Response to Inquiry into Access to Primary Health Care Services for the Standing Committee on Health, Community and Social Services

Steve Doszpot MLA (Chair)

Legislative Assembly for the Australian Capital Territory

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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. Introduction

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 Carers living in the Australian Capital Territory. We represent unpaid Carers who are providing care for families and friends with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail.

Our role is to work in active partnership with Carers, people with care and support needs, health professionals, service providers, government and the wider community to achieve better understanding and an improved quality of life for Carers.

Carers are in an important position to offer insight to the ACT Legislative Assembly Standing Committee on Health, Community and Social Services inquiry into access to primary health care services. In a recent survey of Carers in the ACT, 44% of respondents said they have been negatively affected, physically or psychologically by caring, with the state of their health being one of their top three concerns.[1]

Many Carers gain a high degree of knowledge and experience of the primary health care system through their role in supporting care recipients to maintain optimal health and well-being. Yet this support may come at significant cost to their personal health, as many Carers report that they experience significant barriers to accessing sufficient primary health care for their personal needs.[2] Time and cost are the two most significant barriers reported by Carers. Despite growing awareness of the negative health risks associated with a caring role, it is evident that Carers continue to have specific unmet need, especially in preventive health care and for participation in health promotion activities.

The ACT government has expressed concern that although residents of the ACT enjoy excellent health compared to other parts of Australia, there are health inequalities between population groups[3]. Carers across Australia, as a population group, are experiencing significantly reduced well-being and higher rates of depression when compared with other groups of the population[4]. It is vital that these health issues are addressed as a priority by government as the irreplaceable contribution Carers make to the broader community by performing their caring role will be better supported by improving their health outcomes and preventing injury.

The General Practitioner (GP) shortage in ACT has increased the difficulty many Carers face in meeting their health needs in a timely manner. Limits on the time and financial resources of Carers, due to the demands of their caring role, are key factors contributing to this difficulty[5]. The GP shortage has meant that often more time and more money are needed to access primary health services, as demand for GP services in the ACT far outweighs available supply. Carers ACT has consulted with Carers to develop this submission on the important aspects of a primary health care system which will improve outcomes for Carers. The review included consideration of the utilisation of nurse practitioners and allied health professionals.

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[1] Ashton A, McGrath, D. (2008) *`Have your say` ACT Election Survey Report*. Canberra: Carers ACT
[2] House of Representatives Standing Committee on Family, Community and Youth (2009) *Who cares…? Report on the inquiry into better support for carers* Canberra: Commonwealth of Australia
[3] ACT Health website (2009) *http://www.health.act.gov.au*
[4] Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Deakin University.
[5] ibid 2

2. Methodology

Carers views contained in this submission were informed by direct consultation and previous research activities with Carers, including the `Have Your Say` ACT Election Survey Report[6].

Specific Carer interviews were conducted with six Carers. Interviews were guided, but not restricted to, three key discussion points:

1 Given the number of GP closures in the ACT since 2001, what has the impact been on you as a Carer, the person you care for and your family?

2. What are the key factors for a primary health care model that would meet the needs of you and your family?

3 What is your opinion about nurse practitioners, allied health assistants and other health professionals having a greater role in primary health care and doing some of the work which previously required a GP?

[6] ibid 1

3. General Practitioner Clinic Closures since 2001- Impact on Carers

Many Carers in the ACT have, and are, feeling the impact of the closure of GP clinics since 2001. All the Carers consulted specifically for this submission have been experiencing longer waits for primary medical services, both when attending for their personal needs and as part of their caring role. These Carers have also noticed a longer wait between the request for an appointment and the actual appointment time. They have also spent more time waiting in the surgery for appointments when the clinic is running late or when visiting 'drop in' clinics.

Many Carers have also had to spend time finding a new GP in the event of the closure of their previous GP's clinic. Transitioning between GP practices has also created barriers for Carers. Some Carers reported that their GP did not make contact to inform them of their relocation to a new practice, which they felt made the transition to another GP more difficult. Some Carers have also found this process complicated by the need to meet with several new GPs in order to find one with whom they feel comfortable and able to form a successful patient–doctor relationship.

In recent months, many Carers have reported difficulty finding a new GP who also bulk-billed, and some still haven't found one. Lack of bulk-billing options creates additional stress for those Carers who have limited budgets. Carers often face higher than average financial stresses (due to the costs of providing care and the time demands of their caring role which can limit their ability to participate in the workforce)

3.1 Costs of Transition

Of particular concern is a report from one Carer that the imposed need to find a new GP had incurred new cost and time barriers which were preventing access to appropriate medical care. This Carer was advised that transfer of medical records to the new surgery for the Carer and the care recipient would incur a fee of $50 per person and a waiting period of 3 weeks would be imposed. The cost involved prevented transfer of the records.

Carers ACT is strongly concerned that a failure to share critical and detailed information to enable continuity of care would potentially place care-recipients and Carers at risk. Recounting medical histories can be difficult, especially for those with complex histories going over many years. Carers report that the stress and tiredness created by the caring role can make it hard to select and recall the details which the GP requires. The personal and emotional nature of the information can also make it hard to repeat.

3.2 Stress on Carers

Carers ACT is also concerned that difficulty in accessing primary healthcare for both the Carer and the care recipient maybe a trigger for increasing the stress levels experienced by many Carers, which are often higher than average[7]. The correlation of prolonged high stress levels being linked to further physical and mental health complications is well recognised in both national and international research.

[7] ibid 4

Carers are already at higher than average risks of anxiety and depression due to the demands of high need and/or long term caring roles[8]. Prevention of further health impacts due to a caring situation is critical. Carers need to be healthy to continue in their caring role and prevent premature entry of the care-recipient into supported accommodation and/or tertiary health care facilities. Reduction of preventable illness and injury, especially in vulnerable populations, is also essential to enable an already overburdened health system to meet current and future demand.

3.3 Continuity of Care

Continuity of care is important for reaching optimal care standards and preventing unnecessary costs due to misdiagnosis and/or missed diagnosis. For example, one Carer participating in Carers ACT direct interviews recounted a stressful incident where her child's care was complicated by lack of continuity of care. The child, who has a severe and profound disability, had an appointment with an unfamiliar GP who failed to detect pre-pneumonia signs. The family then travelled to Sydney to obtain an unrelated medical treatment for the child, but were told that because of the signs of pneumonia, the treatment couldn't take place.

The Carer felt that her child's regular GP would have been able to more accurately interpret his presentation due to his greater familiarity with the child's complex needs. The Carer reported that the unfamiliar GP later rang to apologise for the delay in timely diagnosis of pneumonia. Yet the impact on the family was compounded by unnecessary physical and mental stress to their child (and themselves) which had been caused by the wasted trip. They also experienced financial stress in meeting the costs of the unnecessary trip.

The family then had to reschedule another appointment for the procedure in Sydney that could not be completed due to the pneumonia symptoms, and they will have to bear the repeat in travel costs and stress at a later date. It is evident to Carers ACT that familiarity with what is usual, and what is unusual, for the individual is crucial to timely and appropriate treatment in cases where the care recipient has severe and profound disability and/or complex medical needs. Where this is not possible, access to full and appropriate records and extra time for assessment must be enabled without imposing further cost on the Carer.

[8] ibid 4

4. What Would Help – Ingredients for a Best Practice Model

4.1 Accessibility

Carers are a diverse group of people with diverse health needs and access requirements, just as is the broader community, but their situation is complicated by the demands of their caring role and their frequent requirement to prioritise the often complex health and wellbeing needs of the care-recipient. Accordingly, the ACT primary health care system needs to encompass a variety of options for care provision, as each variation or option will suit some Carers/population groups more then others.

Greater flexibility can be achieved by improving options and pathways for access to primary health care. For example, a combination of community nursing/health centres, larger corporate-run medical centres, bulk-billing clinics, and smaller family-practices has potential to offer sufficient options within the model, as long as sufficient capacity is available to meet demand at each site. Generally speaking, Carers consulted indicated that an ideal system would offer the following features:

- a same-day appointment in an emergency
- an appointment system which generally runs to schedule
- ease of physical access (such as sufficient parking and appropriate bus routes)
- an option of GP/nurse home visits when necessary for patients with severe and profound disability or very complex health needs

It is clear that improved pathways to accessing primary health care can result in a better health outcome, especially for individuals with complex care needs. Multiple-aspect service models will also enable Carers to better select the type of GP practice that suits their needs. Yet, all practices also needs to have a system which recognises and supports the needs of Carers as having more complex needs than is evident in the general population.

> **"I need 2-3 doctors who can tune into the different breath sounds he makes, which in turn enables them to make a correct diagnosis. A fast response to the onset of illness in his case can have a particularly dramatic effect, possibly preventing an admission. It is not fair on us, or the doctor, to expect an unfamiliar doctor to come to grips with his history, and what is normal for him, and to provide quality diagnosis. Two to three doctors means that hopefully at least one will be available when I need. I don't like having to plead with the receptionist for a suitable appointment and explain the whole story again."**

Conversely, other care situations and/or health concerns can be effectively handled without the need for a consultation with a familiar GP. Particularly in the current climate of GP shortage, there is a need to ensure that GP appointments are used for health matters which cannot be successfully dealt with in another way and that access to alternative pathways are actively promoted. This would help to ensure that people needing urgent access to GPs are not faced with backlogs created by routine issues such as health

checks, vaccinations or the 'worried-well' patients who are generally healthy but in need of reassurance about non-urgent concerns (e.g. the influx who come in for treatment of common cold systems following media reports of the Swine Flu outbreak).

4.2 Health Direct

The use of Health Direct is one way in which the urgency of health concerns can be assessed. Through Health Direct the user speaks with a registered nurse over the telephone to obtain a triage assessment on the nature of their complaint. Triage systems have proven useful because they assist callers to determine how urgently they need to seek medical help. Those in need of urgent medical intervention are encouraged to seek appropriate, timely assistance. Callers with non-urgent conditions receive reassurance that they can seek needed care over a more appropriate timeframe. Health Direct information is also of value to staff at GP clinics and hospitals as it provides useful information on assessed priority of need.

Consultation with Carers throughout the ACT indicates generally low levels of awareness of the availability of the free and easily accessible Health Direct service[9]. An increased promotion to Carers and the wider community may assist in increasing usage of this resource. The resulting streamlining of urgent and non-urgent cases could assist to improve efficiency of the primary health care system and reduce unnecessary demand on GP time.

4.3 Improved Appointments System

Carers often say that their lack of available time is a reason that they don't access primary healthcare. Much of the population would be unaware that some Carers need to use respite care in order to attend appointments for themselves, as their care-recipients cannot be safely left alone. Respite care is of limited duration and availability, and it also needs time to coordinate in advance. If a GP's appointment schedule is running excessively late this will create a significant barrier to health care, as Carers report that their available respite time can end before the appointment has taken place.

For example, one Carer reported that she had to leave a surgery where she had an appointment to have a pre-cancerous mole removed. After waiting for three hours and being told by the receptionist that there was still three people ahead of her in the queue she had to leave. At the time of discussion with Carers ACT she still hadn't had the mole removed because she had no time free to follow-up and make another appointment

"They don't understand that Carers just don't have time to wait at surgery"

Increased GP awareness of the existence of respite-linked appointments could assist these Carers to better meet their primary health care needs. Carers do understand that late appointments are often unavoidable, particularly if the doctor is delayed by patients requiring emergency care. However, increased communication regarding waiting times could be helpful, as knowledge of a

[9] Carers ACT research in progress - pending publication

significant wait could mean that Carers could attend to other important needs during their limited respite time instead of wasting it by waiting in the surgery for an appointment that cannot be kept.

Some suggestions from Carers included:

- GP practices to encourage Carers to feel welcome to telephone the clinic in advance to ascertain any changes in anticipated waiting times
- if the delay occurs after the Carer has arrived, for the clinic to allow the Carer to leave and alert the Carer on their mobile when the doctor will be shortly available
- clinics to use internet-based services such as 'Twitter' to inform patients of delays

Additional access requirements include appropriate parking and bus routes. Carers have also raised the issue of the need for home visits from GP's or other medical professionals such as community nurse practitioners, when care-recipients are so incapacitated that they cannot make the trip into the doctors, including in the circumstance when care-recipients are living in a nursing home.

4.4 Affordability

As mentioned previously, financial stress is a concern to many Carers. Research has confirmed that Carers often face significant deficits in income as a result of their caring role and this deficit can accumulate into significant disadvantage over a lifetime due to the inability to accrue assets and save for retirement[10]. Financial stress is one of the top three concerns stated by Carers in the ACT and it is evident that lack of money is a barrier to many Carers in accessing sufficient and appropriate primary healthcare[11].

Many Carers are finding it difficult to access GPs and health professionals who are willing to bulk-bill[12].and it can be very time-consuming for Carers to find out which GPs do offer bulk-billing services. The ACT Health website has a link to a private website called *GPs 4 U* which gives listings of GPs located in Canberra and their opening times. This site is currently working on a bulk-billing list, but so far it has only one entry. The ACT GP Taskforce has proposed new legislation to maintain lists of GPs in the ACT. This could be helpful to Carers, particularly if that information included the bulk-billing policy of the GP, fees, location, public transport information and opening hours. Existing services, such as the Commonwealth Respite and Carelink Centre (1800 052 222) could also be used to provide this information over the phone, especially for people who don't have internet access.

It is evident that a greater number of GPs provide bulk-billing services for patients who have a health care card. Carers ACT continues to call on the ACT and Federal Governments to support increased eligibility for low income Carers to be eligible for Health Care Cards, in recognition of the increased financial strain of being a Carer due to costs of care and limitations on workforce participation.

[10] ibid 2
[11] ibid 1
[12] ibid 2

4.5 Continuity of Care

Most Carers contacted regarding this submission preferred having a known point of contact with the healthcare profession. They valued a relationship in which the doctor "takes your information seriously". Carers consider that good healthcare is best delivered by someone who has time to listen, who knows your history and who can be proactive in your health management. It is particularly important for Carers and care-recipients to receive consistency of care from the primary health care system as this ensures that they achieve the best possible outcomes. These outcomes can be achieved through a greater emphasis on early identification/intervention and health promotion, which is proven to reduce vulnerability to preventable illnesses and conditions.

It is becoming increasingly clear that the primary health care system in which a familiar GP is the patient's only gateway is no longer possible because of increasing demands on the system and insufficient numbers of GPs to meet need. However, successful reform of primary health care services depends on the establishment of good communication policies and procedures between multiple health professionals to retain the patient's sense of being listened to, understood and treated, in a manner that ensures their best possible health and wellbeing.

The announcement of $90 million in the recent ACT Government budget towards developing an e-health environment is one way to improve communication about health matters. Many carers have spoken to Carers ACT about the tiresomeness and difficulty of having to repeat their story to each new professional and the costs involved with transferring medical records between surgeries. If executed properly, individual e-health records should help to reduce the number of times that medical histories have to be relayed to medical professionals by patients. It would also ensure that accurate, complete and up-to-date information is always available when needed by treating health professionals.

E-health initiatives also offer increased feasibility for having case coordination (for people with complex health needs or disabilities) met by a professional other then GP. This is potentially of value, as GPs have stressed that they often have less than optimal available time to coordinate the health needs of individuals, due to the demands of overall practice. There is potential for other professionals to take on this role, including nurse/allied health practitioners or disability/carer case coordinators.

4.6 Health Promotion

The urgent need for preventative health care for Carers has been recognised at a national level in the recent *'Who Cares…'* report from the Inquiry into Better Support for Carers by the House of Representatives Standing Committee on Family, Community, Housing and Youth. Recommendation 46 outlines the need for a preventative health care program to be targeted at Carers by extending the Enhanced Primary Care Program to include Carers as an 'at risk' population group requiring intervention[13]. Carers ACT strongly supports this recommendation, and suggests that a preventative health program for Carers in the ACT should include a free annual health check with a reminder system and access to free vaccines as required. There is potential for such a service

[13] ibid 2

to be delivered through community health centres, outpatients services at TCH and Calvary or even by a quarterly 'visiting nurse/health promotion officer' system offered through the Carers ACT centres in Belconnen and Torrens.

Carers ACT local research reflects national findings that many Carers tend to place a higher priority on the health of their care recipient over their own health.

> **"I go to the doctors heaps for my loved ones but not for myself…I try to wait until I have 3-4 things to talk to the GP about. Then I get in there and feel rushed and end up talking about just the most urgent thing anyway."**

One of the Carers consulted for this submission recognised the tendency of Carers to dismiss their own health needs and felt that additional training on how to 'self-manage' would be of benefit. Carers ACT already delivers a number of programs which are designed to improve the health and wellbeing of Carers, including meditation, stress management, yoga and nutrition. Extension and enhancement of these services would be highly beneficial, as there is high demand among Carers, but many are unable to access existing programs because of work and care commitments.

Carers ACT is also currently working with the University of Canberra to develop an appropriate and useful self-care/health promotion resource to improve healthy living habits for Carers and prevent common injuries caused by the demands of the caring role. The research component of this project will be completed by the end of 2009, but funding is needed for the production and progressive rollout of the resource, firstly to the 5,000 Carers who are already members of Carers ACT and potentially to the entire population of Carers resident in the ACT. Improved health promotion for an estimated 43,000 members of the ACT population (who have complex needs and who are at higher than average risk of poor health and wellbeing) offers significant potential for creating a positive impact in reducing future demand for health services.

4.7 Improved GP Utilization of Existing Supports

GPs may benefit from using a more holistic approach when treating their patients to better identify if there is a Carer involved in the care situation. Carers ACT recognizes that GPs could be better supported in encouraging Carers to recognise their health needs, including increased awareness of the Carer's mental and physical state and their capacity to provide needed care. If there is evidence that the needs of the care-recipient are placing increased or unsustainable demand on the Carer, GPs already have opportunity to refer the Carer to the Commonwealth Respite and Carelink Centre or even to call the Centre directly while the Carer is present to have information provided over the phone or faxed immediately to the surgery.

The Commonwealth Respite and Carelink Centre (CRCC) is a free-call service on 1800 052 222, funded by the Australian Government, which offers information on community aged care and disability services in local areas. Calls to the Centre are answered by a locally-based person who can help link Carers and care-recipients into supports available in the local community, including assessment, respite, in-home services and counselling. The ACT

CRCC Centre is linked to a national network of centres and can also assist to link people to services in other locations, especially where an interstate care situation exists.

Carers ACT considers that there is significant potential for GPs in the ACT to make better utilisation of the existing free CRCC service, and is very interested in identifying other ways to better support GPs in proactive approaches which will assist Carers to maintain better health and wellbeing. Potential avenues of support worth developing include:

- displays of Carer relevant information in clinical locations
- 'Carer awareness' and 'Carer skills' education opportunities for clinical and practice staff
- establishing improved referral pathways to existing specialist services offered by Carers ACT (such as Young Carers, mature Carers, Carers of people with disabilities, Culturally and Linguistically Diverse Carer supports, Indigenous Carer supports and supports for families caring for someone with a mental illness, Dementia respite support)

5. Sharing the Load - Nurse Practitioners and Allied Health Professionals

Research into workforce and population trends in Australia indicates that underlying factors causing the current GP shortage are likely to continue, and most probably increase. Factors identified to date include:

- increased demand for health services created by population ageing and the impact of 'lifestyle' diseases
- increasing part-time workers created by the need for many GPs to maintain a better balance between work and home
- shortages in training numbers/places for replacing the number of GPs retiring from the workforce.

Other models of primary healthcare service delivery offer opportunities to expand services to meet need in a more flexible manner. Yet, it is evident that increased investment must also be made in training, recruiting and retaining additional health professionals at all levels of the primary healthcare system.

Nurse practitioners, including those working in nurse-led practises, could have an important role in a primary health system which delivers the best practise model outlined in the previous section. Increased utilisation of nurse practitioners in primary health care could enable greater focus on health promotion, illness prevention and chronic disease management. There is increasing evidence, both nationally and internationally, that positive health outcomes can be achieved by increasing the use of nurse practitioners in primary health care. The strength of a nurse practitioner model offers opportunity to work in a complementary manner to GP clinical practice. The model also has potential to offer affordable options for Carers to access health promotion and prevention services, and may assist to leave GP's freer for more complex consultations, which would then improve general availability of appointments for those people with more complex health needs.

In Carers ACT's consultation with Carers, some Carers unreservedly welcomed the concept of nurse practitioners taking on some of the GP's responsibilities. They welcomed it as a potential cost-saving and time-saving opportunity, to better meet their needs and fit with the demands of the caring role. However, other Carers expressed concern regarding the level of training of the nurse practitioners. They wanted reassurance that the nurse practitioners would have access to sufficient, appropriate training and receive the workplace support they would need to deliver high standards of care. In particular, an issue of concern was the interface between nurse practitioner and GP care, for example, the development of appropriate standards/assessments to ensure quality of care, protocols for clear communication, and systems for timely referral when required. Carers indicated a need for more information and reassurance to assist them to best use a system of nurse practitioners and/or allied health professionals if such supports are developed in the ACT.

6. Conclusion

Consultation with Carers, undertaken in recent years and to inform this submission, indicates that the shortage of GPs has made it more difficult for Carers and care-recipients to access primary health care in the ACT. Current barriers to care include increased waiting times, disruption in continuity of care, and increases in direct costs (due to transitional charges and lack of bulk-billing options). For some Carers, a double impact on their health has been felt because not only are they are less likely to go to the doctor for personal health reasons, but they also experience increased stress levels because of the barriers preventing them from adequately meeting the health care needs of the care-recipient.

Carers need greater assistance to more effectively access primary health services. National and local research indicates that Carers as a population group in our community experience lower health and wellbeing and higher rates of depression than the rest of the community. It is evident that improving Carer access to primary health care will most likely have significant positive impacts on their health and well-being. Good health and wellbeing is vital to support Carers to continue to deliver their caring role.

Carers are a diverse group with diverse needs. In general, they need a system which is more affordable and more accessible, but they also need one that offers good continuity of care. This submission has presented a number of options to enhance and support better early intervention systems, improved clinical care for people with complex needs, increased flexibility of access to primary health care, and greater opportunities to improve health and wellbeing through targeted health promotion for a largely under-recognised 'at-risk' population within the ACT.

Carers ACT offers a number of services which already support many thousands of people in caring roles throughout the ACT. It also manages services such as the Commonwealth Respite and Carelink Centre which has under-utilised potential to provide information services to better assist GPs and health professionals. Carers ACT offers this information for the consideration of the Standing Committee on Health, Community and Social Services, and would be delighted to work with the ACT Government and health professionals throughout the ACT to improve outcomes for Carers in regard to their health and wellbeing needs.