

## Introduction

As a family of 4 caring for a severely disabled 4 year old daughter, we welcome the opportunity to provide a submission to the Productivity Commission on the formation of a National Disability Insurance Scheme. We have reviewed the Disability Care and Support: Productivity Commission Issues Paper, and will refer to specific points where we can add value to the discussion.

## The prevalence and incidence of disability

We agree with the Commissions' position that *"First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the natural process of ageing."<sup>1</sup>*

We also agree with the Commission that *"Second, the scheme is not intended to provide services to all people with disability, many of whom may need no or few supports. Rather, the scheme is intended for those in significant need of support. These would be mainly drawn from those with severe or profound disability,"<sup>2</sup>*

If support was spread too widely to include people requiring only mild support it would dilute the resources available for those with serious needs.

## Rationales for and objectives of a long-term disability care and support scheme

*...informal carers and people with disabilities bear too much of the costs associated with disability,"<sup>3</sup>*

This point cannot be overstated. Existing levels of support in Victoria are so inadequate that parents feel they are neglecting their child if they depend solely on government funded care. In order to give our child the level of early intervention that is required to offset her developmental delay we MUST contribute significantly from our own personal income. This is further exacerbated when you consider that our income is already reduced from two wages to one in order to care for our disabled child.

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<sup>1</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 6.

<sup>2</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 7.

<sup>3</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 10.

*...there is lack of attention to the benefits of early intervention<sup>4</sup>*

We strongly agree with this position. Even well-meaning support groups often focus on the ‘incurability’ of disabilities and do not focus enough on forward loading early intervention therapy in the critical early years. During this critical phase of a child’s life it is not unreasonable to provide as much therapy as the family can handle in order to reduce and offset a lifetime of expensive ongoing support.

*Some people with similar levels of functionality get access to quite different levels of support, depending on their location or the origin of the disability — what some call the ‘lottery’ of access to services.<sup>5</sup>*

Having experienced the level of support in both Queensland and Victoria we feel we are in a unique position to comment on our experience using two very different services.

In Queensland the services provided by the Cerebral Palsy League of Queensland (CPLQ) were far superior to the localized services provided by councils in Victoria. We were very surprised by the drop in service delivery when moving from a smaller city to a larger one – we expected the opposite to the case. Specific areas of concern are:

- The waiting list to enroll into an organization such as Scope. We waited 3 months to receive service during which time we had to fund therapy privately.
- The lack of in house respite. The pressures upon the stay at home carer are enormous – especially if you have another young child to care for. The pressure of giving you special needs child enough attention competes with your other duties as a parent. Having someone come into the home to take the pressure off these other responsibilities is an incredible psychological benefit. The CPLQ provided 10 hours a week of in house respite with great flexibility as our circumstances required. In Victoria we receive 4 hours per week, no chance of increase.
- The lack of support. CPLQ provided physiotherapy in house once a week with an additional speech or occupational therapy on alternating weeks – totaling 2 visits from specialists every week. In Victoria we receive one visit every 2-3 weeks with speech / OT / physiotherapy alternating visits.
- The de-centralized funding arrangements. CPLQ served as a ‘One Stop Shop’ for all of our funding and support needs outside the hospital. In Victoria we have constantly been referred from one organization to the next as we pursue various funding and support opportunities.
- Even in Melbourne service levels vary from the eastern suburbs to the western suburbs. As we live in Keilor (western district) we are ineligible for additional services that friends receive living in the eastern district receive. This level of inequity is beyond absurd – it borders discrimination.

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<sup>4</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 10.

<sup>5</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 11.

We find the following statement concerning:

*However, given all the other competing claims on governments, there are likely to be some constraints in meeting all the preferences of people with disabilities and their families.*<sup>6</sup>

**People with disabilities are our most vulnerable.** If our Federal Government can dedicate \$1.2 billion of annual funding to private elite athletes pursuing lucrative celebrity status, then there are no financial excuses for failing to meet the needs of disabled. We would expect to see privatization of such schemes as Olympic sport funding before funds are cut from disability care.

## Key design elements of a new scheme

**National Disability Strategy.** The NDIS should be run centrally at the Federal level, with local support agencies subsumed by this new structure. While organizations such as Scope and CPLQ would continue to function, they would do so under the guidance and direction of the NDIS. This will result in a more equitable level of service.

**Centralised Data Collection & Information Technology.** Both Federal and State Governments have E-Health initiatives in various stages of development. We strongly recommend that these initiatives are leveraged to provide a central federal platform for the storing of medical information on the disabled (privacy issues and consent notwithstanding).

**Awareness.** As the TAC conducts high profile marketing campaigns with the intent of reducing the future liability incurred by traffic accidents, so to the proposed NDIS should raise awareness and understanding in the community of the benefits of early intervention<sup>7</sup>, rehabilitation and support. This would reduce the future support costs as people are given a higher quality of life and increased participation.

## Who should be eligible?

We believe the following criteria should apply:

- If the person would benefit from early intervention. If this could offset developmental delay.
- If the person has long term needs affecting day-to-day tasks
- If the person has a significant neurological disorder
- If there is significant and provable financial impact to the carers
- If the person is suffering from a catastrophic injury and cannot receive ongoing support through other means

**The scheme must not be restricted to new cases of disability only.**

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<sup>6</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 12.

<sup>7</sup> Myers S. and Johnson C. 2007, Council on Children with Disabilities. Management of children with autism spectrum disorders, *Pediatrics*, Volume 120, Issue 5, pp. 1162–82.

**The benefits must not be means tested.** Disability does not discriminate between financial status – so neither should our support of it. As mentioned above, people caring for the disabled are usually already penalized financially as we have been by losing one income- if I should choose to work harder to support my family why should that extra effort then exclude my child from the care she would normally receive?

Furthermore how do you explain that although you may be faced with a lifetime of ongoing support needs and pressure, but you are also ‘too wealthy’ to be given help? That would indeed be adding a literal insult to injury.

We must also consider the logic of means testing disability assistance when acquiring a disability will almost certainly affect your income regardless of your financial position. Are we to wait until a person’s finances are sufficiently depleted before we step in to help?

Finally, as the TAC benefits are not means tested nor too should the NDIS, for as you rightly observe the introduction of the scheme may be strongly resisted by those in society who are asked to pay the premium by way of an increased tax, but are ineligible to ever receive a benefit<sup>8</sup>.

## Who makes the decisions?

We support the concept of individualized funding. Expenses should be authorized and signed off by the regulatory body to ensure against misappropriation.

## The Nature of Services

**One Consolidated Case Manager.** Families should be given ONE point of contact through which they can channel their requests and needs. This can possibly be managed at the Federal level to avoid discontinuity when families move interstate. This contact point should be an appointed case manager who

- Has the means to follow up the carer’s enquiries with the relevant organizations.
- Has the ability to keep the carer informed of the latest updates with regards to services & support available.
- Will take pro-active ownership of the family and will be accountable for their needs, meaning that the carers should not feel that it is up to themselves to always ask for help. The case managers should initiate frequent and routine contact with the families.

Case Managers should be bound by a level of service (similar to professional Service Level Agreements) that determine response time to carer enquiries. For example: A case worker will return a phone call within 24 hours. A case worker will strive to resolve a serious issue within 5 business days (95% success rate expected). Too often carers are expected to chase support staff who frequently work part time.

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<sup>8</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 22.

In home respite must be increased and families with additional children / responsibilities must be given special consideration. This must be managed centrally as the existing model in Victoria (where local councils deliver the service) is of insufficient quality.

Early intervention / increased therapy is mandatory. People with needs should receive physiotherapy/OT/speech therapy twice a week. This must be the **MINIMUM STANDARD**. As previously mentioned this is a sound economic case as increased early intervention will reduce longer term care costs.

## Financing options

We support the funding method that manages future liabilities as this will provide better incentives to manage future risk through the provision of early intervention.

We believe a margin should be added to the Medicare Levy to fund this scheme as it is the most painless for the general population.

We do not support the following suggestion:

- *at least partial funding from the families of people with disabilities,*<sup>9</sup>

As previously argued, most families/carers of the disabled will face significant financial burdens regardless of which funding model is used. It is unfair to tax them further.

## Governance and infrastructure

One independent statutory body should administer the scheme, serving as the fund holder and the overall decision maker.

Carer-facing roles should not be outsourced to a 3<sup>rd</sup> party. Effort should be made to consolidate and centralize where possible.

A centralized governing body will remove the need to redundantly re-assess people or resubmit information across different agencies. As previously argued, various e-Health projects should be leveraged to prioritise information sharing quickly.

The NDIS should have reviews and open public consultations once a year to obtain feedback and give the community the opportunity to influence the scheme.

We feel that the following are candidates for immediate development (less than 12 months after approval):

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<sup>9</sup> Disability Care and Support: Productivity Commission Issues Paper – May 2010, Page 37.

- In house respite: Centralise management and increase level of service as outlined above.
- Early intervention: increase level of service immediately

These two areas do not require the creation of new processes, rather they are an extension of services currently in place. With additional funding there is no reason why these services could not be increased immediately. Changes in governance could follow.

We feel that the changes suggested in this submission should be fully rolled out within 3 years of approval of the scheme.

Finally we feel that this change must be mandated at the federal level with state and local governments forced to comply. If it is not mandated with firm resolve we risk the issue becoming political football between groups with self-interests at heart.