

QAI Submission to the
Productivity Commission
Disability Care and Support Inquiry (PC, DCaSI)

1. Opening Statement

QAI welcomes the opportunity to present a response to the Productivity Commission's request, in its Issues Paper, for comment on the design implications of the Convention on the Rights of Persons with Disabilities for a National Disability Insurance Scheme (NDIS) or similar scheme. We also would like to acknowledge that most of the text contained in this submission was developed at a workshop conducted in Sydney involving Advocacy Organisation, Peak Disability Organisations and Disabled Persons Organisations. Attachment A

We are encouraged by the recognition of the Productivity Commission of the central relevance of the Convention on the Rights of Persons with Disabilities ("the CRPD") to the design of a NDIS or similar scheme.

a) Introducing Queensland Advocacy Inc (QAI)

QAI was established in 1987, and is an independent community based systems advocacy and legal advocacy organisation. QAI advocates for the fundamental needs, human rights and lives and protection of the most vulnerable people with disability in Queensland.

b) QAI's Strategic Vision:

- Securing entitlement to fundamental needs and full citizenship
- Raising the profile of disability in the human rights context
- Advancing the reform of discriminatory systems
- Promoting and protecting strong, independent, well-resourced and effective advocacy in Australia
- Increasing QAI's capacity and capability to respond more broadly.

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Patron: Her Excellency, Ms Penelope Wensley, AO Governor of Queensland

2. QAI's Knowledge and Experience

QAI is funded by the Commonwealth Department of Families, Community Services and Indigenous Affairs (FaCSIA) under the *Disability Services Act 1986* (Cth) and Legal Aid Queensland. QAI is run by a Management Committee, the majority of who are people with disabilities.

QAI has worked consistently within advocacy and human rights principles. It has structured its organisation to ensure its accountability to the most vulnerable people with disability by fully incorporating qualified people with disability in key board positions and other areas of function.

QAI employs four permanent full time workers and seven permanent part time workers. To this is added the activities of volunteers. QAI Committee members have experience in advocacy, institutional living, community legal service, private legal practice, legal aid, accountancy and community work. To achieve the results it has QAI engages Management Committee and staff who understand aboriginal issues, migrant issues, women's issues, tenancy issues, disability issues and welfare issues.

QAI has been involved in numerous systemic enquiries, reforms, and campaigns including the:

- development of the Queensland Guardianship and Administration Act,
- the closure of Maryborough Hospital disabled persons ward,
- represented the resident inter in the Criminal Justice Commission (CJC) enquiry into Basil Stafford Centre,
- exposure of multiple human rights violations of vulnerable people living in for profit hostels (which resulted in two pieces of legislation being developed to protect the tenancy rights and accommodation rights of people with disability)
- 70 submissions into government enquiries over a 23 year period,
- Ratification Of the Convention on the Rights of Persons with Disability and it's Optional Protocol,
- Disabled Justice report that examined the experience of persons with disability with the Queensland criminal justice system., comprehensively stated the case for reform and to outline the various dimensions of the reforms required,
- development of a national peak body for advocacy organisations (DANA)
- the wasted lives campaign advocating for over 1000 forgotten people with intellectual, physical, acquired brain injury (ABI) LEFT in health institutions in QLD. This is now in contravention of Article 19 of the CRPD.

QAI also provides individual legal advocacy in support of persons whose disability is at the centre of their legal issue.

Human Rights Legal Service

- To facilitate increased access to the justice system for vulnerable persons with disability.
- To provide referral for people with disability to other legal services and agencies within the justice system so that people with disability enjoy the same access to justice as all people within our community.
- To provide specialist legal advice & representation services to vulnerable people with disability in relation to protection of their fundamental human rights, particularly where their rights of people are at risk in the following ways:
 1. Risk to Life - including risk of serious injury
 2. Risk to Liberty
 3. Risk to Fraternity/Property.

Mental Health Legal Service

The Mental Health Legal Service (**MHLS**) is a specialist legal service dedicated to providing free legal assistance in relation to mental health law in Queensland. The treatment and protection of people who have mental illness in Queensland is governed by the *Mental Health Act 2000* (Qld).

3. QAI's Summary Submission

Today persons with disability are subject to multiple and aggravated forms of human rights violation, including the neglect of their most basic survival related needs. These human rights violations do not only occur in far off places that lack enlightened legislation and policies, or the resources needed to meet basic needs. They occur every day, in every region, of every State and Territory in Australia. Virtually every Australian with disability encounters human right violations at some points in their lives, and very many experience it every day of their lives. In 2010, in one of the most enlightened and wealthiest nations in the world, it is possible for persons with disability to die of starvation in specialist disability services, to have life-sustaining medical treatments denied or withdrawn in health services, to be raped or assaulted without any reasonable prospect of these crimes being detected, investigated or prosecuted by the legal system, and to have their children removed by child protection authorities on the prejudiced assumption that disability simply equates with incompetent parenting.

It is factual that people with disability are overrepresented as offenders in our criminal justice system. There is a clear link to this overrepresentation in that the person has failed to receive any service or support and if they have a service it has not responded appropriately to their needs. There is clear cost shifting from the failure of the current human service system, to provide timely, appropriate and personalised support, to the corrective service system, were a person with disability exposure to further harm significantly increased. The eligibility criteria and subsequent assessment mechanisms are driven by a 'crisis' methodology inclusive of limited resources and a huge unmet demand. The assessment process commences with a competition to depict a person with disability in the most degrading and inhumane caricatures in order to be eligible to receive specialist disability services. It is a probability that you are more likely to win gold lotto than to receive a service that is tailored to support the person in a way which respects, protects and fulfils an individual's human rights.

There is much anecdotal evidence that people who acquire impairment through trauma, and receive compensation and have the 'where with all' to strategically

manage those resources has very different life experiences than people who do not receive any compensation. Firstly, they are empowered to take control of their future and destiny in life. People often recommence employment careers or commence small businesses, they continue to be able to define their identity, and role in life as opposed to having some government sanctioned authority defining their identity as burdens and non-productive members of our society. They tailor their paid support to complement their natural relationships with family, friends, colleagues etc. They reduce administrative costs when identifying and purchasing aids and equipment that is required in daily participation in all aspects of life. By significantly reducing administrative costs they effectively increase the capacity of their financial resources to meet their personal support needs. They are more included in all aspects of their local communities often taking leadership roles, being involved politically, to building more inclusive and economic viable communities. And if they have reduced capacity to independently take control of their future there is strong evidence that their established network of family and friends work collaboratively with them to have as much control as possible in their lives, to still dream of possible futures and pursue those dreams and their lives are valued and lived with dignity.

It is also recognized that some people who receive compensation are vulnerable to exploitation of predators, and perhaps family members or friends who have also limited capacity to strategically negotiate the many pitfalls that come with resources. We acknowledge and recognize the need for a range of safeguards to protect vulnerable people or those who have limited experience in being successful. And that there will be some people who have the wherewithal but have no interest in having total control or ultimate responsibility of managing their day to day supports.

Thus, to eliminate the uncertainty and nonviable disability service system that we currently have in Australia we must move to a national scheme which is:

- Based on entitlement for all who are eligible
- Properly funded
- Based on equity for all who are eligible
- Based on Self-Determination
- Committed to the empowerment for people with disabilities
- Portable (national scheme)
- Responsive to changing circumstances of an individual

- A strong independent advocacy support program which is separately funded to support and protect the rights and interests of people with disabilities eligible under the scheme.
- That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.
- Cultural Reform – this proposed scheme will provide the genesis for cultural reform as expressed in the belief that the CRPD provides the mechanism for a paradigm shift, moving from a welfare/charity/medical model to a social model.

a) Overseas Models/Trends

- Recognition that a hypothecated tax/levy is required to systematically address the ad-hoc indiscriminate and crisis driven approach to receiving support to function in daily life (as per comparable approaches in countries such as Germany, New Zealand, Scandinavia, United Kingdom (UK))
- Individualised funding and direct payments, as per the UK Government's Right to Control Initiative (latest evolution of individualised funding and direct payments from the UK).

b) New System Design

i. *Who should be the focus of a new scheme?*

- The new scheme should use an ***inclusive definition*** as set out in the UN Convention on Rights of Persons with Disabilities (UNCRPD). *Article 4 (c) of the UN CRPD requires that States Parties need to take into account the protection and fulfilment of the human rights of all persons with disabilities in all programs and policies.*
- Support ***eligibility for disability support based on needs*** and shaped by the impact of a person's impairment on their capacity to undertake normal activities of daily living. Possibility that a tiered eligibility structure needs to be developed under a new scheme. For example three tiers of eligibility could range from low support needs, medium support needs or high support needs as per the German model. In Control has facilitated the emergence of Individualised Budgets with the various Local Authorities (LAs) in the UK, there have been various techniques used to try to best understand a person's needs and how that links to public funds. The main mechanism is called the Resource Allocation System (RAS). At its heart, it provides a framework for translating levels of support need with available funding. In turn. Levels of support need are determined through a simple-to-use assessment tool. QAI suggests the Productivity Commissioners and staff have further engagement with key disability organisations, and other allies to examine a more detailed and comprehensive framework.
- Recognize the need to include groups from the start that might fall through gaps –
 - refugees and new migrants waiting for residency and citizenship papers
 - People with disabilities living in rural areas and remote areas of Australia
 - Indigenous people with disabilities
 - People with disabilities in correctional services system & health and aged care institutions
- Include ***people with mental health issues*** and ***people with ageing related disabilities***. While ageing related disability has been excluded in the terms of reference for this inquiry, we believe that a new scheme needs to consider this group as the needs and support strategies are similar across the lifespan.

Recommendation that Productivity Commission Inquiry consider links with this inquiry and separate inquiry into aged care.

ii. *What should a new scheme cover?*

- The need to address ***the inter-face and inter-relationship between systemic and structural barriers to inclusion for people with disabilities in Australia and their individual and personal support arrangements*** must be taken into account by the Productivity Commission Inquiry. Investment in making our communities and their services universally accessible and inclusive will lead to a reduction in the level of funding needed in personal budgets for support and equipment.
- 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
- A new scheme should provide support based on ***self-determination of need***. This approach needs to make allowance for supported decision making for people who require assistance and also needs to recognise the specific circumstances of those who are impacted by restrictive practices or who are in custodial settings such as prisons and institutions.
- QAI strongly supports the position that people with disabilities and their families will need access to ***a strong independent advocacy program*** that provides a range of advocacy approaches, both individual and systemic, to ensure that there is an effective capacity to ***protect and promote rights and well being*** in a new disability support scheme. This program should be funded such that both administration and delivery of advocacy support are independent of disability support program funding.
- 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 disabilities and their organisations was 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.

- **Research** funding needs to be allocated under this scheme to identify gaps and program/market failures and successes to inform progressive improvements in both structural reform and models for individualised support.
 - Effective consumer protection to cover people with disabilities.
 - Investment in workforce development and improved conditions for workers.
 - The scheme needs to respect and support for people to maintain and develop social and personal relationships.
- iii. How much funding? Who decides?*
- Level of funding for individual budgets should be **determined through self assessment approach**. Self assessment models have worked effectively in UK and much better than costly bureaucratic controls and assessment process. This requires **an investment in trust** – a complete reversal of current obsession with bureaucratic micro-management and intervention based on distrust of individual and family capacity to make good decisions around purchasing supports. The research evidence, here and internationally, in programs that trust the individual demonstrate greater program effectiveness and efficiency. Self-determination should also extend to **control in decisions about the process of how needs are met**. Self-assessment should have the ability to have regular reviews and be reviewable upon request.
 - Currently the total funding in disability support is administered by all levels of government with large levels of duplication in administration. A significant amount of the total disability support budget is spent before it reaches people with disabilities. We suggest that the Productivity Commission should also **investigate the cost of NOT implementing a fully funded national disability support scheme based on self-determined, individualised budgets**. There have also been many reports on service system failure and waste in various jurisdictions that highlight the broken nature of current approaches. Productivity Commission should be encouraged to include such reports in their research.

c) Governance and Admin

- Creation of an independent body to govern and administer funds. This body could be a statutory authority. This body would be responsible for the governance of a new disability support scheme. Key features of this body would include:
 - A Board with a majority of people with disabilities who are representative of key constituencies.
 - The Board having oversight of UNCRPD implementation as part of brief.
 - The Board making decisions about funding distribution.
 - The Government to fund this body independently and separately.
 - Research and development role to promote cultural/paradigm shift in disability support.

- The Body being underpinned by specific legislation reporting against UNCRPD based performance measures.
- The Body would need to be reviewed regularly by an appropriate administrative review body.
- A new scheme for funding disability support can't be expected to address all the issues that impact on people with disabilities. Ongoing structural reform work to address systemic barriers and remove discrimination needs to properly funded and is not the direct task of a national disability support scheme.

d) Costs and Financing

A **National Disability Insurance Scheme** funded by a hypothecated tax/levy (like medi-care % of individual tax payers income) to fund all legitimate claims for disability support. While the capacity to provide an entitlement based scheme is attractive when compared with current situation, there are also concerns about how the insurance culture might continue to paint disability as something negative to be insured against. To counter the perceptions and practice of economists viewing disability issues in terms of welfare thus expenditure on disability is countered as a cost with no recognition of benefits. The financing of this scheme must be underpinned as an “investment” to value the contributions that people with disabilities can make. For example if a person has an X amount of dollars to purchase their support to function in daily life in their community they are effectively operating a small business employing locals. Other concerns are how an insurance driven scheme might use cost driven thinking to impose support strategies that would undermine self-determination and choice for individuals. E.g. Might some deaf people be pressured to have Cochlear Ear Implants to save on interpreter costs or families to terminate pregnancies if a foetus is identified as having impairment?

- **Private contribution** is also suggested by the Productivity Commission Inquiry paper. QAI does not support an asset test for full entitlement to the scheme around aids, equipment and personal support.

e) Implementation/Transition

- Pressure to rationalise expenditure on such a scheme will always be a challenge. Implementation cannot be compromised by rationing of funding or threatened by resistance to systemic reforms of disability support. It will be important to position this scheme strongly within the government's obligations to implement the UN Convention on Rights of Persons with Disabilities. The Convention requires much more than access to services and is based on supporting “full and equal enjoyment of all human rights by all people with disabilities”.
- While the Convention provides for “progressive realisation” of social, cultural and economic rights, it is the view of people with disabilities and their

organisations that Australia has the economic capacity to address these responsibilities immediately.

- Maintain a separate funding system for independent advocacy.
- Establishment of independent local resource centres to assist in transition, planning and support that are run by people with disabilities and their organisations.
- 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 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, West 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.

4. Conclusion

Thank you for the opportunity to appear before you at the Productivity Commission's (the Commission) public hearing in relation to its Inquiry into Disability Care and Support in Brisbane on 16th of July 2010 and to make this submission. We are concerned that the panel is responding to the call for congregate models of accommodation. This form of accommodation has arisen due to the failure of public policy to recognize the fundamental needs and rights of people with disability and the prevalent culture that underpins public policy in Australia. The prevalent culture considers people with disability as not fully human thus, not fully entitled to citizenship nor entitled to equal access to public goods and services. The CRPD calls for a paradigm shift or cultural reform. It is indeed disappointing to hear the panel is canvassing witnesses' views regarding what size facility they considered to be an institution. It is clearly a failure of the panel too understand that bricks and mortar are not symbolic of institutions it is the attitudinal beliefs and assumptions that are held and deeply embedded in society that formulate the institutional rejection of people with disability in our society. When a person with disability is consigned to live in congregated care they become 'Captives of Care'.

Therefore we fully support the letter written by New South Wales Disability Discrimination Legal Centre (Inc) Attachment 2.

Attachment 1

QAI wishes to acknowledge that much of the text for this submission was developed *by Disabled Persons Organisations and Disability Advocacy Sector organisations including:*

Workshop participants

Karen Lloyd	Deaf Australia Inc.
Sue Salthouse	Australian Communications Consumer Action Network / Women with Disabilities Australia
Annie Parkinson	Women with Disabilities Australia
Kevin Cocks	Queensland Advocacy Incorporated
Julie Hearnden	Queensland Advocacy Incorporated
Daphnee Cook	People with Disability Australia
Amanda Tink	People with Disability Australia
Therese Sands	People with Disability Australia
Lesley Hall	Australian Federation of Disability Organisations
Leah Hobson	Australian Federation of Disability Organisations
Mark Pattison	National Council on Intellectual Disability
Andrea Simmons	Disability Advocacy Network Australia
Corinne Henderson	NSW Mental Health Coordinating Council
Phillip French	Disability Discrimination Legal Centre of NSW
Fiona Given	Disability Discrimination Legal Centre of NSW
Sibylle Kaczorek	National Ethnic Disability Alliance
Zeliha Iscel	National Ethnic Disability Alliance
Andrew Jefferson	People with Disabilities WA
Nicole Lawder	Deafness Forum
Amanda Sullivan	Deafness Forum
Kirsten Preece	Deafness Forum
Niki Sheldon	Physical Disability Australia
Rebecca Doyle	NSW Consumer Advisory Group - Mental Health Inc.

Selina Thomas	NSW Consumer Advisory Group – Mental Health Inc.
Robyn Gaile	Blind Citizens Australia
Jessica Zammit	Blind Citizens Australia
Bruce McGuire	Vision Australia

Presenter:

David Mason	Australian Human Rights Commission
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Facilitator:

David Craig

Attachment 2

27 July 2010

The Commissioners

Disability Care and Support Inquiry

Productivity Commission

GPO Box 1428

Canberra City ACT 2601

Dear Commissioners:

Thank you for the opportunity to appear before you at the Productivity Commission's (the Commission) public hearing in relation to its Inquiry into Disability Care and Support in Sydney on 20 July 2010. We shall shortly be lodging a written submission which will elaborate upon the views we outlined at that time. However, there are two matters arising from our evidence that we would like to raise with you immediately and directly.

In the course of questions, you indicated to us that you had received a large number of submissions that supported congregate models of accommodation and other support services. You asked us to identify what size of facility we considered to be an institution. We also observed you to canvass the views of other witnesses on this subject and with respect to the level or standard of support that any new scheme ought to target, noting that some people currently receive very good supports, while many others receive very little assistance, and there may need to be a compromise.

We appreciate that you were asking questions based upon the evidence you have received, and in the course of deliberation, rather than indicating any concluded view on these matters. Nevertheless, these lines of questioning do potentially have important implications for the way in which the Commission is undertaking its inquiry and in relation to the potential scope of its recommendations, which we say, must reflect normative human rights standards.

We therefore respectfully request you to consider these implications in light of the submissions we outline following.

1. Australia ratified the Convention on the Rights of Persons with Disabilities (CRPD) in July 2008. The CRPD sets out the human rights and fundamental freedoms of persons with disability. As you would be aware, Australia's ratification of the CRPD represents a solemn undertaking to recognise, respect, protect and fulfil the rights it contains. The CRPD is binding upon all Australian governments and their agencies.
2. The CRPD does not create 'new' human rights, but instead applies existing human rights to the specific circumstances of persons with disability. It is comprised of civil and political and economic, social and cultural rights. Civil and political rights are

immediately realisable, which means that they must be complied with at and from the point of ratification. Economic, social and cultural rights are progressively realisable, which means that immediate compliance is not required at the point of ratification. However, parties must work towards their full realisation to the maximum extent of their available resources.

3. Human rights are normative values or standards that are accepted as being applicable to all persons, at all times, and in all circumstances. In an important sense they do not represent 'optimum' conditions. They are 'basic' or 'fundamental' requirements for human dignity. While economic, social and cultural rights are progressively realisable, this should not be understood as meaning that they are aspirational and not basic or fundamental.
4. It follows from this that we believe that the Productivity Commission must take care to ensure that in formulating recommendations for a national support scheme for persons with disability it does not conceptualise CRPD rights as expressing optimal conditions that are to be aspired to, but which may not be achievable, either immediately or at all. The CRPD expresses normative conditions that persons with disability are entitled to expect as of right. This is especially the case in relation to CRPD civil and political rights.
5. In this respect it is important for the Commission to note that Article 5: Equality and Non-Discrimination and Article 19: Living Independently and Being Included in the Community are both civil and political rights.
6. One of many important implications Article 5 has for the Commission's Inquiry is that it prohibits segregation on the basis of disability because this is inherently unequal and detrimental treatment and is therefore discriminatory. This is a basic civil rights principle of long standing that has already been applied in Australian law in other contexts.
7. Article 19 applies the traditional civil and political rights of liberty and security of the person, and freedom of movement, to one of the most pervasive human rights abuses experienced by persons with disability; their segregation and isolation from the community in institutional environments. It requires parties to the CRPD to recognise the equal right of persons with disability to live in the community, and participate in community life, with choices equal to others. The state obligations that relate to this right include the obligation to ensure that persons with disability are able to choose their place of residence and where and with whom they shall live on an equal basis with others; the obligation to ensure that persons with disability are not obliged to live in a particular living environment; and, the obligation to ensure that persons with disability have access to a range of community support services that support living and inclusion in the community, and which prevent isolation and segregation from the community.
8. The right to housing and disability support services are economic and social rights that are incorporated into CRPD Article 28: Adequate standard of living and social protection. Article 28 is subject to progressive realisation, but its progressive realisation must immediately comply with Articles 5 and 19 (among other civil and political rights). In other words, while from an international human rights perspective Australian governments may (indeed must) set progressive targets for the provision of housing and support services for persons with disability, all implementation action

must comply with the right of persons with disability to live independently and be included in the community.

As an agency of the Australian government we view it as essential that the Commission's commentary and ultimately, its recommendations, are formulated so as to reflect Australia's international human rights obligations under the CRPD. To put it another way, we don't view it as being open to the Commission to be canvassing service models that would, if implemented, violate these obligations.

We acknowledge that the Commission will hear a variety of views about the acceptability and even the desirability of institutional models in the course of its inquiry. However, consistent with the Australian Government's obligations under Article 8 of the CRPD, the Commission has an important role to play in this Inquiry in raising awareness of, and fostering respect for, the rights of persons with disability, and in combating stereotypes, prejudice and harmful practices impacting upon persons with disability. We respectfully suggest that this is especially necessary in the area of housing and support for persons with disability.

We would welcome the opportunity to discuss these matters with you further should this be of assistance.

Yours sincerely

PHILLIP FRENCH

Director