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**Submission to Productivity Commission - Long-term disability
care and support scheme.**

PHYSICAL DISABILITY AUSTRALIA LTD (PDA)

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INTRODUCTION

PDA is pleased to see the Productivity Commission Report (PC Report) of 2010 'Long-term disability care and support scheme' and agrees with the findings that Australia is in serious need of a new national scheme that does not disenfranchise people with disability further than they already are. .

PDA believes:

that people with disability:

- are excluded from much of 'mainstream' life including employment that so often determines a person's relative status in Australian society;
- are often treated like second-class citizens;
- experience very high levels of unmet need for support;
- have high levels of need that are not fully met, even for those who receive some support

and

- that these problems will escalate because of the ageing population.

We believe that any new scheme must be viewed from a social model of disability and cover all Australians at some time in their life. The UN Convention on the Rights of People with Disabilities is underpinned by the principles of the social model that value the citizenship rights of people with disability in all areas of social participation. The underlying principles of the convention include a non-discriminatory environment, accessibility, independence, dignity and equity¹.

PDA has pleasure in providing this submission to the Productivity Commission (PC) in response to the Inquiry into a long-term disability care and support scheme, (NDIS) report. .

PDA endorses the overall proposal for a NATIONAL Disability Insurance Scheme, which provides long term disability care and support in Australia.

However, PDA does have some reservations and identifies these reservations in this submission together with offering suggestions for improving the proposed scheme . .

The People We Represent:

Physical Disability Australia (PDA) is the national disability peak organisation representing the interests and views of people with physical disability across Australia. PDA is funded by the Australian Government through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

PDA is pleased to be able to make this second submission to the Productivity Commission on this most important issue. . We consider the Inquiry and its potential to focus on the needs of a person with the disability and provide surety of funding to be essential to the growth of Australia and to people with disabilities. .

According to the Australian Bureau of Statistics (ABS) in their latest release

“Just under one in five Australians (18.5% or 4.0 million persons) reported having a disability in 2009. A further 21% had a long-term health condition that did not restrict their everyday activities.... Of those with a disability, 87% had a specific limitation or restriction; that is, an impairment restricting their ability to perform communication, mobility or self-care activities, or a restriction associated with schooling or employment.”ⁱⁱ

These are physical disabilities and are the people PDA represents.

Physical disabilities can be permanent, episodic or temporary and can include:

- congenital factors
- trauma including accidents
- infection
- degeneration
- disease
- chronic medical conditions.

Physical impairments differ from one person to another. These differences can range from:

- difficulties with balance,
- gait and coordination;
- dizziness and weakness;
- pain or paralysis.
- communication by way of speech
- level of independence without support
- vision or hearing impairments

The most common physical disabilities are partial or total paralysis, amputation, spinal cord injury, various forms of arthritis, cerebral palsy, motor neurone disease, multiple sclerosis, muscular dystrophy, polio (including post-polio syndrome), spina bifida, and many respiratory, renal and cardiac diseases as well as cancer or diabetes that may affect mobility.

The NDIS:

The PC report recommends reforming the entire disability sector in its market-based approach where cost-effectiveness is the main 'principle' driving assessment, monitoring, evaluating and delivering services or individual funding programs. While the sector's should always be a consideration, the underlying philosophy of the scheme should be aligned to the principles that drive disability inclusion, which were outlined in the production to the report as a non-discriminatory environment, accessibility, independence, dignity and equity. As such the driving

principle of cost effectiveness is very different to being needs-based; it does not promote social inclusion (the report carefully says that whether an NDIS prefers "integrated service options", or by default segregated/congregated ones is determined by their cost-effectiveness). Further, it is contrary to the UNCRPD where disability arises from interaction between impairment, social values/attitudes and environmental barriers. This is a serious challenge to the principles of the UNCRPD, which Australia is a signatory nation.

The PC report appears to forget that attitudes and values are a major force in shaping disability experience and their assumptions that cost-effectiveness and efficiency drive social inclusion are not reflected in the research and practice-based evidence.

Framework:

PDA is concerned that the NDIS governance for example, is argued away in favour of a commercial board, more able to keep an NDIS strategically on track and financially sustainable than to have our direct disability membership on it. . A proposed advisory body that excludes people with disability is ludicrous and goes nowhere to supporting the disability sector belief in "Nothing about us without us". There needs to be recognition that there are very well qualified professionals with disability with the requisite specialist knowledge who should be co-opted on to a commercial board. Any commercial board needs to be well informed in the context to which their operations occur. Corporate Australia has numerous examples where boards did not understand the business to which they were advising.

After all, we are already aware of how watered-down and ineffective our current national advisory body is. The National Disability and Carers Advisory Committee needs urgent reform. This is not a criticism of its people per se as it was always too big to be effective, too amorphous to be decisive, meets too infrequently, has not got the autonomy it requires and has no authority to direct a professional team of staff dedicated to preparing independent advice across the whole of Government.

In addition, PDA believes that there exists in the NDS a formal role for advice from the state and territory disability advisory councils; however it has not been made clear how this relates to the governance structure and how the relationship will be made to work effectively.

PDA believes that any new scheme must be underpinned by obligations to the United Nations Convention on the Rights of Disabled Persons (UNCRDP). . Australia signed this Treaty in 2008 and it is contained within the National Disability Strategy to ensure that Australians with disability are treated equally to all other citizens. . Research is showing that any new system should help people with disability to realise their rights in society and must put people with disability at the centre of the decision making at all levels, in line with the settled will of the Australian Parliament that people with disability have, through the UN Convention, a legal right to be treated equally (Article 3 – General Purposes) and to be supported to be fully participating citizens in society (Article 19 in particular).

The focus of the new system must be genuinely empowering individual service users through personalised budgets, individualised funding and person-centred advice and decision-making

support. Services will find ways to change their service delivery to reflect a new commitment to putting people first as decision-makers.

PDA believes that all people with a disability, regardless of age and circumstance, should be eligible for any NATIONAL Disability Insurance Scheme.

PDA also believes that any new scheme must:

- Apply ‘Nothing about us without us’ as a fundamental way to work with people with disability.
- Focus on individuals and their needs as the foremost principle before the bottom line;
- Work co-operatively with all parties concerned;
- Focus on realistic individual outcomes;
- Allow flexibility for change throughout a person’s life;

PDA also believes that the NDIS should be an integral part of the National Disability Strategy (NDS) released in April 2011.

The lived experience of disability:

PDA in line with the CRPD views disability through a ‘lived experience’ of disability, which seeks to empower people with disability to control and direct their own lives. All PDA board members, where possible staff and all individual members are people with disability themselves. PDA reflects member statements that ‘disability’ can become an integral part of an individual’s life but does not define their life on the whole, however this is difficult to measure when lives are constantly impacted on by a society that does not provide for individual need in order to function. .

People with disability regardless of how that disability was acquired, birth, illness, trauma, often have specific needs in order to live independently in society and to the best of their ability. . In the words of one member referring to a proposed NDIS:

“We can fix the problems of the under-funded, service-focused support systems and fixing the problem is good for people with disability, our families AND for the long-term future of the Australian economy because a good support system turns people with disability into active social and economic participants rather than passive recipients of traditional services”.

The Productivity Commission (PC) report states that many people with disability believe that *‘disability arises socially, rather than medically. . In this case, disability reflects social barriers, such as prejudice, out-of date practices, and poorly designed infrastructure. In other words, while a person may have impairment, their disability comes from the way society treats them, or fails to support them. ‘ (PC Report 2010)*

PDA believes that any NDIS if it is to succeed it must also address the discrimination of separation, mistreatment, being ignored and 'Shut Out' to name a few issues and documents that pervade our disability society and we believe that the Federal Government must regard this as the first premise for any 'scheme' for people with disability in Australia. . Disability does not exist in isolation, and evidence shows that it is no longer appropriate to lock out 20% of the population because of misperceived attitudes and discriminatory practices.

We believe that much will depend on how catastrophic injury is defined. At present it seems that some injuries (such as those which arise from medical error in cosmetic surgery for instance,) could potentially be excluded (most of these are suffered by women and one of the highest rising areas of medical negligence claims is that of women).

PDA is also concerned with how mental health conditions will be dealt with. . We believe mental health should be contained within the NDIS otherwise this can be a further area where inconsistencies occur between states, and also in services available.

Eligibility

PDA believes that all people with disability, regardless of age and circumstances, should be eligible for any NATIONAL Disability Insurance Scheme.

The 'scheme' should be seamless in that it sits beside each individual in Australia from birth through to death in a quiet and unobtrusive way that ensures confidence. That, in the event a disability comes into their life, regardless of how, where or why, that this 'scheme' will meet their disability needs at any stage of their life to come. .

This includes children with disability and ageing with a disability. . Where a person has a pre-existing disability at age 65 for instance (or appropriate age) the individual needs as a result of that disability will be met under the NDIS until the person dies. In other words the person carries the 'package' with them for life.

PDA believes that people with psychosocial disability should also be included in NDIS, as well as people with chronic health conditions as well as their ongoing health and medical treatment issues.

PDA is surprised that people with disability are pushed into the role of a sub group in the report, with a role for an Advisory body for the NDIS. .

We believe that it is essential that people with disability play a large role in being valued as experts when considering their own needs and those of others in similar situations.

PDA therefore recommends that people with disability be included first and foremost in any advisory groups, along with the technical persons and government staff needed for such a body. . Each person on that Advisory body would be an equal partner in decision making.

We believe this is consistent for any truly National Disability Insurance Scheme in our view.

Assessment

Assessors should be selected by an individual who is comfortable and trusting of the person who is to assess them. . These can be through teams of assessors located throughout the country, or an assessor who works for an organisation supporting individuals, or some other method. .

We do not support Government putting in place a team of assessors as this harks back to the old Commonwealth Rehabilitation system in place some time ago, and which has since vanished in its previous form. . People these days want choice and that includes who they trust to work in their best interests.

We find also in the report, that there is little mention of advocacy in the NDIS, when in fact advocacy or the further development of advocacy seems ideal to us to be where assessments should take place.

Co-payment

PDA does not support a charge for any part of the proposed scheme. . People with disabilities are already amongst the poorest citizens in Australia and may not be able to meet any co-payment, resulting in not addressing their needs, suffering further disability or worse. .

PDA in 2001 surveyed its members about the extra cost of having a disability. . One of the conclusions was that there were indeed, significant costs directly associated with having a disability that other citizens of Australia did not experience. . This is supported by several research papers including government studies overseas. . These same costs have not gone away, but have increased significantly, if listening to our members is anything to judge by.

PDA therefore believes that the NDIS:

- Must not exclude some types of disability i.e., mental health,
- Not charge for person with a disability to access the scheme, in any way;
- Must be available by right to babies, children, youth, adults and people who are ageing. . In other words, all Australian citizens;
- Must have a particular emphasis on ‘raising the bar’ on Australia’s First Peoples;
- Must not be means tested in any way;
- Must be rights based;
- Must have criteria for eligibility based on equity, justice, inclusion and realistic outcomes.

The ‘scheme’ should be seamless in that it sits beside each individual in Australia from birth to death in an unobtrusive way that ensures confidence for individuals, their children, their

parents, friends and families, that in the event a disability comes into their life, regardless of how, where or why, this 'scheme' will meet their disability needs at any stage of their life as soon as possible. .

This includes children with disability and ageing with a disability. . Where a person has a pre-existing disability at age 65 for instance (or appropriate age) the individual needs as a result of that disability will be met under the NDIS until the person dies. In other words the person carries the 'package' with them for life.

This is consistent for any truly National Disability Insurance Scheme in our view.

Definition of disability:

Any definition used in the NDIS must take into account and be consistent with the UNCRPD as Australia is a signatory to this convention.

Individualised funding

PDA believes strongly in Individualised funding for those that want to be self-funded. . In the instances where individuals prefer existing systems or other methods of securing services needed, these need to be worked out as part of the NDIS process and a management plan.

Individualised Funding has already arrived in Australia. . For instance in December 2010, the former NSW Premier announced stage 2 of Stronger Together 2, another \$2.04 Billion of much needed growth for disability services.. A large amount of money in anyone's language; enough to make serious change possible. One of the philosophical shifts contained within the announcement was in favour of individualised funding, personalised budgets and more self-directed support. All those service types are available as of now but not immediately to every service user.

From 1st July 2014, however, any and every service user will have the right (but not an obligation) to take their service package as a portable, personalised, individualised, self-managed allocation. One of the good reasons for setting a future date for the whole system reform - as frustrating as the delay must be - is that the current old system simply doesn't have the capacity, new service models, advice, brokerage and decision-making systems in place to allow all people to immediately exercise a choice to take a personalised package.

Funding the NDIS Scheme

PDA believes that any new system must be fully-funded and the PC recommendation to use general taxation appears to be the simplest and most-cost-effective solution.

PDA notes that the PC inquiry did not assess the existing 'dysfunctional' service system for its wasted resources arising from programs where needs are ill-conceptualised and targeted, disabling values drive services and unnecessary bureaucracy sucks up resources a person with a disability might well be able to use for a shower or other personal assistance. Therefore it

seems to us that the PC has extrapolated its figure from what it currently costs the government to deliver a lot of bad services.

National Injury Insurance Scheme (NIIS)

PDA does not support a two tiered scheme for the National Disability Insurance Scheme. . We believe this to be inequitable to stakeholders. . PDA is concerned that this will continue to lead to the ‘haves and have nots’ already experienced in disability by those who are compensated for their disability by accident where insurance is involved, as opposed to those who are not entitled to compensation, for example born with a disability or acquired a disability through ways other than trauma (where fault can be attributed to an insured 3rd party).

In addition those who are compensated under the existing system, face large legal, hospital and rehabilitation costs, as well as taking into account compensating for a future with a disability (pain and suffering, loss of future enjoyment, career impact etc.). Currently this can take years before it is finalised in a courtroom by an awarded amount.

Ideally, there should be one scheme. But we're not starting from scratch. . There are two-tier arrangements already in place (e.g. the NSW disability services system funded through general taxation and the NSW Lifetime Care and Support Authority system for road traffic accidents funded by a levy on compulsory third party vehicle insurance). Similar dual approaches exist in other parts of the country.

However, PDA is concerned that there are many inconsistencies in these current insurance systems (Workcover, Vehicle 3rd Party Insurance) and the many other private insurances that can be purchased, that people with disability will be caught in between the complexities of these systems. . We believe that one system, with insurance playing a part behind the scenes is the best way to move forward for Australians with a more universal No-Fault system similar to that of the NZ Accident Compensation System, where there is a no-fault system of injury insurance in place.

How will compensation be worked out? Would a person who has acquired a disability through an accident receive the same settlement as someone with a disability through illness or disease or from birth?

Will there still be fixed lump sum payments or the option of a structured settlement, although we believe structured settlements are almost never taken-up voluntarily. . In some instances, a court appoints a trustee to administer funds especially for those under-age.

PDA believes therefore that common law rights to seek restitution for damages can exist alongside an NDIS through the creation of a hybrid scheme and we would encourage the Australian Government to explore this possibility further before settling for a system that separates people with disability into different categories and forces a person with a disability to be part of a legal triangle as is now the case.

An NIIS will continue to expose people with disabilities to the 'blame game' in legal circles. . After all someone has to be proven responsible in order to elicit a successful claim from an insurance company, whose brief is to prove otherwise, in order to gain a pay-out regardless of how much information is put forward in this report.

PDA is also concerned that the injured party bears the risk that a final lump sum will not meet all injury-related needs for their lifetime. . For example, if funds are insufficient or mismanaged, social welfare, health and disability services are relied on in the longer term, defeating the purpose of going through the court system in the first place. . In other words, the proposed scheme bears the risk of taking responsibility to meet all injury-related needs (subject to legislated conditions) for the life of the injured person, only to run out of funds at crucial times in the person's life.

Working with other areas of Government.

Crucial to successful lifestyle are the many other services provided by governments. . We believe that there should be processes in places that are person centred and client focused for referral systems in housing, education, employment and income support and health in order to streamline the processes necessary for the bureaucracy to support the NDIS as it should.

This includes, mental health, aged and palliative care sectors to ensure that individuals do not fall through the cracks of the respective schemes and that there are effective protocols for timely and smooth referrals and transitions.

Research

PDA believes there should be a strong emphasis placed on research around and of disability in Australia. . The proposed scheme shows that there is a vacuum in existing research ethics compared to many other countries. . The report also makes it appear as if there is a vacuum in the study of human services, using a market-based framework of efficiency and effectiveness as its main reference point in this inquiry.

PDA is of the belief that a strong research focus will help Australia to develop its own position on disability which is different from many countries, as is evidenced by use of the wording 'people with disability' versus, 'disabled people' used overseas. . Another area of research that is urgently needed is that of 'Why services are not servicing people with disabilities properly' which is referred to regularly, however no research appears to be underway to give any answers. . Surely people with disabilities and governments deserve to know why, when large funds are allocated to these same services from taxpayer dollars.

Ignoring the nature of presently inadequate services is we believe, also based on inadequate guiding values and principles. Much money could be saved by a focus on real needs and quality in service, including through the systematic process of weeding out those programs that do not meet the needs of people with disability. . This is a necessary bureaucracy and management process that should take place before any new system is commenced in 2014. . This could yield immediate results essential for the future of a new NDIS. Failing to research this issue means

that there is inadequate evidence on the extra amount of money needed for disability support, in part because no examination of inefficiencies exists within the existing system.

PDA believes that the lack of any serious scrutiny on the performance of service providers in the 25 years since the passing of the Disability Services Act (1986), means there is no clear understanding of what constitutes a “good” services and what constitutes a “bad” service. . One area of poor service practice is reflected in Section 8.30-31, where the discussion about restrictive practices seemingly ignores the gross human rights abuses that such practices perpetrate upon people with disability, in direct contravention of CRPD. . The new NDIS must operate in such a way as to consign these practices to history.

We believe therefore that a **National Disability Research Institute** based on market-based values, which will strongly influence that view of disability service provision in Australia should also be part of commencing a National Disability Strategy.

Sector Involvement

The Report foreshadows a role for Disability Support Organisations (DSOs) in assisting eligible people with disability in managing their support options. . In other countries groups of people with disability have already been established, such as Centres for Independent Living (CILs), which are user-led organisations assisting others to live independently. . These were well placed to take on assistance roles, when self-directed supports became an option in their jurisdictions.

In Australia most groups are ‘peak bodies’ (as is PDA for example) or advocacy groups and clearly the tasks associated with being a DSO (in the context of the Report) is very different from advocacy. . It is from this sector, however, that the DSOs need to grow and we need to start a dialogue about how this can occur, whilst maintaining the strength and independence of our advocacy.

is The Report has no demonstrable commitment to involving the organisations of people with disability and / or grass roots people with disability in monitoring, commenting upon or shaping the future of the NDS and its priorities. We encourage the PC therefore to include a role for disability organisations (NGO’s) to assist in broadening and deepening engagements with the strategy by a wider community of legitimate interests.

In addition, there should be promotion of access to autonomous, independent individual advocacy and decision-making advice and support for all eligible scheme participants and for Systemic advocacy through the direct participation in system-wide planning and decision-making of democratic, representative organisations of people with disability.

Role for individuals

Disability experience-based contributions towards community are fundamentally those modelling freely-given positive, supportive relationships, engagement, generosity, creativity, diversity, resilience in living well with realities of fragility, dependence, difference, given good care and support. . These qualities usually receive lip service (though there is credible evidence

on their potency in contributing to good lives) and the economic rationalists avoid it in practice like ants do with repellent.

Such inclusive concepts provide tensions in reality and in the minds of those who put disability goals of independence, autonomy, choice, empowerment and rights for example, first. We see it as a matter of what is more fundamental, i.e. a culture of 'care' is more fundamental in our view (centred around 'needs' and involving real participation). . This is able to cover the entire spectrum of disability, including those whose needs are such (because of severe cognitive impairments, manipulation, and utter dependence on others) that their rights are in reality more abstract, rather than real, other than for those who are able to exercise any autonomy - actually the less vulnerable. . The disability movement has been right to try and bring us up from a low level of meaningful choice, expressions of autonomy and independence. . But go too far with this and we are firmly ensconced in the dominant consumer model that disables us. . Professor Anna Yeatman for example has written persuasively on that point (put in a reference).

The questions are what the values should be driving efforts towards good lives and how other components such as those mentioned do fit into these in practices, and for whom. The physical disability movement has dominated much of the disability debate for the last few decades and influenced policy, for obvious reasons: we can articulate our position. However, if we are to call ourselves a disability movement we must include in our considerations, principles, policies and practices for those who have disabilities that render them unable to stand up for themselves, articulate rights or demand 'choice' including those whose intellectual disability, acquired brain injuries, mental or chronic illness etc., (or arising from a low level of education) because that is what society has served up to them in opportunity). This NDIS proposal does not do this either.

The most vulnerable people are central to our conceptualisation of a society in which we are embedded as inherently worthy people, where 'inclusive values' seek to include those with the highest and most challenging support needs. We believe the physical disability movement has a special responsibility to specifically ensure that the most vulnerable are not left behind. This brings with it interesting tasks: to accept that family and carers are an essential part in strategically developing a foundation for sustainable community living so that all people can experience 'a good life'.

PDA believes therefore that all stakeholders in the area of disability must be part of any new scheme.

Conclusion

There must be honest and open engagement with people with disabilities rather than top-down marketing campaigns to passive recipients - where political spin replaces a truly collaborative approach with the electorate. We must be allowed to set our own agenda, clearly stating what we need to those who are presently trying to use our best hopes, needs, and yes, wishful thinking, to serve their dominant worldview and economic interests, rather than developing practices that empower people with disability to live self-determined, independent and

dignified lives. We will no longer be happy with the 'correct' terminology and crumbs from their table. We want to work with Government in a truly collaborative way to focus on supporting and strengthening those values, strategies, and practices that work towards creating a disability citizenship that gives us the same right to way 'good life' through meeting the real needs of people with disability in ways that are empowering and that we know work. Rather than creating new bureaucracy, the Government should reflect on and actively support our grassroots wisdom, networks and coalitions.

There is no time left for games and politicking that amounts to tweaking a government or service provider agenda handed down to us, even though it is also true that the change we need cannot be instantly achieved and we will always need advocacy and other efforts to safeguard and advance the position of people with disability .

Building these positions of collaboration and empowerment are central to an inclusive citizenship. Disability advocacy around the nation has been operating on an anaemic trickle of Commonwealth money, been subject to emasculation by regulating it to death and advocacy development has been largely absent in Australia. Some states have gone so far as de-funding some of their advocacy organisations.

Having the PC and the Government realise that economics is the weakest of buttresses to our inclusion or good lives would be a good start. There needs to be an entitlement to inclusion (not according to the state of the economy) and a cost-effective assessment that is real and based on rights

A focus on real needs is what is needed, one which is founded on a sound economic foundation, not based on a unnecessarily complex bureaucracy and delivers targeted services so that the resources can be used in the most appropriate, effective and efficient way for the people we represent in Australia.

We need a new scheme that has adequate funding, bi-partisan support for the whole system, and a values change starting in heads and hearts.

- ⁱ United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. New York <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>: United Nations General Assembly A/61/611 - 6 December 2006.

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- ⁱⁱ Australian Bureau of Statistics (2009) **Survey of Disability, Ageing and Carers** (cat. no. 4430.0)
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