



Submission No. 666
(Inq into better support for carers)

A.O.C. 10/7/08

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

Re: Submission to the Inquiry into Better Support for Carers

Dear Committee Members,

Thank you for the invitation to prepare a submission to the inquiry into better support for carers.

The Association of Children's Welfare Agencies (ACWA) is the NSW peak body representing agencies providing direct services to children, young people and their families. This year, ACWA is celebrating 50 years of social advocacy, particularly for the Out of Home Care (OOHC) sector.

ACWA's strategic priorities focus on building a true civil society founded on the principles of social inclusion, workforce development, and strengthening community capacity. In preparing for this submission, ACWA consulted with its member agencies.

Should you require further information, please contact Sylvia Ghaly, Policy and Membership Manager, on 02 9281 8822 or email sylvia@acwa.asn.au.

Yours sincerely,

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Executive Summary:

Carers play a vital role in our society through their on-going selfless acts of kindness towards their loved ones. Carers come in all shapes and forms: they are the individuals who provide ongoing support for loved ones due to a medical condition, illness, disability or frailty. They are the sleepless single parent who is looking after a child with a chronic illness; the grandparents who, instead of enjoying the peace and quiet of their retirement years, are raising the children of their children; the young carers who, instead of being supported by the adults in their lives, they find themselves supporting a parent due to illness or frailty. In Aboriginal communities, they are the respected elders who, despite their own needs, are trying to hold the community together by caring for those who are in need; the uncle, aunty, next-door neighbour or family friend who is choosing to provide on-going support to a member of his or her 'extended' family.

In order to better support carers, there is a need to recognise the important role they play in society. It is equally important to address the issues that prevent them from fully participating in society.

While there are numerous issues that need to be addressed in order to provide better support to carers, this submission focuses on the following:

- Genuine recognition of the value of all human lives, including that of the chronically ill, the disabled and the frail, would lead to a greater recognition of the role of carers in our society.
- Adequate respite services for people receiving care would provide opportunities for carers to rejuvenate and to actively engage in society, even if it is only for short intervals.
- Suitable alternative accommodation and support services, with flexible arrangements, for those who receive care would encourage carers to entrust their responsibility in the hands of other professional practitioners while reducing the emotional guilt associated with the feeling of abandoning loved ones.
- Appropriately funded social and emotional networks and support groups for all carers, and specialised groups for young carers, would help reduce carers' social and physical isolation.
- Adequate financial compensation especially for full-time carers would reduce their risk of becoming socially isolated due to their financial circumstances.

The role and contribution of carers in society and how this should be recognised:

In order to recognise the important role carers play in our society, we need a shift in attitudes, not towards carers per se, but towards the 'loved ones' they care for. In recognising the value of the individuals, despite of their illness, their disability or their frailty, we lift the profile of those who care for them. The carers themselves see the importance of caring for their 'loved ones', out of love or out of obligation, they value the individuals they care for. However, a society driven by economic rational might not share the same views when the cost of caring is competing against other pressing issues such as health, education and accommodation for the healthy and able.

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment:

Carers feel obliged to be available 24/7 for the ones whom they care for. Such an intensive commitment, over long periods of time, leads to social isolation. It also prevents carers from participating in the workforce or in other vocational or educational activities, and from having a balanced and healthy lifestyle.

Carers face multiple barriers. Some of these barriers are:

- The absence of adequate financial allowance to offset the cost of caring for someone who is ill, disabled or frail over a long period of time:
 - o In most cases, due to the intensity of the level of support required, carers are unable to secure or maintain long term employment, neither on full-time or part-time basis. Yet the society does not provide them with adequate compensation for the role they play.
 - o Many carers do not receive any type of allowance to support them in their role as carers
 - o The allowance that some carers receive is very basic and inadequate to the important role they play in society.

- The lack of adequate respite care services for carers has an impact on their ability to maintain a healthy and balanced lifestyle while caring for their loved ones:
 - o Respite care is pertinent to ensure the mental and physical wellbeing of carers.
 - o Programs like Aunties and Uncles and similar are vital to provide carers with regular short-term respite and to expose individuals receiving care to other caring adults. In addition, it has the potential to increase the social conscience of society.
 - o Support networks, helpline services and other professional and social networks could help reduce the isolation of carers and increase their ability to connect with other carers and people who might share similar experiences.

- Young carers:
 - o Caring in general is an onerous task, which requires high levels of commitment and dedication. It is particularly harder on

younger carers as they have to care for a loved one while going through the generally confusing transitional phase from childhood to adulthood.

- In addition to general respite, young carers need more support, especially around self-actualisation, self-confidence and identity.
 - The impact on younger carers is more intense as they generally find it hard to plan for their future and to develop their identity outside the parameters of their role as carer and their relationship with the care recipient. Their role as a carer define, and in most cases limit, them as individuals.
- Lack of suitable and supported accommodation for loved ones:
- While carers choose to care for loved one in their own place of residence, the lack of suitable alternative services reduces the carers' options.
 - In many cases, the only way to receive help from the government is when the carer totally surrenders the responsibility of caring for their loved ones (especially people with disability) to the government of the relevant state and territory. Alternative arrangements, including joint effort from the government and the carer (especially relative carers) should be explored further.

The practical measures required to better support carers, including key priorities for action and strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

- Genuine recognition of the value of all human lives, including that of the chronically ill, the disabled and the frail, would lead to a greater recognition of the role of carers in our society:
 - Promotional campaigns to reinforce our social values and emphasise the value of the human life would help lift the profile of carers
 - Promotional campaigns reinforcing the invaluable contribution of carers would also help lift their profile in society
 - A national carers award, similar to the Australian of the Year Award, would lift the profile of carers in the community.
 - Reimbursing carers for caring as their vocational choice of employment, at an adequate level similar to that of a nurse aid or a teacher aid, is another way to recognise the importance of the role they play.

- Adequate respite services for people receiving care would provide opportunities for carers to rejuvenate and to actively engage in society, even if it is only for short intervals:

- Regular short-term respite opportunities would enable carers to look after their mental and emotional health, and to some extent, engage in society through support networks
 - Respite care would also expose those who receive care with an opportunity to have contact with other carers, which might help reduce their social isolation.
- Suitable alternative accommodation and support services, with flexible arrangements, for those who receive care would encourage carers to entrust their responsibility in the hands of other professional practitioners while reducing the emotional guilt associated with the feeling of abandoning loved ones:
 - Regardless of the reasons which lead carers to provide on-going support to loved ones, the lack of adequate alternative options add to the dilemma of carers and consequently that adds to their isolation.
 - Having short-to-mid term alternative accommodation for loved ones would free carers to re-engage, should they choose to, with vocational education or employment, or other social and recreational activities, which would improve the quality of their lives.
- Appropriately funded social and emotional networks and support groups for all carers, and specialised groups for young carers, would help reduce carers' social and physical isolation:
 - Support networks have the potential of reducing carers social and emotional isolation as they realise that they are not the only ones going through the experience of caring for loved ones.
 - Young carers require specialised and intensive support not just to cope with the present but to plan for their future.
- Adequate financial compensation especially for full-time carers would reduce their risk of becoming socially isolated due to their financial circumstances:
 - In a society that defines people by what they do and how much they earn, unpaid voluntary caring roles do not receive much accolade. Paying carers, while it will never adequately compensate them for their selfless act of kindness towards another human being, it will symbolise the value of their work.
 - In many cases, carers struggle financially. Providing adequate allowance, which could be means tested, would alleviate that struggle and help them better care for their loved ones without having to add financial duress to their list of concerns.

Foster carers (Out-of-Home Care):

Given that ACWA is representing agencies that provide Out of Home Care services to children and young people who cannot live at home, we felt the need to have a section dedicated to foster carers.

In a state where the number of children accessing OOHC services has increased by 82% over a period of 10 year (from 1996 to 2006) (AIHW 2007:50) and with the current rate of increase is estimated at 20% per annum¹, foster carers, including voluntary carers and kinship carers, play an increasingly important role in society. However, our society is ignorant of the important role carers play with many carers feeling that they are 'cheap labour', 'modern slaves' and 'second class citizens'².

In NSW, these are two of the issues of concerns:

1) Dealing with allegations:

- While our legal system believes in the concept of 'innocent until proven guilty', when it comes to investigating allegations against foster carers, the practice is that they are considered guilty until proven innocent (unsubstantiated)
- Such practice leads to a disruption of placement, and in most cases, irrespective of outcomes of the investigations, a child does not return to the same foster family.
- Foster carers who go through this process report that they feel betrayed by their agency and by the system, as agencies have an obligation to investigate the matter, which consequently prevent them from supporting their carers through the legal process.
- Foster carers also complain about the duration it takes to clear their names once an investigation is completed.
- A review of the current system is needed to ensure that carers are supported through the investigation process, without compromising on the safety of the child or the integrity of the investigation.

2) Supporting kinship and relative carers:

- Acknowledging the complexity of relationships and the extend of family members who play integral roles in the life of a child in OOHC, and the obligations associated with being related to the child, is important to provide kinship and relative carers with a level of support that matches the level of complexity of their situation.
- Convening forums and other networks could help relative carers better understand their needs and better deal with their situation and its complexity.

Conclusion:

¹ Department of Community Services, NSW Government, 2008/2009 Budget

² Holland, Kate E. et Al. Carers' Perspectives on Caring: A qualitative analysis of open-ended responses to the Carers Health and Wellbeing Index survey 2007. Carers Australia 3 March 2008

Carers play a vital role in society, their selfless acts of kindness towards the people they care for are commendable and they deserve to be recognised for their work with the at most admiration and respect.

Better respite care, better alternative accommodation and support services, and better support networks are needed to ensure that carers do not experience social and financial isolation. It is important for us as a community to acknowledge and recognise the role of carers and, when possible, support them so they can continue to support their loved ones.