



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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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognize the displacement and disadvantage they have suffered since European settlement. Carers ACT celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

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1. Executive Summary

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family carers living in the Australian Capital Territory. We represent unpaid family carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail. Carers ACT believes that all carers and care-recipients are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. This aspiration falls far short of the reality for many carers, who have the lowest wellbeing scores for any group in Australia, being far more likely to suffer chronic health conditions and depression.

Lack of investment in the community services has led to a crisis of inadequate funding, insufficient workforce, and a poor foundation of research and development. The sector urgently requires comprehensive and well-informed reform to more effectively meet the needs of carers. Comprehensive reform requires leadership and a commitment to ongoing investment. The challenges of the ageing population require the encouragement of innovative solutions, national standards of care, and greater cooperation between government, business and the community.

Carers ACT has gathered the voices of over 280 carers through surveys, interviews and focus groups to inform this submission on key issues of concern for carers. A number of suggested macro and micro strategies have been suggested by carers during this process, and have been included for the consideration of the Committee. It is vital that carers are recognized as experts on their own needs, and that they actively participate in the design of future systems which aim to support them.

Carers take on care roles for any number of reasons, and many make a life-long commitment to providing care. Every care situation depends upon there being a pre-existing relationship, whether partnership, kinship or friendship. Carers are not paid workers, but it is vitally important that their contribution is appropriately recognized, that the costs of care are suitably compensated, and that they receive the best support available to meet their needs and assure their continued and future health and wellbeing. Carers bring humanity into 'systems' of care, whether they reside with the care-recipient or not. Their role is often demanding, stressful, self-less and complex, even though it can also be highly rewarding and valuable to both the carer and the care-recipient.

Carers need flexible and responsive supports. They may need additional and specialized assistance to maintain their connections with other family members, with the workforce, and with the wider community. Isolation, depression and poverty are some of the negative outcomes of unsupported caring. Carers are not a homogenous group. They have diverse needs which can change greatly over the lifespan. Many care situations are complex and challenging, while others require only interim support and a 'safety net' to help deal with unforeseen challenges.

Social and economic inclusion depends upon the development of key strategic supports which facilitate access and redress structural inequities. A charter of rights based in legislation would be the most effective means of enabling systematic reform of service structure and ensuring compliance from departments and service providers. Systemic barriers faced by carers when trying to ensure the effective care and treatment of their loved one will be greatly reduced by an inclusive ethos of care which enables the effective and equitable contribution of care-recipient, carer and health or community service professional.

The Federal Government needs to reform the funding of the community support sector, in order to meet the challenge of effectively supporting long-term community care in a sustainable, equitable and responsible manner. As carers themselves best recognise, all the words in the world mean nothing when people are struggling to maintain the basics of life, of food, shelter, and warmth.

The most significant barriers to participation faced by carers include the time needed to care, the cost of providing care, the isolation created by lack of appropriate supports to maintain community contact,

Many carers would like to rejoin the workforce. Most carers would like to have a better system of supports that more adequately meets their needs. All carers want a higher level of social equity and quality of life for the care-recipient.

Key strategies suggested for reform include:

- establishment of a national charter for care
- 'whole of situation assessment' which looks beyond the needs of just the care-recipient and considers all people impacted by the care situation
- easier access to clear information and flexible services, alternate pathways for contact, and flexible options for service delivery
- reduction in bureaucracy
- provision of legal advice and financial services
- provision of advocacy assistance
- appropriate and sustainable financial support
- health and wellbeing support, including a primary health care program for carers
- services which are flexible and responsive to need
- a range of services which allow for real choice between viable alternatives
- additional support with transition periods with access to specialist advice and opportunities for practical skills development

This paper is shaped by the input of carers in the Australian Capital Territory and it is hoped that the ideas and perspectives contained in this submission will assist the Federal Government to implement much needed better ways to support carers.

2. Recommendations

- i) That the existing model of community-based care is already in crisis and requires 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 would be the most effective means of enabling systematic reform of service structure and ensuring compliance from departments and service providers.
- iii) That the government commitment to long term investment in sustainable programs that meet identified need, improve the training and development of staff; those programs which make an ongoing commitment to providing a better foundation of technology, quality improvement and provide opportunity for research activities.
- iv) That current and future carers are properly supported with services and financial compensation for the costs of care, so that they, and the people they care for, are not added to existing queues within an already overburdened health system.
- v) That the government, employers and the community sector work together on effective strategies to help keep skilled carers in the workforce, while also supporting and adequately compensating those carers who undertake full-time caring commitments.
- vi) That both carers and care-recipients are recognized as people who are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing.
- vii) That the government recognizes that there is diversity in care roles and situations, and that care needs may change across time, and that episodic conditions are just as much in need of support as other conditions.
- viii) That the government recognizes that sustainable caring depends upon the preservation of existing relationships, both within the care situation and outside of it.
- ix) That the government commit to funding more Australian research to better understand how caring situations impact upon the nature of relationships – interpersonally, socially and legally – and how some care relationships are easier to manage than other.
- x) That a carer's role should be integrated with a comprehensive system of health and community care supports, based on rights to information, consultation, inclusion, and offering opportunities for real choice. That carers are the experts in understanding what will best help them to continue to provide long-term, sustainable care.
- xi) That the human rights of carers need to be considered alongside those of care-recipients, achieving a point of balance and equity which is respectful of each individual's needs.
- xii) 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.

- xiii) That better strategic support of teachers and schools is needed to give them the skills and capacity to support high-need children.
- xiv) That the government recognise that carers are very likely to be at risk of social isolation due to the demands of providing care for others. The three most significant barriers in the way of participation are time, cost and appropriate respite care alternatives for the care-recipient.
- xv) 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.
- xvi) That carers have free access to specialist advice and training, including advocacy services, legal advice, financial counselling and future planning assistance.
- xvii) 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.
- xviii) That the government commit to supporting the trial development of special needs facilities which allow ageing in place for both carer and care-recipient.

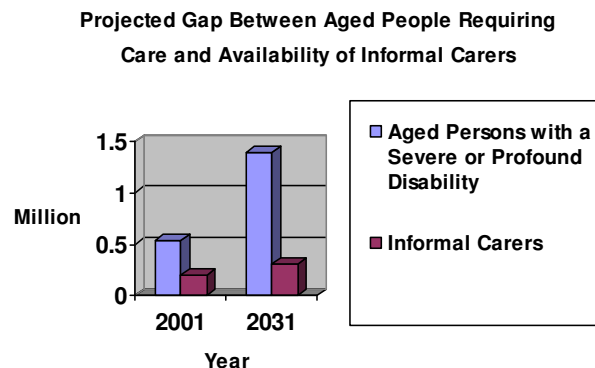
3. Introduction

The Rudd Government has recognized that family carers have an essential role in maintaining the health and social welfare system for the benefit of the entire Australian community. The House of Representatives Standing Committee on Family, Housing and Youth Inquiry into Better Support for Carers is strongly welcomed by Carers ACT, as the existing model of community-based care is already in crisis and requires an urgent and comprehensive reform in order to meet current and future need in a sustainable and equitable manner.

Lack of investment in the community services sector has seen the erosion of services through loss of real dollar value in funding, a shortfall in training and development of staff, and the sustained inability to commit to a better foundation of technology, quality improvement and research activities. There is a comprehensive shortage of workers in the sector, reflecting the lower wages and incentives offered under insufficient funding capacity, and skills are further drained by experienced workers being lured into the public service by better salaries and conditions. The system of competitive tendering for a very limited funding base has also inhibited the development of strong networks within the community services sector and restricted options for development of innovative cooperative ventures. Such a tendering system is usually based solely on value for money and fails to appreciate, address and value the human aspect of the service provision which cannot be addressed by dollar values alone

Reform of the current system needs to ensure the development of sustainable support services that more effectively meet the needs of families caring for someone with a disability, chronic conditions or illness, who is frail and aged or who has palliative care needs. Comprehensive support requires a government commitment to long term investment in sustainable programs that meet identified need, improve the training and development of staff; those programs which make an ongoing commitment to providing a better foundation of technology, quality improvement and provide opportunity for research activities.

It is also vital that current and future carers are properly supported so that they, and the people they care for, are not added to existing queues within an already overburdened health system. Families and service providers throughout Australia are already facing increasing pressures from the changing economy and the impact of the ageing population. The number of people available to provide care will greatly reduce in coming decades. With time, current shortfalls in the carer to care-recipient ratio will widen from a gap to a chasm, as the following chart based on data calculated by NATSEM¹ illustrates:



¹ NATSEM (National Centre for Social and Economic Modelling) (2004) *Who's going to care? Informal care and the ageing population*. Canberra: Carers Australia.

As greater numbers in the workforce are affected by age-related disability, or called upon to care for family members, it is essential that government, employers and the community sector work together on effective strategies to help keep skilled carers in the workforce, while also supporting and adequately compensating those carers who undertake full-time caring commitments. Successful workforce participation depends upon carers having appropriate and affordable options for the quality care of their loved ones while they are working or studying.

Research has consistently shown that carers are already a group more vulnerable to the pressure of external social and economic factors than the majority of non-carers in the population². Yet anyone can become a carer, at any time, as we all have family, friends or neighbours who may need extended care at some time in their lifespan - due to accidents, chronic illness or simply from the increasing frailty of old age. Carers do need support in their own right, as provision of services for people with disabilities and chronic health conditions is an essential need, but it is only half the picture.

It is essential that the direct input of carers and care-recipients is central to every document that intends to represent their needs and views. One of Carers ACT's core roles is to assist the voices of carers to reach the ears of government; therefore this submission has been guided and informed by the participation of over 280 carers. An invitation to participate in the submission process was sent to over 3,500 carers resident in the Australian Capital Territory who had received services from Carers ACT within the last year. 19 carers were able to participate in focus groups (see Appendix A for a group profile) and 5 more provided supplementary information from phone calls, emails and letters received in response to publicity about the review. Discussions were also held with direct service-delivery staff at Carers ACT regarding barriers to effective service provision and evidence of unmet need. Additional data was drawn from written survey forms completed by 259 carers who participated in the pre-election survey on issues for carers prior to the ACT Legislative Assembly's election due in October 2008. This survey was conducted by Carers ACT in May 2008 and distributed to 1754 members via the quarterly newsletter.

All quotations in this submission are sourced from participation in the above processes. Where direct quotes have been attributed, participants were given the choice to use a pseudonym instead of their given name to protect their privacy, and many have elected to do so. All examples and models used in this report are based on real life situations recorded during the above activities; however, some identifying details have been altered to protect the privacy of care-recipients and extended family members.

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family carers living in the Australian Capital Territory. We represent unpaid family carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail. It takes a flexible and responsive organization to effectively support such a diverse population. Carers ACT provides a service focused specifically on the needs of the family carer, from the crisis of diagnosis through to the adjustment in coping if the caring role has ceased. The organization is much more than just a safety net, as it has an active role in service provision, future planning and representation across the community services sector within the ACT. Carers ACT holds a vital role as the conduit between government and community, and aims to ensure that the needs and views of carers are central to

² Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.

the development of sustainable long term supports appropriate to their individual needs.

Carers ACT is a member of the National Network of Carers Associations, which works to assist the government to recognize and address the growing needs of carers throughout Australia. Carers ACT wishes to acknowledge the contribution of members of the Network throughout Australia, who have significantly contributed to extending the body of knowledge regarding carer needs and in developing standards for best practice in service delivery. This paper is intended to stand alongside submissions from Carers Australia and each of the individual Carers Associations, illustrating shared perspectives and the diversity of need across the country. Carers ACT does not intend this submission to be a definitive treatise on carer needs and issues, but to represent critical priorities and suggested strategies, as voiced by carers in the ACT, based on their clear understanding of current and future needs.

4. The Role and Contribution of Carers in Society

4.1 Role of carers in society

Carers are those people who provide 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. Carers usually provide some kind of ongoing assistance to the care-recipient related to core activities of self-care, mobility and communication. People take on care roles for any number of reasons, including:

- they may want to provide that care;
- they may feel that no-one else can provide a satisfactory level of care;
- they may look on it as an extension or variation of a pre-existing relationship;
- they may feel a sense of family or cultural obligation; or
- they may have been asked to do it by the care-recipient.

Each care situation depends upon there being a pre-existing relationship, whether partnership, kinship or friendship. Carers are not paid support workers, but a small percentage of carers receive some form of income assistance from the government, such as Carer Allowance or Carer Payment, in recognition of their caring role.

Australian society is increasingly recognizing the need for care to be provided for those who are unable to live independently. Communities may debate the ways in which support is best provided, but it is clear that all people need someone to care for them on a personal basis, regardless of where they live and how that is paid for. Caring may include the direct provision of life sustaining activity, but it also includes the added value of consideration, comfort, attentiveness and solicitude that gives quality to the life of the care-recipient.

“Bureaucracy cannot bring humanity into the system – only carers can do that. My mum is over 70 and she still looks out for her former neighbour who is now in a nursing home. She’s the one who goes and buys her a new dressing gown and slippers when needed. She’s the one who gets her little treats and organizes a birthday cake out of her own pension money. Someone has to do this for people. It’s not just the human rights basics of food, bedding changes and medication. It’s the extra things, the small kindnesses, that are still an essential human need,” Nique.

However, because of the personal nature of the role and its basis in familial and social relationships, many people do not identify with the concept of being a carer. Lack of self-identification can often be a major barrier to people accessing sufficient support to sustain them in that role in the long term.

“I don’t see myself as a carer – I’m her mum. It’s so damn frustrating that she’s seen as a nobody. Everyone just assumes because she can’t walk or talk that she can’t understand,” Sharon.

It is important that both carers and care-recipients are recognized as people who are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing. It is also important that the embedded inequities which prevent or inhibit participation in family, social and community life, employment and education are recognized as the joint responsibility of both community and government to redress.

Across Australia, the weave of our social fabric is changing. Family composition has been decreasing in size and cohesiveness for some time. People are becoming more at risk of social isolation due to changes in community interaction patterns. In 2006, 32% of ACT residents did not live within any kind of family unit, an increase from only 28% in 1996; a trend which is also reflected nationally. The number of siblings available to share the care of elderly and disabled parents is declining, as

most baby boomers have commonly only had one or two children compared to the average of 4+ children per family born in preceding generations. As longevity increases, many Australians are now providing care for ageing parents and even grandparents while also trying to raise a child with special needs. The emergence of the term 'sandwich generation' aptly describes how some carers feel caught in the middle of competing family care needs.

It is clear that the demand for care will continue to increase in the future. Medical care advances are improving longevity for people with disabilities and increasing post-trauma survival rates, which also contributes to an increasing number of people with disabilities in the population. The Australian Institute of Health and Welfare³ has stated that "the ageing of the Australian population and the greater longevity of individuals, including those with a disability, are leading to increasing numbers of people with a disability and a severe or profound limitation, especially at older ages".

While many carers do gain personal satisfaction from providing care, it is clear that it usually requires a significant investment of time and energy. Caring is truly a 24 hour a day, seven day a week, and 365 day a year job. It often requires carers to multi-task, do heavy lifting, be an expert organizer, and deal with personally confronting situations which engender a significant amount of stress.

"Being a carer is like having another full-time job on top of everything else ... you end up being the advocate, the politician, the everything." Louise.

Indeed, the role of a carer can be so complex and time-consuming that many carers become exhausted by the continuous demand of their daily workload. Despite the demands of care, many carers do have a strong sense of the worth of their role, and even manage to retain a sense of humour.

"The workload is huge. You get to a state where luxury living is having time to go to the toilet," Nique.

Carers also often have to learn new skills, gaining a wealth of specialized knowledge about the issues which they and the care-recipient are dealing with. This, too, goes beyond the usual requirements of familial or social responsibility. Consider Judy's statement below. It is clear that her level of responsibility is significantly higher than that of a parent of a young man without special needs, and will remain so for many years into the future. She manages his mental health and medical care, helps him to build social skills, and tries to find meaningful activity to help him achieve a degree of future independence.

"Our son (22) has serious depression and anxiety with mood swings ... he has no friends. I'm the principal carer and am trying to motivate, encourage and stimulate him." Judy.

Carers make a vital contribution to the Australian economy through their provision of unpaid skilled work. Caring is more than just provision of personal care and administering medication. At various times carers may need to be teachers, speech therapists, occupational therapists, counselors, coaches, safety supervisors, chauffeurs, nurses, social workers, researchers, physiotherapists, financial managers, mobility assistants, or future planners, among a myriad of other roles. Organizational skills are also needed for coordinating management of the medical, social and educational needs of the care-recipient.

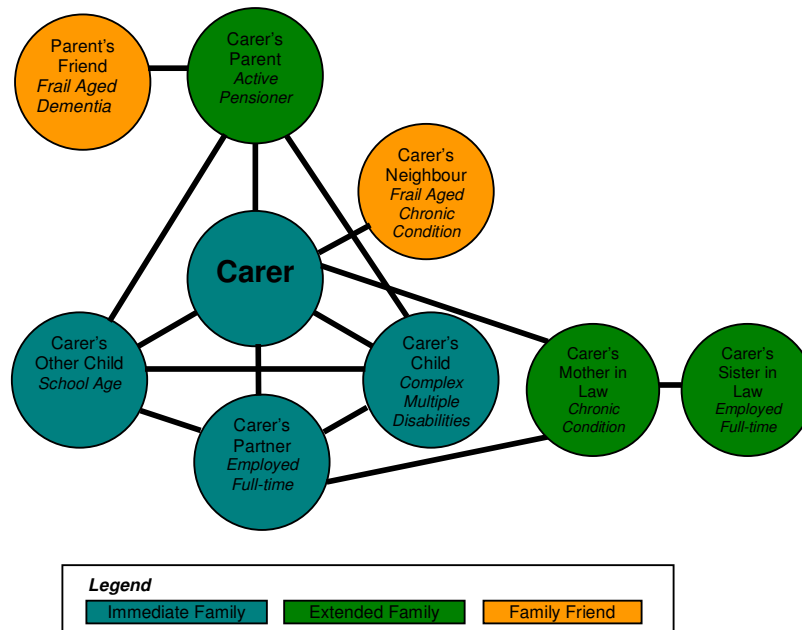
"We are caseworkers. The government doesn't fund caseworkers for Carers, so we need to coordinate services for the cared-for-person. They would be forking out lots of money if they had to pay for that," Louise.

As critical as it is for government to recognize the diversity of duties within an individual care role, it is also important that the diversity of care situations are also

³ Australian Institute of Health and Welfare (2007) *Australia's welfare 2007*. Canberra: AIHW Cat No AUS 93.

understood. Australian families are all juggling multiple roles in response to the complex world we live in, and achieving a balance between family and work has become a crucial part of most people's wellbeing. Accordingly, not every care situation can be neatly divided into one-on-one roles of primary carer, secondary carer or supplementary carer. Care needs may be reciprocal, as in the case of many elderly couples who provide care for each other based on varying need and capacity. Care needs may also be as complex as the following example, based on a real-life situation, where a number of individuals complete a range of care tasks which are negotiated around competing demands from work and other family commitments. It is clear that much of the care in these relationships depend upon the continuing capacity of a few key individuals. Add a serious illness, a major accident or a breakdown caused by stress, and you have a fracturing of the support web; increasing the other participants' stress loads and workloads, which in turn reduces their capacity to provide unpaid care or availability to remain in full-time work. Such an event would have a 'flow-on' effect into the immediate network, the wider community and the local economy.

An Example of Complex Care Needs



Alongside the needs of a care situation, it is also important to recognize the primacy of the pre-existing relationship. Many carers have informed Carers ACT that they struggle to maintain personal relationships, especially when lacking effective support. Taking on a caring role fundamentally changes the relationship between two people, in ways that may both enhance and challenge the pre-existing connection. Sustainable caring depends upon the preservation of existing relationships, both within the care situation and outside of it, as isolation is one of the biggest contributory factors leading to carer burnout. As you will see from Nique's comment, it can be a delicate balancing act between the demands of the care role and maintaining the needs of the family unit.

"We have a child who has needs, and we care for those needs. We are also a family of four. We are a couple. We have another son whose needs must not be forgotten. We like to do normal, everyday things when possible, like sweep our driveway. He is

only one part of things, but everything gets polarized by his need ... I am his interpreter. I am his emotions. He has no ability to express speech or emotion in ways that other people can understand at the moment," Nique.

Or, as another carer expressed it:

"There's more to life than disability, we don't want it to rule our lives," Louise.

More Australian research is needed to better understand how caring situations impact upon the nature of relationships – interpersonally, socially and legally – and how some care relationships are easier to manage than other. For example, many carers of their spouse have anecdotally informed Carers ACT that they find the system easier to negotiate because their rights as spouses (to information, to consultation and to participation in care) seem to be better recognized and understood than those in other caring situations.

Provision of care does exact a cost on the carer. There may be physical demands from lifting and showering or changing a person to completing the extra household work generated by direct care needs. There are emotional demands from providing positive support, encouragement and reassurance, such as when supporting a person through invasive and painful medical treatments.

There are high organizational and time demands on carers, (e.g. obtaining and administering all needed medications, managing appointments, maintaining therapy programs, and ensuring educational, social or activity needs are met). There are also significant direct and indirect financial costs incurred through providing care; examples of which will be detailed later in this submission.

Care needs are not homogenous across the population. Support needs vary with the complexity of issues for the care-recipient, the availability of other forms of informal support, the skills level of the carer and their individual health factors.

Some carers may require intensive support through the bad patches, and the rest of the time may want nothing more than the security of knowing that a safety net is there if needed. Other carers require ongoing assistance on a fairly consistent level due to the complexity of their care circumstances.

It is clear that times of transition, such as diagnosis or adolescence, usually require more support. Many chronic conditions are episodic in nature, especially cognitive and mental health disorders. Carers may need support if the care-recipient moves into residential care, or if the caring role ceases due to bereavement. It is important to recognize that the rest of life does not stop just because someone requires care.

Insight into Caring

Q. How do you see your role as a carer?

A. I look on myself as a shift worker.

Shift 1 is getting the family up and out into the world for the day, while also doing all the things that need to be done for my son – feeding, dressing, toileting, medication and coping with seizures.

Shift 2 is my 'out in the community work' where I go and do reading at school, volunteer in the canteen, and see if my elderly neighbour needs shopping so I can get it when I do my own, that sort of thing.

Shift 3 is school pick up, then playtime, home therapy time, homework time for my other son, dinner time, family time and doing what ever else still needs to be done.

Shift 4 is bedtime, an intensive process where it can take up to 2 or 3 hours to get my son into bed and settled some nights.

I have to fit in the 'care' things alongside all the usual household jobs that need to be done.

There is always extra laundry to be done, plus time spent going to routine medical appointments, therapist appointments, specialist appointments, and keeping track of medications.

Organizing his new wheelchair has been almost a year of paperwork and problems. It all takes time.

Nique

The impact of other 'life events' such as moving house, divorce, death or illness in the extended family can also mean that extra support is needed for a while.

"The demand is constant – I think I need more sleep not less sleep as I get older!" Barry.

Ideally, a carer's role should be integrated with a comprehensive system of health and community care supports, where the care-recipient's needs are met and the carer's health and well-being are also safe-guarded. A system where both the care-recipient and the carer have choice about options for support, and have access to viable alternatives to home-based care when needs increase. An option of 'stepping down' the level of intervention for up to six months when things are going well or new options for care are being trialed, without losing all eligibility for benefits or requiring a new assessment to regain former supports would also be of assistance to many carers and care-recipients.

Many carers deal with episodic conditions where the care-recipient's needs are not at a consistently acute level. Mental health issues, acquired brain injury or cognitive conditions, and some degenerative conditions are the most likely conditions to be episodic in nature. The role of carers for people with episodic needs is not well recognized. Assessment for supports and services is often difficult, with many failing to qualify even for Carers Allowance despite the significant, ongoing impact of the care relationship.

4.2 Recognition of contribution

While recognition of their role and contribution is important to the vast majority of carers, there are many ways of accomplishing such recognition and opinions on the best means will vary across the carer community. Within the context of individual care relationships, recognition for some carers may be as simple as space provided on an assessment form to record information about the care being provided and being consulted and listened to by the support and health care team. On a broader level, the appropriate means of recognition for many carers may reside in a national charter of care or other appropriate form of legislation, where their contribution to the social and economic benefit of Australian society is formally recognized by the Federal Government. Some carers see participation or representation on planning and policy avenues as critical to achieving inclusion and understanding of need within the health and community services sector and in government departments. Many carers consider suitable financial recompense or due compensation for the costs of providing care as the best way of recognizing the contribution of carers.

"I would like to see the Prime Minister try being a carer for a week, and experience what our lives are really like," Dinah.

Recognition by health and community service providers is critical for the majority of carers. The well-being and health of their loved one is a paramount concern for all carers. The provision of ongoing care and support by carers has a proven impact on improving the general quality of life for the care-recipient; yet the complexity of caring for someone while also dealing with 'the system' creates additional challenges for many carers. Systemic barriers faced by carers when trying to ensure the effective care and treatment of their loved one are greatly reduced by an inclusive ethos of care which enables the effective and equitable contribution of care-recipient, carer and health/service professional.

"The role of a carer is totally undervalued and very complex ... governments need to formally recognize carers – it can't be tokenistic or piecemeal," Ian.

Carers need a level of access or participation within 'the system' in order to be able to provide effective care. They can offer a wealth of information to assist with accurate diagnosis or selection of most appropriate treatment. Carers also need information about treatment and care in order to carry out their role to the best of

their ability. The right to privacy is a delicate balance which must be maintained; however misunderstandings and over-zealous interpretation of privacy regulations can lead to ridiculous and potentially dangerous situations developing.

For example, Carers ACT staff report occasions when carers have been included in discharge plans for the care-recipient, usually in a central role for assumed provision of care, but have been refused access to any information about the plan on the grounds of right to privacy. It is clearly unhelpful to the care-recipient if the carer arranges all of their transport and medication, but is not provided with key information about appointments, possible side-effects of new medications, and directions on circumstances when it may be appropriate to return for extra assistance. Anecdotally, it seems not unusual for a carer to go to visit a care-recipient in hospital and find they have been discharged and are waiting to go home, with no more information than a couple of prescriptions and an appointment card.

A critical objective of any healthcare or community service reform must be the right for carers to be consulted on all aspects of care and treatment which will directly affect them in their caring role, unless there are compelling reasons for them to not be consulted. This objective would clarify the expectations and define pathways for treating health professionals and service providers to interact with carers in a more effective and cooperative manner.

It is critical that the needs and perspectives of care-recipients and carers are not assumed to be homogenous. Indeed, sometimes viewpoints and needs may be completely oppositional. Care-recipients retain the primary right to make their own decisions when well, and this may include a decision not to involve their carers in a particular aspect of care.

This right is recognised and respected by Carers ACT, as is the right for carers to make choices about their own health and wellbeing, and about the supports they need to enable them in the continuation of care. To put it simply, the human rights of carers need to be considered alongside those of care-recipients, achieving a point of balance and equity which is respectful of each individual's needs.

A charter of rights based in legislation would be the most effective means of enabling systematic reform of service structure and ensuring compliance from departments and service providers.

It is vital that any national legislation reflects the contemporary reality of community care, and recognises the rights of care-recipients and carers to be consulted and actively involved at every level, from systemic policy or service planning to the development of individual plans for treatment or ongoing care. Legislation is a critical component of social structure. It provides a foundation of support which underpins policy development and service provision. It outlines the rights and responsibilities of all people affected, and it ensures their due protection under the law. Carers may feel more secure when their rights and responsibilities are clearly set out in such a charter.

Insight into Caring

Even getting basic services is difficult. My son has been in crisis for many weeks now. He is psychotic and not sleeping. The sleep deprivation is killing me.

His psychiatrist is away on holidays and the earliest appointment is in over three month's time. I wanted a second opinion about these new medications which I feel are making things worse but the other psychiatrist won't see us when we are already listed with someone.

We have been to the hospital four times in the last five weeks, but there are no beds available. The mental health services are all full up and short staffed so they can't offer us any help either.

I am exhausted and so very frustrated with it all. There is no respite available, we don't qualify.

I feel that as a carer I am often not listened to or taken seriously by medical staff, yet I live with this situation every day so I know the signs much better than they do.

Florence

"It's so hard to know what you are entitled to, and there's guilt too ... I feel bad asking for help, because I feel I should be able to manage things by myself," Nique.

The Federal Government needs to make a strong and unequivocal commitment to establish a system of legislative support for carers. Good legislation for carers can require the development of policies for a responsive and inclusive system of health and community services, it can establish national minimum levels of acceptable support for carers, and can motivate educational institutions and workplaces to achieve a greater level of inclusion through the adoption of carer-friendly practices. Of course, legislation and policy needs to be appropriately supported by sufficient funding. The Federal Government needs to reform the funding of the community support sector, in order to meet the challenge of effectively supporting long-term community care in a sustainable, equitable and responsible manner. As carers themselves best recognise, all the words in the world mean nothing when people are struggling to maintain the basics of life, of food, shelter, and warmth.

"It's fine to have a glossy policy paper saying how wonderful carers are, but if they don't follow through with real supports there's no point," Louise.

Some insight into such barriers and practical solutions, as suggested by carers in the ACT, are discussed in the next section.

5. Barriers to Social and Economic Participation

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

The biggest barrier to workforce participation for the majority of non-working carers is quite simply the time demanded by the provision of care. In real terms, many carers are aware that they are presently of more economic value to the government to be providing unpaid care in the home than they would be in the workforce. Yet, this view is short-sighted as many carers would greatly benefit from the reduced social isolation and improved economic circumstances gained from increased workforce participation. The Australian Institute of Health and Welfare⁴ notes that “primary carers have a lower labour force participation rate (39%) that people who were not carers (68%)”.

“You’re ability to generate income is reduced, and when you want to retire your quality of life is reduced,” Ian.

As the available workforce shrinks with the ageing population, the Federal Government needs to adopt a long-term view by investing in carer skills and encouraging the development of innovative and flexible work practices to better enable the hidden army of carers who wish to increase their level of workforce participation. In the Carers ACT Territory Pre-Election Survey, 160 of 259 respondents indicated that they were not currently in the workforce due to retirement or caring commitments, 25% of these carers said they would like to return to the workforce on a part-time or full-time basis if they could be supported to overcome barriers preventing participation.

The need for appropriate and affordable care alternatives is paramount to carers. There are insufficient day centre activities for frail aged people (both dementia-suitable and non-dementia programs) and a significant lack of options for adults with disabilities. In-home respite is expensive, and carers anecdotally report that agency respite workers are notoriously unreliable and very transient due to poor pay and conditions in the sector.

Flexible work options for carers are also needed. Employers need to be more innovative by offering positions that fit in with school hours, or based around home-based work, compressed or annualized hours.

Carers also need support through sufficient leave provisions in the proposed National Employment Standards, to recognize that they have special needs which must be accommodated and supported by appropriate legislation.

Insight into Caring

I was a registered nurse with a high functioning job before I had to leave work and take early retirement. I am caring for my husband who has Multiple Sclerosis. I used to work for many years but his needs increased and they were not being met by agency workers.

I find that boredom and limitations on lifestyle are the biggest problems we both face, as we are fortunate to be financially comfortable.

He has very little available that is suitable for him to attend. He doesn’t want to go to activity programs filled with elderly people.

I would love to get back and do even part-time work again, but finding suitable care for my husband is impossible.

Maria

Carers need programs that offer them re-skilling opportunities and mentoring support to re-enter the workforce. Many lose confidence after years of caring and

⁴ The Australian Institute of Health and Welfare (2008) *Australia’s health 2008*. Canberra: AIHW.

have no recent references. Some carers also need help with practical problems such as having a few presentable work outfits, working out transport arrangements or transitioning the care-recipient into respite care.

Employment support programs, such as the Employed Carer Innovative Pilot currently being run by Carers ACT (with funding from the Department of Health and Ageing), have been invaluable in supporting carers to continue in work or in helping them to return to work. The strength of the program delivered by Carers ACT lies in its ability to offer flexible support options and to work with the employer as well as the employee. Eligibility for this program is currently restricted to a small selection of carers who must fit into highly specific criteria, and Carers ACT strongly recommends the expansion of eligibility criteria to all carers, a roll-out of the program across the nation, and a commitment to long-term funding.

Employers often underestimate the value of supporting existing carers struggling to remain in the workforce. Many carers hide the extent of their caring responsibilities as they fear the consequences of disclosure. In the end they quit without asking for help, and the employer loses a skilled and knowledgeable worker.

"I had to leave work. Need all the school holidays off, and when she is sick. What employer would stand for that?" Sharon.

A significant number of carers are under-utilised and working at skill levels way below their capacity because their care needs force them into lower level jobs where their absenteeism is more easily covered by an employer. Stress is a big factor for many carers, and they choose lower pay or lower skilled jobs because they understand that they no longer have the capacity to maintain demanding career positions. Yet the wastage of their skills is of concern. Employers are starting to recognise the value of flexible workplaces, but may also consider assessing their workforce for under-utilised skills and negotiating ways to use dormant skills without creating additional stress loads.

"I'm now back working. It's part-time and lower paid than I would have got otherwise because I need to be flexible and available for my child. I focus more on piecemeal work, and take work that is not necessarily interesting. I had to make that choice – family versus career," Louise.

Insufficient support to special needs children in school also has a 'flow-on' effect to parents. Better strategic support of teachers and schools is needed to give them the skills and capacity to support high-need children, and to only contact the parent as a last resort rather than as a first or second option.

"I was being called by the school every day because they couldn't cope. So I'd get to work, have a sigh of relief, then the school would call and I'd have to turn around and leave again," Louise.

Additional after school and holiday care programs are needed for working parents. Few programs have suitable places for children and young people with special needs. Many existing generic out of school care programs are only for children up to age 12, leaving carers of high-school aged children with no option but to limit or withdraw from workforce participation to care for their children.

Provision of additional day care options, responsive and flexible support programs for carers, an educational program for employers, and a safety net of suitable workplace legislation are relatively simple solutions to increase workplace participation for those carers who wish to re-enter and remain in the workforce. The long-term economic benefit of such supports makes them highly cost-effective in a time of growing national skills shortage.

5.2 Barriers to economic participation - the costs of care

The Carers ACT Territory Pre-Election Survey indicated that it was clearly evident that inflation of basic staples, such as food, utility costs and the price of petrol are having a significant impact on carers; with over 63% of respondents agreeing that the changing economy was impacting on their life. Accelerating rents and mortgage costs are also increasing financial pressures to unsustainable levels. High credit debt and lack of capacity to access emergency funds are already issues of severe concern to many carers.

Carers ACT has seen a marked upsurge in the number of carers coming in for food vouchers or seeking other urgent financial assistance for car repairs, and repair/replacement of essential white-goods such as fridges and washing machines. The food voucher and emergency support programs are funded from sponsorship arrangements made possible by the generosity of a leading Canberra construction company. A new development is that many of the families have someone in the workforce, rather complete dependence on government assistance, which indicates the level of economic pressure impacting on all carers. Long-term solutions are needed to redress financial inequity for these carers and care-recipients, living in embedded poverty with insufficient funds to ensure continued health and wellbeing. The 2007 Taskforce on Care Costs⁵ report found that “although the public rhetoric acknowledges the need to help carers of the aged and people with a disability ... in reality tangible support is insufficient and ineffective.”

Carers needing income support may depend on a number of government payments depending on their individual circumstances. Whether on the Carers Payment, an aged pension, a disability support pension or a supporting parent payment, it is clear that current levels of income are insufficient to now meet the immediate, basic costs of living. Many carers struggle with debt and have greatly increased expenditure due to the costs of care. As one carer noted, the complexity of circumstances can quickly snowball into an insurmountable list of financial problems.

“I need a car that can fit a wheelchair. I need finance, but I can’t get it. I can’t do what a normal mum would do for her child. I don’t have super. I don’t get sick days, and I have to find money to pay for a break [from respite services] when I can’t cope anymore,” Sharon.

The Carers Allowance offers an equivalent pay rate of less than 30 cents per hour when providing 24 hour care. Originally designed to be an offset for some of the costs of care, the allowance also fails to keep pace with even the basic needs of medication, therapy, care-related transport, or equipment required for supporting most people with disabilities or complex care needs. The complexity of application process and restrictive criteria for eligibility are also a significant disincentive to many carers.

“I can’t accept charity. I look on the support we get as wages for what I do,” Nique.

Carers who are on self-funded superannuation fund pensions are also often caught in a gap of inequity, as they do not qualify for the discounts available to aged or disability pensioners. Meeting the full costs of their care quickly erodes much of the initial financial advantage. This problem may be further exacerbated by the expected poor returns on investment expected at the end of the 2007-08 financial year, due to the poor performance of the stock-market.

“We’re not entitled to things like Utilities Allowance because I’m not on Carer Payment, and Ian is not on a Disability Pension. He has poor temperature control so he needs the air-conditioning on all the time. Those bills are enormous,” Maree.

⁵ Taskforce on Care Costs (2007) *The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability*. Online version: www.tocc.org.au.

“The organisations that provide respite and other services don’t take these bills into account when they calculate how much you can afford to pay,” Ian.

Carers often need to maintain private health care cover, due to the nature of medical and therapy care needed. The growing costs of such cover, the premium rates needed, and the increasing gaps between actual cost and benefit can all place increased demand on limited budgets. For many carers, the alternative to paying for such cover means lengthy waiting lists for already over-stretched publicly funded services.

“It’s not a luxury for us to have private health fund cover, it’s essential, otherwise we would have no say with the treatment available to Ian,” Maree.

The cost of care can be divided into direct costs and indirect costs. Direct costs include consumables, utility costs, and capital costs (such as equipment and modifications). Indirect costs can include additional wear and tear on items and lost opportunity costs. Consider the following example, based on a real-life carer situation which is fairly typical of a family caring for a child with a disability.

Costs of Care

An Example of One Family’s Current Price List

Direct

\$5,000 juvenile wheelchair (needs to be made to measure for each child and will be quickly outgrown in coming years. ACT equipment subsidy scheme covers up to 20% of cost – ‘optional’ extras such as tray attachments can be completely at family’s own expense.

\$4,000 for modifications to driveway and ramp for wheelchair access (approximately \$1,000 subsidy only is available)

\$2,500 for urgently required paediatric dental care requiring general anaesthetic for child with disability

Additional \$60-\$80 per week in costs for petrol for medical appointments

Cost of special feeding formula as child still bottle-fed. Teats for bottle feeding (average cost per pack of 3 is \$6 – child can bite through four teats a day at times).

4-10 nappies per day (even with full nappy subsidy in place) nappies required have to fit a six year old

Medications: 2 anti-convulsants per month on PBS cost \$5 each, 1 anti-convulsant per month not on PBS is \$30 per month. Side effects from medication create need for additional 1 to 2 prescriptions each month.

Indirect

Restrictions on family budget ensure no funds are available for routine house and garden maintenance which, over time, devalues the family home. Lack of ability to conduct preventative maintenance may also lead to a need for costly repairs in the future.

Loss of future income from reduced workforce participation of parent at home. Loss of future promotion opportunities for parent in workforce due to inability to study, do extra hours or attend work functions.

Own dental care needs in future will be higher because of current inability to afford regular dental visits.

Extra water and power costs for additional laundry loads. Soiling can require daily changes of bedding and multiple changes of clothes.

Additional use of appliances means that washing machines, heating/cooling systems and hot water systems need repairing or replacing more frequently than under average household conditions.

Additional use of car requires more frequent servicing needs, repair costs and replacements for tyres etc.

Own health is placed at risk as health care card only covers care-recipient. Other family members do not visit doctor unless unavoidable due to cost involved. Bulk-billing clinics usually have 2-3 hour wait, which is very difficult in current circumstances.

Funding for equipment is a particular problem for many carers, as items are very expensive. Families of children with disabilities face particular issues as many items are quickly outgrown, and being custom-made for the child's specific needs so are not easily used in a second-hand system. Families are often faced with long delays in accessing approval for even partial funding for items such as wheelchairs. Currently a year long process in the ACT is not uncommon. By the time many families have got approval, their child has grown and needs remeasuring which changes the cost of the item.

"I heard on the radio about someone who needed a wheelchair and a hoist. They were fundraising. Even the DJ asked why wasn't the government providing support. The last wheelchair cost over \$7,000. A few services provided some funds to help, but it still took 2 years to arrange the funds. I am now raising funds for a wheelchair accessible van, it will cost \$50,000 for a second-hand one," Sharon.

Many carers feel like they are being made to feel like a charity case and beg for money for essential equipment. This process is stressful and demeaning for families. Hoists and wheelchairs are essential for enabling mobility and preventing injury to carers and care-recipients. It is inequitable that medical and care facilities would not allow staff to move patients without proper equipment or training in occupational health and safety procedures, but as a society we expect carers in their own homes to do just that. People with complex care needs such as quadriplegia or who need tube feeding rely on an essential minimum level of equipment to physically survive. Costs of this equipment are usually met by carers at their own expense.

While there are some Federal and State funded programs for equipment provision to people with disabilities, including the aged, they are not a whole-of-life program. These are usually age-related and funded at levels that fail dismally to meet real costs, even though they are sometimes indexed. Most schemes are tokenistic and fail to relieve the tremendous financial burden on individuals and families.

"Costs of disability mean paying for the things you need to survive! Before you even put food in your mouth," Ian.

The Federal Government needs to recognise that many carers are financially subsidizing people on pensions, due to the insufficiency of pension income. The cost of residential accommodation takes priority in all circumstances, and some supported accommodation facilities for aged and disabled people often take up to 85% of the pension, which leaves little for personal needs.

It is often the case that the person with the disability has a pension, with a Health Care Card, and qualifies for discounts on rates and utilities. However when that person lives with a carer who is still in the workforce, the carer faces additional costs from providing care (e.g. staying in a bigger house instead of downsizing) but does not qualify for discounts because the house is in their own name. Carers cannot put the house in the name of the care-recipient because they would not qualify for a mortgage.

Another barrier to equitable economic participation is the little recognised problem of care-recipient's misusing credit facilities, which can create significant cost for the carers. Several carers of people with intellectual disability, cognitive conditions and mental illness have provided anecdotal evidence of problems created by easy access to credit facilities, such as store cards, credit cards and mobile phone contracts.

"My nephew has an intellectual disability. He looks okay but he has behavioural problems and a really bad temper. He keeps getting into debt with credit cards and mobile phone bills, and then I have to pay them up to \$600 at a time. The companies call me and put pressure on me to pay. He also gets angry when I say I won't pay and he breaks things in my house. He is sneaky too – I tried to take the card and phone away but he hid it and said it was lost," Neneng.

The care-recipient is not in need of guardianship orders, but clearly has limited capacity to understand the consequences of their actions, or may be suffering an episode of illness where judgement is impaired. Carers are often the ones who are contacted (and in some cases pressured) by companies seeking recovery of debts. Some are also fearful of challenging behaviours in care-recipient if they do not assist to clear the debt. While carers have no direct financial liability for the care-recipient they do need support in dealing with such problems when they occur.

"It's often unrecognised how many carers do get pressured or threatened by family members to hand over money or assets, especially when mental health issues or drug and alcohol addictions are involved. They need a special program to educate and empower people as to their rights, and to give them skills to help them deal with these kinds of situations. Otherwise they just end up supporting bad habits because they don't have any other way of dealing with it without putting themselves at risk," Maria.

Carers of people with mental health issues and drug or alcohol addiction may face an additional problem when their personal possessions are damaged or stolen by the care-recipient. These losses are not covered by insurance. It is also difficult to track down where stolen items have been sold and try to claim them back. Carers will not usually take action that leads to criminal charges against the care-recipient. However carers do need access to advocacy and support when dealing with such complex issues to assist with finding ways to resolve issues without putting the carer or care relationship at risk.

5.3 Social Participation

Carers are very likely to be at risk of social isolation due to the demands of providing care for others. The three most significant barriers in the way of social participation are time, cost and appropriate respite care alternatives for the care-recipient.

"I don't have the time. This event [the focus group] is the first I have been to for over a year. I can only go out if I have support from respite care," Barry.

A vital part of Carers ACT's role is to keep finding ways of effectively reaching completely isolated people; the hidden carers who are often most at risk. Cummins⁶ found that carers "have an average rating on the depression scale that is classified as moderate depression". Social isolation is a significant contributor to depression. It is also vital that carers enjoy the opportunity to maintain relationships with other family members.

"Lack of respite care for adults with mental illness, means I am unable to attend the birth of my first grandchild overseas. I can't leave my son alone, and he refuses to get on a plane," Florence.

Social activities and support groups assist many carers to link with other carers and the wider community, which has the potential to improve their health and wellbeing. It is important for many carers that they access safe and welcoming environments, where there are others who understand their situation.

"I go to 2 support groups and they're good. Dementia is like a slow death, it's so hard to cope with," Riekie.

Other carers choose to access mainstream activities, subject to access (or respite support) being possible for the care-recipient, and whenever they can afford to. Flexible options for support are vital for many families. The assistance of a respite

⁶ Cummins, R. et. al. (2007) *The wellbeing of Australians – carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

worker to care for a child with special needs may be all that is needed for a family to enjoy a day as part of the community.

"We make choices as to what we do as a family dependent upon whether I name deleted I can cope with it. He doesn't like noise or crowds ... and there are financial constraints, it's what you can afford. Respite is great but you have to pay for the worker, so it could be over \$100 just to go to the movies," Louise.

Many elderly carers also find that lack of affordable transport is a significant barrier to participating in social activities. The Australian Capital Territory has a lack of sufficient numbers of wheelchair accessible taxis or other suitable public transport options for people with mobility assistance needs. Many care-recipients in the ACT are eligible and receive Taxi Subsidy Scheme Vouchers (if they know about the Scheme). This scheme is designed to offset taxi fares for wheelchair accessible taxis, and is similar to many other taxi subsidy systems in operation around Australia. However, the ACT Scheme has not increased its subsidy for many years and yet taxi fares have increased quite significantly over the same period. These taxis are expensive and are relatively unaffordable for any long distances. As a comparison, Seniors can have unlimited travel for \$1.40 between 9.30am and 3.30pm daily on Action buses, but the lack of disability accessible buses means this public transport option is not a viable alternative for older people with mobility problems.

6. Practical Measures to Better Support Carers

6.1 Identifying and responding to carer needs

The ageing of the Australian population is due to place even more stress on the national economy as the available workforce shrinks and a greater number of aged and disabled people require care. Yet the health and community care systems are already at full capacity due to systematic under-resourcing and lack of effective long-term planning. The Federal Government needs to commit funding towards research and development of workable and sustainable solutions by breaking down the silos of responsibility; for example, bringing together people with disabilities, the aged, and carers, to work with health providers, housing developers and government planners to develop and establish innovative, sustainable, prototype models for future care and community living.

Key priorities for action have to be ensuring that basic needs for survival are met before 'added value' or quality of life issues can be addressed. Carers cannot even think of future planning or arranging respite when they are struggling to pay bills and put food on the table. It is also critical that across Australia there needs to be a change in our philosophies of care, where a model of care as the joint responsibility of community and government is developed. A holistic model is needed to address issues across the life-span, without sectioning people with special needs into little boxes of 'early intervention', 'adolescence' and 'aged care' and leaving yawning gaps in service provision in between. Most of all the model of care needs to be responsive to changing needs of carers and care-recipients, where choices are available and well-supported, rather than a polemic system of all institutionalized care or all community care.

Regardless of the type of model directing care or the individual service being sought, all carers need support which is:

- Responsive to individual need
- Understanding of the demands of a caring situation
- Flexible in delivery
- Easy to access
- Consistently of good quality.

6.2 Assessment and access

There is a consistent wealth of evidence, both nationally and in the ACT, which calls for the development of a system of 'whole of family situational assessment' when determining eligibility for financial assistance, services and support needs. Fair and equitable assessment of care situations needs to be developed around a matrix tool which examines the impact of care as well as traditional measures such as type of care provided and time spent caring. The assessment needs to be conducted by a trained interviewer either in-home or at a less stressful venue than Centrelink, such as a private room in a family assistance office, as most carers would not wish to broadcast the intimate and complex detail of their lives at a public counter. The assessment also needs to include a fair and equitable assessment of the costs of providing care, with a safety net system for those carers who find that annual costs have exceeded any previous estimates.

"I feel like the government takes advantage of carers, they know we don't have time to chase things up and they make it complicated in the hope that we will go away,"
Judy.

Carers need support for the initial access process, including clear pathways for referral, and to be offered respite support to attend interviews so they do not necessarily have to discuss care situations in front of the care recipient. Bureaucracy is an issue for all carers, and few have the ability to remain on hold in a telephone queue for an hour or so.

"We went to Centrelink to pick up some papers, it took so long to get assisted and to fill in all the forms that we gave up in the end," Maree.

Alternative pathways are needed for maintaining information on current care situations, including electronic facilities for those who have internet access or service-initiated phone calls, home visits, or scheduled appointments for those who have no internet access, mobility issues or who have preferences for face to face contact.

"The ACAT assessment has inconsistent processes. Trying to get a review or an extension of services is difficult. You need to have the consistency of dealing with one coordinator, as you keep going over and over things with different people," Kate.

Permanent disabilities need to be recognised as such, especially for frail aged clients who unlikely to regain youth and vitality. Contacts for these carers need to focus on checking whether more support is needed rather than ticking a box to check minimum service eligibility.

"Every so often, they ask you 'does she still have a disability?' when it's clear that her conditions are permanent," Barry.

Responsiveness in the system also needs to be increased. Care needs change over time, but it is often difficult for carers to get services to respond to changed needs in a timely manner. Episodic conditions seem particularly difficult to manage administratively, despite the proven success of 'step up step down' models of care in the mental health system.

"Care needs change, sometimes it's high and sometimes it's low. The system isn't responsive to any fluctuation," Chris.

"My son had a relapse after 4 years of relative stability. We found that we had to start all over again as far as the system was concerned, we had lost touch with our case manager, and when we tracked him down in the department, he said he couldn't help us," Florence.

Carers also need clear and supportive pathways for appeals and/or dispute resolution, pathways which would be little needed if a fair, accessible and equitable system of initial assessment was properly in place.

"It took over 6 and a half years of messing around for Centrelink to finally approve us for Carers Payment. We had to take them to the Appeals Tribunal in the end. The process is full of inconsistencies. For example, they say you need a form, and the form is in the pack, but it turns out the form is now only on the website. They write you a letter, and you do what it says, then someone in an office says 'Why did you do that?' and you say 'Because your letter told me to' and they say no that's wrong you have to do this and that instead. The impact of all this on a family is huge. They have this mentality where they put everyone into boxes and if you don't fit then they toss it out the window. It's a mess," Chris.

Immediate support is needed for those carers who are going through the process of diagnosis or waiting to see what the outcome will be after a catastrophic event. Information access points offering support and counselling services should be provided, even when it is too early to do a formal assessment of care needs.

"We need more information about what is available to us. I didn't know about the Carers Associations for a while. We do not know to ask for things if we don't know they are there," Sharon.

Once diagnosed and assessed, negotiating a maze of services can be confusing and stressful, especially to older carers. One to one support is needed in many cases, with some carers needing access to case-management support when living with complex situations. Ongoing general information on services available would also assist many carers.

"We need a central resource, in plain English," Louise.

It must also be remembered that many carers are hesitant to make contact, as they worry they may not qualify, they may not identify as being in need, and they often fear they are taking the places of someone more in need.

"I don't ring until I'm at the absolute end," Sharon.

"Because you think others are more needy," Louise.

"I never thought to ask others, I just got on with it," Maree.

All services need to be welcoming and encouraging, which can be challenging when short-staffed and underfunded. Carers who are refused services because they don't meet funding criteria or because there are no service workers available are unlikely to voluntarily reach out again. It is also vitally important that community services and health workers are well trained and empathetic in their customer service approach as carers may be in an extremely vulnerable position, despite seemingly good coping skills on the surface.

"With my first hip replacement, the Community Nurse came to do an assessment and the paperwork. She was very rude. She said that my son, then in Year 11, could do the personal care. I thought then that I'll never ask for any support ever again. I did have to get someone in from another organisation, but the worker would turn up at anytime. All the time I was in hospital, I was stressing about whether anyone had shown up to help get my husband out of bed. I haven't used community nursing services ever again," Maree.

Waiting lists are also a disincentive for many Carers. Anecdotal evidence received by Carers ACT often indicates that carers may be told there is a waiting list and give up without gaining a place on the list. Some carers are not told that the waiting list may be prioritized and that they will never reach a high-enough priority to actually receive services. Community services need to be encouraged to gather data on unmet need, and include waiting lists and waiting times in their minimum data set reporting, without fear that it will be perceived as evidence of service inefficiency.

"I gave a friend information about a service. She rang them, got put on a waiting list and never heard from them again. Even the Education Department delays things. I put in forms before the summer holidays and was still waiting for an answer the next year. It's action you want – not just information. It wasn't until Carers ACT started advocating on our behalf with the respite service that we got any help, as the agency's selection criteria had given us a low score so we never made it up the list, but we still desperately needed respite," Louise.

All carers struggle with bureaucracy and gaining access to information. A clear system of national standards for minimum levels of service delivery and expected timeframes would greatly assist in resolving many issues.

"I requested a copy of my son's medical records from the Mental Health Unit to be sent to his new doctor. There was a huge time delay and a ridiculous amount of procedures involved, for example they blanked out huge sections of information and removed complete documents related to decisions about his care. It seemed more important for them to protect themselves and hide the amount of input I had and how I had to push and push to get anything done, than for his doctor to get a complete picture of all the treatment he had received," Florence.

6.3 Financial support

Allowances, Vouchers and Discounts

As discussed previously, the Carer Allowance at \$50 per week equates to a pay rate of 30 cents per hour for the provision of 24/7 care and is inadequate compensation for the real costs of providing care. Carers Associations across Australia have been consistent in their calls for an immediate doubling in the amount of the Carer Allowance.

"I get a Carer's Allowance on one hand, and on the other hand I pay it out to a provider for care. I pay over and above the Carer's Allowance for support. All of the rest of the time I am in my care, I don't get any payment," Maree.

Vouchers for specific services are seen by some carers as a viable alternative to additional cash allowances. Vouchers for services allow carers to make a choice about their preferred service type and also to exercise choice in provider. Vouchers present an advantage to government as allocation and costs can be easily managed, as providers simply claim back the agreed cost of service from the government. Vouchers may also be allocated according to complexity of care needs. For example, 6 counselling vouchers per year may be allocated to all carers, but someone with mobility issues may get 12 therapy vouchers per year to use for their choice of physiotherapy, hydrotherapy or occupational therapy (or any combination they choose).

"Many carers ask for a system of voucher funding, so they can select their own support from community services or the private sector depending on their preferences," Carer Support Worker.

Many carers support the concept of a national carer identification card, which qualifies the carer for a range of discounts and supports from both government and private industry. For example, a fortnightly allowance of 10 litres of fuel or a 5% discount on utility charges. Many businesses are already happy to offer 2 for 1 admission when a carer accompanies a care-recipient to an event. A national card scheme would encourage more businesses to improve their community support profile, facilitate greater access for people with disabilities, and generate new patronage at the same time.

"A discount card is more discreet to use, and we would need to have a list of information on where it can be used," Nique.

Assessments of income

Income and assets assessments for all allowances and services need to incorporate a calculation for actual costs of care incurred by the carer. Alternatively, a second schedule of income threshold limits could be developed to apply at a guaranteed minimum level when carers are assessed for services/supports.

"I think that the government makes it too hard for Carers who have reasonable income from superannuation and other investment. When they assess your income, they don't take into consideration any allowance for what you pay in care costs, and we are losing out because the cost of caring is eating away at our assets at a faster rate than is reasonable. We are on a middle level income, yet get charged full price for everything. They need to increase income thresholds, and give every person with permanent incapacitation access to a Health Care Card, to simply make it equitable with services offered to aged people," Maria.

Recognition that assessments have a wider impact on the entire family income is important. Carers often express concern that assessments are short-sighted, leaving no allowance for the carer's future financial security and potential care needs.

"You should be allowed to split income when you are assessing as a couple. It ends up that all the money gets used to pay for care for the cared-for-person and when it comes time that the carer needs care there will be nothing left. All we want is a little more equity in the system. The nursing homes grab every cent of assets that they can," Maria.

Tax deductions and rebates can only apply for parents when a child is under 25 years of age. Some carers have called for abolition of age limits for dependent children. It also needs to be recognised that compensation through the taxation system only benefits carers who are able to stay in the workforce.

"If you're not a taxpayer then tax deductible medical costs are no help. People get locked into a cycle of poverty. Carers don't have opportunities and they are further disadvantaged because they can't enter or stay in the workforce," Ian.

Debt Management

Interest free loans for carers may be a viable option for carers on income support who need help to break the cycle of indebtedness. Interest free loans for the cost of equipment (for the portion not covered by other subsidy) may also be of assistance for some carers. Free financial counselling, education and future planning services for carers are also urgently needed.

"When I became a carer for my blind and frail grandmother, I had to stop working because Nan couldn't be left alone. I now have less than 50% of my former income, but I still have 100% of the debts I owe and no way to repay them," Carer via telephone interview.

Many carers also need help with downsizing their home at or even before retirement. A scheme to help carers plan for retirement would be of significant assistance to many people, as would the waiving or reduction of property taxes such as stamp duty in such circumstances. However, a more critical and immediate need is the provision of reasonable quality, supported accommodation options for those care-recipients in need.

"I cannot maintain my current house, I need help with downsizing, but I also need somewhere for my son to go. I can't take him with me to a retirement home," Florence.

6.4 Legal advice and advocacy assistance

Legal Advice

There is a clear and pressing need for a free or low-cost legal advice service for carers, which can provide advice and assistance on issues such as rights and responsibilities for carer, wills, guardianship, and contracts.

"Carers need help with all sorts of legal issues, guardianship, advance care agreements, enduring power of attorney, and if you don't have the resources to pay for legal advice then you are always going to be at a huge disadvantage. The carer ends up paying for mistakes and problems which could have been easily avoided with some independent advice from a solicitor," Maria.

"Even getting a letter from a solicitor that says 'I have seen Mrs. X and advised that given these circumstances her rights are ...' can be really powerful when dealing with a lot of places. It's a simple solution but it really can work," Judy

Advocacy Support

Independent advocacy assistance is also urgently needed, especially for guardianship, appeals and dealing with bureaucracy. Fighting an unsympathetic and complicated system alone greatly adds to the stress levels suffered by carers. Existing advocacy services for people with disabilities are already overburdened, and often reflect a conflict of interest for carers, as they must naturally place the interests of the care-recipient before that of the carer in all issues.

"People don't know who to go to for advocacy support, and they don't have the energy to pursue it. You have to fight to get services into place. I had to quit my job last year to deal with the education arrangements, because of the time and the stress involved. So many parents don't have the capacity, skills or energy to do advocacy. They don't have the energy left to fight anymore," Louise.

Some carers also need advocacy assistance when dealing with medical issues, as it can be a struggle for them to get their voice heard.

"Advocacy to help get a second opinion would be good, someone who could help you stand up to doctors when they are not listening. There is nothing that says that doctors have to listen to carers, but we often see what is going on because we live with it every day. My son has had three different diagnoses over the years. I actually think the second one was about right, I don't agree with the new drugs they have him on or the diagnosis, but the psychiatrist won't listen to me," Florence.

Many carers also need simple one-to-one support to manage information and to provide assistance for filling out forms.

"The wording used on forms is a barrier. People will always self-assess and mostly under-estimate what they do or need. It's a humiliation in getting a letter back saying you are not entitled," Nique.

This need is recognised by both carers and community services workers who receive many requests on a daily basis from people struggling with forms.

"We need a staff member whose expertise is helping with filling out forms – Centrelink, permanent placement applications, allowances, disability forms, forms, forms, forms!" Carer Support Worker.

Dispute Resolution and Complaints

Some carers also need support to access dispute resolution services. It is critical that both government and services recognise that not all families are harmonious and in accord on care decisions.

"There was conflict with my husband's children from his previous relationship, it became very complex," Dinah.

"You have to be an advocate for the person you care for, as well as their carer. Sometimes you have to protect them as family reactions and responses can be an issue. My family is not supportive," Louise.

Complaints and problems with service provision can be an issue also requiring advocacy support from people who understand issues faced by carers. Querying support providers when not happy with services can often be difficult. Many carers and care-recipients do not complain because they fear a loss or reduction in services.

"If I challenge their decisions, they say I have 'issues'," Ian. "I have been in the system for over 27 years now. We need to tell providers that 'I have the right to talk to you about the service'."

“My husband gets support. If I need to make inquiries or ask questions of the service I tend to get a hostile reception. We just made an innocent mistake once and they had me in tears,” Riekie.

Specialist advocacy assistance is vital for carers, as they can sometimes struggle to recognise and express the reasons why they have different needs to non-carers. Support also greatly reduces the stress impact on carer wellbeing, proves to be a cost-effective service to government when measured against the high cost of stress related illness and the formal care needed to replace unpaid care following a breakdown in care-relationships.

6.5 Health and wellbeing support

The Carers ACT Territory Pre-Election Survey asked carers to rate their top three issues of concern about their own situation. The top three concerns were: high stress levels (70%), personal health concerns (55%) and financial stress (49%). An overwhelming 84% of respondents agreed that they had felt at risk of being affected mentally, emotionally or physically because of their caring role. This result is consistent with findings from Deakin University’s national research into carer health and wellbeing.

Of the total number of 259 surveys returned in the Carers ACT Territory Pre-Election Survey, 116 respondents (44%) provided additional written information to illustrate how they had been affected. Of this 116, 35 carers provided detail of how caring had negatively affected their physical health. Conditions discussed included: back or neck injuries, chronic conditions such as fibromyalgia, heart conditions, ulcers, arthritis, high blood pressure and cancer. In regard to psychological impact, 25 carers stated that they now suffered from depression, anxiety attacks or other stress-related illness at a level requiring medication or other medical care. Another 56 participants provided information on how caring has impacted their general wellbeing, citing issues such as negative self-esteem, fatigue, anxiety, emotional and physical exhaustion, stress and severe social isolation.

Cummins⁷ research into carer health and wellbeing discovered that “the major reasons carers are not receiving treatment for themselves is that they have no time or cannot afford the treatment”. Financial pressures and potential solutions have been detailed previously in this submission. It is essential that carers are provided with sufficient support to assist them to maintain their own health and wellbeing, alongside the work they do to maintain the health and wellbeing of the care-recipient. Limited options for free treatment complicate timely access to medical care, as does availability of affordable and accessible respite options.

“Having limited public health facilities and limited access to doctors makes it so hard to manage issues, and private medical care is too expensive,” Jazzy.

Carers themselves often come up with the best solutions, based on their own intimate knowledge and expertise regarding the demands of providing care. Key needs include making time for an annual health check. Provision of a Health Care Card (subject to a reasonable income threshold) to primary carers and immediate family members living in the same household as a child with a disability would greatly reduce the negative financial impact of the costs of basic health care.

“They need to recognise that carers are a group at higher risk of health problems, and put in place a Primary Health Care Program to prevent illness. This program should include a free annual health check for all carers, with a reminder system, a free annual Flu-vax, hepatitis vaccinations if needed, and a Health Care Card,” Maria.

⁷ Cummins, R. et. al. (2007) *The wellbeing of Australians – carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

Additional unmet health need included access to dental services. Carers noted specific difficulty in waiting periods and costs of private care. Many also found that they simply had no time to attend for preventative care, and only went in an emergency by which time more costly treatment was usually needed.

"It takes over a year to get a public dental appointment," Florence.

Many carers in the Carers ACT focus groups also asked for programs to be developed in the following areas:

- to manage sleep deprivation experienced by carers
- ensuring personal safety and managing challenging behaviours
- occupational health and safety for carers

Services already received are important to carers in maintaining their own health and wellbeing, and they strongly expressed their desire for those services to continue.

"I value the counselling services the most, without that I honestly don't think I would have survived," Louise.

"Having a break is the most important thing for me," Sharon.

6.6 In-home services

Accessing health services is an acknowledged issue for many people with severe mobility problems. Carers have suggested that in many cases it would be simpler and may even be cheaper to establish a system based on home visits for basic nursing care, especially when compared to the cost of disability taxis and multiple GP visits.

"I wonder if a lot of the time it would be simpler for a district nurse to visit people with disability in their homes for many medical issues rather than having all the problems and costs associated with getting access to medical treatment," Ian.

Carers greatly appreciate the in-home support services they do already receive. It is vital that funding be maintained at a sufficient level to continue much needed Home and Community Care programs for people who are aged or who have a disability.

"I rang the Alzheimer's Association for help when I was desperate, and they got the ball rolling. It was terrific! I have a package now that gives my husband 3 morning showers and gives me 3 hours respite per week plus I get another couple of hours help from the Alzheimer's Association," Riekie.

However, there is a desperate need for services to be funded at a level which enables them to attract and keep good staff. Continuity of care is important. Carers find that having a parade of strangers through your home is intrusive and disruptive to them and that continual transition of personal care and respite workers is distressing for the care-recipient.

"A service comes in the morning to help with personal care and getting up for the day. We want to live a normal life, and be private. Sometimes people try and push things on us. Sometimes people don't turn up in the morning and that's it, but I'm trying to live a normal life. We used to have 3 boys at home in past years. My son felt it was the saddest thing in his life that we had to have a stranger come in every day to help support his Dad," Maree.

Carers also need additional flexibility as to when and how they access services. Often support plans are when best suited to the agency or service worker rather than when most needed by the carer and care-recipient.

"There's a lack of support for nights, and that's when I found it the hardest – it breaks you," Riekie.

"I thought that with of the package, equipment, carers etc, it would be really good, but once it's in place there doesn't seem to be the flexibility to allow people to use it in a way that suits themselves. I want to know what's in my support package. How much is used by the provider and how much goes into direct support?" Ian.

Social isolation and community connection were also considered to be key needs for in-home support.

"Carers need choice about the amount of intervention they can access, but the government also needs to increase funding for community visitors and support programs that get carers and care-recipients out more. Isolation and loneliness are huge problems for so many people," Maria.

Though not all home visits were considered to be appropriate or valuable by some carers. It was clear that the type of service and the person who delivered it should be carefully chosen, and only available to those who really needed. Carers are usually very aware of escalating costs of services, and don't wish to see wastage or inefficiency in the system.

"Pharmacist home visits are not always necessary, and this was about the only service offered to us. It would be more efficient if the funds were used for General Practitioners to make a home visit and look in the home 'pharmacy store' before prescribing more medication. Proper case-management services would sort many issues, and would be much cheaper for the government. Also pharmacy assistants more than pharmacists are dealing with the public when medications are dispensed and very few medication packets contain the drug information slip," Maria.

6.7 Respite care

Emergency and short term care is insufficient for prevention of Carer burn-out and the national program tends to support Carers aged 65 and over. Existing regular respite programs are failing to meet current need due to underfunding, inflexible funding criteria, and an inability to recruit sufficient support workers, this means that many agencies have long waiting lists, and respite is only offered on a critical needs basis. Many families report that they can get some funding but can't find anyone to do the job. Paid support workers need training and sufficient salary to enable them to provide quality respite. However, respite care, both in-home and residential, is greatly appreciated by those carers who do access it successfully.

"I value my respite. I can visit my mum, I can go shopping, I'm free!" Dinah.

The current system needs improvement in flexibility of respite delivery to meet a diversity of respite needs. It also needs to be a safe, quality experience for care-recipients and affordable enough for carers to make reasonable use of the service. Some parents never get the chance to have a break and stay at home in peace and quiet. In-home respite care means that parents must leave the home to get a real break, which is problematic if they don't have funds to pay for a motel room or travel costs.

Out of home respite facilities are needed which offer a safe, harmonious and healthy environment where parents can be sure that their children are cared for at an equivalent standard to home care. Non-suitable respite creates great stress in the care-recipient which removes any benefit the carer may have received from getting a break.

"I get frustrated that the respite services don't look after her properly, and I'm paying them for it. I'm supposed to be having a break – relaxing!" Sharon.

"My very frail, elderly mother-in-law lives in a granny flat at our house. She is really independent and very mentally alert, but she does need daily help with meals and housework, and is completely dependent on us for getting out and about. We can't get anyone to provide respite for us so we can have a brief holiday. The only places available are with dementia patients and that really distresses her," Kate.

Additional day program places for adults are needed in the ACT. The costs of accessing respite for carers who are also pensioners are still a barrier.

"A day respite centre would be most helpful, but the costs of respite are often a problem," Barry.

There is also insufficient flexibility to meet periods of changing need. Consider the following issue where a married couple do not wish to be separated during the carer's recovery from an operation.

"It's hopeless getting respite for Ian. He's too high care, so he has to go into a nursing home for respite. How can I look after myself? I need a hip replacement op. Who can give me respite? I need to book care in advance to book the operation," Maree.

It is also important that siblings are not separated in order for a carer to take respite. Sibling care is often needed alongside special needs care. Some parents have discovered that existing respite criteria prohibits care of siblings alongside a child with special needs, even when it is the family preference for siblings to stay together. For these families, getting a break means paying a private babysitter to come in and work alongside a respite support worker or splitting up siblings to put the special needs child into respite care alone, which can often greatly increase separation distress for all siblings. This is especially important in many sole parent families where the carer is in higher need of a complete break. Cummins⁸ notes that carers who are without partners are in strong need of additional support, as when it comes to health and wellbeing "the most disadvantaged group is sole parents".

"Respite staff will only look after the child with a disability, not the siblings, but I need a break from all of them as I am a sole parent," Sharon.

"Providing respite for parents who have one child with a disability and one child without is always an issue! We need more flexibility for whole family support that best suits their needs," Carer Support Worker

6.8 Transport assistance

Transport issues are an ongoing problem for many carers looking after someone with mobility issues. It also affects elderly carers who can no longer drive. The costs of taxis are prohibitive for regular use, even with subsidy vouchers. Public transport is inefficient and often uncomfortable for people with high pain levels. There is a huge demand on community transport services, but these services are being negatively affected by rising fuel prices, lack of volunteers and insurance costs.

"Transport is a problem if you can't drive. You need to go through hoops to get community transport and there's no help for urgent visits to the doctor. My husband had diarrhoea and our only option was to go by bus. He soiled everywhere," Dinah.

Innovative schemes are needed to provide long term, sustainable solutions. Increased home visit systems may be more cost effective and efficient in some circumstances, as mentioned previously. Small community vehicles operating out of local medical centres may also be a cost-effective option. Patient transport systems

⁸ Cummins, R. et. al. (2007) *The wellbeing of Australians – carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

for hospital appointments are very useful, but more service funding and increased efficiency is needed to avoid very lengthy waiting times.

"We go to Canberra Hospital for my daughter's treatment, it takes only five minutes to do but you have to wait for hours for transport as she needs a disability access bus. What am I supposed to do with my other children while I am there?" Sharon.

6.9 Post-school support

Suitable post-school options are needed for young people with special needs, including opportunities for meaningful training and supported employment. Inclusive social programs are urgently required to offer the opportunity to learn and maintain social skills, and build ongoing relationships with peer groups.

"What do you do when they are 22 and still completely dependent on you? The impact on the family is huge. The police have been involved, and we have been on a frightening learning curve from his behaviour. The less understanding and support there is from outside services, the more his dependency on us, his parents, increases," Judy

Barriers to participation identified by families include: no programs or places available, transport problems in getting the care-recipient to programs, and poor understanding of disability in the wider community (which leads to negative experiences due to prejudice and ignorance when in the public domain).

"I'm scared when thinking about the lack of services post-school," Sharon.

7. Strategies to Improve Carer Access

7.1 Capacity for choice within carer role

The majority of carers feel that they have little or no choice in taking on their caring role, but they strongly wish to have choice about how they provide care. Choice for carers means having viable alternatives to choose from, whether for funding options, respite care, services available or any other type of support. A choice between two bad options is really no choice at all – it's just an exercise in damage control.

*"I have the choice - to be the best carer I can be or to be a c**p carer. We do it to a higher level of 'customer satisfaction' because we have an emotional investment with the person we are caring for," Nique.*

"People would feel there was choice if the supports to enable choice were in place to start with," Ian.

Parents, who can no longer care for their child, whether due to ill health or old age, often have no real options for alternative care beyond abandoning the child to become a ward of the state. Supported accommodation facilities are limited, overcrowded and often of questionable quality. Accommodation in an aged care facility is patently unsatisfactory for the needs of a young person. There is an urgent, identified need to develop a range of options which offer a real quality of life with meaningful activities and appropriate care to meet the needs of people with disabilities, as can be read in the following statements.

"My son is not capable of independent living. I am 80; it's not possible for him to be living with me. He needs suitable, permanent, accommodation with meals supplied, but he has no choice and neither do I. They label any kind of supported accommodation as an 'institution' and before you know it, it's shut down or becomes just a transient hostel. I have been told by every mental health professional in this town that he needs supervised accommodation with meals, otherwise he just won't survive. Somewhere like Watson Hostel before they closed it 15 years ago," Rose.

"I could see the problems he was having. There was no choice but to bring him home and be there for the long haul. It's very isolating looking after someone, and it gets worse as you lose touch with networks and can't re-establish them," Florence.

"It took 18 months to get him properly diagnosed. In the end he had a complete physical and emotional breakdown and was admitted to hospital. He has psychotic episodes and is paranoid. He has been in and out of care and hostels for the last 25 years. Now he has nowhere to go, so he is now home with mother. He has nothing to meet his needs, no interests and nothing to occupy his time," Jazzy.

Carers need assistance with placement, transition, and the development of supported accommodation systems which encourage their ongoing involvement in their child's life, even if they cannot continue providing direct care.

7.2 Transition into caring

Every carer's experience of diagnosis is unique, yet some key strategies may help smooth the transition into a caring role. Primary need is for people to self-identify as needing support, and this may be difficult as it can take some time for people to view themselves as having become a carer. Indeed some choose never to accept the term.

"It takes a long time to recognise yourself as a carer. In the lead-up to diagnosis it was very difficult to convince doctors and specialists that there was something wrong with my son. He was in that shadowy area where they are not sure what it is, and

they keep questioning you as to whether or not you are imagining things. I started feeling like a freak or a poseur. I started keeping an incident log and gathering other evidence to prove there was something really wrong. I couldn't reach out for help at this stage because I didn't know if I qualified for any assistance. After four years we now have a diagnosis, and I feel like I can legitimately ask for some help," Judy.

Diagnosis support needs to be accessible and responsive to whole of family need. It is important that people are given options for immediate support, rather than sitting in a doctor's office, being given the bad news and then being told to 'just go home and try to get on with your lives'.

Information is the next priority need. Carers depend upon timely ways to get accurate and up to date information. Variety of pathways to information is also important, as some people prefer to do their own research on the internet while others prefer to talk to a real person.

Insight into Caring

Q. How did you react to becoming a carer when you received your son's diagnosis?

A. I thought 'well I can never die'. No-one is going to look after my kids as well as I can. To have to start being a 'squeaky wheel' to ask for help is very difficult. Bring a partner into that and it's even more difficult – he can't fix this with a hammer or screwdriver!

Nique

"There is a need for assistance to develop coping skills, so people know how to adjust their own lifestyle and focus on the priorities," Ian.

Services may seem like a maze of pathways when first beginning as a carer. Peer support is helpful to many carers, whether provided by a peer support worker at a hospital or through a support group program. All carers face a steep learning curve after diagnosis. Practical skills development and education opportunities are particularly useful for many carers.

"I had to learn how to cook and do things around the house. What would have been good is someone to show me how to do things like cooking and cleaning. How to sort through stuff and get rid of it," Barry.

Psychological counselling may be needed by some families, to support them through the diagnosis period. Many people struggle with issues of shock, grief or denial. Usually the earlier people access help, the better the transition period.

"In the early stages, I denied she had a disability. We got the diagnosis when she was 2. I don't think there was a lot that would have helped because of her unique disability. I would have liked to have been told what to expect, and information about wheelchairs or financial assistance. I still get the impression that people think I am asking for trips to Disneyland when I apply for funding, but I just want my daughter to have a normal life," Sharon.

7.3 Transition out of caring

The end of a caring role can be a time of huge adjustment for a carer. People who have devoted all their time to a role can suddenly be left with a complete loss of direction. Some former carers have anecdotally described their transition as needing to 'rehabilitate' to life post-caring. They may also be grieving at this time if the end of caring was caused by a bereavement.

There is a perception that transition into residential care signifies the end of a caring role. While residential care changes the pattern of caring, many carers do still find that they are devoting a large amount of time, energy and money into providing for the care-recipient.

Regardless of the transition circumstances, it is vital that carers are supported and connected to the wider community. Post-caring or bereaved carer groups may provide assistance for many carers, while others may prefer to access individual counseling support when needed.

Palliative care supports are also vital for carers. Coordinated, non-intrusive and affordable services are essential at a time of such stress.

"It is a huge relief for carers to have support for their loved one when they are in palliative care and want to be at home during the final stages of their life. The transition from hospital, hospice or facility needs to be an easy one," Carer Support Worker.

Post-caring situations unfortunately leave many carers in a precarious financial position. They may have had many years out of the workforce, but not be old enough for a pension. They may have significant debts from years of providing care and little in the way of assets or superannuation.

Financial recognition for years of caring is non-existent. Carers Australia has been leading the call for a national superannuation scheme for carers based on the federal minimum wage to reduce the systemic inequity of caring supports.

Transition programs are an integral need for assisting carers to deal with the emotional, practical, financial and legal matters left after caring has ceased. One on one support with access to free legal and/or financial advice is imperative.

Government departments and agencies such as Centrelink need to link into a cooperative case-coordination arrangement with other service providers to help put a transition package into place, with sufficient flexibility to meet individual needs.

Insight into Caring

Rob* has cared for his daughter for over 14 years since his wife passed away. They have been living on his small farm on the regional NSW/ACT border. His daughter, Katherine*, has multiple disabilities, is high dependency and no speech or other means of communication.

A rare vacancy has come up in a regional group home. When Katherine moves in to supported care, Rob will immediately be ineligible for Carer Payment or Carer Allowance.

The local Centrelink office has advised Rob (aged 62) that he will have to claim Newstart and start applying for work. However the value of the small and mostly unproductive farm makes it very likely that he will be ineligible for Newstart.

Rob does not wish to move from the farm at this stage, and it would be unlikely to sell in the current market.

**Names changed to protect privacy.*

7.4 Future planning

The majority of carers are so focused on issues of day-to-day survival that they have little time or energy to devote to future planning. The fear of what will happen if they can no longer provide care lurks in the corner of most carers' minds, becoming an overwhelming problem as they age and have few financial resources in place to give them any hope of realistic choices for their own care and that of the care-recipient.

Carers ACT has been working to address the needs of mature age carers and encouraging people to engage in structured future planning by running a series of well-attended and informative workshops which brought together guest speakers from a number of government departments and other services.

"You need a holistic plan, an approach that takes into account the emotional, medical and financial needs, both of the carer and the cared for person," Judy.

Future planning is needed by all carers. From the development of emergency care plans if the carer needs to go to hospital to permanent care options, wills and special disability trusts should the carer die. Many carers need specialist support to develop care plans, and access to free legal and financial advice.

"I need to ensure that the physical cost of my own survival will not be so high that I cannot afford to live. The cost of living is going through the roof and our support funding is not keeping pace," Ian. "If anything happens to Maree, I'm concerned that I'll have to go into a nursing home, but I won't be able to practice any hobbies there."

The emotional issues of succession caring also need to be addressed with suitable support. Carers often feel intense emotions about seeming to expect siblings or other family members to provide care, especially when they are a single parent.

"I have told my two other kids that they are not expected to look after her, but to visit her once a week in the nursing home. I had my third child after her partly to make sure there was someone else to care after I was dead. I am scared that because she can't speak, she won't be able to tell anyone whether or not she is being looked after or if she's being bathed etc.," Sharon.

More than anything, carers need options for their own future Care as well as the surety that their loved one will be suitably cared for in the future.

"I am the sole carer for my son, but I am 80 now. Who is going to care for me?" Rose.

Developing options for special needs facilities which allow ageing in place for both carer and care-recipient is considered a highly desirable option by many people. Flexible facilities which can accommodate graduated support needs and allow for a real quality of life are already being developed in Victoria. The Federal Government needs to support this model to expand to trial sites in each state which has sufficient demand for such a facility.

"I'd like to see more focus on a model whereby elderly carers get to move into a residential facility with their severely disabled son/daughter. As the carer becomes more frail they can move through hostel and then nursing home care, if need be, on the same campus as their child is being looked after in whatever type of accommodation is most suitable for their own needs," Carer Support Worker.

7.5 Research into caring

A nationally led program of research into caring needs to be funded on a priority basis. The recent study into effective caring by the University of Wollongong⁹ has highlighted many gaps in current understanding of critical issues for Australian carers where further research will be of significant benefit.

There also needs to be a whole of government commitment to the sharing of data on care-related issues across portfolios and with the community services sector, with a focus on building cooperative relationships and strengthening national expertise on caring.

7.6 Need for national standards

A national charter of care would help to establish a clear set of standards for government and services to adhere to when dealing with carers. Such benchmarks would help to remove much of the confusion and inconsistency carers face in regard to information provision, consultation and inclusion.

Where acts have been put in place, such as the United Kingdom, carers organizations are still struggling to get those rights enacted within the wider domain. Placing a national charter alongside the Human Rights Act would allow more opportunity for recourse if carers rights are breached.

⁹ Eagar K et al. (2007) *Effective Caring: a synthesis of the international evidence on carer needs and interventions*. Centre for Health Service Development, University of Wollongong.

"Legal changes are a long term solution. It takes the community at least 10 years before they understand it and use it," Ian.

The development of national standards both in the disability service sector and public transport systems throughout Australia have generated improvements in disability support services since their inception. People with disabilities and their carers are now seeing ongoing improvements in accessible public transport services for those with mobility problems, albeit over a 20 year time frame for public transport improvements.

Cross-jurisdiction agreements are needed for more effective support for those moving between states. Many interstate migrants find they have to 'start over' within a new system, proving their case and joining waiting lists at the bottom of the queue.

"We need to have transferable disability support packages between states, especially for those families such as Defense families who have to move regularly," Carer Support Worker

There is also a need for the establishment of national standards for health and community care to remove inequity between the states and territories.

"All states should be uniform! Why should care be different when you go interstate?" Maree.

7.7 Need for sector reform

Reform of the community sector funding model is urgently needed to assist service providers to meet surging demand. The following issues are highlighted as needing priority attention:

- Federal funding formulas to include an operational base enabling service delivery recovery of 'whole of provision' cost, instead of funding based solely on population formulas, which currently disadvantages smaller jurisdictions such as the ACT and Tasmania.
- Federal procurement of community services to focus on evidence-based, local area need, and include an assessment that examines for potential duplication of state-funded services.
- Use of compatible data sets and reporting templates for Federal departments (and also state/territory compatible where possible) to minimize community sector costs in compliance and reporting.
- A clear statement of Federal priorities for investment in services, supported by transparent and accountable procurement processes. Priorities to be reflected in multi-year Service Funding Agreements.
- Improvement in the Federal timing of allocation for new program funding. Bureaucratic delays result in allocation of new program recurrent funding to community agencies as late as eleven months into the financial year, with a requirement to fully expend first year's allocation within weeks or days.
- Increased flexibility for new program agreements, as it can take up to two years to fully establish and promote the program to effectively engage with sometimes 'difficult to reach' groups of people in the community, resulting in underspend in years one and two with full expenditure occurring in year three. Requirement for expenditure in equitable proportion to the term of the contract negates capacity to plan, as approval for rollover can take up to nine months in the following year. Accrual accounting practices across a three year framework rather than an annual cash basis would redress this problem.

- Federal leadership on collaborative projects, and encouragement for sector participation through funding allocated specifically for the development of collaborative partnerships, and the recognition of collaboration as a quality service delivery output.

Effective service reform is certainly supported by many carers. As experts in the system they use every day, they can see, better than anyone, just where the need for improvement is most critical.

“Putting it simply, the government needs to understand that it’s all about putting troops in at ground level. If they don’t maintain funding to all the services who support us, then none of us will keep going in the long term,” Ken (Carer for 8 ½ years in phone interview).

8. Conclusion

The need for comprehensive reform of the way Australia delivers community services is urgently needed to meet the challenges of current care needs and the future demands of an ageing population. Reform is needed at every level, from macro level of legislation and funding provisions, to the micro level of the flexibility of services needed by individual carers. A redefinition of the philosophy of care is needed to reframe it as a joint responsibility of all levels of government and every member of the wider community, as every person in Australia will either provide care or require care at some time in their lifespan.

Carers are the experts in understanding what will best help them to continue to provide long-term, sustainable care for their family members, neighbours and friends. They also know the sorts of alternatives they would like to have access to if they are no longer able to provide care. This submission has sought to outline many of their key concerns and suggested strategies for what may help them do their caring work in a better, more sustainable manner. Carers have an emotional investment in providing the level of care that they do, but they also need effective support to help them to maintain their own health and wellbeing at optimum levels.

Critical changes are urgently needed to ensure that carers have better access to the sort of services which are most appropriate for their needs. These services need to be flexible in delivery and responsive to changing circumstances. Far too often carers are endeavoring to access information about care options only to find the complexities in the care systems across the nation that have unfathomable bureaucracy, inflexible eligibility criteria and limited supports which are prohibitive to assisting with the simplest of care choices and options sought to assist with the caring role. Carers need the security of reasonable levels of long-term financial support to help them meet the costs of care and to avoid becoming trapped by debt and embedded poverty.

Research for this paper was only made possible thanks to the generous input of many carers in the Australian Capital Territory and it is hoped that the echo of their voices and the resonance of their stories will remain with the Honourable Members of the Standing Committee on Family, Housing and Youth when they make their recommendations to the Federal Government on better ways to support carers.

9. Appendix A: Focus Group Profile

In order to facilitate understanding of carer needs and issues, 16 of the 19 participants in the focus groups gave permission for the following data to be included into a brief profile, and for opinions and statements to be directly quoted in this report. Some participants have chosen to use pseudonyms instead of given names to protect their privacy.

<i>Profile of Participants</i>			
<i>Name</i>	<i>Age</i>	<i>Gender</i>	<i>Caring Situation</i>
Judy	60	Female	4 years caring for adult son with Pervasive Developmental Disorder Not Otherwise Specified, anxiety and depression.
Rose	80	Female	22 years caring for adult son with Chronic Paranoid Schizophrenia.
Nique	37	Female	6 years caring for son with Autism Spectrum Disorder, Epilepsy, developmental delays and mobility issues; also secondary carer for mother-in-law with Multiple Sclerosis.
Riekie	67	Female	4 years caring for husband with Alzheimer's Disease.
Barry	87	Male	10 years caring for wife with multiple chronic conditions. Culturally and Linguistically Diverse (CALD) carer.
Florence	63	Female	10 years caring for adult son (32) with mental illness.
Neneng	59	Female	12 caring for frail aged husband; also cares for nephew with intellectual disability and behavioural problems. Culturally and Linguistically Diverse (CALD) carer.
Chris	38	Male	17 years caring for partner with mental illness and chronic health conditions; also cares for son with Autism Spectrum Disorder and chronic health conditions.
Louise	43	Female	Cares for child with disability.
Dinah	66	Female	Cares for husband with mental illness. Culturally and Linguistically Diverse (CALD) carer.
Jazzy	69	Female	Caring for adult son with schizophrenia.
Maree	61	Female	35 years caring for husband, Ian, with quadriplegia.
Ian	<i>not stated</i>	Male	Care-recipient.
Sharon	38	Female	9 years caring for child with disability.
Maria	55	Female	28 years caring for spouse with Multiple Sclerosis (previously cared for 3 frail aged relatives).
Kate	71	Female	20 years caring for 97 year old mother-in-law; also previously a carer for husband with cancer (now in remission).