SUBMISSION TO THE PRODUCTIVITY COMMISSION

On

Draft Report Disability Care and Support Overview and Recommendations

April 30th **2011**

INTRODUCTION

Physical Disability Council of South Australia believes everyone should have access to a decent life and enjoy all the benefits of citizenship. For too many people disability exacerbates disadvantage and excludes full participation in mainstream life. This lack of inclusiveness creates a tiered social structure, which can mean that people with disability can spend their lives in the lower strata of Australian society with limited opportunities to achieve positive quality of life outcomes. This harsh reality contravenes the United Nations Conventions of human rights and is grossly inequitable.

- The core principle of individual client choice and flexibility with regards to the development and implementation of support services for people with disability. Therefore we welcome and applaud the development of a national disability strategy. The introduction of an entitlement scheme for people with disabilities is, in our opinion, paramount. An entitlement based scheme would, for the first time, give Australian's with a disability and their families security, peace of mind, an ability to plan and empower themselves to have more control over their lives.
- Special needs groups require innovative flexible models of care including, people with multiple disabilities, Indigenous people, those from diverse cultural and linguistic backgrounds, and those living in rural and remote areas.

Agreed assumptions

The Productivity Commission Report begins with an acknowledgement that "the disability support 'system' overall is inequitable, underfunded, fragmented and inefficient." Although politicians from all political parties have raised these issues from time to time, governments of all persuasions, both state and federal, have been unwilling or able to make significant changes and improvements to disability legislation for almost 30 years, across Australia with a fair and equitable support system. Physical Disability Council of South Australia is pleased that the Commission has recommended key issues which underpin the dignity and fundamental human rights of people with disability and their families, and provide people with some real choices and flexibility. These issues include:

- The Australian government taking full responsibility for the entire needs of the NDIS:
- The NDIS being a federal authority with strong governance arrangements and an independent Board with legislation protecting the scheme from outside political influences;
- The reliable provision of services to ALL people with a no-fault basis;
- Fair and independent assessment procedures based on the person's support needs;
- Developing a real 'person-centred' approach. Not one size fits all;
- An assessment and support package which is portable;
- The ability for people to choose their service providers and, when appropriate, to employ friends, neighbours and family members to provide some aspects of their support;
- Encouraging service providers to develop and be rewarded for new and innovative initiatives in support services, thus allowing people with disabilities opportunities to

- choose support that meet their needs, interests and expressed wishes rather than simply trying to fit into existing well-entrench programs.
- A set of standards for service providers that will be evaluated by "directly observed and adhered to "consumer outcomes" rather than the current methods which often rely on the auditing of paper files and ticking of boxes.
- Funding for NDIS is provided by the Federal Government from General Revenue rather than a levy.

The Transitional Period

Although we appreciates the complexities of implementing the scheme, we are concerned about the length of the transition period from its initial introduction in 2014 to progressively cover "all relevant people with a disability" in 2018 (page 44).

In South Australia in the past two years, we have seen increases of 28% and, over the 12 months to June 2010, an increase of some 54% in the number or people with disabilities in urgent need of supported accommodation on the Category 1, Critical Unmet Needs List. This list is for those people who are in urgent need of support and who are described as an 'immediate and high risk of harm to self or others'.

Given the current dysfunctional disability support 'system' in South Australia, Physical Disability Council of South Australia can only see the numbers on this list continuing to increase before the introduction of the NDIS and over the initial years of the Scheme. Although the Commission's Report lists some priorities for service provision during that initial period (page 44), many of the individuals on the Category 1, Critical Unmet Needs List do not fall into any of those priority categories.

The Productivity Commission needs to add a high priority category, to operate from the initial introduction of the Scheme in 2014, which will allow urgent funding when required in situations of critical need.

The Productivity Commission also recommends that States and Territories with funding levels below the National Average will be raised to levels commensurate with those states that otherwise enjoy funding levels above that of the National Average.

Assessments

Physical Disability Council of South Australia believes that assessments must be "as objective as possible" and made finally by people "independent from the client" (page 17). It is essential that all stakeholders including families, treating doctors, specialists and any other person with knowledge of the person, their disabilities and needs, must have the opportunity to present their views during the assessment process (Recommendation 5.2).

We MUST assess ALL people with disabilities from the viewpoint of the 'whole person'. We MUST start to address the needs of the person, NOT JUST THE DISABILITY!, PEOPLE FIRST!

We must start to think about prevention and early intervention strategies and move a way from an emergency driven approach in assessment and service delivery.

NIS should provide funding at a range of levels according to the person's care needs and not based on funding caps and restrictions.

- The system should be easily accessible with easily identifiable points of entry.
- Where possible there should be one assessment to avoid multiple assessments.
- As people age the disability service system should be responsible for their ongoing support at an appropriate level.
- Models of accommodation needing to have the same freedom as everyone else in the community. Some sense of security tenya is required as well as individuals to be able to come and go freely, and for it to be a home life environment.

New models of service should be developed in response to changing community and consumer requirements.

Mental Health Sector

Physical Disability Council South Australia is concerned about the assessment and support of people with mental health issues (page 22-23). That for many people with long-term health issues. It is essential that they be eligible to access the same range of support options as people with other forms of disability.

People with physical disability struggle with a lack of disability services on a daily basis, it's common for clients to miss out on meals or only have two showers a week ,or be left in a wheelchair over night, this lack of basic personal care support leads to depression and other mental health issues.

It is understood that mental health illnesses may often be episodic with periods of disability interrupted by long periods of ability to cope with and live effectively in the community.

It is becoming clear that many people with a disability, as they age, are at a high risk of developing a range of mental health problems which may significantly impact on their ongoing support needs (dual disability). Co-morbidity of mental health in people with disabilities can be high. This may require NDIS to develop tools and procedures to identify these individuals and appropriately adapt their support packages to meet their changing needs.

For many years, governments have saved money by simply moving people between the Mental Health Services and Disability Services. Unfortunately, most of these people 'fall between the gaps and receive no support at all, as it becomes a cost shifting exercise between government departments.

Complaints system

The report raises the need for a complaints system and suggests the appointment of an independent person to act as 'Complaints Officer' as part of the National Disability Insurance Agency (NDIA) (page 32). This position must be seen as completely independent of other NDIA procedures. Perhaps the Commission could also entertain the notion of

appointing a Disability Commissioner who must have the legislative and statutory frame work to exercise immediate powers in the event that a report of abuse is made or a systemic problem accurse.

The process must be very simple, easily accessible and transparent. Many people with disabilities, after years of unfair treatment, are reluctant to complain about an issue they clearly see as an error or oversight because of the fear that a complaint will simply make their situation worse. For many others, years of failure to receive even a basic hearing of the issue have left them and their families feeling that to complain would be 'a waste of time'. We need to foster an environment where this process is seen as an opportunity to improve service quality.

There must also be a mechanism in place to ensure a rapid and efficient resolution of complaints. Unlike many other government promoted schemes, the NDIA must develop a reputation for dealing with complaints in a fair and Timely manner. Failure to do so can only increase further harm and bring about a lack of public confidence in the sector. Both systemic and individual Advocacy rights and services must be preserved and strengthened and remain independent of the disability service system and funding should be increased to meet demand, the success of overseas models should be investigated. We suggest the Commission include the right or even a requirement for, Case-managers, service providers and/or support workers to report issues on behalf of the people they support which they feel are unfair or of concern. Abuse by families, service providers or support staff, in its many forms, has always been a major issue across the disability sector and especially for those people with more severe disabilities.

Mandatory reporting of all forms of abuse of people with disabilities of all ages should be a feasible option and over time, should become a legislative requirement. There is increasing evidence that abuse and lack of involvement of people with severe disabilities in their support may be a major cause of 'challenging behaviours'.

The first review in 2020 should be moved forward to be held within two years of the commencement of the NIIS to help reinforce public acceptance of this structure.

The NDIS and NIIS systems must ensure that the community realises the fairness of and the reasons for the two schemes.

Mental Health

It is essential for many people with long-term mental health issues, to be eligible to access the same range of support options as people with other forms of disability. On-going mental health illnesses are simply another form of disability.

Mental health illnesses may often be episodic with periods of disability interrupted by long periods of ability to cope with and live effectively in normal community situations or the illness may develop later in life.

Long-term, on-going and permanent mental health problems should be able to apply for assessment by NDIA, and if found eligible, to receive the same type of support package as any other person with a disability, a whole of life approach must apply.

For those people with episodic mental illnesses, a broadening of the current Medicare system to include a wider range funding options for mental health treatments and supports may be a better alternative.

Inclusion of costs

Costs or expenses that are necessary to meet the needs of a person with a disability MUST be included in the funding provided by NDIS.

A person with an artificial limb has huge advantages over a person forced to remain in a wheelchair in terms of general mobility, ability to access activities, work options and community integration and acceptance. Who can possibly decide on a manual versus an electric wheelchair except the person who is going to have to use it?

Therefore, any item which increases the person's quality of life and helps the person to better interact with their community must be included in NDIA support packages.

For many disabilities including Multiple Sclerosis, or people with a spinal injury, hypersensitivity to heat or cold is a major problem and access to air-conditioning and heating is considered essential for a persons well being and longer life expectancy. Which is more expensive – electricity or hospital care?

ALL costs that directly impact on the needs and quality of life of the person with a disability MUST be met by NDIS helping to elevate the cost of disability.

Transport & Taxis

Transport is a major problem, particularly for people with physical disabilities. In South Australia, the Public Transport services fail to meet even the basic needs of people with disabilities. The Access Taxi service, because of the small number available, also fails to meet those needs. And yet, as the Productivity Commission reports, being able to attend community venues and to go to one's workplace greatly improves a person's quality of life.

The NDIS attempting to fund all necessary transport needs. However, just as for household items and modifications, NDIS should fund, or assist in funding, the purchase of a car or the modification of a car to enable a person with a disability to be free to transport themselves.

Currently, public transport and taxi services are state government responsibilities. State governments are aware of the need to expand and improve these services to meet the demand. They are also aware that an increase in the subsidies paid to people with disabilities would greatly assist people with disabilities to be more independent.

The funding of the NDIS should reduce the financial responsibilities on states to provide funds for disability services. Perhaps, as part of those Federal – State and Territory negotiations, an increase in mobility allowances and subsidies available should be negotiated to assist with this problem. The issue of Disability support must be seen as a' whole of government' responsibility and not just sit with disability Ministers.

Other issues and comments raised by Physical Disability Council SA members

- Change of culture is needed within Disability services.
- Rising Cost of Electricity, water and gas.
- Little or no consultation with stakeholders and consumers at a state government level in relation to the self managed funding trial in South Australia, poor process leads to bad service.
- Creativity and innovation is needed at all levels of government.
- Update and further support is required, mainly in regards to financial advice and assistance: for example, accessibility of disability representation and full participation at meetings.
- No or lack of awareness within Disability services, of what individuals with a Disability are fully entitled to under the law.
- Country people are naive to Disability Services. Only basic services are made available. For example: Individuals with a Disability residing in the country that needed alternative accommodation, only have the option to move to the city as that is where the services are located.
- Country people are geographically discriminated against, no consideration given about the extra cost involved with disability support in remote areas.
- "Country councils should have Disability Transport Access Representatives.
 Awareness of issues confronting people with disability should be initiated within country councils".
- "Parents must be included in care plans for family members with a mental illness."
- Mental Health requires more intensive counselling and support plans, with a strong focus on empowerment and promoting individual independence.
- For children with a disability needing equipment, the long time delay between when you are assessed and measured for a piece of equipment and when it finally arrives, the equipment is no longer suitable for the child's needs.
- "I am sick and tired of being a square peg in a round hole"
- "Having strangers in your home is hard"
- There needs to some recognition of the basic maintenance and cleaning is at the bottom of the priority when it comes to Disability waiting lists. A good healthy environment is vital for good quality of life.
- People with a Physical Disabilities can wait long periods of time for support workers to be replaced or employed. This lack of service provision has created a barrier for those with Disabilities. The Productivity Commission needs to give focus to rebuilding the Disability sector

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