August 2010

Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Dear Commissioners

RE: Inquiry into Disability Care and Support

I applaud the Government's asking the Productivity Commission to inquire into Disability Care and Support, and thank the Productivity Commission for the opportunity to make a contribution.
I apologise for the slight delay in finalising and sending my submission.

Background

By way of introduction, I am the parent of a profoundly disabled daughter, who is twelve years of age. My daughter's disability falls into the broad category of 'global developmental delay'.

- She requires assistance with almost all aspects of her life.
- She is not able to talk or use conventional alternative communication for people with disabilities. (She communicates her needs through her own personal indicators).
- She is not able to walk. Although she is in a wheelchair she is not able to use it independently.
- She requires assistance with all aspects of her personal care, including eating, bathing and toileting.
- She has a cortical vision impairment. This means that her eyes are healthy, but her brain finds it more difficult to process the information she receives visually.

Yet like other twelve year old girls, she loves music, enjoys chocolate, likes to look at herself in the mirror, and is self-determining to a certain extent. Over the last five years she has learnt to crawl and she crawls around our house as she pleases, in order to play with some of the things she most enjoys (tambourines are a favourite). Despite her age, we encourage her crawling as it builds her strength and coordination. My family and I love her dearly.

My daughter's disability was not present at birth. I had relatively uncomplicated pregnancy, other than a threatened miscarriage, and my ultrasounds had all been healthy. My labour was difficult but not completely unusual. Yet discussions with medical professionals have been ambiguous and to this day I wonder whether I should have questioned more and investigated possibilities; of course, at the time I was coping with a major life trauma.

In the weeks that followed my daughter's birth, she failed to thrive due to difficulty feeding. Initial failures to meet milestones were attributed to medical 'failure to thrive'. It was only after she was six months old that comprehensive blood testing was completed, which all came back clear.
At around ten or eleven months of age she had an MRI of her brain which showed an underdeveloped corpus callosum and hypomyelination. We have had genetic counselling on a number of occasions over the past 12 years but at present our daughter is in the 'too hard' basket.

At this point I would like to outline some of the difficulties I faced at the early stages of realisation of my daughter's disability. Following our paediatricians pronouncement that she was indeed permanently intellectually disabled, we were very much left to navigate the maze of disability life by ourselves, unsupported, save for some family members and close friends, and the kindness and understanding of some of our daughter's initial therapists. We had referrals to a multitude of specialists (neurologists, ophthalmologists, and others) and fortunately most did not involve much out-of-pocket expense (because our daughter's diagnosis entitled her to a Health Care Card) though the time, petrol and parking was indeed considerable. No medical practitioners alerted us to possible assistance we could receive. I do not wish to cast aspersions on them for this as they cannot be expected to know everything. However, it does highlight the lack of information surrounding disability services, and the need for a contact or centralised assistance from one point (rather than a confusing plethora of places that may or may not be funded or resourced to provide assistance). The confusopoly added anxiety and pressure to an already extremely stressful situation.

Fortunately we were able to access limited physiotherapy, speech therapy and occupational therapy through government-run agencies (which were, unsurprisingly, under resourced), extremely limited dietician services through a hospital, and visual therapy through a non-government organisation. Even 12 years later, we only recently discovered that our daughter is eligible for assistance with her continence products. (We have been purchasing them ourselves - with no relevant tax deduction for medical expenses.)

Sometimes disabilities can be the result of particular behaviours. For ourselves, our daughter's disability was particularly frustrating because we did not have cause. We had lived clean, drug-free lives; I did not consume alcohol during my pregnancy; and there was no history of genetic conditions in both our families. As one of our doctors said, this was a completely unexpected and unanticipated tragedy. We do not see it this way now, but at the time our world fell apart.

In decades past, a child such as my daughter would have been institutionalised from a young age. She would have lived with others with similar conditions, with around the clock carers. I would not wish this for my child; she brings a beautiful dynamic to our family life that I would not have appreciated before having had her. In addition, given some of the stories that have emerged about events that have occurred in institutions, I would not risk her wellbeing.

However, despite savings delivered to governments following deinstitutionalisation and moving to support people with disabilities to live at home, it does not appear that governments have provided commensurate support to families and carers supporting children and adults with disabilities, and certainly not on a per capita basis.

Our experience of disability funding and support services

As you are no doubt aware, disability funding in Australia is fraught. Underfunded organisations are all forced to compete for a slice of the disability funding 'pie', and many go hungry. Unfortunately the pie simply isn't big enough to adequately provide for all; there needs to be larger pie. I will come to specific areas of deficiency later in this paper.

My daughter and our family are ones who miss out completely on many disability funding opportunities because there is not an organisation to argue for programs for those without diagnoses, no matter how severe their disability, and we are unable to access services in other programs as she does not have such a 'label' (of autism, cerebral palsy, Down syndrome, etc). 'Global developmental delay' can apply to someone who is able to walk, talk and self-care, if they are behind their age group in all areas of their development.

Fortunately, we were able to access a couple of Territory-run limited grant programs, which helped purchase our daughter's $8000 wheelchair, and provided assistance in purchasing some other necessary equipment. We also received a subsidy for our bathroom renovation to make it wheelchair accessible. Most notably, we are able to access subsidised respite care services. We use these services only occasionally, because we want to include our daughter in our family life, and we are mindful of the many unmet needs in this area and don't wish to deprive others of much needed respite, particularly single parents (who tend to be the norm for families of a person with a disability).

We feel fortunate that our daughter's disability, while stressful, does not entail some of the added burdens of significant behavioural issues that can accompany some disability conditions. That said, both my husband's and my families live in South Australia so we do not have much in the way of support networks where we feel comfortable to ask for assistance. In any case, my husband's family would not have the capacity to assist much and my own parents live rurally so assistance (especially in emergency situations) has always been difficult. We are currently establishing a 'Circle of Support' for our own support as well as providing for our daughter's social needs and future direction.

As flagged, we have borne significant extra costs because of my daughter's disability, such as medical appointments, continence products, equipment, bathroom modifications, respite care (which is admittedly subsidised) to name a few. In addition, we have also had to face a number of opportunity costs. We are unable to do many things that other families do regularly (such as go hiking, certain holidays, or to a film or theatre production), for which I feel deeply for our other children. Career opportunities are somewhat limited by my need to stay where I can work suitable hours, particularly as after school care places for disabled teenagers are almost non-existent due to very high demand (and until relatively recently, no such services existed). Down the track, I am aware that I will not be able to continue my career, as I expect I will have to care for my daughter after she leaves school. There will also be tangible costs related to this, as our family income stream will be restricted. Day care places for disabled adults are rare and have a considerable cost. At present we are planning ahead for the option of a small business, similar to 'Jackmail', which disability advocate Sally Richards established for her son.

Some disabilities result in significant compensation paid by motor or medical insurers, work cover, negligent businesses, or the government. At times I have applauded this but at other times I find it rather frustrating that a culture of blame and a litigious nature is required in order to be compensated, particularly if the public bears the cost of the compensation. It is similarly frustrating that an accident victim can be compensated, even if the accident is their own fault, but an accident of human frailty is not a cost that is shared meaningfully by the community. Even some of the most neoliberal economists admit that certain incidents, such as the chance occurrence of a congenital condition, should not be borne by the individual but should be sustained by wider society.

A disability support scheme

We welcome support in the form of a long-term disability care and support scheme (I would be mindful of the implications of how such a scheme may be named – already there is some debate and controversy about the nomenclature).

Who should be eligible?

The scheme should include those who have untreatable, permanent problems in at least two core life skills (communication, self-care, and mobility). The priority should be for individuals who have untreatable, permanent problems with all three core life skills (an estimated 40,000 people – I apologise that I have not been able to locate the reference for this in time to submit this paper).

Eligible persons could practically and reliably identified by at least three health professionals, including at least two medical practitioners. This may sound cumbersome, but I am aware that access to such schemes could be open to abuse (in the same way that the Disability Support Pension has blown out in cost as people realise they could possibly benefit, and seek the professional advice to give the result they want). Ideally, this assessment would only have to be given once (given that it is for permanent conditions).

Recognising the bias of my own situation, it is my opinion that those with severe intellectual disability and physical disability are most in need. Constantly managing life while caring for either situation can be difficult, but with both intellectual and physical disability the strain is doubled – physically and emotionally.

In addition, from my daughter’s perspective, the social isolation she experiences (even in the company of family and friends) due to her disabilities and communication difficulties is a significant hurdle. For some reason, society appears to accept those with one or the other, but if one has both, it can be extremely difficult to integrate with the community (particularly as such children are usually educated in special education settings). Such isolation is not likely to be ameliorated in the future without pro-active inclusion and participation strategies, which a disability care and support scheme could assist.

With regard to reducing unfairness, a disability support scheme should avoid tying funding to particular diagnoses where possible. Within many diagnoses there can be a range of ability. Unfortunately there can therefore be some potential for a lot of unfairness surrounding this. As evidence, I would cite my own case, where as mentioned, we have not been eligible for a number of services (including siblings support programs) because my daughter does not have a ‘label’. The eligibility assessment should examine the particular abilities of the individual, and test them if necessary.

I am not convinced that some of the programs that are funded under the auspices of disability should be considered to be ‘disability support’. The Productivity Commission’s circular noted that disability that is the result of the natural process of ageing is not included in your inquiry. I agree that it is important to separate the issues of ageing to the issue of disability.

On a related matter, I am concerned that the word ‘disability’ has become cheapened by its appropriation by people receiving disability support pensions for ailments which can be controlled by medication, such as painkillers, or by people who experience disability as a result of their own life choices (for example, morbid obesity). While they should be given assistance to transcend their circumstances, I note that these are temporary ailments (or can be). I would similarly argue that many common mental illness issues are not suitable for ongoing support through the disability system. Although the evidence is anecdotal, I know people who have had a significant mental health issue that have continued to contribute to society through their work (albeit with some time off, alteration to duties or part-time working conditions), where they have had support through psychiatric help, counselling or medication. I also know of people who have taken advantage of the system to minimise their contribution to society or the economy and maximise their monetary benefits and relaxation, despite being completely functional in day-to-day life.

Who gets the power?

My family would appreciate an individualised funding program, to provide us with the autonomy to make decisions as we see fit for our daughter and our family. That said, better resourcing and implementation of services would improve choice in how we decide to allocate our daughter's own funds. If this discretion was given to us, service providers would have an incentive (rather than an obligation) to take greater account of people's individual needs, because as consumers of their services, we would have 'purchasing power'.

I am aware that some members of the community would be concerned about the lack of accountability for individualised funding programs. There are a number of mechanisms available to ensure that funds are not misused, including at the simplest level, the provision of receipts to the funding authority.

With regard to whether a person is in the scheme or not, or regarding the amount of financial support and services, appeal processes could be through an agency such as the Administrative Affairs Tribunal. If necessary, the AAT could order an appropriate independent practitioner to assess the needs of the person.

One final point I would like to make is that funding decisions should not be based on the resources of the family or carers of the person with the disability, but only in relation to the person with the disability. The reason for this is because parents and carers can die or become permanently incapacitated themselves. Funding needs to be available for the person with a disability, and their ongoing support and accommodation needs.

The decision about the amount of financial support and service entitlements should be decided by an Office of Disability Policy Coordination, similar to the Office of Indigenous Policy Coordination. I will discuss this concept further later in this paper.

What services are needed and how should they be delivered?

As far as I can tell, the services most in need of being increased or created are after school care programs for adolescents with intellectual disabilities, day care programs for adults with intellectual disabilities, supported accommodation for adults with disabilities, and support programs for siblings. These are all woefully under resourced. To this, I would add communication technology, equipment, continence aids and respite care services.

For our personal requirements, we prefer respite care services on an irregular basis. Overnight respite care almost always requires the person with a disability to sleep somewhere else for the night. If people so choose, overnight respite care should be able to be provided at home.

In addition, carers of people with disabilities should be able to utilise allocated respite care funds to appoint carers as they see fit. This is where individualised funding packages would be useful. For example, I would feel more comfortable asking a relative in Sydney (who has a relationship with my daughter) to look after her overnight if I could provide some recognition of her assistance or the time and travel involved to come to Canberra.

At this point I do not have much to offer regarding the coordination, costs, timeliness and innovation in the disability sector. That said, coordination of disability information would be invaluable to me. I am not sure how many hundreds (thousands?) of forms I have completed throughout my daughters life. Much of the information is repeated, but need to be provided to different agencies without central coordination. Moreover, I am often required to reiterate this information on a yearly basis to maintain a service, despite the fact that my daughter's disability is permanent and untreatable. I am required to keep returning to our General Practitioner to have forms completed, for disability service or if my daughter is to attend school excursions.

On another coordination matter, the cost of allied health service delivery could be greatly assisted by having allied health professionals in special school settings. I know much time is wasted by my daughter's occupational, speech and physio- therapists travelling to and from the school, where they are often seeing a number of children, when their time could be put to better use than driving.

Raising the profile of disability services is an important priority. Some tertiary institutions (for example, Flinders University in SA or RMIT in Victoria) offer degrees in disability. This should be encouraged and supported. The professionalisation of the disability sector will result in greater expertise and innovation in the disability sector. Moreover, this could become a potential career path for professional respite carers or disability support workers.

A new, revamped disability support scheme would provide greater options for families and carers of a person with a disability. A new scheme should foster both the carer's and the person with a disability's participation in the workforce and the community, by either assisting with care and support, or providing options for beginning a business for the employment of a person with a disability. Very importantly, it also ensures better inclusion of people with disabilities in wider society. I believe very strongly that people with disabilities should not be segregated from the community, and that it is just as important for the community as it is for people with disabilities, that this be the case.

I believe it is false economy for governments not to support participation of carers (such as myself) and disabled people in the workforce. Not only do governments then receive tax dollars that would otherwise not be received, they do not have to fund carer's pensions to the same extent, and there would likely be a reduction in respite required as carers have a life outside of their caring role. Supported work is normally cheaper with greater economic benefits than day care (though I perceive there would be spin-off economic benefits provided in both employing disability support workers or day care workers). More importantly, work provides self-determination and self-fulfilment for individuals, and benefits for the wider community.

Early intervention strategies should also be promoted and prioritised for funding where shown to be effective. The early intervention program my daughter attended was wonderful and assisted her in becoming more engaged with the world, but was under constant threat of closure due to funding limitations. Having said that, I am concerned that as with many government programs, there is the potential for waste. Evaluation and analysis should always be completed (even if it is long-term evaluation) to ensure early intervention programs are achieving results.

Similarly, evaluation and analysis of any public policy initiative should be accomplished, including evaluation and analysis of where and how any individualised funding packages are being spent to record 'market' signals of disability 'consumers' going forward.

The evaluation of the current system may be more difficult than with a 'purchasing' scenario, but a new system should begin with the Office of Disability Policy Coordination evaluating current programs to measure their effectiveness. Obviously, measurement is not an exact science, but feedback from clients of services should provide a strong indication. Successful programs should be maintained and developed where possible.

However, there will be times where market signals fail and this should be reflected in any analysis. For example, there may be issues around individualised funding packages for rural and remote area clients, where services may be few. Even so, I believe individual funding packages may redress some of the difficulties faced by rural and remote clients.

A new, centralised system would drastically reduce overlapping assessments, waste and duplication.

Funding

The most logical funding option would be to have a tax or levy, akin to the Medicare levy, for funding this scheme. I am mindful that politicians are always wary of ‘a new tax’, but I think there is considerable goodwill and momentum for such an initiative. If other citizens are reminded of the reality that disability can occur to anyone, anytime, they will understand and support the need for an ‘insurance’ scheme.

Organising and implementing a new disability policy

I consider that a national approach to disability is the most appropriate strategy. Like many areas of public policy, disability policy lacks strategic direction, is disjointed and fragmented in approach and resources, varying across jurisdictions. While harmonisation is an option, it can lead to fragmentation in the future. I consider that the best way to address disability services is for the States to refer their powers to the Commonwealth, and the Commonwealth has responsibility for disability policy and services.

I have mentioned earlier my proposal for an Office of Disability Policy Coordination, similar to the Office of Indigenous Policy Coordination. This Office would probably report to the Department of Family, Housing, Community Services and Indigenous Affairs [and Disability], or the Department of Health [and Disability]. This Office would have the legislative and regulatory requirements required in transitioning to a new scheme; providing a centralised contact point for those newly diagnosed as having a disability or caring for someone who has a disability; providing information, education and resources for these people; assessing the needs of people with disabilities, and their carers; deciding their eligibility for the ongoing disability support scheme, and their entitlement; ensuring there are adequate service providers; responsibility for service providers; the promotion and development of disability sector work, including training requirements and short-term solutions to staff shortages; other initiatives in disability policy; and interim service delivery arrangements prior to the introduction of national legislation.

I do not believe the process to a national disability support scheme need be lengthy. I think one year is a reasonable timeframe if the government allocates appropriate staff and resources. In the interim, States and Territories could plan to utilise resources planned in their forward estimates budgets, and the Commonwealth could reallocate existing budgets to the new scheme.

A disability support scheme is the most logical way forward. The main obstacle will be persuading politicians to have the integrity, conviction and valour to promote the scheme, without giving into fear about finances (which I have every confidence the Productivity Commission will model aptly). I have appreciated the efforts of our current Parliamentary Secretary for Disabilities and Children's Services in listening to disability groups and carers and for drawing attention to this issue.

I heartily believe that there is community support for such a scheme and that the Australian community will accept a new tax for such a worthwhile undertaking for their fellow citizens. In the words of Mahatma Ghandi, '*A nation's greatness is measured by how it treats its most vulnerable members.*'

Thank you for taking the time to read my submission.