June 2008

Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family, Community, Housing and Youth

Rec 17/7/08

Submission No. 908
(Inq into better support for carers)

Carer: Johanna

Please refer to my response to the Carer Payment (child) Review dated July 2007 for an appreciation of my son's medical condition, and further information/comments (attached). In June 2007, Angus was assessed as moderately developmentally delayed. As such, I feel that I now have two absolutely major issues to deal with in Angus' care. I must say, that I struggle to attend to both issues adequately, and as a consequence, I feel that I do not spend enough time trying to help his development. That is, most of my efforts are in caring for his medical and nutritional needs. Having said this, I am doing various planned activities each week to try to assist his development (speech therapy and visits to EarlyEd North Sydney).

Angus' medical special needs have not altered since my description in July 2007.

As an update on Angus' health since July 2007, I can report that he had a total of 10 hospital stays in 2007, comprising 36 nights. In 2008, we have so far had one hospital stay comprising 2 nights. So, 2008 has overall been an improvement for Angus and our family in that regard.

Angus and his twin brother also commenced pre-school for two days per week in early 2008, which has proved to be a very good experience, despite some early hiccups, and ongoing challenges (refer to Problems section below).

How I feel about my role as a carer

My role as a carer is by far the hardest thing that I have ever done in my life. I feel that it almost consumes my existence. It feels like every waking moment, I am dealing with, planning, thinking about, or worrying about my son's health and special medical and developmental needs. It is almost like I live day to day in a bubble, where no one else but I know how hard and all-consuming my caring role is. I feel that to fully explain the effect of my son's special needs on him, me, and my family, I would need to write a book.

My contribution to Australian society as a carer

Other than the necessary role of trying to best care for my son, and provide the rest of my family with the best life possible in our circumstances, I'm not hugely sure of how to answer this question. I feel that I will never be able to 'give back' the equivalent 'cost' of the excellent medical care, medical support and drugs that the Sydney Children's Hospital at Randwick (and the Government) provides to my son.

My contribution outside my family unit includes helping young doctors in the Sydney Childrens Hospital, by agreeing whenever possible to be interviewed by them to help with their studies/exams. I have also volunteered twice with my son Angus (2005 and 2006), to participate as a patient in the Royal Australasian College of Physicians paediatric clinical examinations. Another contribution, is to try to give responses to government requests for information from carers, with my first such response being in July 2007 to the Carer Payment (child) Review Taskforce, which has been included as an addendum.

I feel that I currently indirectly contribute financially to our society, as I not only undertake the primary carer role for my son, but I also support my husband in this, by trying to minimise the impact of Angus' condition on my husband's ability to run a company employing c. 85 people (not his own company). I work very hard to support him, by trying to do all of the household functions, including arranging house maintenance, paying all household bills, running all of our household financial affairs including arranging bank loans etc. In doing this, my husband is able to spend his precious and limited free time being with his two sons and me, and doing activities with us. I should note that nearly every weekend, my husband must do at least 2 to 5 hours of work at home, in order to successfully manage the business he is running, and I support him in this. I feel that if I did not do all of the chores that I undertake, as well as try to shield my husband from a caring role during times of hospitalisation for Angus, then he would be unable to meet his potential in running a company in a very competitive and difficult industry.

I have also undertaken to help with the formation of a document for the Department of Medical Genetics at the Sydney Children's Hospital, to provide timely and better information/support to parents of newly diagnosed children with significant long term illnesses/disabilities. This has not yet been done.

My husband and I do volunteer maintenance and spring cleaning work for our sons' preschool.

Problems that I face as a carer

- As outlined in the attached document written in July 2007, I think one of the biggest problems that carers face is timely access to information about what resite help and other benefits are available or can be applied for.

  If your child is suddenly diagnosed with a serious chronic medical condition, the hospitals tend to mainly focus on the child, which is quite right. However, there should be a better, concurrent focus on the parent or carer, to ensure that accurate and up to date information is provided to them about things like access to non-means tested quality respite, cheaper hospital parking, applying for a Health Card, applying for the Carer Allowance or Carer Payment. In my case, this did not happen, and what was the most difficult and stressful time for our family was not alleviated in any way.

- I also found that I had a very difficult time with getting to and from appointments etc, as you are currently not able to apply for an RTA Mobility card for a child between the ages of 1 and 3. In my case, this would have helped me quite a bit, in that I would not have had to worry about coins for parking meters, and returning to my car on time during a period when I was absolutely struggling to keep my son's blood sugar levels stable. I have explained this problem more fully in the attached document. On this, I also have a problem now that Angus has an RTA Mobility card. As most people seem to be unaware that a child as young as three can hold a Mobility card, some members of the public (and indeed other holders of Mobility cards) often challenge me on the rare occasions that I actually park in a Disabled car space. I know that this happens to other parents of disabled children as well. I find this quite hurtful and I also feel a sense of anger considering how difficult my day to day life can be as a carer. I think the "Dob in" campaigns that the RTA and sometimes the media engage in, should clarify this aspect. That is, people should be very careful before they start accusing someone of abusing this system.

- I am often at the Sydney Children's Hospital at Randwick with my son for in-patient stays when he is ill, outpatient appointments and to collect medicines, drugs and other supplies, and will continue to do so for his childhood years. I notice that although my son has a serious medical condition with significant ongoing impacts on his and our family's life, the focus by the media, and indeed on directed donations, live-in camps and sponsored family activities, is almost solely on kids with cancer, or large patient groups such as diabetics. While I see these as a very worthy causes and extremely worthwhile for kids with cancer (of which my 6 year old nephew is one), and diabetes, I, and some hospital employees that I have spoken with, suspect that the focus could be a little bit more balanced between the groups of patients and families that must have a long relationship with the hospitals and their diseases/conditions. I often feel that as a group, children with rare genetic or other life-long diseases must be quite large, but are not recognised adequately in the above-mentioned ways.

- Finding time to do anything other than that related to my son's illness, or household chores/admin. My two half 'days off' while the two boys are at preschool, has so far this year mainly involved either shopping for family food so that our family can spend as much time together on the weekend; helping my sister prepare and paint her house while she was heavily pregnant with her twin girls; or doing work related to being Angus' carer (such as writing this document). I know that I need to prioritise a bit more time to do something just for me, but it is difficult to do this with so many competing pressures. I know that no one can help me with this but me.

- Coping while my child has painful treatments. Angus is noted at the Sydney Children's Hospital for being very difficult in getting an IV into his veins. It usually takes three or four attempts to get it in – despite him not struggling much. Angus also is given an injection every second day by me, and he absolutely hates it, and struggles every time. (The relatively large amount of liquid required to be injected, means that the needle must be larger than the small insulin needles used by diabetics). This is a very distressing aspect of his constant care.

Problems with pre-school/child care for my special needs son

- As I have mentioned, our pre-school experience has been a good one overall. This is mainly because we are dealing with a large community based pre-school network, with Head Office and special needs support.
- Generally, my understanding is that smaller community based pre-schools or small private pre-schools/child care centres are less able/and or willing to support my child with significant special needs and risks. Given how much time and effort went into preparing Angus for his pre-school, I believe that possibly not every centre can cater for every child.
- The lead up to commencing Angus in pre-school was extensive with regard to documentation, training of staff, and finding a suitable carer.
- The first person to agree to be Angus' primary carer pulled out in December 2007, as she felt she was unable or unwilling to cope with his special needs and/or the risks associated with his day to day care.
- I was made aware that the carer was not available to start care for Angus, on the morning of his very first day of pre-school. This was very disappointing and distressing. Some weeks after that, a carer that worked in the centre for the parents of another child (on different days) agreed to become Angus' carer, so Angus commenced pre-school in March 2008, about a month later than the other children.
- Documentation for Angus' daily care took a lot of work. I wrote a comprehensive document, and had his doctors sign it off. Some nurse specialists also helped me with its content. The pre-school HO Enrolments officer then re-wrote it into a format that was more acceptable and easier to read for Angus' carers. I vetted the document carefully and my husband and I signed it off.
- Angus primary carer and most of the other staff at the pre-school had medical training on gastrostomy feeding and taking blood sugar readings from two nursing specialists from the Sydney Children's Hospital. Arranging this was very challenging, as the nurses are very busy in their jobs and had to find time to visit the centre. The training had to be done outside of the pre-school hours. Training for the gastrostomy feeding was done twice due to the original carer pulling out of the role.
- When Angus finally started at pre-school, I stayed at the pre-school for the first two full days to train his primary carer in a more 'hands-on' manner. For the next two days I came back and forth to the centre for most feed times, to help train the other staff as well. The idea is that if Angus' primary carer is absent, some of the other staff can tend to his care. This has generally worked quite well. However I have recently had one day where Angus' carer was away with a sick child herself, and no replacement for her could be found. On that day, I was asked to pick Angus up two hours early, as the staff could not cope with him for the full day without the extra carer, due to his developmental delay.
- Due to Angus' combined medical special needs and his developmental delay. The pre-school Director (also being Angus' class teacher), is adamant that a carer is required for Angus (one on one) for at least five of his six hours at pre-school. She maintains that the last half hour of the day after his carer has left, is very difficult, as Angus is tired and his behaviour starts to deteriorate further than usual.

- Under the various government funding mechanisms, and although Angus meets the highest level of need and entitlement, he only receives funding for three hours of one-on-one care per day. The Director recently confided that the pre-school is covering the cost of his carer's employment for the other two hours.
- I am very grateful to Angus' pre-school for helping with the cost of his care, and for all of their efforts in accepting Angus and caring for him well, and helping him with his development.
- While my understanding in not complete, the system of funding special needs children in NSW appears very strange and not at all helpful to pre-schools or to the parents of children requiring that funding. My understanding is that the pre-school never knows from term to term, how much funding they will get next term. In our case, the pre-school did not even know how much they would receive until after Angus had actually commenced. My understanding is that the government funding bodies have various budgets for each geographical area (which total amount may change each year), and they split up the budget each period only after the special needs child has commenced in care. So if many more children suddenly need funding in an area, they each get less than they previously might have. Also, if there are less special needs children requiring funding in a certain geographical area, then each child in that area receives more funding. I have been given the example by Angus' pre-school, that recently a child with special needs to the same degree as Angus, who lived in Orange (country NSW, would receive about $95 per day, but Angus receives about $55 or $60 per day. There is apparently no other reason for this inconsistency, other than the different numbers of children applying for funding in each area.
- The pre-school must re-apply for special needs funding for Angus each term. This is time consuming and I feel it puts too much pressure on those centres that are doing the right thing, and accepting special needs children. They should have access to funds for at least 12 months, and be required to refund unused funding if necessary (i.e. if a child pulls out of care/preschool prior to the end of the funding period).

Difficulties in participating fully in social life

I certainly do not participate fully in social life due to having a child with significant special needs.

Organising appropriate care for Angus, coupled with my reticence in making social commitments for fear that he will be ill when the commitment time arrives, makes me less willing and able to participate socially.

I try my best to keep in contact with friends, but I know my friendships suffer somewhat.

The Commonwealth Carer Respite Centre is crucial for me to plan commitments such as family wedding attendance, or attend (rarely) a major social function such as a New Year's Eve party.

I sometimes ask my parents or trusted friends to care for/baby-sit Angus and his brother. This is so that I can have relatively short outings close to my home with my husband. In these cases, I am always contactable, and ready to rush home if there is a problem with Angus, or with his feeding, or night time pump feeding.

I tend to do most of my socialising with other mothers generally in my local area. In this way, I can interact with them while also caring for my sons. This is extremely important to me as a mother and carer.

I sometimes have periods of respite while my husband cares for the children on the weekend. He is able to care for Angus, but I would only ask him to do this if Angus is well enough. There are also problems with this, as happened last weekend. I thought that my husband could cope with almost any situation that might arise. However, Angus' gastrostomy fitting was pulled right out of his stomach, and my husband phoned me in a panic, fearing the wound would close up if I didn't come home immediately and replace the fitting. I came home and fixed the problem, and tried to teach my husband how to fix the problem too. This is a very rare occurrence, but Murphy's Law ensured that it happened while I was having a rare break from my caring role.

Issues with employment

As an update to my comments from July 2007, I considered it necessary to resign from my long term employer, Westpac, in March 2008. This was after extended Maternity Leave and Unpaid Leave was granted to me by Westpac since my twins birth in November 2004, in the hope that I could return to part-time employment in March 2008.

I considered it necessary to resign, as Angus' health has not proven stable enough to make a commitment to an employer. As mentioned previously, Angus had ten hospitalisations last year, and one this year. This does not adequately describe the frequency of his bad health issues. For example, in the last month, Angus has had two bouts of bad diarrhoea lasting two weeks and one week respectively. For the first bout, if he had deteriorated further, he would have been hospitalised. In other cases, he gets coughs/colds/mid-range temperatures, and often his feeding is affected. I must carefully monitor him during these frequent periods of illness, to ensure that his nutrition intake is sufficient and that his blood sugar levels are stable.

In addition to Angus' frequent ill health, I find it very time consuming to make sure Angus goes to all of his medical appointments; that all of his medical and dietary supplies are ordered and sourced; that all of his developmental appointments and special education needs are met week to week.

I look forward to the day (but with some nervousness about Angus' needs being met) that I am able to go back to my professional life. I do worry when, and if, that day will come.

Worries about my future

I am often too busy to spend time worrying about the future. However, concerns include:-

- Losing touch with my professional life. I am particularly concerned about having such a long, un-planned and unintended non-employment period in my professional life, and how this may impact on my ability to secure a good job in the future (both in work content and remuneration).

- Will our family survive as a unit over the medium to long term? i.e. will my marriage endure? I am not sure how I would cope emotionally (as a single mother with significant special care responsibilities to my son), and financially, if my marriage were to fail.

- How will Angus' special needs affect his brother's childhood and adult years?

- How will Angus cope with his special needs as he grows up, and will he be able to care for himself? What if he can't care for himself?

What I think Works for Carers and some ideas for improvement

- Commonwealth Carer Respite Service – a wonderful and crucial service to families/carers with children/adults with highly specialised care needs. In addition to their highly experienced support, it is absolutely critical that this service is not a means tested.

- Carers NSW and Carers Australia – excellent that membership recently became free to carers. Maybe all people registered for Carer Allowance and Carer Payment should automatically be registered with the appropriate state body, so that relevant information gets to them as soon as possible after becoming a carer (not sure about privacy issues regarding this suggestion, but it should be highly recommended to individual carers).

- EarlyEd – this is a family-centred early childhood intervention service for young children with disabilities or delays in development, and their families. This service has been very good for my son in his development, and for me, in ensuring that I get relevant information and assistance where required.

- Chatswood Assessment Centre – developmental assessment for children, which is recognised by all relevant schools, institutions, government departments, and it is free for the child/family regardless of family income (important).

- Childrens' hospitals - excellent quality of medical care in Australia's hospitals for all children, regardless of family income – an absolute cornerstone of a caring and humane society.

- PADP – provides specialised medical equipment on indefinite loan, and various medical supplies that are expensive for families each year, all for a $100 contribution per annum. Excellent service and not means tested which is good.

- Health Care Card – very necessary to keep medicine costs reasonable for the chronically ill.

- DADHC – Whilst the early intervention services provided by this NSW Government genebody are well intentioned and the individual therapists are good (speech therapy for eating/drinking and for communication, physiotherapy, occupational therapy, psychology and case management), the wait list for speech therapy appears to be one or more years. The number of sessions is also limited, so expensive, private therapy is the only option for those who are able to afford it in the crucial early childhood years.

What could be done better?

- Improve the system of funding for special needs children in preschools and childcare centres.

- Consider providing the Child Care Rebate to those receiving Carer Allowance and Carer Payment, regardless of whether they are employed or not, and regardless of which type of care they use (eg. Registered Care or Approved Care).

- Consider some kind of non means tested (or at least with a cut off level much higher than $150k pa family income) financial support to carers with children/dependents with significant care needs, who decide that they can return to employment. This financial support should be greater than the existing support given to non-carers, as the cost of care for individuals with significant special needs is generally higher.

- Consider making Carer Payment available to those carers with significant care responsibilities, regardless of family income. This would help families pay for the high costs of various therapies such as speech, occupational therapy, physiotherapy etc). Another option is to make the Carer Payment available to such families, to be expended only on various intervention therapies and possibly on respite care costs.

- Better recognition and support for carers who are spending time in, or constantly visiting hospitals with their children (or person they care for). I feel that the Allied Health social workers in hospitals could do much, much more to help all carers, regardless of family income. I am unsure as to whether my less than satisfactory experience was a result of limited funding, or lack of adequate focus on carers. I suspect the latter.