

Submission No. 335
(Inq into better support for carers)

A.O.C. 1/7/08

SUBMISSION TO
THE FEDERAL PARLIAMENTARY INQUIRY INTO
BETTER SUPPORT FOR CARERS

JUNE 2008

by
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22/6/2008

Summary

This submission is made by the full time carer of a person with disabilities. It attempts to address each of the 4 key terms of reference, by describing some of the problems and frustrations faced by carers, accompanied by suggestions about how they might be mitigated.

In particular it makes the point that in Australia governments have accepted responsibility for looking after people with disabilities. Carers (by default) are carrying some of this burden and there are consequences which should flow from that.

The submission discusses 4 barriers to social and economic participation of carers and what might be done about them.

The submission also suggests a strategy for providing better information to carers about what help is available from the complex mix of sources, and it makes an appeal for a "CarerCover" scheme to be set up for the support of carers who injure themselves as a direct result of their carer's role.

Introduction

I am the full time carer for my wife Ingrid, who was diagnosed as suffering from multiple sclerosis (MS) in 1984. At the time she was 42 years of age, although with hind sight, she probably had MS since her teenage years. In our case, the progression of her illness has seen a mercifully slow but nevertheless inexorable decline in her physical capabilities, so much so that she now needs a "walker" to help her with her mobility and balance, and the weakness in her hands and arms means she has difficulty manipulating cutlery to feed herself. Dressing and undressing is also a problem. As the years passed I pictured myself eventually washing, dressing and feeding her and moving her in her wheelchair from one pleasant location to another, and I thought I could cope with that. However, a few years ago she suddenly developed trigeminal neuralgia with excruciating pain in her jaw, and I found myself powerless to help. Fortunately, the neuralgia has now disappeared again. (But for how long?)

Through Ingrid I have come in contact with many carers of people with disabilities and have come to realise that Ingrid and I are relatively lucky by comparison, but I fear for the future and where MS will lead us. I want to tell you about some of the problems and frustrations carers face, and I am grateful for this opportunity to do so.

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

In Australia we believe in equality of opportunity for everyone irrespective of race, colour, sex, creed and many other things, including disability. There may be references to some of these things in the Constitution (I don't know), but we have certainly made laws about guaranteeing equality of opportunity for all. This means we want, and our governments have accepted the responsibility for looking after people with disabilities. The reasons motivating carers to look after people with disabilities are many and varied, but whatever motivates them, by looking after people with disabilities carers, by default, are carrying some of the burden for which our governments (at society's request) have accepted responsibility. It does not seem unreasonable, therefore, to expect that the efforts of carers be recognised by funding, and other forms of support, as any other agency of government, created for this purpose, would be, i.e. the maximum the nation can afford for this purpose.

No one should be tempted, as a result of the above reasoning, to substitute an "efficient" bureaucracy for the existing network of voluntary carers. It is the things which motivate carers to take on their caring role, which produces the difference in the quality of care no bureaucratic body can match.

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

There are at least 4 types of barriers affecting the social and economic participation of carers:

- Lack of time
- Random nature of the person with disabilities' requirements
- Changing requirements over time of the person with disabilities
- Isolation

Caring for people with disabilities may be part time, but often it is 24/7 365 days a year for the rest of your life. In either case it takes time - time which a carer can no longer devote to either searching/applying for a job, to earning an income by performing a paid job, or to participating in training for professional advancement. In many cases carers cease paid employment in order to take care of the person with disabilities. One might argue that the caring role has become the job. The time required for the caring role also is not available for social interaction. This may not be such a problem if the caring role is part time, but it is a severe problem if it is 24/7.

People with disabilities have requirements which do not arise in a nicely ordered timely manner, e.g. sanitary requirements, seizures, falls, medical appointments, psychotic episodes, etc. They occur in a random manner, so that even if a carer could find the time to perform paid employment (at home for instance) the random nature of the demands on his/her time can affect the reliability of job performance. This in turn affects the range of jobs carers can contemplate doing, and it affects employers' perceptions about their employability. Similar comments can be made with regard to the effects on social interactions.

People with disabilities have requirements which change over time. If the person is a child, the changes may be just a consequence of their growing up. In other cases the variability may be due to the progression of disease, which is often unpredictable with respect to time and severity (as in MS). In any case, social and job arrangements which were appropriate at one time suddenly become unsatisfactory and have to be changed. It makes planning for the future very difficult.

Caring for people with disabilities can lead to social isolation of the carer (as well as the person with disabilities). In part this is due simply to the lack of time and other time constraints as outlined above, or because participating in social activities such as going out for dinner, BBQ's, sports, concerts, etc is no longer possible or requires too much preparation of the person with disabilities, so the carer does not go either. As relationships are neglected friends, and even family, eventually forget to call. Sometimes this process is exacerbated by feelings of embarrassment and/or lack of knowledge and understanding by non-carers about the disability. Whatever the combination of reasons may be, it leads in carers to a feeling of loneliness and abandonment in the struggle.

It seems to me that the difficulties described above will continue to exist for as long as a carer continues in the caring role. However, there may be some jobs which are more tolerant of the consequential effects than others, i.e.

- Jobs which the carer can perform in the presence of the person with disabilities, most probably, but not necessarily, at home.
- Jobs where time lost due to random interruptions can be caught up without undue detriment to the quality of the job performance and the achievement of deadlines.

It would be helpful if employment agencies contracted by government could be charged with the responsibility of identifying such jobs as they become available, and have their key performance indicators (KPI) modified to require them to place a certain number of carers in such jobs in a given time period.

Going a step further, it could also be argued, that if the caring role has become "the job", performed by carers on behalf of governments, it should be remunerated appropriately by governments and the recipient taxed in the normal manner.

In order to counteract the social isolation of carers, particularly full time carers, it is important that the provision of respite for the carer is continued and, if possible, expanded.

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

Financial and non-financial assistance for carers should ensure that the maximum amount of flexibility is provided. For example, making a rule that funding to assist in the purchase of a new wheelchair will be provided every 3 years may be adequate for a grown up, but a fast growing child may need a new wheelchair at shorter intervals. Similarly, the progression of disease may dictate shorter intervals. Consequently, to deal with this example, applications for assistance should be assessed on a case by

case basis. In a similar vein, if funds are available to provide physiotherapy for a person with disabilities, then they should be made available without dictating which physiotherapist is used, as long as it is a properly trained and experienced physiotherapist. It should not matter whether the physiotherapist has a "contract" with the body providing the funds, otherwise people with disabilities may be forced to sever relationships with health professionals they have learnt to know and trust in favour of strangers.

Many carers voice their frustration with Centrelink. The impression that Centrelink staff assigned to deal with people with disabilities and their carers, do not know much about disabilities and are unsympathetic, is widespread. Even the layout of Centrelink offices is criticised, when it requires people with disabilities to traverse the complete length of the office to a desk in the furthest corner, where the interview then takes place. However, perhaps the most frustrating aspect is the number of times the same information about name, d.o.b., address, telephone numbers, etc. has to be entered into forms afresh. With present day IT capabilities it should be possible to provide the necessary forms populated with the already held information, with clients asked to check what is there, and make corrections only when changes (or errors) have occurred.

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

Assistance for people with disabilities and their carers is already available from many different sources, e.g. from each of the three levels of government, as well as from charitable organisations and other private bodies. It is delivered in a multitude of different ways, and eligibility criteria are many and varied. Initially, when carers first take on their caring role, after a fresh diagnosis or an accident, most carers know nothing about any of this. One of the most frequently expressed frustrations which carers have is, that they do not know what assistance is available and what they may be entitled to, i.e. we have a communications problem. It would be really useful if someone would take on the task of collecting ALL forms of assistance available to people with disabilities and their carers, from ALL sources, in ONE database. It would need to be structured in a way which is logical from the point of view of the people trying to access the information relevant to them, rather than from the point of view of the people trying to assemble, maintain and manage the database. Once the information has been assembled its existence needs to be publicised. There is little benefit to carers in assistance which no one knows about, and those making the assistance available do not get much credit for it either. Consequently, a publicity campaign is necessary, targeting the places and organisations through which people with disabilities and their carers can be reached, and explaining where and how the data base can be accessed. The internet is a valuable tool for many, but it should be remembered that not all carers are able or comfortable using it. Most people with disabilities and their carers come into contact with the medical profession in some shape or form, therefore, obtaining the cooperation of the medical profession in disseminating the information in pamphlet form through their practices and hospitals etc. would seem to be an obvious aim. Radio and TV public service announcements would also be useful. They could be low key, but would have to be repeated at regular intervals, since new carers are constantly coming "on stream".

The database mentioned above, I think, would highlight the complexity which carers face in trying to determine what assistance is available to them. It may even identify some areas of duplication. A next step would be to reduce the complexity in the availability, eligibility and delivery of assistance.

Some carers suffer injuries as a direct result of their caring role, e.g. back injuries from lifting or turning the person with disabilities. The injury may affect their employment choices while they are carers, and even when and if their caring role ceases. Some of them may have given up paid employment to take on the carer's role (as has already been mentioned). If the injury had occurred as a result of their paid

employment, it would have been treated as a work related injury covered by Workcover. I would like to propose that a "Carercover" scheme be set up for carers injured as a direct result of their caret role.

Conclusion

In conclusion, I would like to, once again express my gratitude for this opportunity to tell you about some of the problems and frustration faced by carers, and to make a few suggestions. I wish you well in your deliberations, and look forward to reviewing any recommendations you make to improve the life of carers in Australia.