

Submission No. 1089

(Inq into better support for carers)

AOC 28/7/08

Submission: Carer Inquiry

My name is Faye and I live in Western Sydney NSW, I am the mother of two little boys who have a disability, Jack aged 8 and Ben aged 5. Jack and Ben have a severe complex disability, Chronic Lung Disease, hearing and vision impairments, they are unable to walk, sit up or communicate, Jack is fed via Gastrostomy Tube as well as orally. Both boys require full assistance with every aspect of daily living, they require full assistance with washing, dressing, feeding, mobility and both wear nappies. Jack is often very ill, he has Cyclical Vomiting Syndrome and a very poor immune system further complicated by his Chronic Lung Disease. Jack and Ben have a sleep disorder and we have many sleepless nights.

Despite all of Jack and Ben's difficulties they are very happy, interactive and bright little boys, they love going Horseriding at RDA Nepean, visits from Pets as Therapy, watching Cartoons and going on days out, especially to the beach. Jack and Ben enjoy life very much and we strive to give them a good quality of life, this is constant hard work and we often feel exhausted - both physically and emotionally. We have often felt like giving up.

Jack and Ben are amazing, strong, intelligent and resilient little boys and we are very proud of them, they find happiness in the simplest things most of us take for granted, they often spend most of the day giggling and laughing, they love school and get very excited in the morning when getting ready for school. Jack and Ben are very warm and affectionate little boys, they love cuddles. Jack and Ben deserve better than the pitiful amount of assistance currently on offer from State and Federal Governments.

I have often said that the most difficult aspect of having children with a disability is not so much having a child with a disability as such but having to fight to the point of exhaustion and despair for services and supports which should be freely offered by Government to parents and carers in our situation. I have heard many people say this. By no means is life easy but it is made a whole lot harder by bureaucratic red tape and the simple absence of funding in the area of disability. When it comes to disability I have seen very little from successive Governments in the way of **empathy, compassion and human decency**, it is an issue that has simply been ignored and neglected to the detriment of so many families and children.

SOCIAL ISOLATION

I believe that disability is a major Human Rights issue in Australia and that a **social apartheid** exists in our society between those who have a disability and those who don't. There are glaring inequalities. I am stunned that a relatively wealthy, developed country such as Australia refuses to acknowledge this issue and do better. How developed are we if we can't offer more support to those with disabilities and their families? In comparison with other developed countries Australia is decades behind in terms of disability **social policy**, support and services offered to people with disabilities and their families. This week my children have "cabin fever", it is school holidays and my Husband is at work, how am I supposed to take two children in wheelchairs out on my own? This is socially isolating for me and my two children. We can't afford to pay someone to help because we get such a paltry amount of assistance from the Government and already struggle to make ends meet. We are simply housebound for the duration of the holidays. It is very depressing and demoralising and I am not surprised there are so many "blocked beds" in respite centres, where Carers have simply burnt out and given up - relinquished care of their loved one as a last resort.

SOCIETAL ATTITUDES

My Husband and I worked for a few years in the UK in the disability sector, the services and supports offered here pale in comparison. There is far less funding and choice. Services here are **totalitarian** in nature, people are **told** what they need (never asked) and patronised by those working for services. Services and sector workers often embark on a power trip and for some reason lord it over people with disabilities and their families. This is best summed up by a friend of mine who was told by a Homecare co-ordinator "you should be grateful for the services you get." Complaints about such treatment often lead to further victimisation. I have encountered attitudes like this many times in the past few years and have often felt bullied, harassed and discriminated against especially after speaking up, on one occasion I spoke up about the behaviour of a staff member and had the service withdrawn. I have often wondered why such awful attitudes exist within the sector in Australia and I've concluded that these attitudes exist because of how disabled people and Carers are perceived in general in Australia. I rarely ever saw attitudes like this in the UK and I believe this is an aberration here because of how the disabled and Carers are treated - we are exploited, ignored, told what we need and when we need it (never, ever asked) and taken for granted by Government - why would we expect services to behave any differently towards us. The Government don't exactly model appropriate behaviour towards those with disabilities and the rest of society just follow the leader. Services here would benefit from learning the concept of **anti-oppressive practice**, disability workers in the UK are taught such concepts. "**Choice**" and **self-determination** feature big in all service policy and are the backbone of disability policy.

The UK recently ran a media campaign using characters from the "Creature Comforts" series, this was aimed at increasing the profile of people with disabilities, no such campaign has ever happened here - why? Because no Government has ever deemed disability an important or valuable enough issue to warrant a media campaign and the spending of money. I have never seen an Australian Government with an ethical, moral approach to this issue. Governments have refused to acknowledge the issue of disability - how utterly unethical and morally bankrupt. To ignore probably the most vulnerable members of society. I believe here we have tried to administer disability services on the cheap, most other developed, progressive societies have accepted that disability supports are as crucial part of social policy as healthcare and education, it will never be cheap - it will always be essential and necessary not to mention the decent and right thing to do. Whether or not to adequately and properly fund the disability sector is not a choice.

THERAPY SERVICES

The last couple of years has seen an erosion of the very services that are meant to assist and support Jack and Ben in reaching their full potential, The Department of Ageing, Disability and Homecare (DADHC) have downgraded therapy services to children like Jack and Ben. Where they used to have access to a Multi-Disciplinary team including a Caseworker, Physiotherapist, Occupational Therapist and Speech Therapist they are now barely able to access any therapy at all. Jack and Ben have not seen a Physiotherapist for about a year despite needing this service, we have been forced to source this therapy privately at \$140 per hour. We can ill afford this. It will simply plunge us deeper into debt. But what choice do we have? The State Government no longer deems my children worthy of this investment, and therapy is an investment - it enables a child to reach their full potential and shouldn't we all want that?

Last week Jack's Speech Therapist closed his service. I disputed this and was arrogantly told by this out of touch therapist from DADHC "Jack has met his therapy goals", these were never goals I set for him. Jack is still not communicating in any way so I fail to see what goals she is talking about. My goal for Jack is for him to communicate. This incident cemented my resolve and belief that parents and not out of touch so-called professionals should be able to exercise some control over what services their child receives. Incidentally this Speech Therapist had merely handed me "therapy plans" at the few appointments we had, she never did any face to face therapy with Jack. Ironic really when you think this referral was for

“Communication” and she never once communicated with Jack. This would be funny if it wasn’t so ridiculous and detrimental to Jack.

I believe a model of funding where a parent is given a certain amount of **autonomy** over their child’s services is the more sensible and cost-effective (value for money) approach. The old fashioned over-bureaucratic funding model that is currently in place - where services dictate and have total control over what a child receives should be replaced with a more progressive funding stream such as the “In control” model operating in the UK. Families are given different amounts of funding to be spent on different supports, for example a parent is given an amount of funding to be used solely for therapy, the parent can then choose what therapy would benefit their child most and purchase this. **Self-determination** is the basis for this model of funding. It would be a more cost-effective model as much of the bureaucracy and infrastructure that is currently spent on Government-run services could be re-directed into actual appropriate face to face services for people. Effectively cutting out the middle man. Many families express a need for more **control** over the services their child receives. More value for the dollar would result if a parent could also choose services specific to and targeted at their child’s needs and choose a therapist who understands a child’s needs and would be of the utmost benefit to the child. Currently we have no say whatsoever in what services our children receive. Therapy needs to be **outcome based** rather than simply rationed by totalitarian **bureaucrats**. I believe the DADHC Community Support Teams are not supporting families adequately, any small bit of therapy is tokenistic, these teams should be abolished in favour of a therapy package. Many families with disabled children say that they feel they have little or no control over their lives - this would be a mutually beneficial way of handing some control back. A more dynamic approach needs to be taken in terms of therapy, the “therapy plan” based system used by DADHC is simply outdated and an inappropriate use of resources.

RESPIRE SERVICES

Flexible respite - currently DADHC funds flexible packages, a non-government service such as Sunnyfield or Anglicare is given an amount of money to control (administer) on behalf of the client, how much easier (and cost-effective) it would be if we could cut out the middle-man and give the parent control over this package themselves. So much money is wasted in the actual “administration” of these services that simply isn’t necessary and often more hassle for a parent. A more autonomous and progressive model should be adopted as a choice for families. So much of the dissatisfaction with services simply would not occur if more choice of supports and control within services existed. It would also be less stressful if families did not have to “beg” each year for these services, currently families are assessed each year and **given points** how patronising that a Carer is “scored” an amount of points whereby more points are scored if your marriage is breaking down, more points if you are depressed, more points if a family member is dying! This is utterly abhorrent and I can not imagine any other Government but the NSW Government administering such a heinous system. I was informed that my children scored 27 and 29, I had had no input whatsoever in this process, it was carried out by someone who barely knows my family. Families have no input into this process just to add further (patronising) insult to injury.

CARER PAYMENT

Australia is certainly not the lucky country for those with a disability. We struggle financially as we are unable to get much in way of support. Interestingly most of the eligibility thresholds set by the Rudd Government for assistance were **\$110-\$150K**, indicating that the Rudd Government viewed households on more than this not to need any assistance, the Carer Payment threshold is **\$65K** – another glaring inequality, without even considering the additional costs of a child with a disability, we spend so much money on special food, medication, medical expenses, petrol getting to the frequent medical appointments, the list

goes on.....I have to report my Husband's income on a fortnightly basis and my Carer Payment is adjusted accordingly, most of the time I receive \$0, sometimes I will get \$6 or some other pitiful and insulting amount. We are not on a high wage yet we receive very little assistance. The threshold for the Carer Payment should be increased in line with other thresholds to \$150K and a component should be non-income based, taking into consideration that a child with a disability needs many things that are very expensive. Even better would be a non-means tested Carer Payment - actually acknowledging the hard work and sacrifices of the Carer themselves.

The Child Care Rebate is now quite high yet childcare is comparatively affordable, childcare happens in a group setting and so is relatively affordable for a working family. A Carer of a disabled child has no such luxury of having affordable care for their child so they can go to work. Another inequality.

CARER ALLOWANCE

I know many people who are in receipt of the Carer Allowance - it seems to be a payment that is very easy - maybe too easy - to meet the eligibility criteria for. With my two severely disabled children who require full-assistance with all aspects of daily living I receive no more financial assistance than a family whose child has asthma or a partial hearing impairment, because my Husband earns just under the \$65K threshold. This is very unfair and does nothing to acknowledge the hard work of parents like us whose children require full around the clock assistance - 24/7. It is grossly unjust that because a person has a child with a disability they are expected to live in abject poverty - and if one parent chooses to work and contribute to the economy as a tax-payer they are penalised. I receive the \$1000 Carer Payment Bonus, the same as people who have only one child with a disability yet we have **double the costs** having two children with a disability.

MOBILITY

The UK has a system to support the mobility of people with disabilities, people receive a "**mobility allowance**", this program is aimed at decreasing social isolation and it works. Families are able to receive assistance with buying or hiring a wheelchair accessible vehicle. I had to write away to charities for this assistance, we were luckily and kindly helped by a local Leagues Club and The Variety Club to purchase a double-wheelchair converted HI-ACE. Most people aren't so lucky. www.motability.co.uk

ACCESSIBILITY

I am stunned that a country as wealthy as Australia still has train stations without disabled access, meaning that if you have a disability and live near one of these stations you have to travel to another station further away from home just so you can get onto the platform, these scenarios should be legislated against and disabled access should - in 2008 - be mandatory.

HEALTHCARE

I would like to see a system of subsidised healthcare for Carers, Carers are recognised as having poor general health. I have a disc prolapse in my back but can little afford the necessary Chiropractic and Osteopathic Treatments needed. I attend Yoga classes and can barely afford this. An incentive and assistance needs to be given in order for Carers to remain as healthy as possible.

ADVOCACY

The area of Advocacy is a minefield and fraught with inconsistencies and conflicts of interest. It's interesting to note that to date no Government has agreed to fund actual family advocacy such as The National Carers Coalition. Governments instead continue to fund "professional advocacy" organisations most of whom advocate only for their repeat funding the following year and are **fundamentalist** and unyielding in their ideologies. I could not get a decent advocate last year to help me deal with DADHC. Proper family advocacy needs to be funded - an organisation made up of Carers such as the National Carers Coalition.

DISABILITY EQUIPMENT

How shameful that children wait for years for essential equipment such as **wheelchairs** in NSW. This area is chronically underfunded. My youngest son Ben has severe Scoliosis which has been caused by - or exacerbated by - the prolonged wait for a supportive seating system in the form of a powerchair. Many families apply to The Variety Club - yet another case of a charity doing the Governments work and families having to beg.

SPECIAL SCHOOLS

Only a Special Private School has access to therapists, we applied for Alice Betteridge in North Rocks however my son did not meet the entry requirements - only a few children a year are accepted, why then does the public school I send Jack and Ben to not have access to all of the therapists on site and the better ratio of children to teacher that Alice Betteridge does. In the last couple of years Jack and Ben's school has increased the class ratios and now they have 6 children to one teacher and one teachers aide. This is appalling, 6 children in wheelchairs who require full-assistance all day - how are they ever expected to ever learn anything? Are Jack and Ben no longer deemed worthy of a proper education?

HOUSING

Housing is barely affordable for families on two wages, how are families on one wage expected to be able to afford housing in Sydney? Exemption from some of the taxes that apply to housing such as Stamp Duty would be a great help for Carers.

TAX

Provisions in the tax system given to parents with dependents should extend further and the threshold for income tax should be increased for parents with disabled children.

QUALITY OF CARE

Service quality needs to be improved, we have had several occasions where care staff have smoked around our children, Jack and Ben have Chronic Lung Disease and so this is very dangerous. I have also had a staff member telling my son to "shut up" when he was crying. My son had his birthday money stolen by a Homecare worker. All of these issues are bad enough however they are made worse by a system where my children have no legislated rights and complaining simply attracts further victimisation and in some instances service withdrawal. Services need to **implement** an ethical and legal framework - not merely have it written into policy.

THE IMPACT OF CARING

It is not surprising that 80% of marriages break down where there is a disabled child, sadly this is simply because of lack of supports from Government. The Rudd Government like to talk about "working families", yet if you are a "working family" with a disabled child you don't matter. As Parents we are discriminated against, how is this not the case when Foster

Carers are supported so much better? Through no choice of our own we are on a single income with very little Government assistance.

Earlier this year Kevin Rudd apologised to the Stolen Generation for the fact they had been disempowered and disenfranchised by Government policy. Is this not also the case for people with disabilities and families with disabled children? Instead of forced removals of children families with children with disabilities are often faced with no other choice but to - out of complete despair and desperation - reluctantly relinquish care of their children to a system that simply does not care and Governments that so far have had no heart. Disabled people and Carers are simply treated as second class citizens, in 2008 that is hard to accept.

PRIORITIES

The top priorities for my family would be to:

1. Increase the threshold of the **Carer Payment** in line with other Government payments (\$150k) or remove the means test altogether.
2. Stagger the **Carer Allowance** to give more support to families who provide very high 24/7 support.
3. Fund **proper therapy** for children, abolish the tokenistic "therapy plan" based model where a therapist merely gives a piece of paper telling the Carer what they should do. Give parents some control over what services their child receives.
4. Fund proper **advocacy**. Advocacy by Carers for Carers.
5. **Ratify the UN Convention** on the rights of the disabled person. Thus committing to a legal and ethical framework ratified in many other countries - including many developing nations such as Bangladesh and Namibia. Surely a country as wealthy as ours can keep in step with these poorer countries.
6. Implement and enforce ethical and legislated **standards** in the disability sector.
7. Adequately fund disability **equipment** such as wheelchairs.
8. Decrease class sizes in schools and add supports such as school based therapists (Physio's, OT's, Speech Therapists)
9. Carer contribution and consultation. Carers never have an opportunity to contribute in any meaningful way - actually in no way at all - to policy. The "everything about us, without us" phrase is correct. We have NO voice when it comes to policy and planning - probably a reason why services are such a bureaucratic minefield and resources are mis-directed and misused.
10. Healthcare subsidies - a system of subsidised treatments should be available for Carers. It is recognised that Carers have very poor general health, any assistance that could be given here would be of great help - subsidised gym passes, massages, Chiropractic treatments, etc. In order to keep Carers as healthy as possible.

Thankyou for the opportunity of providing this submission.