

Submission No. 900
(Inq into better support for carers)

Susanne

4/07/08

The House of Representatives
Family and Community Committee
Parliament House
Canberra ACT 2600

Re: Submission for parliamentary inquiry - Better Care for our Carers; due 4.07.2008

Dear Sir, dear Madam!

As a mother of an 11-year-old child with an intellectual disability I'm pleased to learn that the government is searching to improve the situation of carers. Looking for more adequate support for carers and an urgent need to change things for the better is certainly welcomed!

As a NESBy I have to cope with a different language and a different system. As I find it difficult to find the time to write this submission, feeling tired and exhausted, I only can hope that my submission will be comprehensive enough, wondering at the same time how extremely difficult it must be for less educated people from NESB to cope with the complexity of the support system in Australia. While parents need to find time for writing submissions, some might not even know that here is a possibility offered to have a say and some hope for improvement in the future. I only got the information by chance!

I wonder also what the response to the enquiry will be - keeping in mind an estimated figure of 470 000 primary carers – and how comprehensive this enquiry can be.

Please find below *my* addressed points of reference.

Terms of reference:

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

While there are different types of carers and different lengths of caring periods (lifelong, for a few years, for a short time) it needs to be recognised that while the "caring role is an unpaid role" that caring is *actually work!* Parents of children with disabilities care for their children usually for a lifetime, either till the parents die or the child they care for dies. The caring doesn't stop when the disabled child has grown up and starts to live his/her own life like our other children do. Stress really starts to impact! What happens when I'm getting too old and what happens to my child when I die? The lifelong caring role needs to be recognised as 'work'.

- Perhaps in form of acknowledgement in superannuation and certainly in more adequate funding for allowances eg the fortnightly carer allowance and increase of the once-a-year-payment currently \$600. Why should life long carers have to live in poverty and poor health? They deserve the same rights and opportunities as other citizen. Very few carers are able to participate in the general workforce on a full time

basis!

- A lot of carer have a tough time and have to stretch them selves on a lot of different levels all the time:
- **Increase of financial assistance for carers:** \$ 100 a fortnight for 24/7 care doesn't go far and certainly doesn't pay the bills if the care of the person with disability (pwd) doesn't allow the carer to "work" somewhere else. It doesn't cover the costs of Early Intervention, speech therapy, optometrist, glasses and extra healthcare to name a few of the extras we had to cope with. Our family lives 36 km from the nearest town and 45 km from the nearest center. We live on a marginal / regional edge. Regional boundaries discriminate against access to some services. Travel costs are extreme especially with rising petrol costs.
- **Better primary health care for carers and prophylaxis is urgently needed** rather than bandaids and crisis intervention at a time when every thing is too late and the carer hits the wall. In some funding applications (eg STOP) the care arrangement needs to be breaking down before funds are considered!! Most carers suffer from poor health, stress and often poor diet because of the inadequate finances. Carers need to look after their own health, but often can't do exactly that due to the financial restrains a caring role implicates. **"Health Packages" for massage, acupuncture, counselling and dental and optical care is needed etc.** Carers need to be able to relax and de-stress. Carers need to look forward to special things rather than patching up while in crisis. Holidays would be nice!! Some extra money would go a long way!
- I'm living in a rural area. I can't use/attend city centred subsidised events due to the time and costs of travelling as well as time away from my family situation. Funds for Life Connection-Programs are service bound. I would like to get some funding which supports me a few \$ a class in my local yoga class, painting class or swimming. I'm socially and culturally isolated and when I apply for funding to assist me to attend events to give me some respite I'm always told: "It is not in the guidelines!" **the guidelines for funding need to be changed**
- Pensioners get free car registration and rate reduction, but not carers. Why not? Support workers have their travel expenses paid; Travel for carers is very expensive—particularly if carers live in rural Australia and looking at rapidly increasing petrol costs in 7/08! More flexibility in guidelines for funding that if carers need and want assistance for travel expenses, they can use some of their funding, if this is what they want to do. Car expenses for workers in the industry – but not for carers seems rather unfair to me.
- **Recurrent funding with flexible guidelines** a family can count on each year for respite / after school care arrangements, so that regular respite can be planned and looked forward to. Currently our family, in this area, could theoretically access from 12 different pots of money for different things. Maybe there are even more pots? Who knows? Just keeping track of all the funding options and their constant changes, or changes while you are on the funding, putting applications in and living with the **uncertainties** that maybe we'll get some funding, maybe not is - a job of its own. This certainly causes a lot of stress in my life. There *is* money in the disability sector. How it is spend, is a different thing. Too much money is spend on services, not enough flows through the families. Dealing with disability services for the past 11 years has caused me more stress than caring for my disabled child!
- While I love my son and will care and support him till I die I feel constantly the financial restraint of my caring role -while paid worker can have a nice time with client/my son and getting paid for it - makes me feel in times resentful – not towards my son, but the system. The feeling you have to beg for support and that "you are not working",

because you only care!!!

- Caring for the disabled and frail needs to be a valued role in society, but if people with disability and the frail are not valued, the caring for them is not valued either – only the paid worker becomes a valued person in this scenario! It needs a lot of **education** around these issues!

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

Living in a rural area, where after school and vacation care doesn't exist or if they exist, they are not registered to access ISS, how do you actually have time to "work" if caring is not considered to be work? If my child experiences problems in school, the school rings me and asks me to pick him up. If I'm lucky I might have the occasional funds for after school respite rather than ISS – however if my child needs to be picked up during school hours – the respite doesn't cover school hours!! Even if the school demands the child needs to be picked up!

→ Families need funding which is regular and recurrent. Families need to be in control of their own funding. The guidelines need to be flexible and family friendly, so that a family is able to spend funds to support their family member and their family situation best and increases the possibility that the primary carer can "work" to earn money.

If my child can't be transported in the local school bus due perhaps to behaviour problems, issues in bus safety– Taxi services are 38 -45km away! While I get a small amount from the transport department towards travel expenses for the costs of petrol, what about my time, the break up of my days for years to travel from and to school – why can't I be employed to travel my child in the car to and from school, rather than wasting money on getting a taxi twice a day from 38 -45km away? (School is only 9 km from family home) It would save costs and employ me at the same time. But the system does not work like that!

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

Every caring situation is different and needs different consideration! What exactly is respite??? It is a different need for each family. Lack of flexibility in the guidelines, how money can be used/spend make it really hard for carers.

Support is currently city centred (for clients, sibling support, life connection program, transport and so on); most guidelines for different funding schemes are quite inflexible. While a lot of money is spend in the disability sector -you have to ask, does it actually help the people with disabilities and their families? How much money is wasted? Can money be spend differently? And how individual needs can be met in a better fashion?

Current funding comes from a lot of different pots. What we need is simplicity. Too much carer's precious time is wasted in applications and chasing funding options. We need individualised **funding packages and more flexibility in the guidelines**. Our family needs to have control over how the money is spent. For my family situation I would like to know each year how much funding we have, so that we can plan and spend it most effectively without wasting it. So many different pots of funding and options and keeping track of it requires admin and management skills. Since 1.1.2008 Germany has introduced a personal budget for people with disability. (Reference: <http://www.budget-tour.de/>)

4. 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.

- Substantial increases of carer allowance/payments
- Free dental care for carers! Not pulling out teeth, but keeping them!
- A lot of services are city centred. Life connection programs / Bridging carers to work program don't work for rural people.
- 1800 numbers are needed where people ring from non-metropolitan area (eg. Down Syndrome NSW, Tweed Valley Respite Service (TVRS) Tweed Heads, Northern NSW
- While community transport is a good idea, petrol contribution /km money to use own vehicle in rural areas would be better and more sensitive if carer have their own vehicle
- Hi there! Rural Australia exists! We like to be considered too!
- Recognition that carers work!!

Due to my caring commitments and time restrictions I'm not able to address more aspects in reference point 4. It is the last day and I need to send this submission in. Sorry!

On a last note: While having a child with a disability and coping with the extra work is one thing - dealing with services is another thing. While services are supposed to help the family, eg give respite, services can cause and add an enormous amount of stress to the whole situation of caring. In our situation, with a few exemption - dealing with services creates more stress than "caring" it self does.

While the idea of respite is good, to organize respite often takes as much time as the respite it self!

Sincerely
Susanne