



Submission to
***Joint Select Committee Inquiry:
Preventative Health Care***

March 2013

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About Carers Tasmania

Carers Tasmania is a non-profit, community-based, incorporated association and registered charity dedicated to improving the quality of life of all caring families living in Tasmania.

The *vision* of Carers Tasmania is to achieve recognition of the value and contributions of Carers and endorse caring as a shared whole-of-community responsibility. The *mission* of Carers Tasmania is to enhance the health and wellbeing of Carers in Tasmania, and promote their rights and needs.

Carers Tasmania is committed to consulting with Carers to identify and respond to their needs. Carers Tasmania provides a diverse range of services across all areas of the State, including information, education and training, counselling (both individual and therapeutic groups), health and wellbeing activities, and social support.

Carers Tasmania is governed by a volunteer Board of directors which oversees the strategic, financial and legal direction of the organisation. Members of the Board contribute professional expertise and offer perspectives drawn from their own experiences.

The key objectives of the organisation are to:

- Provide quality Carer-focused services
- Encourage awareness and community support for Carers
- Advocate on behalf of Carers to government and other stakeholders about identified Carer concerns and options for solutions
- Operate a progressive, sustainable, accountable and transparent organisation
- Be recognised as a leader in the provision of support to Carers.

"I've been caring for my husband for the past 16 years. He had a major CVA at that time. He lost his speech. I do everything, banking, cleaning, washing, ironing, account paying...what else haven't I mentioned....beij call more or less night an the 16 years I've had one

"I care for a 21 year old non-verbal Autistic son."

A Carer is an individual who provides, in a non-contractual and unpaid capacity, ongoing personal care, support and assistance to a person with a disability, medical condition (including terminal or chronic illness), mental illness or frailty due to age.

"I'm a full time Carer for my wife who had a stroke. Unfortunately she's completely paralysed on the right side and I have to be there 24/7. She can't even take herself to the toilet. We're trying to run a farm as well so it gets pretty stressful at times."

Summary of Recommendations

1. In light of the substantial evidence on the social determinants of health both within Tasmania, nationally and internationally, Carers Tasmania recommends that the Government, in partnership with the community sector, develop a comprehensive policy and action plan for reducing inequities in health through action on the social determinants of health. Such a policy should be long-term and multi-sectoral, and incorporate adequate resourcing, evaluation and accountability mechanisms. Most importantly it must seek to affect real change for the people who are most disadvantaged, such as Tasmania's Carers. Carers Tasmania supports the call made by others that the Government recognise the work of the World Health Organisation's Commission on the Social Determinants of Health.
2. Carers Tasmania recommends that the Government funds Carers Tasmania to implement specific actions that will contribute to the outcomes of the Tasmanian Carer Policy 2013.

These actions include:

- Bringing together existing information and undertaking further research so we can build a better understanding about Carers and the caring role in Tasmania, so that as a society we can better respond to their needs now and into the future
 - Empowering Carers to have a stronger voice in Tasmania by establishing mechanisms that will enable Carers to have a greater say in the decisions that affect their lives and developing a speakers program
 - Raising awareness about Carers and the caring role through the development of a comprehensive communication strategy which will include delivering training to Government departmental staff
 - Establishing and providing secretarial support for an Advisory Council to monitor implementation of the Tasmanian Carer Policy and Carer Action Plan.
3. Carers Tasmania recommends that the Government build equity-impact assessment processes into all its policy, program and service development.
 4. Carers Tasmania recommends that the Government actively foster greater sharing of responsibility for health across sectors.
 5. Carers Tasmania recommends that the Government facilitate collaborative efforts involving government, non-government and the private sectors, and strengthen community engagement mechanisms for participation in planning and developing action on the social determinants of health.
 6. Carers Tasmania recommends that the Government invest in developing a stronger understanding about Carers and their interaction with the social determinants of health so as to better plan action for the growing number of Carers in Tasmania.

1.0 Introduction

Carers Tasmania welcomes the opportunity to present this submission to the Joint Select Committee on Preventative Health Care.

Carers provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail. Carers are not paid to undertake their caring roles. They do so out of love, dedication and concern, and often because they have no choice. The caring role ranges from providing personal care such as assistance with dressing and showering, to helping a loved one with mobility or communication, to behaviour management, emotional support, supervision, or assistance with accessing appropriate health care services.

In 2009, there were 66,200 Carers in Tasmania who provided assistance to those who needed help because of disability or old age.¹ Just over one third of these (31%) were primary Carers; that is, people who provided the majority of the informal help needed by a person with a disability or aged 60 years and over.²

It has been predicted that by 2028, the number of people in Tasmania requiring assistance with a core activity of daily life such as communication, mobility or self care will increase by 47-52%.³ This will lead to a total of 34-37,000 extra people who require care by 2028 and an increase in the number of Carers to 80-88,000 by 2028.⁴

Being a Carer has a direct impact on health and wellbeing. In this sense the caring role is seen as a social determinant of health in itself. In addition, Carers are further disadvantaged by barriers to accessing many of the social and economic factors that have the potential to positively shape health and wellbeing – factors such as a decent income, the opportunity to complete education, a meaningful job, strong support networks and freedom from discrimination.

Carers Tasmania calls on the State Government to give greater recognition to the impact of the social determinants of health on all Tasmanians, and specifically to Tasmanian Carers.

¹ ABS 2010, 4430.0 - *Disability, Ageing and Carers, Australia: Summary of Findings, 2009.*

² Ibid.

³ IMC-Link, 2008, *Report on the profile of Carers in Tasmania*, Carers Tasmania, Hobart, Tasmania.

⁴ Ibid

2.0 Term of Reference 1: Caring and the social determinants of health

The social determinants of health are the conditions in which people are born, grow up, live, work and age. Carers Tasmania believes that caring in itself is a social determinant of health in the sense that the caring role is a 'way of life' and it is the conditions associated with this role that directly impact on health. Furthermore, the caring role has been shaped by social, health and economic policies to the point where Carers are recognised as a socially excluded 'group' that are denied the same opportunities for optimum health as many others in the population. The caring role also interacts strongly with many other social determinants of health. Table 1 below summarises some key data relating to social determinants of health that impact on Carers.

Table 1: The impact of some key social determinants of health on Carers

Social Determinant	Key Data
Caring - A large and growing number of Tasmanians are Carers	<ul style="list-style-type: none">• In 2009, the ABS identified that there were 66,200 Carers in Tasmania.⁵• This equates to 13.3%, the second highest in the country next to South Australia, and compared to 12.2% nationally.⁶• As outlined in section 2.1 below, caring contributes to poor health on a number of levels.
Age – Carers are mostly people aged 55-64 years. Tasmania also has a significant proportion of young Carers	<ul style="list-style-type: none">• Age interacts strongly with other social determinants of health, and has a direct impact on Carer health and wellbeing.• In 2009, the percentage of people living in households that were identified as Carers increased gradually with age from 3% of 18-24 year olds to 15% of 55-64 year olds, then declined to 9% of those aged 75 years and over.⁷• The proportion of people who were primary Carers also increased gradually with age, from 3% of 35-44 year olds to 5% of 55-64 year olds.⁸• Tasmania has a high proportion of young Carers with around 8% of Carers in Tasmania aged under 25 years.⁹
Education – young Carers face	<ul style="list-style-type: none">• Education and health outcomes are strongly linked.

⁵ ABS 2010, 4430.0 - *Disability, Ageing and Carers, Australia: State Tables for Tasmania*, Table 32.

⁶ Ibid.

⁷ Ibid, Table 31.

⁸ Ibid.

⁹ Ibid.

enormous challenges to continuing their education

- The situation for young Carers is of great concern - only 4% of Carers between the ages of 15-25 years are still at school or in post-secondary education, compared to 23% of the general population in that age group¹⁰.
- Those young Carers who do manage to continue their studies often report that school attendance provides a respite from the adult responsibilities they must face at home and offers an opportunity to make social connections and receive information and support.¹¹
- Despite this, a study of young Carers at school found that caring can have a number of negative impacts on their school experience. Almost 50% reported poor attendance (missing or being late for school because of caring responsibilities).¹² 44% felt they did not achieve the results they were capable of for a number of reasons associated with caring, including tiredness due to sleep interruption (78%), lack of concentration because of worry about the care recipient (82%) and lack of time for homework (54%)¹³.
- Lack of access to flexible options for undertaking education and training as well as support for their caring responsibilities whilst they undertake education and training programs present barriers for adult learners.¹⁴

Gender – Carers are more likely to be female; females Carers have poorer wellbeing than male Carers

- In 2009, over 70% primary Carers were female.¹⁵
- Female Carers have significantly lower wellbeing than male Carers (57.8 and 61.2 respectively).¹⁶

Income – Tasmanian Carers have lower incomes than non-carers

- Adopting a caring role can have a major impact on family finances, which in turn affects health and wellbeing.
- The median gross personal income per week for Tasmania's Carers in 2003 was \$250 compared to \$326 for non-carers.¹⁷
- Even considering other income sources such as

¹⁰ Carers Australia 2002, *Reading, Writing and Responsibility: Young Carers and Education*, report prepared by Institute of Child Protection Studies, ACU National, in IMC-Link 2008, Op-Cit, p. 12.

¹¹ IMC-Link 2008, Op-Cit.

¹² Carers Australia 2002, Op-Cit.

¹³ Ibid.

¹⁴ Ibid, p. 11.

¹⁵ ABS 2003, 4430.0 - *Disability, Ageing and Carers, Australia: State Tables for Tasmania*, Table 27.

¹⁶ Deakin University and Carers Australia 2007, *Australian Unity Wellbeing Index*, Survey 17.1, Report 17.1, Special Report, *The Wellbeing of Australians – Carer Health and Wellbeing*, October 2007 in IMC-Link 2008, Op-Cit, p. 13.

¹⁷ ABS 2010, Op-Cit.

	<p>Government allowances, investments etc, Carers are likely to live in households with lower incomes. 37% of Carers and 45% of primary Carers live in households in the lowest two quintiles of household income, compared to 26% of the general population.¹⁸</p> <ul style="list-style-type: none"> • Many Carers report that their financial position worsens after adopting a carer role due to decreased income (21%) and/or increased expenses (23%).¹⁹ • 61% of these people reported difficulty in meeting day-to-day expenses.²⁰ • Carers receiving Carers Allowance or Payment were more than twice as likely to report difficulty in paying electricity, gas or telephone bills on time than were the general population.²¹ • Carers are also almost twice as likely to report being worried about their ability to pay for household bills than are non-carers²².
Rurality - Tasmania's Carers live in rural and remote areas	<ul style="list-style-type: none"> • Health and rurality are closely linked.²³ • 65% of Tasmanian Carers live in inner regional areas (as opposed to major cities) and 34% live in outer regional and remote areas of Tasmania.²⁴
Workforce participation – Carers are not able to participate in the workforce to the same extent as non-carers	<ul style="list-style-type: none"> • People who have a job generally experience better health than those who do not. • Primary Carers had a lower labour force participation rate (40%) than people who were not carers (64%)²⁵ • 12% of primary Carers in Tasmania spent on average 40 hours or more per week providing care and 23% spent 20 to 39 hours per week.²⁶ • Among those in the labour force in 2003, Carers were twice as likely to be employed part time (59%) rather than fulltime (29%). Primary Carers were three times as

¹⁸ ABS cat. no. 4430.0.55.003 Table 6 in IMC-Link 2008, Op-Cit, p. 11.

¹⁹ ABS 2005, Cat. no. 4430.0.55.003 Table 12 in IMC-Link 2008, Op-Cit, p. 10.

²⁰ Ibid.

²¹ Higgins et al 2008, *The nature and impact of caring for family members with a disability in Australia*, AIFS Research Report No. 16, 2008 in IMC-Link 2008, Op-Cit, p.9.

²² Deakin University and Carers Australia 2007, Op-Cit.

²³ AIHW 2008. *Rural, regional and remote health: indicators of health status and determinants of health*. Cat. no. PHE 97. Canberra: AIHW.

²⁴ ABS 2010, Op-Cit, Table 32.

²⁵ Ibid, Table 33.

²⁶ Ibid, Table 37.

- likely to be employed part time (67% pt, 22% ft)²⁷.
- The most common barriers to employment reported by Carers were “difficulty arranging working hours” (23.0%) and “no alternative disability care arrangements available” (22.4%).²⁸ Even after the caring role has finished, barriers to employment such as lack of recent job experience, currency of qualifications and lack of confidence remain.²⁹
 - Over 70% of employed female Carers reported having changed jobs or working arrangements to meet their care responsibilities. Changes included reducing hours, adopting flexible hours, or changing to a job with shorter or more flexible hours.³⁰
 - Carer’s lower rates of employment participation affect not only their immediate income, but also their ability to save for retirement in the form of superannuation. The caring role may be prolonged. In 2003, 60% of primary Carers over the age of 15 had cared for five years or more, 33% for 10 years or more, and 6% for over 25 years.³¹ Moreover, the impact of caring on employment does not end when the caring role finishes.³²

It is important to note that we are not just talking about access to material resources. Social inclusion and a sense of control over life circumstances are crucially important for the health and wellbeing of Carers. Carers need to feel that they have at least some level of control over their lives, their jobs, their housing and their environments. Sadly for many Carers this sense of control over life is often absent.

In addition to the impact of the caring role itself, the presence of many deficiencies in the social determinants of health in the lives of Carers further compounds their risk of poor health. Many Carers experience the coal-face of inequity in health outcomes. Health inequities are the avoidable inequalities in health between groups of people.

Carers Tasmania believes that we must act on the social determinants of health so as to give Carers the opportunity to achieve optimum health. Section 2.1 below provides some poignant examples of how the health and wellbeing of Carers is affected by their role and associated social determinants of health.

²⁷ ABS cat. no. 4430.0.55.003, Table 6 in IMC-Link 2008, Op-Cit, p. 22.

²⁸ Higgins et al 2008, Op-Cit, p. 9.

²⁹ Ibid.

³⁰ Ibid.

³¹ ABS 2004, *2003 Disability, Ageing and Carers: Summary of Findings*, Cat No 4300.0, Table 31 in IMC-Link 2008, Op-Cit, p.10.

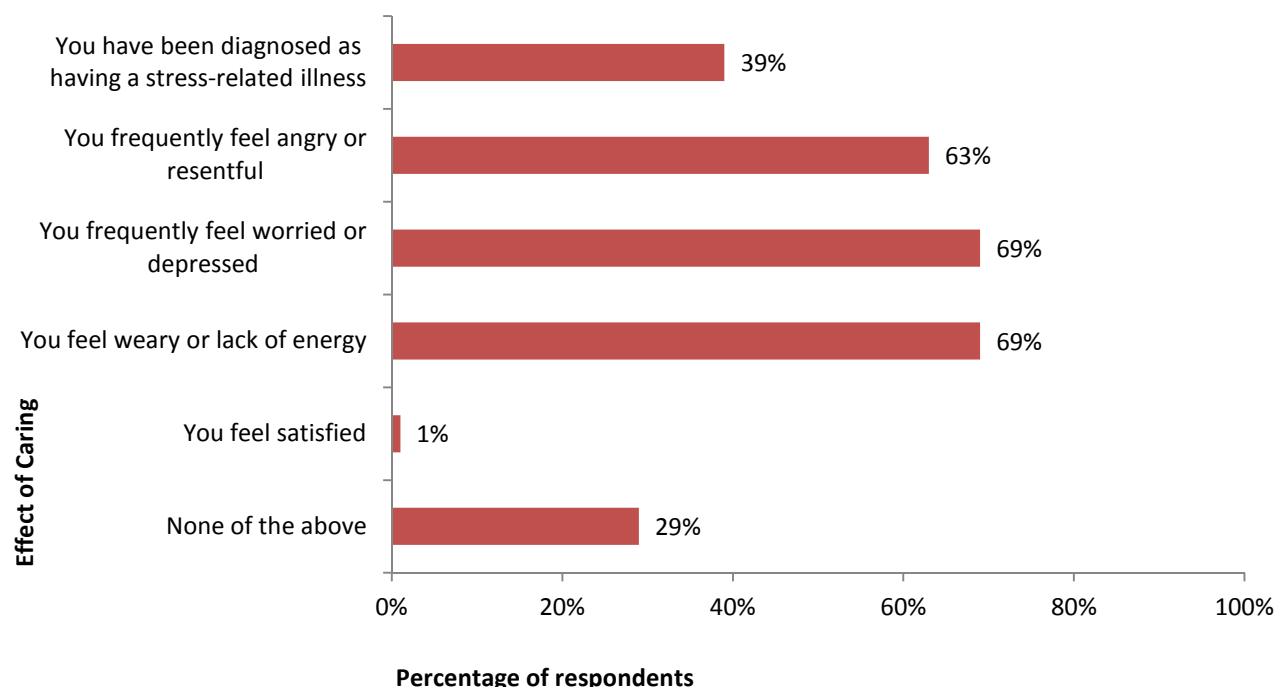
³² IMC-Link 2008, Op-Cit, pg.10.

2.1 Health Outcomes of Carers

Caring for a person with a disability can have considerable psychological and physical impacts upon those providing care; it can also have an impact upon the health of other family members.³³

A 2008 Tasmanian study involved asking Carer participants to indicate if they suffered from one or more of a list of 18 health conditions.³⁴ Only 25% indicated no health conditions, with 20% reporting one condition and 55% more than one. **Figure 1** illustrates the proportion of Carers experiencing a range of health conditions.

Figure 1: Effects of Caring on Carer Health & Wellbeing



International and Australian large-scale studies that focused on the mental health of primary Carers suggest that:

- Carers have higher levels of depression and stress, and lower levels of subjective wellbeing than people with no caring responsibilities;
- female Carers have higher levels of depression and stress, and lower levels of wellbeing than male Carers;

³³ Edwards B 2008, *The nature and impact of caring for family members with a disability in Australia*, Research report No. 16, 2008, Australian Institute of Family Studies.

³⁴ IMC-Link 2008, Op-Cit.

- greater care needs (e.g., behavioural problems, cognitive and physical impairments of the person with a disability, and number of caregiving tasks and more hours of care are associated with higher levels of Carer depression; and
- lower levels of depression are associated with informal support from friends or relatives, formal supports from professionals, and income.

The literature on primary Carers' physical health suggests that:

- Carers have poorer self-reported physical health, higher levels of stress hormones and lower levels of antibody responses than non-carers; and
- Carers are more likely to have a major health problem, use medication and experience physical pain than non-carers.³⁵

2.2 Capacity of the Sector

Tasmania lacks leadership and a vision to drive action on the social determinants of health. Carers Tasmania believes that this vision must strongly articulated by the highest level and filter down – as well as back up - through government, non-government and the private sectors, as well as the wider community. Critically, the community must share in this vision and be central to it. As a State we must make the health and wellbeing of people a central goal.

In light of the substantial evidence on the social determinants of health both within Tasmania, nationally and internationally, Carers Tasmania recommends that the Government, in partnership with the community sector, develop a comprehensive policy and action plan for reducing inequities in health through action on the social determinants of health. Such a policy should be long-term and multi-sectoral, and incorporate adequate resourcing, evaluation and accountability mechanisms. Most importantly it must seek to affect real change for the people who are most disadvantaged, such as Tasmania's Carers. Carers Tasmania supports the call made by others that the Government recognise the work of the World Health Organisation's Commission on the Social Determinants of Health.

3.0 Term of Reference 2: Preventative Health Care

Clearly we must do more to prevent the poor health outcomes of Tasmania's Carers. However, in order to address these problems, we must act on the 'causes of the causes' – the social determinants of health.

Carers Tasmania supports the development of an integrated and collaborative preventative health care model that focuses on the prevention, early detection and early intervention for chronic disease

³⁵ Ibid

however this must not be prioritised over action on the social determinants of health. As illustrated earlier caring is a social determinant of health and many Carers experience the double jeopardy of additional barriers created by particular social determinants.

What Carers need in the first instance are their rights to education, employment, a decent standard of living, access to transport, freedom from discrimination and social support needs addressed. Once we have this strong foundation in place they will then be able to make the healthy lifestyle choices that are needed to prevent chronic conditions. Carers Tasmania believes that the Government should priorities equity in health as a central goal.

Carers Tasmania was very pleased that the Government launched the draft Tasmanian Carer Policy last year, and that it stated that it intended to develop a Carer Action Plan and table appropriate legislative amendments. The Tasmanian Carer Policy is an important step towards greater recognition of Carers, which will hopefully act as a catalyst for further positive change that will ultimately lead to Carers having greater control over their lives. Carers Tasmania would be deeply troubled if this Policy and Action Plan were not progressed. We encourage the Committee to explore its progress.

Carers Tasmania presented a submission to the Government during the Community Consultation process for the development of the 2013-2014 State Budget. In this submission Carers Tasmania offered to work with the Government to progress the efforts surrounding the Tasmanian Carer Policy. We wish to bring our recommendations to Government to this Committee's attention as they have direct relevance for improving the health and wellbeing of Carers. Our recommendation to Government was as follows:

Carers Tasmania recommends that the Government funds Carers Tasmania to implement specific actions that will contribute to the outcomes of the Tasmanian Carer Policy 2013.

These actions include:

- Bringing together existing information and undertaking further research so we can build a better understanding about Carers and the caring role in Tasmania, so that as a society we can better respond to their needs now and into the future
- Empowering Carers to have a stronger voice in Tasmania by establishing mechanisms that will enable Carers to have a greater say in the decisions that affect their lives and developing a speakers program
- Raising awareness about Carers and the caring role through the development of a comprehensive communication strategy which will include delivering training to Government departmental staff
- Establishing and providing secretarial support for an Advisory Council to monitor implementation of the Tasmanian Carer Policy and Carer Action Plan.

In commenting on the Draft Tasmanian Carer Policy, we called on the Government to undertake an equity analysis of the draft policy, stating the following: "An equity assessment can help the Government identify the unnecessary and avoidable differences in health, wellbeing and quality of

life outcomes for Carers, compared to the non-caring population, as well as differences in these outcomes among various sub-groups of Carers (young, old, Indigenous, Culturally and Linguistically Diverse, Lesbian-Gay-Bisexual-Transgender-Intersex, single parents and so forth). This will enable the Government to develop a list of principles that truly reflects the needs of the diverse caring population and will assist in developing an action plan to act at the root causes of inequities in outcomes for Carers.

An equity approach to policy development can help ensure a fairer society where everyone has the opportunity for good health and a quality life; an inclusive society, where everyone has a sense of belonging and feels that their contribution is valued; improved health and wellbeing for the population as a whole, as well those groups, such as Carers, who experience poor health; and a stronger economy because a healthier population can contribute to a richer social and economic life.

An equity approach can help to answer questions such as:

1. What inequalities exist in relation to the needs of Carers? This will encompass a range of issues relating to culture, socio-economic status, geographical location, age, gender etc.
2. Who is most advantaged and how? This is about looking at the strengths as opposed to the deficits and failings. What are the strengths within the system and how can these be shared more equally?
3. How do the inequalities occur? What are the mechanisms by which the inequalities were created, maintained or increased? This includes looking at socio-economic factors (e.g. income level), social and cultural factors (e.g. discrimination and social support), environmental factors (e.g. living and working conditions), and population-based services (e.g. healthcare).

This type of understanding will help the Government to determine if there are particular groups that require additional support to enable them to lead better quality lives. It will allow a list of critically informed principles to be developed.”

Carers Tasmania recommends that the Government build equity-impact assessment processes into all its policy, program and service development.

4.0 Term of Reference 3: Structural and Economic Reform

Carers Tasmania would like to see greater collaboration across Government departments and a move towards joined up funding for initiatives related to health - which clearly should involve numerous sectors. Carers would undoubtedly benefit from structural and economic reform that would lead to greater income equity, equal opportunity to access and stay involved in education and

employment, enhanced access to health and social support services, and strategies that will tackle discrimination. Such issues clearly cross portfolio boundaries.

We recognise that some of the issues faced by Carers such as low incomes are issues that go beyond the State Government. We do however look to our Premier and Ministers to be strong advocates on income and taxation reform both locally and at the federal level so as to work towards creating a fairer system across society.

Carers Tasmania recommends that the Government actively foster greater sharing of responsibility for health across sectors.

5.0 Term of Reference 4: Expertise

Carers Tasmania does not have knowledge about the extent to which experience and expertise in the social determinants of health is appropriately represented on whole of government committees or advisory groups. We do however believe that expertise is not confined to government circles. The community sector has a wealth of knowledge and expertise relating to the social determinants of health. The recently established Social Determinants of Health Advocacy Network with its 160 members (of which we are one) is a clear indication of this. We encourage the Government to strengthen its community engagement mechanisms so that we can work together – across government, non-government, the private sector and the community – to mobilize expertise on the social determinants of health to make a difference to Tasmania as a whole.

Carers Tasmania also believes that we must make greater efforts to enable the voices of citizens to be heard. This is why in our Budget Submission to the Government last year we called for the Government to support Carers Tasmania to *“Empower Carers to have a stronger voice in Tasmania by establishing mechanisms that will enable Carers to have a greater say in the decisions that affect their lives and developing a speakers program.”*

Carers Tasmania recommends that the Government facilitate collaborative efforts involving government, non-government and the private sectors, and strengthen community engagement mechanisms for participation in planning and developing action on the social determinants of health.

6.0 Term of Reference 5: Research

Funding in Tasmania for research into the social determinants of health is currently very limited. There is much that we do not know about Carers and their interaction with the social determinants

of health. Carers Tasmania supports further investment in initiatives that will deepen our collective understanding of the social determinants of health, provided this does not come at the expense of action. As stated by the World Health Organisation: *“There is enough evidence on the social determinants of health to act now.”*³⁶

Carers Tasmania recommends that the Government invest in developing a stronger understanding about Carers and their interaction with the social determinants of health so as to better plan action for the growing number of Carers in Tasmania.

7.0 Conclusion

Carers Tasmania would like to thank the Joint Select Committee for the opportunity to participate in this Inquiry. This is a critical step towards greater recognition of the social determinants of health for Tasmanians, one we trust will lead to concrete actions. We look forward to meeting with the Committee to discuss this submission and our recommendations further.

³⁶ Commission on the Social Determinants of Health 2008, *Closing the gap in a generation – health equity through action on the social determinants of health*, Final Report, Executive Summary, WHO, p. 30.