SUBMISSION NO. 119 AUTHORISED: 9-05-05



4/05/2005

House of Representative Standing Committee On Family and Human Services. Inquiry Into Balancing Work and Family Parliament House Canberra ACT 2600

Dear House of Representatives Standing Committee Members,

I am presenting this submission to advocate on behalf of families who care for people with a disability. I have enclosed a number of letters from people whom I have met whilst in my role of Program Co-ordinator for a disability support service. (Please see attachments, letters) The opportunities available to these families are often severely impeded due to the high care needs or constant supervision required for their family member.

The second point of your inquiry is clearly where this submission is aiming, however if one were to hypothesise or had a crystal ball and could foresee the birth of a child with a disability, the financial, social and career disincentives one could state to starting a family listed under point one of the inquiry would be exceedingly magnified. In my work role for a small not for profit organization on the Sunshine Coast, QLD, I meet a number of families and career living in the area. All of these families have restrictions on their working, marital, social and financial lives, a large proportion have major restrictions. I have included the latest statistics that I could get from the Department of Disability Services Queensland from 1998 that show the numbers of people living with a disability in this region. (Please see attachment, figures) It is the percentages that are important in these figures, for each of these communities they are relatively the same and are, I think, incredibly high. From these figures, one can begin to deduce how many families are being impacted throughout this region and across the country.

A typical situation:

Hypothetically, a person with a disability is born into a family. Below is a broad snapshot of what I observe is occurring with families in this sector in QLD.

- They may have to assist to bathe and toilet, dress and feed their child for as long as the child remains in their care. This regularly involves setting fairly rigid routines throughout the day to achieve these tasks. This is often one parent's fulltime occupation. This sometimes leads to breakdown of the family unit. Other siblings often miss out on parental attention and opportunities such as sport and recreation. I have met aged parents who have cared for their child at home for over fifty years with very little weekly support.
- Parent's opportunities and availability for work commitments are often obstructed by care commitments and fatigue.
- Families will generally have much higher costs associated with healthcare and general medical expenses.
- Parents will generally have a greater responsibility, be under more stress and be required to spend more time on the supervision of the child with a disability.
- When the child reaches school age the family carer at least gets a break as the child's care needs are met during school operating hours by the state education system.
- Once the child leaves school most parents receive little or no care support from Disability Services Queensland at all. Only Carers Allowance and Disability Pension for the adult child. Parents of children with mild to moderate intellectual disability fall through the gaps in service funding.

- The Home and Community Care block funding to service providers is meant to support as many members of the community in need as is possible. This type of facility may assist a stay at home carer to cope by providing some respite but does not offer the level of support to meet the needs of a working carer.
- Those parents who have adult children who are severely disabled, or have high support needs may receive a DSQ funding package. An average package buys approximately 18 hours of service time per week for a 48 week period per annum. They may have access to little or no respite services at any other time. If a parent manages to work during the child's service times they come home and are the primary carer the rest of the time, often resulting in poor health through isolation, depression and fatigue. In the Sunshine Coast Region, approximately one in two school leaving applicants for DSQ funding were successful in 2005. Adult Lifestyle Support Funding saw approx 4 successful applicants out of approx 170. Please note that I quoted applicants, many simply don't apply.

Parents who decide they can no longer cope with caring for their child at home, may, usually through desperation, decide to hand their child or adult child over to the Department of Disability Services Oueensland.

This may cost government \$50 000 per anum upwards in wages to care for the individual plus costs associated with housing.

System Failures that leave families unsupported.

There appears to be a lack of cohesion between HACC and DSQ departments often results in gaps in service provision and costly duplication.

- Lack of adequate job places and placements for young intellectually disabled school leavers, many of which are not maturely ready for this transition straight out of school.
- Inadequate funding to provide for transitional support for young school leavers results in individuals going from a social environment five days per week to uncertainty and isolation. This creates anxiety for the family and the individual.
- This results in families being unsupported as these children miss out on DSQ Funding Packages. Under prepared job networks and little private sector opportunities for people with a disability sees people registered but without real prospects or support in the meantime. Many parents of these young adults have to leave paid working opportunities to facilitate supervision and community integration strategies of their children.
- Apparent unwillingness from all levels of government to face the responsibility to increase funding to support families. Severe sector under-funding and fragmentation of responsibilities from State and Commonwealth. The current State Minister for Communities and Disability Services, Warren Pitt openly admitted that the state has grossly under-funded this sector for 20 years.
- Lack of support system that identifies and monitors the needs of the individual from birth. This would help ageing carers whose children's needs have increased through deteriorating health as they have aged. Add to this the often-deteriorating health of the aging carer.
- Inequity in childcare provisions available to parents of adult children with a disability. This is evidenced by parents caring for adult children with a disability without the same level of support offered to parents caring for young children without a disability. i.e. No rebated childcare for parents caring for adults with a disability. Respite can cost up to \$50 per hour. The right and opportunity to earn a living is often denied by the burden of care and lack of support.
- Personally I feel the Commonwealth, State and Territories Disability Agreements are failing to offer equity across the states and territories to all Australian families. One area in particular, relevant to this committee, is support for employment opportunities to the carers of people with a disability. This can be achieved through a greater number of carer respite options, but it has to be affordable and incentive based.
- Dual levels of government agencies, HACC and DSQ, who cannot agree on a standardised assessment
 tool or a standardised minimum data set reporting system for NGO's in Queensland. The failure to form
 agreement on these two issues is very disappointing considering it could save a lot of time and money in
 the sector that could produce more services. NGO's have to buy expensive software to connect into
 HACC and DSQ reporting software or spend the time manually entering into the system. Without a
 standardised assessment process individuals are often lost between two systems. Some people appear to
 get more support than most whilst others in similar situations can't get any at all.

Broad based solutions

- The current Federal government is at present publicly floating all manner of reforms in its dealings with the states. I believe a lot could be achieved on the CSTDA agreement. The Federal Government looks after people's welfare through Centrelink and to my understanding we have equity in a national system. It is a basic right of our society that a person who registers and attends to the requirements of Centrelink will receive a welfare payment. Funding an employment scheme for carers to care for people with a disability so that their parent or parents may choose to return to the workforce looks to be cost effective to me. It is an investment in the quality of Australian lives and whilst this would have substantial costs there would be the potential savings of two or more lots of welfare benefits for every position created. The worker and the carer. One paid carer at a respite facility maybe able to care for several disabled persons at a time.
- Many young intellectually disabled school leavers are not maturely ready for the workforce and I feel that linking job placement agencies with adult training facilities for these young people could facilitate the transition. Centres could provide linkages to the community with social stimulation, education, lifestyle, leisure and volunteer opportunities whilst providing respite care options to working families. Training for support workers through partnerships with TAFE Colleges would see cost effective training opportunities and a skilful workforce.
- I feel that after hours and weekend respite is an area where more money needs to be allocated and invested. The health cost and cost of low productivity from families who are stretched to the limits supporting their disabled children must also be expensive. Again I see this as an investment in the quality of Australian lives with dollar savings potential over the longer term.

In Closing

Society expects and requires that people with a disability are cared for and as the legislation states, have the same rights as any other member of the community. As long as their parents are doing the caring, generally speaking, it appears society and government doesn't want to know much about it. Parents care because they love their children and want the best for them, but they cannot be expected to do so on their own. This is a social issue and requires a social response, good governance can deliver that response.

I thank the House of Representatives Standing Committee on Family and Human Services for allowing me the opportunity to present this humble submission. It is from my heart and from a belief that more can be done to create positive win-win solutions for what is a large, and by virtue of time and the ageing process, an increasing percentage of our population, carers.

Yours Sincerely

Michael Packman



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BECAUSS OF OUR CONS OTABILITY HE REQUIRES CONSTANT CARE BY OUR FAMILY AT AULTIMES, WE ARE LIVANUE TO BELY ON OUR FAMILY FOR RELATE AS THEY FAME OUR SONS DISABILITY VORY DIFFAULT TO MANAGE, AND GOURIMENT PROVIDES RESTATE IS ACHIET IMPOSSIBLE TO ACCESS.

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NO SCHEMARY WE AS A FAMILY EXPERING GLEAT SUFFICIETY BACACINE WORK / CNERING FOL A ABSON WITH A DISABUTY AND UNLESS SOTETHING CHANGES, THIS SUTURTION WILL NOT IMPROVE

YOLS FATTHFULLY

Deborah Taylor

QLD

12 April 2005-04-14

To Whom It May Concern:

I am a single working mother of two children. I have a daughter turning 11 this September and a son turning 9 this June. My son was diagnosed with Autistic Spectre Disorder and ADHD in March 2003. They firstly mentioned Autism to me when my son was in preschool, which was in 2001. It took time to compile necessary information for this particular diagnosis. I have been working part-time on and off for the past 8 years that I have been solely raring my children. Finding suitable employment has been rather difficult.

In fact, I even tried going to TAFE in 2002 to try and further my education for the purpose of getting more suitable employment that would fit in with my family's needs. I soon realised I was not getting anywhere fast and decided best just to stick with what you know.

So in February 2003, I decided to get back to the work force, so I could provide more adequately for my family financially. As the Parenting Payment only allows for the immediate living costs of my family. I had also not been receiving any maintenance for quite some time and my car was in desperate need of mechanical repairs, which meant money.

I began employment at a Service Station with hours of work, which did not suit my family, but enabled me to get a start on my necessary car repairs. I stuck with this position that did not suit until I could find other employment.

I took a position with a cleaning company but inevitably this was also unsuitable, as the position required me to work every Saturday and Sunday. Which in turn meant my children spent their whole weekend at the babysitter. This was unacceptable for my children and me.

I began at a butcher's, starting at 10 hours a week and then due to other staff resigning put my hours up to between 20-28 hours per week. All was going well at first until I lost my babysitter and then my son began to have problems at school. In the end my son was coming home at 10.30 am and I would have to finish work early in order to pick him up from school and then home school him by myself on these particular days. So in the event of both of these circumstances it was inevitably apparent that I could not continue my employment at the butchers. Regretfully, I resigned from this position, I say regretfully as I really enjoyed this particular position.

I yet again sought employment in 2004 with yet another cleaning company, OPTIMUM, which was based in Mooloolaba. After 1 month of employment it was evident this position was not suitable for my children, and me as I was either running late or leaving work early in order to drop off and pick up my children from school.

I resigned from this cleaning company and decided to look for a position of employment in the local area of Nambour where we live. It had to be in the hours that my children attended school, that being 9.00am- 2.00pm. as this was the only way I could see that would enable me to work at all.

I came across a job advertisement for Jamra Cleaning Company.

Cleaners needed, hours of work Monday-Friday in school hours.

I applied to this position, explaining my family's needs and what hours of work would be suitable for me and my children. I also explained my son's disability and his unique challenging physical behaviours and his support all times. So if neccessary at given time, I would have to leave work at such times if required to assist my son. Also I would need to take any needs. Also explained that I had no family support or other support of any kind to help or assist me with my children. I would be unable to work if holidays.

I was employed by Jamra Cleaning Company on the understanding and acceptance of the above needs of my family.

I did however organise some Respite Care for my son over the Christmas school holidays for a couple of days a week. This was so I could financially be able to enjoy the Christmas school holidays with my children. As a couple of days a week, enabled me to have some extra money to take my children out on outings over the school holidays.

It became apparent after a couple of incidents occurred at two seperate Respite Care Organisations that the care was not suitable or appropriate for my son. In fact, the care provided has been detrimental to my son and his family.

Needless to say we longer use any Respite Care and have no intentions of in the future, as there is no suitable or appropriate Respite Care available for my son. My son's unique challenging physical behaviours are quite complex and he is unable to fit into the Services that are available to him. Realistically my son is in need of Respite Care with a one on one basis which would need to be tailored to my son's needs rather than my son tailoring to the needs of the Services available to our family.

I would not be working at all if I was not employed by Jamra Cleaning Company, as they are very aware of the difficult support needs of disabled children.As both of my bosses have desabled children and aware of how difficult it is to maintain employment.

I feel I am very fortunate to be employed with such an understanding Company whom appreciate and respect my working limitations.due to the needs of my family.

Thanking you Deborah Taylor

Debbie White QLD 11/4 /2005

House of Representatives Standing Committee On family and Human Services Inquiry into Balancing Work and Family Parliament House Canberra ACT 2600

Dear Standing Committee Members

My name is Debbie White, I am a single mother with four children, three of which still live with me at home. My second born child Brent was born with Williams Syndrome; he is now nineteen years old. His two younger brothers still living with me are fourteen and twelve years old.

Up until the end of 2004 Brent attended the Currimundi Special School. During his school hours I worked at my parents fast food restaurant for approximately 20 hours per week. This was to fit in with school hours and to leave me enough time for home duties and shopping. I would care for Brent as his primary carer at all other times. This was primarily a supervisory role as he got older. This arrangement suffed me because it was flexible and I did not have to work on school holidays.

At the end of 2004 I applied for DSQ Funding and was rejected being offered no support from any source. Not wanting to overburden my daughter and her young family I gave my employment, as I could find no respite facilities. I am now financially struggling (broke) and feeling trapped with the care obligations for Brent.

How can a system provide care for a child for twelve years and then suddenly withdraw all support. Brent still needs supervision and stimulation; I am driving him down to a nursery in Calourdra 2 days per week where the people there are kind enough to allow Brent to volunteer with some small jobs. This costs me petrol but allows Brent and I a break from each other and other contacts. I still need to support my family and put my two youngest children through school. I have needs to fulfill in my life also. I would like to lead a normal life, working supporting my family and having some time for myself. I do not have the opportunities with my youngest children as other parents have due to the obligations to care for my son. I cannot do this without some other support. A respite or care facility is desperately required for people in situations like mine to lead fulfilling and productive lives.

Unfortunately I do not see any changes in the immediate future and I worry how long I can continue to live this existence. This is not fair on Brent or myself.

Yours Sincerely

Debbie White

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8 March 2005

To Whom It May Concerns

missed out. Because of his disabilities, my son is unable to do most everyday things for now to drive him to different agencies as I do not have funding for him to catch a laxi. I was totally shocked about I even asked for a reviewing process to be done and still he himself. He cannot catch public transport or be left mattended. Therefore it is necessary He is 19 years of age and unfortunately missed out on post-school services funding which situation. My son, Jesse, finished schooling at a local special school at the end of 2004 I am writing this so that you are aware of the need that is required for people in my

my son backwards and forwards is financially challenging for me agencies is minimal but even so, when totaling them up, and the cost of fuel from taking family support on the Sunshine Coast as my parents are elderly. The cost of each of these stressful and rushed affair to get to work on time. I am a single mother with very little situation is unsultable as she lives a fair distance from me and therefore I find it a very of my son's activities. Tafe, Scils and Spiral start at 9am or 9.30am and pick-up time are usually around 2.30pm. My hours at work are 8.30am to 2.30pm so therefore for the time I am currently working part-time at a local high school in the special education unit Mos being, I am relying on a friend to drop hun at these facilities and pick him up. I find this

even if he could go) so therefore I must stay home with him. My job is only temporary a requires me to do. Financially, I need to work to support my son and myself. not know whether I will be considered because of the hours and the times that school the moment but the position is going to be permanent after this coming school term. I do decline as my son has no agency to attend on the Mondays (and I cannot afford the costs The head of my department has asked if I could work an extra day but I have had to

ongoing for the past 19 years. I do not see any chance of this changing in the future. With respite of a few days a year. I find that I am very stressed during the week and then my this commitment and my work outside of the home, I have only been getting minimal Looking after and caring for Jesse is a fulltime 7 day a week requirement and has been **Januly** weekends are taken up caring for my son. Therefore I would like to get more respite These are some of the points I would like to mise at this time in regards to my work and

- Ť I am temporarily having to rely on someone else to transport my son as I cannol I cannot get my son to and from his agencies because of my work schedule.
- attord any other means
- I am having to decline work offers because of lack of funding.
- More respite is needed for families in similar situations as mine. The expenses of the agencies and transport are causing me financial difficulty.

I hope that you are able to assist my son and myself in some way

Yours faithfully,

JANELLE CUMMINISTON 30/3/05

I am the primary care giver of my 50years old intellectually and physicially disabled son, his degree of disability falls in the high support needs. He also has had some major health issues in the past few years.

So why did I want to work as well as be my son's carer because I have a desire to give myself and son a quality of life, to achieve the basic goals of life e.g. buying a home, a car, going on a holiday, being able to afford the extra medicial expenses that my son's disability incurs.

When I made the decision to work I also did my homework on what help would be available for myself as my son's carer, NONE only that I could work 20 hours a week and that was taken from when you leave your home and that you are means tested. With this in mind I decided to start a business

Why? Because I would have a business partner whom would understand the extent of care my son needs and the limited hours I would be able to work.

This business has been operating for Syears now, it certainly could have grown more but I am realistic on how much I can put into it. I work whilst my son is at day services as I am not allowed in-home respite for my son if I'm at work. As I stated my business partner takes up the greater portion of the work load and this enables me to hang in there.

I know it's my choice to work but I deserve a chance to achieve things that other people can take for granted. Work challenges me I'm giving back to society, it enables me to have normality in a small part of my life, it enriches my life, which in turn I believe makes me a better carer.

To be able to maintain working there needs to be assistance with in-home respite, flexibility of the hours to be able to work and a broader means testing. I love my son and he is and always will be my first priority but in the work years I have left I want to be able to give it my best shot and to do that I need support.

Janell lummington



Dear Standing Committee Members,

Our son Timothy is an intellectually impaired, uncontrolled epileptic. He cannot speak; he walks with difficulty and requires 24-hour care. He has to be fed by hand, needs to be showered (cannot take a bath) and physically aided at the toilet. The difficulties for us, his parents, as his carers are:

- 1. One of us must be home with him at all times
- 2. His mother cannot look after him by herself so the father must do most of the physical caring (showering, toileting etc)
- 3. Father has not had a holiday for 6 years due to the lack of adequate respite facilities.
- Difficult to attend social functions or community activities unless held at the times he attends his day service. These are three 6 hr days per week. Tuesday, Thursday and Friday from 9am-3om.
- Due to his weight (104kgs) both parents are required to lift him if he falls. This is becoming increasingly difficult as we age. (both in our 70's)
- 6. Both parents worry about our son Tim's future following our demise. Unable to make arrangements now that will become effective at a later date. We do not want his siblings to inherit this responsibility.

Kind Regards----

Elicar Max Allwood

P.S I have included this family and their story to show the committee members the long-term neglect from government at all levels to support this family and others like them. Now in their retirement they have worked hard together. Max also working in the legal profession, to support their son at home for 40 years. The savings to the government through caring for their son at home are considerable. Will the young families that have written to you with their stories be writing to future committees in forty years to tell similar stories to that of Max and Doris.

As parents/care givers of individuals with a disability, we work towards empowering our sons/daughters to move toward more independent living skills, improved life quality and to achieve a greater level of integration in the wider community.

Hope this is something along the liver you are wanted. Third is

With this in mind, we look to provide every opportunity to maximise their potential and therefore we ensure that quality educational programs, recreational/social/therapeutic activities, rehabilitation and extensive support networks are made available.

By receiving support, services, training and motivation, people with a disability can lead more satisfying lives and participate to a greater extent in the community in which they reside. We can watch our loved ones grow and develop in the following ways. They:

- make new social networks/improve communication skills meet new people - improve social competence
- a participate in the wider community.
- u develop opportunities to access and participate in public activities
- a become more autonomous

Att. Michael P-

- u improve existing skills/adaptive behaviours
- u improve sense of well-being, self-esteem, self worth, confidence
- take pride in their achievements
- Li improve their ability to concentrate
- receive appropriate rehabilitation
- enjoy therapeutic activities
- u enjoy increased levels of stamina and energy
- enjoyed improved health alleviate depression
- a enhance their employment opportunities
- a empower people to move toward independent living
- a improve functional capacity/coordination/balance
- increase community awareness of the abilities of people with a disability

Unfortunately, people with a disability often receive very limited funding or small pensions. Consequently, the opportunities outlined above do not always become a reality for this marginalised group.

Trish Osborne

Thus, it falls back onto the parents to provide the extra financial support, which will give their sons/daughters the opportunities they need to be 'included' in the wider community.

However it is often the parents, who are the caregivers for their sons/daughters and therefore they not only provide a high level of care, but they also have to find ways to raise the extra finance needed to ensure their child/adult can lead a quality, satisfying life.

Unfortunately, a tremendous amount of stress is placed on the caregiver. They not only care for their loved ones, but many have to try to work outside of the home to bring in extra financial support. This can be very stressful as it can make the workload 24/7, especially if they have to care for an individual who also needs attention during the night.

There are no weekends off, no time to pursue a career, no time to relax and socialise. Parents will give up everything to support their sons/daughters.

It is therefore important that parents receive the necessary financial support to ensure that their sons/daughters can take advantage of the available services. Support at this level will help to relieve the burden associated with having to find extra work to make ends meet.

Also a point that I believe is worth mentioning, the carer's pension is approximately \$250.00 per week. In some cases this is only the mortgage or rent payment! A parent is allowed to work 20 hours per week. However, as soon as they claim their earnings, the pension is so reduced, it is not worth them working in the first place considering the stress levels that come with working in and out of the home.

This also makes it impossible to employ a qualified carer, as they earn so little money but are expected by the government to work a full week. If they work 20 hours outside of their caring job, their pension amounts to just a few dollars. This situation makes it almost impossible for a parent to reenter the workforce, as they canfiget the help they need on the home front.

Trish Osborne

We learn a great deal from our children who have suffered injuries leaving them with a disability and from children who have been born with extraordinary challenges. We learn more about courage, unconditional love, patience, compassion and kindness than we ever thought would be possible.

These individuals, who have so much to offer us, deserve the right to experience every opportunity, that will maximise their opportunities and enhance their life quality. This requires adequate financial and family support, so that doors may be opened for these special people to pass through.

Trish Osborne

	Total population in 1998	People with specific restrictions							
LGA Name		Profound	Severe	Moderate	Mild	Schooling or employment restriction only	People with a disability but with no restriction	Total people with a disability	Total %
Caboolture Shire	96,790	2,154	3,705	3,827	4,899	2,082	2,612	19,279	20%
Caloundra Shire	62,232	1,585	2,322	2,914	3,728	1,297	1,958	13,804	22%
Cooloola Shire	30,407	722	1,162	1,270	1,640	656	866	6,316	21%
Kilcoy Shire	3,036	68	118	125	162	63	86	622	20%
Maroochy Shire	101,769	2,365	3,749	4,237	5,526	2,165	2,929	20,971	21%
Noosa Shire	34,106	829	1,274	1,495	1,908	732	1,014	7,252	21%
Sunshine Coast Region (Department Of Communities)	328,340	7,723	12,330	13,868	17,863	6,995	9,465	68,244	

People with disabilities living in the Department of Communities – Sunshine Coast Region.

Data Source: Survey of Disability, Ageing and Carers (SDAC) 1998, Australian Bureau of Statistics (ABS)

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