Inquiry into Long Term Disability Care and Support

People with Disability Australia (PWD) Response to the Interim Report by the Productivity Commission into Disability Care and Support

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People with Disability Australia Inc

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1. Introduction

People with Disability Australia Inc. (PWD) is pleased to submit this document in response to the publication of the Productivity Commission’s Interim Report on Disability Care and Support, distributed on 28 February 2011.

PWD has made it clear in correspondence to its members and more broadly that it believes the Interim Report (hereafter known as “the Report”) to be a comprehensive document, that has successfully brought together a wide diversity of views and reflected the enormous interest shown by the Australian community in this matter, and manifested in the unprecedented number of submissions to the Productivity Commission, and attendances at its hearings. In addition, PWD has publically stated that the document is perhaps the most significant statement about the disability services system in Australia for almost 30 years, and its scope and detail, contained within its discussions and recommendations, form the platform from which people with disability in Australia now can see the possibility of significant paradigm change in the way that specialist disability supports are provided. In broad terms, PWD supports the idea of a funded National Scheme which would provide personal support for people with disabilities on an entitlements basis.

This submission will not attempt to comprehensively address the content of the Report, nor all of the recommendations. PWD is confident that Final Report, due in July 2011, will serve as the key reference document for service system change into the future. Given this, the current submission will address the following:

- The points and questions on which that the Productivity Commission has sought further information
- Aspects of the Report which are either missing or which PWD seeks amendment prior to the release of the Final Report;
- Key elements of change to the disability service system which need to be addressed by governments and their departments after the release of the Final Report, and to which PWD and other peaks will continue to make constructive contributions.

Finally, PWD thanks Commissioner Scott and Assistant Commissioner Walsh, and all of their staff, for the professional and inclusive way they have conducted this inquiry.

2. Issues the Productivity Commission seeks feedback on

The Productivity Commission has sought further information and feedback on a number of specific areas throughout the Report. This section addresses PWD’s response.

While the Commission has proposed a simple approach for the separate funding responsibilities of the aged care and disability sectors (draft recommendation 3.5), the Commission seeks feedback on other possible funding approaches (3.21).

Firstly, PWD believes that there is significant support for the bringing together of both the disability and aged care sectors, so that the boundary issues that the Report highlights, for those people with disability who attain an age where they become eligible for aged care support, are not faced with potentially disadvantageous conditions, either financially or in terms of the quality of the supports they will continue to receive.

The interim arrangements proposed by the Productivity Commission, whereby a person with disability who attains the requisite age for aged care, may continue to receive their disability support through their existing NDIS arrangements. The notion of paying for these supports, in the same manner as do people who have entered the aged care system (and not the disability service system), does not fit with the ethos of the NDIS being available to all those in need, and not being means-tested. We would be very concerned to see people with disability, who had been enabled through their own endeavours with assistance from NDIS, to participate in work, and achieve a reasonable standard of living, have that standard threatened by suddenly being required to apply the value of their cash and assets to funding their daily support – especially if this has increased, and if their income through work has ceased.

The current proposal is also discriminatory of people who are over the eligible age for aged care, and who experience a significant impairment that would, were they younger, render them eligible for NDIS. Our reading of the Report is that the reluctance to grapple with the possible bringing together of the disability and aged care sectors is largely to do with the relatively recent recommendations for change in the latter made by the Productivity Commission, and the need to affect significant and urgent change in the former prior to considering any such merger. We accept this, but in the meantime would recommend that any person with disability, regardless of age, be eligible for NDIS, if they meet the criteria which are eventually established, that enable a person to access Tier 3 supports. The effect of this would be, we believe, to enable many more people who are ageing and who have disability, to remain living with dignity in their own homes, rather than being placed in specialist, medicalised accommodation where their individuality and capacity to participate would be compromised.

The Commission seeks feedback on where the boundaries between the mental health sector and the NDIS might lie. In particular, the Commission would appreciate feedback on which system would be best placed to meet the daily support need (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia), including:

- which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified
- the magnitude of the budget that would be required
- how to guard against cost shifting
- how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector, including any shared responsibilities of case managers in the two systems (3.30).

PWD is pleased that the Productivity Commission has raised this point, and will be happy to work in the future with governments and their departments to arrive at a clear point of distinction between those goods and services accessed by eligible people with disability which should be resourced by NDIS, and those which should be resourced by other sectors, including the Health sector.

For the purpose of the Final Report, we believe there are a range of services delivered in the community currently, which could be easily understood as funded disability supports, and which would readily translate to provision under NDIS. In NSW, the rollout of Housing Accommodation Support Initiative (HASI) programs in recent years constitutes one of the biggest investment in supporting people living with psychosocial disability, and its method of sourcing housing from public and social housing providers, means that it draws on resources from a number of different agencies. The support offered in types of programs, where they exist, should be transferred to the NDIS for administration, as these arrangements could and must also be individualised. The coordination on the ground between housing and support and other providers, around the individual, easily constitute a Tier 2 arrangement, whereas the various MOUs that are required to guarantee the supply of housing fall within the responsibilities in Tier 1.

Some responsibilities which would lie with medical and health providers would include those delivered within a medical/hospital setting (such as acute admissions for people who are unwell), clinical case management services focused on the health and wellbeing of a client, community-based crisis response services, as well as regular primary health services and allied health services that are required as part of a person’s ongoing treatment. There will be some grey areas, especially around therapies (such as physiotherapy, psychological consultations etc), which could be construed as having a health orientation, but which tend to be available for purchase in jurisdictions where they have moved into individualised resources. There will undoubtedly be services which get their course funding from health departments, which will be available for purchase under NDIS, and it will be important not to proscribe these from NDIS. The way in which rehabilitation services are sourced and funded under NDIS is something that also needs further investigation prior to the implementation of the new NDIA.

In terms of funding, the above discussion indicates that funds currently allocated by Health departments (or state-based human service departments) for the obviously disability-oriented supports, should be transferred across to NDIS. Health services will remain funded under health, and it is likely that the source funding for therapeutic services will remain a responsibility of health departments, with it services being purchased through NDIS funds on an individual basis. The best guard against cost shifting is to make the system logical and straightforward, and to minimise the benefits to cost shifting. In NSW, there were significant savings made through lower acute admissions to hospital when HASI 1 was implemented, in addition to providing the type of support that people with psychosocial disability had been demanding for many years. Mechanisms of individual funding and choice should assist with ensuring that funds are targeted toward those goods and services that people really need.

In terms of shared responsibility and case management, this submission will later address the issue of NDIS case management (see section 3.1), and believes that case management is appropriate and will continue in the health sector, but is unwarranted in NDIS. Case management in the health sector will coordinate and oversee the various health and medical interventions which are required, and liaison will occur between the NDIA Local Area Coordinator and the medical case manager to ensure that the range of community supports are in place, or in need of modification of enhancement at any particular time.

Finally, and very importantly, PWD believes that people with health conditions, such as HIV/AIDS, were overlooked in the Interim Report, and need to be very much a part of the new NDIS, to the same extent as others who have disability (as defined under the Disability Discrimination Act 1992). Similar differentiations between support types are relevant to people in this group, as they are to people with psychosocial disability.

The Commission considers that the NDIS should fund artificial limbs and seeks feedback on the desirability and practicality of this option. What items should be included in the NDIS (4.9)?

PWD believes that a program of resourcing for prosthetics should be available through NDIS, but appreciates that many procedures to implant prosthetics are considered to be medical procedures. PWD is unsure how best to define procedures which clearly are medical in nature, but believes that the distinction can be made to differentiate between those which are medical, and those which refer to the provision of a prosthesis. The provision and fitting of an external prosthesis, which does not require a medical procedure, should be fully funded by NDIS.

Likewise there are complex issues in other areas and PWD believes that the emphasis should be on *consumer* choice within a rights framework in line with the emphasis on consumer control within the philosophical parameters of the NDIS. This choice should mean that there are no ‘’trade-offs’ between community access and assistive technology.

For instance, within the disability sector there is some controversy over the fitting of Cochlear Implants. Whilst these are fitted by choice by some (although it is often the hearing parents of deaf or hearing impaired children who take these decisions on their behalf), there are many in the Deaf community who choose instead to communicate fully using Auslan.

Were Cochlear Implants funded under NDIS PWD would advocate *against* making tradeoffs between this and the continued availability of Auslan resources as the maintenance of Auslan as both a language and a cultural tool is important to the wider community of people with disability.

In line with the overall direction of the NDIS we would want to see an emphasis on real choice and work to ensure that the provision of prosthetics does not drive perverse outcomes, such as tradeoffs against other supports, for those that choose different options to negotiate community barriers and maintain inclusion. .

The Commission seeks feedback on the arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disabilities (4.11).

PWD is of the opinion that additional costs of disability must be compensated for, if essential services and utilities impact in such a way as to endanger a person with disability, or lead to impoverishment. The privatisation of many utilities means that market forces now largely regulate prices, and there is evidence that electricity prices, for example, have risen exponentially in the past three years, and are at risk at rising further with measures to counter carbon usage. Whereas the “carbon tax” is in fact a range of measures designed to buffer the poorest of our citizens from the impact of rising electricity prices, price rises imposed by the private utility providers in recent times have not taken into account the impact those rises have had on those most challenged by poverty.

It is the view of PWD that government should require of utility providers, whether private or still under public control, that they take measures to rebate the cost of essential services, based on measures of affordability to pay, and on need. For many people with disability this will mean both that their capacity to pay will be reduced, and bills for usage should be amended accordingly. But all people with disability, who require additional service usage to assist in the support for their disability, must also attract a rebate for this essential usage.

The NDIA, as part of its Tier 1 activities, should be tasked with organising arrangements with all service and utility providers, to install these rebates. Some thought will have to go into how appeals and complaints about these rebates are made, as the NDIA is likely to be the obvious contact point for many people with disability who feel aggrieved by the bills they receive for essential services and utilities.

The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductable where the value of this support exceeds some government determined level. The Commission would welcome feedback on what that level should be (4.33).

PWD understands the focus upon contributions, given that what is proposed is an insurance scheme, but does not in any way support the requirement to contribute sums of money, either at the front-end or at any point during the period of time in which supports are provided to people with disability. It is only when looking through the prism of an insurance model that the logic of waiving fees for those who are able, in effect, to provide elements of assistance themselves, by means of informal or natural support, makes any sense. But from the point of view of seeking to implement supports which address the barriers which people with disability face, this actually imposes a further barrier, and discriminates unfairly against those who face even greater hardship, because they do not benefit from the receipt of family or other natural support.

In terms of “needs assessment”, PWD is still of the view that a robust and valid self-assessment process is preferable to the alternative that has been proposed by the Report, and this process will be holistic in its nature. The purpose of the self-assessment is not to prove entitlement or to lay claim to support resources for their own sake. It is, rather, to place the need for support within the context of the person’s life, so that the relevance of the support to the person’s aspirations, goals and needs can be clearly articulated, and its usefulness made obvious. In this process, the extent to which natural supports, as well as availability of local resources, are available should be assessed, so that the formal supports which are then provided are integrated and work well to achieve the desired outcomes.

The Commission seeks feedback on whether these tools, or any other assessment tools, would be appropriate for assessing the care and support needs of individuals having regards for:

- *the role of the assessment process in the context of an NDIS*
- *the desirable traits as outlined in section 5.4 (5.17).*

The Commission seeks further feedback on the effectiveness of monitoring instruments and any others that could potentially be used to assist oversight of the disability sector (8.35).

As discussed under the previous question, PWD reaffirms its commitment for recommending a self-assessment process, and does not accept that the Report’s preferred option of having unattached, independent assessors taking charge of this crucial process will deliver anything of quality that will be of use either to people with disability or to staff of NDIA. This is addressed below at 3.5.

The Commission seeks further feedback on the merits of the NDIA funding prevention and early intervention measures specifically targeting Indigenous communities, and how this could work in practice (9.15).

PWD has long been involved in working with Aboriginal and Torres Strait Islander people with disability. A significant proportion of people from ATSI background utilise our NSW Statewide Advocacy program, and in 2005-2007 we piloted a capacity-building program, which led to the formation of first the NSW Aboriginal Disability Network, and more recently the First Peoples Disability Network of Australia.

Our approach has been to develop capacity within communities, so that the identification of disadvantage associated with disability can be identified and addressed in a manner which is in keeping with the cultural requirements of that community. It is not the lack of identification of diagnosis which is the problem in the communities, but rather the lack of any suitable means to redress the significant disadvantage that people with disability living there experience. The lack of basic infrastructure in many communities means that the problems experienced by people with disability are different in nature to those experienced in non-Aboriginal communities, in that it is not so much about exclusion, labelling and the stigma of segregated provision, but more about the general lack of anything which can be of use.

The section in the Report on ATSI issues canvasses some important areas, but PWD would see the role of the NDIA as helping to create the general infrastructure within communities, that could address many of the needs of those people with disability living within them. A mix of “block” funding earmarked for infrastructure development, as well as individualised funding which focuses on the provision of equipment, modifications and personal supports, may be required, which raises questions about where else funds for these communities should come from.

In short, PWD believes there is much more that needs to be discussed about how to best equip Aboriginal and Torres Strait Island communities to ensure that their people with disability are included and valued. The capacity-building approach, whereby ownership of the responsibility for making this happen rests with the community itself, is a key foundation stone to then building necessary infrastructure and individualised supports, which will render communities accessible, and afford the opportunity of inclusion for the people with disability living within them.

PWD would like to see the Final Report of the Productivity Commission make recommendations for immediate research to be done on the lack of infrastructure and services within ATSI communities, as a matter of priority, and endorsement (and funded extension) of the capacity-building approach which has been adopted by the NSW Aboriginal Disability Network and the First Peoples Disability Network of Australia.

The Commission seeks feedback on a workable funding arrangement for catastrophic injuries resulting from water, air and railway modes of transport (16.10).

PWD has no expertise in this area, and trusts that others will provide the Productivity Commission with the information it seeks. However we do support the general principle that the arrangements should be structured so that people are entitled to the care and support they need regardless of how their disability was acquired.

The Commission seeks feedback on practical interim funding arrangements for funding catastrophic medical accidents covered under the NIIS (16.16).

PWD has no expertise in this area, and trusts that others will provide the Productivity Commission with the information it seeks. However we do support the general principle that the arrangements should be structured so that people are entitled to the care and support they need regardless of how their disability was acquired.

The Commission seeks feedback on an appropriate criterion for determining coverage of medical accidents under the NIIS (16.18).

PWD has no expertise in this area, and trusts that others will provide the Productivity Commission with the information it seeks. However we do support the general principle that the arrangements should be structured so that people are entitled to the care and support they need regardless of how their disability was acquired.

The Commission seeks feedback on the benefits and risks of requiring nationally consistent disclosure to an appropriately charged body responsible for monitoring and publicly reporting trends in legal fees and charges paid by plaintiffs in personal injury cases (16.41).

Again, PWD has no specific expertise or experience in this area, other than to comment on the general principle of requiring the disclosure of personal information for the purpose of monitoring. The balance between gathering information of a personal nature and the requirement to report useful information, must be tempered by the utility of the publically available information to those who are required to disclose. This issue will have to be addressed also in relation to the provision of personal outcome information, as the principal means by which public funds for support are acquitted.

3. Issues PWD believes need amendment or addition

In addition to the specific issues raised by the Report itself, PWD believes there are a number of issues that remain unclear, or are expressed in a way which are contrary either to the spirit and logic of the overall NDIS, or to CRPD, and which should be addressed prior to the publication of the Final Report. This section will canvass these specific issues.

3.1 **No NDIA Case Managers.** The Report recommends the establishment of a cadre of case managers to staff the local offices of the new NDIA, and to provide individualised support to people with disability who are eligible for assistance under NDIS. PWD instead recommends that, for the time being, the model of Local Area Coordinators (LACs), as developed in Western Australia, be adopted as the template for the role which locally based staff of the NDIA play in getting support to people with disability. These positions have worked well for many years within Western Australia, with the focus not on placing people in specialist services, but working to shape existing resources and add to them, to ensure that each person receives a unique set of supports which will work for them. People with disability are not “cases”, the new system is not about “management” of a suite of disconnected services – so the term is reflective of current service paradigms, and not appropriate to the new system. Finally, for those people with disability who interact with the health system, the practice of case management is still common, and having the position named in both systems would cause confusion.

3.2 **Need to recognise and respond to non-residents with disability**. The analysis undertaken by Dr Wadiwel indicates that the restriction of eligibility to residents of Australia does not comply with Australia’s obligations under CRPD, which does not discriminate on these grounds, and also does not comply with Australia’s obligations under the Convention and Protocol Relating to the Status of Refugees (CRSR). PWD joins with other peak disability groups to urge the Productivity Commission address this and other human rights omissions in its final report.

3.3 **Role of Advocacy must be acknowledged.** PWD, like many other Disability Advocacy groups and peak bodies, is disappointed with the lack of reference to the role that these organisations will play in the new system. In its original submission PWD clearly distinguished between the role of support agencies (which broadly has been described in the Report as operating as “Disability Support Organisations”) and Advocacy groups, who are needed for safeguarding the variety of issues which may occur for people with disability both within and external to formal support/service arrangements. There has been no explicit acknowledgement of the expertise that peak groups of people with disability provide on an ongoing basis to governments and to policy makers and enquiry bodies such as the Productivity Commission, and little consideration of the role that such groups need to play in the discussions and negotiations which must follow the release of the final report at the end of July 2011. Finally, there is no consideration of the paucity of funding currently available to these groups to undertake the amount of work that is expected of them, nor how the NDIS will support them into the future. It is our hope that this omission will be corrected in the final report, and that there is scope for much greater involvement by Disability Advocacy and peak organisations in the discussions to come about how the new system will be funded and implemented.

3.4 **Governance and decision-making by people with disability**. PWD is disappointed by the recommendation of the Productivity Commission to ignore the expertise that could be provided by people with disability in the governance of the new NDIS, and does not accept that token representation on an advisory body constitutes any effective way of translating their expertise in support delivery to the decisions that will be made by the recommended Board, which has a preponderance of financial experience. The rate of change which will occur within the support and service system in the early years of the NDIS, will require decision-makers who not only have experience and expertise of support delivery, but also can contribute to issues such as workforce development and training, and broader concerns about quality of support and how it can be measured and improved. Expertise in these areas will not necessarily sit within the governance structure as envisaged by the Productivity Commission in the Report, yet is as vital to the successful implementation of a new system as is the fiscal management that is undoubtedly required.

3.5 **Independent assessment process will not work.** PWD does not agree with the view of the Productivity Commission that the best and fairest way to assess for eligibility and identify need to be resourced through support, is by the resourcing of a cadre of independent assessors (Draft Rec 5.4.). Draft Recommendation 5.2. appears to endorse the process of assessment as valuable in itself, and in this regard PWD would agree – people with disability who have been subjected to miserable accommodation and other support options, with little or no choice, will benefit greatly from a process of understanding the possibilities for support and linking these to personal goals, ambitions and needs. But this will not occur if they are linked in with professionals who deliberately have no long-standing connection with the person, and the notion of “independent outcomes” appears to endorse the production of assessments which represent nobody’s interest. In place of this PWD believes that the process of self-assessment, backed up by person-centred plans, assessments of functional needs, and other assessments which are going to demonstrate the need for support, should be the principal means by which the needs of people with disability are presented to the NDIA for their consideration of the resources required to meet the reasonable outcomes for that individual.

3.6 **There must be an independent complaints body.** PWD believes there should also be an independent, complaints handling body, which has powers similar to State/Territory complaints and investigation branches to look into complaints about issues of support and service quality, abuse and neglect, systemic failure in mainstream services etc. This would stand apart from any complaints mechanism that operates within the new statutory body of the NDIA, whose function (the latter body) would be to investigate claims of eligibility or lack of resources, or other grievances which might occur from decisions made within NDIA. In these cases unresolved grievances could be escalated up through management of NDIA, and ultimately taken to external complaints handling mechanisms such as the Administrative Appeals Tribunal (AAT) and the Commonwealth Ombudsman. The independent complaints handling body would investigate complaints that occurred within any other area of the support arrangement, including the quality of support provided by service providers, the decision-making advice and support offered by DSOs, and the way in which generic services are delivered within a supportive framework created by NDIS funds. It could also undertake an important function of checking on the suitability of people who wish to work as direct care workers or managers within services or support arrangements funded through NDIS. The concept of a complaints handling body, with significant powers, which remains independent of government, has been recommended in the Rights Denied Report (French, Dardel and Price-Kelly 2009), and is dealt with further at 4.2.2.

4. Specific Issues raised with PWD at Canberra Hearing 8 April 2011

At the Canberra hearing on 8 April 2011, a number of specific issues were raised by Commissioner Scott and Assistant Commissioner Walsh, based on comments made by PWD, which in turn they asked PWD to provide further information about. These were:

- how to apply the framework of CRPD to the various aspects of the proposed NDIS
- what type of complaints handling scheme should be implemented, if that recommended in the Report did not suffice
- how a person with significant levels of disability, no speech, and ? can be supported – and how this support and housing arrangement can be distinguished from specialist "accommodation"
- how the ICF can be applied in a human rights framework to establish suitable benchmarks for eligibility and need assessment which meet the test of "reasonableness".

4.1 In relation to the application of CRPD, PWD does not intend to offer a detailed critique of the Report, but does wish to draw attention to a few instances in which findings and recommendations made have either ignored the CRPD as the overarching framework under which certain options are chosen over others, and, in other, where actual breaches of the CRPD would be incurred should practice be followed as the Report indicates it should. In this endeavour PWD is ably assisted by a draft report, prepared by Dr Dinesh Wadiwel, on behalf of a number of disability peak organisations, which directly analyses the proposed NDIS from the point of view of compliance with CRPD, and with a range of other human rights instruments which also need to be taken into consideration.

The issue of ensuring that eligibility for support under NDIS is equitable under existing United Nations treaties and conventions, specifically in relation to non-residents, has been addressed at 3.2. above.

Of particular concern is the section in the Report at 8.30-31, titled restrictive Practices, where practices that are unlawful are treated as requiring clear guidelines and regular scrutiny and reporting". As Dr Wadiwel has pointed out in his report, these practices violate a number of key human rights obligations, as well as being at significant odds with Articles 12, 13, 14, 15, 16 and 17 of CRPD, and contravene the spirit and intent of that convention. PWD believe that inclusion of this section in the Report, in its current uncritical form, serves to sanction the current unlawful practices that are perpetrated upon people with disability in our current, broken system. We would recommend that the Productivity Commission take note of the significant human rights breaches which Dr Wadiwel has pointed to should such practices continue, and make recommendation in the Final Report that the new legislative framework which governs NDIS must put into place strong mechanisms to outlaw and take action to prevent any such practices occurring under NDIS.

4.2 The Report recommends that an internal complaints handling process will suffice to offer to recipients and potential recipients of the NDIS an avenue for complaint on any matter which relates to any aspect that falls under the responsibility of NDIS/NDIA (check this). PWD believes that two, separate a venues of external complaints are vital to ensure that people with disability, as consumers of services, are protected.

4.2.1 The NDIA should have an internal complaint mechanism, which is essentially one of appeal, which can look into complaints related to allocations of resources, determinations of how resources are made available to individuals, under-allocation, and non-allocation. The conduct of NDIA staff would also be subject to this mechanism, which would seek to achieve resolution of complaints, but also escalate unresolved complaints to the level of the AAT (?), which would have the power to review and overturn decisions of the NDIA, but whose rulings would be binding. The framework for decisions and appeals would be the new legislation which is brought in to regulate the NDIS.

4.2.2 There should also be an independent, complaints handling body, which has powers similar to State/Territory complaints and investigation branches (eg, the Queensland Complaints and Investigation Branch of the Department of Community Services) to look into complaints about issues of support and service quality, abuse and neglect, systemic failure in mainstream services etc. Currently the Complaints Resolution and Referral Service resolves complaints made against disability services funded by the Commonwealth, but has limited resources and no statutory powers to conduct investigations into serious breaches that occur within funded services. The concept of a complaints handling body, with significant powers, which remains independent of government, has been recommended in the Rights Denied Report (French, Dardel and Price-Kelly 2009), accordingly:

> It is therefore recommended that the Commonwealth take immediate action to re-establish the CRRS under specific purpose legislation as an independent 'watchdog' agency. The legislation under which this agency is established ought to explicitly recognise the human rights of persons with disability, and require the agency to apply these rights in the performance of its functions. It ought also require the agency to recognise and address the multiple and aggravated forms of human rights violation and disadvantage that results from the intersection of impairment and disability with another characteristic including racial, cultural or linguistic minority status, indigenous status, gender and age. It ought to be invested with royal commission equivalent compulsory powers, and have at least the following functions:
>
> - A complaint handling function – the ability to receive, investigate, determine, and make recommendations in relation to, complaints raised by consumers

of Commonwealth provided or funded disability services and their associates;

- The ability to initiate 'own motion' complaints;
- The ability to conduct reviews of the circumstances of a consumer or group of consumers of Commonwealth provided or funded disability services. This ought to include the power to make recommendations to relevant respondents, including the Commonwealth, for remedial action;
- The ability to conduct policy and programme reviews and 'audits.' This also ought to include the power to make recommendations to relevant respondents, including the Commonwealth, for remedial action;
- The ability to undertake own motion enquiries into systemic issues impacting on consumers of Commonwealth provided or funded disability services. This ought to explicitly include power to investigate conduct of the Commonwealth and its agents in relation to the provision or funding of disability services;
- The ability to publicly report on the outcomes of systemic enquiries and group, policy and programme reviews, or audits;
- The ability to develop and publish policy recommendations, guidelines, and standards to promote service quality improvement;
- The ability to collect, develop and publish information, and conduct professional and public educational programmes.

Additionally, it is essential that the legislative scheme establishing the agency also provide for the enforcement of its recommendations, at least with respect to individuals, and personal remedies for harms perpetrated. In practice, this would probably require the matter to be referred to the Federal Court. Remedies ought to include prerogative remedies such as the power to make a declaration as to the lawfulness of particular conduct, the power to prohibit particular conduct, and the power to order the performance of a particular duty. Remedies ought also to include restitution and damages. The legislation ought also to provide for injunctive relief pending the final outcome of a complaint. The Federal Court's jurisdiction to provide injunctive and substantial relief ought to be 'costs-free.' (French et al 2009, 82-82).

4.3 At the Canberra hearing PWD made the point that to begin to achieve real change in the way that supports were conceptualised, we needed to separate the concepts of "housing" and "support", and to refrain from using the term "accommodation". It is argued that the latter term has tended to denote models of accommodation which integrate both support and housing, and which focus on efficiency of support delivery first and foremost. This in turn leads to difficulties for people living in such residences to make significant choices about their housing, or to claim their rights as tenants, and confuses the relationship for the service provider as one of providing support and also of being a landlord. Basic arrangements which place responsibility for housing in the hands of one organisation, and support in the hands of another, immediately solve the problem of conflicts of interest, and require us to think in terms of the extent and type of support that is required, and the best, most suitable and affordable housing in which a person with disability might choose to live.

The question posed to PWD effectively asks how both support and housing might be addressed for a person whose support needs are complex, and for whom safe and secure housing, in which that support can be easily delivered. Under individualised funding arrangements overseas there are no “models” as such – these are remnants of the traditional service system, which has continued to believe that specialist (and often thereby segregated) housing needs to be constructed, and people with a shared or specific diagnosis placed there. The particular example does not allow for the person to be identified or their context understood, which is the starting point for any person-centred support arrangement. However, accepting that the system needs to address the needs of people for whom environmental circumstances such as poverty, disadvantage, lack of family, social isolation, lack of employment and opportunity etc form the context in which support must be delivered, the question is whether or not mechanisms of individualised funding and self-directed support can adequately bring together the need for personal support and suitable housing. The answer to this lies in the evidence from overseas jurisdictions, where the focus has tended to be upon people whose needs are complex – whether this be people with physical disability and complex (24-hour) medical needs, or people with cognitive impairment and no speech. People with complex needs, once their support needs are worked out, have tended to make their homes in regular housing, with whatever modifications are required. Accessibility of housing, of course, needs to take account of the neighbourhood and access to local amenities, transport etc. But in general, the important element to get right is the support, which can greatly assist in making housing choices similar in scope to those which are made by other members of the public.

To conclude on this question, the important aspect of support for a person who shares the characteristics described above, would be the focus upon the decision-making and other support that is provided as part of that person’s daily domestic and personal support. The ability of many people with disability to make informed choices is limited, not only by cognitive impairment, but more generally by the woeful lack of effort made by service systems in up skilling people and honouring choices over the past 25 years. Adults, who are respected as equal before the law, will be at various stages of preparedness to make the kind of life choices that are required to direct the support they receive. Person-centred planning, external to the service delivery planning processes, will be more intensive and more frequent for people who need to learn these skills, and develop the trusted networks of support that are required to enable the person with disability to be at the centre of decision-making. Models such as the Microboards in British Columbia have proven effective in establishing these decision-making frameworks and networks of support to make this happen.

4.4 The International Classification of Functioning, Disability and Health (ICF) was developed after extensive consultation and vigorous international discussion, in the early 2000s, and represents the redevelopment of the International Classification of Disability, Impairment and Handicap, which had been in existence since the mid-1980s, and which had helped coined those terms/labels applied to people with disability worldwide. The international movement of people with disability, led by Disabled People International (DPI) original advocated that the World Health Organisation (WHO) abandon any form of classification, as it represented, amongst other things, the imposition of a medicalised understanding of the experience of disability, and helped reinforce the widespread commonsense view that the disadvantage and exclusion experienced by people with disability emanated naturally from their impairments. A compromise was reached when the two sides agreed to work toward a classification framework which included the basic premise of the “social model of disability”, that the principal disabling factors that impacted upon a person with impairment’s life were external to that person’s own abilities and experience. This led to measurements of disability being based upon three interacting dimensions: activity limitation, participation restriction, and environmental factors, with the interaction between each not necessarily being hierarchical.

This would indicate that the rights basis of the social model is infused in the way that the ICF works. Any assessment of eligibility and/or need could rely wholly upon a diagnosis, and assumptions which might be drawn from that. Instead it requires a description of a person’s activity limitations, and how these, together with the various environmental factors, limit their participation – and supports are implemented to address these with the goal of ensuring participation on an equal basis.

The question posed by Assistant Commissioner John Walsh, regarding how the ICF can ensure equity through a consideration of rights, and also by addressing the requirement for “reasonableness”, can only be partially answered by reference to the above. However, the three-tiered approach to the NDIS make much more explicit the requirement of the new system to face and eliminate systemic barriers which effectively exclude people with disability from participation. Many of these barriers lie in areas outside of specialist service delivery, such as within the education, employment and health systems. The alleviation of these barriers must come from effective policy action to ensure that generic systems do not remain discriminatory – but in the absence of quick action in these areas, some provision will have to be made by means of the individual support arrangements which are put in place for eligible people with disability, so their disadvantage does not continue. This will create a tension within the management of NDIS, to put pressure on other Australian policy and departmental institutions to reform more quickly and reduce the amount spent on specialist services which effectively duplicate what is available to the general population – or to continue funding this duplication indefinitely.

Discussion will be generated over the following months and years which will begin to address how this vast classification system can be practically applied to the task of assessing eligibility and contributing to a codification of individual need for the purpose of applying resources. The interplay amongst the three dimensions does offer, however, the basis for a reasonable assessment of a person's need, based on their lack of capacity to participate, and to target resources at assisting with their impairment issues, and/or addressing the various environmental barriers which hinder them.

5. Conclusion

In conclusion, PWD believes the Draft Report is a great step forward as we work for the introduction of a funded National Scheme which would provide personal support for people with disabilities on an entitlements basis. However in building a new system we have an opportunity and an obligation to get it right so that we are left with a sustainable system that supports our obligations under the UNCRPWD and principles of personal control. PWD maintains that there are many aspects of service quality which have remained unexamined in the process of the Productivity Commission enquiry. Three issues, already discussed above, epitomise the need for future deliberation to engage with service quality issues, and establish suitable mechanisms which will guarantee fundamental change:

- *Supported Accommodation*. The continuation of "supported accommodation" as a support/service option is predicated on the false assumption that it is better for both people with disability and services (in terms of the efficiency and effectiveness of the latter) to congregate people on the basis of arbitrary distinction, such as diagnosis, in a single building, and deliver support by staff rostered onto shifts. While the Report is strong on advocating a new and different system, built by resources channelled through individuals, the inclusion of these old and tired models as part of the mix reflects the lack of critical appraisal that has been granted to the impact of supported accommodation currently and in the recent past.

- *Restrictive practices.* The failure of the Report to critically engage with CRPD, in its arguments for progressive change (such as individualised funding) and against current repressive practices, is epitomised in the section on restrictive practices. This is perhaps also symptomatic of too much engagement with service providers in the push to change the system, or the credence which is given to their views over the views of Disability Advocacy groups and peaks. These issues are not service quality matters – they are issues of fundamental human rights, and it is the peaks who have been engaged with these issues over the years, and not service providers. A new system must take CRPD as its framework, and put its intent into practice.

- *Individual Choice and Decision-making*. The lack of focus on enhancing the ability of individuals to become informed consumers in the current system, is not emphasised strongly enough in the Report, again because there is too little note taken of current service quality failures. The new system will succeed only when consumers are informed, when choices are made based not on what service people can "get", but on what supports can assist the person "achieve". A different ethos in service provision to people with disability needs to be adopted, one which greatly enhances their capacity to take control of their lives, and to guide the supports they receive toward this end. This change in focus will not occur if the detail of how NDIS is developed and implemented takes place solely within the confines of

COAG and other forums where only departmental officials and service providers are present. The process from here must include Disability Advocacy groups and peak organisations, who can continually consult with their memberships and provide the expertise in how quality supports can be delivered within a human rights framework.

Finally, PWD has pointed to issues in the Report which we believe need addressed in the Final Report, and has pointed to other areas where discussion needs to take place after the Final Report has been delivered, so that the important details can be worked out in a truly consultative and collaborative manner.

Reference:

French, P., Dardel, J., & Price-Kelly, S., Rights denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment, People with Disability Australia, 2009