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Standing Committee on Family and Human Services
House of Representatives
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RE: INQUIRY INTO BALANCING WORK AND FAMILY

Thank you for the opportunity to present my late submission. Congratulations to the committee for the time and effort devoted to this issue which is indeed a timely examination. Fundamental to happiness is the well-being of the men and women in our workplace and their families and for government to re-affirm that we are all part of a society not merely an economy. Unfortunately when examining social services government policy reviews put too much value on cost rather than worth and for this reason there is a skewed result when it comes to value-adding to social capital.

Being in Canberra on Wednesday 21 June, 2006 I attended the Committee Hearing to see the committee at work. On that day a young woman from the northern beaches of Sydney gave evidence of the trouble she had to find child-care places for her two young children one 18 months the other 4. No doubt her evidence reflected similar circumstances for many young mothers who wish to continue to remain in the workplace whether in metropolitan or regional Australia.

Basically my experience is that every working woman needs a wife. That not being possible what is it that can be done by government to support and sustain people in the pursuing a balanced work and home life?

My own experience

Having come from country NSW I embarked on my own business enterprise at 21. This business is still operating and still employing up to 11 other Australian workers. However after devoting many years to building and working in that enterprise, after the birth of my second son I have been unable to continue to work in the business I commenced in 1976.

We wanted to have children since I married at 24. I was 30 when my first son was born - a biological imposition rather than a time-tabled choice and my second son when I was 36 again the age gap was for similar reasons. Had I been a brood mare it would have been the glue factory for me.

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The experience I bring is what happened with the birth of my two very different children.

Our first child

When my first son was born I remained at home for 12 months during which I cared for my infant son, my twin sister's toddler son and my elderly mother who had undergone open heart surgery and who required constant assistance with dressings, doctors' appointments and the like. This was a situation which I did not question and I did all this willingly and happily without any consideration that I required any assistance whatsoever. I was at home and revelled in the opportunity to help my small family, my sister's family and my mother.

When my son was 12 months old I returned to work. My mother provided informal care for him in her home with some help during the day from private child-care workers. I would rise at 6 am to prepare for the 40 minute drive to my mother's home, gave my son breakfast when we arrived and settled him back down to sleep and I went to work at about 7.30 am. This was the course until my son was 2 years old when I then placed him in formal care through Family Day Care run through our local council. My son thrived and was a very happy child who developed very well in every aspect of his life. He was loved, safe and secure. At 2 & ½ he commenced at a private pre-school and at a government primary school at 4 & ½. Before school he was cared for at his aunt's (my twin sister) house with his cousins and with his grandmother now residing there. There was consistency and continuity of care for him. Their home was across the road from the school. After school our son was in formal after-school care on the school grounds which provided him the opportunity to socialise with other children given that he was an only child in an older suburban area where there were very few children. We had no need to expect anything from government in terms of assistance and regarded our life as average if not fortunate.

Our second child

When our second son was born about 2 years later this all changed in a radical way. Our second son is severely intellectually disabled however at birth this was not immediately obvious. He was very small but for us and his paediatrician there seemed to be no need for concern. He thrived and grew well but sleep was a major problem for him and for me.

Devastation at knowing our child was severely intellectually disabled

The devastation of having child with disability came when our child was 9 months old and not meeting the required milestones. From then on our secure and ordered world completely unravelled. Because there was no diagnosis for almost 6 years there was no guidance, no help, no counselling and no support group. We were truly alone. However we know we are not alone in this situation. We know this happens to many families when there is a diagnosis of disability for their child.

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The cycle of seeking assistance began. Without a diagnosis and armed only with a caring/sharing (not) eminent neurologist's "Your son is retarded" we were sent on our way. The Child Development Unit arranged early intervention but very little else in terms of guidance or counselling. I can only describe the feeling as akin to drowning in molasses.

Our son with disability eventually walked at almost 3 years old at which time the early intervention ceased and we finally found a pre-school for children with disability in a suburb a considerable distance away. Our son cannot speak and we are told will never speak, suffers debilitating episodic epilepsy, has severe behaviour problems with his behaviour on the autism spectrum.

Unable to return to work

I was not able to return to work for almost 4 years due to the severity of my son's disability. I had an arrangement with my sister-partners where I was to return to work for 6 months. My younger sister and twin sister both had babies within 6 months of each other and I was to steer the helm of my company for just this short time. However a month before I was due to leave work again my twin sister's 11 month old son was diagnosed with cancer. Because of this I remained at work for 15 months while her family went through the devastation of surgery, chemotherapy and so on.

Necessity to return to work

The necessity of returning to work was a major problem. Because of his disability my second son could not be placed into pre-school and was unable to access pre-school until he was 4 years old. To further complicate matters our son's disability remained undiagnosed for many years accordingly our son's high needs required us to employ a full-time nanny who worked from 7.30 am until 6 pm for the working week. The nights and weekends our son's care was solely left to us and most specifically to me. Remembering that our child did not sleep refer to No 9 below.

We certainly did not gain any financial benefit whatsoever from my working I virtually emptied my paypacket into the of the nanny's but there was no other alternative. I could not get informal assistance because by this time my mother was too frail and elderly as were my parents-in-law. The problem also arose because the nannies only ever last 6 months because our child was difficult and the work tiring. So every 6 months we had to find a suitable person to care for both our children.

Little or no help given to families of children with disability (especially intellectual disability)

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Despite being allocated a social worker our family remained totally unsupported by any respite or any centre-based care, apart from early intervention. We had no idea what a social worker was supposed to do so we did not know what we could seek in terms of assistance. The stress and distress of our family was exacerbated by our son's condition which was one where he did not/could not sleep. He would sleep no more than 2 hours at a time. At night he would wake and be unsettled for hours then finally fall asleep only to wake again after 2 hours sleep. At times he would not sleep for up to 72 hours. This continued for 12 years. Now at 15 things are improving in that regard but he still wakes in the wee hours of the morning but now does return to the sleep.

What about the siblings?

Please bear in mind when reading this that we also had an older child who needed nurturing and care. As his brother grew and his high needs became more manifest our older son was pushed more and more into the background. He literally grew up locked in his room because as our son with disability grew he became stronger, his behaviour became violent, aggressive and destructive. This is when we had to introduce locks on every door both for his safety and the security of his brother. Our house became the Carter detention centre. Things were really difficult for our older son, to what extent we will never know but he did have a breakdown in the early years of high school, which again was difficult to examine but his school was extremely supportive in this regard for which we were thankful.

Entire family is disabled

This is the experience of so many families who have a child with disability. The family becomes disabled, institutionalised within its own 4 walls. The family is socially isolated. More likely than not invitations from friends and extended family slow to a trickle and then cease entirely. This is a most crushing blow and precipitates many family breakdowns.

Families are not only affected in a social sense but it is the health of every member of the family which is at risk. Not only the physical health but particularly the mental health of the primary carers (invariably the mother) and siblings is of great concern.

Husbands and family relationships

The capacity and elasticity to maintain a loving relationship between husbands and wives (read partners) and children is stretched to breaking point. And with each challenge the resilience of relationships is tested and diminished. Most men are seriously traumatised by their incapacity to make things better or to fix things. Other siblings also suffer in ways undocumented. Although the benefit is generally to the good there remains the difficulty of not having a life enjoyed by their peers or the freedom to have their peers visit the family home and develop a relationship with the family.

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Family breakup is another aspect of life which when dealing with a child with disability leaves a family very vulnerable. There is a very specific need to have mandatory and immediate parenting orders put in place when the parent with sole responsibility for the day-to-day care of the children is put under unbearable stress. The imperative for this is to avoid the complete breakdown of the family which would precipitate the out-of-home placement of the child with disability. The family law sector must be more responsive having regard to the normal human frailties and the capacity for one partner or the other in a breakup to delay and frustrate the settlement process.

Inflexibility and few options for schooling

When our son with disability was 4 & ½ we had his schooling to consider. Because we had no diagnosis we had no guide of what the future would be. The stress and distress of our lives was indescribable. We merely accepted what we were told by the professionals in the area of disability. When it came to schooling we were given no options and we were too exhausted to ask questions or seek alternatives.

Our son with disability attended a government special school because this is the only model ever offered. There was absolutely no other information given to us in relation to any other models of schooling. We were greatly misled in this regard because there are other options but are so limited as to be virtually impossible to access. These are weekly residential boarding schools for children with disabilities. Only the most severe children now access the very limited places that exist and they exist only in the private sector. Our son was able to access this education when he was 12 although there is constant comment from his carers that he would have benefitted from much earlier commencement however he was precluded from access to this education model due to government's stance informed not on evidence but on misguided untested ideology.

I refer you to the second report of the Inquiry into children in institutional and out-of-home care released 17 March, 2005 entitled *Protecting Vulnerable Children: A National Challenge*. Particularly the Conclusions of Chapter 5 and recommendation No 10. These schooling options have a genuine place in the overall care, socialisation and community-building for children with disabilities and their families.

Ample evidence of stress and distress

I make this submission because I know that there are so many families who are going through what my family went through and I know they are unsupported, unassisted and in enormous distress. There has been any number of costly reports on the issue of lack of disability services and the lack of support for families and still nothing changes for these worthwhile and wonderful people.

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Specifically a report by the NSW Ombudsman in April 2004 called DADHC - The Need to improve Services to Children, Young People and Families is particularly scathing. A report released in 2006 shows DADHC has made improvements however, with the qualification that those improvements still in their infancy. Which essentially means that nothing much has changed to give parents in July 2006 and family any real relief or hope.

I refer to the recent report of the Australian Institute of Health and Welfare which was released in early July, 2006. This report confirms the following:

- * 91% of all children and young people with disability are cared for by their mothers - this is because the incidence of family breakdown when there is a family member with disability involved is enormous with over 85% of all families breaking down.

(In the last 4 months I know of 2 families which have broken down with the mother having not only the care of the children (there is usually always a sibling or more involved) but also the distress of going through the property settlement which is as often acrimonious and bitter as any other marriage breakdown.)
- * 63% of all mothers who have children with disability are not in paid employment compared to 36% of mothers of children without disability.
- * The lack of capacity to sustain employment impacts enormously on the capacity for the family to live above the poverty line.
- * If the family remains in tact it still means that the family has very little opportunity to asset-build, save to buy a home or accumulate sufficient superannuation for their old age.
- * Because of family breakdown mothers who cannot work have no capacity to accumulate superannuation at all.
- * There is great disincentive to work because the tax-free threshold for a mother/parent caring alone for a family in which there is a family member with disability is far too low.

If a mother/parent works, for every dollar earned the family loses 60c in benefits which makes the effort almost worthless. There must be a change in the tax-free threshold for families caring for moderately to severely disabled family members particularly when the disability is intellectual.

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Long-term requirement to care

The lot of families who care for a family member with disability is unique in that the work of caring is not merely for the few years that the child with disability is at school. When the adult child leaves school at either 16 or 18 the caring continues. By this time the parents are 18 years older and the rest of the sibilings are either still being cared for and still at school or the sibilings have left and the parent is caring alone with limited access to adult services and respite.

Generally young families with children without disability under 5 have the reality that eventually the children will be at school and will make the usual progression to independence, the parents will eventually be able to return to work. Many families caring for a family member with disability, particularly if the disability is intellectual, will live a totally different reality. They will be caring for decades sometimes for 40 or 50 or more years.

Families lack opportunities to seek employment

Because we were unable to have children for many years we were able to purchase our own home and set up a stable and eventually financially secure family situation. This I know is not a luxury afforded to most young couples. And given the rate of family breakdown of families where there is a child with a severe disability rarely is there the opportunity to accumulate a substantial asset base or adequate and/or substantial superannuation. These mostly single parent families eke out an existence close to or below the poverty line.

Parents caring for a family member with disability usually gain employment in only menial low-paying employment because of their lack of capacity to pay for formal or informal care. By the time their child leaves school their own informal care options that is parents and friends are older as well and that option is rarely accessible.

Lack of emergency care services in case of illness of either the parent or the child with disability or the child without disability makes obtaining, sustaining and retaining employment extremely difficult. At the drop of a hat you just can't ask the next door neighbour to look after your severely intellectually disabled child.

Lack of opportunity for paid employment in later life

The usual transition to independence with out-of-home accommodation is not facilitated because there are no accommodation options available. This is not only unhelpful for the parents but also for their adult children who are now mostly at home with elderly parents who are basically no fun.

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My 15 year old son with disability leaves me in no doubt that he doesn't see me as his peer. He loves us but he prefers the company of HIS peers, his friends who are also intellectually disabled and also he wants to spend time with his 21 year old brother and his girlfriend who are both generous and giving of their time but they are both at university and have their own timetable with rarely the luxury to socialise with our high-needs son.

Lack of access to out-of-school hours services and sporting programmes for children with disability

After school services for children with disabilities are so scarce as to be virtually impossible to access. Vacation care is rare and limited and there is limited access to sporting programmes which means that obesity and fitness is as real a problem for people with disability as for everyone else.

These observations are a chronicle of my experience. I make them because I have the luxury to do so and even so it has taken me two months to find the time to formulate my submission. You will possibly not have numerous submissions of this kind because the families are completely enervated by the life they live. These people are courageous, brilliant and fearless. Do not think that because you don't hear from them that you can ignore them because I am telling you something of what they all experience and the figures disclosed in the report of the Australian Institute of Health Welfare are real and recent.

As I sat in on the hearing of 21 June, 2006 I watched the committee earnestly listen to the circumstances as evidenced by the eloquent young woman from the Northern Beaches of Sydney. The problems she has in terms of accessibility to child-care and the special circumstances which relate to her children's health, vis a vis intolerance to peanuts are all valid and important in order to maintain the balance of her work and home life and to the relationships that ebb and flow in that life. As I listened I realised that young men and women must have the confidence to bring children into the world, our very survival as a society depends on it.

The observations in this submission are a chronicle of my experience. I make them because I have the luxury to do so and even so it has taken me two months to find the time and energy to formulate my submission. You will possibly not have numerous submissions of this kind because the families are completely enervated by the life they live. These people are courageous, brilliant and fearless. Do not think that because you don't hear from them that you can ignore them because I am telling you something of what they all experience and the figures disclosed in the report of the Australian Institute of Health Welfare are real and recent and attest to what I have set down.

These people vote as to do their families and friends. Every government legislation must include a Carer Impact Statement which takes into account the effect that any new law will have on the work/life balance of families caring for an adult- child/family member with disability.

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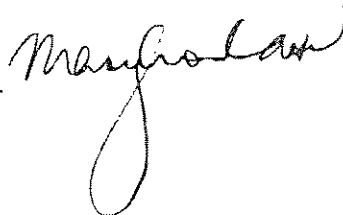
Every submission you receive will bring a different perspective and for every different perspective there is a family with a child(adult) with disability that fits within that perspective. They are ordinary families with all the ordinary stresses, deadlines, in-laws, kids and their problems, mortgage repayments, transport costs and so on and blanketing all this is the overarching responsibility to care for a child/adult with disability. Most especially affected are the families whose children are severely intellectually disabled to the point where they cannot speak or communicate their needs who will have a life-long dependent disability.

They deserve more than transient and token concessions. They deserve the same opportunities open to other Australians to better their life circumstances and that of their families. It comes back to having the confidence to have children and whether through an accident of birth or life something goes wrong and their child is disabled that there will be structures in place that will sustain the family what whatever comes along.

I appreciate the time you have taken to consider my submission and take this opportunity to extend my best wishes to the committee in its important work.

Yours faithfully

Mary Lou Carter



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