

Submission No. 1297

(Better support for carers)

ASC 6/1/09

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
Dear Secretary,

I wish to make a personal submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers. I am writing as an individual and not as part of any organisation.

My submission is limited to addressing only one of the terms of reference:

* the practical measures required to better support carers, including key priorities for action;
As background, I have concurrently been a Disability Pensioner, house-husband, and long-term carer for various family members over the past 10+ years. My experience informs the following practical recommendations to improve the ability of carers to do their (in)voluntary jobs. I have read the previous 26 submissions and didn't see the following ideas covered elsewhere, so here they are.

These recommendations are offered from the same perspective that we use to recognise and support the wonderful work of volunteers like the SES, rural Fire Brigade volunteers, etc with the important differences being that the carer work is more hidden and largely performed at home, and the voluntary nature of being a carer is questionable as the alternatives can be unthinkable to the family involved. In terms of costs, I believe that the practical measures outlined below could actually cost less than existing interventions and provide better long-term outcomes. They will also assist in targeting the right amount of help in the shortest timeframe to the carers that most need it.

Practical Recommendations & examples:

1. Adopt a policy of nurturing and supporting Self-Sufficiency and Resilience within carer families, but have a co-existent Safety Net for carers unable to comply with this policy.

Example #1: Require every recipient of Carer Allowance/Carer Payment to create and maintain an up-to-date Emergency Care Plan (ECP) as a kind of mutual obligation

But recognise that for many reasons some prime carers will not be able to carry out this task by themselves. Have a safety net of measures in place for such carers (eg. social worker/Carer mentor/case manager) to assist the prime carer to fulfil their task. Looking at it another way, every carer who does NOT have such a plan in place is a potential crisis waiting to happen (with commensurate community costs) due to alternate carers and process not having been identified in advance.

ECP notes: This is an existing Federal Government document and process with poor awareness and uptake rates. The ECP contains a written plan of steps to follow and identifies alternate carers to step in should the prime carer have an accident or be ill. Copies of the plan are lodged in advance with the nominated alternate carers. The prime carer also carries a special ECP card identifying the prime carer, people requiring care, and containing the contact details of the alternate carers. Emergency services are expected to look for this card and act on it. Implementation of the ECP process can give significant peace-of-mind to the prime carer. Conversion of the existing paper-based ECP to electronic form could make the tool much easier to update and distribute as required whilst reducing costs.

Example #2: Consider the qualifications and training of paid respite staff as compared to the prime carer; amongst other skills they are expected to hold a first aid qualification and to keep it current. Yet the prime

carer who looks after the disabled individual for the other 150+ hours per week usually has no such training. Shouldn't we expect the prime carer to be able to offer at least the same quality of first aid/medical care as the respite worker can? Isn't it reasonable to offer targeted first aid training to prime carers for zero cost, as is done for other volunteers like the SES and fire brigade as mentioned earlier? If a charge needs to be levied, have a financial safety net in place to waive costs for those on, say, income support payments. Following this train of thought, why not have other in-service training normally provided to professional respite carers made available to the prime carer if they want it.

2. Have a litmus test for carer support funding - How will funding contribute to the Self-Sufficiency and Resilience Policy mentioned above? (need to distinguish between disabilities that can or cannot be rehabilitated with present medical knowledge).

Example: If a care recipient has both behavioural problems but also high IQ and a passionate interest in a hobby, perhaps using a small amount of money to assist the disabled person to engage their area of interest will provide better long-term outcomes both to the individual and their carer than simply a lot of money being used to provide respite without materially improving the family situation. Naturally this approach may not offer any direct benefits where the individual has long-term high dependency needs, but re-directing individuals capable of rehabilitation as described above will free up money from the limited disability funding budget to provide more support to the remaining higher-needs group.

3. Set up a mentoring scheme to enable matching up experienced carers with 'newbies' just getting started. No formal carer support system can be perfect, and a mentoring arrangement would assist inexperienced carers to navigate the maze of support and focus on the "most bang for the buck in a timely manner" resources relevant to their specific situation. Even professional case managers can only see a portion of the total formal and informal help available out there. Carer members of disability-specific support groups have their own collective knowledge and networking potential that could be leveraged better.

Example: A prime carer of a newly-diagnosed child is commonly overwhelmed by the actions that now need to be taken in addition to coming to terms with the diagnosis. It can be hard to know where to start, and to the "newbie" carer it is impossible to know which resources and programs will in fact deliver very little immediate benefit in return for the overhead incurred in filling out forms, attending interviews, chasing up phone calls, being put on waiting lists etc. How much more efficient for all concerned if the confused carer can simply phone a mentor (another carer of a child with the same condition who "has been there and done that") and get some truly independent guidance.

4. Create a Disability 'Showbag' for Health professionals to distribute to carers of newly diagnosed patients (including Through The Maze resource guide and similar)

Example: The Paediatrician tells the parents that their son Johnny has autism. In the ideal world, instead of leaving it at that he will be able to give them a kit that contains all the information required to allow them to:

- * link up with a carer mentor as explained in point 3. above, and become aware of accessible autism-specific support groups,
- * apply for Centrelink support including Carer Allowance/Payment,
- * prepare an Emergency Care Plan,
- * explore further support options (eg. Through The Maze - published by the Association for Children with a Disability)

Isn't it strange that when a baby is born the parents often do receive such 'showbags' which can contain samples from manufacturers and information from service providers, but when a major life turning point is reached like a disability diagnosis there is nothing similar on offer. In the age of the internet a portion of such a 'showbag' could be made available online to reduce costs.

In closing, I wish to note that I have no idea whether these recommendations are within the scope of the Federal and/or State Governments or where the line of demarcation lies. What is clear to me is that failure to act impacts adversely on both levels of government.

Thank you for taking my recommendations into consideration.

signed...

Joe