

Submission No. 376

(Inq into better support for carers)

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FAMILY, COMMUNITY,
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Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

Becoming a carer irrevocably changes the course of ones life in ways that are subtle and profound, covert and overt. For many parent/carers the caring role comes with a big price: the loss of 'normality', of relationships, dreams, and freedom, career and future work prospects. The caring role impacts upon the physical, mental and emotional health and wellbeing of the carer. The additional challenges of chronic sorrow and guilt mixed with depression, health issues and frustration of an often restricted life for both our children and us can lead to a state of burnout. The report 'The Wellbeing of Australians: Carer Health and Wellbeing' clearly shows that 'carers have the lowest wellbeing index score' for any previously researched 'large group' in the Australian population. We are caring for our loved ones because we love them AND of necessity: if we did not, who would?

Carers have to cope with circumstances that exceed the complex demands of 'regular' parenting- often in isolation, under deteriorating health conditions due to unrelenting stress, a lack of understanding and support from family, friends and medical professionals; and in some cases the community at large. Behavioural issues that often accompany intellectual impairment can be extremely difficult for all concerned.

Being a carer is an emotionally draining, physically demanding fulltime job with no holiday pay! We are expected to liaise with medical professionals including occupational and physiotherapists, specialist doctors, geneticists and professors- a process that is often very time consuming and intimidating. Carers become 'expert' in their child's condition, illness or syndrome: 'telling the story' repeatedly to doctors, service providers and schools, not to mention attending to the volume of paperwork required. Becoming expert involves keeping up to date with current research, wading through reams of medical jargon and literature often bewildering to the lay person. Sometimes a definitive diagnosis is elusive; in our case it took years. This can make the application for funding and services more difficult. The 'assessment of need' process is both confronting and draining, inadvertently reinforcing the stressors and limitations faced daily and indefinitely. By necessity the focus must remain on the deficits and disabilities, and this can be demoralising for the entire family.

Parent/carers advocate for services on the child's behalf and this process is difficult for numerous reasons. A perception of existing 'unmet need' ("there are others who seem to 'need' it more...") coupled with an ingrained belief that we 'should' be able to cope--- and the shame that we are not coping deters a lot of carers from asking for help until they are in severe crisis! Lack of knowledge of appropriate services and constant rejection can be a barrier for some. Receiving funding can seem like winning the lottery and as much as carers are immeasurably grateful for the help received, the requirement to be a proactive part in coordinating the delivery of the services is both empowering and stressful when one is already feeling totally exhausted and overwhelmed.

Carers are expected to implement intervention programs at home and often find that the time and energy devoted to this undertaking inadvertently leaves 'less' attention for siblings, spouse, family, and friends and for individual pursuits. For years I had no 'time off' and suffered recurrent injuries from having to lift and carry two children with low muscle tone who did not start to walk until they were four-five years old. There can be a sense that existence has become all about the 'disability' at the expense of a more balanced life. Life can seem to be 'on hold' indefinitely. Parenthood comes with a reasonable expectation that children will grow to develop the skills and ability to be self sufficient individuals capable of leading fulfilling

independent lives. This is not the case for many carers who face a future with apprehension and anxiety, asking the inevitable question: Who will look after my son/daughter when I am gone? Our children will grow to become vulnerable adults who will need high levels of support for the rest of their lives.

Carers are more likely to experience marital/relationship conflict, disharmony and breakdown than families without these extra pressures. The carer is then often in the position of becoming a sole parent whilst dealing with the fall out of separation: having to deal with custody issues and agencies such as Centrelink and the CSA.

My experiences as a carer for two children with a rare genetic syndrome are deeply personal; but not uncommon. It is both a blessing to have some knowledge through a diagnosis and a concern as there is a number of possible future health complications associated with this syndrome; Some vigilance will be required. Life is complicated by a number of ongoing personal, medical and psychological challenges which affect my ability to cope on a regular basis. I had to hit 'rock bottom', seriously facing the prospect of relinquishing my children before I received any help. The time and energy required to coordinate the children's lives constitutes a job in itself. I liaise with teachers, respite and service coordinators, DSQ, doctors and therapists. The children can not be left unsupervised at home after school, on the weekends or during school holidays. I am required to be physically present to see them on and off the Education Department school bus every day, and have no one who could do so should I be required to work at those times. The girls tire easily and are not suitable candidates for after school care.

The reality is that I am unavailable for shift work outside of school hours, cannot work during school holidays, am limited in doing physically demanding work and unfortunately have no Superannuation fund. When my daughter leaves school she will need to have an alternative place to attend during the day. She is addicted to routine in the sense that she needs to have a structured timetable, and requires a high level of support to go about daily life eg travel, money handling and so forth. She does not cope well with a lack of structure, and I certainly would not feel comfortable leaving her at home for hours on end while I go to work. If her Post School Options are limited it will again impact upon my availability for study/work.

I find the Activity Agreement /Mutual Obligation Initiative to be both a blessing and a curse. What is less 'understood' or allowed for in generic Centrelink rules, regulations and requirements is the very precarious position many carers are constantly in: there is a very fine line between 'coping and not coping' and it takes very little to push us over into 'not coping'. I understand that carers may apply for an exemption if necessary, and I do not want to have to go down that path if I can avoid it. Taking my caring responsibilities into account; however, I have been given the opportunity to undertake a University degree on-line. This will lead to meaningful paid work down the track in a field that I intend to work in. In the meantime; I take my caring role very seriously by trying to support my beautiful girls in manifesting their true potential. Contributing to the 'greater good' by writing articles for our service provider newsletter and by giving 'telling it how it is' talks on 'Being a Carer' to lifestyle support workers is also important to me.

Our family is very fortunate to have secured a funding package through DSQ. This has made the difference in keeping our family intact as I would have been forced to relinquish the children as I could no longer cope on my own without any respite. For this I am so very GRATEFUL. I see it as my obligation to 'stay well'. Yet the feeling of being overwhelmed still sits just below the surface, and my health issues continue to impact upon me. The University course is hard, and a lot of work. I need peace and quiet in order to do it. I am technically 'working' during the 'time out', however because it both feeds my soul and is an investment in our family's future I can endure the difficulties. I can not emphasise enough that as a direct result of THE FUNDING

FOR RESPITE CARE I am now able to undertake this study, contribute in the ways described above and continue to care long term for my three children. Recurrent respite care is absolutely non-negotiable for our family and so many carers. This practical support assists me to continue to care for my children and to study with the intention to become financially self-sufficient in the future with a vocation that will contribute to the good of our community.

I am very grateful for the carers bonus and the small role it plays in relieving some of the extra economic pressures we deal with as a result of me having to forgo full time paid work. No amount of money can 'compensate' us for the challenges we face daily, however the symbolic recognition of our worth and value in society will be destroyed by proposed cost cutting of the carers bonus and funding to NGOs. Many carers will feel utterly betrayed by a Government that gave pre-election lip service to the importance of the contributions of carers to our communities. We are not motivated by greed or a sense of entitlement! Many carers view the bonus as a small investment in our wellbeing and continuing ability to care for our vulnerable loved ones. We are also mindful of the costs to Governments of relinquishment should we be no longer able to do so. To receive the lump sum in smaller increments across the year is not a solution as that extra money would be simply and quickly absorbed into a budget already stretched by rising living costs, and hence not available for one-off purchases such as car repairs or replacement white goods. Essential car repairs (on a 12 year old car) and worn out part replacements such as solenoids in the auto transmission alone have cost me \$1700 since last October. (Credit: a necessary evil!) It only takes one unexpected bill to severely set me back. Saving is currently not an option. I pride myself on managing the income we have yet I am aware that it would be extremely difficult if not impossible for me to find another affordable place to rent in the private market should my understanding landlord decide to sell. Our rent has already increased \$50 in 18 months. We do not have a flamboyant lifestyle; it is tough out here, yet again, a little gratitude for what we have goes a long way.

Another vitally important practical measure that must be considered by this committee is SIBLING SUPPORT. Ongoing recurrent block funding to organisations such as SIBLINGS AUSTRALIA is absolutely essential. My son is struggling with

being a sibling of two sisters with high support needs. He is one of thousands of Australian children who are vicariously affected by disability.

Fortunately he currently has access to a sibling program that is assisting him to deal with his circumstances. In a few short months I have noticed subtle 'understandings' seep into his being. I try to impress upon him that he has a choice as to how he deals with the hand that life has dealt him. Underneath his introverted persona and anger is a caring compassionate person. The world needs more people like this and the reality is that siblings may be a wonderful resource for support of our children with special needs and their aging parents in the future IF the proper resources are invested in them NOW! I do not expect him to become a primary carer of his sisters but I do want him to develop the strength of character to not let anger and frustration ruin his life and inform his choices from here.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I very much look forward to reviewing the recommendations you make in order to improve support for carers.