Summary Submission to the
Productivity Commission enquiry on disability care and support

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People with Disability Australia Incorporated (PWD)

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People with Disability Australia Inc

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1. Organisational Background

People with Disability Australia Incorporated (PWD) is a national disability rights and advocacy organisation. We exist within the international human rights framework and provide a number of activities, which include individual, group and systemic advocacy, complaints handling, information, education and training.

Individuals with disability and organisations of people with disability are our primary voting membership. We also have a large associate membership of people and organisations committed to the disability rights movement.

We were founded in 1980, in the lead up to the International Year of Disabled persons (1981), to provide people with disability with a voice of our own. We have a fundamental commitment to self-help and self-representation for people with disability by people with disability.

We have a cross-disability focus – membership is open to people with all types of disability. Our services are also available to people with all types of disability and their associates.

We are governed by a Board of directors, drawn from across Australia, all of whom are people with disability. We employ a professional staff to manage the organisation and operate our various projects. A majority of our staff members are also people with disability.

We are part of an international network of disabled people's organisations through Disabled Peoples International.

We are a non-political, non-profit, non-governmental organisation incorporated under the Associations Incorporation Act 1984 (NSW).

Our activities are supported by substantial grants of financial assistance from the Commonwealth and New South Wales Governments, as well as a growing number of corporate and individual donors. This financial assistance is acknowledged with great appreciation.

2. PWD’s Knowledge and Experience

PWD conducts a range of activities, including individual and systemic advocacy, and the operation of the Complaints Resolution and Referral Service (CRRS) and the National Disability Abuse and Neglect Hotline (the Hotline) on behalf of the Australian Government’s Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

PWD has a NSW, national and international focus, and conducts significant work developing the capacity of disability organisations in the Asia-Pacific region.

PWD was instrumental in Australia’s involvement in the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and committed its resources to bringing this to fruition at a time when there was little support from the Australian Government.

In relation to this submission, PWD takes pride in representing the many voices of people with disability to bring a unique, yet crucial, perspective to this Inquiry. PWD is an actively inclusive organisation with:

- a strong affirmative action policy in relation to the employment of staff with disability. Of our more than 40 staff over 50% are persons with disability.

- a range of strategies to ensure the participation and inclusion of persons with disability from indigenous and diverse cultural backgrounds in its service delivery, including supporting representatives of indigenous and culturally diverse communities to participate in PWD’s Board, implementing an affirmative action policy in relation to staff from indigenous and culturally diverse backgrounds, providing information about its service in culturally sensitive ways, and ensuring that services are delivered in a culturally sensitive manner by providing staff with ongoing training in culturally competent service delivery.

3. PWD's Summary Submission

This summary submission firstly outlines PWD's position on the proposal for the delivery of a new disability care and support scheme that operates by directing resources at eligible individuals with disability, so that the specialist disability supports that they are provided with can work toward goals of inclusion and participation in the Australian community. This position will be articulated by a set of principles, which will also tie the proposed new scheme to Australia's obligations a signatory to the Optional Protocol of the CRPD, and reference specific articles of that Convention when assessing the types of outcomes that the new scheme must achieve. The principles also consider the potential for a National Disability Insurance Scheme to fund the new disability care and support scheme.

PWD and the Australian FDO have worked jointly to bring peak representatives and advocacy organisations together to explore and discuss the questions posed by the Issues Paper. This work has been done with support from the Australian Human Rights Commission (AHRC) and the National Disability and Carers Alliance. As this discussion progresses PWD may develop the ideas and issues raised in this summary report further, and report back to the Productivity Commission in its final submission.

The summary submission will then provide, in bullet-point form, responses to the key questions raised in the Issues Paper, which was released on 17 May 2010. These brief responses will describe the overall position that PWD takes on the various issues, and foreshadows a more comprehensive submission, which will be made available to the Productivity Commission prior to 16 August 2010.

1: Key Principles

1. **People with disability and Disabled People's Organisations (DPOs) are to be involved in all levels of governance in a new disability funding and support delivery system, and to have significant decision-making power regarding the distribution of funds that are available to the new disability care[i] and support scheme.**

2. **The CRPD is the framework for design of a new system requiring a significant cultural paradigm shift based on a human rights and social model of disability[ii].**

3. **PWD believes that the proposed scheme should be 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 the specific needs of children;**
    e. **based on self determination, in terms of both its operations and the outcomes it achieves for people with disability;**
    f. **committed to the empowerment of people with disability, in both its delivery and its outcomes;**
    g. **consistent nationally, and portable across all Commonwealth, State and Territory jurisdictions;**
    h. **responsive to changing circumstances of an individual over their lifespan and;**
    i. **respectful and trusting of people with disability to articulate their needs, be in control of their supports and understand the supports they require to participate in the community and have the same opportunities as people without disability.**

4. **People with disability who require assistance and support have the right to be directly involved in the process of assessment, in planning how they wish to use the funds, and in the discussions where the acceptability of the plans are decided.**

5. **A robust complaints mechanism must be established to ensure that people with disability have the right to complain if purchased supports and services do not meet their obligations or achieve negotiated outcomes; and this mechanism must be at the heart of the quality assurance system that governs specialist disability services into the future. All quality assurance and complaints mechanism must reference the human rights outcomes required within the CRPD.**

6. **There must be role clarity in the various functions that characterise the new system, between those who allocate and monitor funding; those who assist individuals to plan supports and those who deliver services. The system must be structured and resourced to ensure this role clarity is enabled.**

7. **A large range of service delivery options must be developed and available to accommodate the difference and diversity of people's needs, and to reflect their different aspirations. Any tendency to one-size-fits-all models of service must be avoided at all costs.**

8. **All existing obligations and commitments by governments, non-government organisations and the private sector to non-discrimination**

and inclusion of people with disability within the broader community and delivery of human services are maintained outside this scheme – i.e. costs are not to be shifted to individuals and preventative mechanisms are developed to prevent this happening.

9. **The scheme will form a major initative under the National Disability Strategy**

10. **A strong independent advocacy support program is separately funded to support and protect the rights and interests of people with disability funded under the scheme.**

11. **There must transparency in funding arrangements and appropriate consumer rights protection mechanisms.**

2: Key Questions (from Issues Paper)

1. Who should be in the new scheme and how could they be practically and reliably identified?

1. People with disability who require support and assistance. The definition of disability should be that utilised by the Disability Discrimination Act 1992. Amongst others, it includes people who are mental health users[iii].
2. The scope of the new scheme may not, initially, include people with disability who are over the age of 65 (and thus eligible for aged care support and services). Reform of the aged care system needs to take place, to better and more comprehensively cater for the needs of people with disability who are aged, but this needs to be considered separate to, and accommodate the positive reforms of, the new disability care and support system. However, it would be expected that, as the new system is implemented, progressively people with disability who are eligible for its supports, and who achieve the age of 65, remain eligible whilst the process of reform in the aged care system is underway.
3. Eligibility for inclusion in the scheme should be determined by a robust, internationally valid framework, and we recommend the utilisation of the World Health Organisation's (WHO) International Classification of Disability Functioning and Health (ICF-10), which meets the key criteria of validity and objectivity, and which also determines eligibility and assesses need according to a sophisticated classification that takes account of the functional limitations of a person, and their level of (dis)advantage relative to the social, economic and environmental context in which they live.
4. The development of the new system, and the level to which it is funded needs to take account of the interface and inter-relationship between systemic and structural barriers to inclusion of people with disability in Australia and people's individual and personal support needs. Given that infrastructure, social policy and community attitudes in large part continue to work against people with disability being included and participating to the same extent as those without disability, the initial outlay of funds to adequately cover the cost of the scheme will be significant. The growth in funds required in later years, as the population of people who are eligible for its funding grows, can be mitigated to some extent by the achievement of much greater accessibility within infrastructure, social policy and community attitudes. This should be the incentive for governments to continue to invest in making Australian more accessible and inclusive overall.

2. Which groups are most in need of additional support?

5. A key aspect of the new scheme is that it must be entitlement based, and universal. It must be a scheme that recognises the disadvantage that people with disability experience relative to people without disability, and must seek to include people in order to provide them with the assistance they require to be able to participate in the life of the Australian community.
6. All people with disability are in need of more, better and more consistent support across Australia, and the assurance of receiving support wherever they might be located. There are significant gaps in the current "system" of delivering support

and service to people with disability in Australia. There are, in fact, many different systems operating at local, State/Territory and Commonwealth levels, which, amongst other things, means that people with disability, if they move between or even within States, can expect differential treatment based on where they are located.

7. Systems must address areas of significant unmet need, and make responses available wherever these needs may arise. Particular discrepancies in consistency and equity of service delivery where a) the system in place does not address the needs of a particular minority, such as people with disability from a culturally and linguistically diverse (CALD) or Aboriginal and/or Torres Strait Islander (ATSI) background; or b) where different systems are in operation to meet the needs of people with similar needs, but who have different diagnostic tags, eg, people with mental health problems, who in NSW can have access to the Housing and Accommodation Support Initiative (HASI), but a HASI type program is not available in most other States; and the Home and Community Care (HACC) program, is differentially targeted in different areas across the country.
8. Supports must be available on an equitable basis (with the same expectations in terms of outcomes) for sub-groups of the target population, such as women, children, ATSI people living in remote communities, CALD communities, people living in segregated settings such as boarding houses and institutions.
9. The new scheme must not provide funds to operate models or types of support that do not comply with the CRPD. Despite disability services legislation in all jurisdictions, models of supported accommodation such as institutions have continued to be funded and even redeveloped.
10. Particular supports need to be provided to assist children and young people with disability, and to assist them and their families, to enable them to grow and develop to better be able to take up the choices that are available to Australian people when they achieve adulthood and move away from reliance upon their families as carers.
11. Funding for independent advocacy in all its forms (individual, self, citizen, systemic and legal) is woefully inadequate in Australia, and needs to be enhanced and increased by additional funding. There may be a case for funding to be sourced from elsewhere, but it is important to flag this as a continuing priority for funding in any future disability support system.

3. What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

12. The way that this question is currently understood underpins one of the fundamental problems we have in the delivery of disability supports, as it assumes an understanding of disability needs as solely related to diagnostic labels and to activity limitations. Thus, the goal of equity appears to be one of attributing the same resources and supports to people who share these two criteria, which in reality is wholly inadequate and will lead to outcomes which are not equitable.
13. The purpose of funded supports and services must be to provide assistance to people with disability to achieve their wishes and goals, as well as their needs. The idea of a service which exists for its own end must become a thing of the past. Currently people with disability, and the families and carers of people with

disability, aspire to “get into” services, and not to utilise services as a means to ends which they choose.

14. There will remain a need to administer the new system, based on principles of fairness, and ensuring that resources are targeted at meeting needs and achieving outcomes. There will be local differences in terms of the amount of resources provided and the type of supports that are able to be purchased, and the outcomes achieved. Locally based administrators will make decisions, based on nationally valid criteria. Currently we are working toward determining how funds can be administered most effectively at the local level, and are considering models similar to that operating in Western Australia (Local Area Coordinators), and also at locally run Disability Resource Centres, which could be governed by people with disability, which would provide more than just the administrative centre for the new scheme.

4. How could people with disabilities or their carers have more power to make their own decisions (and how cold they appeal against decisions by others that they think are wrong)?

15. The most straightforward mechanism to ensure that people with disability are empowered to make decisions, about their support, and also about their everyday lives, is to provide funds to direct to the person with disability, so that supports are purchased on the basis of what outcomes they can provide to that person as an individual. There are a number of support mechanisms which can be applied to ensure that a person with disability is enabled to manage these arrangements, but the fundamental principle is that the choice and decisions about support are in the hands of the person with disability, so that services become responsive to need and reliant upon quality service delivery to cater for individual need for their ongoing survival.
16. A contractual arrangement will likely have to be entered into to ensure that both the person with disability, and the service provider (if a specialist disability service is contracted), clearly understands what is expected of each other. Steps will have to be taken to ensure that people with intellectual disability and other cognitive disability, who are eligible to receive funded supports, can enter into valid contracts, without having to sign over ability to consent to a legal guardian (Article 12 of the CRPD requires all jurisdictions to look into strengthening mechanisms of supported decisions making, rather than substitute decision-making, wherever possible, and the new disability care and support system must lead the way in this respect. Representation Agreements in British Columbia have been use to enable people, chosen by the person with disability (on reaching adulthood), to represent them and their views when entering into agreements or contracts, without the need for guardianship. This could be one of the formal mechanisms which aid people with cognitive disability to formalise service agreements in the new system).
17. A key aspect of the new, individually-funded system of supports, is the provision of independent third-parties, who can perform a number of supportive roles to the person with disability in devising, managing and trouble-shooting the support and service arrangements that are put into place. Again, this is consistent with the expectations of Article 12 of the CRPD.

5. How should the amount of financial support and service entitlements of people be decided (and by whom)?

18. PWD believes there is a need for the establishment of an independent national body (possibly a statutory authority similar to the Crown Authority in British Columbia) responsible for the governance of a new disability support scheme. Key features of this body would be:
    - A Board made up of a majority of people with disabilities who are representative of key constituencies across Australia.
    - The Board having oversight of the implementation of the CRPD as part of its brief.
    - To make funding distribution decisions.
    - Costs of operating the Board would be funded separately by Government.
    - It would have a research and development role to promote significant cultural paradigm change around disability support.
    - This body would be underpinned by specific legislation and report against CRPD based performance measures.
    - Body to be reviewed regularly by relevant administrative review body.
19. The scheme would be practically administered through local offices across the country, where authority officials would interact with both service providers and people with disability, to make decisions about funding allocations, look at infrastructure issues, address service quality issues with relevant departments and organisations, and have a community development function, to ensure that goals of inclusion and participation for people with disability in that local area are met and sustained.
20. A fundamental principle must be the input of the person with disability into determining what needs of theirs need to be met through funded supports, and this information being valued in all discussions about how many resources are to be allocated, and for what purpose.
21. The assessment procedure should be used, by an explicit method, to generate a figure indicating the approximate sum likely to be available to the individual. However, this should be used only as a guide, with the actual amount determined through a process of discussion and negotiation between the individual and officers of the new system, who have the authority to make decision.
22. In the short term the assessment procedure will need to take into account the unpaid support (eg from families and carers) that is available to the individual. However, there should be a clear policy intention to move toward a procedure that disregards current unpaid support, in order to assist the person with disability move towards greater levels of self-determination. If this is not achieved, then people will continue to end up living with their parents and families, when in fact this might not their preference, nor that of their families.
23. The final amount of assistance provided should be agreed on the basis of a Support Plan, submitted by the individual, which identifies the resources required, a costing of how those resources are to be provided (regional variations need to be agreed upon, as the cost of support delivery in remote regions often greatly surpasses that delivered in metropolitan regions), how the money will be spent, how its use will compensate for the disadvantages experienced by the person with disability, and what outcomes will be achieved.

24. The basis on which the acceptability of the Support Plan is judged must be explicit and available to individuals with disability. A strong governance structure of and for people with disability at the authority would assist in ensuring this principle is maintained.
25. The criteria used to determine whether a Support Plan is acceptable should not reflect any assumptions that the funds must be used in a particular way e.g. on specialist services, or on services rather than equipment. They should avoid creating any pressure on the individual to adopt particular lifestyle challenges.
26. The final agreement to allocate individualised funds should be the outcome of a face-to-face negotiation between the individual, and/or representative and decision-making representatives of the new authority.

6. What kinds of services particularly need to be increased or created?

27. The new system needs to be focused on the delivery of supports, rather than the provision of services. This means a fundamental shift in the way that service provider organisations conceptualise the delivery of supports, to being flexible in the delivery of what is required to actually achieve outcomes for individuals. Many of the aspects of support provision that are currently delivered will continue, but the focus will be on achieving for the individual directly, not to the broad constituency of service user, with the hope that some good may come from the support that is provided. Targeted, professional and responsive services will need to be provided to ensure a significant paradigm shift in the supports that people with disability receive.
28. The past twenty four years, since the passing of the Commonwealth Disability Services Act 1986, have been spent trying to replace the totality of the institutional model with a patchwork of specialist services that cater to a particular aspect of a person with disability's life, eg. accommodation, day placement, employment, recreation, respite, behavioural support etc. The skills that practitioners have gained from applying these discrete services must be retained, enhanced and transferred to the delivery of individualised support responses that will need to draw on many skills from the one staff member/provider.
29. 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,
    - allow for changing needs due to changing circumstances across the lifespan
    - have a capacity to respond to a crisis situation
30. 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, detention centres and institutions.
31. PWD strongly supports the position that people with disability, and the families of people with disability, will need access to a national, 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.

32. 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” has failed, specific development of supports may be necessary. The development of regional/local disability resource centres managed and operated by people with disability and their organisations is suggested as a possible structure for doing this work. These disability resource centres might also play a role in stimulating and supporting informal supports of families, friends and neighbours within local communities.
33. The continued development and improvement of service infrastructure will need to continue, with less emphasis on forcing competition based on cost (for general disability support), and more upon the filling of skills and service gaps in particular locations.

7. How could the ways in which services are delivered – including their coordination, costs, timeliness and innovation – be improved?

34. The primary concern here is to ensure that supports are tailored to the individual’s needs and wishes, and are effective in meeting the goals of inclusion and participation which must lay at the heart of all support arrangements.
35. An individually funded system will drive innovation at the individual support level, which in turn will drive the growth of skills in being responsive and flexible in meeting individual needs.
36. The distribution of specialist skills, such as those utilised by therapists and allied health professionals, has never been well coordinated, and should fall to the responsibility of each State and Territory to ensure that all areas where people with disability may be part of the population, have access to the required professionals and their expertise when required.

8. Are there ways of intervening early to get improved outcomes over people’s lifetimes? How would this be done?

37. The principle way that early intervention can be applied is through a comprehensive, Person-Centred Planning process, which is implemented once a person is identified as being eligible for the scheme[iv].
38. Person-Centred Planning will be applied at regular intervals, especially in early life, to assist the person, and, at that time in their life, their family, to ensure that the supports are put into place to enable the child with disability to develop to her/his full potential, and to be included in the life of the community by way of attendance at school and other community activities.
39. Person-Centred Planning will continue throughout adolescence, addressing the major transitions and life changes, up to adult-hood, and also have the capacity to be implemented to take account of any unanticipated life changes, such as medical needs, changes in living or family circumstances, traumatic events etc.

9. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

40. The scheme will mandate that all supports and services are delivered in ways that involve and include people with disability in the life of the community, and will also frame the goals of people with disability in terms of community outcomes.
41. There are currently other Commonwealth programs recently reformed, that encourage and support people with disability unto paid work (Disability Employment Services, administered by the Department of Education, Employment and Workplace Relations). The new scheme should focus on how individual choice and decision making will impact upon other activity and employment options, such as Australian Disability Enterprises (administered by the Department of Families, Housing, Community Services and Indigenous Affairs), and day options (administered by the States/Territories) to ensure that more emphasis is placed on appropriate and properly remunerated work that people with disability have the capacity to engage with, and there is greater opportunity for training, development and transition to open employment. A more strategically integrated system of training, work options, together with industry development so that workplaces better understand the contribution that people with disability make, will assist in working toward more participation in the workforce.

10. How can a new system ensure that any good aspects of current approaches are preserved?

42. The governance structure will include people who are representative of people with disability, and will take responsibility for banking knowledge of best practice, and communicating this to the sector. Knowledge of best practice not only aids the delivery of supports, it also informs people with disability when they are seeking to make decisions about what supports they would prefer to meet their needs and achieve their goals.
43. The new scheme will have a significant research component attached to it. This needs to include oversight of the training and educational needs of all practitioners within the disability services sector. It may involve the development and implementation of a national curriculum, which addresses the adaptation required to bring best practice into an individualised funding context.
44. The new authority must quickly establish firm contacts with the Australian Industry Skills Council, and work quickly to identify new competency-based qualifications, and units of competency, that need to be established in order to provide base-level skills to workers in the sector.

11. What should be done in rural and remote areas where it is harder to get services?

45. The needs of people with disability living in remote areas of Australia are exacerbated by the lack of infrastructure (often), and the lack of suitably trained staff to provide the required support (frequently).
46. The flexibility inherent to the individualised packages, and the way in which funds are spent, allow for local innovation in terms of purchasing the required support, perhaps not from a specialist disability service provider, but from local people who

can be provided with specialist training to undertake the support required. Individually funded arrangements from around the world (in particular direct funded arrangements where people with disability employ their assistants directly) are characterised by the resourcing of local people, who may not have previous disability service experience, and who are trained up specifically in how to assist that individual.

47. Opportunities will also arise from a better funded system, so that service providers, who are able to respond to user requirements, may be better able to establish themselves where currently lack of resources do not allow.
48. The local offices that will administer the new scheme, will operate similar to the Local Area Coordination offices in Western Australia. Being based on local areas, and having recourse to a local advisory group, will assist in addressing shortfalls and innovating with locally available resources. Significant infrastructure deficits can be reported to the central authority, and begin to be addressed at the local level.
49. The administration of the new scheme, through local offices which are staffed by officers with a delegated authority to resource individuals, will allow for consideration of differential costings, based on the increased pay rates that staff in remote areas may command. This is one area of infrastructure improvement that needs to be addressed, and until it is solved the additional cost to the person with disability needs to be compensated.
50. Specific consideration needs to be given to working with people with disability from ATSI backgrounds, who are living in remote areas of Australia, and in communities which are self-governing or governed by structures which relate specifically to ATSI people. In these communities the notion of disability is not commonly recognised, and in addition to the scarcity of established service providers there are not the same mechanisms available to people to identify their needs or plan for outcomes. There needs to be a commitment on the part of the new authority to work sensitively, but persistently, to begin to communicate with people with disability from ATSI backgrounds about how to recognise disability, what supports can be put in place to address needs, and how best to assist people to be included in their communities.
51. An ATSI strategy (or suite of strategies) should firstly be a priority of the research function of the new authority, with a view to making it part of the infrastructure and community development function of the local officers of the authority.

12. How could a new system get rid of wasteful paper burdens, overlapping assessments (the “run around”) and duplication in the system?

52. The current disability system is administered within a range of complex Commonwealth and State/Territory programs, by multiple departments that answer to different Ministers, again Commonwealth and State/Territory, and is characterised by complexity, over-bureaucratisation and, ultimately, disarray. A single, nationally administered authority, needs to cut through this, by focusing decision-making on the individual at the local level.
53. The Commonwealth Disability Services Act is clearly in need of significant reform, both to bring it up to meet Australia’s compliance needs under the CRPD, and to accommodate the increasing numbers of people who require the type of support that the legislation was enacted to regulate. Significant omissions from coverage pertain in the legislation as it operates throughout Australia (with some variations

according to each jurisdiction), with an example being the lack of coverage provided to people with psychosocial disability. The service delivered to the latter tend to be administered by Health departments, and are not subject to scrutiny under the Disability Services Standards.

54. The single point of entry to the scheme should reduce the risk that people with disability who require support will be given the “run around”.

13. How should a new scheme be financed?

55. PWD supports the development of a nationally funded and administered disability support system, with funding levied specifically through the taxation system at a level sufficient to provide improved assistance for citizens with disability throughout Australia.
56. It is clear that revenue needs to be raised separately and distributed solely for the purpose of delivering the individual supports that people with disability require. A separately funded and administered scheme offers some protection to changes in governments and their policies, and marks a long-term commitment to ensuring that a significant proportion of the population is provided for.
57. Significant support is being given to a National Disability Insurance Scheme, funded by an insurance levy (like Medicare) to fund all legitimate claims for disability support. There is much to recommend this approach, especially with isolating the funds raised and ensuring that they are distributed through the one scheme, which requires that those funds be calculated and administered on an individualised basis. A negative of this approach is the tendency to paint disability as a wholly negative experience, which sets back the agenda to change community attitudes, which is an as yet uncosted barrier, but one which could be perpetuated should the scheme be launched amid this negativity. Another potential problem might be the imposition of, apparently, cost-cutting options, which again ultimately are costly to the community because they reinforce negative stereotypes about people with disability, their behaviour and their choices e.g. might some deaf people be pressured to have Cochlear Ear Implants to save on interpreter costs?
58. Another option being considered is a new hypothecated tax that is fixed on a set percentage of Gross Domestic Product (GDP). The net effect of this tax would be the same as the NDIS, but would be raised by means of the existing tax system, rather than be imposed as an additional levy on the tax returns of individuals.

14. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

59. The points raised above speak to some extent to the issue of separating both the income and expenditure for this scheme from other items of general income and expenditure in the Australian national budget. Greater certainty about the adequacy of funding can only be provided once it is better understood what the overall cost is. Thus, the new authority needs to develop economic modelling as part of its research agenda, so that it can quickly determine optimal funding levels, work out the shortfalls, inform funding decisions in the interim, and move

toward policies and strategies that can increase revenue through a variety of public-private partnerships and other means.

60. In the end enough money can only be guaranteed if the political will remains solid in this being a "non-negotiable" area of social policy in Australia. A commitment to viewing disability care and support in the same light as the need to provide education and health, would be a good outcome, although even then there is no guarantee that the level of funding would always be adequate to meet the goals set in the CRPD. However, the issue of entitlement should no longer be as much of an issue, if disability care and support was thought of in the same way as education and health.

15. What are your views about the "nitty gritty" aspects of a scheme that will make it work practically?

61. The fact that the scheme is national in its approach, and will aim for consistency and equity of outcome, is a strong point in terms of how services and supports can be counted on to deliver what people with disability need. The integrity of the Disability Services Act 1986 can now be re-established, and no longer watered down by State or Territory governments.

62. The national focus of the scheme also ties outcomes for people with disability to their enjoyment of their rights as citizens of Australia, and no longer consigns them to the vagaries of State and Territory interpretation of disability policy.

16. How long would be needed to start a new scheme, and what should happen in the interim?

63. 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 CRPD. The CRPD 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".

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

65. People with disability 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.

66. The following points suggest some of the steps that might need to be taken:
    - Identify all existing disability support 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 hypothecated tax to address any shortfall in addressing current demands for disability support for all who meet eligibility requirements.
    - Develop individualised budgets for eligible target group.

- Adopt learning from current initiatives that have already been commenced in various jurisdictions (esp. Victoria, Western Australia, and 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.

67. Consideration needs to be taken of the needs of service providers to up skill their workforces, and to adapt to the new, responsive support/service environment, in order to offer what people with disability will require to have their needs met. Some concrete indicators of service capacity need to be developed and measured, with the expectation that services can achieve full adaptation to the new system within two years.
68. Targets need to be set about the quality of life outcomes that people with disability are seeking to achieve as a result of the new scheme, and each service's ability to meet these targets needs to be assessed six monthly within the implementation period of two years.
69. In the two year timeframe the new authority needs to be fully constituted and established, the number and location of its local offices decided, and established, and local advisory groups also established.
70. In the interim comprehensive sector transition plans are developed.

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[i] PWD considers that the word "care" contains at best confusing, and at worst negative connotations, and will be advocating later for its replacement with "support and assistance" or something similar. Howevwer, for the purpose of this response it has been retained as the terms of reference refer to a disability care and support scheme.

[ii] The social model of disability refers to a body of scholarship, which has traditions in Europe (predominantly in the UK) and the North Americas, which identifies commonplace understandings of disability as informed by medical assumptions of loss or incapacity, and replaces this with the definition of disability as a form of disadvantage and oppression, experienced by people who experience impairment. The social model asserts that significant changes in the built environment and social policy need to take place to enable people with disability to participate on an equal basis with those who don't have disability, in terms of inclusion in the community.

[iii] We note that across Australia, within the Commonwealth and State/Territory jurisdictions, disability services legislation currently governs the delivery of specialist support and assistance. This legislation in need of review, firstly to ensure its compliance with the expectations of the CRPD, but also to extend its currently very limited coverage, which appears to more reflect portfolio demarcations (eg health departments and disability departments) rather than identified need.

[iv] It is noted that the term Person-Centred Planning is now commonly used to denote service-led individual service planning. When used here it refers to a developed set of methodologies that have been applied, largely overseas, to assist people with cognitive disability to identify their long- and short-term goals, outwith a service provider context, which can be used to inform specialist support delivery, but which is not constrained to this purpose.