of information and services received amongst some participants.

Recruitment, retention and sample size

With respect to recruitment, since this was a pilot study with limited funding, the method adopted was for the ACAS clinicians to invite participation at the time of the assessment. This imposed extra time burden on the clinicians. In addition, it adversely affected the sample size because some older people who might have been eligible were not recruited because the clinician judged that additional time spent on recruitment (after the assessment) would be too demanding for the client. Future studies with this study population would require adequate funding to engage suitably trained interviewers to recruit study participants a few days after their assessment.

Considering the characteristics of the study population, the drop-out rate of 43% is to be expected and reasonable. Nearly two-thirds of those who dropped out of the study entered residential care, declined in health or died. With a more effective recruitment method, the initial number of recruits could be considerably higher; and then even with a high drop out rate the study would have more statistical validity. Even though the small sample size does limit the generalisability of the results to the broader population, this pilot study achieved its aims of identifying key issue and directions for further examination and for developing key recommendations for improving the provision of community services.

Use of secondary data

A further problem was the fact that we were unable to access MDS data in the cases where carers were recruited without the participation of the person for whom they were caring. This meant that information on ACAS recommendations was missing for some of the people whose service uptake was being examined. Taking into account the problems of low recruitment and high drop-out rates, it would be preferable in future studies with this study population to apply for ethics approval to access MDS for older people who are not themselves participating but whose carers are. A further valuable addition would be to gain access to the corresponding HACC MDS and to CACP and EACH electronic waiting lists in order to follow up actual uptake of ACAS recommended services.

Research becoming an intervention

A further methodological issue relates to the study becoming an intervention. The study involved three follow-up interviews, as well as phone conversations to set up the interviews. Interestingly the number of participants dropping out of the study was highest between baseline and T1. Closely spaced follow-up times and repeat visits by the same interviewers (where possible) assisted in retaining the majority of the remaining participants. This suggests that members of the research team in many cases became welcome visitors for the study participants. Acting out of duty of care, the interviewers provided information to a few participants to gain access to formal support and in three cases people were supported to access additional ACAS assessments. This may have

marginally increased service uptake and therefore had a slight effect on results. Intervention effects may be avoided through recruiting a larger sample and excluding participants who received significant intervention.

Research tools

This study produced some interesting findings about relationships between community service use, social isolation carer burden and client mood. These findings indicate a case for including standard scales for measuring these factors in ACAS and HACC assessments.

The single item used in this study was simple to administer and appropriate for this type of study population. It was used in preference over a well-being scale such as Goldberg's 12-item General Health Questionnaire (Goldberg & Williams 1988) because of the limitations of the recruitment strategy. It would be interesting to compare the validity of the mood question used in this study with the widely used and highly valid GHQ-12.

The social activity scale used in this study was derived from the 1994 Health Status of Older People Study. The follow-up interviews also included some questions on social networks. The study findings suggest that a scale such as the abbreviated Lubben Social Network Scale (Lubben et al. 2006) which examines both the quantity and the quality of interactions with family, friends and neighbours would be a useful tool for assessing social isolation.

Gilleard's (1984) carer burden scale used in this study was found to be both simple to administer and reliable over the period of the study. Other screening tools for social isolation, carer burden and psychological well-being that could be considered are those in the SCTT psychosocial profile which is currently in place and the standard carer instrument that is currently being developed for the Australian Community Care Needs Assessment (ACNNA)

Directions for future research

Future directions identified include:

- the interaction between formal and informal care
- coordination of informal and formal care
- the relationship between older people's psychological well-being, ACAS recommendations and access to community services
- the relationship between client risk factors (such as low mood and social isolation) and accessing community services
- the relationship between carer risk factors (such as carer burden) and accessing community services for frail older people.

5 Conclusion and recommendations

The main conclusion of this study is that achieving optimal post-assessment outcomes for the majority of older people with complex and chronic needs will involve three key directions in the future:

- identifying and supporting older people at risk of not accessing community services
- supporting the carers of frail older people living in the community
- reducing the structural barriers to accessing community care

The patterns of service uptake suggest that careful consideration should be given to enhancing the case management and the care coordination models of community care for frail older people who are socially isolated, are experiencing low mood or whose carer is experiencing high carer burden.

There could be roles for ACAS and HACC providers in achieving optimal post-assessment outcomes. ACAS and HACC assessments could include standardised client and carer risk assessment tools such as Gilleard's (1984) carer burden scale, the carer burden and social isolation screening tools currently being developed for the Australian Community Care Needs Assessment (ACNNA) or the psychological well-being measures currently being used in the SCTT tool. Risk assessment of carer burden, self-rated low mood and social isolation could be a trigger for targeted support to older people and carers.

Currently ACAS is involved in care coordination for some clients until the required supports have been put in place. The ACAS MDS has recently begun collecting data on ACAS care coordination activity. Future research will be able to determine affect of this activity on client outcomes.

For clients who are assessed as socially isolated, experiencing low mood and whose carers are assessed with high carer burden, post-assessment support could be provided by measures such as:

- increasing the availability of ACAS care coordination (care coordination conducted by ACAS until the required supports have been put in place)
- ongoing monitoring of client and carer well-being by HACC providers
- increasing the availability of case-managed care at diverse levels of need.

Recommendations

This study acknowledges that the following recommendations have resource implications for both the ACAS and HACC workforces and that they cross state and federal program boundaries.

Identifying and supporting at risk older people

Recommendation 1: A standardised assessment should be made of the older person's psychological well-being and social resources at the time of the ACAS assessment.

Recommendation 2: Respite-recommended people who have a carer should also be recommended to a Carer Respite Centre (and assisted to access the CRC where necessary).

Recommendation 3: There should be post-assessment follow-up and assistance with linking to services for older people at risk of not accessing community services.

Supporting the carers

Recommendation 4: The ACAS assessment should include assessing the capacity of carers to provide care.

Recommendation 5: The ACAS assessment should include assessing carers' burden.

Recommendation 6: There should be post-assessment follow-up of carers experiencing high carer burden.

Recommendation 7: The support (physical, emotional and financial, according to need) for carers of frail older people living in the community needs to be enhanced.

Reducing structural barriers to accessing community services

Recommendation 8: The policy and funding constraints that influence the cost, quality and quantity of community services for frail older people should be examined.

This study has been able to demonstrate that limitations of the present community care system put certain groups of older people and their carers at risk of not taking up recommended services. The emphasis on community care solutions to enable people to remain in their homes seems likely to continue. It is therefore highly desirable that the present system is enhanced so that needs and potential risks are both effectively identified and addressed.

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Appendix: Summary of baseline and 3-monthly follow-up data collections

Questions and scales for use of health services, use of community services, self-rated health and mood and social activity were derived from the 1994 Health Status of Older People Study (Teshuva, Stanislavsky & Kendig 1994).

Table A1 Data collection at baseline and follow-ups

Baseline data collection	
Client	ACAS MDS data, socio-demographic data, case manager, use of community services, social activity, self-rated health and mood, use of health services
Carer	Carer burden scale, carer providing help or supervision
3 and 6 month follow-up data collections (T1 and T2)	
Client	Self-rated activity limitations, use of selected community services, social activity, self-rated health and mood, use of health services, care packages and case managers, service experience (quantitative and qualitative)
Carer	Carer assessment of client's activity limitations, carer burden scale, change in level of help, carer assessment of client's health and mood, care packages and case managers, service experience (quantitative and qualitative), carer providing help or supervision, use of carer support services
9 month follow-up data collection (T3)	
Client	Income, self-rated activity limitations, use of selected community services, use of other HACC services, social activity, self-rated health and mood, use of health services, care packages and case managers, service experience (qualitative)
Carer	Carer assessment of client's activity limitations, use of other HACC services, carer burden scale, change in level of help, carer assessment of client's health and mood, care packages and case managers, service experience (qualitative), carer providing help or supervision, use of carer support services

Use of health services

Information on the frequency of use of health services and visits to health professionals was collected only from older people, both at baseline and at T1.

Use of community services

In the baseline interview, information on clients' use and frequency of use of community services in the month prior to the ACAS assessment was collected from participating older people. This information was collected again at T1 from older people and this time also from carers who were participating without the ACAS client that they were caring for.

Self-rated health and mood

Information on the ACAS client's self-rated health and mood was collected from older people only at baseline and T1. Data on self-rated health was collected using the following question:

In general, how would you say your health is? Has it been: excellent, very good, good, fair or poor?

Information on mood was collected using the following question:

In general how would you say your mood has been over the last few weeks? Have you been feeling: very good, good, ok, a bit down or miserable?

Social activity

Information on the ACAS client's social activity was collected from older people at baseline and at T1. Participants were asked how frequently they engaged in different forms of social interaction, and what they felt about their overall level of activity. In order to summarise overall level of social activity, responses to the different questions about social activity were factor analysed and an overall scale derived from six items which seemed to reflect an underlying common dimension. These items include spending time with friends and selected recreational or other social activities.

Service experience and satisfaction

The service experience and satisfaction is based on the Client Perceptions of Coordination Questionnaire (CPCQ) developed during a trial of care coordination in Australia in the late 1990s (McGuinness & Sibthorpe 2003). At T1 both client and carers were asked a series of questions derived from the CPCQ about their experiences of services they had received. An eight-item scale of service satisfaction was developed. The scale has high statistical reliability (Chronbach alpha score=.707). The eight items in the scale address the following dimensions of the service experience:

- waiting for a service or appointment
- transport to the service provider
- understanding of the roles of different service providers
- consistency of advice from service providers
- coordination between services
- communication of GP with other service providers
- complaints about care
- satisfaction with care.

Satisfaction with services was rated on a five-point scale, ranging from very satisfied to very dissatisfied, where a high score represents a more positive experience and a low score represents a more negative experience.

Carer burden

Carers completed a carer strain scale in which they were asked to rate the amount of strain or burden (from 1=no strain, to 5=a great deal of strain) they were experiencing in the following areas: emotional, physical, financial, social and overall.

Table A2. ACAS Assessment Data of Study Participants & General ACAS Clients
(Derived from 2005–06 ACAS Minimum Data Set)

	Study participants	St George's & North West ACAS	All ACAS assessments (Victoria)
	(n=61)	(n= 723)	(n= 6355)
Use of community services at the time of ACAS assessment			
CACP	8.2	11.8	11.5
EACH	0	0.8	0.8
HACC	53.2	52.1	51.9
Veterans' home care	6.6	6.6	7.9
Day therapy	6.6	2.2	2.3
Carer respite	4.9	3.5	5.7
None	11.5	23.4	23.4
Use of respite in the last 12 months			
Residential respite	6.8	12.2	10.5
Non-residential respite	3.4	4.0	4.5
None	83.1	77.5	81.3
Recommended community services			
CACP	26.3	34.7	31.6
EACH	1.6	5.4	5.1
HACC	70.5	53.0	53.7
Veterans' home care	8.2	7.3	8.8
Day therapy	8.2	2.9	3.5
Residential respite	83.1	71.5	72.3
Non-residential respite	13.6	12.4	13.7
ACAS Approvals for:			
Residential care (low level)	45.8	33.5	32.1
Residential care (high level)	6.8	10.5	9.1
Respite (low level)	76.3	58.4	54.4
Respite (high level)	6.8	11.9	12.5
Community care	23.7	33.2	28.5
Flexible care (EACH)	3.2	6.0	2.7
Any approval	86.9	60.8	71.6