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23 February, 2006

THE HON Bronwyn Bishop, MP
Chairman
The House of Representatives
Standing Committee on Family and Human Services
House of Representatives
Parliament House
Canberra ACT 2600

Dear M/s Bishop,

**RE: ABSENCE OF BEFORE & AFTER SCHOOL CARE/SCHOOL HOLIDAY PROGRAMMES
for Special Needs Children who have Behavioural Issues and/or High Needs or who
are 12 years and over**

I write to you in the hope that you may be able to assist me and the many families who fall into a carer abyss for special needs children who have behavioural issues and/or high needs or are 12 years and over.

My situation as a sole parent, raising a child with multi disabilities, including Autism, is a typical one. I am unable to work full-time as there is **no** provision for my child's care within the community for me to do so. As a result, I am denied a full-time position within my own company that would offer a good income and a company car. I am approached on a regular basis to apply for a particular position in the company but have to decline, as I am unable to commit to the full-time hours. This part I realise is my "lot" and I accepted it long ago. What I am finding hard to come to terms with is that it is becoming increasingly hard to maintain my part-time hours. My son is 13 years old. I have maintained part-time employment for 10 years now - 25 hours per week. The long-term stress and constant struggle to maintain care for my son so I can continue my employment has been grueling, to say the very least. Without such an understanding employer (and true grit and determination to remain employed), I would have been terminated from any employment many times over and probably given up as a result.

Some of the difficulties I have experienced have been due to my son's disabilities and illnesses but in the main, it has been unavailability and unreliability of care to allow me to work. At present, I can only access 1 hour per evening, 4 days per week - this is 4 hours per week (3 hours Council and 1 hour respite agency), just so I can maintain my 25 hour employment. Some School Holidays has resulted in Agency staff at \$28 per hour for many days simply to allow me to keep working, there were no other alternatives as I had exhausted my annual leave on prior school holidays. I'm entitled to 4 weeks annual leave per year, school holidays equate to 12 weeks

Things are becoming so difficult; it would be easier for me not to work. This is unfortunately, the mentality within the disability field - **it is all too hard**, and I can understand how people get to this point. With great reservation, I have contemplated giving up my job due to situations as I have described and others such as last minute phone calls from my carer made to my work, leaving me to dash home to collect my son off his school bus; or the carer is no longer available and no other carers are able to take their place requiring me to make further adjustments within my work place to accommodate this and maintain my employment at the same time or the very high cost of in-home care because there is nothing else available. There is an ever-looming threat that I shall lose what little care I have sometime in the future.

The life of a carer is not only more demanding than the norm, presenting so many daunting challenges; it is also a responsibility for "life". With everything else that we have to do now and in the future, surely the lack of care for our children is an unnecessary additional burden and stress, one that I fear will beat me (and others) eventually if something isn't done and soon; hence my letter to you.

There is a black hole for children with Special Needs for Dedicated Before & After School Care and School Holiday Programmes - absolutely nothing exists. It's major impact is that it cripples the ability for working parents to maintain their employment outside of school hours. A secondary and just as important issue is that there are many children staying at home, isolated with little or no contact with others.

Integration into Mainstream after school care and school holiday programmes are at the discretion of the programme provider. If there are any issues involving the child, which the provider feels are causing difficulties within the programme or complaints are being received from parents about the child, then the provider has the right and does not hesitate to deny the service to the child involved. Very often the child with Special Needs reaches 12 years and older and is considered too "big" for the programme.

A child over 14 (I think is the legal age) without special needs is able to be left alone at home, whereas a child with special needs cannot be left, it would be unsafe and irresponsible. Where does he or she go??? Is isolation the only alternative here??? It is at this point that so many parents are required to give up their employment.

We need dedicated Before & After School and School Holidays Programmes for children with Special Needs. There are facilities aplenty ie; Special Schools, that could provide for this and with a bit of proactive thinking, could be set up to provide for these children most successfully. It could also prove to be a "great" opportunity for those studying within the Special Needs field to have "hands on" experience whilst caring for the children. I do know of a pilot trial of a School Holiday Programme at Monash SDS and I believe this to be most successful thus far. A more wide-spread programme such as this would encourage more parents to return to or remain in the workforce.

I have heard "institution" mentioned when I have discussed the possibility of a Dedicated Programme. If you look at what is currently occurring, perhaps my suggestion could be seen in a different light. I am referring to a child returning from school to his/her home with no playmates to visit, no birthday party invitations and during the school holidays, totally reliant on his/her parent to entertain him/her, often spending his/her days behind 4 walls. I call this involuntary imprisonment! I do know this occurs in many homes and to some degree it occurs in mine. It breaks my heart that my son does not fit in the community and that people do not understand; we have tried so hard to integrate without much success. In an appropriate setting as I have suggested, he would belong and would be so happy to attend and to play with his friends, just as he does at his school. School being the highlight of his week.

What are the current options:

- **Mainstream Before/After School Care & School Holiday programmes** - already addressed above
 - usually terminates at age 12 or if the child presents with behavioural problems or high needs. It is at the discretion of the provider.
- **Ad-hoc Special school holiday programmes**; these are few and far between, offering only 1 or 2 days per school holidays and often between the hours of 10:00 & 3:00. The hours alone do not allow for a full working day and the scarce number of days do not cater for even a part-time position ie; 3-4 days per week.
- **Council Respite** - I am afforded 3 hours per week (and I am one of the lucky ones)
- **Respite Agency** - charges between \$28 - 32 per hour - more than anyone I know, earns.
 - Carers are at a premium - in order to secure 2 days care recently whilst my son was recuperating and to allow me to keep working (after 2 days at home with him), I was provided 4 carers on one day and 3 carers on the next, simply to cover a 2-day shift. No other days were possible.
 - This is only one instance, there are so many more.
- **Family In Home Day Care** - the burnout factor resulting in high turnover is excessive. The training provided to these carers is insufficient and the carer's cannot cope with the extra demands such as my son's and other children's conditions encompass.
- **Stay at home** - perhaps work school hours and compete with everyone else who is trying to do the same and if a sole parent, pray that one can rely on a part or full pension.

- **Family Support and help** - very often there is an absence of both due to the inability for the family to cope with the Challenging Behaviour and/or high needs.

None of the above equate to regular, feasible or reliable Before/After School or School Holiday care to allow us to continue to work.

Then of course there is the more drastic option:

- **Placing Child Into Permanent Care** - to allow the parent to earn an income to help provide for the child, themselves and any additional family members

I believe that those of us who wish to work and not rely on Government Welfare to raise our children should be given the infrastructure to do so. Sadly, the integration of some children and certainly in latter years, all children with special needs, is not successful in mainstream After School and School Holiday Programmes. The Government are encouraging carers to return to the workforce, surely the infrastructure needs to be in place for this to occur, without this, it is virtually impossible.

I recall The Hon. Peter Costello mentioning how valuable carers are in the community. This may be his view but in the area of care for our children, it is not visible to us.

I am typical of other families with children with disabilities. We not only strive to be good parents and carers but we strive to be good citizens. We need the same opportunities as main-stream families to allow us to work so we too can be **contributing** citizens. We really want to contribute!

I guess, we all know that it all comes down to the \$. I sincerely believe, a dollar invested in this area will save the Government many dollars in the near and long-term future (not to mention it assisting the disadvantaged). In support of this, I have outlined the following:

Benefits for Before/After School Care & School Holiday Programmes for Disability

1. A place of belonging and fun for the children - a safe, structured and secure environment - happy children, improved behaviour, building of social and self-help skills.
2. A vehicle to assist parents in either joining or continuing in the workforce
3. A vehicle to assist parents to study to return to the workforce
4. Parents able to spend time with their other children & be involved in their activities
5. Increased spending capacity, resulting in less financial burden on the Government & Community
6. Increased finances, facilitating access to more specialised therapies for the child ie; Brain Development Programmes, Wholistic Doctors, Speech Therapy, Behaviour Intervention Programmes, Physio Therapy etc etc.
7. Higher self-esteem for the parents/carers and the family - better functioning families.
8. Better mental health for all concerned and in turn, better general health

Disadvantages of No Before/After School Care & School Holiday Programmes for Disability

1. Financially Disadvantaged
2. Self esteem low for parents & children
3. Higher incidence of broken marriages
4. Families feeling and becoming isolated
5. Siblings disadvantages and isolated
6. Mental and Physical Health Issues Manifest
7. Absence of specialised therapies and programmes that might otherwise be affordable
8. Families disappearing from the community into isolation and irrelevance
9. Families contemplating placing their child/children into care, permanently adding a greater financial burden on the Government
10. Unseen and long-term financial burden for the Government - families stagnating and relying more on welfare and handouts to exist.

Please consider my plight and the plight of other carers and their families; our circumstances are dire in the area of care. If there is **anything** at all that can be done to change the circumstances surrounding Before/After School care and School Holiday Programmes, the Disability Community would benefit greatly and so would the Government and the wider community. If there is any way in which I could assist in this, I would be only too happy to do so.

I thank you in anticipation for reading my letter and considering my suggestions and look forward to your reply.

Yours sincerely,

Amanda Stapledon

Mother, Sole Parent and Carer & Part-Time worker

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