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Productivity Commission

**People With Disabilities ACT
Submission to Productivity Commission
Inquiry into Long Term Disability Care and Support**

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Introduction

People With Disabilities ACT Inc, (PWD ACT Inc), is a not for profit consumer systemic advocacy organisation which represents the interests of people with disabilities in the ACT. Our commitment is to improve access to all amenities and to all forms of information and activities in the ACT community. PWD ACT also works to inform the community about disability issues.

Implications of the United Nations Convention on the Rights of People With Disabilities (CRPD)

We refer to the submission by the Australian Human Rights Commission in relation to the implications of the CRPD for the development of a National Disability Insurance Scheme

http://www.hreoc.gov.au/disability_rights/inquiries/NDIS.html

We believe that the CRPD provides the framework for the design of a new system based on a human rights and social model of disability and refer to the AHRC's comments on this aspect of the Commission's inquiry.

Critical Principles

We believe that there a number of principles that are critical to any systemic reforms of disability support. These are:-

1. The proposed scheme is a national scheme which is:
 - 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.
2. That all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. – costs not to be shifted to individuals and preventative mechanisms put in place to prevent this happening.

3. 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.
4. That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.

5. RESPONSES TO PRODUCTIVITY COMMISSION INQUIRY QUESTIONS

Who should be the focus of a new scheme?

We believe that a new scheme should use an ***inclusive definition*** of ‘disability’ as set out in Article 1 of the CRPD. Article 1 provides that

- ‘persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on

An equal basis with others.’

We also believe that a new Scheme should 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.

The new Scheme should recognize the need to include groups from the start that might fall through gaps –

- Refugees and new migrants waiting for residency and citizenship papers
- People with disabilities in correctional services system
- People with disabilities in segregated settings, such as institutions and boarding or rooming houses; and *people with psychosocial disabilities* and *people with ageing related disabilities*.

PWD ACT also asserts that while ageing related disability has been excluded in the terms of reference for this inquiry, that a new scheme needs to consider this group as the needs and support strategies are similar across the lifespan. Exclusion of people over 65 could lead to anomalies and situations in which age, rather than need, determines the supports which a person gets.

We support the view that an intermediate position in relation to ageing related disability should be established. 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.

Assessment Processes

The new Scheme should have an ***assessment process for individuals*** that:

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

What should a new scheme cover?

1. We believe that as a starting point, a new scheme should cover 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 CRPD***. The Scheme should include a definition of disability support needs. This definition should:

- be broad to take into account the diversity of support needs according to the individual context – cultural diversity, geographic remoteness,
- allow for changing needs due to changing circumstances across the lifespan, and
- have a capacity to respond to a crisis situation

2. A 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.

Need for Advocacy

We strongly support 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.

3. 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.
4. Significant work and investigation is needed to better understand how a ***“mixed market” that blends purchased services, informal supports of family and community and an individual’s own resourcefulness and strengths to achieve optimal outcomes***. There is limited understanding and support for this blended approach in the current service system arrangements and that a new system should enable this to be developed.
5. ***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.

How much funding? Who decides this?

This question 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. The level of funding for individual disability support should be **determined through a self assessment approach**. Self assessment models have worked effectively in the UK and are 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. We believe that the research evidence, here and internationally, supports the view that 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**.

Financing New Scheme

A number of suggestions have been put forward about how the global budget required to resource a new scheme is established. One proposal is a **National Disability Social Insurance Scheme** funded by an insurance levy (like medicare) to fund all legitimate claims for disability support. The capacity of this proposal to provide an entitlement based scheme is attractive when compared with the current situation. However, 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? Further, if this scheme is to closely link 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 CRPD.

Another option is 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.

We believe that **further research** is needed to develop a better understanding about both the market place economics and different models of insurance and taxation that could be considered to support such a scheme.

We point out that currently the total funding in disability support is administered by all levels of government with large levels of duplication in administration. A significant amount of the total disability support budget is spent before it reaches people with disabilities. There have also been many reports on service system failure and waste in various jurisdictions that highlight the broken nature of current approaches. We would encourage the Productivity Commission to include such reports in their research.

How should the scheme be governed?

We strongly advocate for **the establishment of an independent national body (statutory authority?) to be** 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”. This body would have a Board which is made up of a majority of people with disabilities and DPOs who are representative of key constituencies across the nation. Representation would also need to take into account the need for gender equity and input from indigenous people and people from culturally diverse backgrounds. The functions of this body could include:

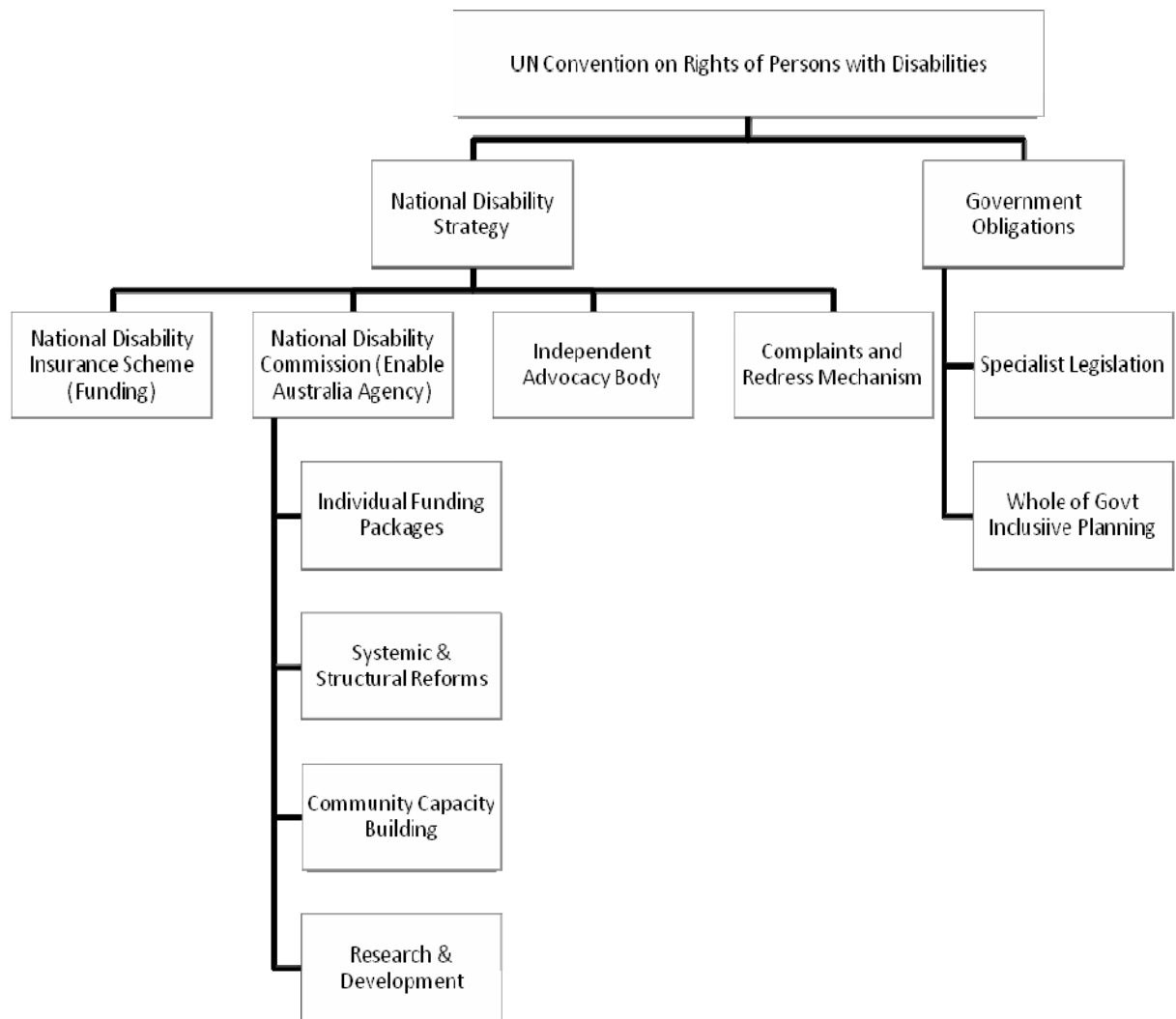
- The making of higher policy level funding distribution decisions and the resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation.
- The costs of operating the body would be funded through this scheme by Government, taking into account the full participation costs for board members and payment of sitting fees. This body 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 CRPD based performance measures. This would include funding for an independent complaints and appeals. This Body would be reviewed regularly in accordance with relevant Commonwealth Government practices.

Where does the proposed scheme sit with other government responsibilities to support the full inclusion of people with disabilities?

A new scheme for funding disability support can't address all the issues that impact on people with disabilities. Ongoing structural reform to address systemic barriers and remove discrimination needs to be properly funded and implemented. This is not the direct task of a national disability support scheme.

The chart below sets out how the proposed scheme might sit alongside other areas of action to promote the rights and full participation of all people with disabilities and their families



*****Description of chart for screen readers***

The chart inserted at this point sets out a hierarchy for elements discussed in this framework document and graphically represents how the elements fit together.

- *Level 1 Text Box – UN Convention on Rights of Persons With Disabilities*
- *Level 2 Text Boxes – Text box to the right is Government Obligations and listed under it are text boxes for a) Specialist Legislation and b) Whole of Government Inclusive Planning.*
- *Level 2 Text Box – Text box to the left is National Disability Strategy*
- *Level 3 Text Box - Under National Disability Strategy are four text boxes that have the following text – a) National Disability Insurance Funding, b) National Disability Commission (Enable Australia), c) Independent Advocacy Body, and d) Complaints and Redress Mechanism.*
- *Level 4 Text Box – Under the National Disability Commission (Enable Australia) text box are four elements: a) Individual Funding Packages, b) Systemic and Structural Reforms, c) Community Capacity Building, and d) Research & Development.*

How should a new scheme be implemented?

We are very aware that in the implementation of a new scheme, there will be substantial pressure to rationalise expenditure on the Scheme and to find cost savings. Accordingly, it will be important to position this scheme strongly within the government's obligations to implement the CRPD. The CRPD requires much more than access to services. It is based on supporting "full and equal enjoyment of all human rights by all people with disabilities".

While the CRPD provides for "progressive realisation" of social, cultural and economic rights, it is our view and the view of people with disabilities and their organisations that Australia has the economic capacity to address these responsibilities immediately. Accordingly, we will be advocating strongly for implementation of a new Scheme in a manner that is not compromised by rationing of funding or threatened by resistance to systemic reforms of disability support.

We suggest the following points as some of the steps that might need to be taken to implement a new scheme.

- Identify all existing disability support funding and administration funding provided through all levels of government. These include – National Disability Agreement, HACC & Mental Health.

- Consultations with consumer advocacy groups in aged care sector about whether people with ageing related disability should be part of this reform and at what stage should this happen.
- Identify capacity of existing funding to address current demands for support.
- Introduction of a new dedicated tax to address any shortfall in addressing current demands for disability support for all who meet eligibility requirements. This dedicated tax should include existing expenditure.
- Develop individualised funding packages for eligible target group commencing with current recipients of funding and then addressing unmet needs through a significant investment of new funding.
- Adopt learning from current initiatives that have already been commenced in various jurisdictions (esp. Victoria, West Australia, and FAHCSIA Business Services reforms) and utilise experience from working models in other countries.
- Significant investment required in workforce development and training to support a significant cultural paradigm shift in disability support. There is a need to better understand how far market needs will drive this reform and how much intervention from a more managed approach is needed to ensure sustainability of the workforce. Article 4 of the UN Convention should be used as the basis for professional training and development for support workers and their agencies if we are to achieve cultural change in disability support.
- Conduct a dialog within the disability sector and commission research on the topic of the merits and risks of professionalization and accreditation of the disability support workforce.
- Conduct a dialog within the disability sector to address current and projected Occupation Health and Safety barriers and associated risk management culture in agencies that provide disability support.