Submission to the Productivity Commission public inquiry into long-term disability care and support scheme by Fiona Anderson-Porter.

If you have a disability, or a family member does, *it is as if Australia is 8 different countries*. Our family's experiences when we moved from Sydney to Brisbane show how Australia's uncoordinated state-based disability systems restrict individuals with disabilities and their families from freely moving to and living and working anywhere in Australia, as the rest of the population can do.

Every problem we had to deal with was directly related to the inability of state government departments and disability systems to understand that moving from one state to another did not change the fact or effects of our son's disability.

Although he can't sit, stand or walk, has a Healthcare card and uses a power wheelchair as his only form of independent mobility, we literally had to "reprove" to the state health, education, local government and transport systems that our 14 year old son with cerebral palsy had a physical disability. Among the myriad of government funded service providers and advocacy groups, we could not find any that could provide tangible, individual support as we gave up employment income to navigate the complex disability "service" system. Sympathy, yes; personalised support, no.

We filled in enough forms to decimate a tree plantation continually restating the information about our son which hasn't changed in 8 years – permanent brain injury, requires support with all core tasks, uses a powerchair for mobility, types with one finger etc. You'd think someone who was considered disabled enough to receive an accessible parking permit in NSW would automatically qualify for the same thing in QLD, or for a carer companion card, or taxi transport subsidy, or in-home support, or school support. But it doesn't work like that. It is utterly illogical.

The system could not be more inefficient if it tried.

Why we moved inter-state

All four of our family were born and raised in Sydney. When our son was 13 we sold our Sydney home and moved interstate as disability refugees. We could manage our average Sydney mortgage of $300K, but not on top of our then disability debt of $470k with a family income that had no potential to rise when one of us could not work full-time due to lack of after-school support to child with disability. All our after-tax income in the last 14 years was invested in therapy, equipment and education to maximise our son's ability for an independent, productive, tax-paying future, plus giving him opportunities to enjoy his everyday life. There was none left to invest in superannuation for our retirement.

To continue to invest in our son's future and also be able to look after ourselves in our later years we had to reduce our disability debt. We sold our house and used the proceeds to pay down debt and set ourselves up with a little more long-term financial security inter-state. Our criteria was a location that had the right educational setting to meet our son's needs, our daughter's tertiary education needs, the employment needs of one of us, capacity to fund an independent home for our son in his adult life and a community where we could live in moderate comfort. We chose Brisbane, not for services which we do not receive, but then we received few in Sydney, so we didn't miss them.

To paint a clear picture of the stark differences between an able-bodied and disabled person moving interstate, I'll refer to the different experiences encountered by my children.

- To get a driving permit my non-disabled daughter had to hand over her NSW licence to Queensland Transport, and receive a new QLD licence, for free
- To register her car in QLD, she took it to a registered motor mechanic, paid for the inspection and registration slip, and arranged registration
- To enrol at university in the course she chose, she had to produce her UAI, obtained following completion of NSW HSC
- To find a doctor she called a few local medical practices and within a week received an appointment
- To get to university, her part-time work, friends' houses and other activities, she simply walks out the door to rail, bus or drives our car
- It doesn't matter to her if there is a footpath, kerb cross-overs, an accessible bus or rail route where she alights and disembarks. The availability or lack of availability of these things does not restrict her freedom of movement.

What her disabled brother and we continue to go through is a stark contrast:

Nothing simple about registering a roadworthy wheelchair van
Our son's 100 kg power wheelchair cannot be transported in a car, only in a modified van. The QLD Transport Centre did not automatically certify our van's wheelchair modifications, even though they were certified by the NSW RTA to comply with Australian Standards. We lost employment income for over a week trying to find out what we had to do to legally drive our van. Miraculously it turned out the van complied with Australian Standards in QLD, just like it had in NSW. However unlike NSW the QLD safety standards did not include the seatbelt restraint system for the wheelchair and its occupant. There was an additional fee for this compulsory inspection of a vehicle that was already certified as complying with Australian Standards.

Solution: A vehicle conversion certified to comply with Australian Standards in one state should be automatically accepted in every other state and territory. Otherwise why bother having Australian Standards? **An NDIS should define and enforce acceptance of national standards.**

Disability support at school
Like parents all over Australia, we researched and selected a school which we felt best met all our son's needs, not just those needs related to his disability. A genuine, demonstrated inclusive culture – not rhetoric – was vital to developing our son's strong sense of self-worth. This time we selected a non-government school.

In Sydney our son's government high school received around 5 hours of disability-related funding per day, not all of it used towards meeting his specific educational needs. Apparently his disability disappeared when we crossed the border, as his non-government school receives only 1 hour per week disability support funding to be spent on meeting his needs. But his abilities and support needs haven't changed.

The reason for the illogical disparity in funding is because state governments fund disability support only in government schools, and the federal government funds to a much lesser extent disability support in non-government schools. Yet again as parents we made up the gap in funding by supplying our son's digital technology and even his personal care at school.

As soon as we arrived in Brisbane we had to find a doctor for our son. Not because he was sick, but because to be recognised as having a disability and to access even a paltry 1 hour support funding per week he has to be "verified" by Education Queensland as having a disability.

His severe physical disability wasn't "proved" to Education QLD, despite:

- his use of a power wheelchair for independent mobility
- the recent letter from his Sydney GP of 8 years listing his diagnosis
- the comprehensive report about technological and other support to his education provided by his Sydney learning technology/occupational therapist
- our offer to supply the funding documents used by NSW Department of Education for previous 7 years to specify our son's education funding support needs

Education QLD would only accept a recent report from a medical specialist confirming our son was disabled. So we spent two months finding a GP who would take our son on his books, to then refer us to a specialist (with a 2 month wait list) who had never met our son to confirm that our son was indeed disabled. I lost count of the number of medical practice receptionists who told me "disabilities" were too much work, too many forms to fill in taking up too much doctor's time, too much government red tape. But until our son was "verified" as disabled, his school received no disability support funding.

Solution: Education support funding of students with disabilities should be a **federal responsibility**; the funding should be **portable**, going with the student anywhere in Australia to ensure consistency of funding regardless of school system. A national curriculum needs to define an **educational support process** for students with disabilities that identifies and provides targeted supports to meet individual needs and can be **measured against assessable outcomes**, and requires schools and education systems to use existing education, therapy, medical and technology reports about the student, not reinvent the wheel to suit the vagaries of individual State education systems.

Getting to school and moving around our new community
Although he can't stand, let alone walk, our son doesn't qualify for school transport service, because he attends a non-government school. We believe this discriminates against him and sends the message to us that to obtain taxpayer-funded services which our taxes contribute to, we are compelled to send our son to a government school, unlike other Australian families who have a democratic right to select their children's schools. The local school bus service is not wheelchair accessible.

Other than paying a maxi-taxi twice a day the only way my son can get to and from school is by me driving him and his wheelchair in our van. So unlike most parents of teenage children, my income-earning hours are limited to 9:00am – 2:30pm for a maximum 37 weeks per year.

Therefore our first criteria for buying a house was it had to be close enough to the school and within a built environment of maintained footpaths, kerb cuts of the correct gradient and traffic lights to enable our son to get himself to and from school independently in his wheelchair. Of course we then have to modify the house to make it wheelchair accessible and maximise our son's independence inside his home. None of these costs is tax deductible; they are extra expenses on top of regular living expenses.

Although Brisbane has almost zero private accessible rental or residential housing to meet current or growing future needs, there is no State or local council awareness of how to speed the renovation/building approvals process to increase housing stock which is accessible to all occupants and visitors, not just able-bodied people.

And there is certainly no financial incentive to make a house physically accessible. Our governments value the ability to use less water or power far more than they value the capacity for disabled people to move safely around their homes, or for older people to be able to remain living in their homes instead of getting moved to expensive and scarce nursing homes. There is no guarantee of funding support based on need from government-funded home modification services although their purpose is to enable disabled people to live in their own homes. Like every other service, demand far outstrips supply and the planning process does not reflect actual current and future needs.

Solution: An NDIS should cover modifications to an existing home or owners should receive financial incentives to retro-fit. Make accessible homes the same national priority as energy-efficient homes with a mandatory requirement for all new homes to include basic accessibility features within two years, not 10 years.

Therapy

Our son received no therapy in Sydney from the age of 3, other than what we paid for ourselves (chalking up a big proportion of our disability debt). Plus we have for 14 years spent several hours each day performing a home therapy program to maximise our son's muscular-skeletal function, general health and capacity to function as independently as possible.

As there is no funded support worker assistance with core tasks (getting out of bed, showering, personal care, dressing) despite his severe disability, it is clearly in his and our long-term interests to do all we can to optimise his physical capacity for maximum independence, or else simply accept the prospect of providing all his personal care until we are dead or disabled.

In Brisbane there is no provision of therapy other than what we continue to provide and pay for ourselves. Our health fund covers about 10% of our therapy expenses. The tax system rebates 20% of some therapy costs, leaving us with an ongoing therapy expense of $15,000 - $25,000 per year. It certainly leaves no money for us - the therapy providers – to attend to our own physical dysfunction caused from providing 24/7 physical support.

Solution: This is a key area where personalised funding in an NDIS would be so logical and useful. Acknowledge the variety of rehabilitation, therapy and exercise programs available, not just those recognised by some professional associations with a vested interest in maintaining the status quo. Allow individuals and families the "right" to explore options and use the combination of programs which achieve the best results for the individual with the disability, not force them to use the one-size-fits-all "review" services in the current system. Document the results to share information with other users and promote evidence-based therapy.

Disability equipment

In 14 years we have paid for about 70% of our son's disability equipment, to ensure he got what he needed when he needed it not when the State chose to provide it, avoiding corrective surgery to redress spinal and hip problems with the right equipment and therapy during child and adolescent development. Now our son needs a new power wheelchair to replace his 5 year old power chair, and a new manual wheelchair for use in all the areas which are inaccessible to power wheelchairs (shops, houses, recreation facilities et), and a new walker $8,500.

We are advised MASS QLD will pay up to $5100 for a power wheelchair. Our son's new powerchair customised to meet his independence and mobility needs is estimated to cost around $18,000. We have to make up the shortfall, or beg a charity to help provide our son with his only means of independent movement.
We have to buy from an Australian distributor; if we import a chair at reduced cost no-one will service the chair.

We will also have to pay for a new manual wheelchair around $8000. Nor would MASS fund our son's shower chair, which our son's service provider asked a charity to fund. Of the $21,000 we will have to pay, we will get a 20% tax rebate of the amount over $3000. This amounts to a total disability equipment tax rebate of under $4000 which we will put towards the additional $15,000-$20,000 therapy costs each year.

We have already 100% funded a wheelchair accessible van – a commercial van retro-fitted with accessibility features, not tax-deductible. This basic vehicle cost us $84,000 – the cost of a luxury car. It would be cheaper to import a factory-modified accessible vehicle from Japan or Germany. But none of Australia's state regulatory authorities will certify imported, modified vehicles. I suppose we can't assume Japan or Germany would be able to build high-quality, accessible vehicles as well as Australia does …

All our therapy efforts and expenses and our son's tenacity and hard work means tax payers do not have to pay for our son to have surgery to fix muscular-skeletal problems. Our family's hard work also greatly boosts our son's physical and intellectual ability to learn and eventually work and pay tax. But this financial year we will have to find around $46,000 for therapy and equipment and about $80,000 for house modifications to meet our son's needs, on virtually a single income. So we go further into debt with even less chance of increasing our income to pay our debt.

Solution: An NDIS with personalised funding would enable our family to plan and decide what equipment our son needs and which helps our family to support him. We would consult with specialists where needed, although most useful information comes from other families we connect with world-wide. Streamline the process so that only major expensive equipment purchases go through professional therapist consultation. Legislate that ANY equipment which is privately funded to meet disability needs is 100% legitimately tax deductible. I assure the Tax Office that I would not rush out and buy a $20,000 wheelchair unless my son really needed it. If my son could walk I could instead spend $20,000 replacing my 13 year old car.

Our vision

In a wealthy, civilised nation we do not expect either of our children to be marginalised from society unless they commit a serious crime. Yet in reality, severe disability results in exclusion from much of everyday life. Yes, one of our children needs flexible, targeted supports to help him participate more in some areas. Big deal. Our other child, or we ourselves, may one day need some level of support to participate in everyday life. It makes sense to insure against that possibility for us personally, and for the nation.

We see a **radically transformed disability support system** as a tool to help our son – and hundreds of thousands of others with disabilities – reach his potential to give to and participate in our everyday world. And the multiplier effect of supporting our son would enable us – and hundreds of thousands of others – to again be simply mothers, fathers, sisters and brothers, not "carers" who are unable to use our professional skills, experience and qualifications to earn income and connect with the world because we are expected to be the sole, life-long caregivers of a family member with severe disability.

Supporting our son automatically supports our family. We are not isolated individuals labelled as "disabled person" and "carer". He is our son, he is our daughter's brother, we are a family whose past, current and future are intertwined. Support our son, and you will support all of us to have far better physical, mental and emotional health. A stable, supported family is surely good for the country.

So we would like the stated purpose of a national disability scheme to be framed in outcomes, not inputs. For example, not how many hours per week our son is "entitled to" in paid personal support, but what combination of equipment, technology, paid personal support, voluntary support from family/friends and environmental changes are needed to achieve a particular goal, like take a shower safely, get to and participate actively at school/TAFE/university, maintain a fitness routine to promote good health and social connections, participate in regular recreational activities with people we choose to be with.

We believe an NDIS is not just a framework for funding and delivering services. We believe consideration should be given as to how to maximise potential for strong, mutually respectful relationships between people who provide paid and unpaid support to the person with a disability, to optimise their inclusion in ordinary life. Effective relationship management is no less important to supporting people with disabilities than it is to managing business relationships in the corporate world.

The strongest relationship bonds lie within immediate and sometimes extended family. We love our children and will do whatever is humanly possible to ensure they not just survive, but thrive. It is often in the early years of the life of a child with a disability that families are under the most stress, feeling as if they are floating adrift without the anchors of the "normal" life their friends have that connect them back into their ordinary world. They are almost forced to seek refuge and solace with other families "like them" – who understand the enormous issues they may be grappling with, from complex medical management of a child with multiple disabilities down to the grief of losing an ordinary way of life.

We believe while there are many service providers and systemic advocates of various quality levels, there appear to be few family-focused advocates who will guide, support, coach and mentor individual families – in whatever form the family may be - at key stages of their journey through life, which is different sometimes from other families because their family member has different needs. We believe the Commission should consider incorporating **models of capacity building and family support** which teach how to create, sustain and value a wide variety of relationships throughout the life of the person with a disability. There is a role for community family advocates to meet local needs.

We expect our son to increasingly take responsibility for defining how he wants to live his life and what supports he thinks he needs to do so. While he is under 18 we play a key role in helping him define and communicate these views, and after he is 18 if he wants our input. We expect our family to be acknowledged as the "experts" in supporting our son, and respect given to our research, exploration and assessment of therapies, equipment, service providers, education and supports which we think best meet our son's changing needs.

We do not think there should be any expectation that our daughter should give up her studies, work and life to take entire responsibility for her brother's physical support, personal care, transport, accommodation, recreational and social needs, as her parents have done. We know she will care *for* her brother for the rest of their lives – that is not the same as care *of* her brother.

Finally, while I am critical of Australia's dysfunctional disability systems, I am grateful for the opportunity a democratic political system offers to me and many others to offer our views, experiences and suggested solutions and know they will be listened to. However, this freedom to fully engage with our world is denied to literally millions of severely disabled Australians and the families who support them. It is absolutely time that Australia treated ALL our citizens with respect and supported their active participation in the nation's economic and social life. Otherwise our nation is not worthy of the political definition of "democracy".