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

(Personal Response – This submission contains no confidential material)

Disability is an inescapable reality which our family deals with every day. We have three sons aged 8, 6 and 5 each with a diagnosis on the autism spectrum, with different degrees of functionality. We live in a regional area of Queensland with no family support close by. We deal with state, private and non-profit service providers of services in central and south east Queensland.

Recently after approaching Disability Services Queensland (DSQ) when our family circumstances had changed and Joanne was seeking some household help to reduce stress on her as the primary carer, she was told that if we brought our children into the office, left them there and walked away, we would be able to receive some assistance. This of course will never be an option for us and so after a short period of help we were again left without support.

Systemic Shortage of Funding for Disability Sector

In the past, DSQ and community organisations have usually been unable to provide us with respite funding although as noted, on one occasion DSQ did provide us household help for a short period. We understand that there are many such requests and limited funding. We also realise that our needs are not as great as others and we also appreciate that state and federal government are increasing their funding to the sector and this once neglected policy area is now on the radar screen. However, it sometimes seems that it is those families who make the most noise who receive the available funding rather than those in most need. Correct diagnosis and ongoing reviews of a person's disability are therefore essential for fair outcomes to be achieved.

Regardless of our perceptions of unfairness in outcomes, in our view there is evidence of a massive and systemic funding deficit in Queensland, particularly for those families caring for disabled people between the ages of 6-65. When a child turns six they are released from the disability sector and Education Queensland is then required to meet all therapy needs until they reach school leaving age. (Joanne is a Special Education Teacher in the Queensland education system.) Respite is funded by DSQ if you have an approved package, however as noted, most families pay for this themselves.

When a disabled person leaves school, they have access to funding to assist with work placement, however, there is no other funding available to families to cover respite, therapies and household assistance unless you have a funding package. There are limited rebates through Medicare for medication and therapies and also up to $5,000 via the Medical Aids Subsidy Scheme (MASS), however families can find the relevant paperwork and processes so imposing for MASS that they don't try. The media has provided recent examples of Australian families emigrating to the UK, as services for disabled people there are provided by local governments in accordance with their statutory obligations to meet the actual needs of the disabled person.

Inflexibility of Funding Programs

When new funding does become available, the narrow restrictions that go with it sometimes seem deliberately designed to render the funding unusable on the presumption that people should not be able to decide for themselves. For example, the HCWA program was very welcome, but it does not enable us to purchase (for our son aged 6 who is severely autistic and non verbal), valuable new technology such as an iPad with software such as Proloquo2Go.

We have a friend who was lucky enough to receive government funding packages from DSQ; a family support package; only six were offered last year in central Queensland. However, at the moment she is told the only way she can currently use her funding is to pay for respite. Whilst respite is a godsend for most families, there always many other needs such as therapy services, communication resources and household assistance. We recognise that guidelines are needed to implement these programs, however, without some flexibility this funding can cause families more stress than it offers help.

Families need more control over their options when it comes to meeting the needs of the person they care for. Much unnecessary stress is caused to carers by their lack of any influence over whom provides therapy, respite, resources, household assistance and how this is provided. For example, if a family applies for respite funding, why should they not be able to use this for help to go on a family holiday, rather than putting the disabled person in care?

Early Intervention for Autism and Other Disabilities

This is so important and we urge that governments to study existing successful models across Australia and expand the use of these.   It is essential that follow up and services to disabled children after early intervention are provided so that gains made are not lost. Professional bodies and governments must also promote working as a professional in this sector as a very satisfying and fulfilling career choice.

If you are fortunate like us to live in a regional area like Rockhampton, there is an early intervention centre (provided by Autism Queensland). If you live outside of SEQ, the quality and quantity of early intervention may be non existent. If Australian children who need early intervention have the same right to an education and to reach their potential as do neuro-typical children, the lack of resources provided for this can only be described as a hidden tragedy for our nation.

How to finance a Disability Insurance Scheme?

There should be a transparent methodology to calculating a disability insurance levy, based on hard data on related expenditure, similar to how health expenditure is linked to the Medicare Levy. The Medicare Levy is well accepted and a similar scheme for funding disability would be relatively more easily explained and accepted.

Personal contributions for health insurance, private education and child care are driven by consumer choice for a desired higher level of service. In contrast, disabilities are not a matter of choice and the cost of care and support services are generated to enable people with disabilities to attain a minimum benchmark for inclusion and opportunity in main stream society. Free public hospital care is provided at a minimum standard without a personal contribution and this is seen as our right as Australian citizens. Why should support of disabled people be seen differently? Many families are already forced to seek financial support from service clubs, charities and churches for needed equipment and therapies. This is hardly comparable to choosing a private education.

Issues in Regional and Rural Areas

Generally, in regional areas, key difficulties facing families with disabled children are:

1. Specialised services beyond age six for autistic children (post early intervention) do not exist, eg no schools exist for autistic school aged children;
2. An overall lack of funding available to families and local service providers;
3. A shortage of health and allied health professionals, often only transient and inexperienced appointees are available and there are many vacancies;
4. Long waiting lists for available services;
5. An ignorance of available services (people tend find out about services through friends, not the service provider or DSQ)
6. A lack of respite services (particularly overnight and for young children)

Parents dealing with disabilities can find the grind to be disheartening, stressful and tiring. It seems that they are required to advocate and explain their children’s needs and their family’s needs many times over to every provider they deal with, often without any success. The disability system can be degrading, complex, inflexible and completely unable to meet the needs of the person with a disability.

We are therefore so pleased that a Disability Insurance Scheme is now being publically debated and is seen as a genuine policy alternative. Whilst it is early days we commend the Commission on its Issues Paper and look forward to seeing its Report.

Yours Sincerely

Ewan Filmer Joanne Filmer