Disability Care and Support

Productivity Commission Draft Report

Submission on behalf of the
National Federation of Parents, Families and Carers

Background

The National Federation of Parents, Families and Carers was formed in August 2007 by a broad range of parents and families from all states and territories. It aims to represent and advocate for the interests of parents, families and cares as interests which are distinct from those of governments, service providers and charities.
http://www.civilsociety.org.au/federation.htm

The Federation's public policy principles are:

1. Person-centred and family-centred arrangements should become the norm in all forms of social support, service delivery and social investment – systems and institutions should be tailored to meet the personalised needs of individuals and their families. The 'one size fits all' model should be thrown in the dustbin of history in practice as well as in rhetoric.

2. Integrated whole-of-life arrangements should encompass all forms of social support and service delivery – individualised consolidations of funding from different programs, funding streams and jurisdictions should be introduced to enable these arrangements.

3. Empowerment of parents, families and carers to exercise enhanced choice and self-determination should be established as a guiding ethic in public policy.

Summary

1. The aggregation of existing Commonwealth and State disability funding programs in person-centred formats should be supported, but this does not require a new quango (NDIA) for its implementation. Block grants to service providers should be abolished, and existing funds made available to people with disabilities and their families in personal budgets.

2. The *Draft Report*'s proposal to increase disability funding by $6.3bn should be rejected until such time as a systemic restructuring of disability funding has been implemented. Only then will it be possible to know, with any precision, how much additional funding is required.

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Response to the Draft Report on Disability Care and Support

1. The *Draft Report's* recommendation for the aggregation of Commonwealth and State disability funding (a total of $6.2 billion annually) in person-centred formats, with a provision for mechanisms for self-directed and self-managed support, should be supported and implemented promptly.

It's implementation does not require a lengthy delay until 2014 for commencement. It can be done immediately where people with disabilities and their families have in place an existing capacity for managing a personal budget. In these cases, the funds should be simply transferred from existing programs to personal budgets, and not siphoned through a yet to be established intermediary or agency.

2. The *Draft Report*'s recommendation for a spanking new Canberra quango, the *National Disability Insurance Agency (NDIA)* should be rejected. People with disabilities and their families do not need a kind of Super Ministry with new Super Powers on all things disability. Restructuring $6.2 billion in block grants by allocating this money to 360,000 individuals in person-centred formats is not rocket science. New technology makes the use of self-management tools viable and inexpensive.

A transfer of funds and funding management authority to personal budgets under the authority of people with disabilities and their families can be undertaken quickly and quietly.

3. An independent mechanism is required for determining eligibility for disability support. The *Draft Report* does not contain any recommendation for such an independent mechanism. Instead, it assigns decision-making authority on eligibility to the same *Agency* (NDIA) that it assigns responsibility for managing the financial liabilities of the Agency (NDIA). This is a conflict of interest, a fundamental structural flaw, and a recipe for continued injustice.

This conflict of interest should be rejected in favour of a legislated schedule of entitlements for disability care and support, along the lines of the *Medical Benefits Schedule*, which is a transparent public document outlining entitlements to medical services.

4. The *Draft Report's* recommendation that funding for disability support be doubled, that is, increased by an additional $6.3 billion each year, should be rejected as a wild and groundless plucking of a figure out of the air, since no audit of existing waste, inefficiency and duplication in the system has taken place.

Normally, assignments given to the Productivity Commission require it to investigate inefficiencies and potential productivity gains that may flow from revised industry arrangements. In this case, the disability industry escaped scrutiny. The Commission's *Draft Report* accepts at face value the industry's claim for $6.3 billion in additional taxpayer funding, without any audit or investigation of inefficiencies and waste.

No-one knows how much additional funding, if any, is required to meet unmet needs in disability support. Without an audit of the economic cost of the current fragmentation in service provision, the Commission cannot know how much additional funding is needed. There is no integrated information system in disability that crosses service and disciplinary boundaries. There is no method for accounting for the financial cost of multiple assessments, constant form-filling, service duplication, and the perennial turnover of personnel.

Nor does the Commission or anyone else know how many people with disabilities require funded supports in a restructured system. The *Draft Report* states that 360,000 of the 4 million Australians with disabilities will receive funded support in a new system, but this too appears to be a figure plucked out of the air. Assessments of eligibility for supports have been highly variable and discretionary over the last 30 years. Some people with disabilities and their families receive regular interstate holidays at taxpayers expense. Others with high level needs receive nothing. Many who encounter a dysfunctional service system drop out, preferring to be left alone than to constantly jump through the system's hoops.

In Victoria, people with disabilities and their families are finding that service providers are routinely deducting 40% of the value of an individual support package in administration fees. These deductions are in many cases theft by another name. Individuals and families who self-manage these packages can reduce the administration costs to 3%.

In a current trial of disability support self-management in the ACT, people with disabilities have found that they can increase the number of support hours available to them **threefold** by eliminating the brokerage and administration fees siphoned off the middle man.

Without large scale use of systems and tools for self-management of support packages, additional disability funding will simply disappear into the coffers of the industry. There is no point in asking the Commonwealth to come up with an extra $6.3 billion in funding only to have 40% of the new figure disappear into the pockets of the middle men.

The *Draft Report*'s recommendation for an additional $6.3 billion in funding for the disability industry by the Commonwealth should be rejected until a restructured service system is in place. Only then will it be possible to determine, with any precision, the size of the budget required.

5. The *Draft Report*'s recommendations for the development of a viable retail market in disability services are half-baked and should be rejected. An accessible database of

comparative price and service quality on services should not be run by NDIA or any other agency that also determines eligibility for support and the amount of support available. Such information should be independent of both government, the services industry, and service providers, and should be developed under strictly delineated consumer governance, without a vested interest in the industry. Nor should such information be centralised. Competing sources of such information will serve the consumer interest more effectively.

6. Running throughout the *Draft Report* is a conspicuous lack of understanding of the importance of developing natural supports for people with disabilities and their families. The extent of the capacity for people with disabilities and their families to achieve a Good Life, with extensive community inclusion, is largely determined by the strength or weakness of their natural supports (family and kinship networks, friends, clubs and communities).

The *Report* fails to specify any initiatives for the development of natural supports. Models such Circles of Support, Mentoring, and Supported Living Networks, are being incorporated internationally into the building of support networks for people with disabilities, but the *Draft Report* appears to have never heard of these, or to not consider them to be important.

Specific resourcing should be considered for the development of assistance in building and strengthening natural supports for people with disabilities as an integral part of a new system of Care and Support.

Conclusion

The Productivity Commission Inquiry into Disability Care and Support was instigated by the Commonwealth Government in response to lobbying by the disability service provider industry for additional funding. The *Draft Report* has accepted at face value the industry's ambit claim for additional funding.

The *Draft Report*'s neglect of natural supports in favour of funded supports reveals its acceptance of the industry's worldview and its failure to explore in a holistic way the requirements for a new Disability Care and Support system.

In their *Final Report*, the Commissioners should reject the industry's push for additional funding of $6.3bn until the structure and culture of a qualitatively new system has been built on the ground. It should reject the concept of an all-powerful quango (NDIA) dispensing money, information, and access to services, as an ill-conceived and unnecessary incursion of a managerial culture into the living affairs of people with disabilities and their families.

A Good Life for people with disabilities and their families requires the building of supports which resemble, as much as possible, the culture of the natural community and which avoid, as much as possible, the culture of managerialism. Reform in disability requires the building of a person-centred support system, rather than a modern, corporatised, provider-centred, services-bound industry.

In their *Final Report*, the Commissioners should make an effort to incorporate this shift in culture into the *Report*'s assumptions, its thinking, and its prescriptions for system change.