

1 March 2010

Smarter, Stronger, Healthier, Safer
C/- Office of the Leader of the Opposition
Parliament House
Macquarie Street
SYDNEY NSW 2000

Re: NSW Liberals and Nationals Social Policy Framework

Carers NSW welcomes the opportunity to provide feedback on the NSW Liberals and Nationals Social Policy Framework, *Smarter, Stronger, Healthier, Safer*.

1. Introduction

1.1. About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

1.2. Who Carers NSW Represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW, there is estimated to approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Carers exist in all communities, including amongst Aboriginal communities, those of cultural and linguistically diverse backgrounds (CALD), amongst Gay, Lesbian, Bisexual, Transgender and Intersex communities, and throughout metropolitan, regional and rural NSW.

1.3. Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics (2003) Survey of Disability, Ageing and Carers (SDAC)¹:

- There are 748,000 carers in NSW, representing 11% of the NSW population
- There are an estimated 186,000 or 25% of carers from CALD backgrounds²
- There are approximately 10,600 Aboriginal carers in NSW
- 54% of all carers in NSW are women
- 45% of primary carers provide 40 hours or more care per week on average
- 79% of people with a disability who live in households receive care from relatives and friends
- 55% of primary carers rely on a government allowance or pension as their principal source of income
- Carers save taxpayers an estimated \$30.5 billion annually (the cost of replacing carers providing informal care with paid care workers) which equates to nearly \$10 billion for New South Wales³.

1.4. About this submission

Cares NSW is a member of the Council of Social Services of NSW (NCOSS) Health Policy Advice Group (HPAG). NCOSS HPAG is a forum of peak and statewide consumer and community non-government organisations, academics and individuals that provides NCOSS with advice on health issues. Carers NSW has already contributed to the joint submission by NCOSS HPAG to the Coalition's framework. However, as the peak organisation for carers in NSW, Carers NSW is also providing a separate submission that specifically focuses on carer issues.

This submission will address the social policy principles which underpin the NSW Liberals and Nationals Social Policy Framework, and three of the goals areas; Smarter, Stronger, and Healthier, in relation to issues affecting carers in NSW.

2. The Social Policy Principles

Whilst Carers NSW agrees with the Coalition's six social policy principles, which underpin the social policy framework, Carers NSW believes that the social determinants of health approach should also be included to acknowledge the interrelationship between health and other social domains. According to the World Health Organisation (WHO):

"The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices"⁴.

There is growing recognition nationally and internationally that any health policy needs to incorporate coordinated action, which addresses "the social and economic conditions that make people ill and in need of medical care in the first place"⁵. The Coalition's social policy platform can

be strengthened if there are intersections with areas such as, affordable housing, affordable community transport, strengthening inclusive communities and equality of access to health and other services for rural consumers.

In addition, the Coalition's social policy principles could be further strengthened by including the social model of disability as a guiding principle. The social model of disability proposes that systemic barriers, negative attitudes and exclusion by society are the ultimate factors defining who has a disability and who does not. It argues that disability is not so much an attribute of the individual as much as of the social and physical environment in which a person with a disability lives. The social model of disability is widely accepted by Australian governments and service providers as the preferred model of disability for legislation, policy and service delivery⁶.

In Australia, the *Disability Discrimination Act 1992* defines disability using the medical model (total or partial loss of the person's bodily or mental functions) but the requirement of employers and service providers to make reasonable adjustments to their policies and practices or physical aspects of their premises usually follows the social model of disability.

The United Nations Convention on Rights of Persons with Disabilities also follows the social model of disability. It recommends specific strategies aimed at removal of barriers for social participation of people with a disability.

Recommendation 1: Carers NSW recommends that the Coalition's social policy principles should incorporate both the social determinants of health and the social model of disability.

2.1. Policy principle 1: The importance of early intervention and prevention

Carers NSW welcomes the incorporation of the importance of early intervention and prevention as one of the Coalition's guiding social policy principles. Early intervention is an approach that seeks to put the right supports in place early so that better outcomes are achieved in the long-term. Early intervention is also often used as a strategy to prevent crisis from occurring.

Carers NSW found through the development of the *Carer Life Course Framework*⁷ that carers require specific interventions at certain phases of their caring journey or life course. However, carers are not always engaged or identified upon the commencement of their caring role and this has possible implications for outcomes for carers in the long-term. For example, it is vital that young people providing care are identified and supported at the earliest possible stage. For young carers, in particular, early intervention greatly assists in reducing the negative impacts caring may have and which may arise from their caring role⁸ (Carers ACT, 2008).

Carers NSW believes that the potential benefits of early intervention for carers are:

- Prevention of crisis and carer burn out
- Better outcomes for the carer and care recipient
- Increased perceptions and experience of support
- Limits the carer becoming 'hidden'
- Improved relationship between the carer and care recipient
- Increased carers ability to 'cope' with the caring role
- Carers have more choice about their caring role and care support
- Limited impact on carers health and wellbeing.

It is these potential benefits that makes further research about strategies and approaches to early intervention with carers so important.

While there is an emphasis on identifying hidden carers in NSW (Priority Two of the *NSW Carers Action Plan 2007-2012*), there are few examples of approaches or strategies for early intervention with carers. In fact, intervention with carers is often ad hoc and relies on the carer's ability to successfully navigate their way through the maze of services or for a service provider to identify the carer and provide some support⁹.

The Who Cares...? Report on the inquiry into better support for carers identifies that carers have diverse information needs and increased access to information, education, training, family and carer advocacy, case management and care coordination services are required. A number of barriers to accessing information for carers were listed, including an overly complex and fragmented service system, limited time of carers, language and unawareness of rights to services and lack of available information in specific service settings such as Centrelink¹⁰.

A report released by Access Economics in December 2009, *The economic impact of youth mental illness and the cost of effective early intervention*, found that there has been very little research conducted in Australia on what is effective intervention. According to the report, "there have been comparatively few studies of the effectiveness of prevention and youth mental illness, fewer still of early intervention and seemingly none providing sufficient information to conduct cost effectiveness analysis"¹¹.

Unfortunately, evidence also indicates the low uptake of aged and community care support services by carers, and other eligible recipients. Research to identify what constitutes early intervention needs to be implemented by the Coalition to fully inform this priority of its social policy platform.

Because Carers NSW believes it is imperative that evidence about what is early intervention is available, it has recommended that the NSW Government fund research into what is early intervention for carers in its NSW Budget Submission 2010-11.

Recommendation 2: Carers NSW recommends that the Coalition's policy should include funding for research to identify what is effective early intervention for carers in order to gain a better understanding of how health consumers and carers can be supported and outcomes achieved through appropriate early intervention.

2.2. Policy principle 3: The rights of individuals to make informed choices and the expectation they will accept responsibility

Although Carers NSW agrees with the principle that individuals have the right to make informed choices, it is concerned about the reference to the expectation that individuals will accept responsibility. A policy principle that focuses on individuals accepting responsibility raises questions regarding the individual's capacity to do so due to literacy, mental, psychological, or physical constraints. Furthermore, the expectation that an individual will accept responsibility needs some qualification in relation to the impact of an individual's socioeconomic status, in line with the social determinants of health approach.

In addition, the rights of individuals to make informed choices are reliant on having access to publicly available information. As mentioned earlier, the *Who Cares...? Report*, found that there are a number of barriers to accessing information for carers, which can make it extremely difficult for carers to make informed choices for themselves and their care recipient, and as such cannot be expected to accept responsibility for what might be an ill-informed choice.

Carers already have a greater proportion of responsibility for those they care for and for this to continue carers require access to up-to-date information and resources.

Recommendation 3: Carers NSW recommends that the Coalition's policy principle should include reference to individuals taking responsibility according to their individual capacity to do so.

3. Goal Area One: Smarter: Education, Skills and Youth Affairs

Carers NSW welcomes the Coalition's first goal *Smarter* that focuses on education, skills and youth affairs. Carers NSW would like to provide feedback on goal three; *ensure every young person has opportunities in education, training or employment*, in relation to young carer issues.

3.1. Young Carers and Education

In NSW there are estimated to be approximately 90,200 young carers aged under 25 years, with an estimated 347,700 young carers in Australia (5.2% of all people under 25 years)¹². The actual number of young carers is likely to be higher. The reasons for this include families seeking to keep care needs private, or not recognising that assistance provided is deemed as 'caring'¹³. In addition, young Aboriginal people and those from CALD backgrounds are more likely to be young carers than other young Australians. Young carers are also more likely than non-carers to live in low income and sole parent households. In 2003, 24% of lone parents with a disability were being cared for by one of their children aged under 25 years¹⁴.

One of the most significant issues for young carers is their participation in school and other learning institutions. Young carers report difficulty in attending school and completing homework due to the demands of their caring role. In addition, cost of school fees, books and extra curricula activities can be prohibitive to participation at school for some young carers in families facing financial hardship.

According to the Australian Institute of Health and Welfare, "young people who become carers may experience a restricted social life, lower educational achievement and increased stress. Young carers mental health may also be affected through social isolation and the stress of extra responsibilities"¹⁵.

ABS data indicates that only 4% of primary young carers (aged 15-25) are still in education compared to 23% of the general population in this age cohort; and that 60% of primary young carers (aged 15-25) were unemployed or not in the paid workforce compared with 38% of the general population in this age cohort¹⁶.

There needs to be a greater awareness of young carers within the school system, community care sector and general community. Young carers need to be identified as a specific group of young people at risk. Schools need to be better informed about, and more supportive, of young carers. Awareness training for school teachers is needed to assist school staff to identify young carers and support them to remain at school. Young carers identify needs such as flexibility in completing schoolwork at home rather than class attendance, and having someone to talk to about their caring situation¹⁷.

Schools need to be more proactive in identifying and supporting young carers. Primary and secondary school teacher information kits have been sent out by Carers Australia (these were funded by the Australian Government), to raise awareness in schools about young carer identification, needs and issues. However, additional follow-up is required by the NSW Government in terms of implementing information and recommendations. Carers NSW would like to see participation of young carers in education, training and employment at rates approaching that of their peers who do not have caring responsibilities.

Carers NSW believes that the current *NSW Carers Action Plan 2007-2012*, should be incorporated in the Coalition's social policy goals. The *Action Plan* outlines a whole of government policy

commitment to recognising and supporting carers over this five year period. It includes strategies to increase the respect and recognition of carers, reach out to family members who may not see themselves as carers, improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work and caring.

The *Action Plan* specifically refers to identifying and supporting 'hidden carers'. Young carers have been identified within this group. The *Action Plan* identified both the need to support young carers directly, as well as supporting parents who need care in their parenting role to reduce inappropriate levels of caring for young carer children.

A Stronger, Fairer Australia (national social inclusion strategy) released by the Australian Government in January 2010 identifies young carers as a group of young people who may be at risk of particular long-term disadvantage because of their caring responsibilities and because they may not be identified and offered support¹⁸.

Recommendation 4: Carers NSW recommends that the Coalition incorporates the *NSW Carers Action Plan 2007-2010* into the Coalition's broader policies and plans that support young carers in NSW.

4. Goal Area Two: Stronger

Carers NSW welcomes the Coalition's commitment to the development of policies and strategies, which aim to create stronger, equitable and inclusive communities. Carers NSW would like to provide feedback on two of the goals under the goal *Stronger*, in relation to carer issues.

4.1. Better protect the most vulnerable members of our community and break the cycle of disadvantage

Carers NSW supports the Coalition's belief that "a government's success can, in part, be measured by the support it provides to the most vulnerable"¹⁹. Carers NSW believes that carers in NSW are disadvantaged socially, physically and economically. It is well documented that the impact of providing care can have a significant negative effect on the carer's own health and wellbeing, with many carers experiencing a significant decline in their own physical and mental health. Unless well supported, caring can also have a detrimental impact on carers employment and education prospects, their financial position, and their ability to participate in social and community life²⁰.

Recent research has shown that:

- Carers have the lowest levels of wellbeing of any Australian group²¹
- 30% of carers delay their own health care
- Carers reasons for not accessing health care include not having the time, or not being able to afford the treatment
- 60% of all carers have worse physical health than non-carers
- 40% of carers rated their health as fair or poor
- The majority of carers perceived that their physical and mental health was affected by their caring role, with carers reporting a higher level of orthopaedic or spinal problems, cardiovascular problems and emotional problems since becoming a carer
- A third of all respondents reported having been physically injured, at least once, in the course of providing care²².

The Who Cares...? Report identified the impact that caring has on carers and their families' health and wellbeing, noting that the key issues for consideration are:

- The psychological health of carers
- The psychological and emotional wellbeing of carers and their families
- The social isolation experienced by many carers²³.

The report also noted, in response to these key issues, the importance of:

- Options for assisting carers to maintain and improve their psychological health
- Options for carers to have sufficient time out of the caring role and access to counselling support for carers and their families
- Considering options for increasing social inclusion.

The Committee made a number of recommendations to address the underlying causes of a number of issues impacting on the health and wellbeing of carers. These recommendations include:

- To assist carers to access information and acquire necessary skills
- To alleviate the financial disadvantages facing carers and their families
- To improve access to appropriate respite and other support services
- To provide greater choice in relation to participation in employment and education²⁴.

Carers NSW supports these recommendations, and believes that it is vital for both NSW and Australian Governments to address these issues in order to improve the health and wellbeing of carers.

Carers save the health system billions of dollars a year. When carers are supported to minimise the impact of caring, including enabling carers to maintain their health and wellbeing, the health system will be more cost effective, and carers may choose to continue their caring role for longer.

Recommendation 5: Carers NSW recommends that one of the Coalition's goals should be to increase access to affordable respite and other services to allow carers to maintain their own health and wellbeing.

4.1.1 Disability

Carers have a key role in the aged and community care system, supporting the person with disability, advocating for his or her own needs in the planning process, safeguarding their wellbeing and participating in substitute decision on their behalf.

Carers NSW supports the Coalition's proposed introduction of a personalised service delivery model for people with disability, which will create greater choice for people with disabilities, their carers and family.

Carers NSW believes that giving carers and people with disability more control over how funding is spent and what services are purchased is important for increasing their choices and quality of life. However, it is important that personalised service delivery model is chosen by a person with a disability, their carer and family and that they are adequately supported to take full advantage of the model and its benefits.

Designing policy to support carers of people with a disability to engage with personalised service delivery models and minimise the impact of caring poses a significant challenge for policy

development and service provision in NSW. Special attention would need to be paid to timely involvement of the person with a disability, their carer and family at the onset of individual service planning. The provision of adequate training and support, and streamlining service provision so it is easier to navigate the system for the carer and care recipient, is also necessary.

In addition, many carers worry about what will happen to their care recipient when they are no longer able to care because of death or because of their incapacity to do so. Policy development around the personalised service delivery model needs to ensure that non government organisations are recruited as support workers to assist and support people with a disability, their carers and family in implementing personalised support plans. Ageing, Disability and Home Care (ADHC), Department of Human Services NSW are currently piloting this model in various areas in NSW. Participatory Action Research Strategy, and Carers NSW is coordinating a pilot 'My plan, My choice: Individualised (Packaged) Support' through Carers NSW's Coffs Harbour office that provides additional funding to purchase services for families and carers so they can maintain their caring role.

Recommendation 6: Carers NSW recommends that the Coalition's proposed introduction of a personalised service delivery model should be designed to enable the person with a disability, their carer and family to be involved and adequately supported from the onset of personalised service planning.

4.2 Strengthen our communities by increasing the level of volunteering and recognition of carers

Carers NSW welcomes the introduction of the NSW Private Member's Bill – *Carers Recognition Bill 2010* – in front of the current parliament for consideration. Carers NSW believes the Bill is a landmark for the recognition of carers in NSW, and Carers NSW commends the Coalition for this initiative.

Over the last five years, a number of strategies have been introduced that have had a strong focus on a whole of government approach to improving services for people with disabilities, mental illness, chronic conditions and their carers. These include:

- *NSW Carers Action Plan 2007-2012*, highlighting the NSW Government's commitment to carers
- *Stronger Together*, the ten year plan for disability services
- *NSW: A New Direction for Mental Health*, the five year commitment to mental health services
- *Better Together*, the whole of government plan providing the overarching framework, and
- *A New Direction for NSW*, the NSW State Plan providing priorities for better health and community services including services for people with chronic conditions and their carers.

However, despite these plans to improve coordination and delivery services to better support people with disabilities, mental illness, chronic conditions and their carers, unmet need remains considerably high. In addition, future trends, in relation to the ageing population and the increasing age-related health and disability conditions, demonstrate that the need for these services will increase dramatically over the coming years. This will place growing demand on NSW and Australian Governments to meet this need in NSW.

Carers NSW believes that the Coalition should incorporate these initiatives into its social policy framework, to ensure that there continues to be a strong focus on improving and increasing services for some of the state's most vulnerable people.

It is essential that governments and health services recognise carers as 'partners in care' and incorporate the right for carers to be included as a member of the care management team and be informed of the decisions relating to the care of their care recipient.

The *NSW Mental Health Act 2007* is an example of legislation in NSW, which outlines the requirement for services to include carers, by giving them greater access to information about the consumer while still allowing consumers to have some control regarding who is provided with information about them. This legislation treats carers as 'partners in care', including involving them in the care plan. The Act achieves this by:

- Enabling consumers to nominate a particular person to be their 'primary carer' so this person can receive information and be involved in treatment planning
- Establishing a process for identifying who will be the primary carer when the consumer is not able to, or does not nominate a particular person
- Enabling consumers to exclude a person or persons who they do not wish to receive information about them or their treatment.

The importance of treating carers as 'partners in care' directly relates to the interdependence and interconnectedness of the caring relationship. The wellbeing of a person with a mental/illness and/or disability always impacts the carer because they are often engaged in every aspect of the care recipient's life.

Recommendation 7: Carers NSW recommends that the Coalition's policy recognises carers as 'partners in care', and incorporates the right for carers to be included as a member of the care management team, and informed of the decisions relating to the care of the care recipient.

5. Goal Area Three: Healthier

Carers NSW supports the Coalition's commitment to a holistic approach to health. However Carers NSW believes that the Coalition's holistic approach to health would be strengthened if it incorporates the social determinants of health principles, which recognise the social, economic, environmental and political factors that influence a community's health.

Carers NSW would like to provide feedback on all four of the goals under the goal *Healthier* in relation to carer issues.

5.1. Provide NSW with world-class clinical health services and infrastructure

Carers NSW welcomes the Coalition's aim to provide NSW with a world-class clinical health services and infrastructure. However, Carers NSW is concerned that the focus on clinical health services in this particular goal, reinforces the medical model of health. This goal does not seem to acknowledge the key role non-clinical primary and community based services play in the broader health services of NSW.

Furthermore, it does not recognise the vital role of carers in Australian society, by providing the majority of care to people with a disability, chronic condition, mental health problem or drug and alcohol dependencies. The recently released interim report from the National Health and

Hospitals Reform Commission (NHHRC) described carers as an ‘invisible unpaid health workforce’ and stated that:

“The availability of Australia’s carers and their ability to continue their caring role is therefore critical to the long-term sustainability of the Australian health and community care systems”²⁵.

The rapidly ageing Australian population and the corresponding decreasing carer ratio need to be urgently addressed. For example, it is estimated that there will be a 160% increase in the number of people aged over 65 needing care between now and 2031. The caretaker ratio during this timeframe is expected to decrease from 2.5 to below 1²⁶. In addition, according to the recently released *Intergenerational Report* (2010) labour force participation is expected to reduce by 4% over the next 40 years²⁷. The projections on ageing, the expected reduction in future labour force participation and the decrease in the number of carers have real social and economic implications for Australia’s future.

If carers are to continue to undertake their important task it is essential that carers health and wellbeing is addressed and that the Coalition incorporate carer policies and strategies to support carers. Furthermore, the Coalition’s health policy needs to include objectives in which hospitals and allied health services are required to incorporate carer policies and strategies to support carers maintain their own health and wellbeing. This includes carer recognition through a carer identification field in consumer and client health records, training and development for carers, carer awareness training for service providers to identify carers and include them in care planning, and to provide good carer support services and systems, such as additional respite so they can attend health-maintenance activities.

Recommendation 8: Carers NSW recommends that the Coalition acknowledges the vital role carers play within the NSW health system and includes objectives within its health policy in which hospitals and allied health services are required to incorporate carer policies and strategies to support carers maintain their own health and wellbeing.

5.2. Build a more active and healthier community to minimise avoidable illness

Carers NSW believes that the goal of building a more active and healthier community to minimise avoidable illness, can only realistically be achieved by adopting a social determinants of health approach, which would address the socioeconomic conditions intrinsically linked to creating healthier communities.

Carers NSW also believes that the Coalition should acknowledge the key role that non government and community based health care services play in health promotion and early intervention and prevention in local communities. It is the view of Carers NSW that the Coalition health policy framework needs to address the evidence of increasing age-related disabilities and the ageing population, and the consequent reduction in the proportion of carers. There is a need for any current or future NSW Government to provide ongoing funding to peak NGOs and the age and community care sector supporting carers, the ageing population, and people with disabilities to reflect the additional requirements for policy and advocacy and support services.

NGOs and community services who provide support to carers, the ageing population and people with a disability play a vital role in the wider NSW health system. NGOs not only provide services to their clients and other services providers, they also inform government on emerging issues, invest in research to inform policy and program development and are often leaders or ‘centres of excellence’ on issues relating to carers, the ageing population and people with a disability.

Carers NSW made the following suggestions in its response to the NSW Health NGO Program Reform Discussion Paper, in relation to how NSW Health can improve its partnerships, collaborations and communication with the NGO sector:

- increased use of information technology, such as the proposed Carers NSW Carers Communication Hub and a NSW Health Portal, or promote and strengthen the HSNet Portal to increase utilisation of this site by NGOs
- implementation of a consultation/communication activity in NSW Health-funded NGO programs to increase access to NGOs, particularly rural and remote NGOs, and other stakeholders
- review of the NGO Advisory Committee and identification of mechanisms for NGOs to inform the committee of issues for representation to NSW Health, and for reporting back by the committee or NSW Health to NGOs
- establishment of a Rural and Remote NGO Advisory Committee to consult with NSW Health or to inform the NGO Advisory Committee on issues for rural and remote NGOs and their stakeholders
- facilitation of regular NGO forums in its Area Health Services to inform stakeholders of NSW Health's initiatives and to identify emerging and current issues for rural and remote NGOs and their stakeholders.

Carers NSW believes that supporting the NGO sector will play a vital role in achieving the goal of building a more active and healthier community.

Recommendation 9: Carers NSW recommends that one of the Coalition's goals should be to provide ongoing funding to peak NGOs so that they can continue to play a vital role in health promotion and early intervention and prevention in local communities.

5.3. Support people with illness and disabilities reach their potential

Carers NSW welcomes the Coalition's goal of supporting people with illness and disabilities reach their potential. However, Carers NSW believes that this goal would be strengthened if it included carers.

As indicated above, a considerable amount of evidence demonstrates the negative impact caring can have on carers health and wellbeing. Carers NSW believes that the disadvantaged, vulnerable position of carers within NSW qualifies them to be included within this goal.

Recommendation 10: Carers NSW recommends that the Coalition's health goal should be replaced with 'support people with illness and people with a disability and their carers to maintain optimal health and wellbeing'.

5.3. Ensure all stakeholders, including patients, carers, clinicians and providers have more choice and stronger say in the system

Carers NSW supports the Coalition's goal to ensure that all stakeholders, including patients, carers, clinicians and providers have more choice and stronger say in the system. However, Carers NSW is concerned about the reference to 'patients' and 'clinicians' within this goal, both of which reflect the medical approach to health and not the social determinants approach for health, which Carers NSW, have advocated previously throughout this submission. Carers NSW suggests that the terms 'patients' and 'clinicians' be replaced with the terms 'health consumer' and 'health

workforce', which will reflect the role non-government and community based health care services play within the NSW health system.

Furthermore, Carers NSW believes that this goal would be strengthened if it involves a genuine commitment to by the Coalition to acknowledge carers as 'partners in care'. Both the *NSW State Health Plan* and the *NSW Carers Action Plan 2007-2012* have placed a strong emphasis on identifying the integral role that carers and families play in supporting people with health needs, both while using formal services, and at home in the community.

Carers NSW believes that for carers to be recognised as partners in the health care system genuine empowerment through engagement, provision of information and facilitating active participation is needed. It is the view of Carers NSW that carers, as 'partners in care' should be called upon to utilise their expertise in all relevant forums such as advisory councils and committees.

There is a need for health professionals to understand the vital role of carers, what carers do and the impact caring can have. The complexity of the hospital and community service systems mean that there can be a lack of understanding about carers and awareness of the impact of caring on their life choices and social, financial and health wellbeing. It is important that all health professionals receive carer awareness training on an on-going basis.

Feedback from carers indicates that within NSW Health there is a lack of understanding at all levels of the role of carers in a range of settings and the impact of caring on a carer's own health and wellbeing as well as that of the person they care for. In particular, carers often feel that their knowledge and experience are not sufficiently acknowledged or used in health care planning.

There is a need for inclusion of the carer, as appropriate, throughout the health consumer journey. The pressure within hospitals is toward clinical and technical health delivery, which can mean that carers are viewed as extraneous to the process, even though non-hospital health care for the health consumer will often reside with the family. Carers frequently do not receive the information, education and training that they need. At every level of the health system carers need to be identified and supported whether it is at the birth of a child, diagnosis of a condition, the end of life, or at any stage throughout.

Carers also require on-going professional education and training as well as access to up-to-date information and resources. All carer supports need to take into account cultural differences and diversity needs.

The Who Cares...? Report, identified carers as experts of their own experience of caring and recommended that this expertise needs to be recognised and utilised in the health and community care service settings. In addition, by treating carers as 'partners in care' valuable knowledge about the care recipient can be shared with health and community care professionals²⁸.

Recommendation 11: Carers NSW recommends that one of the Coalition's health goals should be to launch a state wide program of education for health and community care professionals to better understand carers as 'partners in care'.

Key recommendations

Carers NSW recommends the following:

- **Recommendation 1:** Carers NSW recommends that the Coalition's social policy principles should incorporate both the social determinants of health and the social model of disability.
- **Recommendation 2:** Carers NSW recommends that the Coalition's policy should include funding for research to identify what is effective early intervention for carers in order to gain a better understanding of how health consumers and carers can be supported and outcomes achieved through appropriate early intervention.
- **Recommendation 3:** Carers NSW recommends that the Coalition's policy principle should include reference to individuals taking responsibility according to their individual capacity to do so.
- **Recommendation 4:** Carers NSW recommends that the Coalition incorporates the *NSW Carers Action Plan 2007-2010* into the Coalition's broader policies and plans that support young people in NSW.
- **Recommendation 5:** Carers NSW recommends that one of the Coalition's goals should be to increase access to affordable respite and other services to allow carers to maintain their own health and wellbeing.
- **Recommendation 6:** Carers NSW recommends that the Coalition's proposed introduction of a personalised service delivery model should enable the person with a disability, their carer and family to be involved and adequately supported from the onset of personalised service planning.
- **Recommendation 7:** Carers NSW recommends that the Coalition's policy recognises carers as 'partners in care', incorporates the right for carers to be included as a member of the care management team, and to be informed of the decisions relating to the care of the care recipient.
- **Recommendation 8:** Carers NSW recommends that the Coalition acknowledges the vital role carers play within the NSW health system and includes objectives within its health policy in which hospitals and allied health services are required to incorporate carer policies and strategies to support carers maintain their own health and wellbeing.
- **Recommendation 9:** Carers NSW recommends that one of the Coalition's goals should be to provide ongoing funding to peak NGOs so that they can continue to play a vital role in health promotion and early intervention and prevention in local communities.
- **Recommendation 10:** Carers NSW recommends that the Coalition's health goal should be replaced with 'support people with illness and people with a disability and their carers to maintain optimal health and wellbeing'.
- **Recommendation 11:** Carers NSW recommends that one of the Coalition's health goals should be to launch a state wide program of education for health and community care professionals to better understand carers as 'partners in care'.

Conclusion

Carers NSW thanks the NSW Liberals and Nationals Coalition for the opportunity to make this submission on their social policy framework; *Smarter, Stronger, Healthier, Safer*.

If you require any further information about Carers NSW response to the policy, please contact Laylla Amnsor on 9280 4744 or email layllaa@carersnsw.asn.au

Yours sincerely

A handwritten signature in black ink, appearing to read 'Elena Katrakis', written in a cursive style.

Elena Katrakis
CEO
Carers NSW

Endnotes

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