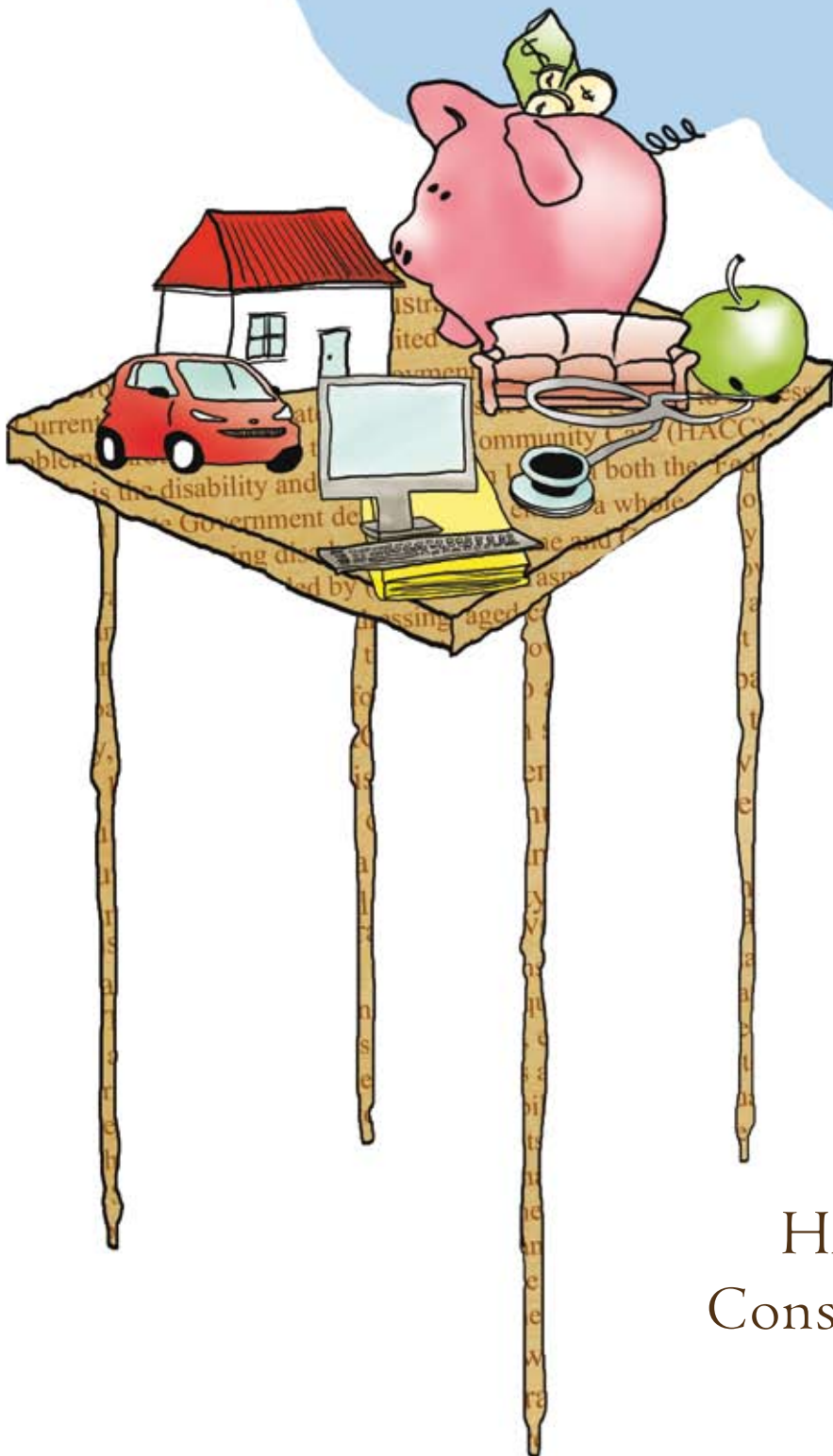


# Enhancing Quality of Life

Addressing Poverty and Disadvantage through the HACC Program



HACC Consumer  
Consultation Report  
**2008**

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# **Enhancing Quality of Life**

Addressing Poverty and Social Disadvantage through the HACC Program

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**Home and Community Care Consumer Consultation  
Project Report  
2008**

The TasCOSS Home and Community Care Consumer Consultation Project is jointly funded by the Australian Government Department of Health and Ageing and Tasmanian Government Department of Health and Human Services.

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## Consumer Consultation and the HACC Program

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*A service designed and delivered with an understanding of the views and needs of those who are to use it is more likely to effectively target these needs. It follows that involvement of consumers in health service planning, delivery, monitoring and evaluation is likely to result in services which are more accessible and appropriate to service users.<sup>1</sup>*

Consumer consultation in the community care sector aims to draw on the knowledge and experiences of service users to improve the overall quality of the service and also the outcomes for consumers. The Home and Community Care (HACC) Consumer Consultation Project, conducted by TasCOSS, provides a means for consumers' voices to influence and improve the accessibility, appropriateness and effectiveness of the HACC program.

Since 2001 the HACC project has had a range of focus areas including dementia (2004), regional issues (2004), issues specific to people from diverse cultural and linguistic backgrounds (2005), intake, assessment and referral processes (2006) and vulnerability of elderly consumers (2007). Issues arising from these consultations and related recommendations have been presented to the Tasmanian HACC Program of the Department of Health and Human Services, for consideration in planning and prioritising within the HACC Program. An evaluation in 2008 found the project has positive benefits for HACC consumers.

Copies of past reports are available from TasCOSS.

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<sup>1</sup> Consumer Focus Collaboration (2001) p5.

## Acknowledgements

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I would like to thank all the participants in this research, Tasmanians living on low incomes, for being willing to talk openly about your experiences of poverty and social disadvantage.

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Pauline Marsh

# Terminology

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In this report the following definitions are used:

**Cumulative disadvantage:** The interconnectedness of disadvantage indicators, and the combined impact of those indicators, for example, early school leaving, unemployment, poor health and low income. Also called the web of disadvantage.

**Deprivation:** An enforced lack of socially perceived necessities; going without because of a lack of resources.<sup>2</sup>

**Fee Waiver:** A fee exemption granted to people who are assessed as unable to pay for HACC services, as documented in the draft National HACC Fees Policy.

**Locational disadvantage:** Also called concentrated disadvantage, this term is used to refer to a range of disadvantage indicators that occur within and are influenced by geographical boundaries.

**Low Income:** In Australia as of June 2008, family incomes of \$40 000 per annum or less, and individual incomes of \$30 000 per annum or less; this definition includes all households whose major source of income is government income support payments.<sup>3</sup>

**Poverty:** in the absence of a universally accepted measure of poverty the following is used: *a state of deprivation in which a person's standard of living falls below a minimum acceptable standard,*<sup>4</sup> insufficient income being a key determinant.

**Social disadvantage:** A range of difficulties that block life opportunities and which prevent people from participating fully in society...[including] economic poverty...poor health, disabilities, lack of education and skills, and being subjected to inequitable treatment or discrimination in a variety of forms.<sup>5</sup> Social disadvantage is inclusive of poverty, deprivation and social exclusion.<sup>6</sup>

**Social exclusion/inclusion:** Social exclusion is the outcome of people or communities suffering from a range of problems such as unemployment, low income, poor housing, crime, poor health, disability and family breakdown – there is an overlap between social exclusion and poverty.<sup>7</sup> An associated term is marginalisation.

A socially inclusive society is one where all people feel valued, their differences are respected, and their basic needs are met so they can live with dignity.<sup>8</sup> Social inclusion indicators include the opportunity to secure a job, access services, connect with others, deal with a personal crisis and be heard.<sup>9</sup>

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<sup>2</sup> Saunders (2007) p10.

<sup>3</sup> ACOSS [www.acoss.org.au](http://www.acoss.org.au).

<sup>4</sup> Greenwell (2001) p10.

<sup>5</sup> Vinson (2007) p1.

<sup>6</sup> Saunders (2007) pviii.

<sup>7</sup> ACOSS [www.acoss.org.au](http://www.acoss.org.au).

<sup>8</sup> VicHealth *Social Inclusion* (2005).

<sup>9</sup> Gillard (2008).

# 1. Executive Summary and Recommendations

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The Home and Community Care (HACC) Program aims to enhance the quality of life of people in the target population - frail aged people, younger people with a disability, and carers. The Program's National Guidelines identify "financially disadvantaged people" as a group with special needs within that population. Tasmania has high a proportion of financially and socially disadvantaged people compared to most other states and territories, and the HACC target group are particularly vulnerable. Currently, approximately 90% of HACC clients rely on government income support payments of some sort as their primary source of income.<sup>10</sup> Consequently there is an important role for HACC to play in addressing the negative impacts that poverty and disadvantage have on people's quality of life. This research project explores those negative impacts. It is underpinned by the premise that a person's quality of life is in part influenced by external, structural factors which, in the case of the HACC target group, can be positively influenced by effective HACC policy responses.

## Key Findings

The key findings of this report are that a good quality of life for people living on low incomes includes, broadly:

- having enough money;
- being healthy;
- being part of a community;
- having enough time; and
- eating well.

A consistent finding is that government income support payments are absorbed by housing expenses and basic living costs, such as groceries, power and phone bills and vehicle and transport costs. As a result, people are unable to afford additional essential items that foster health and wellbeing, for example, medical and para-medical health services, regular nutritious food, social activities, clothing and holidays. Debts and high interest loans compound difficulties and add to financial burdens. However, being able to supplement government income support with an additional income has a positive impact on people's lives.

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<sup>10</sup> National Program Guidelines (2007) p24

The negative impacts of the social determinants of health, that is, the social factors that affect health such as housing, income, employment and education, are evident in this research. Furthermore, having a disability or chronic disease is expensive: medications and equipment are key costs, but disability and disease can also impede access to employment, which in turn exacerbates poverty and disadvantage. Poor physical health is shown to impact negatively on mental health and general wellbeing, as does a low income, traumatic life experiences, a difficult caring role and inadequate access to health services.

Closely related to the social determinants of health are the structural barriers to inclusion, for example inadequate or inappropriate transport and unaffordable social options. Poor health, discrimination, poor family relationships and feeling unsafe also preclude social engagement for many people. Demanding caring roles, and inadequate or inappropriate respite prevent many people from being active in the community, from having meaningful social contact and also from being able to take a break. Employment-related social and economic participation is difficult for many people, and impossible for some, particularly for those who are elderly, have disabilities, low education levels, or are carers. Those who live in rural areas or who do not have access to child care, transport or other support services also find social participation more difficult.

### **Implications for the HACC Program**

The key implications that arise for the HACC Program from these findings are that improvements in the quality of life for financially and socially disadvantaged people could be facilitated by:

- increasing the accessibility and uptake of the fee waiver option;
- broadening the scope of very low cost community care services; and
- increasing the HACC Program's focus on social inclusion through funding programs that create opportunities for reciprocity and community connectedness.

This research concludes that community care in Tasmania plays a significant positive role in improving the quality of life for many people, but has the potential to play a much bigger and more effective role through addressing the problems of poverty, social disadvantage and exclusion through the modification and/or expansion of existing services.

## Recommendations

### **Recommendation 1.**

That the Tasmanian HACC Program seek to improve the quality of life for clients who are living in poverty and who are socially disadvantaged by prioritising funding for the following types of programs:

- Programs that are consistent with health promotion principles;
- Diverse, low fee, social support programs;
- Programs that enable active community engagement, volunteering and paid work options for HACC clients;
- Programs that facilitate reciprocity opportunities;
- Food and nutrition focussed programs – for example social eating programs, nutrition promotion and education programs for HACC clients, and assistance with food preparation in people’s homes;
- Flexible transport provision, especially in isolated areas; and
- Programs that facilitate community involvement, including projects run by existing community organisations such as neighbourhood and community houses, health centres and schools.

### **Recommendation 2.**

That the Tasmanian HACC Program maintain the policies of low fee caps for services and fee waivers for people living on low incomes and experiencing social disadvantage.

### **Recommendation 3.**

That the Tasmanian HACC Program undertake a review of the distribution and uptake of fee waivers amongst service providers.

### **Recommendation 4.**

That the Tasmanian HACC Program explore ways to incorporate the services that are currently exempt from HACC fee caps or waivers for people living on low incomes and experiencing social disadvantage.

**Recommendation 5.**

That the Tasmanian HACC Program provide additional support to the Community Nutrition Unit to expand the work of the HACC Nutrition Service, in particular to enable:

- the implementation of nutrition standards for all HACC funded services, including standards relating to nutrition assessment, screening and management and guidelines for the provision of food, and ongoing monitoring, review and assistance to services;
- assistance with the monitoring of the nutritional status of HACC clients in relation to their overall health and wellbeing; and
- dietitian services to support clients individually, in addition to the whole of service approach.

**Recommendation 6.**

That the Tasmanian HACC Program investigate and address geographical gaps in the provision of community transport services.

**Recommendation 7.**

That the Tasmanian HACC Program provide funding to build awareness of the impacts of client poverty, disadvantage and social exclusion amongst HACC service providers, and the role they can play in alleviating these impacts through service delivery and referrals.

**Recommendation 8.**

That the Tasmanian HACC Program work with the Tasmanian Social Inclusion Unit to ensure the HACC target group is part of that Unit's broad agenda to address poverty and disadvantage. In particular, to advise the Unit on the most appropriate ways, as highlighted by this report, to address the needs of HACC clients who are socially excluded as a result of low income, poor health, unemployment, caring obligations, inadequate transport, social isolation and/or discrimination.

**Recommendation 9.**

That the Tasmanian HACC Program advocate for the inclusion of nutrition service standards into the HACC National Service Standards.

## 2. Introduction

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Tasmanians experience generally high levels of poverty and social disadvantage, relative to Australians living in other states and territories. These high levels are not limited to a particular set of indicators, but are evident across a range of areas, such as employment, education, income and health. Currently, the Australian Federal Government and the Tasmanian Government are seeking ways to address poverty and disadvantage through changes to health, disability, education and ageing policies. Most notable is the implementation of social inclusion strategies at federal and state levels, which adopt a whole-of-government approach to addressing disadvantage.

The Home and Community Care (HACC) Program, jointly funded by the Federal and Tasmanian Governments, plays an important role in addressing the needs of people who are disadvantaged. This is chiefly through the provision of low cost services and of fee waivers for clients who are unable to pay. Importantly however, in addition to addressing people's needs, the HACC program also seeks to minimise and prevent social disadvantage amongst vulnerable members of the community, frail elderly people, younger people with a disability and carers. The Program intervenes when people begin to experience difficulties living at home independently, with the aim of enhancing clients' quality of life.<sup>11</sup> The interventions include basic maintenance and support services that assist with tasks such as gardening, transport, and personal care, and providing social supports.<sup>12</sup>

In order to know how to enhance a person's quality of life, it is necessary to understand what it is that constitutes a good quality of life. This is a difficult task because of its inherently subjective nature, and the task is made more complex because each person's understanding indicates not only what they value in their lives, but also what they are missing. However, targeted consumer consultation with clients living on low incomes and experiencing social disadvantage can assist to identify the elements that some of the most marginalised members of the HACC target group consider to be essential for a good quality of life. Knowing these elements can then assist in the development of HACC policy which will result in

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<sup>11</sup> National Program Guidelines (2007) p4

<sup>12</sup> National Program Guidelines (2007) pp31-33

service delivery that meets people's needs, and minimises and prevents poverty and social disadvantage, and thus improves the quality of life for this special needs group.

## 2.1 Project Aims

This project aims to:

- explore more fully the nature of poverty and social disadvantage amongst Tasmanian HACC consumers by hearing their experiences of living on a low income; and
- inform the Tasmanian HACC Program of opportunities to improve the capacity of the HACC Program to prevent and minimise poverty and social disadvantage amongst the target population, and enhance people's quality of life.

## 3. Background and Project Design

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### 3.1 Context

In Tasmania, the HACC Program is unavoidably concerned with addressing the needs of people experiencing poverty and social disadvantage. While there is no widely accepted single measure of poverty and disadvantage, much research has been conducted to identify the indicators of social disadvantage. Disadvantage indicators in Australia are evident across a range of areas:

- income;
- employment;
- educational attainment;
- health;
- housing; and
- provision of services.

Within these areas there are a variety of specific measurable indicators that demonstrate the likelihood of disadvantage, for example, mortality rates and length of time unemployed.<sup>13</sup> By most measures, Tasmania has high levels of poverty and social disadvantage. For example:

- approximately 17% of households are classified by the Australian Bureau of Statistics (ABS) as living in the lowest three equivalised disposable income deciles (compared with 12.9% of all Australians);<sup>14</sup>
- the Tasmanian unemployment rate, whilst falling, is the highest in Australia and there is a persistently high long-term unemployment rate;<sup>15</sup>
- Tasmanian school retention rates beyond year 10 are the lowest in Australia, and the number of adults with post-school qualifications is also the lowest in any state;<sup>16</sup>
- in Tasmania, cancer, diabetes, suicide, heart disease and chronic disease rates are all higher than the national average;<sup>17</sup> and

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<sup>13</sup> For current research on indicators of disadvantage, deprivation and poverty see Peter Saunders (2007), Tony Vinson (2007) and the Australian Institute of Health and Welfare (2007).

<sup>14</sup> TasCOSS (2007) p4.

<sup>15</sup> Ibid p6.

<sup>16</sup> Ibid p5.

- in Tasmania there are long waiting lists for public housing, and many people experiencing housing stress.<sup>18</sup>

The elements of disadvantage are interrelated, or cumulative. Research indicates that poverty, social disadvantage and social exclusion exist simultaneously for many people.<sup>19</sup> Tony Vinson's work on clustered disadvantage in Australia identifies seven Tasmanian local government areas of significant cumulative disadvantage - that is, areas where people scored highly on a range of indicators. These are Break O'Day, Central Highlands, Derwent Valley, Brighton, George Town, Southern Midlands and Tasman.<sup>20</sup> These areas have high numbers of people on government income support payments (including Allowances, Benefits, Pensions and Payments), low educational attainment levels and limited access to a range of services, including internet access.

The HACC target group - frail aged people, younger people with a disability and carers - are vulnerable to both poverty and social disadvantage. It is estimated that currently approximately 90% of HACC clients rely on government income support payments of some sort as their primary source of income.<sup>21</sup> Tasmania's rapidly ageing population projects greater numbers of older people who will be reliant on the aged pension for a significant period of time, and consequently the high numbers of HACC consumers living on a low income will continue. Furthermore, the HACC Program guidelines identify special needs groups who find access to services more difficult than the majority of the population and require special consideration. These groups include "financially disadvantaged people".<sup>22</sup> Identifying this client group demonstrates the HACC Program's commitment to addressing the specific needs of people living in poverty.

In order to implement programs that achieve the HACC Program's aim of enhancing the quality of life of people in this special needs group, an understanding of the causes, extent and impacts of poverty and disadvantage is required. Past TasCOSS HACC consumer consultation reports have identified the need to conduct further research into the impacts of disadvantage on the HACC target group – specifically, into vulnerability issues for young people with a disability, low cost option alternatives

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<sup>17</sup> Ibid p10.

<sup>18</sup> Ibid p9.

<sup>19</sup> Saunders (2007) px.

<sup>20</sup> Vinson (2007) p28.

<sup>21</sup> National Program Guidelines (2007) p24.

<sup>22</sup> National Program Guidelines (2007) p6.

to day centres, and the impact that the presence or absence of equipment has on people's quality of life.

### **Existing HACC poverty and disadvantage policy**

HACC services have a number of measures in place to protect consumers against the exacerbation of poverty and social disadvantage. For example, the draft Fees Policy contains the following protective principles:

- The inability to pay cannot exclude people from receiving a service, and agencies should waive the fee in these instances;
- Fee scales are used to ensure people on low incomes are charged at low rates and fee limits (or caps) are included in the scale [currently in Tasmania a single visit is \$5, and two or more visits a week are capped at \$10 for full pensioners, for most HACC services];
- There is no charge for HACC services that provide information, advocacy or friendly visiting;
- The fee covers the cost of all materials;
- The fees should take into account the situation of special needs groups, including financially disadvantaged people;
- The assessment to determine whether someone needs a fee waiver should be simple, unobtrusive and confidential; and
- Clients have the right to appeal against a fee determination.<sup>23</sup>

Some services, however, are exempt from fee scales and the costs are met by consumers or other support services. These include some transport services, day centres and delivered meal services. The cost of home modifications and some equipment are also not included in the HACC fees policy.

In addition to some financial safeguards to protect clients from further disadvantage, the HACC program funds services that actively aim to prevent or minimise social disadvantage. For instance, some services are centred on health-promotion and aim specifically to increase people's capacity for social interaction and community involvement, these include, social support services (such as visiting and assistance to go shopping), and centre-based care (which includes group activities in a day

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<sup>23</sup> At the time of writing this policy was in draft form, but is included in the National Program Guidelines as an active policy document – see National Program Guidelines (2007) pg 24.

centre or similar). Other HACC services have an indirect effect of increasing an individual's capacity for social interaction, for example, through personal care assistance, transport services, and nursing and allied health care.

### 3.2 Social Exclusion/Inclusion theories

Poverty and social disadvantage is currently most commonly discussed using the language of social exclusion or inclusion. That is to say, at political and policy levels particularly, the framework for addressing disadvantage is a social inclusion framework. To contextualise this research within this current dominant political and policy framework, and to locate the HACC program within the discourse, a brief explanation of social exclusion follows.

Social exclusion is defined as exclusion from civil society, from access to social goods and resources, and from social production and consumption through "the normal routines connected with employment and other aspects of daily social life".<sup>24</sup> Social exclusion has a firm link with health and wellbeing. For example, the World Health Organisation (WHO) define health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease and infirmity",<sup>25</sup> and state that along with poverty and relative deprivation, social exclusion has "a major impact on health and premature death...[and] increase[s] the risks of...disability, illness, addiction and social isolation".<sup>26</sup>

Much social exclusion literature focuses on the structural barriers to inclusion. For example, on economic systems and their inequities;<sup>27</sup> limited access to social resources and post-basic education;<sup>28</sup> or on housing and employment issues.<sup>29</sup> Thus, social exclusion theory largely centres on understanding the structural barriers to participation, and does not construct exclusion as a fault of individuals, to be overcome by individuals. The links with the social determinants of health and the principles of health promotion are evident in the theory.

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<sup>24</sup> Gray (2006) p284.

<sup>25</sup> WHO (2006).

<sup>26</sup> Wilkinson (2003) p16.

<sup>27</sup> For example Gray (2006) p284; Ballick and Lee (2003) p101.

<sup>28</sup> For example Victor (2005); Swanson (1999); Simonsick (1998).

<sup>29</sup> For example Saunders (2006).

The Australian Federal Government has established a Social Inclusion Unit, which will aim to ensure Australians are given opportunities for employment, access to services, connections with others in their communities, the ability to deal with a health crisis and to be heard.<sup>30</sup> The Tasmanian State Government has also established a Unit, with similar aims, that will implement a whole-of-government strategy to address social exclusion in Tasmania. Such an approach provides an opportunity for the Tasmanian HACC Program to participate in this strategy.

### 3.3 Project Design and Methodology

The research project was designed to hear consumers' experiences, and to gather ideas for change from HACC clients and potential clients in Tasmania who live on low incomes and who are socially disadvantaged. Qualitative research methods such as this add depth to the poverty discourse, and humanise commonly used terms such as disadvantage, exclusion and marginalisation. Obtaining qualitative information about poverty also provides depth to statistical measurables, such as income and cost. As Peter Saunders observes, "There is an urgent need for poverty research to reach beyond statistical tabulations to speak a language that the community can understand and have confidence in. Without this, research will simply compound the existing confusion."<sup>31</sup>

In the design of the research questions, factors identified in disadvantage and exclusion literature that exacerbate or mitigate poverty and disadvantage were incorporated. These factors are summarised by Saunders as:

- power and agency;
- opportunity and freedom;
- choice and constraint;
- exclusion and participation; and
- needs and deprivation.<sup>32</sup>

A quality of life framework was chosen for this research to enable the use of a subjective indicator of health and wellbeing status. This framework demonstrates:

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<sup>30</sup> Gillard (2008).

<sup>31</sup> Saunders (2005) p11.

<sup>32</sup> Saunders (2005) p17.

“the degree to which a person enjoys the important possibilities of his or her life”<sup>33</sup> and enables people to express their understanding of the impact of poverty and disadvantage on their lives, in a way that articulates their experiences and is readily understood by others. The framework also enables people to talk about issues affecting both themselves and their environments, that is, about the individual and structural elements. In addition, it provides a means of discussing not only what people value in their lives, but also what they are feel their lives are missing.

In order to determine both the nature and impacts of living on a low income and of social disadvantage, the key research questions were:

- What are the essentials for a good quality of life?
- What are the barriers to achieving them?
- What can be done to change things?

A purposive sample group was sought, consisting of people who had been granted HACC fee waivers, had difficulty paying for community care services, or were reliant on government income support payments. In addition, people who access a range of non-government community sector organisations that provide services for people on low incomes were included, and these organisations included HACC service providers, neighbourhood houses, housing support organisations, adult literacy programs, and advocacy services. Participants were specifically sought from geographical areas of high disadvantage as identified by Tony Vinson<sup>34</sup> and the total sample group included a mix of age ranges, ethnic backgrounds, disabilities/abilities and genders.<sup>35</sup>

One-to-one semi-structured, in-depth interviews were conducted with 44 HACC clients and potential HACC clients. Information regarding the research was provided to participants and written consent was obtained prior to the interview. Interviewees were initially approached by the staff of the referring organisations. Interviews were approximately one hour in duration, and were audio recorded and transcribed. Focus groups were held with 104 people from around the state, in groups of 5-20 people. All

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<sup>33</sup> Centre of Health Promotion (2005).

<sup>34</sup> Vinson (2007) p28.

<sup>35</sup> See Appendix A for the demographic details of the participants.

discussions were recorded by a scribe and/or digital recording device, and transcribed. Participants were reimbursed with cash or voucher payments.

Discussions centred on the issues that current poverty research identifies as factors contributing to disadvantage in the areas of health and wellbeing, employment and income, education and training, housing and access to services.<sup>36</sup> Towards the end of each interview people were specifically asked what they thought they needed for a good quality of life.

To maintain confidentiality, the names of participants have been changed in this report, and the names of some service providers and geographical areas omitted where necessary to protect privacy.

### 3.4 Project Limitations

The following limitations may have an influence on the project findings:

- Participants involved in this research had all been in contact with community care or other services. Consequently, people on low incomes who were not receiving assistance in this manner are not included or represented.
- This research project does not attempt to determine the causal factors of poverty or social disadvantage.
- The research is not longitudinal, and so does not attempt to make claims about the influence of changes in external environments on people's lives over time.
- This research does not attempt to produce measurable indicators of a good quality of life.
- Discussions about the psychological theories of resilience are beyond the scope of this research project. Rather, it presents the current experiences of people who are living on low incomes and are socially disadvantaged, and it is these experiences that are analysed within the scope of this research.

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<sup>36</sup> See Appendix B for interview guide.

## 4. Findings

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### 4.1 What is a good quality of life?

In order for the HACC Program to enhance clients' quality of life, it is necessary to understand what a good quality of life means to people. Furthermore, to enhance the quality of life for members of the special needs target group, "financially disadvantaged people", it is important to understand what these people value and need.

Much academic work has been undertaken to measure and understand the notion of a quality of life, including the development of theoretical models, tools and measurable indicators.<sup>37</sup> This research project draws on some of that work and operates on a premise derived from this field, which is:

People may function at a particular level of wellbeing that is independent of external factors, however, the level is increased or decreased by the presence or absence of external factors, such as access to resources, including income.<sup>38</sup>

That is to say, people's quality of life decreases and increases according to varying levels of personal resources and external supports.

Towards the end of each interview, research participants were asked what they thought they needed for a good quality of life. This ensured that the question was framed within the context of the interview discussion, that is, of the experiences of poverty and social disadvantage. Consequently, people talked about not only what they value in their lives, but also what they go without and need in order to have a good quality of life. It also meant that people talked about tangible, material elements as well as intangible elements.

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<sup>37</sup> See for example Deakin University's Australian Unity Wellbeing Index, and the University of Toronto's Quality of Life Research Centre.

<sup>38</sup> Cummins (2007) pxii.

## **Themes**

Because people talked about the broad range of issues affecting their lives, inevitably issues were raised that are beyond the scope of a possible response by the Tasmanian HACC Program. People talked about psychological factors that impacted on their capacity to cope with their situation, for example, about having a good sense of humour, “cutting your own cloth”, and making the best of things. Although many of these quotes are included in this report, the report focus is not on the psychological factors that influence resilience or coping capacity, but rather on the external structural factors, and in particular those factors that are within the boundaries of the HACC program.

With this in mind, this report presents the research findings in a way that focuses on the opportunities for practical input from the HACC Program to address poverty and social disadvantage.

The findings have been grouped broadly into thematic areas that participants identified as the elements necessary for a good quality of life, and these are:

- having enough money;
- being healthy;
- being part of a community;
- having enough time; and
- eating well.

## 4.2 Having enough money

This section details people's experiences of poverty and deprivation and demonstrates some of the impacts that a low income has on their lives. It includes descriptions of weekly expenses, what people go without, and the factors that exacerbate financial hardships. These experiences highlight the interplay between poverty and social disadvantage. They also raise issues for the HACC Program, and highlight the roles the Program can take to respond and address poverty and disadvantage.

### **Not enough money for a good quality of life**

An inadequate income has a significant negative impact on people's quality of life. Poverty and deprivation are major drivers of poor health and social disadvantage and the reverse is also true - poor health, disadvantage and exclusion exacerbate poverty. Inadequate money means people are unable to meet their health needs, pay for housing costs, afford to eat as well as they would like, socialise, buy clothing, or go on holidays. Participants commonly cited money as essential for a good quality of life, not in order to live extravagant lifestyles, but to be able to afford basic things that others take for granted, as the following quotes illustrate:

*Well, a good quality of life, I think, comes back to money. Because if you haven't got a jingle in your pocket you've got no quality of life really. Because you can't go nowhere, you're so handicapped, and you know, you can't tell people you can't go because you've got no money, it's like begging.*

Alma

*It would be good if you had enough money to keep you going comfortably, like if you had money left over, you could pay the bills, do the shopping and then you had some left over. To be able to go out and buy decent clothing. It would be nice to be able to live just comfortably. I haven't bought myself anything in years. It was always for the children I was buying for.*

Sharee

### 4.2.1 What is a low income?

The Australian Council of Social Service, as of June 2008, defines a low income as a household income of \$40 000 per annum or less, or an individual income of \$30 000 per annum or less. On this measure all households whose major source of income is government income support payments are low income households.<sup>39</sup> Consistently, people involved in this research were adamant that the government income support payment they received was inadequate: they could not stretch it to make it meet their needs.

Participants detailed the amount of money they received and explained how it was spent. They drew comparisons with their past incomes or with incomes of people in well-paid professions to explain the differences and to highlight the impact of poverty on their lives.

Bridget highlights the difficulties of being widowed and living on a single Age Pension income:

*The thing that is the worst is when you come off a double pension and you drop back onto the single pension, there is no way, even owning your own home, that you are going to find it easy, unless you have a little money invested. You will live from week to week otherwise. It's that transition, you will also be very upset, and suddenly you only have half of what you used to have. Your expenses only drop for food and clothing, and people my age don't buy that many clothes. I've had five years to adjust, but I've noticed with my friends that suddenly they need that support. It really works out that once a month you have one big bill to pay, and the water hasn't even come in yet, I'm dreading that. It's these things that governments need to take into account. I walked into the Chemist and it was \$28, for tablets recommended by my rheumatologist – cod liver oil.*

Bridget

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<sup>39</sup> ACOSS [www.acoss.org.au](http://www.acoss.org.au).

People also have difficulties managing on Newstart Allowance, the Disability Support Pension and the Overseas Pension:

*In Parliament House they are living on clover, and people on a low income, well I get \$429 on Newstart, but after my rent is taken out, the money I have to pay for my NILS loan I took out for my washing machine, and my Centrelink loan, I'm left with \$232 to live on for a fortnight. Yet the Parliament House people are living on \$70-80 grand. I'm struggling from fortnight to fortnight, I have to borrow from other people it's got that bad. Literally, I struggle from day to day, week to week.*

Sharee

*It's very tough being on the Disability Pension, I would love to be able to go out to work and bring home a cheque and buy my own house.*

Sue

*On the Disability Support Pension I get \$537.00 a fortnight, with a pharmaceutical allowance of \$5.80. They take out a lump sum allowance payment of \$38.50, my rent \$114, electricity \$15, and telecommunications \$30. So in hand I have \$346.*

Rita

*My pension just is \$2800 for 3 months. Sometimes it goes up sometimes it goes down, \$100 or more. When we came to Australia we have to wait for a permanent visa, for 10 years you don't get any money from Australia. No money! Australia doesn't give us any money, for example by Centrelink, only for medicine, \$100 for one half year and we have a Medicare card, and last time Centrelink gave us \$200 for year for the telephone and something, this is a special.*

Michael and Ila

#### **4.2.2 Where the money goes**

When people talked about what they spent their money on, the majority stated their income was consumed by the daily basics and essentials, such as rent, food,

electricity and phone bills and transport costs. People were keen to stress that they are not wasting their money on extravagances, but that basic general costs of living exceed their income. The costs associated with chronic health problems or disabilities take a large proportion of many people's incomes, however these are discussed in the following chapter 4.3 *Being Healthy*.

### **Housing expenses**

Housing expenses affect people in all forms of housing: the private rental market, privately owned homes, private homes under purchase, independent living units, and housing department properties. Home-related expenses include rent, mortgage/loan repayments, rates, maintenance, modifications for disabilities, body corporate costs, and moving costs.

Many people who privately rent their homes feel the strain of high rents – and participants noted recent increases in rental prices – coupled with the insecurities of renting. Along with others, private renters Michael and Ila cite rent as their biggest financial burden:

*The first problem was rent, rent, regular rent, it was very difficult for us. From the 15<sup>th</sup> of March, up \$25 dollars; two to three months later, another letter, your rent will be up. Up, up, up.*

Michael and Ila

The costs associated with owning a home such as rates and maintenance were considerable costs for many people:

*I own my own house so I have to pay rates and taxes and that. I find it hard when you only get so much, pay the bills. Rates are around \$1300, \$1400, they went up last year – about \$355 a quarter.*

William

Some people also had body corporate costs, which they found difficult to meet, as Barbara states:

*Another bit of a problem is that we have to make an annual body corporate payment, they send me a letter and I always have to send a reply saying I won't be able to pay it until the next pay day, the next pension pay day. One year it was \$173, the following it was about \$200, or \$230, they would prefer that I pay it immediately, but I can't, it simply can't be done.*

Barbara

Some people had bought homes to accommodate their disabilities or had paid for modifications to enable them to keep living in their homes. For example:

*We bought our house 2 years ago, mortgaged ourselves up a bit so that our [disabled] daughter could have her own space, be set up a bit independently but in our home.*

John

The relief associated with low cost housing is significant for people who successfully obtain public housing accommodation. However, some participants felt that it was still difficult to get ahead financially as public housing rental is taken as a percentage of income, so rises in pension payments are absorbed by corresponding public housing rental increases:

*If you get a bit of a rise in your pension, Housing takes it. How do they expect us to survive when things are getting dearer and they are taking every little cent? I think I'd rather sometimes go private and take my chances, at least you can get rent assistance which helps, but here you can't. If it was a caravan park and it was just like a unit type thing with your own bathroom or something like that, we could move in there.*

Kaye and Peter

Naomi also stated that her public housing accommodation was more expensive than a past private rental:

*We pay more now with Housing than I did with private. I pay \$170 a week, in Housing, no rental assistance, where I was paying \$155 with rental assistance.*

Nicole

## **Groceries**

Many participants cited groceries, in particular the increases in costs to food and other grocery items, as a cost that accounted for a large proportion of their weekly expenditure:

*There are some ways around it, but still the basics we all buy have gone up a lot in a short amount of time. I get it all home and it doesn't look like much, but most of the money is gone on shopping.*

Matilda

In addition to basic food costs, some participants purchased hampers of food over a period of 9-12 months, paying monthly instalments of around \$70 for the annual delivery of a hamper at Christmas time. (The details of the impact of grocery costs are discussed in further detail in chapter 4.6 *Eating well*.)

## **Transport and vehicle costs**

The running, maintenance, insurance and registration costs of private cars were significant, and many participants discussed the difficulties they had in meeting these costs:

*I've got a car and I've got to register it. I'm just wondering why every year it goes up. It seems like a person with means like me can't get a full 12 months, I can only get six. 12 months is about \$600 and I can't pay that. I've been to Service Tasmania and asked why you can't let a person who is unemployed pay it off bit by bit, that would help the battlers, but unfortunately they didn't want to do it. Car rego is behind the 8-ball on that, you can pay a lot of other things in instalments now. I've seen people who have actually had to sell things to get the money.*

William

Many people felt they needed a private car due to a lack of suitable public or community transport options:

*You have to have a car in this area, because we don't have any transport. Redline [private bus company] have even cut off*

*their services. Maintaining a car is really expensive, and so is petrol. And even insurance – “what’s that?” – and if you have an accident you just get put back.*

Louise

For some people the only suitable transport option was a taxi, and even with a taxi concession provided through the Transport Access Scheme, these costs were great:

*Transport is shocking, I haven’t mentioned it before, but it’s just so miserable, we fall back on the “maxi taxi” and they charge outrageously, on top of the 60% they get from the government...I don’t know whether they’ve changed because I have complained about it, but to go to [the nearest large town 15 minutes drive away] from here I have to pay \$25, on top of my 60% voucher.*

Vonnie

HACC funded community cars meet the transport needs of eligible people in some areas, and these are effective in providing low cost, flexible transport, as Sue’s example demonstrates:

*The community transport here is excellent. The availability is great, they have a reasonable amount of cars and it’s well organised. If you have an appointment you tell them a week in advance. It’s \$12 to Launceston and \$28 to Hobart, and if you have to go more than once in the week you only have to pay for the one trip. If you give them one week’s notice it’s fine, it’s only been twice they haven’t been able to take me. They take you right to where you have to go and hang around for you, it’s excellent.*

Sue

### **Bank Fees**

An additional cost felt by many people living on low incomes is regular bank fees. Although they are often small amounts, the regular payment is keenly felt. People also expressed a sense of injustice that banks could take additional money from

people with small accounts, and not from those with large amounts of money in their accounts.

*Bank fees, I find that to be quite bad. At the end of every month they take out, they reduce my balance based on the number of cash withdrawals I make. And they have just increased it by another two dollars.*

Barbara

*Certain banks charge more fees than others. I've just closed an account with the Commonwealth...They said 'is there anything we could talk to you about why you are closing your account with us', and I said "it's the fees, they are really terrible", I mean I can be naïve at times but I know there's no Father Christmas in banking. ANZ have a progress saver and if you are saving they don't take fees, and they waive the fee for disability pensioners, and there's unlimited transactions.*

Matilda

To avoid fees, people attempted to meet the bank's conditions to leave a minimum amount of money in their account. This was not an easy task, as Alma highlights:

*For me to have a bank book I have to leave \$300 in there, it's got to sit there, otherwise I get charged \$4 for every withdrawal, so that would be the rent withdrawal and me withdrawing and it's best to leave the \$300 in there. But it's ridiculous really. I really do think they should waiver that for pensioners, for people struggling. I don't want a card, I haven't had one and I don't want one. We used to only have to leave \$200 in there, it's a very big temptation to draw it out sometimes when you're struggling. I rang the bank to see if there was any way I could get out of it sort of thing, but there wasn't.*

Alma

### **Other incidental costs**

In addition to housing costs, food, transport, health costs and bills, people talked about additional costs that they need to meet. Additional expenses include: child-related costs such as school excursions, clothing and gifts; home contents insurance; and sport or recreation costs such as swimming pool entry fees. Many people help out other family members in financial difficulty also.

For example, Rita has a funeral plan so that her son will not have to meet the costs when she dies:

*There's my funeral plan, \$27.50 per month, and insurance on this place \$13.15 per month for the contents. The funeral plan is so my son's not stuck with the funeral costs, because he's only on the pension. I've been doing it for ages, and I keep going until I cark it. Like he said, everything goes up all the time.*

Rita

Carol's situation exemplifies the impact of the cost of basic necessities, such as replacing underwear:

*I took off down to Big W and bought 3 bras for \$99 and that was it – wipe out, my bank account was wiped out.*

Carol

### **4.2.3 What people go without**

A low income deprives people of many things that people on more substantial incomes are able to afford. For example, people are prevented from socialising because they can not afford to pay for activities, or transport costs. Some people can not afford to buy a coffee in a cafe, gifts for friends and family, to eat well, or to take a holiday. People also go without new clothes and without telephone land lines because they are unaffordable. As a consequence, people are deprived of some of the essential elements that enhance their health and wellbeing, that is to say, they are influenced by the impact of the social determinants of health.

## **Food and groceries**

Generally people buy food that is on special or cheap, and go without high priced items. Many people stated they were unable to eat out, or may do so only on a special occasion. However, some people are unable to afford basic foods towards the end of the pay fortnight. For example, Naomi was unable to afford to provide her children with an adequate lunch:

*Once I've paid the bills I'm left with nothing. It's a struggle, it is a struggle. My kids went to school with no lunch today. I rang my ex-husband and said 'you need to buy lunch and take it up to them'. He just has to on the pay week. He'll go out and buy nappies as well today. Now bread has gone up and I just go through so much. I am struggling, I will admit it to you. But I'm not selling anything, I'll go without my needs as long as the kids have theirs. They had stuff for recess, but I didn't have bread for sandwiches. They want to buy a lunch order once a week, but they can't, I can't do that.*

Naomi

(The costs of food are discussed in more detail in section 4.6 *Eating Well*.)

## **Clothing**

New clothes were frequently cited as an “unaffordable luxury” and many people bought only second hand clothing, or relied on gifts of clothing from more wealthy relatives. Being able to buy new clothes is desirable for many people, and it is sometimes embarrassing to be unable to afford them.

*Clothing, my clothes are years and years old, I don't have any money to buy new clothes. My family buy me any clothing I need, usually at Christmas, Mother's Day, my birthday.*

Alma

## **Social activities**

Many participants said they could not afford to socialise because their money was taken up meeting the basic needs of food and living expenses. Social activities were seen as costly and unessential, and therefore could be sacrificed. (These issues are discussed further in section 4.4 *Being part of a community*.)

Nevertheless, socialising was stated to be highly desirable and the loss of social activities was keenly felt, as Bruce and Lois describe:

*I used to go to the movies every Tuesday, it used to be cheap, but now they've put that up. You've got to get out and about a bit on your own, its ok to come here [a day centre], but you have to get out. I love the movies, I used to go every fortnight. I used to go and do my shopping and go to the movies but they've got too expensive, I can't do it now, I've had to cut that out.*

Bruce

*Every week the money is spent on things we need, there is nothing left over. You don't go anywhere because you can't afford to go out - once in a blue moon. If you do, you pay for it over the next two payments. It's humiliating to say you can't go to a party because you're broke.*

Lois

### **Gifts**

Participants also stated they were unable to afford to give gifts, and went without gifts themselves. The inability to participate in gift giving and receiving was unpleasant and undesirable for people.

*For me, every year it is a problem when Christmas comes and we want to give small gifts for our grandchildren, and we have to tell them we haven't got anything for them. "Where is our present?" they ask, and for me it is not a good thing, it's a terrible thing.*

Michael and Ila

*I say I don't want presents because I can't give presents, you don't have the pleasure of buying a present and giving it to them, but they know and they understand.*

Alma

## Holidays

Holidays were beyond the reach of almost all the participants in this research and this significantly diminished people's quality of life.

*I wouldn't know what a holiday was. I've never been on a holiday in my whole life. I probably would if I could. At the moment I couldn't afford to, not with the prices of things.*

Sharee

*I organised to go away for Christmas, but we can't afford it. I even booked the accommodation in St Helens for 4 days, but I've got to ring up and cancel it, we can't afford it.*

Jay

Those who did go on a holiday either went to stay with family on the mainland, or used a credit card to cover the costs and some, as Kat describes, feel guilty as a result:

*I can take a holiday if it's on the credit card. I did that this year, I applied for a \$2000 credit card and we went to Queensland, and I felt guilty the whole time that I did it, because then it took so long to pay off. It wasn't until I got some cash for the car trade-in that I paid it off and then cut it up.*

Kat

## Land phone line

Rather than a fixed land line home phone, pre-paid mobile phones were popular amongst people living on a low income, chiefly because they avoided a monthly bill. If people could not afford a pre-paid card then they were inclined to go without.

*I haven't got a home phone, I prefer Telstra pre-paid [mobile] because that way I haven't got any bills coming in.*

Sharee

However, not having a land line left some people feeling anxious about their ability to communicate readily with others, and impacted on relationships with family. As Sophie explains, her elderly parents were less inclined to keep in contact by phone:

*I haven't felt like I needed a land line, but I probably will now so that Mum and Dad can ring me more often. They only ring every now and then, when they really desperately want something, because they can't afford it. But if I had a land line she could ring when she wanted to have a talk.*

Sophie

#### **4.2.4 What makes a low income lower**

A low income from government income support payments or a low paying job is frequently exacerbated by other related factors. That is to say, a low fortnightly income is lowered by the effects of poverty. The intersection between poverty and social disadvantage is illuminated further in the following findings.

##### **Insufficient resources**

A history of low paid work or unemployment contributes to an inability to build up a store of material and/or financial resources, such as a house, superannuation or savings. In these instances there are no spare resources for a crisis or unforeseen circumstances. Participants who had worked in the past but were now receiving a pension were able to articulate the difference they found in their capacity to save and build resources, as Sharee's situation exemplifies:

*When I had the job I was able to save, and not worry about it. I was able to bank some, use some, and at that time I even drove a car. Usually if I'm short of money it's, "Mum, can I borrow some money off you" and I go down and she gives it to me and I don't have to pay it back. She's on the pension herself. She owns the house outright, so she never says no. Lately it's every week I'm ringing up Mum, and it's for bread and milk, something to eat, sometimes for Pay As You Go [electricity] when you're on the emergency \$10, otherwise you sit there with candles.*

Sharee

Without the resources to cope in a crisis, the impact of the crisis is magnified:

*If an emergency arises you have no money put aside, you never get on top, you end up having to borrow and the cycle goes on.*

Sean

People can run low on social resources also when access to social contact is limited and the capacity to sustain social networks is inhibited by poor transport or an the costs of socialising. For example, people like Alma, who state:

*I don't socialise one bit. I would like to, but as I say, the funds, it doesn't meet it.*

Alma

### **Debts**

The impact of large debts was felt by a number of participants, and increased the strain on their incomes. People incurred debts through a variety of ways, for example, through drug and alcohol dependency or gambling problems, debts to health insurance companies or to Centrelink for over-claims, debts for unpaid credit card expenditures, and when relationships ended.

Janet was frustrated about the “dead money” involved in paying off debts:

*This fortnight we are really scraping...We had a car repossessed basically a month after my husband did his back in, and we have to still find the money to pay that off, as I say it's dead money going to pay off something we haven't got, that's why it's a hard fortnight.*

Janet

Financial pressure put a strain on some relationships, as Jay highlights:

*I want a house phone, I just can't get it in my name, I've got bad credit with the phone. I would like to have it though just for emergencies. My husband and I went through bankruptcy, but not full bankruptcy, we're still paying off so much in the dollar or something, it comes out of my money because I made the debts. It put a strain on our marriage.*

Jay

## Loans

For many people, loans are critical for meeting the costs of large one-off payments. Many participants used the option of a no-interest loan from either Centrelink or the No Interest Loan Scheme (NILS). Generally, these loans were taken out to pay large bills, such as car registration, and for expensive items such as white goods. However, they were also used to build up a supply of basics such as food and clothing. Sharee's situation highlights this experience:

*My washing machine died and I found out about the NILS loans, and I got two quotes...and the NILS people approved it, and you pay back about \$36 a fortnight. Before that I was hand washing for six months. I used the Centrelink loan to buy food and things like that. I'm due in September and I'll get it to stock up my cupboards, bulk stuff and make it last as long as it can. My son's a big eater and I like to have food in there. At the moment the cupboards are a bit bare.*

Sharee

In addition to No Interest loans, people take out loans from family, friends and retail outlets. The reason is often due to an immediate need for money, brought on by a cluster of due bills, highlighted by Colleen's situation:

*I've borrowed money from my mother, and through Coogans, furniture and cash loans. Mainly for furniture, but we had 2 car registrations came at the same time, so we went and got a loan through them to pay the registrations. Paying back is sometimes difficult, when the hydro and phone come in, trying to scrape all of them at once, so I pay a bit each fortnight so it's not coming out each month, makes it easier, I pay a bit extra each fortnight. I always try and get them a month ahead so you've got something to fall back on.*

Colleen

High interest loans are also used by some people, with some private lending organisations charging very high interest rates and/or charges that make repayments

very difficult and debilitating, and add a significant cost onto the original loan. Sophie exemplifies this experience:

*I'm about finished paying one loan at the moment. I got it for a vacuum cleaner, and a computer, it was for \$1000. I had 23 weeks to pay it back, through Global Money Line, it's 20 weeks for anything \$900 and under. It also helped pay for the grandkids' Christmas presents. \$93 a week to pay it off, but I'm not going to get another one when this is finished. On that \$1000 I'll end up paying \$1435.*

Sophie

### **Inaccessible bonuses, concessions or benefits**

Over recent years, bonus payments from the Federal Government have been made available to particular groups of eligible persons. Participants stated that the bonus payment for people in receipt of the Age Pension is useful for paying large one-off payments. Some people appreciate that the money is separate from fortnightly payments and therefore does not impact on payments, such as public housing rent, that are calculated as a percentage of people's fortnightly income.

However, younger people with disabilities are not eligible for such a bonus, but may have similar needs:

*I had a talk with [my local politician]...I said, I've got a problem and I want to tell you about it, but realise it the way I'm looking at it. These elderly ones on the old age pension, they get that \$500 a year, why can't the disabled and what not have it too? Most of those old age people have had a chance to work and build up a bit of super or things to help them in their older years, but, us disability people have tried to do things like that and we can't and haven't got anything behind us and...someone said it was for utilities, and what's the difference between elderly people and us disabled people, we should be able to get it.*

Carol

Many people, in particular older people, would like to see an increase the range of concession benefits, and suggest the inclusion of private dental costs, petrol and the Medicare gap costs.

Some people find accessing Centrelink benefits difficult, due to the large amount of paperwork required and, for some, the requirement of proof of identity. Dean spoke about the difficulty he had accessing benefits after being homeless for a few years:

*When I tried to get on the dole after being on the streets, just trying to get access, I had no ID, they wanted 100 points [of identification] but if you didn't have that you were pretty well stuffed. I had no money to get a birth certificate, no driver's licence - I haven't had one for years. They wanted a passport, now of course you carry a passport with you all the time. If you haven't got it you don't exist. To be quite honest I was happy on the street with no money and just surviving. But as soon as you get on the rock and roll you got to go here, go there, fill in this form, that form.*

Dean

Some people prefer to forgo entitlements to avoid the rigmarole of paperwork, or the risk of losing the benefits they already had:

*They said that if you go on the carers' pension, if something happens to the person you are caring for then it's hard to go back onto the disability pension, so that's why we just get the allowance.*

Kaye and Peter

### **No child support payments**

Women who are, or were, entitled to child support payments are significantly disadvantaged when their ex-partners do not pay, or have not paid, maintenance. For some women with grown children, they had not received assistance for all of their children's lives:

*When I met my husband all my money dwindled away. I wasn't well off, but I had money in my account and if I needed it I could go and get it. He was a heavy drinker, he would buy*

*beer instead of milk, and that was when we had kids. Housing kicked him out, the kids have had nothing to do with him. I've had not one red cent from him, I don't think he'd ever pay maintenance.*

Sharee

### **Drug and alcohol**

Drug and alcohol dependencies create a large drain on finances for people and their families. People with dependencies themselves, or with partners with dependencies, reported they were unable to save any money and it also increased their chances of being in debt. These financial costs are in addition to the emotional, physical and psychological costs brought about by their dependency.

*I wasn't able to save any money. I had 2 daughters, I had a husband but he drank all his money. He drank 6 big bottles every day. I had to leave him twice...I'm going to have a little cry I can't help it...I've had a hard life, a real hard battle.*

Alma

### **Barriers to earning a higher, or additional, income**

People who were able to work and earn an income in addition to their Centrelink benefit reported a marked improvement in their quality of life. However, many people stated that there were a range of obstacles that prevented them from obtaining work, or from earning money in addition to their pension. For example, people reported few opportunities for work in rural areas, in all areas people noted a lack of flexible work options that would accommodate disabilities or child care or other carer responsibilities, and age discrimination was also felt to be a barrier.

Participants also felt that complicated Centrelink processes were a barrier to seeking employment, and that any gains made from low paid employment did not offset the loss of benefits:

*So why my wife hasn't worked for a while is because I calculated that the first person to go to work needed to be on a wage of about \$32 000, and that wasn't going to put us miles ahead, that was just to pay for itself to keep my wife sane. That's not going to give you enough money to pay everything and put aside for a new house, or car, or go on a holiday. When you go to work and*

*the government gives you these 1000 work credits, and I think that gave us about six fortnights of work income before it started to affect our income, so you could see they were trying to help. But they go on the gross amount, so if you are doing reasonable hours...with the carers money you are allowed to work or study 24 hours a week...you have to say how much income all up, and that has to be before tax, so if you are paying say \$120 tax (don't get me wrong I'm for tax) you lose that, then they take the \$280 off, and then we're left with whatever, then it's 20 cents in the dollar for each of us, basically 40 cents in the dollar. So roughly we end up with \$150 in the bank better off. But you've got to take into account your extra costs traveling, buying clothes for work – the government do give a payment for employment entry, but they only give you that once you are full-time, or have done the same hours as full-time work.*

Roger

Low educational levels were also raised as a barrier to securing well-paid employment. Many participants, across the age ranges, had not reached year 10 at school, and significant numbers had left school at a very young age. Alma's story highlights what the situation was like for girls from working class families in rural Tasmania during the 1930's and '40's:

*I left school when I was 13, I went to work housekeeping for an old lady. In those days they employed someone to do their work and you lived there, you had a little room. This lady came - there were 10 in our family - and this lady came knocking on our door, they used to do that in those days, and wanted to know if Mum had anyone. The other girls were out working for Toffs (we used to call them Toffs because they had money). They don't do it now, one would be a cook there and a housemaid somewhere else...and Mum said the next one is me and I was 13. She wrote a letter to the government and got me out of school.*

Alma

Some participants had taken opportunities provided by Mission Australia and other organisations for adult literacy classes to further their education, and talked about the significant positive impact this additional learning had on their lives:

*I never passed anything at school. I just stopped trying. I thought I've got to see if I can do English and Maths, and the kids were asking me to help. I worked the day after I left school. I worked at Coles for 18 months, then I got married and stopped working. I'm just about up to my 160 hours at Mission Australia, I've noticed a difference, my maths teacher loves me, I do twice as much work as everyone else, I love maths. I really want to learn now, I didn't when I was 16-17.*

Sophie

Caring obligations prevent some people from being able to earn money. Len's wife is a full time carer for their adult child:

*Originally my wife was working, and we look back now and think how did we survive? We just wonder how we did it because it was a pretty tough time. But then she stopped...so now she can devote her time to our daughter. As it turned out we weren't that well off financially, but we had no choice.*

Len

Injury or disability can also prevent people from working:

*I've been unemployed since 1992, but trying to find a job...well its pretty hard...even though I've got the qualification...but I had a bit of an accident, I lost some fingers and...I've been on unemployment benefit since. I've been trying to get a job, but it's hard to get one.*

William

People with health problems or a disability require a workplace that can accommodate physical needs, as Lena explains:

*I was going to go and do more study at the TAFE when it first started, but then I got arthritis really badly so it went by the way side. Lifeline just rang me to see if I would go back and do some, they would pick me up in the wheelchair, so I'm thinking about it.*

Lena

Jay lives in a rural area and is experiencing a range of locational obstacles to gaining employment:

*I need a job that suits me and also my family...I keep applying for jobs, but it's hard around this area. Hopefully the stuff I'm doing will get me somewhere. I don't want to move just to look for work, I want to stay here.*

Jay

Sharee, like others, felt that she was discriminated against because of her age in her search for employment:

*I'm finding it hard to find a job because they want the younger people not the older people and they want qualifications. The younger ones, they pay them less.*

Sharee

#### **4.2.5 The benefits of a higher income**

Many people stated that they did not need a lot of extra money, but that an additional small amount would make a big difference:

*A bit more money would help, I think the way I'm going, \$200 a week for a while, then down to about \$100, there's just a few things I've got behind on and I hate having money owing, it wouldn't be frivolously spent. One is the loan for me walker, one I owe dad \$40 cause he took me to Launceston and back (he got some money from the government), he came and did my yard and we said we'd give him \$10. Meals on Wheels, I've got behind, it adds up quicker than you think, I'm giving them \$40 a fortnight to pay them off.*

Carol

*This time next year I want to be working. I want an income: I don't want to be listening to the news and worrying about the price of bread, scraping my pennies every week. They give you a rise in pensions and allowance but it still doesn't cover it. I'd love their income, the government. Not everyone out there is beyond help - they just need a little bit more cash.*

Dean

### **The role of emergency relief**

People sometimes seek support from agencies that provide food vouchers and other forms of assistance during particularly difficult times. Some people expressed their embarrassment and awkwardness at having to use such services, interpreting it as an admission of failure to cope. However, the important role of such services is also clear:

*When we get stuck we go to [the neighbourhood house]. They used to give you a cheque, but now they give you a voucher for Woolies. If you have to pay off your bills, you just have to tell them and they'll give it to you. You can only do it if you really need it, not all the time. Sometimes I go overboard on the bills to try and knock them on the head, just to get them down a bit, and I go overboard. The car is giving us more bills all the time.*

Kaye and Peter

### **Supplementing the pension**

Being able to earn money without it impinging on benefit entitlements is of great value to people. Some participants worked odd jobs for people such as gardening, washing dishes, sewing and clothing repairs, selling their art and craft work and received small cash-in-hand payments. People who have access to superannuation or income from a part time job or higher paid job experience a range of benefits:

*On the two pensions with two children, you can earn \$280 a fortnight without it having an affect on your pension. Then anything over that you lose 20 cents in the dollar each. Where if you were on parenting payments or Newstart - big*

*difference. That's why the seriousness of being on Disability Pension and Carers' Pension is that the income tests and assets tests are a lot bigger, but the payment is a bit more. But the big difference is the \$280 a fortnight.*

Roger

Additional money from better off family members, or adequate income from ex-partners for child maintenance are two other examples of the ways of supplementing government income support payments. For some people, these additional incomes are essential:

*Every month I get \$700 maintenance from my ex husband, and that goes to the house payments and any other big bills. I'm very lucky my parents are rich because I often have to borrow money off them, every fortnight...*

Sam

#### **4.2.6 Conclusion**

Having an adequate income is essential for a good quality of life, but in Tasmania many people are living on inadequate incomes. People receiving government income support payments report that their income is insufficient to cover their basic needs, such as housing expenses, electricity costs, groceries, transport and vehicle costs, and health care. These findings demonstrate that a result of a low income is a negative impact on people's quality of life. That is, people's wellbeing is compromised because they are unable to afford the costs of socialising and other health promoting activities. The negative impacts are compounded by the effects of poverty and social disadvantage such as an inability to save money or build up resources; incurring debts and taking out loans; and an inability to secure work due to disability, caring obligations or low education levels.

The relationship between a low income and poor health is strong, and is discussed in detail in the next chapter.

## 4.3 Being healthy

This section details the interrelationship between quality of life and physical and mental health and wellbeing, poverty, and social disadvantage. In particular it documents the impacts of the social determinants of physical and mental health, disadvantages that are created and exacerbated by inadequate access to health-related resources and the additional financial strains caused by poor health.

### Health and quality of life

When asked what they considered to be necessary for a good quality of life, many participants stated that good health was a significant factor. The following exemplifies these responses:

*I'd say, just keep going on like I am going and not getting any worse than I am. That's about all I'd say...just staying as it is and not getting any worse. I know I won't get any better, but as long as I don't get any worse.*

Wendy

*I'd like to be in less pain.*

Sam

*Generally we are happy because we are not sick.*

Marilyn

### 4.3.1 Social disadvantage and health

Participants demonstrate how the social determinants of health, such as a low income, housing stress, inadequate or inappropriate transport and inadequate access to health resources generate poor health, and visa versa. The interplay of poor health with disadvantage is evident in these findings.

#### A low income and mental health

Struggling to live on a low income can have a direct negative impact on people's mental health, for example:

*At the moment I'm pretty vulnerable, it doesn't take much to upset me. Since I've been homeless, and no job, it gets to me, it doesn't take much to make me snap. I've got lots of personal crap to get out of. I know I've got to get myself out of it. When you get in a slump it's really hard to get out of it. I get help from Mission all the time, when I get down I go and see the counsellors, and get help.*

Dean

### **Housing stress and mental health**

Alma is elderly and lives in an independent living unit, in a complex that provides most of her meals and covers the cost of electricity. Her story provides an example of the significant impact that financial pressures can have on a person's mental health.

*We came and had a look and I put my name down at the council, because the council owns these...I think we are self sufficient here, with our fees and our board and lodging sort of thing. Oh no, it broke my heart to give my little unit up, actually I wished to die, I didn't want to keep living...I was actually looking for ways to, what I could do to die, just to myself you know, I just, yeah, sat thinking "what can I do, which way can I do it", yeah, I was at that point. I came here and I thought the world is going to end, I didn't want to wake up in the morning, ever. Because I didn't think I was ever going to be able to afford it. Because I'm solely dependent on the pension, not a halfpenny anywhere, and with 85% of your pension taken for board...this is different to living here than to living in a nursing home. Because in a nursing home you just pay your 85% of the pension and then you - that's it. But here, we have a fair amount of expenses besides. We have all our cleaning things, all our washing stuff, anything we need in the kitchen, we have all that besides.*

Alma

### **Insufficient and inappropriate transport services and health**

In many rural areas people reported very inadequate, unsuitable and/or costly transport services. This was particularly the case for people who had significant

physical disabilities. Vonnie's situation highlights some of the issues for rural community care clients:

*When my husband was better I used to go to the pool...but to get there, talk about a hassle. I rang [the closest large town], they have a bus for wheelchairs, but they said they don't come this far, and [a town in the other direction] don't come this far either, so where does that leave us? In no man's land. I've been ringing anyone and everyone, including politicians...Red Cross and transport commission, then I went back to the place where the pool was and said what if I pay for the bus to come out and they said they only go to the municipal boundary, but that's only 3km from here! In the end I paid \$10 up and down and they picked us up.*

*Then I thought my husband should go to the day centre, but then how to get there? I talked to Community Options and she said "look we will pay for the taxi if that is the only way you can get there", so that was really good they paid for the special taxi. They've got a bus in [a large town near by], a transport bus for people who need it, so I thought "ok let's use that". But it's just not suitable for him. At the end of the bus they've got a seat and you can put the wheelchair next to it and then you have to slide onto the narrow seat, everyone got a shock, it was not safe. I mean the government pays a lot of money for transport, but it's not the right sort of transport. Like this bus, it's a great bus, for people who can't walk very well it picks them up, takes them shopping then picks them up again, its great for those people but my husband just doesn't fall into that category. I suppose it comes down to the point that he should be in a rest home, but we chose not to. Everyone suggests staying home...it made such a difference when he came home, nobody could believe how he picked up.*

Vonnie

A couple who live in a remote area on the NW coast highlight the difficulties associated with transport to Burnie and Launceston for specialist medical treatment:

*We're waiting on a [Housing Tasmania] transfer from here to go to Devonport, because it's a lot easier to get to medical treatment in Launceston, where we have to go a lot. Sometimes we'll have an appointment at Burnie, but with all the road works it's a nightmare. But in Devonport, the road works aren't as bad. The specialists are in Launceston. Its just too far. We'll probably drive ourselves to Launceston, but we have to work out how to get there. Its about \$40 to Launceston and then you get some back when you've been to the doctor. I used it twice a long time ago. You don't get all of it back, you get about \$20. If I drive myself it would probably be cheaper. You need a car around here – there is no public transport, no buses, only taxis.*

Kaye and Peter

### **Access to health resources**

Participants who have access to services that assist them to maintain good physical and mental health and wellbeing demonstrate that this has various positive effects. For example:

*If I needed a nurse or a cleaner tomorrow they would be in here straight away, they're very good. When I went into hospital they got an alarm for Doug, and someone to help. There was no rigmarole, I just went in and they said Doug will need this, this and this. They even offer to give you more hours than you ask for.*

Sue

However, many participants have difficulties accessing health resources, in particular transport services, financial assistance and some community care services, and these problems diminish their quality of life.

The ability to access some health resources was dependent on participants' capacity to pay. Assistance to meet costs, or exemptions from costs, were effective means of overcoming cost barriers. The HACC fee waiver option is one example:

*I've got a waiver with the nurses, that's very good, I couldn't have them if I didn't, I just couldn't have them. I definitely couldn't have them, my money just wouldn't go around to that.*

Alma

*It was the way three to four years ago that I might have had to go into a nursing home. I was too young to go, but they've still got me on the books. But now I have the nurses and carers coming in – they help out with cleaning, my shower, without them I wouldn't be able to live at home. I've got a waiver for that, we've just updated that. They come and review me. I had to ask for it, I've used an Advocate to do that, she helps me organise it and we usually get it for a couple of years.*

Charles

The low fee structure of the HACC Program was also valued:

*With the HACC services...I'm happy with what I'm getting, because I pay \$40 a month, and with all the time they give me, I think that's nothing, and I couldn't live without it, so I have no complaints at all.*

Vonnie

For some, obtaining financial assistance for medical costs through Centrelink was a difficult process. However, with a diagnosis the process is easier:

*If you are diagnosed with one of the recognised disorders, then you basically jump 27 pages on the forms.*

Roger

Some participants reported that in their local area they had access to good health services, such as GPs and community care services. But not was not the case in other areas. Sue had contrasting experiences in two locations:

*It's easier here in some ways than in other places, because the community is pretty well set up. You have access to things a lot quicker than you do say in Kingston or Launceston – home care, nursing, things like that. I had my knee operated on and I stayed*

*with my son in Kingston and I had to see a GP about my knee. And I couldn't get to see one there for love or money. Even the health centre was closed, so that put us off a lot. Even here, if there is no doctor, there are other medical staff available.*

Sue

Some younger people with disabilities think there are insufficient services for younger people, but an abundance of services for older people:

*I'm sick of the government saying "old and frail", and "young people with a disability", because people my age, once I got above the age to ask for help, no one's got any money for me. My father, it's great, he's going out for respite and to the movies and to comedy shows, he gets there because he's above 60. So the government is saying they are all for carers and disability, and thank God they have improved some things for parents with children with disabilities and for seniors, but when they are saying other people with disabilities, I don't get anything.*

Roger

### **4.3.2 The financial impacts of poor health**

Many people have high material costs associated with health needs, and the inability to afford these impacts negatively on their quality of life.

#### **Equipment**

The costs of some pieces of equipment are beyond the capacity of many people on low incomes. In particular, people have difficulty affording expensive equipment that is not available under government funded equipment loan schemes, such as replacement spare parts and batteries for motorised wheelchairs. The following statements demonstrate the impact of these costs on people's lives:

*The two batteries for the chair cost \$200 each, and then the tyres are \$1000, so I think the government could do more for equipment, it's a lot of money...when you get these sorts of costs, plus other sorts of equipment that he's got, well you have to provide for that. You can't say to someone I'll give you \$100*

*now and \$100 in a month, you need the batteries now. I think a lot of people in my situation are finding that the equipment situation is not sufficient. The maintenance on these wheelchairs is like the maintenance on a car.*

Wynn

*The only thing sometimes is when we have equipment from the equipment hire, and see...any repairs and maintenance is without me having to pay, but the parts I have to pay for. I find that a bit distressing. My husband has a mattress that alternates pressure, and the motor needs some work and we pay for that. And then it's always that there is not enough money, and then you have to wait. For instance, we need a new commode chair for showering, it's all such a rigmarole, you have to go through the OT, then it goes to the Department, then you have a meeting to see if it is necessary, and then you have to find a tradesman to do the job, or a supplier. Sometimes I have to wait for 3 months for the simplest thing...I think if my husband was in a nursing home then all that equipment would be there, I suppose.*

*Any batteries [for the hoist] they are \$100, all these things, in the end, I think if my husband wouldn't be home, then I wouldn't have to pay for it. We have a chair, another chair, first I went to equipment hire and I thought it was absolutely necessary and so it went on the list and I thought well we might wait a year, and we might not even get it, so I thought we'll just have to buy it ourselves. Because my husband is so tired in his ordinary little chair, which we bought ourselves as well, he can't sit up for long, he needs a chair where he can recline and the way he is, we can't do anything anyway, the only thing we can do is go and sit outside, but in the chair he gets too tired. But if we have this other chair he can lie back, so I decided we will buy it ourselves. But then we had this lady, Community Options, she could see that it was really needed, so she talked with her superior and they offered to go halves in the price, so that's good, because the chair is \$3700, so you know it turns into large numbers.*

Vonnie

*I'm on the Commonwealth Equipment Scheme, but I've still got to pay for the batteries for the scooter and the tyres, money is really, really tight, I don't have much for any incidentals. I can't save any money.*

Charles

Carol borrowed money from a friend to buy a walker that was not covered by a government subsidy:

*No, I had to save up \$244 for that walker, the government couldn't help, actually I'm still paying that back because a friend lent it to me, because his dad died. That's disgusting how the government can't help you. He's been letting me pay off \$20 a fortnight, that's paying back without taking a big bite of your pension.*

Carol

People who were reliant on continence aids found these costs particularly steep:

*Also my husband is with the incontinence scheme, uro-sheath and urinary bags. The Government pays up to \$500 a year, but that's been changed I hear, I think it's \$430 then everything you need comes out of your own pocket. I don't know if that's going to work, because with the \$500 a year I pay also \$500. I pay half, we often need more. I mean, that is a dear expense, and they are things which are absolutely needed, you can't do without.*

Vonnie

*With what I have to pay out it's easy to demonstrate that I need it. I have a supra pubic catheter, I have extra medical supplies, I've got to have pads, catheters, leg bags and all that sort of thing. After the costs are covered you have to start forking out – it lasts about 3 months, \$470 odd dollars, and I've used that all up.*

Charles

## Medications

The costs of medications, both prescription and non-prescription, create significant financial difficulties for many people. The inadequacy of both Centrelink pharmaceutical payments and the pharmaceutical safety net system are evident, as is the impact of the seemingly insignificant cost of a Webster Pack.

*I pay \$50 a fortnight for the chemist. That's on top of the safety net I've already reached by April or May each year. My sleeping tablets aren't covered, and the creams and lotions, all that sort of thing.*

Charles

*A lot of our outgoing costs are with my illness and with my medications, about \$70 a fortnight even with concessions, and with the gaps with psychologists or doctors, and the private medical insurance. We are very, very tight on Centrelink.*

Roger

*My money it just hardly covers me for my tablets, I'm on a lot of tablets, I take 18 a day, and I am on the safety net at the moment and I reached that in the beginning of July, but I'm on a cancer tablet...I have to take 5 white tablets and I was doing my own because I couldn't afford the Webster pack at the chemist, but when it came to the 5 white ones I was getting a bit confused, and they all looked the same, and I thought I could be taking 2 heart ones. So I thought no, I better get the Webster pack and I've had it all this year. I have a lot of trouble with the Webster pack. It costs \$4.90 to put the tablets in, and then it costs \$6.90 to make up the bill for the month, yes, and besides that when I was getting the bill I was paying sometimes \$20 and I'd query it and they'd say leave it with us and we'll work it out, and we'll give you a ring. Well they wouldn't ring, and I'd have to ring and then they decided why I was being charged more was because when they open a new box of my tablets or anything that was going down as \$4.90. I said I'm on the free list now, but I'm not benefiting from it. The Government gave us \$500 back in*

*July, and do you know what? That got me out of debt for the chemist, that's how much I owed the chemist. That was a godsend, I was free of debt. It's awful owing money that you know you can't pay. I'm waiting to get my next bill, I'm waiting to see if they can fix it. I said I can do without all this worry....I think I would knock off the Webster pack and keep all my tablets here, I'm not going to charge myself \$4.90 to open a box. But then I think, well, I can't do that because I'll get them mixed up again.*

Alma

### **General practitioners, medical specialists and dental care**

The costs associated with visits to a general practitioner (GP) were raised by many participants, in particular, meeting the gap costs for non bulk-billing GPs, and the difficulty of finding a bulk-billing GP.

*Yesterday they ended up quite crabby with me because you're meant to pay the \$36 up front, so that would have been nearly \$70 for the two of us to see the doctor. I said look, I had a fifty dollar note and I said this is all I've got for a fortnight can I pay the \$15 gap instead of going into Medicare because I still have to buy medications. She was horrible, she said 'I'll let you do it' but they only let you do it once.*

Lyn

*I don't think that as a pensioner I should be expected to cover the gap between what the GP charges and what Medicare pays. I don't want to change to a bulk-billing doctor, I like my doctor and I feel comfortable there. I don't want to change, but it's expensive.*

Polly

The costs of specialist para-medical and medical assistance contributes to many people's financial difficulties, for example:

*Because of our illnesses and everything, we've never been financially well off. We've really struggled...because of the stage in our son's life he was still getting diagnosed and we were still getting him help privately. He was going to a physio on a*

*Monday and speech therapy on Tuesday and Thursday. He's been through a lot...Someone from HACC came around and listened to our story and my wife was then put on the Carer Payment for being my carer. It would have made a bit of difference to our lives and to the strain if we had been told about that four years ago. It's extra money and you're not always told, it seems a lot of hard work to apply for it. Medicare started this year where they didn't really advertise it, it was only that we heard a rumor about it, and we investigated it, that if you got a referral form the GP then the GP passed that onto Medicare and they gave you seven visits to the psychologist, but it wasn't very well advertised, but that helps towards the consults.*

Roger

The costs of GPs and specialists deterred some participants from using these medical services:

*I tend not to go to the GP unless I really need to, because I have to pay for it. There's not many that bulk-bill around here, I did try to get into one health centre, but they weren't taking new patients.*

Dianna

*It's very expensive to go to the specialist doctor, so I just don't go. I just wait until something really bad happens. Especially in Tasmania, there are so few of them.*

Paula

Dental costs were also raised as a concern for many people:

*I meant to go back and have a crown in my tooth and that will cost \$600-800...about two or three years ago. I haven't even had a chance to save money for that...He said it would have to be done privately...I thought well if it fell out then it fell out.*

Lyn

*If you go to the private dentist you have to pay \$600 out of the pocket, why? If you want to go to the Government dentist you have to wait 2-3 years, why?*

Sara

### **Private health cover**

A number of participants stated that they were unable to afford private health insurance, so it was not an option:

*I haven't got private health insurance because on the pension you just can't afford it. And really, when you cut through the media hype, the chances of you having to use it would be quite slim. You would never be left high and dry.*

Barbara

However, some participants felt that the public health system was unable to adequately meet their needs, and that it was essential for them to pay private health care insurance. The costs of the insurance, including the costs of services not covered by particular schemes, was raised. The following examples highlight these issues:

*I went to the private hospital, but it costs a lot of money, it's very bad, we can't do it, we are pensioners. We have private health insurance, but it doesn't cover everything. Even with cover, it's very expensive. I went there one time and it was nearly \$2000. Just for the specialist, I had full hospital cover, all the \$2000 was for the specialist. We are pensioners, I said we can't do it. It's not good. I showed them the pension card and they said it doesn't matter. We went to the dentist last week and we paid a lot of money. It paid some, it was \$485 dollars and MBF paid half. I go to the specialist for the gums, and I don't get anything back. That's why we keep a little bit of money for when we need it. We went to the private emergency, \$150 for nothing, that's very bad. They have to work that out.*

Rosa

*Private medical insurance...unfortunately it puts a financial strain on us, but because of my problems and the surgery I've*

*had to had I've had to go private, because the public system just isn't the right place for me. With my problems I don't fit in the normal kind of small boxes. We actually ended up going bankrupt because, even with 15 doctors' letters that my wife suffered from this particular condition, the insurance company decided they would call it pre-existing, so we ended up bankrupt over \$37 000, and high proportion of that was hospital fees. That put a strain on things.*

Roger

*We need a special discount for private health insurance, for pensioners. Private health insurance is very essential, if you don't have it you have to wait such a very long time for operations. When you have the insurance you can get the operation straight away. But it's very expensive, there is no discount for pensioners.*

Lillian

### **4.3.3 Mental wellbeing**

Alongside the financial costs associated with health problems are the costs to people's mental health and wellbeing. Poor physical health, poverty and social disadvantage interact with people's mental health and sense of wellbeing.

#### **Physical health and mental wellbeing**

Participants made direct links between their physical health problems and their mental health, for example:

*Since my accident I'm just trying to keep myself above water, it is hard, but I try not to let myself go down, get into any, like you hear of people going into a real depression, I try not to let myself get into that. There's only me, but that's the way it is.*

William

*I don't get depressed, but I do get a bit fed up. And lately I've been really, really fed up. It's mainly to do with the health issues. That's the frustration.*

Sue

Roger has a disability that keeps him in bed for most of the day, and prevents him from working and being socially active:

*I hate the situation I'm in, it eats me out big time. Because this is not the life I wanted to provide my wife when I asked her to marry me, and it's not the life I wanted for my kids, not what I promised when they were born. So it eats me out.*

Roger

### **Traumatic life experiences**

Participants who had experienced traumatic events during their lives talked about the lasting damaging effect that these events have on their sense of wellbeing. The following examples are from older women who had been in violent relationships or who were abused as children:

*Then I broke up with my husband after 24 years together and that's when my health went down hill...He was overbearing, abusive, so when I moved out I had sexual assault counselling, and pain management counselling, I'm still going through that.*

Charmaine

*I'm on anxiety tablets, I get panic attacks and that. It's come from the violence, and being by myself. I was literally bashed to within an inch of dying. If I'm not on the tablets I'm a rambling mess, I've got to be on them.*

Sharee

*I'm trying to deal with being abused as a kid now, through Victims of Crime. He got charged, but he didn't go to jail. But you have to go to victims of crime within 3 years, you can apply for an extension of time, but they reckon because I'm not a drug addict or alcoholic it didn't affect me enough - but if only they knew.*

Naomi

#### **4.3.4 Conclusion**

A good quality of life is influenced by good health and wellbeing. However, good health and wellbeing is elusive for many people, in part due to the negative impacts of the social determinants of health - such as a low income, poor housing or housing stress, inadequate or inappropriate transport and difficulty accessing health services. This research demonstrates the adverse affects of these determinants on both physical and mental health. Poverty and social disadvantage is further exacerbated by the associated costs of poor health, both physical and mental, in particular the cost of equipment, specialist services, medications and private health insurance costs.

## 4.4 Being part of a community

Interacting and connecting with people and feeling part of a community are important elements of a good quality of life. Conversely, social isolation and feeling disconnected from people and communities are highly undesirable situations for many people. Feeling a part of a community is not simply about having contact with people, it is also about feeling that you have a legitimate contribution to make and that you are respected, whether through paid employment or other means. This chapter focuses on the inter-relationships between poverty and social disadvantage and feeling isolated or disconnected from people and the broader community.

### **Social participation, company and quality of life**

According to many participants in this research, having good relationships with family and friends, keeping company with others, having a job, feeling supported and able to give support in return are essential components of a good quality of life. Associated with this is the need for social activities:

*And I'd love company, play cards, talk to them, play different games ...*

Carol

*A good quality of life is someone to say "I love you", a happy family, I couldn't say money, 'cause to me it wouldn't, because if you had money everyone else would be wanting it, and you wouldn't know who was your friend or not. I know it sounds odd, but that's it.*

Sophie

*Happiness, family, knowing you can go to them for support. Friends, not be afraid to ask for help if you need it. Being loved.*

Lyn

*You need things that people in their own homes can go to, like day centres, they have some but only so many people can go there. What they haven't got is things for people who are in between, not the kids, but the 20-30 year olds, they are the ones that are in the lost stage. They just sit at home, or wander the*

*streets. So many can go to St Vincent's or things like that, but they're not catching the rest of them.*

Lena

*Get a job. At the moment, just a part time job, I don't mind part time or casual. A licence too would be good.*

Jay

#### **4.4.1 Social isolation**

Social isolation and social exclusion are closely linked: those most at risk of isolation are people who are socially excluded, and those who are socially isolated are most at risk of social exclusion.<sup>40</sup>

There are many barriers that prevent people feeling socially connected, for example, inflexible or limited work options, inappropriate or inaccessible transport services, poor health, unaffordable social options, inappropriate streetscapes, prejudices against older people or people with disabilities, and perceptions of unsafe communities.

#### **Low income and isolation**

The cost of socialising also acts as a barrier to participation for people who cannot afford to pay for social activities. Many people cannot afford to go out with friends for dinner, to the movies or to any activities that incur a cost. (This issue is discussed in more detail in section 4.2 *Having enough money.*)

Alma's situation is particularly grim; she describes how being on the single person Age Pension and paying 85% of her income on her board means she cannot afford the smallest of social costs:

*You know you don't even have enough money to go and have a cup of coffee down the street. You just haven't. I think no, I can have a cup of coffee at home. You can't sit and have a cup of coffee. You don't have two dollars left over, sort of thing. You can't even go to anything that's only going to cost you five dollars, you can't go. It limits your outings. I go for little*

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<sup>40</sup> Wilkinson (2005) p18.

*walks, round here, but I don't socialise one bit. I would like to, but as I say, the funds, they don't meet it, you can't invent money, you can't stretch it.*

Alma

Low cost social activities, such as those funded by the HACC Program, provide affordable options for HACC eligible people, as typified by Rosa:

*We don't go to the restaurant, or anywhere for holidays, or anywhere because we keep the money for what we need. We might need the doctor, the dentist, or something, that's all. It just covers life, nothing more. We have a group at the Migrant Resource Centre, just ladies, we play Bingo, and every second week we go somewhere in the bus, have coffee, talk and that's all. It's good. It's free, from the government. We pay just five dollars a year for membership.*

Rosa

### **Health and isolation**

Poor health can have an effect on people's capacity to be socially active. Physical limitations can prevent people from participating in activities that do not accommodate for their health needs, or from being able to go to places that are physically inaccessible for people with disabilities. This can affect activities as basic as the shopping or travelling in a car, for example:

*I need [my husband], I wish him good luck, because I can't go to town, I can't go shopping, he does the driving, he takes me everywhere, to the supermarket. I don't do anything else because if I go for half an hour I'm tired and I feel very bad in my back. I can't stand up anymore.*

Rosa

*Travelling long distances in the car, or going around the town, well that's not easy, it is difficult. If I have to travel a long distance I have to take tablets...so I can have a few hours free from the loo...because I have to use the machine, the hoist, the lifting machine.*

Wendy

## **Transport and isolation**

Inadequate and inappropriate transport prevents people from leaving their homes to socialise or participate in the community. Transport problems are not limited to rural areas, although they are felt keenly in smaller and remote towns, they also affect people in urban areas who are unable to use public transport or afford taxis. The main transport issues raised by participants in this research include affordability, suitability for disabilities or physical frailty, flexible time scheduling and the suitability of transport routes.

The following examples demonstrate a lack of affordable and suitable transport in rural areas:

*At one stage I was hitching 24 kilometres to get to care for Mum each day and back again – I couldn't get a house in the area.*

Janet

*I know a bloke who hitchhikes into Launceston to pick up his three year old so that he can afford to bring the two of them back on the bus.*

Kerry

*There is no bus service up here. It's hard for me being a bit out of town because I can't drive, I've got my learner's, but that's as far as it's got. I've got my mother-in-law just down the road. She gives me a lift when I need it, and my friend gives me a lift. I do my shopping on the weekend when my husband is around, and my mother-in-law usually drives in every day. I rely on a lot of people and I don't like that. Money goes to food and petrol mainly. It's a lot more expensive up here than in New Norfolk. We mostly go to New Norfolk once a fortnight or a week. Some people go to New Norfolk just to get petrol cause it cheaper. My husband spends \$200 a week on petrol, and he only gets paid fortnightly.*

Jay

Community transport has great benefits for those who are eligible, but is principally provided for trips for medical purposes:

*There is a community car here now and a small bus, and you can use it for any appointments like the dentist or doctor. You can use it if you really need a lift.*

Colleen

### **Employment and social contact**

Being employed not only brings additional financial benefits (as discussed in section 4.2 *Having enough money*) it also enables people to interact with other people and to make a contribution in the community. For many people it is the social interaction and contribution elements of employment that create a good quality of life:

*I'd like a job where you get to know a lot of people. I have to do work for the dole. I'm volunteering [in a neighbourhood house program] and so they allowed me to do that for the work for the dole. Because of my age I only have to do six hours a week, but I do a lot more than that, I've probably already got my hours up. It's something for the community, I've got to know a lot of people, a lot of people respect me, I respect them.*

Sharee

### **Physical impediments to social contact**

Streetscapes with curbs that are suitable for walkers and wheelchairs play an important role in facilitating people's social involvement. Wendy is not able to travel long distances, but can get about in her own small town in a motorised wheelchair:

*You can get out along the street because the streets have been all done up and it's quite easy.*

Wendy

In contrast, an unsuitable streetscape caused an injury that had put her out of action for a long time:

*I got tipped out of my wheelchair in Launceston one day, and got the back of my leg pinched there, I had to go to doctors in*

*Deloraine and Launceston for 12 months to have it treated and dressed every day.*

Wendy

Sue and Doug value being able to get down the street also, and in their case it is more important than moving near to family where the streets are not age- or disability-friendly:

*Our son wanted us to move down to where he is, but what's there? At least here Doug can go down the street in his electric scooter.*

Sue

### **Stigma and isolation**

Discrimination also prevents people from social engagement. Disrespectful attitudes towards elderly people, people with a mental illness, or people with a disability were raised by participants as isolating factors. For example, Barbara is an elderly woman who has had a mental illness for most of her life:

*The social stigma many of us by and large still have to put up with is terrible. People in general, say, they might keep you waiting 10-15 minutes in a conversation with someone else, in a public gathering say. I will engage myself with someone in a conversation and they'll talk for ages with another person, and I wait for ever to say what I want to say and then they will dismiss it straight away. Even people in the Catholic church are like that, not all of them, but some of them. It shouldn't be happening in the 21<sup>st</sup> century.*

Barbara

### **Friends and kin**

Not having friends or good relationships with family can be debilitating for people. Some participants described how depressing it was to feel they had no one to talk to, for example:

*Friends, I virtually haven't got any that I can go and talk to, I say hello to people in the street, but nothing else. A couple of months ago I was really, really down.*

Janet

Some people are isolated from their family in spite of them living in close proximity; the close location of family is not always a guarantee of their contact, company or support:

*Our son is in NSW, but the girls are in Tassie...one is very close by, but I see her perhaps once every 6 weeks, which is a bit disturbing because she only lives 2 minutes away. I know they are busy, when you have your own children...it's easy to make an excuse, but I don't think it counts when you live 2 minutes away. I just try not to worry about it. A few times I've said something, but I think, no, it's not worth destroying the relationship. But the others are a help, if they can make it.*

Vonnie

### **Feeling unsafe**

A willingness to participate in the community is also dependent on feeling safe in the community. The majority of people state that they feel safe in their communities, but others feel as Sally does, that their neighbourhood is an unsafe environment, and this impacts on their willingness to leave their homes:

*There's a lot of elderly people that won't open their doors to people because they don't feel safe...I don't feel safe, I double lock my doors at night.*

Sally

### **4.4.2 Reciprocity**

Being able to give something back to the community is an enabler to feeling a valued member of a community. Paid employment is one means of contributing, but many people who are not in paid employment contribute in other ways, for example volunteering for organisations and providing care for friends, family, neighbours and others. Some participants were very active, regardless of age or disability:

*I do four full days volunteering...It's not paid, but I'm just pleased to be able to do something for the community. Having a coffee at the centre is like payment for me.*

Jan

*I work at the Bowls Club, I'm on the executive of the Health Group, I'm on the committee of the Bowls Club and the Housing group.*

Betty

*I run the Girl Guides, and I've just joined the Lions Club.*

Liz

*I think there are not enough hours in the day - you have to put yourselves out there and get involved in things. Anyone that comes into this town I say "it's up to you, you either like it, or you don't, it's up to you".*

Erica

*We seem to raise more money for charity than we do for ourselves. There are 2 service clubs on the peninsula and they have helped a lot of people over the years - \$19,000 to \$20,000 is raised by the Lions Club each year.*

Noel

Many neighbourhood houses that provide services for people on a low income, also provide the opportunity for people to be actively engaged in running those services:

*I like to be involved, like the International Women's Day, just helping out. I got on the stage, introduced people.*

Naomi

However, people are aware of the pressure that sometimes comes with volunteering, due to a high workload and level of responsibility with some types of work. Providing transport services is one example:

*The transport is only as good as the volunteers. It seems to be round here you get a new volunteer and they are keen and they volunteer for everything, and they get asked. Then they're working full time and they burn themselves out and they say*

*they're not doing it anymore, and then you're down to no one again. It seems like they burn them out.*

Sue

### **Reciprocity and the HACC Program**

For many HACC clients, their chief interaction with other people is through contact with HACC employees and volunteers, as is the case with Vonnie:

*We had so many friends, but I look now and say "where are they now? Why don't they come?" One or two still come and I really appreciate those people, they come and they care. It's the same with the girls that come from HACC, they really care, it's not just a job. I can't expect them to get too involved in our lives, but you know they care. One said to me, "I look after your husband like I would look after my Dad".*

Vonnie

However, as Lena describes, sometimes people feel awkward about receiving a lot of care, without being able to do anything in return:

*I got to the stage when I felt really bad about the people coming in doing things for me, because they come in the evenings when I think they should be home cooking tea for their own families, and in the winter they have to come out of their nice warm homes. It can be quite late too, to put me to bed. But they tell me not to be silly, but sometimes when you're here by yourself you think, "oh I hate putting people out".*

Lena

Reciprocating enables people to feel easier about receiving assistance, and it also facilitates social activity. There are many ways that people reciprocate the informal assistance they get from family members, for example, by looking after grandchildren, neighbours or cooking for other family members:

*Things look very positive. I think if I can help someone like [my neighbour]...you can't be such a bad person.*

Jeannie

*I cook for my son in big lots, I make up casseroles with mince or sausages, and I send them into my son to help out because he's badly depressed and can't work, and she's working at McDonalds, and 4 kids, so he's just got to get it out of the freezer and sit it on the bench then heat it up. I might have corn coming in my hampers, and I was going to swap it, but I'll put it away for the casseroles.*

Carol

Reciprocity is also about balancing the amount of care received and given:

*You know we have very good and fine children, and when we have some problems and they see, they want to help us. And we don't feel we are unhappy. But we, we help them too. For example, my son and daughter-in-law are very busy and they have a lot of shirts and trousers. I go to their house and iron everything. It goes this way and that way, this is good, and if he needs help I say "of course" and I go there. We have lived here for 4 years, and in all this time we help them. It's not much, he helps more, but we can cook dinner, or breakfast, and we call them to come around. It's a good arrangement, a balance, there is a balance between us.*

Michael and Ila

People also use formal systems to enable them to reciprocate the help they receive. For example, Dan uses formal respite services for his adult daughter with disabilities, and is also a host himself, providing weekend respite for young adults:

*We are also a host family ourselves for a child with Down Syndrome. One of the reasons is because our daughter is an only child and we thought she needed to learn to share and so on, apart from the fact that the family were quite desperate for respite.*

Dan

### **4.4.3 Conclusion**

Feeling that you are a respected and valued member of a community is an important factor for a good quality of life. The reverse – feeling isolated, disconnected and stigmatised – diminishes quality. Some barriers to feeling part of a community are related to a low income, which can prevent people from participating in activities that are costly. Other structural barriers also prevent interaction, such as inadequate facilities for people with disabilities, inappropriate transport or poor streetscapes. Less tangible factors also prevent people from feeling part of a community, such as discrimination, loneliness and feeling unsafe.

An important component of social engagement is equity in relationships, that is, an even power balance between people. For HACC clients, a power imbalance arises as a result of the lack of opportunities for care receivers to reciprocate to care givers. When people are able to give something back in return for help they receive, the care becomes less like a 'handout' and the power imbalance shifts to a more equitable and comfortable position.

## 4.5 Having enough time

This chapter focuses on the relationships between quality of life, having time for rest, relaxation and self-care. Participants stated they did not have enough time to do the things they would like and to look after themselves as they need. Not having enough time is partly about a need for rest and relaxation and the barriers to leisure time, but also includes not having enough regular time to spend with loved ones. For many people the barriers to rest, relaxation, self-care and family time arise from their heavy caring responsibilities, and for others they include poor health, a low income and the demands of low paying employment.

### **Time and quality of life**

Some people interviewed stated that what they need for a good quality of life is more time. For some this meant time to themselves, or a break from their caring and working responsibilities, for others it meant time to be with family.

For example, Sam is a single parent who cares for her two children with disabilities, she states a quality of life is:

*Time for Sam. Most of my life has been just doing things for the kids, you know what I mean, and now they are in full time school I have a bit of time to do some things for me, and get a better balance, that's quality of life for me.*

Sam

Joanne, a single parent in a low paying job said that quality of life was restorative time for herself:

*Time for yourself – sort of self-preservation time.*

Joanne

And Jay, whose husband works long hours in a low-paying job, thinks that a good quality of life is to have time to do things as a family:

*To have more time with your family; my husband can't get time off. He will be working Christmas day and it's been like that for*

*the last 11 years. Sometimes he says he's just going to give up and not go, but...*

Jay

#### **4.5.1 Caring responsibilities**

Carers in particular feel they need more time to look after themselves, and to have a break from what can be a demanding, constant, physically heavy and mentally draining role, as the following situations illustrate:

*I am always amongst somebody in the family, I don't get five seconds break because of having to look after both my mum and my husband, and still one child home from school. I can't drop them on anyone's doorstep and go.*

Janet

*Well, it involves 24 hours per day really, because he's been classified as highly dependent, because nothing really works for him. I go once a week to art classes, and I can feel that helps, you need a break.*

Vonnie

*My mother has dementia, and is in a nursing home. There is no way I could look after her, you'd have to have a 24 hour nurse to look after her. My late step-father he had to look after her for the first few years, and that was really bad for him. She'd wake up and want to go for a walk in the middle of the night, and he'd have to walk with her.*

William

An additional burden on some carers is the sense that the community health nurses and others who are assisting them are stretched and unable to provide extra cover if the carer needs a break:

*I know the nurses...they are very busy, they always have many people to see, and no one to replace them when they are sick.*

Vonnie

## **Impact of constant caring on mental health**

Some participants described how not taking a break from caring can have bad effects on health and wellbeing:

*I was a carer for my mother for 5-6 years, she passed away and I absolutely lost the plot, hit the bottle, and I just lost everything and at the age of 45 ended up on the streets with not a cracker in my pocket. It was a bit of an eye opener. I got good support as a carer at the very end, but it was far too late. I didn't know it was around until right near the end, and that was far too late. I had people ringing up after she died telling me I could have respite and windows cleaned. I really did need some respite occasionally, at one stage I was showering her every day, then the nurses came and helped. Some people in the caring industry they do a bloody great job, I know what it's like, I was doing it 24/7. It gets to you, it really gets to you in the end. It broke me, I think I was a pretty tough bastard, but it broke me.*

Dean

### **4.5.2 Unable to take a break**

Being able to take time off to recuperate or rest is not possible for many people. The carers in this research talked about a range of barriers that prevented them from taking a break.

#### **Respite**

Vonnie is concerned that out-of-home respite care is not as high quality as the care that she and community care workers provide at home, chiefly because of the time constraints on workers in respite services. This makes her, like others, reluctant to use respite services:

*There is respite close, but I don't feel happy going there. I think if I really badly need it then I would rather have someone come in the house. I've seen my husband need that much attention that people just can't give him that, he needs continuous help and because he doesn't quite look, well at the moment he does look tired, he doesn't come across like that and...to eat breakfast*

*takes about an hour and it's too much to ask, even in a nursing home. And the showering, it's over two and a half hours in the morning, and if I were to take him to a nursing home...I'd be sitting here worrying about what was going on, I wouldn't be having a break.*

Vonnie

Dan's reluctance to use respite was due to the inadequate gender mix of staff that he had encountered at his adult daughter's respite service:

*We went to drop our daughter off at respite the other weekend...but when we went in, we noticed that the place was full of much older men, and no female carers at all. Our daughter threw a huge tantrum and there was no way she was going to stay there. It was an incredible tantrum. Fortunately we had organised for a friend to be a backup. There was no way that she would be able to survive that weekend, and we complained bitterly about it. A place full of old men.*

Dan

In-home or out-of-home respite services are not always readily available. Roger was frustrated about what he sees as a mismatch between rhetoric about looking after yourself and the lack of respite services for carers:

*I got annoyed because they produce all these big packages about carers, and my wife has walked away once when it all got too much, she was crook and she just couldn't handle it. We got all this information saying 'have a break' and all that, but nobody has anything set up for her to go and have a break. She just needed to get out of the situation for a couple of days, and have a rest. They reckon they've got all this stuff out there but there was nothing. Don't get me wrong, I'm very appreciative of the help we get, but when they spend all this money on big packages and give you all these numbers to ring and then they can't help you, it's no good.*

Roger

### **Demanding work arrangements**

Another obstacle that prevents carers from having time off is the complicated, overlapping working arrangements that many people have, to accommodate their caring obligations and earning an income. Many people need to work weekends, evenings or nights, which cuts into potential leisure time. John, for example, describes how he and his wife organise their work to enable one person to care for their adult daughter whilst still earning money to pay for their special purpose house:

*My wife works Saturday, Sunday, Monday, Tuesday and I work Monday to Friday...because although she is an adult, intellectually she is five. If you left a five year old alone at home people would be bashing on the door. We get a carer in for a few hours on Saturday afternoon in the summer so I can play bowls. I would like to have a few hours on a Sunday, but you just can't. It's just the way it is.*

John

Other people are working long hours in employment that is poorly paid, in order to make an income that is sufficient to meet their needs. For some this means working during holiday periods which impacts on the capacity for people to spend time with family.

### **Insufficient money**

An additional barrier to being able to take time off is the cost of using respite care, and/or of having a holiday. (This is discussed in more detail in section 4.2 *Having enough money.*)

*People say, "why don't you use the respite for the kids, have them go and stay somewhere one night". But you have to pay \$50 a kid, imagine what that would cost me [with a few children]? Just for one night's break.*

Naomi

People who rely solely on government income support payments are generally unable to afford to travel:

*If we had the money, we'd love to go over to the mainland to friends and family...If someone said here's x amount of dollars to go on a holiday, I'd take it.*

Kaye and Peter

*I think the invalid pension is a real killer like that, it doesn't allow you to do anything like that, or at least only with very, very great difficulty. And when I see other people without pensions, people in general, who are able to go overseas at any tick of the clock, it leaves a bit of a sour taste in my mouth, in terms of why they can do that and I can't.*

Barbara

### **Health constraints**

Further constraints on people being able to take a break are health issues that make it difficult for people to leave their homes or their daily routines. (This issue is discussed further in section 4.4.1 *Social Isolation*):

*There are other reasons why I can't [go on holidays] as well, one is the psychiatric disability. To go away it wouldn't be a good idea at all, I wouldn't feel safe, particularly in this day and age of terrorism. The [supported group] trips are quite different, you are in a group and they organise it all. They do a good job, they keep the costs to a minimum and we fundraise to get more money.*

Barbara

### **4.5.3 Conclusion**

Having enough time for oneself, for family or to take a break from caring responsibilities is an important enabler for a good quality of life. Caring responsibilities place high demands on people's time, and some carers are providing continuous heavy physical and emotional care for people, which is exhausting. Respite services are designed to give carers a break, but this research shows that respite can be unsuitable, unavailable or unaffordable for some people, and as a consequence these people do not get to take time off from caring. Being unable to take a break impacts negatively on many carers' mental health and wellbeing status, and lowers their quality of life.

It is not only caring obligations that limit people's capacity to take a break. For people on low incomes, the impacts of poverty and disadvantage mean that costs of travel, health constraints and/or demanding work arrangements also prevent them from having relaxation time. Without the health promoting activity of self-care and relaxation, the impacts of poverty and disadvantage are exacerbated.

## 4.6 Eating well

The importance of eating well and having adequate food is a consistent theme that emerges throughout this research. Many people regularly have insufficient money for enough good quality food. People in rural areas face particular challenges to eating well, principally due to less availability of affordable and quality food. Low rainfall, and the associated cost of buying water in rural areas, also limits people's capacity to grow their own food. This section details the issues raised in the research about the relationships between quality of life, poverty, social disadvantage and poor nutrition.

### **Eating well and quality of life**

A good quality of life for many people means not having to worry about being able to afford food. It means having good quality, nutritious food and having a choice of the types of food to eat. The following quotes illustrate this finding:

*I think, just to be able to wake up every morning and afford to pay your bills, buy food without too much of a worry, just live a comfortable sort of life without all that shit and worry. I'm not a greedy person, I wouldn't want to win lotto or anything, just to be able to go out and buy something, without having to worry about what you go without this week. That's all. Just live life like every other bugger should be able to. That's all I want.*

Dean

*Be able to eat what you want. "I'd like a rump steak tonight" - go out and buy a rump steak.*

Jeannie

*More food for the kids to take to school, and more choice with what to put on their sandwiches.*

Sophie

*If I had a job I would put more food in the cupboards.*

Jay

## 4.6.1 Difficulties affording food

### High costs

There was a general feeling that food prices had risen over recent times:

*I buy vegies and fruit each week, and prices just go up and up.*

Naomi

*I buy Homebrand Weetbix because they have folate and wheat and they are a really good basic food, but even the Homebrand used to be about two dollars for a pack of 24, but its up around three dollars. And cheese has gone up, I mean that's only two items, but they have risen quite a lot.*

Elaine

People stated that food prices rise at a higher rate than pension payment increases, making food less affordable:

*I don't think the pension goes up with prices, our pension might go up two percent, but food and petrol goes up ten percent.*

Sam

### Cutting back

People stated that they regularly went without food, or cut back on the amount they bought in order to make ends meet. For example, two elderly participants stated:

*I try not to eat too much, during the day, I have a good breakfast but then have a nice meal at night.*

William

*I can have white coffee until my milk runs out...then I can have black which I don't like very much...if your bread runs out it runs out...if you haven't got the money you can't buy it. I don't eat meat which is probably a saving, occasionally I will have some chicken.*

Sally

### **Taking out loans for food**

Some people take the option of the no-interest Centrelink loan, or borrow money from family, to stock up on food. For example:

*I used the Centrelink loan to buy food and things like that. I'm due in September and I'll get it to stock up my cupboards, bulk stuff and make it last as long as it can. My son's a big eater and I like to have food in there. At the moment the cupboards are a bit bare.*

Sharee

### **4.6.2 Foregoing quality**

Compromising on food quality is a common way that people living on low incomes stated they are able to meet living costs. David, Levi and Lora exemplify how costs are cut by making lower quality food choices:

*Bulk buy anything you can, don't buy the flashy cereals. Go to No Frills and Island State markets. Grow your own vegies. Eat a lot of canned food. A lot of frozen food. Eat out once every few months, just for a special occasion.*

David

*People eat a lot of pasta, rice and lamb's fry – God I love lamb's fry, it's one of the cheapest things in the supermarket. You go to the baker's and buy a bag of duck bread for two dollars, it's still good for toasting.*

Levi

*You don't go and buy all the very best, you buy Black and Gold – these are strategies that are not put to older and younger people enough.*

Lora

Alma's meals are provided where she lives, and she thinks the quality is compromised:

*No, [the meals] do leave something to be desired – quality. I think we get all the cheap food, we don't have any luxuries.*

Alma

### **Health impacts**

The long term impact on people's health of eating poor quality food is raised as an issues of concern by some participants:

*The thing is you tend to buy crap and then it effects your health and you end up paying out for that. You can't buy the healthy stuff, all the crap is cheap. The stuff that doesn't have much nutrition. We eat a lot of bread, which in the long run isn't really good for you.*

Levi

Physical difficulties can prevent people from being able to prepare fresh vegetables, and as a result some people choose frozen foods as a substitute:

*I eat vegetables and I do prefer fresh vegetables but I can't always stand long enough to do them so I have frozen ones...when my carer's here I get her to do some.*

Sally

### **4.6.3 Rural issues and food**

People in rural areas of Tasmania raised issues about the cost and availability of food in their towns. People feel that they pay higher prices for basic foods than are paid in the city, for example:

*The shop here is as dear as anything. What you pay for a three litre milk in [the next biggest town] you pay for a two litre one up here.*

Jay

*It's a lot dearer here than it is in Hobart – that's always been the same. A two litre bottle of milk is \$2.99 in town. Down here it costs \$4.50.*

Ella

*There are two supermarkets in town now. For a long while there was only one – it was a monopoly. There's 20 cents difference between them for the cost of milk. Cost of milk, butter, eggs is high.*

Sheila

Affordable good quality food, particularly fresh fruit and vegetables, is thought to be less available in rural areas:

*The price of fruit and vegies, it doesn't encourage people to buy it, they talk about all this health food stuff, but we haven't got a cheap place out here, we only have what we can get at Woolies.*

Scott

*Food is too expensive and not good quality. People [here] have a poor diet because they can't get reasonably priced fresh produce.*

Kylie

#### **Paying for water**

People in rural areas who need to buy tank water, state that this prevents them from offsetting high grocery costs by growing their own vegetables:

*You have to buy tank water down here. It's \$85 a tank. If you run out of water in the summer then there's no water for drinking or washing.*

Francis

*We can't afford to buy the water – it's \$200 to get the water a load – so I've stopped watering the garden so we can't grow vegies.*

Louise

#### **4.6.4 Using food vouchers**

Some participants used food vouchers when they were unable to afford to buy food, provided by community-based organisations. This generally occurred when large bills

needed to be paid, or unforeseen events depleted funds. For some, admitting that they need this assistance was humiliating and demeaning:

*The trouble with getting food vouchers, they ask so many questions, it's too embarrassing to even go for one now. It's 20 questions to get a food voucher now, they want receipts for everything, "what have you done with your money, how come you need a voucher?" I don't even bother now.*

Kim

#### **4.6.5 Conclusion**

Worrying about the prices of food, food quality and having enough food to eat contributes to a diminished quality of life for people who are socially disadvantaged and living on low incomes. Good nutrition is an important determinant of health, and a poor diet is a cause of poor physical and mental health and wellbeing. This research demonstrates that some people have a poor diet because they are unable to afford the cost of food when living on government income support payments, and that people go without food, or good quality food, in order to afford other basics. Thus, the impacts of poverty and social disadvantage can be exacerbated by the negative health effects of a diet low in nutritional value.

## 5. Implications for the HACC Program

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The HACC Program is well placed to assist in improving the quality of life for clients who are living in poverty and who are socially disadvantaged. Good foundations for such assistance are already laid in the accessible nature of the draft Fees Policy, the recognition of “financially disadvantaged people” as a special needs group, and the provision of funding for health promoting and socially inclusive programs such as social activities and transport services.

These research findings illuminate three specific ways in which the HACC program can further minimise disadvantage and improve quality of life, and each involve the continuation, modification or expansion of current services. These are, broadly:

- increasing the accessibility and uptake of the fee waiver option;
- broadening the scope of very low cost community care services to cover more services; and
- increasing the HACC Program’s focus on social inclusion through funding programs that create opportunities for reciprocity and community connectedness.

### 5.1 Waivers and Caps

The HACC Program has a sound draft Fees Policy that minimises the risks of creating additional hardship. This policy states that people can not be excluded from services because of an inability to pay, that fees for people on low incomes are to be capped and to include materials, and that clients have the right to appeal against an inappropriate fee determination. This research demonstrates that these measures are absolutely vital to people on low incomes, those who are most vulnerable to poor health and wellbeing. The association between poverty and poor health is in part due to foregoing health services due to cost. The costs incurred through poor health or disability can be high: equipment, medications and modifications, combined with an incapacity to work, all create financial burdens.

This research demonstrates that many people are embarrassed to admit they are unable to pay for services, and this prevents them from asking for fee exemptions. For some, there is also a reluctance to receive what is perceived as charity, because this admits a failure to cope.

For people who live on very low incomes, saving \$10 per week through a HACC fee waiver makes a significant difference – as participants said, *every little bit helps*. There is also a long term value in granting a fee waiver. When people are financially better off, their overall health and wellbeing improves, and thus the long term costs to community care are potentially lessened.

This research identifies potential HACC clients and existing clients who experience the most significant financial hardship and for whom fee waivers are a high priority. These are:

- people who are solely reliant on government income support payments such as the Age Pension, Carer Payment or Disability Support Pension;
- single pensioners without their own home or without income from any other source;
- people who have had a history of exploitation by partners or ex-partners; and
- people who have significant health needs, either for themselves or their dependents.

It is important that the HACC assessment process include an offer of a fee waiver, made with sensitivity to the possible negative impact that admission of need may have on a person's self-esteem. The draft Fees Policy stipulates that the actual fee waiver assessment also needs to be "simple, unobtrusive and confidential".

## 5.2 Broadening the scope of low cost options

Community care services that are exempt from fee capping and waivers are costly and can be either financially debilitating or unaffordable for people on low incomes. Transport services, equipment parts, modifications and continence aids are all essential for many people with disabilities and frail elderly people, however many are unable to afford them, and this impacts negatively on people's health and wellbeing and diminishes quality of life. Furthermore, people are forced to take out loans and incur debts in order to purchase these essentials, and as a consequence are placed in more financial difficulties, exacerbating the strain. By increasing the scope of HACC funded and subsidised services the positive impact of these low cost options will be greater.

## 5.3 Taking a Social Inclusion focus

### **Social engagement**

This research demonstrates that many HACC clients are socially excluded as a result of poor income, poor health, unemployment, caring obligations, inadequate transport, social isolation, or through feeling stigmatised. Often a combination of factors are evident.

Currently, the Tasmanian HACC Program funds programs which facilitate social options for the target population – and this is an acknowledgement that social engagement is essential for people’s health and wellbeing.<sup>41</sup> However, social inclusion is not just about being socially active, it is also about feeling valued, respected and dignified. There is ample evidence to support the statement that “being excluded from the life of society and treated as less than equal leads to worse health and greater risks of premature death.”<sup>42</sup> There is scope for the HACC Program to broaden and diversify the social supports that it currently provides and to move towards more actively facilitating genuine social inclusion.

For example, this research shows that one way people feel valued and respected is when they can make a contribution to the health and wellbeing of others and the community, whether within families or via more formal structures, such as participating in interest, sporting, cultural or political groups. Many older participants in this research spoke about their lifetime of opportunities to engage with others, for example, as children caring for adults, parents for children, friends for friends, or as work or social colleagues. These experiences are also consistent with discussions held at a forum for older people in Tasmania in 2007, where participants stated that they felt opportunities to contribute to their communities as they aged were vital.<sup>43</sup> However, as people age these opportunities appear to diminish.

One cause contributing to this decline in social engagement is the connotation that people who are ‘frail elderly’ are passive recipients of care, incapable of being contributors to the community themselves or active care givers.<sup>44</sup> Jeni Warburton

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<sup>41</sup> See, for example, Wilkinson (2005), and Davis (2008) p59.

<sup>42</sup> Wilkinson (2005) p23.

<sup>43</sup> TasCOSS, *Our Lives Our Future* (2007).

<sup>44</sup> The negative impact of ageism on social inclusion of elderly people is explored by Minichello et al (2000) who describe “society-wide forms of ageism” and the way these limit

states that it is critical to the health of communities that ageing be spoken about not in terms of economic costs or burden, but rather in terms of the positive social contributions that elderly people can and do make.<sup>45</sup> Another cause is that as people have less access to resources – material, economic and social, they are less likely to volunteer.<sup>46</sup>

The HACC Program has the capacity to resist ageist constructions of elderly people, and to facilitate opportunities for people on low incomes to continue to take an active and constructive role in the community.

### **Reciprocity**

Currently, the HACC Program policy direction is away from a model of passive dependence towards one of enhancing independence.<sup>47</sup> There is a large amount of research that supports this move, including past TasCOSS HACC consumer consultation project research. This is principally because it is accepted that, in general, people want to remain independent in their own homes as they age and if they have a disability. A move towards an independence focus can not only boost self-esteem, but can also provide opportunities for people to actively reciprocate the care that they receive, for example by providing opportunities to care or support other people.

An example of a successful reciprocity model is the Eden Alternative Aged Care programs, widespread across residential aged care services around the world. The Eden principles state: “to give care to another makes us stronger. To receive care gracefully is a pleasure and an art. A healthy human community promotes both of these virtues in its daily life, seeking always to balance one with the other.”<sup>48</sup>

Facilitating reciprocity also facilitates social inclusion, through social engagement and by providing opportunities for people to feel they not just receiving, but are offering needed services. To facilitate opportunities for reciprocity requires an increased focus not only on programs which enable social activity, but also on creating

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people’s involvement in society. They also cite literature that draws strong connections between ageism and widespread ill-health amongst elderly people, fuelling exclusion.

<sup>45</sup> Warburton (2005).

<sup>46</sup> Osbourne et al (2008) p119.

<sup>47</sup> The title and focus of the 2008 National HACC Forum was *Promoting Independence: Exploring the evidence for adopting wellness, restorative and capacity building approaches in HACC Services*.

<sup>48</sup> Eden Alternative.

opportunities for people to make contributions which result in their feeling valued and important. Some examples may include:

- day centre programs involving people in meal preparation, program choices, peer education programs or running activities;
- transport services that transport clients to and from their friends' homes;
- social visiting programs using local HACC clients as visitors;
- education sessions run by HACC clients on topics of interest, in their areas of expertise, at Community Health Centres and neighbourhood houses; and
- opportunities for direct client input into HACC staff training programs.

### **Transport**

This research demonstrates that flexible and accessible HACC funded transport is highly valued by people who use these services for medical appointments and for transport to social activities, such as shopping and attending day centres. However in many areas throughout Tasmania, transport is inadequate, unsuitable and/or unavailable and this severely limits people's capacity to get out and about from their homes, furthering the social exclusion impacts of poverty and social disadvantage. The recently completed Core Passenger Transport Services Review by the Tasmanian Government Department of Infrastructure, Energy and Resources confirms these findings. The review states that there is widespread poor compliance by bus services to meet the Disability Standards for Accessible Passenger Transport, made under the Disability Discrimination Act of 2002.<sup>49</sup>

Rural areas of Tasmania are the least well serviced for transport. Unfortunately, these are also the areas that have proportionally high numbers of people living on low incomes, and thus have elevated needs for transport services.<sup>50</sup> Other research has shown that the lack of transport in rural areas is felt particularly by older people, who historically have been dependent on their private car. When people lose their capacity to drive or are unable to afford to run a car they are particularly affected by a lack of alternative forms of transport.<sup>51</sup> The high costs of rural bus services, the maintenance of a private car and registration costs were concerns raised by many participants. There is a need to continue to expand the availability of HACC

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<sup>49</sup> Tasmanian State Government *Connected Communities* (2007) p89.

<sup>50</sup> Davis (2008) p57.

<sup>51</sup> *Ibid* p58.

community cars and other flexible, affordable transport particularly in areas that are currently without these services.

### **Food and nutrition**

Many people living on low incomes go without adequate food, in order to pay rent or bills or to meet other costs. People are unable to regularly buy fresh fruit and vegetables or good quality food, and feel that their health suffers as a result. In addition, in many rural areas, lower cost, healthy food options are less available.

The HACC Program funds many activities that involve providing food, for example, day centre programs and Meals on Wheels. This research shows that services that provide low cost or free meals for people are of great value and importance to many people. By providing these services, the HACC Program can play a positive role in minimising the health and wellbeing impacts of an inadequate diet. However, this positive role also depends on those programs providing high quality, nutritious food. Apart from delivered meals services that have nutrition standards in place, all other HACC services choose for themselves the types of food they will provide. The HACC Nutrition Service supports service providers who voluntarily want to improve nutrition, however without an obligation for all services to meet these guidelines, not all services will be involved, and therefore not be providing optimum choices. As cost is already a barrier to people eating well, additional barriers – such as providing only food that is low in nutritional value – need to be minimised.

In addition, as participants note, some people grow up with little or incorrect information about nutrition, and thus as adults they require the opportunities for education and advice about a healthy diet. This research also highlights the value of food preparation assistance, which enables people to cook with fresh produce, rather than buying pre-prepared meals. The HACC Program is able to provide some funding for both these types of assistance, for example the development of the 'Appetite for Life' nutrition education resources by the HACC Nutrition Service, and also through programs that assist with shopping and meal preparation.

## **5.4 Recommendations for future HACC consumer research**

Based on the findings of this research and the resultant implications for the HACC Program, it is recommended that further HACC-related research be undertaken into

whether improvements in the health and wellbeing and quality of life of HACC clients arise as a result of changes to programs that:

- address nutrition needs;
- enhance independence;
- facilitate interdependence; and
- enable opportunities for reciprocity.

## 6. Conclusions

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In many ways the findings of this research are affirming of the HACC Program, and the role the Program plays in addressing poverty and social disadvantage. The Program already seeks to improve the quality of life of disadvantaged Tasmanians by offering community care services that address health problems and provide social opportunities, and these are generally provided at low, or no, cost to clients. It also focuses particularly on providing services for “financially disadvantaged people”, an identified special needs group of the target population.

However, this research also highlights the further potential of the Program, and the scope for improvement. Statistics indicate high levels of poverty and disadvantage in Tasmania and the experiences of the participants in this research foreground the debilitating impacts that poverty and disadvantage have on people’s lives. A low income, insufficient material and financial resources, poor physical or mental health, inadequate services such as transport, a poor diet and no opportunities for relaxation are all cited as key elements contributing to and exacerbating disadvantage. The cumulative nature of poverty and disadvantage is strongly evident, as is the interconnectedness of the various elements.

This research provides an indication of the types of actions that the HACC Program can take to better help address poverty and disadvantage. By outlining what it is that people on low incomes need to improve their quality of life – less financial burdens, good health, community connectedness, time for relaxation and good nutrition – the ways to address these needs are evident. The actions principally require a continuation, modification and/or expansion of existing community care services.

The following aims need to underpin HACC interventions to address poverty and social disadvantage:

- to minimise financial stress;
- to minimise physical and mental health problems;
- to maximise social connectedness; and
- to offer more opportunities for clients to feel valued and respected through active community participation.

The adoption of these aims will firmly align the HACC Program with social inclusion principles, and thus increase the Program's effectiveness in addressing poverty and social disadvantage in Tasmania and assist to improve the quality of life for vulnerable people with the highest levels of need.

## 7. Recommendations

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### **Recommendation 1.**

That the Tasmanian HACC Program seek to improve the quality of life for clients who are living in poverty and who are socially disadvantaged by prioritising funding for the following types of programs:

- Programs that are consistent with health promotion principles;
- Diverse, low fee, social support programs;
- Programs that enable active community engagement, volunteering and paid work options for HACC clients;
- Programs that facilitate reciprocity opportunities;
- Food and nutrition focussed programs – for example social eating programs, nutrition promotion and education programs for HACC clients, and assistance with food preparation in people’s homes;
- Flexible transport provision, especially in isolated areas; and
- Programs that facilitate community involvement, including projects run by existing community organisations such as neighbourhood and community houses, health centres and schools.

### **Recommendation 2.**

That the Tasmanian HACC Program maintain the policies of low fee caps for services and fee waivers for people living on low incomes and experiencing social disadvantage.

### **Recommendation 3.**

That the Tasmanian HACC Program undertake a review of the distribution and uptake of fee waivers amongst service providers.

### **Recommendation 4.**

That the Tasmanian HACC Program explore ways to incorporate the services that are currently exempt from HACC fee caps or waivers for people living on low incomes and experiencing social disadvantage.

**Recommendation 5.**

That the Tasmanian HACC Program provide additional support to the Community Nutrition Unit to expand the work of the HACC Nutrition Service, in particular to enable:

- the implementation of nutrition standards for all HACC funded services, including standards relating to nutrition assessment, screening and management and guidelines for the provision of food, and ongoing monitoring, review and assistance to services;
- assistance with the monitoring of the nutritional status of HACC clients in relation to their overall health and wellbeing; and
- dietitian services to support clients individually, in addition to the whole of service approach.

**Recommendation 6.**

That the Tasmanian HACC Program investigate and address geographical gaps in the provision of community transport services.

**Recommendation 7.**

That the Tasmanian HACC Program provide funding to build awareness of the impacts of client poverty, disadvantage and social exclusion amongst HACC service providers, and the role they can play in alleviating these impacts through service delivery and referrals.

**Recommendation 8.**

That the Tasmanian HACC Program work with the Tasmanian Social Inclusion Unit to ensure the HACC target group is part of that Unit's broad agenda to address poverty and disadvantage. In particular, to advise the Unit on the most appropriate ways, as highlighted by this report, to address the needs of HACC clients who are socially excluded as a result of low income, poor health, unemployment, caring obligations, inadequate transport, social isolation and/or discrimination.

**Recommendation 9.**

That the Tasmanian HACC Program advocate for the inclusion of nutrition service standards into the HACC National Service Standards.

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## Appendix A

### Demographic Profile of Participants: Interviewees

Variable	Category	Participants (number)	Participants (percentage)
Gender	Male	11	25
	Female	33	75
English as a primary language	Yes	40	91
	No	4	9
Indigenous	Yes	2	5
	No	42	95
Location	N/NE	5	11
	N West/W	20	45
	South/SE	19	43
Age	18-30	10	23
	31-64	25	57
	>65	9	20
Remote- ness	Rural	13	30
	Urban	29	70

### Demographic Profile of Participants: Groups

Variable	Category	Participants (number)	Participants (percentage)
Gender	Male	38	37
	Female	66	63
English as a primary language	Yes	76	73
	No	28	27
Indigenous	Yes	7	7
	No	97	93
Location	N/NE	33	32
	N West/W	15	14
	South/SE	56	54
Age	18-30	23	22
	31-64	50	48
	>65	31	30
Remote- ness	Rural	41	39
	Urban	63	61

## Interview/Focus Group Format and Guide

Introductions, explain the project and interview process.

Discussion prompts

- Opening: Tell me a bit about your life  
Who you live with (dependents? Carer?)  
What do you do?
- Education: level of attainment  
post-school qualifications
- Health: chronic disease  
waiting lists (surgery, community care, specialists, dental)  
disability  
costs (preventative, meds, specialists, equipment)
- Housing: type  
cost  
suitability (heating, access, furniture, crowding)  
safe/secure?  
maintenance
- Employment: length of time unemployed  
type of work  
conditions
- Income: type  
adequacy – bills, school stuff/activities, holidays, savings,  
maintenance, groceries, medications, insurances, cars, socialising,  
clothing.  
other assistance (vouchers)
- Infrastructure: services in the area  
transport  
social options

Keep in mind:

Power and agency; Opportunity and freedom; Choice and constraint; Exclusion and participation; Needs and deprivation.

Finishing questions:

- What's a good quality of life?
- What are the essentials?
- What stops you from having them?
- What needs to change?



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