Introduction

My husband and I are based in Brisbane, Queensland and have three young children - two boys and a girl. Our delightful six-year-old daughter was born unexpectedly 12 weeks early due to an undetected bacterial infection in-utero, causing damage to the part of her brain responsible for mobility. Thanks to the excellent resources and care by medical staff at the Royal Brisbane Hospital, our daughter survived this traumatic beginning, though was diagnosed at 10 days old as having cerebral palsy (CP). Her CP manifests as severe quadriplegia.

She has virtually no controlled movement of her hands, arms or legs, and also has very 'floppy' muscles in her neck and trunk. Her postural support and mobility needs are significant. Because of her physical impairment, she requires full assistance with feeding, washing, dressing, toileting, playing, learning – every aspect of daily life. She requires constant physical therapy to prevent her musculo-skeletal structure from mal-forming as she grows.

Our daughter is a very bright, conversational little girl, and we know she is a good investment - with the right support, she, like her two brothers, will have a viable future and will indeed one day be a taxpayer herself. First though, she is a child – one who deserves the same opportunities as any other child in this so-called ‘lucky country’.

She has been a client of the CP League of Qld since she was five months old. She received ‘Early Intervention’ services until she began school, at which point she was transferred to the ‘School Age Team’. She also received services from Education Qld and the Inclusion Support Agency during her pre-school years.

Our daughter is currently in Grade One at our local state school, in a mainstream classroom. She is relatively well-supported at school; we began preparation for this at least 18 months before she entered a classroom. She is a popular member of her class and like her classmates, she is enjoying age-appropriate learning and participates in school sports days, concerts etc. She has many friends, attends birthday parties and play dates, enjoys sibling banter with her brothers and has a regular presence in our community - in other words has as NORMAL a life as possible, given that her needs are anything but normal.

We as a family work incredibly hard to achieve this ‘normality’, and it’s not our daughter that makes this difficult, it’s not even necessarily societal attitude that makes normality difficult to achieve. What frustrates us most is the severe lack of service, equipment and therapy provision that is supposedly available to families like ours, particularly the extreme cost and unavailability of ‘disability’ aids and equipment - the things that could help our daughter so much, yet always seem most out of reach.

Our vision for our daughter

We envision that our daughter will grow up with her brothers and peers ultimately living as full, rich and independent a life as possible. Her body will be well supported as she grows, because the therapy and equipment needed to achieve this will be funded and available. She will receive an education as any other child does, and enter tertiary studies (and beyond) if she so chooses. She will no doubt be part of the workforce as an adult. She will certainly participate in community life. As an adult, we envision her being supported in her own universally-designed/modified home with her mobility and therapy needs met and updated as needed; her daily needs will be provided by people of her choosing, as employed by her under a self-directed funding scheme.

We envision her being able to live, study, work and enjoy life where she chooses, like any of her peers, knowing that she will receive adequate support through self-directed funding as provided by an NDIS.

We see the introduction of a *national* insurance/entitlement scheme, or NDIS, as being crucial to allow us to systematically and intelligently plan how to support our daughter's needs, in the short and long term, ensuring her long-term supports will be in place to allow her to live fully and give back to the larger community.

Problems we face under the current [broken] system:

- **No therapy -** Our daughter received some regular therapy from our local service provider (CP League of Qld) between the ages of 5mths to 5yrs under the Early Intervention program, as well as some equipment provision/assistance with funding applications. As part of the School Age Team, she receives some school support by way of occasional visits by therapists (during which limited time they make adjustments in the school as necessary to enhance her learning), and assistance with some equipment provision. However, since she began school she gets NO hands-on therapy. It seems this is an accepted tradition – once a child turns school age, there is no more Early Intervention from the service provider (any service provider) - in our daughter's case she is not getting much-needed physical therapy (from a professional therapist). This is one example of the 'one size fits all' approach by service providers whose funding doesn't seem to stretch far enough.

- **Financial strain –** Private therapy is expensive. Equipment and aids are outrageously expensive (see below). Car and home modifications are currently beyond our reach. All of this on top of the cost of living for a family of five. My husband and I have been in the workforce and paying tax for 60yrs combined. Currently we both work part-time to be able to meet the needs of our children.

- **Difficulty accessing subsidised therapy -** there is a subsidy for allied health care available through Medicare, though it is only for 5 therapy sessions per year and requires lots of form-filling from us and our GP (we find some GPs are loathe to do this paperwork). Our daughter requires *at least* two sessions of decent therapy *per week*, so we feel it is hardly worthwhile to bother accessing this plan. We would love to see privately-paid therapy services for people with disabilities being **100% tax deductible.** A tax offset like this would greatly ease the financial burden of therapy on families like ours.

- **Family strain -** Despite not having studied in any of these fields, my husband and I are expected to be physiotherapists, occupational therapists, speech therapists, as well as facilitators for our daughter's participation in eating, play, backyard games, parties, whatever… We hardly get a chance to just be *parents*, a point not lost on our two boys, aged 9 and 3 years. We are aware siblings of children with disabilities have a different 'norm' than most, and we struggle with the emotional strain of sibling jealousy in our son/s.

- **No respite care** – when she is not at school, my husband, myself or my own mother tend to all of our daughters many needs (as well as those of our two boys). As she grows older, longer and heavier, this is getting more and more difficult for us, particularly my mother. We are on a waiting list for respite help/help in the home.

- **Application form misery -** To receive services or funding, we are often expected, indeed encouraged, to complete long forms, repeating once again all the information about our daughter, as if it were at all possible that her diagnosis may have changed in the interim since the last application (it hasn't). Sometimes the forms are cruel, with heart wrenching answers being required to questions such as "How are the applicant's siblings affected by the applicant's disabilities?" (in the case of DSQ). As if life isn't difficult enough, do we really have to sit down and remind ourselves of the negative ways our lives are affected? I am loathe to fill out these forms because it is just too emotionally difficult to do, and I personally object to the implication of the 'Misery Olympics' – it feels like only those that can make their story sound the worst are rewarded with funding.

- **Ignored by those whose job it is to help -** Of course, having completed one of these arduous and stressful applications for services or funding (at the behest of the agency/govt department concerned), one need also be prepared for the dejection of being COMPLETELY ignored by the agency/govt department concerned, or being met with a laissez-faire attitude that feels like it borders on malicious indifference. Often, it is only after making several follow-up phone calls that we get any word at all on whether or not we have even been put on a years-long waiting list.

- **Long waiting lists** for specialist appointments, respite care/funding, equipment, therapy services (physiotherapy, hydrotherapy, hippo-therapy, speech therapy, etc), etc.

- **No funding support** for new and evolving therapies, despite strong anecdotal evidence of their benefits. Our family has spent thousands of dollars of our savings accessing a therapy that has been very beneficial for our daughter (and possibly lightened her ‘burden’ on the health system) but it is not recognised in any funding scheme (Medicare, private health insurance).

- **Lack of certainty** in our daughter’s long-term future in terms of housing, care, etc when she’s an adult, and we are dead or unable to support her needs. Lack of trust that current service providers will see it through well or at all.

- **Lack of accessibility** to homes, schools, shops, venues - having to second guess and modify plans when we go out, limiting our scope of activities. Or just miss out all together.

One of our biggest problems is equipment provision

When we first became aware of the high costs involved in supporting our daughter, we mockingly called it the 'disability tax'. Now of course it is something we cannot afford to joke about. Below is a list of items our daughter currently uses on a daily basis:

- a small manual wheelchair (custom made by local supplier/manufacturer), cost $5600.00 (we were subsidised by Qld Health's Medical Aids Subsidy Scheme (MASS)). A small (but necessary) perspex table attachment to this chair costs $290.00 (not subsidised).
- a posturally supportive high-low chair*,* retails for $5500.00 (currently on loan to us)
- a toilet/shower commode which retails in Australia for approx $4000.00 (again we were part-subsidised by Qld Health's MASS; because of delays with the supplier, we had to wait more than 16wks for this to come to us once it had been paid for). *A quick internet search shows the current price for the exact same item in the UK to be GBP£1299.00 = in AUD$2183.00.*
- a standing frame (currently on loan) which retails in Australia for $5000.00+ *(or in the US USD$2,790.00 = AUD$3,177.74)*
- a bath lift (also on loan), retail approx $1500.00
- Orthotic Boots (Ankle-Foot Orthoses), cost $400.00/pair. New [custom made] boots required every 8 - 12 months. Private Health Insurance covers a fraction of this cost.
- Assistive Technology - Laptop computer $900.00, *Intellikeys* computer interface $570.00, *Traxsys* Roller Joystick $750.00, *Clicker 5* literacy software $360.00, *Jellybean Twist* switches $180.00 (for two) - all currently on loan from a charity.
- Our daughter previously used a supportive ‘special needs’ stroller when she was younger, this cost approx $3,600. To accessorise with a simple sunshade to suit our climate cost $400.00!

Often when purchasing equipment, there is a long process of trialling and prescribing, measuring up, applying for funding and waiting for funding approval. When approval is finally granted one then begins the process of ordering (and sometimes, custom-making) the item. For children with disabilities, by the time the item has arrived/is ready to use (it can be many months wait), it may no longer be suitable or even fit.

If families could purchase equipment, once prescribed, using funds granted in a Self-Directed Funding scheme, a lot of the time spent in applying and waiting for funding approval would be saved.

In the list above I have alluded to the fact that if bought independently from overseas, equipment for disability can cost a lot less (and is shipped in a fraction of the time) than if bought here in Australia. Unfortunately some overseas manufacturers have exclusive deals with suppliers here, meaning we are forced to buy through those local suppliers, paying premium prices and waiting longer for shipment. We would love to know how suppliers and distributors in this country justify their huge mark-ups in price and long waiting times for shipment. To say we feel held to ransom in a captive market is really understating the issue.

It is our hope that the introduction of Self-Directed Funding will create genuine competition in this market, seeing a reduction in costs of equipment, and improved service for people with disabilities.

Power wheelchairs and vehicle and home modifications

We are currently looking at trialling and purchasing a powered wheelchair for our daughter to have independent mobility for the first time. Under Qld Health's MASS funding scheme, we are limited to a choice of three chairs if we want subsidised funding. Despite costing $8,000 - $14,000, none of these three power chairs may be the most suitable for our daughter. We would like to be able to choose any chair for trial, and make a decision on what mobility provision she will have for the next 5-7 yrs based on suitability, not economy or availability.

Of course, once we have the power chair, we need to make our family vehicle accessible to get it to school and into the community. We have been quoted $35,000 for this, and there is currently NO govt subsidy/funding scheme for vehicle modifications in Qld. In fact, two years ago I was given the opportunity to ask a [then] Minister for Disability Services why this was so, I was told that there never will be funding for “cars” and in fact she supposed it was a better option for the government to encourage the use of subsidised accessible taxis, even suggesting that in our case we could send our daughter off in a cab and follow her in our own car, “or whatever”. This ‘solution’ is just not realistic, or even rational.

If we don’t have a wheelchair-accessible vehicle, our daughter won’t get to experience the joy of moving independently (via her power-chair) in her community, something we know will boost her self-esteem, confidence and dignity as well as accessibility. Also, we will have to continue carrying/lifting our daughter into her car-seat, a back-breaking exercise that is not going to get any easier as she continues to grow and our weary bodies continue to age.

In addition to this, the mere idea of travelling anywhere as a ‘family’, but with our bubbly six-year-old daughter separate in a taxi (as per the minister’s suggestion) and therefore not participating in family conversation, singing, jokes with her brothers, etc, is not only painful, but too ridiculous to contemplate. The difficulty and cost of relying on an accessible taxi for a quick trip up to the shops, to friends’ places, school, therapy, the park or to the doctor, not to mention the family weekend camping trip…unimaginable.

We also need to make our house accessible for a powered wheelchair - we anticipate this cost will run well over $50,000. We have had our bathroom modified to be wheelchair accessible, this cost $20,000, exactly half of which we received in funding support through HACC.

In many other countries, full vehicle and home modification funding is granted as a matter of course. It is ludicrous that we have to fight and struggle for these basic (albeit expensive) needs, that people without disabilities don’t have to think twice about. We would hope that an NDIS would fully support such funding on a national scale. An NDIS should also ensure mandatory universal access to business/educational/public spaces, and mandatory universal housing design implementation in all new housing, effective immediately.

How Self-Directed Funding through an NDIS could support our family:

If we received a specific amount of funding from an NDIS each year, we would be able to plan with certainty how to provide the supports and services our daughter needs, based on changing priorities and her changing needs, NOT based on what we are told is available to her.

For example, in the short term we could:

- Employ home help for therapy/help with daily needs at home – train a student to help our daughter with therapy, core tasks, studies, etc a few times a week, so we can tend to our sons’ needs knowing our daughter isn’t missing out on her requirements. This alone would take an enormous amount of pressure off our family.
- Ensure ongoing (private) therapy support, both mainstream and alternative – we would use what therapies we KNOW work for our daughter and enjoy watching her skills develop.
- Fund equipment – get the most suitable equipment, not be forced to choose from paltry options, and be able to buy from whichever supplier we choose, including those overseas if the costs were lower or equipment more suitable.

For the long term, we would:

- Have certainty in our daughter's path for the future. Knowing that funding and guidance would be in place to ensure her on-going care and accommodation needs are met when we are no longer able to support her would relieve enormous stress on our family
- As an adult our daughter would have autonomy over decisions made regarding her lifestyle needs, and not be forced to use inappropriate "one size fits all" service provision.

Suggestions on how aspects of an NDIS-style scheme could work: (Though I am certainly no expert in this arena, the following are my thoughts on some aspects of an NDIS…)

Who is Eligible?

- People with disabilities who need provision of any services, equipment, accommodation, respite and care to live their daily lives. Certainly those born with a moderate-severe disability and who have no claim to litigation/compensation should be given priority during implementation.
- A national assessment criterion could be established to help assess and categorize types of support required and level of need. Though all people are different, and likewise all disabilities are different, it could be argued that broadly speaking, some types of disability have certain specific needs compared to others, eg, neuro-muscular impairment as compared to vision impairment or intellectual impairment. Categories would be flexible when funding is considered, to allow personalized care.

Who has control?

- Individualised Funding/Self-Directed Funding could be overseen by a national, over-arching, impartial body that adjudicates criteria, advises people with disabilities and provides accreditation/assessment for service and equipment providers, etc.
- Individualised Funding could be funnelled through the ATO/Centrelink/another external body? Ultimately the person with a disability (and/or their carer) has control of how and where they spend their money, driving market forces to create more competitive service provision.
- Financial support should not be means tested. 'Lifestyle package' funding should benefit all, not just those deemed to be in crisis as is currently the case.

Services

- Nationalize system of information about applicants, having a *national* database from which relevant information given in *one initial* form can be accessed and updated simply as required, eliminating the need for duplication and re-assessment, particularly if moving schools, health programs, interstate, etc. Likewise any funding should be portable across state borders.

- Specialist staff would provide advice and assistance regarding using Individualised Funding, while acknowledging people with disabilities/parents/carers are more often their own experts in their individual needs.
- Investment required in training allied health staff (therapists), respite carers etc – there is no point in providing funding if there is a shortage of services to spend it on.
- Therapy throughout childhood and into adulthood should be essential, not just for Early Intervention.

Aids and Equipment

- All equipment purchased for people with disabilities should be **100% tax deductible**. A tax offset like this would greatly ease the financial burden on all people with disabilities and their families/carers.

Funding

- New scheme could be financed through a Medicare-style levy and existing taxes.
- Increase GST?!
- An NDIS-style scheme could only be sustainable if there is legislation to guarantee funding continuity.

Finally, I understand there are concerns that expectations are high, and that not all needs could possibly be met with an NDIS. Despite her severe disability, our daughter currently only receives services concerning her education. She does not receive services from any other government agency. She currently does not get any publicly funded physical therapy, respite care or any other service. We have had assistance with *some* aids and equipment through Qld Health's MASS, and relied on charities for others. Are our expectations high that we will get a better chance to provide for her and also have our burden as carers eased? You bet!

Guaranteed funding that serves all people with disabilities and their families/carers is essential to improve outcomes for all concerned, and the Australian community at large. It is important to look at the provision of an NDIS not just in terms of economic input, but the positive social outcomes as well.

On behalf of my family, I thank the Commission for the opportunity to add our voice to this discussion.