This is an informal submission, though since I have received the email about this tonight I have replied to the email sender that I am willing to become part of a formal submission process with a local care group or even a group of groups in combination as a single submission. Where the heck was the broadcast for we the affected public to know this was happening and to provide the productivity commission with a broad response??????

Secondly, can I say the national disability insurance scheme is the most sensible and kind suggestion I have ever heard towards those of us who have been unfortunate enough to have children who were born or through a shocking accident have became permanently dependent on parents and the community for simple life needs such as food, clothing and a roof over the head? I only wished I had thought of it!! It costs the community such a small personal contribution for such a broadly received benefit.

Thirdly, I would like to wholly agree with the submission of another family's ideas who have actually spent the time to read things though properly with this whole proposal, time being something I am acutely short of:-

> **I agree** with the Commissions' position that *"First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the natural process of ageing.*[1] *"*
>
> **I also agree** with the Commission that "*Second, the scheme is not intended to provide services to all people with disability, many of whom may need no or few supports. Rather, the scheme is intended for those in significant need of support. These would be mainly drawn from those with severe or profound disability,*[2]
>
> If support was spread too widely to include people requiring only mild support it would dilute the resources available for those with serious needs.

I am married, though I have divorced the father of my three children. My ex-husband and I gained our eldest daughter who has a rare syndrome called Cornelia De Lange Syndrome. She has the intellect of approximately 18 months old (at best), has internal digestive system and skeletal deformities, cannot talk, walks with assistance (since 7 years old), can feed herself with a spoon from a bowl, can drink from a cup with help, needs assistance with toileting (and defecating in the bath if I don't keep watch is the worst of it), cannot tolerate crowds and has general autistic phobias.

I live in Central Queensland and any services that used to be available have been retracting at a rapid rate in the past three years – even though the population has been expanding equally rapidly due to mining expansion. An organisation that was once able to give me a measly 3 hours respite per fortnight so I didn't have to cope with my daughter screaming and linging herself to the ground when she had decided we had visited more than the 3 shops she can cope with at a time, had a new CEO come on the scene - who suddenly decided that the constitution did not include anyone under the age of 18. All services ceased with a single letter in the mail.

It seems to me that there is a lot of funding and assistance when the child is young in the hope of preventing disability from progressing, but once the child is of an age where it is obvious that absolutely no intervention is going to change the progress of the child, funding almost ceases by the time the child is about seven. Government sourcing almost comes to a halt – including Rudd's initiation of disability and ages services. I was told when I visited the office of such in reference to the ceasing of services from the community service provider referred to below (which had an office some 20 metres away) that they "mostly provided for the aged care of the community".

The only overnight respite 'house' I once had access to has become so paranoid about dispensing medication that I threw the towel about 3 years ago in after one too many arguments with the poor carers who were badly trained on what to do/not to do. If I had to turn up to give my daughter medication and then walk away again the confusion and pain for her was too much for me to bear.

Disability Services Queensland (DSQ) is an absolute shambles. It is merely an administrative department for all of the community service organisations that receive funding from it. There is an enormous amount of staff working within it, providing a travelling road show to regional Queensland approximately every two years asking for our input on how they could improve services for us.

We never ever hear anything back.

We only view the next road show advertised profusely in the local newspaper for months in advance, and nothing ever changes.

On one occasion a one of these meetings ended in such acrimony from a parent of a blind daughter that he had to be physically removed from the room by other parents - such was/is his level of frustration.

To give you an example of the administrative nightmare and level of paranoia we have to deal with when it comes to DSQ, I'll provide the following story.

> Three people from DSQ plus a staff member from the now defunct respite service mentioned above visited my home to discover for themselves whether my daughter really needed care and whether I needed respite, and to decide whether my home was safe enough for an employee to enter the premises. This involved three separate visits including an OH&S Officer who inspected the house and yard.

During the OH&S's inspection (and this was a separate visit again) she advised that I should put in an application to have my three steps at the back door converted to a ramp and that DSQ would be able to assist me.

I followed up this suggestion and filled in approximately 45 pages of application, which included reports from her doctor and paediatrician (read = cost) on her future prospects of improvement or lack of.

I duly sent off the form to be informed by phone call that I had missed out on funding this year because other people were in need of more urgent assistance, but would I consider putting in another application?

I did so because it was the beginning of a new financial year and could see the validity of the reason to put in another application – with fresh forms from her doctor.

I received a phone call that I just might qualify for that recommendation from the OH&S Officer, but first I had to get three separate quotes from three separate registered builders WITH a Physiotherapist or Occupation Therapist present for each quote. I couldn't believe what I was hearing. A **quality** registered builder does not quote on replacing three steps with a ramp. They build HOUSES for pete's sake.

In addition (and I hope my recollection is correct here because it was about 4 years ago) I was told the following:-

- If the job was to be less than $1000 I was to apply to community service organisation (a) for funding
- If it to be more than $1000 but less than $1500 I was to apply to community service organisation (b) for funding
- If the job was to be more than $1500 but less than $3000 I was to apply to combined community service organisations (b) and (c) for funding
- If the job was to be more than $3000 then I was to apply to DSQ for another funding process in collaboration with applying to community service organisation (c).

I refused the application affirmation.

I was then practically *harrassed* by the DSQ case manager to pursue with the funding application.

I told her to throw it in the bin.

I am lucky enough to be a person who has consciously made a life outside of my daughter's disabilities, but I have until 2015 (when she turns 18) to have a job secure and well paid enough to have a carer look after her, or find services that will occupy her during the day whilst I am work that I can afford to pay for. I am currently studying full time to further my prospects toward that goal.

I refuse to entertain the thought that I will have to quit work for the rest of my life simply so someone can be with my virtually helpless daughter once she has turned 18. She does not even have the intellectual level to be enrolled and re-enrolled in TAFE courses that might enhance her future employment prospects (another idea from Qld government that looks good on paper for young people over the age of 15 or sp and satisfies Centrelink requirements) for years at a time – which I understand from contact with local TAFE staff recently is a standing joke amongst staff. The joke is not against the disabled, they adore them and feel sorry for them being trapped in 'the system' – the joke is about bureaucratic intelligence on how these schemes work in a real life situation.

My biggest concern about my very near future is somewhere else for my daughter to live or at least stay at for some part of the week so I can lead a normal life – you know – a *social* life. I am doing the best I can to make sure I have a house that she may live in and possibly have other boarders pay rent, because DSQ processes seem so arduous that I don't even want to start the application process. I will lose my cool. But I will virtually have to become a house manager to ensure things run smoothly and I will have to employ people to be present to make sure all who are living there are being looked after and are looking after themselves more than just adequately.

Transport - I had the support of the local taxi service for four years to pick up my daughter and take her to school in the morning until 18 about months ago when I moved address. There are three parties now involved in transporting disabled children here in Qld - Dept of Education, Department of Transport and the taxi company. Because I changed address, the whole situation was thrown into chaos. Without a form filled in and sufficient notification to Dept of Transport (Qld) the taxi company could not legitimately pick up my daughter from my new address. If the Dept of Transport didn't have prior justification from the Dept of Education to notify the taxi company it too was paralysed to change the request details to the taxi company, so any urgent requirements for other family needs were totally disregarded because the paperwork wouldn't justify the change in enough time for departmental time frames for that required justification. Too bad if there was a family emergency where the taxi picking up the disabled child would have been a godsend! It takes weeks to have a change of details recognised. I no longer have a taxi service pick up my daughter for school (which was considered a life skill for her future) because the arguments involved became too much to cope with. It is easier if I just be late for wherever I have to be and hope I don't get too much flack.

I am absolutely in hope that the federal system takes over the current state system of 'sharing the money around' and thereby restricting rip-off for value of money given to shady providers.. I used to be involved in the (Qld) Medical Aides Subsidy Scheme (MASS) run by the state government for nappies. It would take 4 – 8 weeks for the faxed application to be acknowledged and the rules changed so often that often 4 to 6 weeks *after* the application for 6 months funding had been sent I would receive a phone call to say another form had to be filled out, or the school nurse needed to put in a signed form, or the paediatrician needed to fill in a form, or her doctor or *someone* needed to proved further justification! I signed up for the Commonwealth Aides Subsidy Scheme and after my first phone call I received 6 months supply within 3 days. It was beautiful, and such a relief after dealing with Qld's version - MASS.

SUGGESTIONS:-

We need ***housing, housing, housing***. And as much as the do-gooders see it as a wonderful process for the disabled to live independently in their own ‘home’ I fret a lot about the carers who are left on their own or to their own devices under the current scheme of independent housing where one carer is left with four totally unpredictable adults who have severe deficiencies in cognitive skills. I want a return to the ‘terrible’ old ways where there is an institution similar to aged care homes and care, medical attention, emotional and intellectual stimulation activities and social interaction for the similarly dysfunctional are planned and funded for. Civil libertarians? They’re idiots. They don’t live it. They just observe it and make recommendations for the benefit of one (the disabled), not all (the rest of the family and the community in the streets who have to face the runaways from these set ups).

I understand that here in Queensland a process is underway where if the family of a disabled person is submitting an application for their disabled person to obtain public housing, they must submit something akin to a ‘future plan’ for the person they are applying for. This takes an enormous amount of time, effort and the cooperation of extended family members and friends,(to some extent) legal and accountancy advice for financial and death benefits of the disabled ‘child’ should the extended family cease or become disinterested, includes nominated persons who will look after financials, job prospects, wages and payments, carers, medical needs, etc. I am appalled but apparently this proposal is to be finalised by the Qld department for public housing by July/August of this year 2010. I do not know whether a decision has been made yet.

National unity on disability carers to be paid an <u>adequate wage for the emotional and physical toll they must endure</u>. Currently they seem to be paid around $12 - $15 per hour if they are simply a caring for a disabled person. Not only does this put off those who have a genuine interest in caring for people who aren’t of the ‘normal’ stream of society, they can’t afford it. An aspect that also needs to taken into consideration is the level of injury these people often endure because of the physical and emotional strength of the disabled person that they are looking if they become unmanageable. These injuries prevent them from obtaining future employment and the lack of support and recognition of the source of the injury often prevents them coming back to the industry of looking after the disabled – particularly the emotionally and intellectually disabled. They are looked down upon and almost feel shame in dealing with the disable and yet their lives are changed because of the injuries they have sustained because of their job.

I want the following statement to be considered and dwelled on: - because of the low wages paid to disability workers, **working with the disabled also attracts people who can’t get a job elsewhere and are decidedly whacky themselves.**

Case managers provided with realistic workloads of contacting families, proceeding through a lists of assistance programs with well defined support services who has personal contacts, using a computer data program that includes **time allocation for simply researching client**

personal needs and does *not* include offensive questions for parents of young children that ask *"does the client smoke or take drugs*", *"is the client sexually active or promiscuous"*, *"does the client have an alcohol dependency"* such as certain DSQ funded organisations.

Choice by the client on how funding will be spent. Because everyone's needs are so different and individual, we should not be forced to use service providers chosen by someone who has no personal knowledge of what the disabled person needs. It is currently an industry of favours and favoured people/organisations that receive an enormous amount of funding that is chewed up considerably by administrative costs. This is a complete waste of taxpayer funded monies.

A once and once only recognition of disability that should not be means tested as "an across the board" state and federal government department recognition if the disability is absolutely and without any uncertainty going to be a lifetime infliction. Current electronic communications systems can allow this to happen. A nationally recognised system would also assist the many paid-for services provisions that we gain from doctors, remedial practitioners etc who have to spend time to fill in all of the paperwork requirements to prove that the person we/them are dealing with *really has a disability*. The current system is incredibly arduous for everyone concerned.

On a personal note, I have refused to go through the time, expense and seemingly dozen or so contacts from whom I must provide proof about my daughters condition simply to have a disabled parking sticker allocated to me. I have endured three confrontational verbal attacks in the past three years from those who have nothing better to do than 'police' disabled parking in streets and parking lots - though I must admit I gain intense amusement at their discomfort when I lean in and help my daughter get out of the car and they catch sight of her.......

I absolutely hate to have to put this to paper put **productivity reports from in-home childcare service providers**. There is a state run in-home childcare service here in Central Queensland where the organisation specialises in gaining services from people who will look after your child in your own home. However, phone call after phone call and email after email fails to get a response. I don't know what the coordinator does with her time but she certainly doesn't look for employees. One of the carers that I was able to have arrive said she was called by the coordinator after she advertised that she was looking for work in the local paper. ????..

Updates of changes to disability services sent out to the client or their carer similar to the Child Support Agency or Centrelink. Centrelink brochures currently really focus on Centrelink issues.

Transport specified toward those with disabilities. My daughter will never drive a car, but those who need to buy a car and then outlay an enormous expense to have the car converted who should be fully funded. Centrelink demands are currently geared towards having the disabled prove through a vigorous process that they do not have the physical and intellectual capacity to be employed. If the disabled person is proven to have capacity, or wishes to have personal means to be employed then they should be fully supported in having a vehicle modified to help them live an independent life. Let's face it – there isn't a bank in Australia that will provide a loan without someone else's security being put up for a car to be converted to enable a disabled person to drive it.

A recognition that emotional and financial resources for parents and carers of the disabled is exhaustible. Just imagine what society would be like if every single family had to put up with for the whole of their/their child's life looking after a baby – who is as large as an adult. We get tired, we get upset, we feel there is no light at the end of the tunnel until death – who dies first doesn't make the searching for the light any easier. As a matter of fact, most of us live in paralysed fear on what will happen when we die, because no-one in our family wants to take on the burden of our disabled child once we are gone.

****

The downside of being a parent to a child who is born with a disability is personal shame at not being accepted by the general community versus the personal pride we feel at our child reaching what seemed to be an unobtainable goal (it is very hard to gain genuine excitement from the parent of an ordinary child when your own child first walks at the age of 7). We suffer high statistics of emotional breakdown, marriage break up, suicide, a sense of hopelessness because there is no light at the end of the tunnel.........

> ***Nobody can know or understand the level of entrapment we live in unless they live it too.***

I go back to my opinion of those civil libertarians who shaped the current format of care for the disabled, and the fact that they don't live it. If I had had a crystal ball back in the 80's when it all seemed such a good idea, I would be throwing frisbees of information left, right and centre. The idea of independence and community support/acceptance seemed good at the time, but with our current 'age' being totally out of control by 'keeping up with the Jones' consumerism and image reward wins hands down. Community is seemingly even less tolerant of those who are 'different' now then it was then.