# Submission to The Productivity Commission Inquiry into Disability Care and Support

I am a 36-year-old man with high-level quadriplegia as the result of a diving accident 18 years ago. At the moment I self-manage my funding as I was one of the "lucky few" able to claim some compensation for my injuries. However, before receiving my settlement I lived on the disability support pension for thirteen years relying on the benevolence of the bloated autocratic service provider that is Home Care NSW. I have also worked part-time and lived in both NSW and Queensland. As a result I am familiar with both the pitfalls of juggling part-time work and Centrelink and the lack of portability when carrying funding interstate.

This submission is from the perspective of someone with a physical disability only. It focuses mostly on service provision for ongoing care, as this is the largest component of any feasible NDIS. However, the general principals outlined below apply equally to medical aids and equipment.

## Who should be eligible for the scheme?

Anyone aged from 0-65 who has acquired a disability that affects their activities of daily living. The amount of assistance required could be assessed using impairment tables similar to those used by Centrelink. If any means testing is used it should be very generous – preferably the scheme shouldn't be means tested at all. The real cost of a severe disability is high even for someone on a large income.

## Funding the National Disability Insurance Scheme

It would be a tragedy if a NDIS were established without adequate funding to meet unmet need. Please overestimate rather than the other way around – the levy can always be reduced in subsequent t years. A medicare-style levy would be the fairest way to raise funding for the scheme. State-based CTP and workers compensation schemes could be abolished and replaced with a national equivalent that pools the levies. Additionally, levies could be put on activities known to be quite risky (eg a $25 levy on anyone who goes skydiving etc)

## Administering the NDIS

Where possible, the NDIS should be run at a federal level with uniform national standards and guidelines across all states. I can only comment on NSW and Queensland but both states have demonstrated questionable commitment and competence in providing disability services. Cut out the middle layer of bureaucracy and make it nationally administered and use the savings on direct service provision.

## Service providers, service users, empowerment and efficiency

Basic economic theory tells you that for the disability services "market" to function effectively it needs lots of service providers, service users fully informed about market conditions, and low barriers to market entry. Failure to ensure these market conditions will result in a form of community-based institutionalisation. Large autocratic service providers will simply end up dictating terms to service users.

**To avoid this, a NDIS needs:**

- Individualised funding tied to the individual service-user, rather than block funding tied to a service provider. Block funding can of course be an option for those that prefer it – but it should not be the "default" option.
- The option for Self-Managed Individualised Funding (SMIF) for people who are both capable and interested in pursuing that option.
- Co-tenancy should only be used at the express request of service users and enforced co-tenancy should not be allowed under any circumstances.
- To encourage innovative and flexible small-to-medium sized service providers as a way of increasing competition and to offer consumer-focused service delivery models (for a good example, see Allowance Incorporated)
- An independent complaints body with proper powers to investigate allegations of abuse, neglect and intimidation of service users in a confidential manner
- Funding packages that are portable nationwide
- Disability information resource centres in every state to inform and educate people with disabilities of their rights and the services available to them

## Vested interests in the NDIS debate

The needs of the person with a disability are paramount in this debate. Use caution with the following groups who, while often well intentioned, have their own agendas beside the best interests of people with disability.

*Carer groups*

The interests of carer and family groups are sometimes but not always aligned with those of people with disabilities. I wish to acknowledge the enormous contribution of families, carers and support workers - but not at the expense of my own autonomy.

Please do not let the debate on the NDIS become hijacked by carer groups. Some carer groups are very balanced and have well reasoned policies. Others are very dogmatic and interested only in the needs of carers, not the person with the disability. As quite often the children/relatives of carers are so profoundly disabled they cannot articulate themselves, some carer groups find it hard to sympathise with people with disabilities who can speak up for themselves. Having basic needs met take a much greater priority than any notions of empowerment and autonomy. For some carer groups, the ends tend to justify the means, which leads to favouring "easy" solutions like block-funding and co-tenancy.

Simply put, I do not wish to live in a group home pooling my resources with other people I may not want to live with, simply because some carer groups find this the most effective way to provide care for their dependants.

### *Service Providers*

Similarly do not let the debate on the NDIS become dominated by large service providers or umbrella bodies representing them. There are some very good service providers and even more very good people who work for them. However, the larger an organisation gets, the more likely it will focus on what's good for the organisation and not necessarily what's good for the individuals they claim to represent.

Some state government disability departments have displayed a preference for dealing with large service providers (not-for-profit or otherwise), presumably as they find this easier and more manageable. Smaller and often better service providers end up squeezed out of the industry. The downside for people with disabilities is they are left with complacent autocratic service providers - who quite literally "do less with more."

For too long in the crisis-driven model of service provision people with disabilities have felt obliged to be grateful and not rock the boat. Service providers instead need to compete for the right to provide service. A wide range of small to medium sized service providers, preferably with service users on their management committees, would go a long way to ensure service provision is tailored to the needs of people with disabilities.

### *The Insurance and medico-legal industry*

Insurance companies stand to gain enormously from the introduction of a NDIS as the trade-off will be tort law reform. As someone who went through the legal system and racked up expenses of over $100,000 for medical and other expert reports attempting to quantify my ongoing support needs, I know reform of the system is needed. However, I don't believe tort law reform should take away a person's right to be compensated for loss of income in cases of gross negligence.

It is quite difficult for people with severe to profound disabilities to find and keep meaningful employment. Current government policies make seeking part-time work (often the only viable option for severe disabilities) a significant financial disincentive. In short, if you acquire a significant disability your earning capacity is greatly diminished. People should be able to claim for loss of earnings if their disability is the result of someone else's negligence.

In the case of here the defendant being clearly "at fault" there should be some simplified system for claiming compensation for lost earning capacity. Having lifetime care and equipment support is one thing – but why should a plaintiff who had a six-figure career (doctor/lawyer/whatever), or someone simply earning average weekly earnings, **now be condemned to a lifetime scraping by on the DSP?**

## Occupational health and safety – let's have some sanity please

The final point I'd like to make is how destructive overzealous workplace safety regulations (or more precisely their interpretation) have been for people with disabilities. When workplace incidents occur it is usually assumed that it's the client's fault rather than the care worker being poorly trained, or badly unfit/out-of-shape, or simply lazy, inattentive or incompetent. An Occupational Therapist, or perhaps a team of health professionals then assesses the service user's routine. To play it safe, they will insist that two people must now do a morning routine that could be safely done by one competent care-worker.

This is disastrous for the service user as it effectively cuts their support hours in half. Furthermore, if overzealous safety assessments become widespread, it will **double the cost** of an NDIS.

All this happens because too many workplace health and safety assessors are inexperienced or have been told to err far too much on the side of caution. People with disabilities are being expected to keep their home to the same standards as a hospital ward, which is just not practical. Some common sense needs to prevail here - not everybody needs to use a hoist and not everybody needs two people to use a hoist.

I recently had a potential service provider inform me I would need to keep a medication register to be signed off by each carer that visits me. "Don't worry - you don't have to keep it on your bedroom wall if you don't want to," I was cheerfully told by the service coordinator. Aside from the fact that I can administer my own tablets independently, the fact they felt they were doing me a favour by not making me display a medication chart **on the wall of my own home** speaks volumes of their attitude in general toward disability.

Service providers need to be reminded that when they assist people in the community – it is the service users **own home** and not a hospital ward.