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To:

Committee Secretary
Standing Committee on Family and Human Services
House of Representatives
PO Box 6021.
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Email: fhs.reps@aph.gov.au

RE: INQUIRY INTO BALANCING WORK AND FAMILY

Ms. Catherine
Secretary
Member
2006

Att: Committee Secretary
Standing Committee on Family and Human Services
House of Representatives
PO Box 6021, Parliament House
CANBERRA ACT 2600
AUSTRALIA

10th November, 2006

Dear Sir/Madam,

RE: INQUIRY INTO BALANCING WORK AND FAMILY

I have become aware of your current inquiry into balancing work and family; I feel it necessary to inform you of our personal situation and experiences. I feel they are extremely relevant to this inquiry and somewhat typical of the experiences of many families with children with special needs.

Family Background:

- My husband and I are small business owners with a successful Building Design Business.
- We have two sons aged 4yrs and 3yrs, the youngest of whom was diagnosed with Autism (ASD) in April this year.
- I have been a stay at home mum for the entirety of our children's lives. I have also continued with tertiary studies in Music and Education whilst caring for the children.
- We receive minimal Family Benefit Payments and have no access to respite services or government funded therapy programs.
- Our son with ASD attends a child care setting 1 day per week – this environment falls short of meeting his communication/social/emotional and educative needs.

- We are currently on waiting lists for early intervention programs through Autism Queensland, Grovely SEDU and AEIOU (Autism Early Intervention Outcomes Unit).

It is for many reasons that I feel we are disadvantaged by the lack of funding and services available to families and particularly those with children who have disabilities. Our son's diagnosis of Autism and the reality of what it means for him and our family have had many ramifications for us which I will outline below.

Financially we have found it has been difficult, and I often wonder what happens to those families that can't provide the money for private therapy. My husband has had to focus on promoting and expanding our business by working longer hours so that we can provide the funds needed to give our son the best start in life through therapies and interventions. We have financially supported the diagnosis process and his therapy interventions at great cost. We honestly believe this is necessary not only to avoid lengthy waiting times, but to ensure continuity of care and the execution of individually appropriate interventions.

Emotionally, there has been strain at times on our marriage; we have endured great periods of stress largely due to the lack of services and their poor availability. The most stressful time was prior to and just post our initial diagnosis - which was a year long process. During this time it was evident that little support was available particularly information, support services and parenting programs. We were lucky to be involved with a Parenting Program for children with Autism called "Growing Stronger" run through The University of Queensland. This program proved invaluable in setting up the strategies we needed to cope as a family and taught us many skills to aid our son's development.

Physically - my husband and I regularly experience great exhaustion. Being small business owners, constructing a new home, studying and being for most part the primary care giver to our young children, as well as meeting our youngest son's special needs is totally consuming and fatiguing. We receive no respite services, the time I get to engage my studies is when childcare is provided by family members, this is somewhat limited as they have their own work commitments.

I would not consider **returning to the workforce** for a number of reasons. The primary reason being that I can not find adequate care for my child. The current day care system does not meet the needs of children with ASD. In the current placement my son holds, he has an aid for five hours of the day. The aid (our third since February) has limited English language skills and although his physical needs are met, no strategies for enhancing his communication were put in place until prompting and enquiry from myself. Having completed tertiary studies in Education I found myself being not only his mother and advocate but an educator of staff. On many occasions I have provided resources and information for the benefit of my son's development. In my experience, many staff have misconceptions of what ASD is, how it can affect an individual, and how

to develop a learning environment which is inclusive of their learning styles. Each and every child with ASD has differing sensory, communication and social needs. This should highlight the importance of employing trained professionals for these children.

Many childcare institutions employ TAFE educated students whose understanding of the needs of children is limited, largely due to the structure of the TAFE course. Current research demonstrates that, the best possible chance these children have for their future is through Early Intervention. Most brain connectivity for passing and processing information (the process called synapsis) happens in these early years. Quality Early Intervention will provide these children with the best chance of entering the workforce as adults rather than being welfare recipients.

We are currently on the waiting list for an Early Intervention Program called "AEIOU" or Autism Early Intervention Outcomes Unit. This program understands the needs of children with ASD and provides a 25 hour per week individually designed program for our son. Their staff include a Speech Pathologist, Occupational Therapist, Music Therapist, Special Education Teachers and Experienced Teacher Aids, The ratio of teachers to students is: 1:2 This program provides regular reporting and establishment of individual goals for each and every child. Some graduates of this program are mainstreaming without or with minimal Teacher Aid assistance. Sadly this program comes with a large \$37K per year price tag per child, of which parents currently pay \$14K - this is unaffordable for many people. Sadly other programs simply pale in significance when examining the quality of staff, amount of hours per week and the age of the child on intake and general outcomes for the child.

If the government does not provide quality early intervention for these children, they will come at a greater cost for society in the long term. The very real possibility that our son may be unable to communicate, illiterate and socially disadvantaged will cost more for the government in the length of his lifetime than two years of early intervention. In Canada and the US each child receives \$20K per year for the purpose of early intervention until the age of six. In the US Programs costing \$78K per year are totally government funded and free to those who require them. I believe Early Intervention Programs in Australia are widely demanded and largely under-funded. As a parent I urge the government to consider the impact and importance that quality early intervention has for children with ASD.

Yours Sincerely,

Fiona Engwirda