Brotherhood
of St Laurence
Working for an Australia free of poverty

What value independence?

Is it a barrier to HACC services for financially disadvantaged older people?

Brotherhood of St Laurence

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Foreword

The Brotherhood of St Laurence provides a range of services for older people: day programs, residential aged care, independent living units and the brokerage of care packages. These are funded from a variety of sources, including the Home and Community Care (HACC) Program. As part of our tradition of innovation, we endeavour to understand the experiences and views of people we work with and to find ways to improve the responsiveness of services we provide.

The overall objective of the HACC program is to enhance the independence of frail aged people and younger people with disabilities and their carers to enable them to remain in their home and community. A recently released report, *A Vision for Community Care*, proposes that: ‘Community care will support lifestyle choices to enable people who need support and their carers to live optimally in their own communities’.

Remaining at home—rather than relocating to residential care—will continue to be the preferred accommodation option for our ageing population. Governments are supporting this preference through policy and service initiatives such as the annual expansion of the HACC program, the yearly growth of community aged care packages and the extension of respite care services.

Community care is underpinned by the philosophy of care that places the client and their needs at the centre of decision making and care. Support services must find flexible approaches that respect lifestyle choices and focus on maximising independent living in the community.

The research project described in this report arose from earlier work conducted at the Brotherhood by Mandy Leveratt—*You wonder what’s going to happen next*—which showed that some elderly people entitled to HACC services were not receiving them, even though their health and social status suggested that they could benefit from those services.

The Brotherhood received funding from the Department of Human Services HACC program to investigate this question further, with a particular focus on the meaning that the concept of independence had for older people.

The project included interviews with 50 older people living in and around Fitzroy and with a small number of local service providers. The results showed that many older people viewed independence as being able to get by without help from others. Dependence, which also meant help from service providers, was something to be avoided. It signalled a loss of identity, both personal and as part of a ‘make-do’ culture of people who had struggled for many years financially and also often experienced poor health, dislocation and addiction. Service providers, on the other hand, thought that independence meant continuing to live at home, if necessary with the assistance of HACC services. These contrasting views pose significant challenges for those interested in HACC policy and service delivery.

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Acknowledgments

We would like to thank the people who were interviewed for this project for volunteering their time and their views. We would also like to thank staff from the following services who were interviewed, who provided comments on the project, or who helped recruit volunteers:

- City of Yarra Aged and Disability Services
- North Yarra Community Health Centre
- CarerLinks Carer Support Service
- St Vincents at Home Nursing Service
- The Lodge, Old Colonists Residential Care Facility, North Fitzroy.

We particularly wish to thank the Department of Human Services for funding for the project.

Changes of staff and management since the project began in 1998 have meant that many people were involved in designing, carrying out and writing up this research. Mandy Leveratt designed the project, did an initial literature review, conducted some interviews and began the data analysis. Rachel Hawkes also conducted interviews, contributed to the data analysis and wrote much of the report. Linda Martin, from Martin Bonato and Associates Pty Ltd, wrote some of the discussion and edited an earlier version of the report. Philippa Angley also wrote some sections and further edited the report, and Sandra Hills and Stephen Ziguras made comments on the final report.

Finally, recognising that the final product probably looks quite different from what was anticipated at its inception, we would like to acknowledge members of the project advisory group that met at the start of the project:

- Nick Matteo, City of Yarra
- Jill Thompson, Council of the Ageing (Victoria)
- Janny Hall, Department of Human Services (Northern Region)
- Liz Ozanne, School of Social Work, University of Melbourne
- Mandy Leveratt and Don Siemon, Brotherhood of St Laurence.

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Purpose of the project

This research has sought to analyse the disjuncture between the different meanings of ‘independence’ as held by the Home and Community Care (HACC) target group and service providers within the Northern Metropolitan Region of the Department of Human Services.

It sought to examine the ways in which HACC services could be marketed and delivered to ensure that older persons’ perceptions of independence do not unnecessarily exclude them from access to, and use of, valuable services.

Methodology

The project methodology incorporated the following key elements:

- a literature review of relevant research in Australia and overseas
- interviews with the target group to explore their life experiences and the influence they have had upon framing their current behaviour and belief systems with regard to independence
- interviews with relevant service providers to determine whether current modes of service delivery and promotion may serve as a barrier to access for the target group.

The interviews with HACC consumers, potential consumers and service providers were undertaken in 1999. A literature review was also undertaken at the time and has been supplemented in 2003.

Background

This project arose after an earlier exploratory study undertaken by the Brotherhood of St Laurence and funded by VicHealth entitled *You wonder what’s going to happen next* (Leveratt 1999). This study looked at whether low-income older persons living in insecure accommodation within the City of Yarra were able to gain access to the support services they required.

Whilst some of the 30 older persons interviewed in depth for the VicHealth project were receiving HACC services the majority were not, even though their health and social status suggested that they could benefit from those services.

Many of the people interviewed had little or no contact with their families, had few friendship networks and lived somewhat isolated lives. The study found that many of the target group, as a consequence of their life experiences, were unlikely to seek assistance from formal support services, preferring instead to cope on their own. A key finding of the study was the strongly held belief, by those not receiving services, that to receive them would jeopardise their independence. Acceptance of HACC services was seen by many as ‘giving up’ and the ‘beginning of the end’ of an independent life.

These beliefs are at odds with the HACC Program which ‘aims to promote and maximise the independence of its consumers’ (DHS 2002, p.19).

One consequence of these people not receiving assistance is that they may move into a high need classification before they come to the attention of service providers, which may have significant personal and financial implications.

As a result of the Leveratt study (1999), the Department of Human Services commissioned the Brotherhood of St Laurence to further examine issues surrounding the concept of independence as held by older people, service providers and policy makers. The findings of this study are summarised below.

Findings of the study

The perception of independence as presented by policy makers, service providers, consumers and potential consumers identified some common values but also reflected significant diversity of interpretation.

Independence for policy makers

Policy makers often used independence in two diverse manners, one strongly entrenched and the other still emerging. The first is an economic rationalist view, focused on maintaining people's independence to reduce the cost of welfare and to keep people out of expensive institutional care, such as hospitals, nursing homes and hostels. The second is a more humanitarian view, focusing on maintaining people in their own homes and communities. As policy is filtered through constrained resources and prioritised service delivery, the two concepts merge into a simplistic service delivery model which can only supply services to a limited percentage of older people who are eligible for the HACC services.

With demand being greater than supply, the study found that there was no incentive for providers to actively market the service to people with limited alternatives. While the policy promotes use of the HACC services, the program's limited resources means there is little scope for the provision of customised services to meet an individual's needs. This also meant that HACC services went only to those who had the most significant need (usually the very old and frail, or people with significant physical and mental health problems).

Consumers' views

A high value is placed on 'independence' in our society; the corollary being that dependence is a state to be avoided. For many of the low-income consumers and potential consumers of HACC services interviewed, dependence was something to be feared and avoided. It signalled a loss of identity, both personal and as part of a 'make-do' culture of people who had struggled for many years financially and also often experienced poor health, dislocation and addiction.

All of the people interviewed were constrained in their choices when they reached a point where they needed support. Depending on their circumstances, they might have access to assistance from friends, neighbours, families or HACC services. The first three options were limited or non-existent for many. A number were extremely reluctant to call on assistance from their families, from whom they were estranged. The majority of people interviewed also resisted the use of HACC services.

A double bind exists for many potential service users. On the one hand, because of the limited services available (which are targeted primarily to high needs groups), these people have to advocate strongly and demonstrate a significant need in order to receive a service. On the other hand, acceptance of the HACC service contravenes their strong desire to 'get by' and thereby maintain their independence and dignity. In many cases the policy direction encouraged people to request HACC services which were simply not available. Having struggled with a strong cultural barrier to asking for a HACC service, it was extremely demoralising for some of those interviewed not to receive the requested services.

If a service request is refused or provided in a way that does not meet their personal needs, the research indicates that this group, people aged 70-plus and on low incomes, will probably not ask again. A number of people spoke of their negative experiences of being rejected by HACC service providers and their frustration with the rigid and non-responsive assessment and administrative processes.

Service providers

Service providers indicated they were forced to constrain their view of independence within bounds of scarce resources, a restricted approach to resource allocation and ever-increasing demand.

Provision of services was related to a definition of need, focused on the ability of the aged person to undertake personal care activities, such as showering and preparation of meals. Services were allocated to those aged persons who could not meet these basic needs (as they became the highest priority need group).

Consumers and providers shared a number of concerns, including onerous intake and assessment processes, lack of flexibility in service delivery and limitations to the choice of staff by consumers, an issue that was felt to be critical to successful delivery. Many of the service needs named by potential consumers were straightforward and modest in scope. Unfortunately, even when a need is identified by the consumer or by a doctor, time-consuming assessment processes are still required.

An opportunity to build on existing relationships and support networks between friends and neighbours in local areas was identified. There were some indications that people were more likely to accept ‘health’ compared with ‘welfare’ services. The opportunity to link people into services through General Practitioners and post-acute services should be recognised and reinforced.

As people moved into stages of life where they required more support services, they tended to move closer to the provider conceptualisation of independence. This involved an incremental acceptance of support required to maximise independence, rather than a complete acceptance or rejection of HACC services. Providers strongly supported HACC service provision as a way to avoid the need for hospital or long-term residential care. The Commonwealth, State and Territory *Strategy on Healthy Ageing* (2000) expressed a similar view—that the services should ‘enable older people to remain in charge of their lives, even whilst accepting support services’ (Commonwealth Department of Health and Aged Care 2000, p.17).

Being HACC eligible and receiving HACC services are two different states. There is no point being eligible for a service that is not available due to limited funding, filtering processes and staff attitudes. It could be detrimental to actively encourage participation in a service that most people interviewed did not want (unless they were very incapacitated), and then be unable to supply those services when needed.

Conclusion

This study into independence and how it impacts the use of HACC services—such as home care, personal care and delivered meals—raises concerns about how well people on low incomes are currently supported. For the low-income consumers and potential consumers of HACC services interviewed, many of whom live in insecure housing, dependence is something to be feared. It signals a loss of personal identity, and undermines the ‘make-do’ culture that they are comfortable with and that has enabled them to live independently for many years, often with poor health, dislocation and addiction. The result is that some low-income older people avoid the HACC services that might actually assist them to remain independent.

Current policy directions suggest that the expansion of community care will continue, recognising the fact that the vast majority of older people who require care want to receive it in their own home. Removing the barriers that currently prevent many marginalised older people from receiving support must be a component of this expansion of community care. In particular, providing services in a way that is seen to be supporting independence, rather than threatening it, must be a priority.

Part 1 Introduction and background

Purpose of the project

This research has sought to analyse the disjuncture between the different meanings of ‘independence’ as held by the Home and Community Care (HACC) target group and service providers within the Northern Metropolitan Region of the Department of Human Services (DHS).

It sought to examine the ways in which HACC services could be marketed and delivered to ensure that financially disadvantaged older persons’ perceptions of independence do not unnecessarily exclude them from valuable services.

In consultation with financially disadvantaged older people, the researchers:
- examined the extent of formal service usage
- examined the extent to which the exercise of discretionary choice in the use of HACC services was constrained by the long-term experience of poverty and social exclusion
- identified and explored the key factors which frame older persons’ sense of independence.

In consultation with relevant service providers, the researchers undertook to:
- consider how HACC services are promoted and accessed
- analyse modes of delivery
- explore alternative modes of information dissemination and service delivery which will assist the target group in gaining access to services.

The project methodology incorporated the following key elements:
- a literature review of relevant research in Australia and overseas
- interviews with the target group to explore their life experiences and the influence they have had upon framing their current behaviour and belief systems with regard to independence
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Background

This project arose after an earlier exploratory study undertaken by the Brotherhood and funded by VicHealth entitled *You wonder what’s going to happen next*. This study looked at whether low-income older persons, living in insecure accommodation within the City of Yarra, were able to gain access to the support services they required.

Whilst some of the 30 older persons interviewed in depth for the VicHealth project were receiving HACC services, the majority were not, even though their health and social status suggested that they could benefit from those services.

Many of those interviewed had little or no contact with their families, had few friendship networks and lived somewhat isolated lives. The study found that, as a consequence of their life experiences, they were unlikely to seek assistance from formal support services, preferring instead to cope on their own. A key finding of the study was the strongly held belief, by those not receiving services, that to receive them would jeopardise their independence. Acceptance of HACC services was seen by many as ‘giving up’ and the ‘beginning of the end’ of an independent life.

These beliefs are at odds with the HACC Program which ‘aims to promote and maximise the independence of its consumers’ (DHS 2002, p.19).

One consequence of these people not receiving assistance is that they may move into a high need classification before they come to the attention of service providers—with all the attendant personal and financial implications.

The VicHealth study found that whilst the target group's sense of independence and their life experiences appeared to render them less inclined to take up formal support services, they were not necessarily the passive victims of their circumstances. They had constructed meaningful and, for them, coherent responses to the objective reality of their lives.

The study showed that low-income older people had few resources and choices available to them and were thus unable to exercise much control over their material circumstances. The findings could be superficially interpreted as indicating that access to the services they needed was constrained by circumstances beyond their control—such as the rules and regulations governing eligibility to services like public housing, or the combination of cutbacks to and fees for HACC services.

Some of the study's participants gave complex responses to questions about service usage. One way these participants exercised their autonomy was to resist using services, and to reject the very idea of service usage. This finding mirrored the results of research conducted overseas: 'The complexity of the power relationship involved in dependency is reflected in the refusal of services and benefits by elderly people—often in a way that is clearly not in their interests' (Dant 1998, pp.184–185).

Plath comments that 'the process of accessing public services and facilities is … not always a positive experience for older people'. She identified 'some of the negative experiences associated with old age' as 'isolation, marginalisation and ignoring basic needs' (Plath 2002, p.41).

These previous studies and analysis led to a decision to examine the attitudes of low-income older people to independence, through in depth interviews, primarily with individuals. The research has focused on improving understanding of the framework used by potential consumers and consumers of HACC services to assess their own needs and determine whether or not they would choose to use services.

Part 2 Policy context and literature review

Assumptions behind the policy and service delivery model

There are currently two prominent intellectual frameworks encompassing ageing policy. One of these is the concept of ‘positive ageing’ involving a ‘healthy, active, contributing, productive, successful and positive’ ageing. This approach also seeks to promote a positive view of ageing in our society. Australia (like Canada and the United States) has developed national and state policies on positive ageing (Teshuva, Stanislavsky & Kendig 1994).

The other framework presents the concept of the ‘burden of care’ which emphasises the growing burden which an ageing population will apparently place upon future health and welfare expenditures paid for by forthcoming generations.

These current debates are important to this study because they form the context within which policy decisions concerning the aged are being made, and shape or reflect community attitudes. They contribute to the general societal attitude towards ageing and help form the consciousness of older people, service funders and providers and the community on ageing. The concepts are integral to understanding the views older people have about ageing.

The language and concepts applied to ageing

The belief held by many older people that to be young and ‘independent’ is a desirable state merely reflects the dominant belief system of the wider community in Western societies. The diametrically opposed concepts of ‘independence’ and ‘dependence’, where independence is a good thing and dependence is therefore bad, permeates the literature on the aged and welfare and is reflected in policy.

The language used in public discourses about the aged serves to reinforce the image of older people as dependent and needy and—perhaps more damaging—as a burden on society As Fox warns: ‘How we see elders, however, will also frame the social contribution they make; thus the damaging ageist notion of an uncontainable upsurge of demand needs to be considered critically’ (Fox 1995, p.99).

In the latter years of the nineties, with implicit recognition of the power invested in language, governments across the world have been seeking to replace negative representations of old age with a new and positive vision promoting healthy, successful or positive ageing.

Positive ageing

Much of the current Commonwealth and State policy promotes successful or positive ageing and seeks to enhance the capacity of the ageing individual to maintain a healthy, active and independent lifestyle, as well as seeking to promote a more positive view of older people in our society.

This new discourse on ageing forms part of a broader thrust within health policies towards health promotion and prevention. In Australia, the *National strategy for an ageing Australia* (Commonwealth of Australia 2001) identifies ‘the need for positive individual and community attitudes to ageing’, emphasises the importance of ‘healthy ageing’ and ‘the need for age-friendly infrastructure’ (p.1).

The demographic time bomb

The ‘demographic time bomb’ or ‘dependency crunch’ theory has been coined to encapsulate the ‘burden of care’ discourse. Its simplest expression is to be found in the old age dependency ratio predictions produced by demographers. These are then used to support the argument that ageing will place intolerable future burdens upon governments in the form of burgeoning health and income support expenditures, which in turn will burden younger working age cohorts with increased taxes. For example, in Australia, Clare and Tulpule have estimated that the number of persons aged 65 years and over per 100 working age persons would rise from 16.7 in 1991 to between 28.4 and 39.9 (depending on variable estimations of fertility) in 2051 (Clare &Tulpule 1994, p.16). These predictions are problematic for they rely on uncertain future predictions. As McFee and Rowley (1996, p.50) have pointed out, they assume that older people of the future will be employed in the same way (retiring at 65) and to the same extent as they are at present.

Notwithstanding their crudity as a tool for policy analysis and initiatives, old age dependency ratios have been used as the rationale for a general movement away from ‘public pay-as-you-go pension systems’ and for moves to reduce health and social services outlays (Johnson 1996, p.266). Fears of excessive demand fuelled the push for cost-recovery from the deceased estates of pensioners who were asset-rich but income-poor (NCA 1996, in Leveratt 1999). It also lay behind the Commonwealth government’s attempts to introduce up-front accommodation bonds in nursing homes, argued for in apocalyptic terms (‘a tidal wave of frail aged people threatening to swamp the rest of Australia with their needs’) by Warwick Smith who held the federal aged portfolio at the time (cited in Leveratt 1999, p.x).

The public reactions to these proposed reforms, together with the media attention the debate attracted, revealed a deeply rooted paradox between ‘need’ and ‘burden’, at the heart of society’s view of older people. What was interesting about the position adopted by those opposed to the reforms was that they used the same language to argue that it was their very neediness and vulnerability that made older people a special case in society.

Policies were being framed within the notion of an undifferentiated mass of vulnerable older people threatening to swamp younger Australians with the burden of their care. Awareness has however been mounting that many older people remain productive and some have accrued significant assets which might offset the ‘burden’. This may be said to be a rationalist view, predicated upon both the construction of relative advantages (whether true or not) enjoyed by those who are entering retirement and the predicted costs to future generations. This discourse stresses individual risk and responsibility. Neither version denies need but they each construct it differently and may be distinguished from each other by positions of universality versus selectivity (Leveratt 1999).

In 1997, the aged—those aged 65 years or more—accounted for 12 per cent of the population, a figure expected to increase to 22 per cent by 2031 (Productivity Commission 2001). The financial burden associated with increased long-term aged care expenditure, whether borne by taxpayers or by the aged and their families, will depend on GDP growth. If Australia’s GDP growth is similar to that of recent years, it is less likely that increased provision of long-term aged care services will be a financial strain. Ranzijn, Harford and Andrews (2002) suggest that ‘the evidence so far indicates that the Australian economy will be able to cope with population ageing very well’ (p.145). They suggest that we must look beyond the cost side of the aged care equation and consider also the contributions older people make to society.

The interest in developing policies on ageing is evident internationally as well as within Australia (Giles 1993, OECD 1996, UN 1982). Concern about demographic changes and the potential drain on the public purse has been a significant contributing factor. Political responses have been fuelled by concerns about rising social expenditure in a climate of economic rationalism and an emphasis on the effectiveness and appropriate targeting of welfare programs and complex professional systems for assessing need (Plath 2002, p.41).

The manifestation of this policy approach in service delivery is in user-pays, targeting and rationing of services. Supply volumes and practices are adapted to control demand. The impact for low-income potential users of HACC is to reinforce their sense that government services for older people are only to be used when you are no longer able to look after yourself.

Independence

The meaning of independence

Policy makers, funders, providers, and consumers or potential consumers have interpreted independence in numerous ways. The term is ‘open to a wide range of subjective interpretations’ (Plath 2002, p.40). In spite of different philosophical perspectives, policy direction is promoting a fairly consistent, if contradictory, view. On the one hand, policy is focused on longer term savings by diverting people from institutional care. On the other, it is promoting the prevention of problems leading to the need for institutional care. One approach calls for a focus on high-need consumers and the other on low-need consumers. The mixing of economic and social imperatives creates unresolved tension and provides many practical dilemmas for those responsible for service delivery. The budget generally does not stretch to cover both directions.

The views of low-income consumers and potential consumers vary, but are collectively very different from those of policy makers and providers. Consumers have a more individual and situational construction of the term independence than the structural and systemic approach of policy makers and providers.

Whilst policy and service delivery documentation constantly refers to independence and autonomy, the terms are not defined and an understanding of the concepts must be by interpretation. The *Oxford Psychological Study Dictionary* (2nd ed.) defines autonomy as ‘a state of independence and self-determination in the individual, considered to be the ultimate goal of therapies based on humanistic psychology and existentialism’, but does not define independence. The *Australian Concise Oxford Dictionary* defines independent as ‘not depending on authority or control’, ‘not depending on another person for one’s opinion or livelihood’, and ‘unwilling to be under an obligation to others’. It defines a dependant as person ‘maintained at another’s cost’.

A content analysis carried out on Commonwealth and NSW policy documents relating to community care, healthy ageing and retirement income found that ‘independence can be found to mean quite different and at times contradictory things’ (Plath 2002, p.40). The *Commonwealth, State and Territory Strategy on Healthy Ageing* has a vision for older people to ‘maximise their independence and wellbeing’ with principles to ‘support independence’ and ‘encourage personal responsibility’ (Commonwealth Department of Health and Aged Care 2000, p.3).

A key direction of the Victorian government *Making this the age to be in Victoria: A forward agenda for senior Victorians* is ‘to enable senior Victorians to lead independent, active and health lives for as long as possible’ (DHS 2002, p.7), linking independence to health and activity. Much of the current Commonwealth and State policy intent is to increase or enhance a state of undefined independence linked strongly to health and personal responsibility. However, the *National strategy for an ageing Australia: an older Australia, challenges and opportunities for all* does not mention independence in its principles, but highlights ‘independence and self provision’ as a theme. The link to economic independence is clear (Commonwealth of Australia 2001, p.3).

The concepts of dependence and independence saturate the literature on ageing and older persons. Throughout much of the medical, psychological and sociological literature on gerontology, the meaning of independence is elusive. It is an abstract state accepted as a positive attribute and its converse—dependence—is therefore bad. Plath has expressed the view that ‘an uncritical discourse on promotion of independence can act as a diversion’ from more fundamental issues of ‘fair and adequate incomes’, ‘community responsibility’ and the ‘availability of services’ (Plath 2002, p.46). Linking ageing and dependency is a basis for diagnosis, classification and access to services.

There are some theorists who have tackled the meaning of dependence/independence more specifically. In their genealogy of dependence in the United States, Fraser and Gordon (1994) have explored the historically changing meaning of the word through the use of four specific registers:

> … the first is an economic register, in which one depends on some other person/s or institution for subsistence. In a second register, the terms denotes a socio-legal status—the lack of a separate legal or public identity as in the status of married women created by coverture. The third register is political—here dependency means subjection to an external ruling power … the fourth register we call the moral/psychological—dependency in this sense is an individual character trait like lack of will power or excessive emotional neediness (p.312).

Kissane includes dependency as a factor contributing to the demoralisation of older people, citing also social isolation, declining physical health, disability, and concern about being a burden to family as other factors (Kissane 2001, p.110).

Fraser and Gordon (1994) seek through these four registers to track the historical shifts in the usage and meaning of the word dependent. They argue that dependency is [now] an ideological term with ‘strong emotive and visual associations and a powerful pejorative charge’ (p.311), and ‘there is no longer any self-evidently good adult dependency in post-industrial society’ (p.324). Under the fourth register of individualised psychological dependency which is the dominant meaning of the term, ‘all dependency is suspect, and independence is enjoined upon everyone’ (p.324).

A well known scholar in the field of ageing and aged care, Gibson (1998), has suggested that classificatory systems such as that proposed by Fraser and Gordon (1994) fail to fully capture the multi-dimensional nature of dependency. Instead, she suggests that analysis of the various uses of the term needs to be placed in the context of five dimensions: What kind of dependency?; Dependent on what?; Dependent for what? ;What are the causes of dependency? ;and What are the attributes of dependency? Gibson (1998) goes on to filter these five dimensions through four key literatures: the social welfare literature, the culture of dependency literature, the psychological literature, and the ageing and disability literature.

Thus, in the social welfare literature, Gibson argues that dependency revolves around financial dependency on the state. Feminist writings in this field have also focused upon women’s financial dependence on men. In the ‘culture of dependency’ literature, dependency has emerged as a negative personal attribute, leading to blame directed towards those not seen as having a legitimate claim. In the psychological literature, dependency is characterised as an individual trait within a normative developmental process, with dependency in adults considered abnormal or pathological.

Discussions of dependency in the ageing and disability literatures have tended to revolve around physical and mental disabilities where the word ‘dependency’ has been used as a virtual synonym for disability. Gibson (1998) detects an ‘unresolved tension’ concerning the extent to which dependency is a ‘characteristic of the individual or of the level of care needed by the individual’ (p.200). This is exemplified by the measures used to determine functional ability—such as activities of daily living—and their ranking or rating to determine need for assistance (or dependency on the services of others). A further area of this literature particularly coming from the feminist quarter, concentrates on caring where an absence of sufficient public provision creates a burden of care (and often a resultant dependency on welfare in turn for the carers) in the private sphere and specifically for women (p.201).

Gibson (1998) concludes that whilst each of these literatures contains strategies for reducing dependence, they do not address the issue of the ‘potential for reducing the subjective negative experiences associated with dependency’ (p.204). Gibson proposes criteria by which the balance of power in a dependency relationship can be gauged to be asymmetrical:

- the extent to which the dependent individual needs the required service or resource in order to protect his or her interests
- the availability of alternative sources of assistance or service
- the level of discretion which the resource holder or service provider has in providing the required assistance (p.207).

Drawing on this model, the level of vulnerability will be highest when the dependent person has the greatest need for the service, there is no alternative source of assistance or extremely limited alternatives and where the provision of the service is at the discretion of the provider (p.207). Recent theoretical and empirical work undertaken by researchers such as Wenger and Titterton (1992) argues that policy makers have been unduly influenced by an undifferentiated approach to human service provision, suggesting that uniform needs and uniform responses are often simply ascribed to individuals within vulnerable groupings.

According to McNay, the ‘judges of normality’, in the figures of the social worker, the teacher, the doctor, are everywhere assessing and diagnosing each individual according to a normalising set of assumptions (McNay 1994, pp.94–95).

Robertson (1997) believes our very ‘individuality’ exists only as a result of our embeddedness in a network of relationships both private and public. None of us is totally independent of our context—social, political and economic. Rather, we live within our complex webs of mutual dependence or interdependence. In order to better understand these interactions it is important to hear the views of all stakeholders. Those with the least powerful voice are clearly the people on low incomes who are not able to draw on the resources available through government programs such as HACC.

The gradual development of welfare policies from the nineteenth century onwards was based on the belief that the ideal of independence was not available to all and that the State needed to intervene to either facilitate independence or to underwrite dependence. One of the key dilemmas of government is whether to promote independence or to underwrite dependence. Both receive attention in policy documentation and practice. According to Dean and Taylor-Gooby (1992):

> the relationship between the government and individuals has increasingly … been understood in terms of ‘welfare’ and potential service users have constructed a meaning of welfare linked to dependency … The quest is not for autonomy through independence, but through ensuring the mutuality of our interdependence. (p.175)

All our basic social, political and economic institutions reinforce independence as an ideal state to which all should aspire. Dean and Taylor-Gooby (1992) cited a study where participants used the word ‘dependency’ in five ways:

> First it was sometimes equated with addiction … second, some respondents equated dependency with indebtedness … third dependency is linked to poverty…fourth dependency is sometimes equated with the necessity of subsistence … finally some spoke of being trapped, caged or ‘caught in a vicious cycle. (p.150)

It could be argued that the reform strategy which ushered in the HACC Program, and explicitly sought a ‘balance of care’ between community-based and residential or institutional-based care, was predicated upon the dualism of dependence/independence.

We have witnessed a veritable explosion of texts on ageing—part of what Carroll Estes (1979) has called ‘the ageing enterprise’. It seems that the identification of ageing as a problem by demographers and others has occurred simultaneously with the emergence of techniques and knowledge to manage that problem through diagnosis and classification systems.

The notion of individuals as independent agents has resulted in twin foci: older people whose needs that must be managed; and older people who are able to participate in the consumer culture of individualism through private pensions, the purchase of services and through ‘independent’ positive and successful ageing.

In the view of Green (1993), both gerontology and social policies aimed at older persons are framed within the context of a care/dependency continuum. They argue that care is a measurable and distributable commodity.

The meaning of independence for low-income older people

It is critical that we learn more about the different ways in which financially disadvantaged older people construct ‘independence’ as a mediating factor between their objective material, physical and social circumstances and their relationship to welfare services. In other words, we require a more sophisticated understanding of the coping strategies adopted by financially disadvantaged older persons during their lifetimes and how this affects their experience of the ageing process and their participation in support services.

The current policies and community perceptions affect the way older people feel about themselves. Older people on low incomes are dependent upon publicly provided pensions and services. Thus, when policy makers, demographers and politicians speak of the growing burden of older people, it is those who cannot exercise choice when it comes to aged care services, who may feel themselves to be the target of this discourse. Lack of financial resources, combined with a lifetime of disadvantage, also translate into a lack of choice when it comes to positive ageing strategies.

In this context, how low-income older people construct meanings of independence is complex and often contradictory. They are the explicit subjects of the ‘burden of care’ paradigm and cannot attain the idealised notion of independence promulgated by the positive ageing perspective. Implicitly, both these approaches assume independence to be affected by financial status. To be an independent person is to be reliant on your own resources and to actively participate. The only resource people on low income have is their own ability to battle and achieve the desired and valorised state of independence with minimal assistance.

This more complex notion of independence, which emerged in some of those interviewed for the Vic Health and current study, appeared to be more than just a product of the participants’ low-income status—it seemed to be integral to their sense of identity as working class people.

Such a construction of independence has been commented upon before in relation to low-income families. In a recent article on her experiences in living in the East End of London, Maitland reported that ‘the highest virtue on our estate was a complicated quality called ‘getting by’ (Maitland 1998, p.28). ‘Getting by’ meant managing the household finances, keeping the flat reasonable (not just clean, but decorated) not doing anything that got the social workers in, supporting your neighbours, bettering yourself and your family by any means, and above all caring for your children. Maitland concludes that ‘class plays a fundamental role quite other than the function of wealth’ (p.29). In other words, it is the cultural aspect of class that is critical to our understanding of words and their meanings. Thus it seems that ‘getting by’ or its Australian equivalent, ‘battling’, is highly valued within, and an integral part of, the working-class culture. As such, ‘independence’ becomes quite a different concept from that used by policy makers.

The position of older people in our society needs to be placed in a context of a range of social, political and economic policies. Townsend (1986) argues that the condition of dependency of the elderly is not the inevitable outcome of a natural process of ageing, but is socially constructed and hence potentially open to change. He asserts that retirement, poverty, institutionalisation and restriction of domestic and community roles are the experiences which help to explain the structured dependency of the elderly (Townsend 1986, p.21–22; see also Phillipson 1982 and Guillemard 1983).

The generation ‘at the forefront in the elaboration and expression of a public vocabulary of ageing’, and making the policy at this point in history, have different constructs and values from the generation of older people experiencing the outputs (Featherstone & Hepworth 1989, pp.155–156). The cultural factors influencing generational experience are of course variable: the post-war ‘baby-boomers’ for example, will take into old age quite different values and resources from those who preceded them and from those who will follow (Featherstone & Hepworth 1989).

The disjuncture between the concept of independence for low-income older people and the HACC Program

The current study sought to explore the complex relationship between individually held notions of independence and service provision and usage. The main emphasis is upon understanding how current social attitudes towards and policies on ageing, when combined with life experiences, affect the way low-income older people relate to the service delivery network. In doing so, the study seeks to uncover the nature and extent of the disjunction between the major purpose of HACC and other aged care services—the preservation or enhancement of independence for older people—and the belief held by some that to accept them constitutes a loss of independence.

The policy maker's construction of independence and interpretation of need has a strong impact on service provision models and practices and the understanding and willingness of consumers and potential consumers to accept the services. Social context, values, interpretation and communication play a key role in the acceptability of services by older people. Current paradigms focus too much on structural and not enough on social elements. Public funding for HACC comes with strings attached and some of these strings are social and emotional barriers not readily surmounted by a low-income consumer group.

Older people, and in particular older people on low incomes who are the focus of this study, focus on issues of control over their own lives. They are entrenched in powerful family and social values. These values are derived from their childhood and life experiences that constantly reinforced the need for self-help and self-determination. This is overlaid by powerful policy messages about remaining independent and concepts of welfare dependency.

The stated aim of the HACC Program is to provide services 'to assist people to be more independent at home and in the community and to assist carers in their caring role, thereby preventing inappropriate admission to long-term residential care and to enhance the consumers quality of life' (DHS 2002).

From a government perspective, independence is increasingly being defined as not being dependent on the public purse, particularly not using the most expensive services such as residential care and hospital beds. While this coincides with older people's own wishes, it nonetheless sends out messages to restrict their demand on services unless they really need them. The experience of some of those interviewed who had sought services was not always positive.

On the other hand, for those who are actively engaged in delivering HACC services, the fact that services are being refused by some to whom such services are targeted, and who would presumably benefit from them, is a somewhat vexed problem. It is paradoxical that services which are being delivered with an aim of enhancing older people's independence are being refused. As such it is a problem that requires a deeper understanding. This deeper understanding may include respect for what Kissane calls 'autonomous choice' (Kissane 2001, p.111).

In one project undertaken by the Council on the Ageing NSW sought to assess the effectiveness of HACC services in achieving their aims through consultation with older people and to understand how these services had been experienced from the consumer perspective (COTA 1998). The majority of the sample of 550 people were over the age of 70 years and over half were living alone. Most were living on low incomes.

Most of the older people who participated in the COTA study (1998), said they needed help because they were finding it hard to manage, either because of their own frailty or illness or because they were caring for someone else. Some of the participants said that HACC services help them to stay in their own homes longer than they believed would have been otherwise possible. Others said that the services provided them with some companionship in an otherwise lonely life. Although there were some complaints about the services, particularly about the poor quality of meals on wheels, and the unwillingness of home help workers to do any major cleaning jobs, most of the participants said they were happy with the services. On this point however, the authors acknowledged that, typically, older persons were reluctant to complain and were grateful for any service, regardless of the quality. Others were reluctant to complain for ‘fear of recrimination or reprisal’ or a wish not to get the individual worker into trouble. Dissatisfaction with a service was most commonly dealt with by cancelling the service and saying nothing. As a result, the authors concluded that service providers should not rely solely on complaints—or a lack thereof—for feedback on the quality of service delivery. Many of the participants said they had had difficulties finding out about services. Often district nurses or local GPs were the main source of information. Also, few participants knew that fees were negotiable.

In the COTA (1998) study, independence was discussed mainly as something that could be maintained through service use, especially in the sense of thus avoiding being a burden to one’s family. The idea of independence being a barrier to service use was not strongly identified as it was in this study, although ‘the complex attitudes many participants … had towards receiving services’ were mentioned (COTA 1998, p.41). The study also found that many older people displayed a marked reluctance to find out about services with a view to possible future use. Others saw services coming into the home as ‘an intrusion into their life’ (COTA 1998, p.28).

Some research (notably Day 1985) observed that there seemed to be a gap between how service providers believed their services assisted older people and the kind of help older people themselves believed they needed. A British study by Wilson (1993) starts from the premise that service providers and service users must necessarily come from different perspectives in their attitudes to service delivery. Wilson argues older people are generally a compliant set of service users.

She found that service users had ‘low expectations and low feelings of entitlement’ (Wilson 1993, pp.510–11). They also commonly expressed that becoming a client (service user) jeopardised independence. Control, in terms of institutionalisation, was feared and direction (from service providers) was resented. She also found that 31 of the 50 older people interviewed were overtly critical of support services. These criticisms included: lack of punctuality by service providers, irregularity in visiting times of service providers, uncaring attitudes of service providers, long waits for services and, in the case of home help, poor quality work (Wilson 1993, pp.514–515). It is worth noting that although the COTA (1998) study (using a direct-questioning approach) found that its participants were more likely to praise the services than criticise them, the nature of the complaints about services in these two studies was very similar (COTA 1998).

Wilson (1993) identifies a disjuncture whereby community care workers may see themselves as caring whilst the client experiences this care as control. Service users and service providers come from different perspectives in the way they view support services. Wilson (1998) demonstrates how the provision of support services involves many stakeholders and that service users are not the only consumers. At the top levels of a welfare bureaucracy, taxpayers and politicians are also consumers of welfare services, but their demand is for services which control those aspects of society which have been labelled as problems (Wilson 1993). They are working to control consumer demand for institutional care and to retain people in their homes and communities as long as possible. They are making professional judgements about needs to be met to sustain people in their communities. At the lower levels this translates into a tension between the conflicting demands of care and control, affecting both worker and client. Workers will act in ways to minimise risks to the clients as well as risks to themselves. Clients may share the socially legitimated perception of services as caring but at the same time they can feel the loss of independence as a consequence of control. In addition they have to reconcile the very great practical differences between their perceptions of services and the perceptions of community care staff (Wilson 1993).

Leveratt (1999) came to a similar conclusion: ‘We cannot assume that meanings are shared … and that there is an immediate and automatic concordance between the meanings and intentions of policy makers and those of older people themselves’ (p.20). She also argues that for studies into the effectiveness of support services for older people to be truly useful tools for bringing those services into alignment with older people's needs, they need to recognise that 'public' and 'private' accounts of older people's satisfaction with services may be conflicting.

The concept and context of assessment and assessed need

Understanding the policy and knowledge bases behind the practice of assessment, care planning and case management is integral to understanding the tensions within the aged care service systems. The HACC service has conflicting messages, ranging from being a universal and preventative service, to having highly targeted priorities and a finite resource base that have led to tight prioritising of access. The tight priorities mean that most services prioritise people with high needs (and practically, those needing personal care) and other people who are eligible for the service may never receive them. The assessors are placed in a very powerful position and are trying to interpret policies that are conflictual when considered in the context of resource constraints. In some services, such as the one used to draw the sample for this study, assessments for eligibility and priority of access are done over the phone.

Eligibility criteria

A definition of need is implicit in the rationing process known as eligibility. A major supply issue is the control of entry into the needs-based system (welfare) which elicits distinctions between the deserving and non-deserving. Demand is controlled by the practices of eligibility (Stone 1984, cited in Robertson 1997). Eligibility is determined through a process of assessment, and the servicing of identified needs is determined by targeting and priority of access criteria.

A number of critical theorists (many from the structured dependency school) have expressed concern about the whole process of defining, assessing and servicing of older persons' needs by professionals, and question this process as part of an ageing enterprise (Estes 1979). Professionals 'get the kind of answers they are comfortable dealing with because they ask the kind of questions that will provide those answers' (Minkler 1996, p.474). Some of the people interviewed for this study found they had unwittingly been given more services than they wanted and others found that unless they were 'unable to shower', home-based services were 'out of the question'.

'The professionals deal in the business of what they think are real or objective needs—that is, needs as assessed in accordance with the knowledge base of the profession concerned. The disabled individuals think of these needs as their own, as taking on shape and existence through the way they give voice to them' (Yeatman 1994, p.107). Fraser (1990) calls these 'expert needs discourses' and argues that they have been used by governments to have the dual effect of repositioning the people as individual cases rather than members of social groups. This has the effect of positioning people as 'potential recipients of predefined services rather than as agents involved in interpreting their needs and shaping their life conditions' (Fraser 1990, p.212).

However, midway through the nineties there appears to have been a move away from service provision policy guided solely by expert professional opinion, and towards 'user rights' or 'needs-based' assessments, which were to allow for users' definitions of need. This is evidenced by the UK white paper *Care in the Community* (Wilson 1993) and the US community care reforms (Richards 1994), both of which have stated aims to respond to individual need and preferences in service delivery. In Australia, the Commonwealth Government's policy has shifted to guiding services to work with the expressed needs of individuals in the home and community care area (Yeatman 1994). Yeatman (1994, p.107) partially attributes this shift in policy to the social movements by disabled persons in the 1970s and 1980s. Progressing this direction further, current interests include the self management of care plans and service delivery.

Needs-based assessments represent an alternative to service-led assessments in that they purport to identify people's needs rather than simply assess their eligibility for existing services. However, Richards (1994), examining the effectiveness of US needs-based assessments in identifying need from the users' perspective, found that needs-based assessments rest on the assumption that 'need' can be defined objectively. Richards' (1994) research has shown that it is extremely difficult in practice to separate the concept of need—when applied to elderly people—from the concepts of risk and dependency.

This finding is consistent with Gibson's (1998) observation that there is an unresolved tension about the extent to which dependency is a characteristic of the individual or of the amount of care needed by the individual. Thus, assessments designed to identify need, rather than eligibility, rest on the problematic assumption that it is possible to identify need independently of the procedures which determine eligibility. The ways in which welfare workers making assessments perceive and define need are fundamentally shaped by the policies and procedures they implement. For example, it has been identified in the current research that assessors tend to seek needs for personal care, but minimise needs for home help. This may reflect a conflict between the assessor's responsibility to identify need and to control access to provider resources.

The empowerment of service users is one rationale for the use of needs-based assessments. However, despite efforts to reduce the power differential between assessors and users, (by including users' perceptions of needs in the decision-making process) ultimate power to grant or deny access to services and to impose social norms rests with the assessors. It is not clear to what extent the self-defined needs of users will achieve formal recognition, unless they coincide with the existing policies, practices and priorities of the agencies providing the service (Richards 1994).

As Minkler (1996) reminds us: 'even when older people are encouraged to set their own goals, they are in reality, often asked to do so within the context of pre-existing goals that outside experts have determined to be the important ones' (p.476). Gardner and Nudler (1999) argue that 'personal outcomes … address different expectations than do outcomes related to clinical status or functional capabilities' (p.xiii). Day and Harley (1985) conclude that it is 'important to ensure that decisions and arrangements for care are made in the interests of clients rather than in terms of the assessment authority's view, about what may be the easiest and most convenient type of care' (p.40).

Priority of access and high and low needs

Resource constraints skew the goals of HACC and priority of access rules are the tools used to control finite resources. Whilst there is logic in the notion of early intervention, HACC Program is increasingly applying priorities to access which provide for only the highest of needs and require people to argue that they dependent and isolated in order to receive services—circumstances to which many older people would not confess.

A number of recent Australian studies have focussed on either barriers to older people's access to support services or the effects of service usage or (the lack thereof) on older people's health status or residential outcomes. However, although fear of independence loss by older people has been fleetingly noted as a possible barrier to service usage in some of these studies (COTA 1998; Craw & Gilchrist 1998), only the work of Alice Day (1984, 1985) has given this idea any real credence.

A study by Turvey and Fine (1996), commissioned by the Commonwealth Department of Health and Family Services, undertook to investigate the effects of low levels of HACC service use (as a result of targeting of these services) on older people assessed as having low needs. The available evidence suggested that frail older people who were receiving HACC home help services were a little more likely to remain in their own homes longer and were also more likely to believe they could do so, than those who received no help. The study concluded that 'although it was not possible to demonstrate improved health outcomes for recipients of basic home help, the positive effects of this service on subjects' perceived quality of life and subjective well-being were undeniable' (Turvey & Fine 1996, p.67). They proposed a targeting strategy which involved shifting the aims of HACC service provision from maintaining people in their homes to 'a more explicitly preventative and restorative approach … where care is provided for the period of need with the aim of enabling recipients to regain an optimum degree of independence' (Turvey & Fine 1996, p.74).

Accessing services for people on low incomes

Another DHS-funded study, by Craw and Gilchrist (1998), was concerned with establishing whether communities of people from non-English speaking backgrounds (NESB) were accessing the aged care service system in the Northern Metropolitan Region. This study investigated the reasons why the ethnic elderly (other than Greeks and Italians) were not using HACC services and identified ways in which HACC could facilitate service uptake by these groups. The study examined the Macedonian and Vietnamese communities which had a low uptake of HACC services. The results provided some support for the observation that the local NESB community is under-represented in the usage of in-home HACC services (Craw & Gilchrist 1998). The expectations of an extended family caring for its older members was marked with the Vietnamese group but this was less likely to be the case with the Macedonian group, possibly due to changing values and attitudes among the younger generations. The study found a general ignorance that the services existed (as they did not in the countries of origin), that not enough information was disseminated in the relevant languages, and that there were not enough HACC workers who came from the relevant ethnic backgrounds (Craw & Gilchrist 1998).

The finding most pertinent to the current study was the observation that older people from both ethnic groups may resist HACC services—due to a concern they may be pitied by others in the community or that their family would be seen as abrogating their duty to care for their elderly (Craw & Gilchrist 1998). Vietnamese people interviewed for the current study held diverse views, with half of them preferring HACC services to imposing on their families.

A project run by the Royal District Nursing Service (RDNS) Yarra Centre and Homeless Persons Program (the Elderly Services Access Project 1999) targeted low-income older people living in rooming houses and low-cost hotels. They were perceived as in need of assistance, but were either not accepting of, or not accepted by, the usual services (including HACC services) offered by local providers (RDNS 1999). The purpose of the project was to pilot a model of service delivery that would assist disadvantaged older people to effectively access the services. The project concluded that a support and information service, aided by the development of trust, could act to assist disadvantaged older people to access the service delivery network (RDNS 1999).

The RDNS (1999) project also found that coordinated, quality client care seems to be dependent on collaboration amongst service providers and on well-developed service networks. Interviews with service providers identified a lack of common understanding, between workers, of issues experienced by clients and differing perceptions—between agencies—of client need. Service providers contributing to this project also discussed the necessity of flexible, creative, personalised support which responds to both the system's and the clients' perceptions of needs. The RDNS Elderly Services Access Project (1999) is an example of how access for people on a low income can be increased.

Part 3 Interviews with older people

Method

In-depth interviews were the chosen qualitative data collection method. These interviews were conducted with a sample of 50 low-income older persons who were living in rented accommodation within the City of Yarra. These participants were self-selecting, having responded to a flyer, distributed by local service providers, inviting them to participate in the study. These service providers included Yarra Community Housing Group (distributing the flyer through rooming houses); Fitzroy and Carlton Community Credit Cooperative, private medical clinics, community health centres, pharmacies, churches, material aid outlets (opportunity shops), post offices and various retail outlets.

Participants were given a choice as to where they preferred to be interviewed in their own homes or an alternative venue. As the purpose of these interviews was to gain a more sensitive understanding of what these older persons meant by independence, it was considered that this understanding would be enhanced by talking to the participants in their own surroundings. Approximately two-thirds of participants were interviewed in their own homes and twelve were interviewed in the Brotherhood of St Laurence offices. Two groups of Vietnamese women took part in interpreted group interviews at the North Yarra Community Health Centre.

With the exception of the two group interviews and one other interpreted interview, all the interviews were conducted on a one-to-one basis.

A semi-structured interview schedule was used. Questions designed to open up areas of discussion were pitched around various aspects of independence such as getting around the local area, informal networks, housing and accommodation issues and the use of formal support services. Participants were also asked directly what independence meant to them.

The first part of the interview was largely devoted to building up a picture of the participants' lives in terms of their birth, families, childhood and schooling, working lives, marriages or significant relationships and children and grandchildren if they had them. This part of the interview process served a dual purpose. The first was to build an easy rapport between interviewer and interviewee, the second was to gain an insight into how independence had been conceptualised by the participant and even the participant's family and whether it had formed an integral part of their identity from an early age. Due to the personal nature of much of this information these interviews were conducted with a high level of sensitivity.

Data analysis

The 50 taped interviews were analysed thematically to isolate and identify the way each participant conceived of, and defined, independence. This included:

- identifying how individual life experiences (which included long-term poverty and/or social exclusion) may have contributed to the formation of a particular conceptualisation of the term independence as applied to themselves throughout their lives
- identifying what independence meant to these individuals and how important it may be to their sense of identity and self-worth
- identifying how this sense of independence manifested in their everyday behaviours
- determining whether they believed that the acceptance of aged care services compromised their independence
- determining whether the exercise of discretionary choice in the usage of these services was a concrete manifestation of an independence affirming behaviour.

These thematic representations of the construct of independence, together with any other common themes or notable anomalies that emerged during these interviews, were identified for further and deeper analysis.

A typology of the participants was constructed in which men and women were separated, as there tended to be more differences than similarities in their views on independence.

A secondary analysis was then carried out on the interviews in order to:

- ascertain the extent of usage or avoidance of HACC services and attendant reasons for use or non-use amongst each of the groups in the typology
- determine the point at which those in the sample who were not yet using services, would be prepared to use them in the future.

Participant profile

The 50 low-income older persons who took part in the study were asked to fulfil basic selection criteria. They were to be:

- over 60 years old
- residing within the City of Yarra
- reliant solely on a pension or benefit for income
- living in rented accommodation.

Some exceptions were made with three of the participants (two male and one female)—who were aged 54–59 years. One of these had a very small income from a part-time job supplementing her benefit.

Age and health

Twenty-six women and twenty-four men took part in the study. They were fairly evenly distributed across the age categories of 60–69 and 70–79. There was one woman aged in her eighties and one in her nineties. Most of the women (19) self-rated their health as ‘fair’. The men’s answers were more variable. While equal numbers said they were in fair (8) and good (8) health, five said their health was poor, two said very good and one man (aged 75) said his health was excellent.

Ethnicity

Eighteen of the women and thirteen of the men were born in Australia. Six of the men were born in England, Ireland or New Zealand. All the non-Australian born women were from a non-English speaking background (seven from Vietnam, one from Malta). The men from non-English speaking backgrounds (NESB) were more diverse: one from Slovenia, one from Egypt, one from East Timor, one from Malta and one from Germany.

Income and housing

All the women were on the Age Pension except one who was on an unemployment benefit. Fourteen of the men were on the Age Pension, seven were on a Disability Support Pension and three were on a Veteran’s Pension. Nineteen of the women lived in public housing, and only ten of the men. Most of these were Ministry of Housing flats, two were housing co-op flats. Four women and six men lived in privately rented flats or houses. Two women lived in private rooming houses and one in a housing group rooming house. Five of the men lived in Yarra housing group rooming houses and three in private rooming houses.

Relationships with family and children

Most of the 50 people interviewed were living alone. Nearly half the sample (12 women and 12 men) were divorced or separated. Most interviewees were isolated from families and had little or no prospect of someone in their families taking on a carer role, now or in the future.

Only one of the 26 women had never been married or in a de facto relationship and never had any children. In contrast, nine of the 24 men had never married.

While seven of the women were widows, only one of the men was widowed. Six of the women were still married. Only one of the men was married, and another was in a de facto relationship. Twenty five of the women and 15 of the men had had children. There were no marked differences between the genders when it came to rates of contact between parents and their children.

Sixteen of the women said they saw their children often, as did seven of the men. With the exception of one woman who had given up her only child for adoption, all the women were in regular contact with their children, however three of the men said they had lost contact with their children completely. Two of the men in their sixties had dependent children under 16 years.

Findings from the interviews

This section summarises the main findings from the interviews with the older men and women who participated in this study. The findings are separated into three categories—firstly the findings related to women interviewed, then the findings for men and finally there is a discussion of people’s views with regard to their use of family members for support instead of using HACC services.

The women

The people who ‘get by’ – ‘the battlers’ (17 women)

This particular construction of independence had two common threads. The first was the ability to keep themselves debt-free by paying their household bills on time and managing their household on very little money. Many of these women had learnt the skills of ‘getting by’ from their mothers whilst growing up during the depression and spoke with pride of their achievements in running a home and feeding their families on a very tight budget. Molly, now aged 79, brought up 11 children whilst living in various rented houses in Richmond: ‘We always had a feed on payday – put it that way! You had to manage you know’.

Madge spoke of how the outbreak of war improved the lives of families who suffered dire poverty when husbands and fathers couldn’t find work during the depression. In recalling her early working life that started at 14 as a waitress in a city café, Madge spoke of giving her wages to her mother. Reflecting on her own budgeting habits, Maureen recalled that:

> Mum … said always pay your rent and your electric light and gas and you can always get a meal from somebody. As soon as I get a bill, if I don’t pay it that day, I pay it the next day. We’ve always been that way, and to help one another and try to help somebody else in the interim.

Lillian, aged 90 and caring for a bedridden husband at home, spoke of how she managed on the pension by using the same system:

> I’ve got a way of keeping myself out of debt … when I get my pension … She [a girl who assists her] takes out my rent and I always leave so much in that bank. Always. So that when the light and the gas and electricity come I’ve always got it there and then I’ve always got a little bit to spend … I’ve always done that.

Others not only expressed their own pride at ‘getting by’ but were critical of those who couldn’t do the same, as Selma put it:

> I manage all right on the pension. I’ve learnt to … buy the cheaper things and I haven’t had to go and get a food [parcel] yet …My mother taught me how to budget money and also go without some things that you have to, not to go bludging—unless you really have to.

This brings us to the second construct of this particular construction of independence, which is a marked reluctance to ask for help. As Maureen mentioned above, a willingness to help their own kin and others seems to be part of the ethos of this working class culture, but to expect help or charity, or worse still, to claim it as a right, is regarded as unacceptable. Dulcie expressed this sentiment in vehement tones:

> Well I’ve seen them go up to the Brotherhood of St Laurence and they come out of there with bags of food and then they come down here to that one there—I don’t know what this is, a charity [of some sort]—and they come out with more bags of food … I could run out and take the bag off them … no I don’t believe in that, I mean I see people every day that would like the things they get for nothing … because they get their pension, same as what I get my pension and if they can’t stretch it like I’ve got to stretch mine, well I get crook on that …

Unwillingness to take up the challenge of ‘battling’ seemed to some to be crossing an unacceptable line. Even asking neighbours, friends or in some cases family for help was not the done thing, as the following quote from Dulcie illustrates:

> Well that’s the fourth time I’ve had to call the ambulance for him. He’s had four of them [strokes].
>
> *Would you ever call on the neighbours if you need help?* Oh I don’t know … *Is that about you being independent, do you think?* I think so, yes, and I think so more on account of Bob, you know, because he’s—oh well he’s a very independent man, he is … he’d say no to everything. I don’t know, that’s just our way, like I mean when we first got married like, nobody had anything, so you had to make do with what you had and I think that’s just gone right through our whole lives, yet I’d do anything for anybody else and I’d get wild if they didn’t come and ask me.

Dulcie’s difficulty in even considering the idea of asking for help in the event of an emergency (and being adamant that her husband would never condone it) is revealing. It suggests that the system of cooperation that exists within this working class culture depends largely on those who are able to help, offering to do so when they perceive a need. The accepted norm within this culture is that it’s not done to ask—unless absolutely necessary. To do so would be to concede defeat in the battle of life. Pearl (aged 71) is another woman whose complex attitude to giving and receiving help further alerts us to this ethos:

> I’m willing to go round and help anybody if they want help and anything … it’s just me … I mean my girlfriend Gloria … she cannot make out what I do for my age. She said ‘You’re a marvel’. The way I try to help people, you know … But she said ‘Anyone who wants to do something for you—that’s a different story isn’t it’? She said ‘You’re that independent!’ It’s the way you’ve been brought up and that, I think…because when you’ve had a hard life, as I say we had, to start work when we were twelve and a half and with Mum…[dying]

An additional group of 7 women shared this conceptualisation of independence but their ideas were coloured by having experienced domestic violence within their marriages. All these women had been free from abusive relationships for many years and spoke of how much they now valued their independence as single women making choices for themselves. Some said they had learnt a strong sense of independence and standing up for one’s rights from their mothers:

> Well when my daughter was born—she was six weeks old when I left him because he started to knock me around … Lucky I had my mother here, you know, had someone to live with … My word! I wasn’t going to put up with that! My mother always taught us never to

> be frightened of anybody … that's why I think I used to stand up to my old man (husband) when he used to start bashing me around…(Maureen)

Vera and Marlene's independence from their violent spouses took longer to attain. Vera said:

> I stayed with him until I was 41 … I've got to do something about this, he's destroyed enough of me, so I just thought 'Well that's it, I'm going' … and I've never looked back. I walked out and left me own home, I was a fool for not fighting for that, but he used to terrorise me in it.

Vera's life has continued to be a struggle with poverty and extreme ill health. She takes pride in having survived and managed to successfully rear her six children plus a foster child:

> I live from day to day, that's the way you've got to live if you haven't ever got nothing…I can honestly say that I've never been in front all my life … I've been poor my whole life. It's been a struggle since I was 15 (when she had her first child) and I've done it! For the last five years I've been fighting cancer … I've got lung disease because I'm a smoker. I've got high blood pressure, I've got pernicious anaemia and I've got a thyroid problem but I never let them get to me … This year I've had a terrible lot of sickness, like I've been that way that I want to throw in the towel … me doctor keeps saying to me 'you're a survivor'.

Marlene also expressed a certain amount of pride in successfully bringing up her large family and in her ability to keep going without asking her family or anyone else for help. She reflected on how independent she had become in the years since she had left her husband and described it as 'being used to doing my own thing, just doing my own thing and looking after me family'. Like others, she also related this ability to survive back to her childhood and having to take responsibility at an early age for looking after her sick mother.

Maria's life has been so difficult that just surviving to the age of 68 is a triumph. She has raised eight children, experienced abuse in childhood and through a marriage and has cared for four family members who were schizophrenic. At times she has been suicidal. She used to receive meals on wheels but gave them up because the food was tasteless to her Mediterranean palate and lacking in fresh salads. She fears that she would never be able to get them back now if she could no longer see to cook due to developing glaucoma. Maria said she would never ask her children for help because they had already had such a difficult start in life and she wanted to spare them further troubles. She said she would never go into a home because she had been institutionalised as a child. Maria wants to stay in her home now 'until I die'.

Lillian and Joyce were the only two of the fifteen women who were currently using HACC services. Both women were receiving home help at the time of interviewing. At 90 years of age Lillian spoke quite dispassionately about receiving this service, almost as if it was something that was conferred upon her at this age. She commented that the privatised home help was not up to the same standard of that provided by the Council. Lillian was resisting accepting meals on wheels, as she enjoyed cooking and clearly still felt quite capable of doing it. On the other hand Joyce, despite the fact that she was almost incapacitated by her knee problems, described herself as 'one spoilt lady' because she was getting home help.

Two other women in this group said that they had used HACC services in the past, but were no longer using them. One of these was Dulcie. Realising that she had unwittingly engaged home-help when she had agreed to having bars installed in their home to aid her husband after his discharge from hospital, Dulcie decided she no longer needed it after a couple of weeks because 'I'm not one of these people that's got to be going round getting everything for nothing all the time—I can't stand that'. The other woman said she didn't like the meals and didn't believe the home help girl did much: 'She didn't even dust the TV'.

There were two women who told of their experiences of trying to apply for home help and being told that they were not eligible under the priority of access conditions. Madge, aged 69, found it impossible to do the vacuuming due to a bad back. She felt it was an imposition to ask her

87-year-old brother to do it when he was already travelling from Northcote to Collingwood once a week to help her do her shopping:

> She [assessment officer] said can I shower myself? And I said yes, because they came and put bars, you know in the bathroom and that. And she said: 'If you can shower yourself then you don't need home help.'

Beryl, aged 72 and suffering with a bad back which made house cleaning very difficult, was also told by a Council officer that home help was out of the question unless she was unable to shower herself. Both these women seemed to be caught between their need of help with housework and the tight targeting of services. It is worth noting that, given the fact that many of the participants expressed a fear or horror of having someone shower them, having this need as a prerequisite for being eligible for home help would act as a strong deterrent against applying for it.

In many cases accepting HACC services was seen as preferable to asking family members for help. Several of the women in this group stated that they would not ask their adult children for help as they believed their children had had difficult starts in life and they did not want to place a burden of care on them.

Only two of the women actively resisted the idea of HACC services. One of these was Pearl, whose negative attitude towards service usage was an extension of her previous self-identification as an independent person. In much the same way that Dulcie had criticised those she considered to be abusing the food parcel services, Pearl was quite critical of those who were receiving home help: 'There are a lot of lazy people in the world … You can get up and do a little bit at a time'.

On the other hand, Marlene's resistance to accepting HACC services seemed to be less about giving up her identity as a woman who managed her household well, and more about staving off dependent old age. Following an operation, she had resisted getting meals on wheels, preferring instead to make her slow and painful way down her staircase and to walk the couple of kilometres to the senior citizens for a meal. Her reason for doing this was that 'you wouldn't get out then and you'd be in four walls'. The importance of controlling one's own life was a strong theme in the group of women interviewed. They had struggled to maintain their families and meet basic needs and were clearly cautious of loosing that control. One of the people interviewed, Marlene, expressed this as 'being used to doing my own thing' and others talked about their need and responsibility to 'do for themselves'.

For about half of the women who could be described as 'battlers', there was a general resignation about accepting HACC or other aged care services 'when the time came'. They all said they would continue to 'do for themselves' as long as they were able to but were pragmatic about accepting either home help or meals on wheels once they were no longer able to cope. The point of needing services seemed to be associated with a state of being totally unable to manage, as many of the participants would have prima face eligibility for HACC. Nearly all these women expressed a fear of getting to the point where they needed help with showering or other intimate aspects of personal care, as these quotes demonstrate:

> I just pray to God that it never happens to me. I hope I die before that. (Vera)
>
> I try not to think of it, that's the only way out of it. I used to get depressed and I'd have a cry and all that and think I'm here on my own (Maureen).
>
> Oh yes, yes, I often lay in bed at night and think …like suppose I had to have somebody to be cleaning me 'there'—oh no, that would kill me'. (Dulcie)
>
> No that would be very embarrassing [to have incontinence] and relying on somebody to do your shopping and all that. (Beryl)
>
> I'm saying like if you were sick, I wouldn't mind, I wouldn't be embarrassed to use these meals on wheels—what's embarrassing about that? But as for old age, real old age and being in a nursing home, now, that's scary. (Silvia)

Women who experienced and survived war in Vietnam (7 women)

The women who made up this group were Vietnamese immigrants. Their definitions of independence all seemed to have been influenced to varying degrees by their experience of war and their subsequent escape to Australia. Three of them were living with their husbands, the other four were widowed. They all had close ties with their adult children and a few still had children living at home with them.

These interviews took place in a group situation with an interpreter and therefore it was much more difficult to build a rapport with the participants. The war in Vietnam had clearly been the impetus for immigration, and it was obvious that painful memories were attached to these recollections. This was respected and as a result far less was learned about these women's early lives and the factors that may have contributed to their construction of independence. As a result, this data is qualitatively different from that obtained in the other interviews. These women still seemed to define their independence in ways different from other participants. It seemed that these women mostly construed 'independence' in terms of their health and ability to get around and run a household. Nearly all the Vietnamese women placed a high importance on the role regular exercise played in maintaining their health and therefore their independence. At 84 and 72 respectively, Ha Thi and Hoa both still follow a rigorous exercise regime every morning: 'After the revolution in Vietnam, I became very scared and very stressful, and I then began to practise Tai Chi every morning'.

The Vietnamese women's attitudes to service use and asking for help from adult children varied considerably. One woman (Tung, aged 70) was looking after her husband who has dementia and was receiving both home help and meals on wheels. She had five adult children living in Australia, but she preferred to get help from the government than to ask them for help. Three others (two in their 60s and one aged 84) said they would prefer to get HACC services when the time came rather than ask their adult children for help. These women talked about the tradition of 'filial piety' being obsolete in Australian society—here adult children were required to put their jobs and their own children before their elderly parents.

However, the other three women in this group said they did not want to use the services that were available. One of these women, at 66, still had her youngest daughter living at home with her. Another said that she had 12 children, and she would prefer to ask some of them to help her cook and clean when the time came that she could not do it herself. Another (aged 72) said 'the future takes care of itself' and that she did not want to 'demand too much for the government'. Ideally, she would like her unmarried daughter to come out from Vietnam to take care of her in her old age.

It is important to recognise that these people, from a particular culture, were not a homogenous group. They had differing views about independence and the use of services.

Women who defined independence as 'a state of mind'

There were two women who spoke of independence as something that resided in the mind. One was highly educated, having spent many years as a school teacher and political activist. The other had left school at 12 years old and had 10 children through three relationships, battling chronic alcoholism. What they shared, however, was experience of a period of total incapacitation resulting in dependency on others for basic needs—the 'lost years of their lives'. Both women had fought their way back from incapacity to a much more independent life and were profoundly grateful for being able to reclaim their independence.

Stella, now aged 65, has had a running battle with alcoholism throughout her life and spoke with candour of how she had and continues to struggle with this addiction. 'I hate being an alcoholic, but I live with it, but it's a scary business. I became institutionalised …' Stella told of how she learnt to live independently after years in institutions. In recent years she has been living in a Ministry of Housing flat. She explained how she now valued her solitude and enjoyed time on her own to reflect: She believed now that her only hope of overcoming her addiction was to become completely independent. She stressed that at the end of the day independence came down to dignity:

> I don't want sympathy though, we hate it … we're trying to keep our dignity … It doesn't matter how low they get in life, you know poverty stricken or hungry, they need to keep that dignity, we need it 'til the day we die'.

Alice worked as a teacher for 30 years, until she was given compulsory retirement at the age of 63 after she developed extensive scoliosis of the spine, exacerbated by osteoporosis. When her spine 'crumbled like polystyrene' she had radical surgery and it took her six years to recover. Over that period Alice went from being a fully independent woman, working as a teacher and paying off her mortgage, to a bedridden invalid living in a nursing home and dependent on the equivalent of the aged pension. Eventually she taught herself to walk again. Her mobility made her ineligible to stay in the nursing home, and the strain of being uprooted again resulted in a nervous collapse. After months of hospital and nursing home care, Alice was without a home.

Eventually she found secure housing at Abbeyfield aged care homes, but it meant living below the poverty line:

> I look forward to being here for quite a long time. I have my name down for public housing and a flat—which I'm encouraged to do by my doctor, but there's a five year waiting list. I'll be 80 … I don't think that's realistic. I think this is it. This is where I'll stay.

The way in which Alice conceptualises independence is revealed by her unmitigated joy at having regained her mobility and therefore her freedom to participate in life again. These are clearly more important to her sense of independence than reduced material circumstances or the restrictions to her domestic freedom (such as set mealtimes) imposed by living in supported accommodation. Despite the enormous disparity between their life experiences, Alice's definition of what constituted independence was remarkably similar to that of Stella, who said: 'I always do what I have to do—the help I need … I think I would—always ask for … the sense of independence is here [in her head] it stays there—even when you can't walk across the room'.

Neither of these women had a problem with accepting HACC services when they had needed them, but had discontinued them when they had felt that they could manage alone. At different times, Stella had been receiving home help and meals on wheels as well as the Royal District Nursing Service. Alice had also had the nursing service, home help and personal care. For different reasons each had been reluctant to ask adult children for help. Stella had given up HACC services because she had previously fallen behind on her payments, and was worried about getting into debt again. She had considered getting home help again but had been told that to be eligible now 'you've gotta just about have dementia'.

The men

The people who 'get by' – 'the battlers' (4 men)

Only 4 men understood independence to mean 'battling or doing for oneself' in the same way as the females interviewed. Getting by without asking for help seemed to be the credo by which they had lived most of their lives and to which they aspired to continue doing as long as possible. In common with the female 'battlers', they regarded independence as taking a certain pride (which seemed to be inextricably bound up with their self concepts) in coping unaided with the vicissitudes of life. This included coping with poverty and illness without asking for help. All the men in this group had been married. One still had a wife, while the others were widowed or divorced.

Seventy-six years old, Ernie had lost contact with his wife and three daughters 50 years ago. Independence for him was insisting that he was in good health when others were concerned that he wasn't well. He greatly downplayed a stroke that had resulted in partial paralysis. He was proud to have recovered with the help of rehabilitation and the St Vincent's home nursing service. He told of how he'd collapsed whilst helping out at the launderette where he rented a room. 'I've always been independent, you know and nobody helped me out … I wouldn't accept any help'. Speaking about his recovery from the stroke, Ernie gave high praise to the nurses from St Vincent's hospital who got him back on his feet and walking again, and who helped him gain the confidence to get around on public transport once more. It seemed that at a certain point of helplessness (in his case paralysis) he was happy to place himself in the care of others, despite his fierce independence.

In contrast to most of the women, Ernie was happy to accept food parcels from charities if things got a bit tight on the pension and was delighted to make use of the cut-price travel afforded by his senior's pass. However, accepting HACC services was another matter and one that he clearly saw as compromising his independence—'I'm independent! I'm independent! I mop the room out, take the mat down to the laundry'. Ernie said he would only use meals on wheels 'if I was bedridden'.

Reg shared a similar outlook to Ernie. He had lost a degree of independence when ill health and severe depression forced him to spend some time in hospital. He later decided to opt for accommodation where all his meals would be provided, as he had been finding shopping and cooking a big strain. When his health failed he had been working (delivering local newspapers), trying to earn a little extra for himself and his wife who suffers from cerebral palsy and who was also battling cancer. Reg described his demise thus:

> I'd been battling on and doing a bit for Gay (his wife) yeah, and I'd had trouble with arthritis … and then I developed this diabetes and depression and they shipped me down to a psychiatric section and the social worker got me in here [Abbeyfield Homes for the Aged] … I was pretty crook, I can tell you.

Reg realised that his life was less than ideal. The things that bothered him were connected to what he considered a loss of independence. His major problems were a shortage of money and the fact that he was still trying to provide support as best he could for his disabled wife. His full board at Abbeyfield took nearly all his pension, leaving him with very little money to regularly make the long trip to visit his wife in a rehabilitation hospital.

> If I rented cheaper accommodation, maybe I could have a bit more flexibility … I'd go every day if I could [to see my wife] but you know it's not cheap.

He and other men spoke of a sense of solidarity with others who were battling. Max, (one of the bachelors) in referring to the group of friends that he had made at the Brotherhood of St Laurence Coolibah Centre, used the same metaphor: 'They're much in the same boat as me … they're good friends some of them.'

Herb was another 'battler' for whom the sense of community and the culture of battling was of paramount importance. Herb was born and bred in Collingwood. He recalled with pride his childhood, when the Collingwood families would help each other out in lean times by sharing food.

> People in Collingwood might've all had different names, they may have been different in one way but they were family in another … (*So there was a sense of all being in it together?*) Bloody oath there was.

Herb believed that Collingwood was rekindling its old community spirit in the Ministry of Housing units. When asked, whom he would call on in the event of an emergency, he said he would call on one of his sisters if he were 'very, very, very desperate'. However he was confident that his neighbours would look in on him on a daily basis, as he did for more elderly neighbours.

> If I had a fall in the middle of the night, I'd be there until someone came to pick me up, I've got the people next door—they might peep in through the blinds if I'm not up at a certain time, or if I don't go past whistling or something, then they'd know there was something wrong.

Nonetheless, Herb was very concerned that the gentrification of the area would result in the older working class residents, and the culture they had built, being forgotten. He spoke idealistically of fostering a community that looked after its elders:

> What I'd like to be able to do is get everyone together and say 'we're a group, we'll look after each other … Old people … shouldn't be considered as being in the way, they should be looked after because they're the people that made Collingwood … People shouldn't be … thought of as old people … they've got the knowledge, they know the history, people like to know the history of where they're going to be living.

Herb had nursed his own mother at home until her death. He spoke at length about loss of independence and dignity in old age, how this had affected his mother, and how he believed it would affect him:

> Independence is … I can get up when I feel like it, go to sleep when I feel like it … if I want to have a drink or If I want to go somewhere to have a feed, I've got the independence—no-one's going to second-thought me … so as you get older do you think you'll feel the loss of that kind of independence?
>
> Dignity is a big thing … Dignity—you don't want to be treated as a second class citizen—you've got the same rights as everyone else … dignity is your thoughts—[people] should listen to what you've got to say … once you have the chance to say it, it brings you that, it gives you the dignity that you require. Mum was embarrassed; she lost her dignity. She was embarrassed with me … with people nursing her and giving her meals and things that, you know, had to be done and she felt ashamed.

The men had varied attitudes to using Council HACC services. Two were not inclined to consider HACC services an option at this point in time. Reg, at the time of interviewing, was living in sheltered accommodation and was considering going back to a rooming house because it was cheaper rent. Reg's attitude to HACC services was fairly negative. He considered home help to be an 'unnecessary expense', and thought that meals on wheels were 'inedible'. Herb was still far too fit to consider getting HACC services, but believed that he would be more inclined to rely on his local community in the housing estate if he needed any kind of help in the future. The other two men in this group had an attitude to future service use very similar to that of the 'battler' women. Ernie was fiercely independent and proud of his record of never having asked anyone for help. He reluctantly conceded that he would get home help if he could no longer manage to keep his room clean, and meals on wheels only if he was bedridden. Sid was less reluctant about asking for help, saying that he would definitely go to the Council, rather than rely on someone else in his rooming house to help him.

Interestingly, there appears to be a distinction made by older people in the interviews undertaken, between medical services (hospital, nursing, rehabilitation and specialist residential care) and welfare services, such as HACC. However, overall, the concept of accepting services now to reduce needs later on is not part of the make up of these people trying to 'make do'. One person said he'd have to be unable to leave his room to accept HACC services, whilst another said he would have to be unable to get out of bed.

Single men (12 men)

By far the largest group among the men was the group who were bachelors. Of the 24 men interviewed half shared the way they constructed independence, which was inextricably linked to their identities as men, but more importantly, as single men.

Four of these men had chosen never to marry or have children and the meaning of independence for this group was very strongly linked to their identities as bachelors. The reason for choosing not to marry was not wanting to be 'tied down'. The men who used this definition of independence also indicated that significant consumption of alcohol was part of their way of life. They had a cavalier attitude to many aspects of their lives, including to their health and future well-being. This included a tendency to live for the moment and a refusal to entertain the idea that they would ever be in the position to require any kind of aged care service.

Clive, at 76, was the most extreme example of the group. He had recovered from a stroke; the effects of which were evident in his speech. But this experience had left his fatalistic attitude to life untarnished:

> I don't make plans because you see your life's pre-ordained. I didn't drink until I was 30, but since then I've been submerged in the stuff … except that I can no longer afford it… There ain't nobody—I'm alone and a loner.

Brian discovered by chance that he was a diabetic and the resulting diet regime is something he regards as an infringement on his personal freedom. Although he seemed to have grudgingly acceded to modifying his diet, Brian wasn't going to let diabetes interfere with his idea of independence, which meant freedom of speech and freedom to drink beer.

Despite his liking for drinking large amounts of beer, Alf was proud of the fact that he had never reached alcoholic status, just as he was proud of being able to keep control of his gambling. Every weekend he went to the casino or played the pokies in one of the local pubs with his mates.

> I got a gambling kitty put aside … It's separate money, you'd never gamble with your daily living money for example … keep a roof over your head … Never had any debt, never at all.

Dan took pride in the fact that he'd never been in debt despite his penchant for betting on the horses and 'worshipping in the temple of the Amber God'. In his early twenties, he was severely injured in a workplace accident. He returned to the same workplace where a subsequent accident caused him to be hospitalised again. Eventually he was put off by this company with no compensation.

> [Then] I got on the dole for awhile; the dole and the church fed me, and the social worker came down and seen me and said he'd get me on the invalid pension … A lot of them want me out of this house [a rooming house where he is the oldest resident] 'cos I'm an old man, an old age pensioner—they want me to get an old person's flat somewhere—Jesus Christ—don't want to live like that! No bloody way known [they're going to get me out].

Dan did all his own cooking and he had worked out a system whereby he would cook for some of his co-tenants in exchange for their doing the shopping for him. He was currently receiving home help to clean his room, and was very happy with the young man who was doing it: 'This bloke—he's tops—he speaks my language, you know?'

Dan was the only one amongst this group who had accessed HACC services. He was clearly very happy to have someone clean his room for him and did not seem to think that it compromised his independence in any way. None of the other men in this group had even considered using HACC services. Resisting these services seemed to be a way of asserting and preserving their brand of independence. Interestingly, of all the men interviewed, they appeared to be the happiest. It was this factor more than any other that set them apart.

Single men who had suffered serious illness or problems from alcoholism and required greater support (6 men)

These men had much in common with the 'single men who never married', constructing independence as the bachelor lifestyle untrammelled by wives, children or other commitments. However, these men, with one exception, seemed to lack the defiance of the other bachelors who strongly sought individual independence. Ill health (in most cases related to alcoholism) had taken its toll on their independence. Most of this group had been in hospital or rehabilitation centres with serious illness or alcohol related conditions. Three of the men in this group were living in Alcohol Related Brain Injury Accommodation Support (ARBIAS) rooming houses. They had full board, including meals. They were free to come and go as they pleased but no alcohol was allowed on to the premises. The men living at ARBIAS were expected to keep their own rooms clean or apply for home help if they were not able to manage this task. None of these men were getting home help or nursing services.

Four of this group had married and had children, but only one was in contact with his children. There appeared to be a connection between the personal loss these men had suffered in close relationships and their abuse of alcohol.

Clem was the only single man to be in contact with his six children. He regularly travelled to visit one of his daughters and described his family as ‘very close knit’. He hoped to leave the ARBIAS rooming house one day, as he did not enjoy living in an institution. Clem said he would turn to his family, rather than use HACC services.

Despite Kevin’s early ‘battler’s’ definition of independence, his health had collapsed after being beaten up followed by a severe heart attack and he had no qualms about seeking help in any shape or form that would make his life easier.

> My attitude is, you never put things off if you’re sick—you go and see a doctor…you go to a hospital … The reason I wouldn’t accept them [home help and meals on wheels] at this juncture [is] I’m capable cause I’ve got a microwave. I can fend for myself—it’s not that bad. When it gets to a stage that I can’t make a cup of tea or coffee, or cook, that’s it —I won’t hesitate a moment.

In spite of Kevin’s proclaimed willingness to take up services when the time came, below the surface ran the previously referred to battlers’ ethic of not exploiting welfare, typical of many of the older women and men interviewed:

> If someone’s doing mine, there’s probably somebody worse off than what I am…I always look at that … I’ve gone and helped elderly people out, a lot older than myself.

It’s possible that Kevin’s matter-of-fact attitude to service usage was related to his being of a different generation to most of the other participants. One of the women, also under 60 years, was equally sanguine about accessing all the help she could get in the future. Perhaps, for those who were born during or just after the war, the quality of independence was more about individualism, a value emerging in the post-war years. In addition, unlike their parent’s generation, this cohort had gone through their young adulthood with the welfare state firmly in place.

Max was living in a rented room, which his landlady expected him to clean himself. He said he would go to the Council to get help if he was no longer able to manage the cleaning but was less enthusiastic at the prospect of meals on wheels. He had seen them when his brother had been getting them, and believed that the portions were not big enough. He was currently getting his daily main meal at the Brotherhood of St Laurence Coolibah Centre and said that he’d have to be ‘really crippled up’ and ‘unable to leave his room’ before he would accept meals on wheels.

Single men who were immigrants (3 men)

In many regards this group displayed similar attitudes to independence as the above group. All these men (Ivan from Slovenia, Mahmet from Egypt and Patrick from Ireland) seemed to locate their self-concepts in the freedom to act as they pleased. The major difference between this and the previous group, however, was that they placed no emphasis on the consumption of alcohol as an integral part of this identity. In fact one of these men spoke with contempt of the drinking habits of his co-tenants in the rooming house. The major issue behind this group’s construction of independence was the loneliness and sense of failure associated with being an ‘unsuccessful’ immigrant.

Like the other bachelors, Patrick, aged 71, had ‘never got round to marrying’. He emigrated to Australia as a young man and worked on the railways as a builder’s labourer. Patrick manifested his independence in a number of ways that were typical of most of the men and some of the ‘battler’ women. After a stay in hospital with a heart problem, he decided he was not going to take his tablets ‘because I was never used to tablets … I got fed up with them’. Patrick held the belief that he should have done better in Australia: ‘I suppose I should have my own home like, over the years I’ve been here’. He still rides his bike around and declared that if he was unable to get out and about every day he’d ‘feel terrible’. Patrick is philosophical about ending up in a nursing home if he can no longer look after himself: ‘Well, there’s not much you can do about it because they put you in there if you can’t cater for yourself—well if it came to it, you’d have to.’

Like Patrick, Ivan and Mahmet seemed to have many regrets. Ivan was ashamed of his poverty. Although he found his life very lonely, and he very much wanted to see his family, he could not bear the thought that they might see him as having failed. Both blamed themselves for not having made a material success of life.

> Really, I’ve got really bad life. I was born loser, in many ways, it doesn’t matter what I was trying to do—the best [it] went wrong. And if they, if I tell them too, they wouldn’t believe it. They would say you are mad—it’s impossible, after 40 years to be in such low position as I am … I come to this particular point, but it doesn’t matter how you explain, try to explain that—many things was my fault too.’ (Ivan)

Independence for these men was about holding onto dignity by resisting returning to their countries of origin and family in old age. For them, persevering with a lonely life in Australia was preferable to conceding defeat as ‘unsuccessful’ emigrants.

Mahmet was born in Egypt. His main problem was loneliness. He felt he had nothing in common with his fellow residents, disliked their habits of drinking and smoking and felt that the senior citizens club would be ‘very old and too depressing’. Mahmet did all his own shopping and cooking, and like most of the bachelors had not thought about a time when he would need any outside help to do these things. Mahmet was the only person who said that suicide was a better option than getting old and frail and dependent:

> If my health is not good enough—I don’t need my life … I don’t like to be in a weak position. I don’t like to be in need, for someone to help me. As far as I can help myself it’s okay, but if I need someone to … if I am disabled … I don’t want to lose control of my life.

Ivan, despite his ill health, was also resisting assistance: ‘As long as I can walk, I can do it myself’. He liked the freedom of being able to eat what he liked, when he liked, but was interested to know that Italian meals were now available. He said that if the time came when he couldn’t manage he would definitely consider getting the Italian meals. He also said that he would ask for home help if his back became too sore for him to do his housework himself. Similarly, Patrick had resisted getting home help because he felt able to manage his housework. Although others in his block of flats were getting meals on wheels, he didn’t want them because he believed that waiting for them would restrict him during the day. He preferred, instead, to eat at the Brotherhood of St Laurence Coolibah Centre or the St. Mary’s House of Welcome, because it ‘gets him out of the house’.

Others with diverse views (6 men)

This was a somewhat disparate group of men whose life stories were vastly different from those of the men in the other groups and from each other. Their conceptualisations of independence were complex and at times contradictory. They had some shared experiences. Five of the six had experienced marriage break-ups, which had left them emotionally and/or financially shattered. Three of these men had suffered from serious sudden-onset health conditions that had forced them into early retirement. All had battled with mental health problems at some stage of their life. One had personally cared for a mentally ill wife, and also a daughter and a son with a chronic health condition. A shared characteristic of these participants was their tendency to question and at times agonise over the issues of dependency and independence in old age, particularly with regard to service use and dependency on adult children.

Every one of these men had a complex life story that they were eager to tell. At times it was difficult to decipher what factors had contributed to their conceptualisations of independence. Several were, or had been, HACC service users and commented freely on their experiences with service providers. The data analysis for this group concentrates mainly on independence as a barrier to service use and issues of dependence on adult children.

Arthur, aged 69, had been getting home help since he came out of hospital after major heart surgery nine years ago. He was grateful for the help he got with cleaning his Ministry of Housing unit, as he placed a high degree of importance on a clean and tidy house. He also related how he had fainted one day and hit his head on the radiator, and the home help worker had attended to him and called an ambulance. However, Arthur was much less satisfied with the meals on wheels service—a low fat diet was ordered and he had received lamb chops.

Arthur also had complaints about the home help service that had been organised for him following surgery: ‘I had my arm immobile, and for all the six weeks that I had my arm in plaster, they came and showered me [only] once’.

Mervyn, aged 78, had used home help some years previously. In spite of a lot of pain and being unable to walk on coming home from hospital he didn’t want to go through the assessment process.

> Well, I’m afraid now, because it’s all user-pays, you know. Well it used to be social security or welfare but now it’s kind of downgrading everything isn’t it? It’s not that I won’t accept it, I just can’t take any more asking for it and it not happening.

Both Arthur’s and Mervyn’s experiences of needing to rely on HACC services post-operatively and finding that the services were not operating or badly organised demonstrate how vulnerable older people can be. At a time when they needed help the most, they were without it. Charles, aged 68, also spoke of difficulties he’d encountered in accessing HACC services:

> Unless you’re at death’s door or chronic [you can’t get them] … The other thing too, which is really against me, is that I put on a good front. I’m articulate, I’m educated, I have a certain standard that I maintain, both behaviour wise and standard of living wise. Because I’m not shuffling down the street like a dero or displaying signs of being, you know, under the poverty line.

Charles lived in a block of flats rented out as housing for the aged. He felt that people like himself who required a certain amount of help, but who weren’t incapacitated, could fall through the gaps in services. He related the following story:

> I find them very patronising. Now we have a problem here at the moment which is not only my problem, and that’s the removal of rubbish. They reduced the hard rubbish collection in this area very drastically. Now at the moment we’ve got an old mattress here that (another tenant) no longer wants and I’ve got a part of my car that fell off the other day. I phoned up aged care services and said we can’t afford to pay for a truck to come round [and they said], ‘Oh we don’t know anything about that. We can’t help you there. I’ll get somebody to phone you back’. But they never did phone back.

Both Mervyn and Charles indicated that they were well aware of the current government’s policy of ‘positive ageing’ but spoke of the difficulties participating in this on a limited income, as well as overcoming society’s negative attitudes to older persons:

> I think it’s a matter of choices. When you’re younger you have a certain number of choices, but as you get older it gets more and more limited, you know, you just can’t choose and then you kind of get into a pattern where you don’t have to make choices because you know there’s not many [available to you]. You’re up against ageism, you’re up against different prejudices and so you tend to keep out of the way, you know, keep a low profile. For instance I probably need another 30 or 40 dollars a week to live … As soon as the pension goes up, the rent goes up. (Mervyn).

Charles had a very similar attitude to the difficulties associated with getting old on a low income in our society:

> [Ageism] is an indoctrination that starts with all people from an early age. Society does it. They indoctrinate right from the beginning and what happens is when you yourself reach that old age, you're ready to accept the package that is sort of being handed to you, and sit in the corner and knit! Now I don't do that because I reckon the best way to combat it, instead of me moaning about it, is to try and maintain a high profile … but then I do find that this environment I'm living in I very much regard myself as a second-class citizen … there are the limitations [of living on] the pension.

Jim, aged 62, was another man who felt that he had not received the level of after-care he had needed following a bout in hospital for a stroke, which had left him partially paralysed down one side. Eighteen months later he was still walking with the aid of a stick and hiding his paralysed hand in his pocket so people would not see it. The following exchange reveals the difficulty he had in accessing the services he needed to make a full recovery:

> I got the after-care I thought I needed, simply because I kept asking what I could get. I started physiotherapy classes … It was helpful for what they did, but they didn't do enough of it … I think that they had too many customers … They had people there who … were far worse than I was in terms of need, physically.

Like Arthur and Mervyn, Jim spoke about the bureaucratic difficulties he had encountered trying to access home help. He had had meals on wheels for a couple of months (organised for him by his doctor) which he 'thought were great' and had been assessed for home help eligibility but nothing had eventuated from it:

> I had two ladies come round from the Council, I think, had a look around and I've never seen them again. I never heard how they assessed it or what they did. The first time was about two months after I got out of hospital—over a year ago. Another one came round later … Nothing's happened. I rang up the Council [again] one day to see if I could get something done. I need the floor cleaned up. It's grubby and unfortunately I haven't got a vacuum cleaner and they told me that if I needed it, somebody would come around and do it for me … She said the next meeting's coming up in a fortnight and that I'd go on her list and she'd come back to me—well I haven't heard from her.

Jim also had to overcome his own sense of independence as a barrier to accepting that he needed help. He thought independence was 'a family trait'. As a quality, it was clearly part of Jim's self-concept and one that he was proud about. Jim believed that the sudden decline in his health was some kind of failure on his part. He felt he was 'going downhill all of a sudden' and felt depressed.

Choosing between aged care services or adult children for support

In exploring the issue of independence during in-depth interviews with older people, part of the discussion centred on the question of accepting help from adult children, and in some cases from other family members such as siblings or grandchildren. Most of those interviewed who had adult children (36) said that they would prefer to use HACC or other aged care services rather than ask their children for help. As half the men interviewed either did not have children or were not in contact with their children (12), this response was far more likely to come from the women. It is worth noting that the few who said that that they would prefer to get help from their children rather than rely on aged care services (7) were all women. None of the men who were in close contact with their adult children (10), said they would rely on them for help, saying that they would prefer instead to access services.

The reasons given for preferring aged care services to help from adult children varied somewhat according to gender but were mostly related to issues of independence. For some participants the decision not to rely on their children was about autonomy, for others it was to allow their children to get on with their lives without the parents interfering or being a burden, and for some it was embarrassment about what had become of them.

For many of the ‘battler’ women and some of the ‘battler’ men, not asking for help from their adult children seemed to be a further extension of the independence they had identified strongly as being part of their self concepts. Although most of the participants who responded this way seemed to be in close contact with their adult children and in many cases grandchildren, there was marked reluctance to depend on grown children for help with cooking, shopping or housework. Most of these participants volunteered that they would rather go into care than live with their children.

> Oh no, I don’t think I could—I mean my daughter has said to me many a time, in years to come, you come up and live with us … but oh no, I’d rather stop here, I think it’s because I’ve been on me own so long, and I don’t know anybody up there. I’d be lost. Round here everybody knows me. I think I’d drop me bundle if it came to that. (Pearl, aged 71)
>
> Oh well [my son] wanted to build a place out the back for me. He already started it, and I said no. He said Mum, we’ll do your shopping once a week, we’ll make sure everything’s done for you, and I said no, I don’t want that. I said I like to be on me own, like down here. I said you can come anytime you like, but I said the thing is I just want to do my own thing. (Marlene, aged 74)

Another common response was worrying about the effect that depending on grown children would have on the children’s family lives. Several of the women stated that they would not ask their adult children for help as they believed their children had had difficult enough starts in life and they did not want to place a burden of care on them now that they were ‘doing well’.

> I don’t want to be a nuisance to anybody and if I get sick, I’ll get home help and meals on wheels and things like that … I’ve seen other people’s mothers go and live with them and they always seem to be arguing a lot. (Selma, aged 66)
>
> I think they’ve got their own lives to lead and I know that I’d say some thing wrong and then I’d be interfering. (Sid, aged 67)
>
> If I can … it is important to be independent. Of course I’ve got to rely on someone. I’m coming to the stage where I’m going to need a wheelchair or something like that. You know, I’d prefer to be independent as long as I can … It would go very much against the grain [to accept help]. (Clem, aged 72)

Some of the Vietnamese women also said that they would prefer to rely on HACC services rather than ask their adult children for help with cooking and cleaning. The reason they gave for this was that they believed that this was the Australian way of doing things. They acknowledged that their children needed to adapt to the way of life here in order to succeed. This meant devoting more time to their careers and less time to ‘filial piety’. These women had a pragmatic attitude to the services, which was simply, ‘in this country they are available—why not make use of them?’

Jim seemed to regard relying on his grown children as an admission of defeat to them. He had called on a friend in preference. Mick, who at 54 was the youngest person interviewed and who had much in common with Jim in terms of major health problems, took this attitude one step further. He stayed away from his children to spare them the spectacle of what he had become in ill health.

This form of ‘independence’ seemed to come from a sense of shame at being dependent rather than a desire to defend one’s independence and was a common theme among many who had used HACC services. Many men were inclined to rail against old age and infirmity and, by implication, of dependence. Some of these men still saw themselves as being someone that their children should be able to rely on, rather than the other way round.

> I would very much like to move to the hills, nearer to my children and their families. However, short of winning Tattslotto or a small part thereof I can’t see that actually happening. (Malcolm, aged 75)

Five respondents believed that their grown children would be incapable of giving them any help due to the children's own problems. Several participants had children with quite severe health problems.

Maria and Judy, as survivors of domestic violence, were disinclined to ask their children for help. In Judy's case this was not for want of trying: 'I [once] called my daughter because I was frightened about my heart and all I got was 'Oh well, stick a tablet under your tongue and you'll be right!' Fearing further rejection she had not asked again.

There were four women who displayed ambivalence to various degrees to getting help from their adult children. On the one hand they indicated that they would prefer to get help from their families rather than take up aged care services (these included hostels and nursing home as well as HACC services). They then appeared to contradict themselves by adding that they would not ask for, nor accept, help from their children: 'If I get too bad my family wouldn't let me go into a home. I'd go and live with one of them, but I couldn't really live with any of my family.' (Molly, aged 79)

Vera said that although she kept close contact with her children via the telephone, her children rarely visited her because they did not like the atmosphere in and around the high-rise Ministry of Housing flats she lived in:

> If I'm sick I don't want them seeing all, I never complain to them or anything…sometimes I feel like my head's going to fall off me shoulders, but I keep going. (Vera, aged 61)

It was 90-year-old Lillian who showed the most ambivalence about getting help from her extensive family. It seemed that whether Lillian was prepared to rely on her family for help or not, depended entirely upon whether her family were prepared to offer her help. Even with her own family, Lillian adhered very much to the old ethos of not asking in order to receive:

> [If] they like to come and do anything for me—well and good. But if they don't I will never ask them. [Other] people are kind—all but my family—they're the only ones who never ask me if they can do anything. (Lillian, aged 90)

Only four of the 50 participants said that they would prefer to accept help from their adult children than from HACC or other aged care services. Two of these were Vietnamese women who said that they expected their children to look after them in old age, in keeping with the customs of their culture. Hoa, a 75-year-old widow with 12 children, was hoping that her unmarried daughter would come from Vietnam to care for her when the time came. Nhu, also aged 75, said that she was aware of the services available, but preferred her children to help her with the cooking and cleaning.

Both Silvia and Beryl said that they would prefer a family member to look after them, rather than relying on services. However, this seemed to be more an expression of how they would like things to be rather than an actual expectation that their children would look after them. Both women also said that they were willing to accept HACC services. Beryl, a woman who described herself as 'very, very independent', had in fact tried to get home help but had been rejected due to the priority of access rules. Silvia said that she 'hadn't got to that stage yet [of needing help]' but would appreciate the service when that time came.

Analysis of interviews with service providers

Six service providers were interviewed, namely: City of Yarra Aged and Disability Services; Community Nursing Service (operating out of North Yarra Community Health Centre (NYCHC)—Collingwood Branch); Adult Day Activity Support Service (operating out of NYCHC—Richmond Branch); CarerLinks; Carer Support Service—Cities of Yarra and Darebin; and St Vincents at Home Nursing Service.

The service providers all constructed the meaning of the term 'independence' in a programmatic context, as exemplified in the following quotes:

> If you just look at the meaning of the word ‘independent’, it would mean living without supports. But I think the HACC idea of ‘independent’ is living with all the supports as well.
>
> I say to residents who say to me, ‘I want to be independent’—accepting services can allow you to continue to live independent.

Basically, this construction of independence was placed in the context of policy, focusing on aged care objectives of keeping older people at home as long as possible and allowing people to ‘age in place’. The services constructed to meet these policy objectives included HACC services—such as home maintenance, home help, meals on wheels and personal care—as well as support in the form of disability aids, home modification, support for carers (usually respite), and nursing support at home. Few of the service providers recognised the distinction between a common usage construction of the word independence and that used by those working in aged care services.

Providers were asked which service contributed most to older persons’ independence. Following logically from the programmatic construction of independence, the services which allowed older people to keep living as similarly as possible to how they had been living, were named as the services which contributed most to older person’s led to older people living independently. There is, however, an inherent tension between the intent of the service to enhance independence and the perceived threat felt by older people themselves.

Three of the providers spoke of the temptation, when working with older persons, especially with time constraints, to infringe upon their independence by doing things for them. A community nurse, in particular, spoke with regret that tight funding meant that less time could be devoted to explaining the service adequately or to teaching older people how to perform procedures themselves, such as changing dressings. If the policy goal is to keep people at home for longer, this approach is likely to be counter productive.

Another HACC service provider believed that some independence could be lost for those older people who became housebound whilst waiting for services such as meals on wheels. This, in fact, accords with some of the reasons the older persons (especially older men) gave for not getting meals on wheels.

Two of the service providers said that some older people lost independence in the form of freedom of choice by becoming ‘over-assessed’ by aged care services, or in the case of those with dementia, had services imposed upon them because they had been assessed as living in unsafe conditions. In matters of safety, service providers will always be aware of their duty of care. Service providers impose their own frameworks and perspectives.

> I went to a lady’s house the other day and she was really angry that I was there. She was just fed up with too many people coming in [and assessing her] and one more person going in was just too much. The person who had referred her to me had been seeing her about a personal alarm, and thought she could have been in danger of falling. And I probably didn’t think she was in as much need as some of the others I see. I think that you can have too much assistance.

Systemic barriers to service take-up

Three of the providers mentioned the HACC Priority of Access policy as being a major barrier to service access for some older people. This is a rationing strategy to manage demand, and supports what some of the older people said about being ineligible for home help because they were not incapacitated enough. As one service provider put it:

> Priority of access stops a lot of people using the services who would benefit from them, because they are not seen as being particularly high need. Sometimes I think things should be more individualised. People may be told over the phone that they do not meet the priority of access, whereas if a worker was to go to his or her home they might realise that

> that person is eligible. Priority of access is decided over the phone to save time and costs and to use our resources in the most efficient manner. We don't have the resources to see them all personally.

Similarly, the complexity and fragmentation of services was also seen as producing a barrier to older people's understanding of how services fitted together, which in turn was a barrier to easy access. Privatisation was seen to have expanded the number of organisations for consumers to negotiate. The community care system requires a high level of knowledge to negotiate and great persistence to navigate. People who are not well, are resistant to services or have immediate needs are easily deterred.

> A lot [of older people] aren't aware [of the services available]. Especially things like Linkages and the various levels of care, apart from home help. People don't have an understanding that you can start at this level, after that you can go here and after that you can go there. I have spent quite a bit of time going through that sort of thing [with residents]. I've even found that when people have had a visit by Council staff, that they are actually still unclear what say, CACPS is, and they ask me, and I go through it again with them.

Some service providers saw the fragmentation of services under privatisation as causing a hindrance to effective service delivery, and/or affecting the quality of the services provided. Once again this tallied with the anecdotal evidence produced by some of the older people interviewed, that the accessibility and quality of the services had been negatively affected during the changeover:

> Tendering out services makes services more fragmented. With different models and services, it is extremely time-consuming working out who all the workers are and what they provide.
>
> Frequent changes of workers is a very big problem, especially with people with dementia. Also having a number of different people doing assessments can confuse older people.

One provider said it was much easier to coordinate care prior to Council contracting out its services:

> Before, when we shared caring with the Council, If we needed to follow up on some activity, it was just a question of ringing the Council and speaking directly to the person doing the visit. Now a person from the Council has to call the outsourced service provider, who will have to call their worker.

Often there were many workers involved. The need for continuity of personnel was a factor mentioned by many service providers.

Provider perceptions of older people's attitudes to services

Four of the service providers thought that the beliefs older people held about using services—a loss of independence or the beginning of dependence—would act as a barrier to their accessing them. Two also believed that some older people may get to the stage where they acknowledge that they needed help of some kind but may be confused about what kind of help would benefit them most:

> I think a lot of them see accepting services as the first step to giving up their independence. They are not acknowledging their circumstances and not asking for help. A lot of people are asking for meals on wheels or assistance with cleaning, but in fact they need help with personal care.
>
> Having to admit they've reached the stage where they need help, and lack of insight into what kind of help they could do with, particularly with people with dementia.
>
> Perhaps they are denying that they are a little bit older and a little bit frailer. Seeing themselves as becoming dependent [may act as a barrier to their] coming to that decision where they are needing more things or help than perhaps they are used to.

Perceiving services as an invasion of privacy or ‘the authorities’ controlling their lives was another factor which service providers thought may act as a barrier to older people accessing services.

> Letting strangers into their home can be a problem for older people…not wanting the authorities to run their lives and tell them what to do.
>
> Another barrier for older people is just having another professional involved in their lives. [They] can have someone from the XXX and someone from the Council and we are just another one.

One service provider talked about the lack of a mechanism for reviewing a service provider’s compatibility with the service recipient, a view that was consistent with comments made by some of the older people interviewed:

> With personal care or home help, if residents don’t really like the service provider or don’t get on with them, very often they’re reluctant to say it [directly] to that person. They’ll just cancel the services rather than kick up a fuss.

Ways to improve services to enhance users’ independence and overcome barriers to service usage

Four of the service providers believed that better funding of HACC and related aged care services was required in order to enhance the user’s independence or overcome the current barriers to usage: ‘Certainly [we need] more funding for home help, meals on wheels and for personal care.’ They felt if there was more funding they could look at more innovative ways of service provision and individualise it more.

> We need to make more individual assessments and try to base services on individual needs. For example, as a result of developing the Vietnamese meals, there are a lot more people of Asian descent who are happy to try the meals. The other thing that we have implemented with the meals that has increased independence, is the menu system. There is that independence [in] that they have made that choice, and if they don’t like the meal they know not to choose it next time. We are looking at developing new initiatives. Perhaps food vouchers, so that people who are living in rooming houses and don’t have kitchen facilities or don’t want to be home at midday to receive a HACC meal, can perhaps get a food voucher [instead] … Another option would be convenience food.
>
> Most of the people I see can’t afford to buy the equipment for themselves. Sometimes clients are waiting months to get equipment (which is putting them at risk). The equipment is funded through the Permanent Aids for Disabled Persons [sic] (PADP) system. It takes that long for administrative and financial reasons. (ADASS provider)

Others believed that removal of the Priority of Access policy would provide a major reduction in the barriers to service access. At the moment the assessment criteria are just the way they are because of the [lack of] funding. There was a view that older people’s independence could be enhanced by providing some services earlier, before people have deteriorated too greatly.

Several service providers believed that information about how to access services could be better disseminated, particularly for people from other cultures:

> A lot of people have vision impairment, and there’s this stupid little brochure.
>
> [we should be] informing people better. Particularly those from other cultures. New arrivals are not aware of what services are available. If we were able to have all information translated into all languages [it would be an improvement]. The problem is also that people don’t read in other languages so maybe it’s a matter of educating the community through information sessions. In some cultures they don’t want to accept the assistance [in the form of HACC services] and we have to accept that and maybe we should look at other ways of assisting. In the future we could look at using the funds we have to give support to the families that are providing that care. There are lots of ways to look at utilising the money and ensuring that people are supported

> Finding out information on what support is available is also a problem. It’s a huge muddle for service users if they don’t quite know how all the services fit together. One way we’ve heard of carers asking for information is from GPs. We are about to start a program, where one of our carer support workers goes to a clinic (which is quite a large one) which has appointments made beforehand by the GP for carers. And also having an easy referral form so that the doctors can just put the name and address on it and fax it over to us. We held a number of carer’s forums last year and that was what came across. It was really the GP who was expected to be the most likely source of information or referral to support services.

Worker education

The two service providers who were community nurses, believed that more funding should be put into better training of HACC and other aged care providers in how to work more effectively with older people, particularly those with dementia:

> We could probably spend some more time getting education about aged services—what is available, what is a good way of managing people with memory problems.
>
> [What is needed is] personnel who are qualified to know how to deal with some of the problems of older people. For example they must have a better understanding of how to deal with those with dementia. Home-care people are of crucial importance here as they spend a lot of time with these old people and see them regularly. The main problem with achieving this level of personnel is the low wages they pay them.

One service provider believed that more flexible and appropriate day programs would mean that carers would be more inclined to access this service, thus improving their own independence.

> Because the support we give is mainly for the carer, independence for us means giving the carer the opportunity to take care of themselves. We try to encourage carers not to give up all of their lives to caring as that can lead to an unhealthy state of co-dependency. Most of the carers (70–80 %) tend to be elderly women looking after their spouses. Sometimes it is husbands looking after wives, but not often. Usually the carers aren’t ready to accept support for themselves until the person that they care for has the support they need. Respite has to be meaningful and respite options for the care recipient [need to be enjoyable], so that the carer doesn’t feel guilty. We need respite programs that are flexible and appropriate for people with differing needs. For example, in some of these programs people are all lumped in together because they have disabilities. You have frail aged without dementia together with people with dementia and it can be completely inappropriate. (Carer support worker).

Part 4 The meanings of independence

The findings of this study strongly indicated that independence was seen to be a valued state and conversely ‘dependence’ was something to be avoided or rejected. Older people from low-income groups and service providers interpreted the term independence differently. The term was also understood differently by different groups and individuals among the older people themselves. How these older people interpreted the word was very much influenced by their particular experiences of life and their current situations.

The variety of interpretations of the word among a sample of 50 people highlights the importance of not treating older people as a homogeneous group. Even a group of Vietnamese immigrants of the same age living in similar circumstances had substantially different views from each other on the use of HACC services and the concept of independence. This diversity of opinion also applied to other people who had similar problems or experiences, such as alcoholics, women who had suffered domestic violence or people living in special accommodation houses.

A few common themes defining independence for all parties included: competence to look after one’s own basic needs; control over daily living choices and activities; freedom from physical dependency; not being reliant on the government or family; managing their own finances; and not being institutionalised or regimented in daily living. There was recognition that as people became older, the degree of independence possibly varied largely according to health status, financial capacity and social supports.

However, the constructs of policy makers, service providers, consumers and potential consumers in relation to independence and dependence varied, as discussed in the following section.

Independence: differing perspectives

Policy makers

For policy makers, the concepts of independence and dependence strongly relate to a philosophy espousing the positive contributions of older people—having a worthwhile social role and a productive and positive place in society (Plath 2002, pp.42–43).

In this context, independence is strongly associated with a healthy active ageing and well being (Plath 2002). Policy makers generally promoted a positive and successful image of ageing, with aged people encouraged to remain at home and in the community with minimal use of institutional care.

Such an approach focuses on programs that involve the use of home and community care services as an alternative to, and deterrent from, hospital and residential care. Aged persons are to be supported in living alone in their familiar community

Independence also means steering clear of reliance on government income support that is interpreted as welfare dependency (Plath 2002, p.45). Independence is also seen as a means of avoiding a major resource drain affecting potential future governments and future generations of taxpayers.

Service providers

Service providers were forced to constrain their view of independence within bounds of scarce often reducing resources, a focused approach to resource allocation and ever-increasing demand.

Provision of services to the aged was strongly related to a definition of need, based on a narrow professional view, focusing on basic requirements such as the capability of the aged person to undertake personal care activities, such as showering and the preparation of meals. Services would be allocated to those aged persons who could not complete these basic needs (and they became the highest priority need group).

This priority allocation process, combined with limited and scarce resources within provider organisations, resulted in services being allocated to only those aged persons with the highest needs and any aged person with legitimate but lower priority needs would receive no services at all. The various targeting and monitoring policies and procedures instituted by the funding agencies and governments often reinforced this approach.

The inability to function independently (in terms of not being capable of performing the basic hygiene functions) was viewed as a dependency situation and would initiate intervention by service providers. In fact, dependency-based indicators are often used to predict the demand for residential aged care (Gray 2001).

With limited resources an ever present problem, any increase in demand exacerbates the service inadequacies. In this context, increasing dependency as people grow older becomes a major problem with the very old (and more dependent) absorbing more and more resources.

There is also an acknowledgment of the need to provide access to a range of supports and services, including HACC and carer supports and a recognition that continuity of care and supportive relationships are important.

Consumers

Independence was a crucial part of the self-concept and group identity of many of those interviewed. It was a part of their working class culture, a trait passed on through generations of struggling in difficult social, health and economic circumstances.

For consumers, independence strongly related to the aged person having personal control and choice in their lives, of not being beholden to any one or having other people interfere with their lives.

Aged people want to lead their lives with dignity, pride and self respect. Often this related to good health and having adequate resources—providing them with the capacity to live where they choose, support themselves and provide assistance to their families and making ends meet. Good health meant the capacity to do for oneself, to look after their basic needs—meals, cleaning, showering. Not having adequate resources meant that people who had struggled financially and in other ways all their lives would have to accept charity. Public service provision and charity were viewed as an admission of failure.

Many had a strong sense of pride in getting by and of taking personal responsibility for their circumstances. For example, they ensured that they had money to pay for rent and power and did not want to be a burden on their families. By surviving even in the most difficult circumstances, they found in that experience a sense of pride and responsibility.

Many aged people had experienced significant life events and social injustices such as domestic violence, uncompensated accidents and injuries or were trying to manage the negative impacts of conditions such as illness or alcoholism. While they may have been depressed about their circumstances and /or the great challenges involved, they were committed to retaining a sense of self-determination and control in their lives. This generated a strong resistance to institutional care or institutionalised services, even in the home. Being institutionalised meant the removal of independence.

Aged people only accepted such services when they are unable to fend for themselves. The attitude of service providers, and the need to keep asking them for assistance, appeared to compromise people's sense of respect and self-determination. They felt they were only asking for assistance when they were in desperate circumstances and rejection or postponement of services was seen to be a form of criticism and judgement, or other people's determination of need.

Aged people viewed independence as the opposite of dependency and incapacity, of which many were afraid. Dependence was viewed as a lack of choice and balance in a relationship, being helpless, being controlled, having lost the struggle. It was also associated with embarrassment, failure, loss of freedom, loss of identity, constraints on daily living and constraints on choice and capacity to support oneself.

Themes from consumer constructs of independence

The most identifiable group amongst those who took part in the study was a group characterised by life-long struggles with poverty and making do. There was much evidence to be found in the stories told by these people that the meaning of independence for them was inextricably connected to family values and a working class ethos of never asking for help.

The first major theme was that independence was regarded as the ability to get by, or to look after yourself. Many of those interviewed expressed their belief that people should, as far as possible, be able to look after themselves and their households. Comments highlighted the belief that people should take personal responsibility for their own situation in life. There was also a sense of pride in their ability to do this, pride in not getting into debt, and not having to ask for help. Negative comments were made by some about those who sought help rather than manage on their own. This aspect of the concept seems to consist of two main parts—firstly, the competence to look after oneself, and secondly, the willingness to take responsibility for your situation rather than seek help from others. As parents, some believe that they should be there for their children to rely on, not vice versa. Many were willing to support family, friends and neighbours but would accept little assistance themselves until they had no choice due to incapacity.

Most people interviewed who had lived through World War II and the depression had a strong ethical view that people should not be receiving help from the government but should make every effort to support themselves. These findings lend weight to Maitland's (1998) findings and contention that it is the cultural aspects of class which are critical to understanding words and meanings. It also offers an explanation for Day's (1985) observation that income and occupational background seemed to affect the ways in which older people sought help from family and services, and that reciprocity was a major determinant of the acceptance of help.

This view of independence provides support for the notion that for those who have had little control over the circumstances of their lives (through financial and/or other disadvantage), 'battling on' and refusing services may be one of the few ways these older people have to control their lives.

The older people interviewed seemed to want to dissociate themselves from the image of the frail and dependent older person and seemed determined to hang onto their independence as they conceived of it. From the perspective of a service provider, this reluctance in some older people to accept the help that would seemingly render their lives more bearable (and ultimately more independent) could be construed as stubbornness or unreasonable. However this kind of independence, when understood as a value reinforced over a lifetime of hardship, becomes easier to understand. The determination to resist support as long as possible was very strong.

A second theme was the idea of independence as being the absence of ill health or disability that forced people to depend on others. Some people who had experienced long-term disabilities or who had been institutionalised spoke of their frustration at being regimented and controlled. They had less ability to do what they wanted and were forced to rely on others for their needs. One concern was the inability to do what they wanted because of physical disability, drug dependency, psychiatric problems or financial constraint. Yet another group presented as demoralised by debt and addiction. Their sense of having failed was strong, and they felt powerless in most of their relationships. Another concern was being forced to compromise their wishes by depending on staff/agencies that had certain rules and constraints.

A third theme, common among elderly men in particular, was that independence meant autonomy or freedom from the constraints and demands of others. This was often expressed in regard to relationships where men felt that they would have limited ability to make decisions to suit themselves, of coming and going as they pleased, eating whatever and whenever they liked, choosing to drink or gamble. Similarly, waiting around for meals on wheels or other service providers meant they couldn’t come and go as they wished.

A fourth theme, prominent amongst women who had left violent or abusive relationships, was that independence signified freedom from violence and oppression. Not being subjected to physical, emotional or financial abuse was a major benefit of independence, as was the ability to make decisions for oneself.

Some people interviewed were using HACC services or had in the past. A small number were very pleased with the services. Some had received negative responses to requests for service, even when some had made numerous requests. The people interviewed largely knew about the services, but most chose not to use them unless they were in very difficult and dependent circumstances. Not accepting or receiving help was, for many people, a way of life, and it was only when they collapsed or were very incapacitated that help was seen as a necessity. Most people interviewed were not prepared to consider services they might need until help was essential. They generally perceived services as an invasion of privacy or as authority figures controlling their lives. They appeared afraid of the vulnerability they associated with dependency.

It is important to note that baby boomers may have very different expectations from the current generation of older people, and are likely to have higher expectations of support and to be more powerful in their advocacy on their own behalf. The few younger people interviewed in the sample were more accepting of the value of HACC for services.

Themes from service provider constructs of independence

Service provider staff generally identified independence as the ability of clients to continue living at home, rather than in residential care, so that their frame of reference was generally limited to notions of capacity to meet basic needs and living situation. They were operating within a programmatic construct of independence based on government policy. Their focus was short term, and, of necessity, involved making relative judgements in order to ration access.

HACC providers tended to see independence as a relative state. They perceived it as living at home with some support, and would not necessarily see the provision of support such as meals on wheels, personal care and home help as a threat to independence. However, some did acknowledge that many people would see independence as living at home without any support. HACC workers tended to believe that services enhanced or prolonged a person’s independence.

Some service providers also felt that they may represent figures of authority to some older people and that, as a result, services may be associated with monitoring and interference.

Workers assess people for services against stringent and restrictive criteria for priority of access rather than for need and eligibility. Assessment was based on criteria set by staff rather than the consumers—it is felt that consumers often have a ‘lack of insight into what kind of help they could do with’.

From the perspective of a service provider, this reluctance in some older people to accept the help that would seemingly render their lives more bearable (and ultimately more independent) could be construed as an inability or unwillingness to make rational decisions. This kind of independence becomes much easier to understand when viewed from the perspective of older people.

Several providers identified the limited options that HACC services provide for people struggling to retain their independence and the difficulty some people have with accepting rostered strangers in their homes.

Obtaining information about available services is difficult for many people, and even if they seek services the assessment process restricts access to some people who could benefit from assistance. There is, however, a need for proactive promotion of HACC services to people who are not familiar with the service structure.

People eligible for HACC are likely to have views on the services they need and how they want them delivered, but the system appears to process them based on the priorities set by staff. According to the people interviewed, HACC providers took little notice of other providers' assessment of needs (for example, general practitioners and hospitals) and professionals do not adequately coordinate services (for example, post acute care).

Conclusion

This study into independence and how it impacts on the use of HACC services—such as home care, personal care and delivered meals—raises concerns about how well people on low incomes are currently supported. Within our society a high value is placed on 'independence'; dependence is a state to be avoided. For the low-income consumers and potential consumers of HACC services interviewed, many of whom live in insecure housing, dependence is actually something to be feared. It signals a loss of personal identity, and undermines the 'make-do' culture that that they are comfortable with and that has enabled them to live independently for many years, often with poor health, dislocation and addiction.

The people interviewed in this study are constrained in their choices when they need care or support. Unlike many older people, who receive assistance from friends, neighbours, families or HACC services, people in the study have few options. Informal assistance from friends or family is limited or non-existent for many of the people interviewed. They also resist the use of HACC services, viewing them a sign of dependence, rather than as a way of maintaining independence. Accepting a HACC service contravenes their desire to 'make-do', undermining their independence and dignity. This is magnified by their need to prove incapacity to a service provider in order to qualify for services. Unfortunately, there is little incentive for service providers to address this issue as demand for services already exceeds supply.

The current focus of many service providers is on incapacity, an approach that is clearly a barrier to marginalised older people using support services. Assessment officers need to understand this and ensure that they do not reinforce approaches that lead to people rejecting services. They need to:

- listen with an open mind to what consumers have to say
- understand and acknowledge people's views on dignity and independence
- acknowledge people's desire to maintain autonomy and to have choice
- understand that people on low incomes are likely to underestimate their level of need.

Marginalised older people, often requiring responses that stretch the boundaries of service flexibility, could benefit greatly from reform that increased the focus on the needs and preferences of individuals.

Current policy directions suggest that the expansion of community care will continue, in recognition of the fact that the vast majority of older people who require care want to receive it in their own home. Removing the barriers that are currently preventing many marginalised older people from receiving support must be a component of this expansion of community care. In particular, providing services in a manner that is seen to be supporting independence, rather than threatening it must be a priority.

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