Physical Disability Council of Victoria Inc. (PDCV)

Submission to the Productivity Commission Enquiry

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PDCV is the peak Victorian body representing those with a physical disability. The AIM is to promote equality of opportunity for people with a physical disability by providing a representative voice.

Our VISION is to ensure that the needs of all people with a physical disability are met in Victorian Government legislation, policies, services and programs enabling equal participation.

For too long people with a disability have been treated as 'second class citizens'. According to Australian Bureau of Statistics (ABS) statistics, 20 % of Australians have a disability (2003 ABS Survey of Disability, Ageing and Carers). In a 'just' society all citizens should be treated equally, including those with a disability. The much lower rates of employment among those with a disability, the 'costs' of disability, (over and above other living expenses), equipment (wheelchairs, hoists), attendant care, modified dwellings, modified vehicles etc. make a compelling case for a National Disability Insurance Scheme.

PDCV strongly supports the establishment of a National Disability Insurance Scheme.

Such a National Scheme would provide those with a disability the ability to participate equally in all aspects of Australian life.

People with disabilities need to be involved in all levels of governance in such a scheme .UN Convention on the Rights of Persons with Disabilities is the framework for the design of a new system requiring a significant cultural paradigm shift based on a human rights and social model of disability.

Use of the inclusive definition as set out in the UN Convention on Rights of Persons with Disabilities (UNCRPD). Article 4 (c) of the UN CRPD requires that States Parties need to take into account the protection and promotion of the human rights of all persons with disabilities in all programs and policies.

Suchy a proposed scheme is a national scheme would be:

- a. Based on entitlement for all who are eligible.
- b. Properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights.
- c. Based on equity for all who are eligible.
- d. Takes into account the impact of gender, indigenous background, cultural diversity and specific needs of children.
- e. Based on self determination.
- f. Committed to the empowerment of people with disabilities.
- g. Portable (a national scheme).
- h. Responsive to changing circumstances of an individual over their lifespan.

There would be a need for a strong independent advocacy support program is separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding. There needs to be transparency in funding arrangements and appropriate consumer rights protection mechanisms.

Support eligibility for disability support based on needs and shaped by the impact of a person's impairment on their capacity to undertake normal activities of daily living. It is critical that such a scheme maintains its capacity to respond to the complexity, diversity of need and context, allow for flexibility and resist the tendency of eligibility based schemes towards rigidity of policy and application of funding principles.

Recognize the need to include groups from the start that might fall through gaps – o Refugees and new migrants waiting for residency and citizenship papers

- o People with disabilities in correctional services system
- o People with disabilities in segregated settings, such as institutions and boarding or rooming houses

Include people with psychosocial disabilities and people with ageing related disabilities. While ageing related disability has been excluded in the terms of reference for this inquiry it is our view that a new scheme needs to consider this group as the needs and support strategies are similar across the lifespan. People with disabilities under the age of 65 when a new scheme is introduced should continue to be eligible beyond this age and for the remainder of their lives.

In relation to those people over the age of 65 acquiring ageing related disability prior to the introduction of a new scheme, the working group recommends that Productivity Commission Inquiry consider this in the context of links between this inquiry and the separate inquiry into aged care.

Develop an assessment process for individuals that:

- o Assesses individual's needs separately from needs of their family,
- o Is based on a social model of disability,
- o Is nationally consistent with uniform standards and conducted by well trained and prepared assessors,
- o Provides an assessment at a location or setting where the individual is most comfortable.

Funding for individualised disability support needs to support full participation in all areas of life – political, civil, social, cultural & economic – as set out in the various articles of the UN Convention on Rights of Persons with Disabilities. A definition of disability support needs:

To be broad to take into account the diversity of support needs according to the individual context – cultural diversity, geographic remoteness,

To allow for changing needs due to changing circumstances across the lifespan, and To have a capacity to respond to a crisis situation

The new scheme should provide support based on self-determination of need. This approach needs to make allowance for supported decision making for people who

require assistance and also needs to recognise the specific circumstances of those who are impacted by restrictive practices or who are in custodial settings such as prisons and institutions.

PDCV strongly supports the position that people with disabilities and their families will need access to a strong independent advocacy program that provides a range of advocacy approaches, both individual and systemic, to ensure that there is an effective capacity to protect and promote rights and well being in a new disability support scheme. This program should be funded such that both administration and delivery of advocacy support are independent of disability support program funding.

A new scheme will need to invest in initiatives that build community capacity, provide good information, encourage empowerment and choice and promote innovative development of disability support strategies that are life enhancing and value adding for people using individual budgets. In areas where "the market" can't respond effectively, specific development of supports may be necessary. The development of regional/local disability resource centres managed and operated by people with disabilities and their organisations is a possible structure for doing this work. These disability resource centres would also play a role in stimulating and supporting informal supports of families, friends and neighbours within local communities.

Research funding needs to be allocated under this scheme to identify gaps and program failures and successes to inform progressive improvements in both structural reform and models for individualised support.

The question of funding needs to be addressed at the individual level as well as giving consideration to the global budget requirements to make the scheme workable and sustainable.

1. Level of funding for individual disability support should be determined through a self assessment approach. Self assessment models have worked effectively in UK and much better than costly bureaucratic controls and assessment process. This requires an investment in trust – a complete reversal of current obsession with bureaucratic micro-management and intervention based on distrust of individual and family capacity to make good decisions around purchasing supports. The research

evidence, here and internationally, in programs that trust the individual demonstrate greater program effectiveness and efficiency. Self-determination should also extend to control in decisions about the process of how needs are met.

- 2. A number of suggestions have been put forward about how the global budget required to resource a new scheme is established. These include:
- A National Disability Social Insurance Scheme funded by an insurance levy (like medicare) to fund all legitimate claims for disability support. While the capacity to provide an entitlement based scheme is attractive when compared with current situation, there are also concerns about how the insurance culture might continue to paint disability as something negative to be insured against. Other concerns are how an insurance driven scheme might use cost driven thinking to impose support strategies that would undermine self-determination and choice for individuals. Eg. Might some deaf people be pressured to have Cochlear Ear Implants to save on interpreter costs? If this scheme is to closely linked with Medicare, there is a risk that it might reinforce a medical model of disability as against supporting a social model approach set out under the UN Convention on Rights of Persons with Disabilities.
- A new dedicated or specific purpose tax to be introduced to promote universal access to disability support funding. The purpose of such a tax would be to support an individual to fully participate in all areas of community life and to optimise their contribution to Australian society. It was suggested that funding allocated for this scheme could be benchmarked against the percentage of national Gross Domestic Product (GDP) committed to this program. This would create a basis for measuring government performance and assist us to track progressive or regressive trends in expenditure.

There needs to be an independent national body (statutory authority?) responsible for the governance of a new disability support scheme. Article 33.3 of the UN Convention states that "... persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process". Key features of such a body would be:

Board is made up of a majority of people with disabilities and DPOs who are representative of key constituencies across the nation. (Structure similar to former ATSIC but without the same administrative and operational functions). Representation would also need to take into account the need for gender equity and input from indigenous people and people from culturally diverse backgrounds.

It would make higher policy level funding distribution decisions.

It would support resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. Funding (in part) for such activities is already present in some jurisdictions such as Victoria and West Australia.

Costs of operating the Board would be funded through this scheme by Government, taking into account the full participation costs for board members and payment of sitting fees.

It would have a research and development role to drive significant cultural paradigm change around disability support.

This body would be underpinned by specific enabling legislation and report against UN Convention on Rights of Persons with Disabilities based performance measures. This would include funding for an independent complaints and appeals body.

Body to be reviewed regularly by relevant administrative review body.