

## presidentseditorial

## Further news about carer legislation in NSW

## Laraine Toms, President, Carers NSW

Last time I wrote about the Carers Recognition Bill tabled in NSW Parliament by Liberal MP Andrew Constance. Since then the NSW Government, after consultation with Carers NSW, also tabled a Carers (Recognition) Bill. This Bill is essentially the same as the Opposition's Bill. On 11 May I was thrilled to sit in the public gallery of the Legislative Assembly to listen to the debate about the Government's Bill – made more exciting by the rush to get there – I had an hour's notice it would be on! Politicians from both sides of the House came out in total support of the Bill. During debate an amendment was put by Andrew Constance MP, to ensure the Carers Advisory Council would have a majority of primary carers and a Minister to Chair – important elements of his own Bill. His amendment, supported by Carers NSW, was accepted by the Deputy Premier.

Members spoke highly of carers, their contribution and their overdue need for recognition and support. Many thanked Carers NSW for their work on the Bill and for the services they provide to carers. I was very proud to be there on your behalf. The Bill will now go to the Upper House where there is no doubt it will be passed.

This legislation is an exciting breakthrough for all carers and for those of us who advocate with and for carers. Our job at Carers NSW is to advocate for all carers, no matter whom they care for and what type of disability, illness or disorder their family member has. We work to ensure all carers are recognised and valued, their needs met and their voices heard. The advantage of being a peak body with active members is that we have the strength, the numbers and the expertise to be credible to governments and the community.

Thank you to carers and community members who have written to tell us about contacting their local member to seek support for the Bill. Thanks also to all of you who talked about the legislation to friends, family and

colleagues. Your work has really made a difference. Never before have carers been so much the focus for politicians! What will the legislation do for carers? You can read the entire Bill at http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/131a07fa4b8a041cca256e6100 12de17/d908704e7ff4a0b1ca25770b001bccf3/\$FILE/b2010-040-d15-House.pdf

Briefly, the objects of the Bill are:

- (a) to enact a NSW Carers Charter to recognise the role and contribution to our community of persons who care for other persons who have a disability, a medical condition (such as a terminal or chronic illness), a mental illness or are frail and aged. The Charter contains the essentials of the Bill. One of the most important elements of the Charter is that carers will, if they agree, be assessed as to their own health and/or education needs. This will mean that their health will be better looked after. Young carers won't slip through the gaps; they will be identified and helped
- (b) to require certain public sector agencies to take action to reflect the principles of the NSW Carers Charter when providing services that affect carers
- (c) to establish a Carers Advisory Council (with primary carers the majority of members and a Minister to Chair).

I have heard from some carers who are concerned that they will need to have an assessment before they can access services. That will not happen. It is the carer's choice whether or not to be assessed; the same services they have been used to will still be available whatever their choice.

This interesting political process has a wonderful outcome. But it is just the beginning. We will continue to work towards achieving further legislation that will provide more choices and supports for carers and eliminate the need for young people to forgo education, social and work opportunities because they are carers.

## From previous page

"Developing a coordinated national plan for rare diseases will be the first step to improve the current fragmentation of services, promote research and family support, and enable health professionals to provide best practice," said Prof. Elliott.

A Professor in the Discipline of Paediatrics and Child Health at the University of Sydney and a consultant paediatrician at The Children's Hospital at Westmead, Professor Elliott founded the APSU in 1993.

In June 2008, Professor Elliott was awarded the Member of the Order of Australia for academic services to paediatrics and child health, research, education and the establishment of the Australian Paediatric Surveillance Unit.

The Australian Paediatric Surveillance Unit (APSU) facilitates surveillance and research into childhood diseases. Research findings from APSU have provided new knowledge that has significantly impacted on clinical practice and public health policy. APSU is affiliated with the Royal Australasian College of Physicians, the University of Sydney and the Kids Research Institute, and currently funded by the NHMRC, Australian Department of Health and Ageing, and the Australian Research Alliance for Children and Youth. Please go to www.apsu.org.au for more information.

Carers NSW is able to provide carers of people with rare diseases with support, information, referral and access to counselling and support groups. Please call **1800 242 636** (freecall, except from mobile phones).

2 CARERSNEWSNSW

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