



Our mission is to create, develop and maintain a network of support and services for people who have a disability in the Macarthur Region of NSW through a partnership between families and professionals using a whole of life approach

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

Dear Secretary

The Families in Partnership Co-operative wishes to make a submission to the Standing Committee's inquiry into Better Support for Carers.

The Co-operative is made up of both families who have a member that has a disability and professionals members working in the disability field across Macarthur, located in the outer South West region of Sydney. Our submission is based upon the work the Co-operative undertakes within the community with carers and service providers, the stories of family members caring for their family member, and comments and ideas made by carers at networks and forums facilitated through the Co-operative.

Role and contribution of carers in society and how this should be recognised

The Co-operative agrees with Carer's Australia in that the three primary issues for carers are:

- Financial security and income support
- Workforce participation and flexibility
- Carer support services

Carers play a vital and significant role in Australia's society and way of life but are often the unsung heroes, **unrecognised for their volunteer role like other volunteers** in the community as they do not wear any uniform, badges or colourful t-shirts. They are just in their doing what they see as the right thing to do for their child, no matter what age they are.

People are **usually carers for life** as opposed to parents who expect to care for their family member until they grow up into adulthood. It's a 24/7 role even when they are not actually providing direct care. Carers need to be constantly thinking about, planning for and resourcing information on caring whether it be that nights dinner, tomorrows trip to the therapist, next years schooling, or what will happen in the future when they can no longer be the person's carer.

Carers make a high economical contribution to the overall well being of our society but they often pay a high personal price through poor health, reduced ability to generate and sustain wealth, and relationship stress.

Restricted income earning capacity + incurring of extra costs =s poverty or near poverty existence for Carers. **Not a formula society should accept**

I understand that it is my role and I can accept that. I just need financial support to continue my role – family member

I would do anything for my child, but I hope he dies before I do – family member

I have an autistic and epileptic son of 6 years of age who requires 24 hr care. What I and my wife require is access to more carers allowance to cover expenses for ever growing needs of child - schooling and basic health needs and importantly access to developmental therapies like Occupational Therapy and Speech. – Family member

Caring role brings with it new responsibilities and skill levels what Carers often have no prior or limited knowledge or training in. Carers have to learn whilst on the job, risking doing things that are not appropriate for the person or themselves. We do not allow this to happen in the “real workforce” so why should we let it happen to Carers and the people they are caring for? More support is need for Carers to increase their skills and knowledge so they can undertake their caring role’

How recognised?

- Providing full time carers with a Carers Wage that is similar to age pensions and recognised the cost of caring for a person 24/7,
- Incorporation of Carers into the superannuation system to provide wealth for them in later life,
- Remove restrictions on carers needing to seek work under social welfare system. Recognise the volunteer nature of caring and the hours involved that restricts access to work for may carers,
- Make Carers a clearer target group under the Home and Community Care (HACC) program. Review the scope and type of services provided to carers that enable their needs to be adequately met,
- Recognise Carer’s role as the advocate for the person they are caring for, as the “expert in their child”, and
- Empower Carers in the decision making processes about service provision.
- Provide programs for carers that give them access to proper hands on skills development and education in the different task that make up a carers role

The barriers to social and economical participation for carer, with particular focus on helping carers to find and /or retain employment

Whilst **Carers are 24/7** most services and support available to assist Carers are much less – more like 2/1 unless the Carer is lucky to organise and manage a multiply number of services. Afterhours and weekends is when respite is needed to allow Carers to participate in social activities but few services operate then.

The cost of respite is an added burden upon Carers, with many people not being able to be careered for by friends or extended family members at a “for love” price. Families who could afford resite often can not find it when they need it, not when the service can provide it. Quality of respite care is a barrier for carers taking this option as Carers can not fully relax unless they know their child is being properly cared for.

Our family need planned breaks so we can fit in all the things our other children do. Not “we will call you when we have a vacancy” – a family member

*Our families growing need is for more respite than the current 3 hours per week we get.
– a family member*

Access within the community remains poor for many families who have a member that has a disability. Access is both the physical aspect of moving easily around their community and the barriers of public perceptions in regard to behaviour and abilities of people. Modification of transport, whether private or public to meet people’s mobility needs is an issue of equitable access and an economical barrier.

Economical participation for Carers is restricted **by the time they need to devote to their “caring work”**, especially in single carer or older carers households. Many Carers who have given up work to care face barriers of outdated workforce skill levels, reduced confidence and self esteem levels and a complex workforce re-entry environment.

I am fighting with my local school to place my daughter (who has autism) at their pre-school. It is not fair they I could only get 2 days a week – how can I work? I qualifications in lots of areas but can’t get work as we can’t afford normal childcare at \$50 a day. What help is there for me if she gets knocked back and we have to sell our home to pay for childcare so I can work – a family member

Many Carers take the option of working whilst their children are attending school using flexible arrangements and/or part time employment. However, once the child leave school many parents need to take on a full time caring role again due to the capacity of many services to accommodate all young people who have a disability leaving school.

In NSW the Community Participation program is a vital service for many Carers but still restricts Carers ability to continue or gain employment due to the capacity of services if a placement is obtained. This is the case for families with children who have a moderate level of disability who can not be left alone at home or in the care of their siblings.

Carers and their families experience high rates of health and mental health problems with the risk of experiencing a depressive episode of 6 months or more being greatest in the first year of caring. (Australian Institute of Families Studies Report – Nature and Impact of Caring for family members with a disability)

The recently televised program “In my Shoes” highlighted the impact of long-term caring upon the Carer’s own health and wellbeing. It is important that Carers get early support for their caring role and flexibility within their workplace to accommodate their own health issues.

Recently I have experienced pain in my knees a have had physiotherapy to enable me to walk and continue caring for my son. I cannot have an operation as it would mean confinement of up to six weeks off my feet – impossible in my situation – a family member

The Co-operative recommends the Carers Australia Report March 2008 – *Carer’s perspective on caring: a quantitative analysis of open-ended responses to the Carer Health and Wellbeing Index survey 2007*. This report provides many Carer comments on life as carer that all Inquiry members should read.

Action

- Access to employment agencies focussing on needs of Carers
- Support Programs and services provided to Carers early eg The Right Information at the Right time model developed by Hope Healthcare in Sydney at local hospitals

- Use of Caring skills as RPL's for training and education courses.
- Flexible carer friendly work environments. Employers given tax incentives and support in employing Carers.
- Nationally funded programs to allow modification of private vehicles and community based transport to assist Carers participate with their families in the community
- Access to private health care coverage for immediate medical attention for Carers, with a range of recovery supports for the Carer and their family

The practical measures required to better support carers, including key priorities for action

- Focus of Health Promotion initiatives on Carers to improve their overall health status
- Supporting mainstream playgroups for inclusion of children who have a disability that allows interaction for Carers with other parents
- Linking of older carers with mainstream support/recreational groups that includes respite for the person they are caring for
- Greater consideration by Education Departments of the constraints placed upon Young Carers
- Improved role of Centrelink, Commonwealth Carelink and Carer Respite Centres in providing services that Carers need.

Strategies to assist carers to access the same range of opportunities and choices as the wider community

Localised Carer Support Networks, not just those run by peak bodies or state wide programs. Networks that focus on local support, with some one to turn to in time of need or uncertainty - a human faced service with the right information at the right time. Networks can be supported through peak body's web pages, information lines and data bases.

The Co-operative looks forward to the enquiry making a positive contribution towards better support for carers. All levels of government and the community at large need to put in place long term sustainable measures that support carers in their role and give them a quality of life that all sections of society strive for.

Yours in Partnership

Bob Lester
Community Development Coordinator