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# Submission to the Productivity Commission Inquiry into Disability Care and Support

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The Productivity Commission Inquiry into Disability Care and Support has the task of identifying a better national disability scheme for the support of people with disabilities. It has been asked to look at how such a scheme could be designed, administered, financed and implemented.

This submission follows the key questions asked in the discussion paper produced by the Productivity Commission and puts forward some key positions that we believe are consistent with a rights based approach.

The Inquiry has been commissioned on the basis that current arrangements are broken, inadequate and ineffective in meeting the needs of all eligible people with disabilities and their families. ***It is our view that the outcomes of the Productivity Commission Inquiry should lead to significant reform of current disability support arrangements on the scale of reforms similar to the introduction of compulsory superannuation and universal health insurance (Medicare).***

In developing this submission we put forward the following list of important principles that are critical to the success of any systemic and structural reforms in the way a national disability support scheme should operate.

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## Key Features of a Reformed Disability Support Scheme

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1. **People with disabilities and Disabled People's Organisations (DPOs) to be involved in all levels of governance in a new funding model.**
2. **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 a social model of disability.**
3. **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.
4. 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.
  5. This scheme will form a major initiative under the National Disability Strategy.
  6. 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.
  7. That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.
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## RESPONDING TO THE PRODUCTIVITY COMMISSION INQUIRY QUESTIONS

### Who should be the focus of a new scheme?

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The discussion paper released by the Productivity Commission raises the idea that a new scheme should target people defined as having “severe or profound” disability. Working Group recommendations are that a new scheme should:

- Use an ***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.*
- 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 –
  - 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

- 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. Strategically, we felt that an important 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, we recommend that the 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:
  - 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?**

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Our submission seeks to between what activities/initiatives should be funded under a new scheme and which of these should be addressed through a new disability support scheme and which were more appropriately funded and administered through other means. Key considerations include:

1. The need to address ***the inter-face and inter-relationship between systemic and structural barriers to inclusion for people with disabilities in Australia and their individual and personal support arrangements*** must be taken into account by the Productivity Commission Inquiry. Investment in making our communities and their services universally accessible and inclusive will lead to a reduction in the level of funding needed in personal budgets for support and equipment. Research into the additional cost of disability caused by structurally disabling environments and systems should be funded as part of the Productivity Commission Inquiry.
2. 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
3. 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.
  4. 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.
  5. 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.
  6. 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***. It is our view that 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.
  7. ***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.

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#### How much funding? Who decides this?

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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. 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 too 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.
  - **Private contribution** is also suggested by the Productivity Commission Inquiry paper. We do not support the idea of an asset test for full entitlement to the scheme.
  - We felt that **further research** is needed to develop a better understanding about both the market place economics and different models of insurance that could be considered to support such a scheme.

3. 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. It is our recommendation that the Productivity Commission should also ***investigate the cost of NOT implementing a fully funded national disability support scheme based on self-determined, individualised budgets.*** There have also been many reports on service system failure and waste in various jurisdictions that highlight the broken nature of current approaches. Productivity Commission to be encouraged to include such reports in their research.

### **How should the scheme be governed? By whom?**

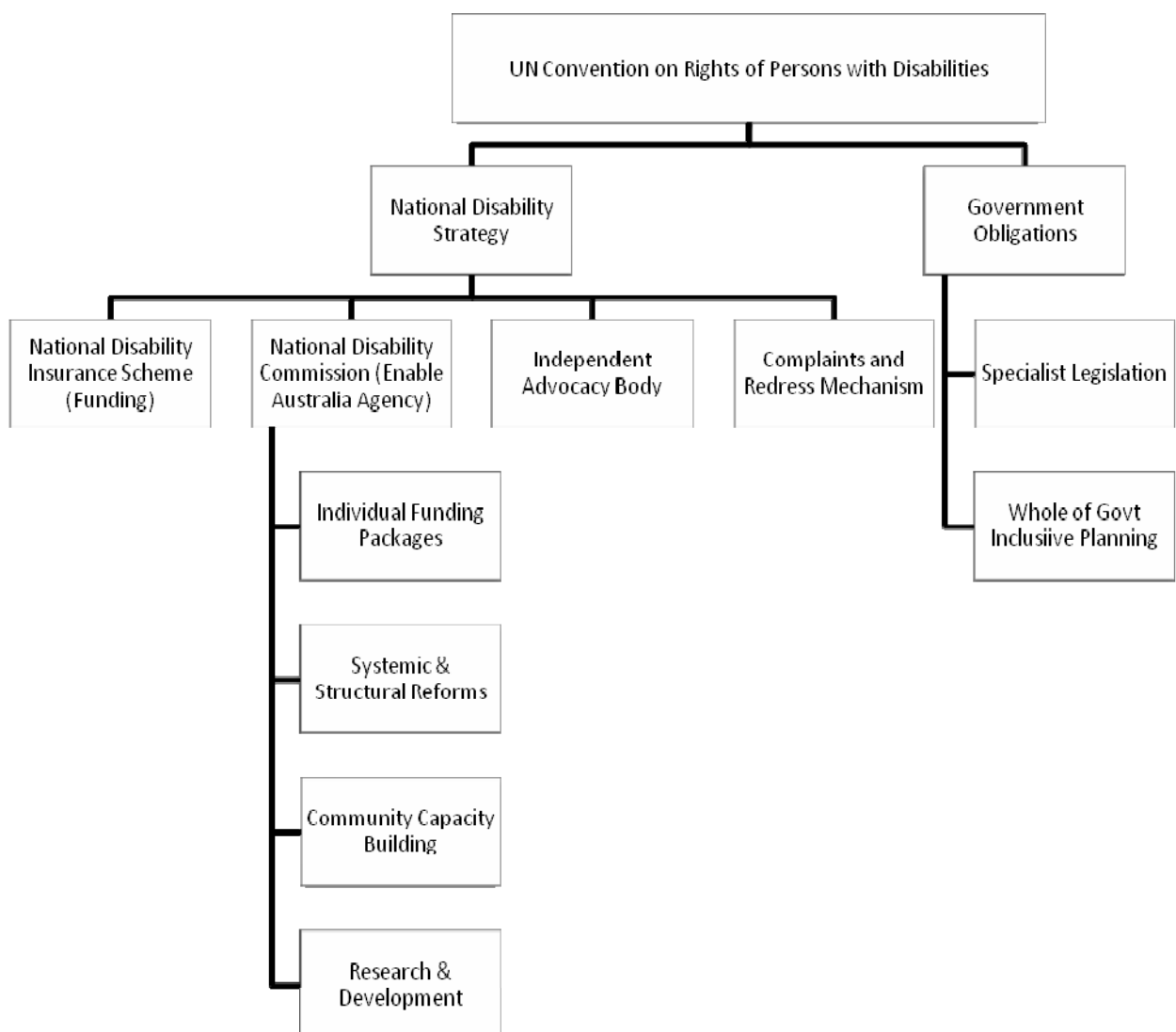
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We strongly believe that there is a ***need for the establishment of an independent national body (statutory authority?)*** responsible for the governance of a new disability support scheme. *Article 33.3 of the UN Convention states that "... persons 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 ATSIIC 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.

## 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 be expected to address all the issues that impact on people with disabilities. Ongoing structural reform work to address systemic barriers and remove discrimination needs to be properly funded and is not the direct task of a national disability support scheme. This chart 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?**

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The Productivity Commission is also looking at how we should move forward to introduce a new scheme. Pressure to rationalise expenditure on such a scheme will always be a challenge. It will be important to position this scheme strongly within the government's obligations to implement the UN Convention on Rights of Persons with Disabilities. The Convention requires much more than access to services and is based on supporting "full and equal enjoyment of all human rights by all people with disabilities".

While the Convention provides for "progressive realisation" of social, cultural and economic rights, it is the view of people with disabilities and their organisations that Australia has the economic capacity to address these responsibilities immediately.

People with disabilities and their organisations will need to advocate strongly for implementation that is not compromised by rationing of funding or threatened by resistance to systemic reforms of disability support.

The following points suggest some of the steps that might need to be taken.

- 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.
- Diverse opinions were expressed about the merits and risks of professionalisation and accreditation of the disability support workforce. This issue requires further attention and research.
- Develop a collaborative approach with relevant unions to address current and projected Occupation Health and Safety barriers and associated risk management culture in agencies that provide disability support.

## Endorsed by

Aboriginal Disability Network NSW  
Advocacy for Inclusion  
Advocacy Tasmania  
Association of Employees with Disability Inc. trading as AED Legal  
Centre  
Australian Federation of Disability Organisations  
Australia for All Alliance  
Deaf Australia  
Deafness Forum  
Disability Advocacy and Complaints Service of South Australia  
Disability Advocacy Network Australia  
Disability Discrimination Legal Centre of NSW  
Elder Rights Advocacy  
First Peoples Disability Network (Australia)  
Mackay Advocacy  
National Association of People Living with HIV/AIDS  
National Council on Intellectual Disability  
National Ethnic Disability Alliance  
NSW Mental Health Coordinating Council  
People with Disability Australia  
People with Disabilities WA  
Physical Disability Australia  
Physical Disability Council of NSW  
Queensland Advocacy Incorporated  
Southwest Advocacy Association  
Women with Disabilities Australia

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