

Submission No. 671

(Inq into better support for carers)

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## **Better Support for Carers**

*A Submission to the House of Representatives  
Standing Committee on Family, Housing and Youth  
Inquiry into Better Support for Carers*

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Enquiries on this submission may be directed to:

Janis McKenna  
Chief Executive Officer  
Carers Tasmania

T (03) 6231 5507  
F (03) 6236 9236  
E [janis.mckenna@carerstas.org](mailto:janis.mckenna@carerstas.org)

This document was prepared by:  
*Janis McKenna, Chief Executive Officer*  
*Annemarie Ashton, Policy Consultant*

## Carers Tasmania

Head Office:

"Westella"  
181 Elizabeth Street  
Hobart Tasmania 7000  
Phone: (03) 6231 5507  
Facsimile: (03) 6236 9236

Outreach Offices:

Shop 8 Jimmy's Shopping Complex  
216 Charles Street  
Launceston Tasmania 7250  
Phone: (03) 6334 9917  
Facsimile: (03) 6334 9916

Unit 5, 15 Wilmot Street  
Burnie Tasmania 7320

Website:

<http://www.carerstas.org>

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## ***1. Executive Summary***

Carers Tasmania is a non-profit, community based, incorporated association and registered charity dedicated to improving the quality of life of the estimated 69,500 family carers living in Tasmania. As the only organisation completely dedicated to supporting the needs and representing the views of carers throughout Tasmania, Carers Tasmania provides a diversity of services across all areas of the state and is committed to progressing and expanding innovative carer support services for the benefit of all Tasmanians.

Carers Tasmania welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Family, Housing and Youth Inquiry into Better Support for Carers, and also supports the submissions completed by Carers Australia and each of the individual Carers Associations. These submissions illustrate the diversity of needs and variety of potential solutions which will enable the better support of carers throughout the nation.

Carers have significant barriers preventing social inclusion. The time needed to care, the cost of providing care, and the isolation created by lack of appropriate supports to maintain community contact all prevent them from equitably participating in family, social and community life, in employment and in education. These barriers can be diminished, and even eliminated, when they are understood and addressed by positive action.

Research conducted throughout Australia indicates that more carers would like to rejoin the workforce than are presently engaged in it. Carers have also indicated that they need an improved network of supports which are flexible and responsive to their needs. The majority of carers consistently express a desire for a higher level of social equity for the person they care for, so that they too can enjoy a real quality of life based on good health and meaningful participation.

Tasmania, alongside the other Australian states and territories, is facing a period of social and economic change. While the state has enjoyed a strong economy in recent times, there remains evidence that many Tasmanians are still socially excluded and suffering the effects of embedded poverty or complex disadvantage<sup>1</sup>. Effects of the ageing population are already being experienced by government and the community services sector and this is evidenced in increasing demand for services.

Accelerating increases in the cost of living, driven by rising interest rates, housing costs, and the price of food and petrol are placing even more strain on family budgets. Carers often incur significant financial expenses through providing care. They need to be recognized for the contribution they make to meeting all or some of the costs of care, and compensated adequately where appropriate. It is clear that basic needs for survival must be met before 'added value' or quality of life issues can be addressed for carers.

Investing in carers makes good sense, as they provide an invaluable social and economic benefit to the state. The value of replacing the hours of informal care with formal care services would incur an unsustainable cost to the Tasmanian economy; this figure was conservatively estimated at over \$847.9 million<sup>2</sup> per annum in 2005.

There is no single 'type' of carer, as they come from all sections of society, and care-situations vary greatly in their structure and complexity. Carers also have diverse needs and some need more support to keep caring than others. Development of

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<sup>1</sup> Stronger Communities Taskforce (2007) *The state of our community report 2007: Starting the conversation*. Hobart: Department of Premier and Cabinet.

<sup>2</sup> Figure based on model developed by Access Economics (2005) *The economic value of informal care*. Canberra: Access Economics.

effective strategic plans to better support carers depends upon the alliance of the government with business and the community sector to create innovative solutions that best meet evidenced need. Carers also need to be recognized to ensure that they are considered as part of the support team when decisions are made about the care-recipient's life arrangement or healthcare.

For many carers reconnection to community is highly desirable but often a complex challenge without appropriate support. Social participation also depends on having practical support and assistance to reforge links with community activities. Greater community education is needed to help people understand more about caring. This will have a two-fold effect: firstly, to assist people to self-identify and self-refer to services if they have support needs; and, secondly, to increase wider community awareness of caring needs and promote inclusion.

While workforce participation rates for Tasmania are improving, they still lag noticeably behind the national average. Tasmania also has the highest rate of underemployment. The ageing population will intensify existing workforce shortages and innovative solutions will be needed to plan for a sustainable economy in the long term. Carers Tasmania considers it essential that carers who wish to re-enter the workforce or increase their level of participation be supported to do so. It is also essential that the estimated 31,600<sup>3</sup> carers who are currently in employment are supported to remain there.

A key need for carers is the ability to be able to access appropriate professional advice and assistance when dealing with legal and financial matters. The costs involved in accessing professional services are well beyond the reach of many carers. Carers Tasmania is investigating ways to expand community capacity, by accessing existing structures and services and utilising supports in innovative ways.

Research has discovered that carers have the lowest level of health and wellbeing than any other group of Australians previously studied. Carers Tasmania supports the call for a Primary Health Care Program to be established on a national basis to encourage a better level of preventative care for all carers. Carers Tasmania also calls for the establishment of a carer health and wellbeing mobile service staffed by registered nurses specially trained in carer health issues to provide outreach and health education services to regional and remote areas in Tasmania.

Reform of the community services sector required a need for improvement in cross-agency cooperation and coordinated whole-of-government action to succeed. Building sector capacity is a critical goal for nationwide sector reform. The community services and health sectors are already at capacity, and struggling to meet increased demand. The sector requires a national commitment to fund the provision of additional services to states which have traditionally been neglected. Reduction of red tape, increase in access pathways, and resources in 'plain English' would benefit carers alongside all other Tasmanians. Tasmania's main hope of achieving equity with mainland Australia will most likely come through the setting of a clear charter of national standards for recognition of care.

Priority needs include additional funding for regional and rural areas in Tasmania, provision for the training of staff, and a realistic increase in funding of existing programs to enable service providers to increase their capacity to retain staff through reasonable salaries, and to provide long-term, sustainable services based on identified carer need. Carers Tasmania is already working with communities, building innovative and responsive solutions, and has the access to new programs and consultant expertise through the network of Carer Associations to enable additional project development if suitable funding resources can be obtained in the future.

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<sup>3</sup> ABS (2003) *Survey of Disability, Ageing and Carers*. Cat No 4430.0

## ***2. Recommendations***

Carers Tasmania submits the following recommendations for consideration:

- i) That the existing model of community-based care be subject to an urgent and comprehensive reform in order to meet current and future need in a sustainable and equitable manner
- ii) That a charter of rights for care based in legislation be enacted to ensure better national consistency for carers
- iii) That the government commitment to long term investment in sustainable programs that achieve better equity for carers in Tasmania and parity on a national basis
- iv) That carers be adequately compensated for the costs of care
- v) That innovative solutions be fostered through cooperative engagement between government, employers and the community sector
- vi) That the government recognizes that there is diversity in care roles and situations, and that care needs may change across time
- vii) That the government recognizes that sustainable caring depends upon the preservation of existing relationships, both within the care situation and outside of it
- viii) That the government commit to funding more research opportunities, especially to identify the needs of regional and rural carers
- ix) That a carer's role should be integrated with a comprehensive system of health and community care supports that are flexible and responsive to their needs
- x) That there is an urgent need for appropriate, safe, quality, and affordable care alternatives for respite and supported accommodation, and this need is paramount to many carers
- xi) That the government recognise that there is an urgent need for programs that reconnect carers with the wider community, as carers have a higher risk of social isolation due to the demands of providing care for others
- xii) That assessment move to a holistic model with the use of matrix tools to examine the impact of care alongside measures of time and type of activity
- xiii) That carers have free access to specialist advice and training, including advocacy services, legal advice, financial counselling and future planning assistance
- xiv) That the government commit to providing a Primary Health Care Program for carers, including a free annual health check with a reminder system, a free annual Flu-vax, hepatitis vaccinations if needed, and a health care card
- xv) That the government establish a carer health and wellbeing mobile service staffed by registered nurses specially trained in carer health issues to provide outreach and health education services to regional and remote areas in Tasmania

### **3. Introduction**

Carers Tasmania welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Family, Housing and Youth Inquiry into Better Support for Carers. The Federal Government's focus on strategies to achieve an inclusive society with strong formal and informal networks of support for people in need will enable them to enjoy more equitable levels of social and economic participation.

This submission is not a definitive treatise on carer needs and issues, but represents core issues to enable better support of carers in Tasmania. Carers Tasmania also supports the submissions completed by Carers Australia and each of the individual Carers Associations, which illustrate the diversity of needs and variety of potential solutions which will better enable the social inclusion of carers across the nation.

Carers have significant barriers preventing equitable participation. The time needed to care, the cost of providing care and the isolation created by lack of appropriate supports to maintain community contact all prevent them from equitably participating in family, social and community life, in employment and in education. These barriers can be diminished, and even eliminated, when they are understood and addressed by positive action.

Research conducted throughout Australia indicates that more carers would like to rejoin the workforce than are presently engaged in it. Carers have also indicated that they need an improved network of supports which are flexible and responsive to their needs. The majority of carers consistently express a desire for a higher level of social equity for the person they care for, so that they too can enjoy a real quality of life based on good health and meaningful participation.

Tasmania, alongside the other Australian states and territories, is facing a period of social and economic change. While the state has enjoyed a strong economy in recent times, there remains evidence that many Tasmanians are still socially excluded and suffering the effects of embedded poverty or complex disadvantage<sup>4</sup>. Effects of the ageing population are already being experienced by government and the community services sector and are evidenced by increasing demand for services. Tasmania already has one of the oldest populations in Australia<sup>5</sup> with a median age 2 years older than the national average.

The Stronger Communities Taskforce<sup>6</sup> considers that the proportion of people aged over 65 could increase by almost 80% within the next two decades. The implications for carer support are clear, as the majority of this group will either be needing care or providing care. At the same time, demand for care will have a significant impact on the available workforce, as many people of workforce age find themselves torn between a need to provide care for family members, friends and neighbours, and the need to earn a living.

The accelerating increases in the cost of living, driven by rising interest rates, housing costs, and the price of food and petrol are placing even more strain on family budgets. Pensioners are finding it increasingly difficult to meet basic needs. It is clear that already disadvantaged sections of the community will be facing even more challenge in the future, and it is the responsibility of every Australian to make sure that our elderly, our sick and our vulnerable are not left even further behind.

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<sup>4</sup> Stronger Communities Taskforce (2007) *The state of our community report 2007: Starting the conversation*. Hobart: Department of Premier and Cabinet.

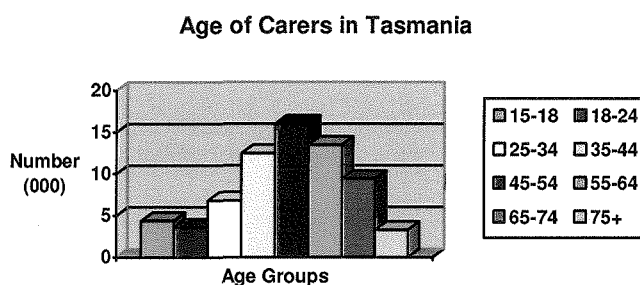
<sup>5</sup> ABS (2007) *Census 2006 QuickStats: Tasmania* accessed online via <http://www.censusdata.abs.gov.au>.

<sup>6</sup> *ibid.*

Investing in carers makes good sense, as they provide an invaluable social and economic benefit to the state. Development of effective strategic plans to better support carers depends upon the alliance of the government with business and the community sector to create innovative solutions that best meet evidenced need.

### 3.1 Profile of Caring in Tasmania<sup>7</sup>

*Tasmania has slightly more carers than the rest of Australia.* There are an estimated 69,500 carers aged over 15 years old, of which 14,600 are primary carers. This represents 15% of the total population of Tasmania (at 470,400 persons in 2003) which is higher than the national average of 13% of the Australian population.



*Groups at higher health risk are aged carers and carers with their own disability.* Around 12,700 (18%) of all carers are aged 65+, with 3,300 of this group aged 75+. Carers are more likely to have a disability themselves, as 23,100 (33%) have a reported disability (compared to 19% of non-carers).

*Carers are 1.6 times more likely than the rest of Tasmania to depend upon the government for the majority of household income.* 44% of carers have government pensions or allowances as their principal source of household income (compared to 26% of non-carers). Carers were less likely than other Australians to be in the workforce, with 48.3% not in the workforce compared to 33% nationally.

*Carers are more likely to be in part-time employment than the rest of the Tasmanian population.* 75% of carers are of workforce age (18-64). Carers in Tasmania also had a lower workforce participation rate than other Tasmanians (51.7% compared to 62.7% respectively). Of the 45% of the total number of Tasmanian carers who are employed, 24% are in full-time employment and 21% are in part-time employment (compared to rates of 29% full-time and 15% part-time for non-carers).

*Men in Tasmania are more likely to be a primary carer than men in the rest of Australia.* Tasmania has slightly more male carers than the national average. Men make up 47% of total carers (compared to 46% nationally). However, Tasmanian men make up 36% of primary carers compared to only 29% nationally.

*Women in Tasmania are still almost twice as likely to be a primary carer.* Women make up 64% of primary carers compared to 71% nationally. Non-primary care roles were split almost equally in Tasmania, being 49.6% of men and 50.6% of women.

<sup>7</sup> ABS (2003) *Survey of Disability, Ageing and Carers*. Cat No 4430.0.



***A significant percentage of carers live in outer regional or remote areas.*** Of all carers in Tasmania, 44,200 (63%) carers live in the urban or inner regional areas and 25,200 (36%) live in outer regional or remote areas of the state. This proportion is consistent with the geographic distribution of non-carers.

### 3.2 Caring for Carers: The Role of Carers Tasmania

Carers Tasmania is the only organisation completely dedicated to supporting the needs and representing the views of carers throughout Tasmania. Carers Tasmania provides a diversity of services across all areas of the state to unpaid family carers looking after someone with a disability, chronic illness, chronic conditions, mental illness, who has palliative care needs or who is frail and aged.

Carers may access specialist support services especially designed to meet their needs. Services available include: information, counselling services, support groups, education and training opportunities, health and wellbeing support.

Carers Tasmania is committed to progressing and expanding innovative carer support services for the benefit of all Tasmanians. Accordingly, a strong focus on rural and remote regions, culturally and linguistically diverse carers, and indigenous carers is embedded in all program design and development.

Programs at Carers Tasmania are funded by both Federal and State sources, including the Department of Health and Ageing, the Department of Family, Housing, Community Services and Indigenous Affairs, the Department of Health & Human Services and the Home and Community Care (HACC) Program.

Carers Tasmania is a member of the national network of Carer Associations, represented nationally by Carers Australia. The network is committed to working with government, business and the wider community to improve understanding about issues affecting carers throughout Australia, to developing workable and sustainable support programs which make a real difference and are based on evidence of carer need, to forging links with international carer bodies to share knowledge and learn from their experiences, and to extending the national body of research into carer needs.

Carers Tasmania is a non-profit, community based, incorporated association and registered charity dedicated to improving the quality of life of the estimated 69,500 family carers living in Tasmania. Membership of Carers Tasmania is open to all carers and associates of carers, including interested professionals working in the disability, health or community services sectors.

#### ***Mission***

*To enhance the health, wellbeing and resilience of Carers in Tasmania, and promote their rights and needs.*

#### ***Vision***

*To recognise the value and contribution of Carers and endorse Caring as a shared community responsibility.*

## 4. The Role and Contribution of Carers in Society

### 4.1 Role of Carers in society

Carers are usually defined as those people who are providing unpaid care for family members, neighbours or friends with disabilities, mental illness, chronic conditions or illnesses, who have palliative care needs, or who are aged and frail. Often others in the wider community have little understanding of what carers do, and why it is important that they are recognized for their contribution. Carers make a significant and sustained social and economic contribution which is to the benefit of all Australians. The value of replacing the hours of informal care with formal care services would incur an unsustainable cost to the Tasmanian economy; this figure was conservatively estimated at over \$847.9 million<sup>8</sup> per annum in 2005.

The type of assistance rendered by carers is usually with the core activities of self-care, mobility and communication. These broad terms may be further broken down into areas such as assisting with personal care, feeding or meal preparation, dietary management, shopping, looking after healthcare and medication needs, doing housework and gardening, providing mobility assistance and/or transport, conducting home therapy programs, ensuring social contact or helping with other activities, looking after financial affairs, and helping the person to learn new skills or retain old skills. Many carers also do things that they don't necessarily recognize as caring, such as supervising a person's safety, supporting them emotionally, or finding meaningful things for the care-recipient to do with their life.

There is no single 'type' of carer, as they come from all sections of society, and care-situations vary greatly in their structure and complexity. Carers also have diverse needs and some need more support to keep caring than others. Consider the following model of comparative care capacity and differing needs:

	Jenny	Joe	Jesse
<b>Care situation</b>	Jenny is a 63 year old woman caring for her adult son, Ben, who has intellectual and physical disabilities.	Joe is an 81 year old man caring for his wife who has severe arthritis, mild dementia and a heart condition.	Jesse is 13 and cares for her mother who has Multiple Sclerosis. She has 2 younger siblings and an aunt living nearby who works full-time.
<b>Capacity</b>	Jenny is finding it harder to manage as she gets older, and has been depressed a lot lately. Ben still requires lots of physical help in his self-care.	Joe's kids live interstate and many of his friends have died or moved away. He doesn't like to trouble his neighbours by asking for help.	Jesse struggles to keep up with her schoolwork. She gets frustrated that her mum relies so much on her and that her friends just don't get it when she can't go out with them.
<b>Support needs</b>	Counselling support. Information on options for Ben's future care. Help planning a transition and some financial counseling to help her prepare for future retirement.	Home and garden assistance. Respite care. Help managing medications. Information on local support groups or social programs for older people.	Information on coping skills. Young carer support group to meet peers. Tutoring assistance. Home help service. Respite care for her mum and her siblings.

<sup>8</sup> Figure based on model developed by Access Economics (2005) *The economic value of informal care*. Canberra: Access Economics.

Many people do not easily identify with being called a carer, preferring to think of what they do as being a natural consequence of a personal relationship or being a family member or friend. Caring starts when the help goes beyond that of usual requirements and when the provision of that care changes the pattern of daily living. When someone self-identifies as a carer they are then able to reach out for support. Carers who have not recognized their own role or reached out for help are usually referred to as 'hidden carers'.

#### 4.2 Recognition of contribution

Carers need to be recognized to ensure that they are considered as part of the support team when decisions are made about the care-recipient's life arrangement or healthcare. It is vital that carers are provided with the information they need to ensure the appropriate care of the care-recipient. Carers also need to be consulted about any issues which may affect them in providing care or which are related to their caring role and may impact upon their own lives.

##### Importance of Consultation with Carers

Laura works full-time as a teacher. She also looks after her cousin, Pat, who is in her seventies and quite frail. Pat has been in hospital after a hip replacement. Laura has been talking to the nurses at the hospital about plans for discharge. She has arranged everything so Pat can stay with her until she is mobile enough to return to her own place.

Laura goes in to the hospital and finds that Pat is confused and distressed. A social worker has arranged for Pat to be transferred to a rehabilitation centre in the next town. The social worker says the plan was approved by Pat's daughter who lives interstate and is currently overseas at a work conference. She refuses to discuss any other information on the grounds of privacy.

It takes two days for Laura to track down Pat's daughter and get her to contact the social worker. In the meantime Pat has been placed in the rehabilitation centre which is too far away for Laura to visit after work every day.

Carers often incur significant financial expenses through providing care. They need to be recognized for the contribution they make to meeting all or some of the costs of care, and be compensated adequately where appropriate. Costs of care can include direct costs like medical appointments, transport costs, tube-feeding formula, wheelchairs, medicines, or extra electricity. It can also include indirect costs such as lost opportunity cost (e.g. part-time instead of full-time hours), extra wear and tear on vehicles and appliances, and limited time and money for preventative maintenance causing greater long term expense (e.g. minor plumbing leak leading to major water damage).

It's also important that carers are recognized for what they do so that the government and the community sector can get their planning right. Identification of needs helps researchers to understand the current and future issues faced by people within a particular area. Lack of participation can mean that an area misses out on much needed infrastructure or services. For example, in just one regional support group in 2006 over half of the families involved failed to self-identify themselves as carers on the Census form, despite having children with significant disabilities. They did not identify with the term 'carer', understand the relevance of the question to them or see the potential impact this could have on future regional services.

Greater community education is needed to help people understand more about caring. This will have a two-fold effect: firstly, to assist people to self-identify and self-refer to services if they have support needs; and, secondly, to increase wider community awareness of caring needs and promote inclusion.

## ***5. Barriers to Social and Economic Participation***

### **5.1 Workforce participation (barriers and enablers to finding and retaining employment)**

The Stronger Communities Taskforce<sup>9</sup> notes that while workforce participation rates for Tasmania are improving, they still lag noticeably behind the national average. Tasmania also has the highest rate of underemployment. The ageing population will intensify existing workforce shortages and innovative solutions will be needed to plan for a sustainable economy in the long term. Carers Tasmania considers it essential that carers who wish to re-enter the workforce or increase their level of participation be supported to do so. It is also essential that the estimated 31,600<sup>10</sup> carers who are currently in employment are supported to remain there.

Research into the barriers preventing carer participation indicates the following needs are required to assist carers obtain and retain employment:

- Flexible workplaces with employers who are knowledgeable and supportive about caring responsibilities
- Suitable and affordable alternative care options while working
- Support to transition back into the workforce, including re-skilling opportunities and assistance with placement, resumes and interview techniques
- Holiday care programs for school-aged children with special needs
- A safety net of national legislation which guarantees a minimum of 20 days paid carer leave in recognition of the people with special needs they support, and access to up to 12 months of unpaid leave if a catastrophic event is suffered by a family member.

An Employed Carer Innovative Pilot project is currently being trialled through Carers ACT. Carers Tasmania acknowledges the success of this program in providing flexible support to carers and assistance to employers through education and workplace negotiation. Extension of a similar funded program to Tasmania would be of significant long-term benefit to the community and economy.

### **5.2 Social Participation**

The Stronger Communities Taskforce<sup>11</sup> recognised that many Tasmanians "experience unwelcome isolation in the community". For many carers reconnection to community is highly desirable but often a complex challenge without appropriate support. Carers are empowered by initial contact with their peers in a safe and supported environment. They can then be encouraged to gradually re-engage with the wider community through graduated and structured activities which promote the development of further independence. Carers Tasmania is exploring options for purchasing the 'Creativity for Carers' program which works to reconnect isolated regional and rural women with the wider community. This program was developed and run in Western Australia in 2005 with the support of the Western Australian Government through the Office of Women.

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<sup>9</sup> Stronger Communities Taskforce (2007) *The state of our community report 2007: Starting the conversation*. Hobart: Department of Premier and Cabinet.

<sup>10</sup> ABS (2003) *Survey of Disability, Ageing and Carers*. Cat No 4430.0

<sup>11</sup> Stronger Communities Taskforce (2007) *The state of our community report 2007: Starting the conversation*. Hobart: Department of Premier and Cabinet.

Social participation also depends on having practical support and assistance to reforge links with community activities. Carers need assistance with accessing respite, obtaining information and sometimes may need help with practical issues such as transport and obtaining equipment or materials needed to join a course or community class. Emotional support is also needed, as many carers are subject to depression and may lack the confidence to break down barriers unassisted. Subject to obtaining sufficient funding, Carers Tasmania is developing models based on successful peer support programs and outreach activities which build a web of community support by carers coming through the program and then acting as mentors to help other carers regain a higher level of participation too.

The reform of traditional human services delivery in Tasmania depends upon the government leading a cultural and attitudinal change towards inclusive practice. The Department of Health and Human Services review of Tasmanian disability services<sup>12</sup> has identified the need for such change. It recommends that this be accomplished through "raising awareness and challenging barriers, encouraging partnerships with non-traditional partners ... creating shared responsibility and understanding the value of diversity". It further recommends the establishment of regional networks which include carers and their families. Consultation is vital for carers to engage with the process of service reform. Carers Tasmania can assist by participating in regional networks, facilitate access to carers for representation, and support carers in their participation activities.

### 5.3 Unmet Need

The Department of Health and Human Services in Tasmania<sup>13</sup> identified that less than 18% of families who were potentially caring for someone with a severe or profound disability were accessing support. Unmet demand for formal support places a greater demand on informal supports such as unpaid carers. The report recommended that people with disabilities and their families be better engaged and supported by a continuum of service delivery models based on flexible and in-home support.

Engagement requires that people needing support are contacted through outreach activities or encouraged to self-identify. Carers Tasmania is ideally placed to reach out to carers in the community and assist them to obtain suitable services by offering accessible, non-threatening supports which encourage families to overcome any hesitancy they may be experiencing. Carers Tasmania also has the advantage of being a non-government organisation, is apolitical, and has no affiliation with any religious organisation, allowing it to reach the widest possible number of people.

A successful program of regional and rural outreach depends upon building trust and rapport with communities. This process can take time and require sufficient resources to test a variety of pathways and to forge links with very insular or very fragmented communities. Carers Tasmania is already working with communities, building innovative and responsive solutions, and has the access to new programs and consultant expertise through the network of Carer Associations to enable additional project development if suitable funding resources can be obtained in the future.

Education and training for carers allows for the development of practical skills as well as building confidence and competence for dealing with 'the system'. Carers Tasmania has been working on one-off projects when funding permits, recent work includes 'Engaging Carers from Diverse Backgrounds'. A pilot program on 'Early Intervention and Crisis Prevention Model' is presently in development.

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<sup>12</sup> KPMG (2008) *Department of Health and Human Services: Review of Tasmanian disability services – final report*. Australia: KPMG International.

<sup>13</sup> *ibid.*

## **6. Practical Measures to Better Support Carers**

### **6.1 Services and Options for Care**

The Stronger Communities Taskforce<sup>14</sup> reported that reform of the community services sector required a need for "improvement in cross-agency cooperation and coordinated whole-of-government action" to succeed. Reduction of red tape, an increase in access pathways, and production of resources in 'plain English' would benefit carers alongside all other Tasmanians. A focus on inclusive practice with clear goals and measurable outcomes is a core strategy that can be adopted by all sectors: government, not for profit, and business.

For carers, it is clear that basic needs for survival must be met before 'added value' or quality of life issues can be addressed. Carers need access to sufficient income to provide care and meet basic expenses. They need security of residence and a safe environment, for themselves and for the care-recipient. They need options for flexible respite care that gives them a real break – to attend to their own needs, to maintain their own health, to maintain other relationships, and to simply re-charge their batteries.

There also needs to be a change in the model of providing care to carers. Carers and care-recipients do not want a polemic system of all institutionalized care or all community care. They want graduated options that allow for families to be adequately supported throughout the lifespan, and have step-up/step-down options which can accommodate changing care needs. Innovative retirement facilities which allow for ageing-in-place for both the carer and the care-recipient are very attractive to many families where an elderly parent is still caring for their son or daughter with special needs.

Regardless of the type of service sought, all Carers need support which is easy to find, which is flexible and responsive to individual need, which understands the demands of a caring situation, which is flexible in delivery and consistently of good quality. Assessment for services needs to look at the whole of family situation, both financially and on a 'needs' basis. Assessment for services must also include realistic calculations for the cost of care being provided. Whole of family assessment is also useful for identifying other support needs. Most of all, it is vital for carers that all service providers have staff who are well-trained, knowledgeable and empathetic.

### **6.2 Financial**

A review of the Carer Allowance and Carer Payment system is urgently recommended. Carers need realistic levels of compensation which adequately meet a fair percentage of the costs of care. Carers save the government significant amounts of money through providing informal support. It is only fair that this contribution is recognised by a system of more equitable support.

The increase of earning thresholds for those on income support would also assist carers who wish to re-enter or increase their level of workforce participation to do so without unfair penalty. Recognition of the costs of care is essential at all levels of assessment for financial or service support. Realistic measures must be devised to ensure that carers do not continue to bear inequitable costs which whittle away their real income, often dropping it to levels significantly below the poverty line.

Long term financial support is also needed through a suitable scheme to address the lost superannuation caused by reduced workforce participation from the time

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<sup>14</sup> Stronger Communities Taskforce (2007) *The state of our community report 2007: Starting the conversation*. Hobart: Department of Premier and Cabinet

needed to provide care. Carers Australia has called for a scheme based on the Federal Minimum Wage, Carers Tasmania supports the need of compensation for all carers on income support payment who are the primary carer of a person with complex, long-term needs.

A national carer card has been suggested by the other Carer Associations. This concept is also supported by Carers Tasmania, as it allows carers in small communities a more discreet way to gain discounts than using vouchers. It also allows for businesses to recognise the card by offering discounts to carers and thus gain new patronage.

### **6.3 Legal, financial and advocacy support**

A key need for carers is the ability to be able to access appropriate professional advice and assistance when dealing with legal and financial matters. Many carers have issues regarding management of the care-recipient's finances and property. Some carers need to access support in relation to enduring powers of attorney or guardianship orders. Carers looking after someone with mental health or cognitive disorders may need advice on consumer credit issues due to poor or impaired decision-making on the part of the care-recipient when unwell. All carers need a proper will, a financial plan, and appropriate insurance.

The costs involved in accessing many professional services are well beyond the reach of many carers. Legal advice services can sometimes assist, but often have case-loads filled with clients who have critical needs for legal representation, and so cannot service 'routine' issues like letters to credit providers or wills. While debt counselling and financial crisis advice can be accessed through agencies, many carers need specialist advice based around the needs of the particular care situation.

Carers Tasmania is investigating ways to expand community capacity, by accessing existing structures and services and utilising supports in innovative ways. The community hub concept is one such example which may be suitable for adaption to Tasmanian needs. The provision of regular community hubs, where people can come and get legal, financial, housing, and community services advice, have been a great success in the Australian Capital Territory. The hubs are held in a local community centre, and representatives from various community services, government departments and volunteer lawyers (coordinated through the Legal Advice Service) all attend for around 3 hours, each having a desk with a couple of chairs and some display space for leaflets and posters. People can just drop in and get free advice and information. There is a strong focus on linking people into systems of support. The hosting community centre also provides free tea, coffee and snacks to make the atmosphere more welcoming.

### **6.4 Health and wellbeing**

Research conducted by Cummins<sup>15</sup> into carer health and wellbeing shocked the nation in 2007, as he discovered that carers have the lowest level of health and wellbeing than any other group of Australians previously studied. Carers are so highly stressed that they are at higher risk of ill health than average, most have a moderate level of depression, and are more likely to carry a disability or have a chronic health condition than non-carers in the national population. Cummins found that the two biggest barriers faced by carers in accessing health care for themselves was time and cost. Carers are also at greater than average risk of stress related to

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<sup>15</sup> Cummins, R. et. al. (2007). *The wellbeing of Australians – carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.

financial hardship due to lower incomes, reliance on government support and the high costs of providing care.

Carers ACT is calling for a Primary Health Care Program to be established on a national basis to encourage a better level of preventative health care for all carers. A free annual health check for all Carers, a free annual Flu-vax and other appropriate vaccinations such as hepatitis, and a health care card for primary carers on low incomes who look after a person with complex needs, are a few of the requests made by carers participating in research in the Australian Capital Territory. Carers Tasmania strongly supports this proposal, and also calls for the establishment of a carer health and wellbeing mobile service staffed by registered nurses specially trained in carer health issues. This service could provide outreach and health education services to regional and remote areas in Tasmania. Such a service would be easy to administer, build community capacity and networks, and be highly cost-effective by reducing the demand on tertiary health services through the provision of appropriate preventative care strategies and early intervention of issues identified during regular health checks. The service could also work alongside the existing carer counselling services, providing complementary support to encourage better health and wellbeing in carers.



## **7. Strategies to Improve Carer Access**

### **7.1 Capacity for choice within Carer role**

Carers achieve greater choice about their role as a carer when they have access to sufficient resources and can choose from a range of realistic alternative options. Issues of critical concern for carers necessarily centralize around the care-recipient. They include access for health care and therapy treatments, availability of supported accommodation, options for meaningful activity, and ability to plan for future care. Carers are empowered through education, support and advocacy assistance. They wish to guide their own futures, but many need specialist advice and support to achieve success. Connection to community and inclusion, both socially and economically, are critical factors for enabling choice.

Issues for people with disabilities and carers are of concern to the wider community too. The first five year review of the Tasmania Together 2020<sup>16</sup> policy saw the community raise concerns about “family and community connection; participation by people with disabilities in the community; land issues surrounding the ageing population”. Increasingly, people are realizing that sooner or later they will either be a carer or need a carer. As the ageing population impact really starts to affect the whole of Australia, a new generation of carers will be demanding greater capacity for choice, and additional options for effective support. It is critical for all Australian states that the planning for the future is accomplished now, and a secure foundation built for a properly resourced and skilled community services sector.

### **7.2 Research into caring**

Research into caring in Tasmania is vital for planning and designing more efficient and cost-effective support services. Carers Tasmania is investing in a partnership with the University of Tasmania to undertake research into carer needs in Tasmania. The needs of special groups of carers in Tasmania are in urgent need of better understanding, especially young carers in rural and outer regional areas, new migrant groups, and sole parent carers. Funding is also urgently needed for the establishment of a range of practical pilot programs with a funded research component, to improve services in small communities and help understand the impact of wider social and economic change.

### **7.3 Need for national standards**

Legislation based around carer needs offers distinct advantages which can underpin reform and guide processes to achieve social inclusion. Carer charters, such as those in operation in Western Australia and in the Northern Territory have proved that legislated minimum standards are the surest way of beginning a process of consistent compliance across whole of government and related services. These standards set clear and achievable guidelines for carer access to information, consultation in care processes, and provision of information. They also provide for strategic consultation, representation and participation in all planning matters related to carers.

Tasmania’s main hope of achieving equity with mainland Australia will most likely come through the setting of a clear charter of national standards for recognition of care. National standards will also allow for greater consistency of service for the significant number of carers who migrate interstate each year. It can also make

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<sup>16</sup> Tasmania Together Progress Board (2006) *Tasmania Together 2020*. Hobart: Tasmania Together Progress Board.

provision for the establishment of cross-jurisdiction service agreements for people with disability support packages who are travelling interstate.

Building sector capacity is a critical goal for nationwide sector reform. The community services and health sectors are already at capacity, and struggling to meet increased demand. The sector requires a national commitment to fund the provision of additional services to states which have traditionally been neglected. Priority needs include additional funding for regional and rural areas in Tasmania, provision for the training of staff, and a realistic increase in funding of existing programs to enable service providers to increase their capacity to retain staff through reasonable salaries, and to provide long-term, sustainable services based on identified carer need.

## ***8. Conclusion***

The role of a carer is of significant value, to the carer, the care-recipient, the wider community and to the economy. Carers often face significant barriers that prevent equitable participation. Time needed for care, costs involved in providing care, and lack of suitable supports to assist with community care are all issues of concern to carers in Tasmania. Carers do want improved quality of life – for the care-recipient and for themselves and their families. Many also want the opportunity to rejoin or increase their participation in the workforce. Future care needs are of critical concern to most carers. Provision of adequate alternatives to informal care, when needed, are vital for maintaining the health and wellbeing of all carers.

This submission has presented a number of suggestions for ways to improve supports for carers in Tasmania. These ideas represent innovative ways to assist the mostly regional and rural communities throughout the state. The House of Representatives Standing Committee on Family, Housing and Youth Inquiry into Better Support for Carers is welcomed by Carers Tasmania because it offers unprecedented opportunity to examine the issues and challenges facing carers across the nation, while also considering the needs of individual states which may need a little extra help to start achieving parity with the more established community support systems elsewhere.



Westella House  
181 Elizabeth Street  
Hobart TAS 7000.

The Secretary  
Standing Committee on Family, Community, Housing & Youth  
PO Box 6021  
Parliament House  
Canberra ACT 2600

7 July 2008

Dear Sir/Madam

Enclosed please find the Carers Association of Tasmania Inc (Carers Tasmania) submission to the House of Representatives Standing Committee on Family, Housing and Youth inquiry into Better Support for Carers. An electronic copy of the submission was forwarded on Friday 4 July at 2.29 PM to [fchy.reps@aph.gov.au](mailto:fchy.reps@aph.gov.au).

Carers Tasmania welcomes the opportunity to provide a submission to the aforementioned committee and also support the submissions completed by Carers Australia and each of the individual Carers Associations.

Yours faithfully

Janis McKenna  
Chief Executive Officer