

FOC 10/7/08

Submission No. 694
(Inq into better support for carers)

Submission from Brotherhood of St Laurence (BSL)

In response to the Federal Government Inquiry to review better support for carers, Brotherhood Aged and Community Care Services conducted a series of focus groups with family carers within its services (Packaged Care, Disability, Respite, and Day Programs). These focus groups represent part of the BSL's ongoing commitment to encouraging independence and self-advocacy.

Carers participating in the focus groups indicated their appreciation for the opportunity to be heard. One of the issues identified by Carers was that the demands of the caring role often left them with little time or energy to self-advocate, so they often felt voiceless.

Carers expressed a desire to see practical changes come about as the result of this inquiry. Most expressed a view that other consultations from Government did not seem to bring about meaningful change to their lives.

Brotherhood of St. Laurence strongly encourages the Federal Government to use the Inquiry's recommendations as a platform for developing long term policies that address the health care, income support, housing, and respite needs of family carers.

Methodology

Four Focus Groups were held with family carers within the Southern Metropolitan Region of Melbourne. In these groups, carers were asked to respond to the terms of reference for the Inquiry to review better support for carers. The carers who attended had diverse caring experiences and backgrounds. They included younger carers, older carers, carers with multiple carer responsibilities and some from Culturally and Linguistically Diverse backgrounds.

BSL gave an undertaking to the carers attending the Focus Groups that their feedback will be passed on to the Inquiry. This submission provides a chance for carers to share some of their opinions about the impact of being a carer as well as practical measures and strategies to assist Carers to continue in their role and improve their overall quality of life.

The results of the Focus Groups therefore include not only specific recommendations under each Term of Reference, but also list some of the feedback we received, relevant to that Term of Reference.

Results from the Focus Groups

One of the most striking aspects of the responses from BSL's Focus Groups was the high number of similar experiences and impacts shared by all carers, regardless of their backgrounds and circumstances. All of the carers expressed the view that their role was '24/7', even when their situation was under control and regardless of whether they lived with the care recipient, most have been in multiple caring roles at some point and many still are, and that caring was "never ending" with carers "never retiring" and constantly having to put the needs of their loved ones ahead of their own needs. All of the carers felt that their role impacted negatively on their lives, citing examples of social isolation, financial disadvantage and hardship, more rapidly declining health and relationship stress and breakdown as common issues.

Responses and Recommendations to the Terms of Reference.

Term of Reference One:

The role and contribution of carers in society and how this should be recognized.

Recommendation 1.1

Ongoing Public awareness campaigns about carers and how they can be supported by the community.

Carers identified that there is a need for broadly based, ongoing, public awareness campaigns at a national level. The campaign could highlight the sorts of demands and pressures carers are under and encourage businesses, service providers, community groups and extended family members to play a more active role in supporting carers to continue in their role. The campaign could also include awards and formal acknowledgements to carers, with involvement from key figures in both state and national government.

Carer feedback:

- *Raise the awareness of caring and promote the view that it is a community/ social responsibility. Many carers felt despair, isolation, sadness, anger, and frustration.. There was nothing positive about caring apart from the fact that the person being cared for was able to remain at home for longer and this was better than the alternative, which was placement.*
- *Public awareness campaigns about the role of carers would improve the ability of carers to maintain social networks. By providing information to the community at large, carers would receive more understanding and supportive responses from the people in their social networks.*

- Carers want to care, and feel obligated to care, for their loved ones. Their role should be celebrated and championed. – A comment from carers was: “ Will the next generation care for their partners as marriage no longer has the same meaning as it did in their days”
- Issues carers would like promoted include;
 - Carers enable people with disabilities, people with dementia and/or who are frail aged to remain living in their own home in the community.
 - Carers provide most of the informal care and it is a 24/7 role and at times some carers have multiple caring responsibilities – looking after parents, grandchildren
 - The role of caring compromises the health of the carer – many carers from our group were on anti – depressants and appeared to see no way out of this situation (either short and/or long term)
 - The perception of caring needs to be seen as positive as opposed to being a burden – not sure how this can be done. “What are the incentives for carers if they choose to care for their loved ones?”

Term of Reference 2

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

Recommendation 2.1

Develop and expand the range of respite options targeted to support Carers in the workforce, particularly those who wish to work full time.

Carers identified that to stay in the workforce, they need secure, reliable access to specific respite options that will provide care across their working hours. Without this level of respite, all carers felt it would be impossible for them to remain in the workforce in the long term.

Carer Feedback:

- “Carers don’t have the option to still work (full time / part time). Not really, when you have a service system which is fragmented and there are inconsistencies amongst different agencies. There needs to be some clarity from Government as to whether carers are able to work fulltime and have access to a range of services to enable this to occur.
Example given: Within the Southern Region there are NRCP providers who receive Employed Carers funding yet there are discrepancies between providers as to how many hours of respite an employed carer can receive – some agencies are not limited and others have a capping – therefore disadvantaging some carers.

- *Another carer is working part time and eating into her superannuation to meet the income short falls. At the moment she sees it as inevitable that she will have to give up employment to work as a full time carer.*
- *Appropriate respite options are required if carers are going to retain employment – respite which is going to reassure the carer and also be appropriate for the care recipient.*

Recommendation 2.2

Expand employed Carer's Leave entitlements for those carers with multiple caring roles through a system of Government incentives to employers

Carers often work part time because they need to have greater flexibility to meet the varied demands of the caring role such as when care recipients are unwell. Working part-time does not allow carers to earn sufficient income to meet their ongoing costs.

Carer Feedback:

- *Do employers have a responsibility to ensure that they have a carer friendly workplace?*
- *Carers within the group did not see employment as an option. A 42 year old carer did not see employment as an option as she had multiple caring responsibilities, therefore her fear was what was going to happen to her when she is 65 years of age and she has no access to superannuation.*

Recommendation 2.3

Increase availability of flexible respite to allow carers to participate in vocational education. Carers are unable to match access to respite with their hours of study. Carers are often unable to participate in other educational opportunities that would enhance their skills as a carer and ability to be employed due to a lack of flexible respite.

Carer Feedback:

- *"I would like to study but haven't got the time and energy."*

Recommendation 2.4

Improve the range and availability of social activities specifically targeted for Carers.

Carers specifically endorsed the types of social, recreation and relaxation activities provided by BSL through its' Socialization Program. This program provides a range of regular activities for both carers and care recipients with a minimal entry charge (by small donation) and assistance with transport to and from the activity.

Carer Feedback:

- *Increased access to supportive social activities/recreation/relaxation. Agencies with a welfare focus are best able to provide these types of activities for carers. Several carers cited very painful and distressing experiences where they dropped out of social activities once they became a carer as the other members of the group didn't understand the pressures they were under and were not tolerant of absences.*
- *Providing opportunities for carers to get together to engage in social opportunities such as this exercise group. (The exercise group is a part of BSL's Socialisation Program)*
- *"Carer support groups are useful but only when you first become a carer. Later on it's nice to be part of a group doing other activities or having common interests, but where you know the other members of the group understand what you're going through and accept you without judgement."*
- *Limited finances is a barrier to accessing social opportunities – carers put their needs aside and the family member becomes the priority.*

Term of Reference 3

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

Recommendation 3.1

Provide a "One Stop Shop" where carers can phone 24 hours, 7 days per week for information and referral to all services for Carers and Care Recipients.

Carers are often in the dark about what services are in their local area and how to access them. They want a centralised information service that will give them general information, specific detailed information about local services and arrange referrals for them so that they don't have to make call after call to find help. The information service would fit well with the existing Carer Respite Centres.

- *Carers need a coordinated service system and access to information. We want a One stop shop for information about local service networks where the information provider also contacts the specific service provider and assists with the referral/contact. There also needs to be more understanding and information from the appropriate departments.*
- *A central agency would be more efficient and economical in handling carers' needs in local areas.*
- *"There needs to be strategies to simplify access to services".*
- *The Commonwealth Carers emergency help line should be brought back to regional areas.*

Recommendation 3.2

Continue to increase the availability and range of Respite Options including specific options for younger adult Carers and Care Recipients.

Carers find the existing services very helpful but still have difficulty accessing services that are local, available at times which suit them, and last for the length of time that suits them. Individual carers have a wide range of respite needs, depending on their circumstances and often the respite services are only available for 1 night, or a minimum of 2 weeks, or business hours. This doesn't suit the lifestyles of many carers who then have to choose between meeting their needs or accessing the respite.

Carers asked for respite that allows them to attend work and includes "after school hours" respite as well as residential respite facilities for younger adults that are an alternative to nursing homes.

Carer Feedback:

- *Continue with community respite programs and provide more flexible respite programs*
- *We need appropriate funded respite, both in home and out of home, overnight and weekends, recreational camps, and opportunities for inclusion in the community.*
- *Establish more respite centres for younger adults – respite should not only be provided in a nursing home*
- *We need more funded respite.*
- *Young carers with after school care, respite and home help.*

Recommendation 3.3

Systematic expansion of permanent accommodation options for younger adults with a disability.

Carers identified that most of the current accommodation options for younger Care Recipients deliver suitable outcomes but there are chronic restrictions on the availability of these options. For many years now, the funding for accommodation options has been expanded in a piecemeal fashion without any attempt to address the unmet need in this area. Carers said the uncertainty of this system creates enormous additional stresses on their role.

Carer Feedback:

- *Appropriate supported accommodation with a wider choice, and with qualified skilled dedicated support staff.*
- *It is almost impossible to access a support package for my child because not enough packages are provided by the Department of Human Services (Victoria).*
- *There needs to be a disability support Needs Register that governments use to plan ahead for peoples needs.*

- *At the moment the State Government just responds to crisis situations.*
- *There needs to be a means of planning for the required level of accommodation in local areas.*
- *There needs to be a program of building a wider choice of quality supported accommodation in areas of need.*

Recommendation 3.4

Exemption for Carers from some of the restrictions of current Privacy Legislation.

Carers asked that there be a simple process where they can obtain exemption from the current Privacy Legislation that prevents all service providers and businesses readily providing them with information about the Care Recipient. At the moment, Carers are often in the situation where they care for a person who cannot give consent to release information to their Carer.

Carer Feedback:

- *Look at current legislation – such as Privacy Laws and how this impact on the carers – getting access and information from various departments when the person has not put in place EPOA*
- *The privacy legislation is so frustrating. Often one service can't talk to another. This is so unhelpful.*

Recommendation 3.5

An urgent review of the systems of financial support for Carers and the provision of a Superannuation Scheme for Carers.

This was the issues that Carers felt most strongly about and that they identified will have a positive impact on all of the areas addressed by this Inquiry's Terms of Reference.

Carers want a more comprehensive system of financial compensation for the work they do. All of the Carers in our Focus Groups know they are not compensated adequately for the work they do. They want a system that provides them with financial security that allows them to be able to maintain their own homes and plan for their futures. Carers want a system that pays them at different levels depending on the level of care the Care Recipient needs and be able to contribute to superannuation schemes like any other paid worker.

Carers want the current rules for accessing Carer Payments simplified and expanded so the focus is no just on Care Recipients with physical disabilities.

Carers Feedback:

- *Additional carer payments. The welfare payment system does not allow Carers to claim more than one pension or benefit.*
- *We need financial security, now and in the future to help families have a lifestyle compared to the rest of the nation.*
- *Assistance with cost of utilities and home maintenance/repairs. For ageing carers and sole parents, help in the home and garden, small handyman jobs etc.*
- *Fewer fees or a reduction in fees. Often carers can't afford the HACC fees without having to do without something else.*
- *Carers have to rob Peter to pay Paul.*
- *"I haven't been able to buy new glasses for years because every time I get close to saving enough money, I have to spend on my son to help him get something he needs. Last time I had to pay for medication. My son couldn't afford it because it wasn't subsidized for him because he wasn't sick enough"*
- *Broaden carer eligibility criteria to include those caring for someone without a physical disability.*
- *Review the value of carers saving the government money, and give them a life comparable to the rest of our nation.*
- *Carers should be remunerated in accordance to the level of care that they are providing.*
- *We want government to really care about how carers are coping and managing financially.*
- *"My husband has severe Parkinson's and I have very little money so it comes down to a difficult choice each fortnight between purchasing medications or groceries. Medications win out every time."*
- *"I am resigned to the fact that I have to sell my home some day in the future. My husband was a reasonably young man when he had his stroke and his needs are getting greater....I now have to work part-time. We are left with no money and growing expenses."*
- *"My goal is just to survive and get through the latest crisis. I don't have any real goals or any expectations for a better future."*
- *"There is no such thing as retirement or just time with my wife. We haven't had a holiday for 14 years."*

Recommendation 3.6

Priority of access for both Carers and Care Recipients to health services such as hospital admissions, elective surgery, specialist appointments, Allied Health services and GP appointments.

Carers often have their ability to continue caring compromised by having to wait for medical appointments or treatments. So many services are reliant on referral by GP's and yet Carers and Care Recipients are often waiting for days or weeks to get an appointment.

Carer Feedback:

- *I often have to wait and wait to get access to health services.*

- *Because it is so complicated and time consuming to see my doctor or a specialist, I just give up and don't worry about my needs.*
- *Better GP education in supporting and referring carers to appropriate services as well as better diagnosis of dementia to ensure early intervention*
- *If the direction for government is to support carers to continue in their caring role then early intervention is required – this also needs to be linked to the health promotion campaigns currently in place*

Term of Reference 4

Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase capacity for carers to make choices within their caring roles, transition into and out of caring and effectively plan for the future.

Recommendation 4.1

Continue to expand Case Management services including those targeting younger adult Care Recipients.

Carers identified that Case Management such as CACP's, EACH, EACHDEM and Linkages services play a key role in creating access to opportunities and choices. Carers emphasised that Case Management services are more effective when they provide support to Carers and families as well as the Care Recipient.

Carer Feedback:

- *Case management assists carers in their caring role – care managers were not only there for the care recipient but also with the carer.*
- *Carers need Care Management that includes support for the whole family and assists with access to services rather than just information.*
- *We know that caring cannot be done by one person and therefore it should be extended to family if possible. Carers do not want to burden family with caring responsibilities but a Care Manager can help to get other family members involved.*
- *Caring can be successful if all family members are involved.*
- *Care management assists carers to plan for the future and we are not judged by the decisions we make.*

Recommendation 4.2

Develop specialist services that can provide information and assistance to Carers about future planning.

Not all care recipients need Case Management but they still need help to plan for the future. This role could be developed into a service that

sits within the centralised information and support service described in Recommendation 3.1.

Carer Feedback:

- *Planning will ease the stress caused by concern as to the welfare of our child when we can no longer care.*
- *How soon do we commence the planning for the future? It is hard to plan for the future because we don't know when problems are going to occur.*
- *I don't know how or when to start planning with my extended family.*
- *Carers need help to plan for a positive future for their children, instead of living in fear of dying.*
- *State /Federal Governments need to work together, to give caring families hope for the future.*
- *Our health is deteriorating with advancing age. We need to be able to die in peace. We need to be given the chance for our child to have a home, when we can no longer provide the necessary care.*
- *I'm too busy surviving day to day, week by week to plan for the future.*
- *It is imperative that the Government address the critical crises in accommodation, respite and support services.*

Recommendation 4.3

Develop national standards and accreditation systems for all services that are mandatory and give powers to investigate complaints by Carers and Care Recipients.

Carers noted that they are not always satisfied with the way they and the Care Recipients are treated by services. Carers want some clear simple processes that will assist them to ensure that Care Recipient needs are properly met by funded service providers and that complaints can be independently and professionally investigated.

Carer Feedback:

- *Review all service providers.*
- *We need better service providers that can support and care for families.*
- *We want our loved ones to be treated with dignity and respect.*
- *Review support staff criteria and pay levels, to attract better and dedicated support staff.*
- *Develop and enforce service delivery standards.*

Recommendation 4.4

Improve access to Carer Education by using a network of local training venues and providing assistance to carers with respite and transport costs as part of the training program.

Carers all felt that they would benefit from training about certain aspect of caring but found it difficult to find the time away from their role as carer to attend courses. Many felt courses were too far away or too costly in time or money to get to.

Carer Feedback:

- *Carers need to receive education and training on caring and to have a point of contact for their caring needs.*
- *Many carers within our group did not know about the Carers Respite Centre – do we need a media campaign to promote this service?*
- *It is really important to get an education on being a carer. I just fell into it without getting any information and training.*
- *Is education on what is caring and who are carers something which needs to be considered – when would this education begin?*

Recommendation 4.5**Continue to improve Carer Advocacy and Carer Representation at senior levels of government.**

Many carers felt they rarely get an opportunity to have their concerns heard. Because of the demands of being a Carer, Advocacy organisations and small, local, organised forums such as the ones which were run by BSL in response to this inquiry are essential to provide opportunities for Carers to contribute to the ongoing response to carers needs and the development of future strategies/services.

Carer Feedback:

- *Listening to carers and carer support groups. They are the experts.*
- *Have a carer representative, with a equal and unrestrained voice on all committees, policies and decision making forums, review panels etc.*
- *I'm too tired or busy to self-advocate.*
- *We need to have a voice and our rightful place at the policy and planning table of Governments.*
- *It's been helpful to talk to people who listen to you.*
- *I hope that government listens to what we are saying and uses it to improve things for Carers.*
- *We want government to really care about how carers are coping and managing financially.*