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NGO in Special Consultative Status with the
Economic and Social Council of the United Nations

Committee Secretary
Community Affairs Committee
Department of the Senate
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25 August 2006

Dear Committee Secretary,

Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement

People with Disability Australia Incorporated (PWD) has pleasure in submitting to you the following for your consideration.

Our submission focuses on the first of the Committee's terms of reference. It discusses the intent and effect of the three Commonwealth State/Territory Disability Agreements (CSTDAs) to date insofar as we explore the fundamental human rights purposes served by the CSTDAs, and make recommendations regarding how those human rights purposes might be better provided for within the forthcoming CSTDA.

As a human rights analysis of the CSTDAs has been totally absent from debates and inquiries around the three CSTDAs to date, PWD urges the Committee to give our submission the most earnest consideration.

Summary

The concept 'disability' is premised on the existence of barriers to access to, or participation in, the ordinary activities of life. This conceptualisation stems from the 'social model' of disability. The social model recognises that the *problems* to be addressed by society do not inhere in a person with disability or people with disability generally, but exist within the environment and a society that has established and

maintains institutional, social, attitudinal and physical barriers to access, inclusion and participation for its citizens with disability.

The social model therefore frames disability as a call for action to identify and break down the barriers that exist within society to a person with disability's fullest participation, and equalisation of their rights and opportunities. Through the social model and its broad acceptance both internationally and domestically, disability has become an important human rights issue.

Disability services, or more accurately services *for* people with disability are premised on overcoming the barriers to an individual's full access to or participation in activities of life, and thereby addressing the disadvantage experienced by individuals with disability when compared to the broader community. Disability services are therefore inextricably engaged in a human rights project, although this is rarely recognised. It follows that human rights concerns are also at the very heart of the CSTDAs.

To the extent that a significant number of people with disability are not receiving the services they require, disability service provision and the CSTDA are failing to fulfill this premise and their human rights project.

To the extent that programmes and services for people with disability fail to overcome barriers or erect new barriers to access and participation for people with disability using those services, disability service provision and the CSTDA are again failing to fulfill this premise and their human rights project. Indeed, human rights outcomes for people with disability are perhaps the key measure of service provision success or quality. Notwithstanding this, a recent review of the CSTDA by the Australian National Audit Office found that the CSTDA contains "no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community or any related parameters", clearly suggesting that the means to monitor the success of the CSTDA and disability services in fulfilling their human rights project are totally absent.

All disability services provided under Commonwealth, state or territory disability services legislation are obliged to conform to international human rights norms and standards, and the Commonwealth, states and territories are bound by international law to ensure that they do.

Recommendations

- 1. Disability services, and policies, agreements (including the CSTDA) and programmes relating to them should be framed clearly as the provision of services necessary to overcome barriers experienced by people with disability to the equal enjoyment of their human rights and fundamental freedoms;**
- 2. Disability services should clearly be held accountable for any breaches of human rights, and should state clearly which barriers they will address, and be monitored and their quality judged (at least in large part) against such outcomes;**
- 3. The fourth CSTDA should contain a provision in identical terms to clause 3 of the first CSTDA. That clause should be expanded to include an obligation on each of the Commonwealth, states and territories to include/ continue to include principles and objectives in accordance with clause 3 within the disability services Act operating within each jurisdiction, and to make the ongoing funding**

of disability services contingent upon conformity with these principles and objectives; and

4. The Commonwealth, states and territories must agree to implement a monitoring framework that places the human rights outcomes of service users with disability at its centre. In this regard we refer the Committee to the work being undertaken by Queensland Advocacy Incorporated to develop a range of 'human rights indicators' for people with disability. Human rights indicators or measures for people with disability could be readily developed and internalised within service administration in areas such as individual planning and service self assessments.

1. Background: about People with Disability Australia Incorporated

People with Disability Australia Incorporated (PWD) is a national cross-disability rights and advocacy organisation. PWD represents the rights and interests of people with all types of disability.

PWD is a non-profit, non-government organisation whose vision is of a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated.

PWD's core membership is made up of people with disability and organisations primarily constituted by people with disability. PWD also has a large associate membership of other individuals and organisations committed to the disability rights movement. PWD is governed by a Board of Directors who are all people with disability.

PWD was contracted by the Australian Attorney General's Department in 2004 and 2006 to conduct national consultations with people with disability about the development of an international convention on the human rights of people with disability. This involved undertaking consultations with people with disability across Australia as well as with particular groups of people with disability and peak organisations, such as women with disability, people with intellectual disability and the Australian Federation of Disability Organisations. Australians with disability spoke to us at length about their human rights. PWD's reports from the national consultations were later used to inform the Australian Government delegation to the United Nations Ad Hoc Committee, which has responsibility for developing the convention.

PWD has Special Consultative Status with the Economic and Social Council of the United Nations, and has substantial experience representing Australians with disability within various international, regional, and domestic fora pertaining to the human, legal and consumer rights of people with disability.

2. Background: about people with disability

2.1 The data and its relevance to disability services

The most recent survey of disability in Australia confirmed that some 3.9 million Australians, or approximately 20% of the population reported some form of disability. The survey defined disability as any limitation, restriction or impairment that has or is likely to last for six months, *and restricts everyday activities*. Of the 3.9 million

Australians with disability, 86% or 3.39 million reported limitations in areas described as *core activities*, e.g. personal care, mobility, communication, or restrictions in employment or education.

The survey also found that approximately 580 thousand people with disability reported that their need for assistance to manage their health conditions or the activities of everyday life were only partly met or not met at all. It also found that the likelihood of a need for assistance remaining unmet in whole or in part increased with the severity of reported limitation. For example, of those with a profound limitation in a core activity, 50% reported that their needs for assistance were unmet compared with 16% of those with a mild limitation.

The survey also confirmed major inequalities between the life situations of people with disability and those with no disability, for example:

- 30% of people with disability had completed schooling to year 12 compared to 49% of those with no disability;
- For people with disability the labour force participation rate was 53% and the unemployment rate 8.6% compared with 81% and 5% for those with no disability; and
- The median gross income of people with disability was \$255 compared to \$501 for those without a disability.

(Source: Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers*, 2003, (SDAC))

The SDAC survey's findings point to a range of concerns that are at the very heart of appropriate social policy responses to the needs of people with disability:

- One in five Australians experience disability;
- 580 thousand Australians with disability experience an unmet need for assistance in their daily lives;
- The more assistance a person with disability requires, the less likely they are to receive that assistance; and
- On every social indicator people with disability fare poorly when compared to Australians with no disability.

It is apparent from the data that a significant proportion of the population with disability is not currently receiving services, or sufficient services, to address their needs for support or assistance to undertake everyday activities on an equal basis with Australians without disability.

In this context the role of disability services is to ensure that those many Australians with disability requiring assistance in their daily lives, and not able to receive that assistance from services available generally to the community, do actually receive that assistance, and that through the provision of that assistance the life situations of people with disability begin to and do approach those of Australians without disability.

2.2 A broad conceptualisation of disability and its relevance to disability services

There are many definitions of disability, and related terms such as impairment, handicap, activity limitation and participation restriction. Notwithstanding the plethora of

definitions, it is simplest to recall that people with disability are those 3.9 million Australians with a condition (impairment) who experience a barrier to participation in an ordinary activity of life (disability). People with disability can therefore be contrasted with the 4.1 million Australians who report a long-term health condition (impairment), but who experience no such barriers. (Source: SDAC).

It is central to an understanding of disability to understand that disability is really an umbrella term for a *relationship* that exists between a person's experience of a health condition and their interaction with the social and physical environment around them. When that interaction imposes a barrier or *barriers* to the person being able to *access* or *participate fully* in an ordinary activity of life, be that a direct action, e.g. personal care or eating, or a social role, e.g. employment or education, then the person has experienced a *disability*.

Disability is therefore premised on the existence of barriers to access or participation in ordinary activities of life.

Such an approach is broad and inclusive. No particular list of health conditions or diagnoses is required. Disability can encompass people living with HIV/AIDS, people living with cancer, people living with addictions or dependence, people with depression, people with brain injury, people who are blind, deaf, mobility impaired, etc. If a person has a health condition and they experience a barrier to participation in an ordinary activity of life that flows from the relationship between the person, their health condition and the environment around them, then they have a disability. (Source: World Health Organisation, *International Classification of Functioning, Disability and Health*, Geneva, 2002)

The relevance for present purposes of conceiving disability broadly is that the assistance to be provided by disability services should attempt to overcome the various barriers to access to, or participation in, the ordinary activities of life experienced by people with disability. Services for people with disability only exist, therefore, to overcome these barriers and to thereby overcome the disadvantage experienced by people with disability when compared to the broader community. The success or otherwise of a service for people with disability therefore depends totally on the extent to which a service can deliver these outcomes.

The success or otherwise of a programme for the provision of disability services similarly depends on the extent to which the program can deliver these outcomes. (Notwithstanding this, a recent review of the CSTDA by the Australian National Audit Office found that the CSTDA contains “ no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community or any related parameters”).

2.3 The 'Medical Model', the 'Social Model', Human Rights and their relevance to disability services

No two people will have exactly the same experience of disability, and even those with identical medical diagnoses will not have the same experiences, needs, skills and aspirations. Clearly, therefore, focusing solely on a person's diagnosis (impairment) is unlikely to tell us much about a person's whole of life needs, or aspirations. However, historically society's understanding of disability *did* focus solely on a person's diagnostic label, and was mediated through what has come to be known as the *medical model of disability*.

The medical model is created and dominated by medical, scientific and technological professionals and their search for diagnosis of impairment, and cure, without necessarily considering the consequences or after-effects of impairment for a person's or group's ability to participate meaningfully in society, or for society's need to adapt to ensure that participation. Society's understanding of disability was therefore at one time essentially biological, focused upon an individual's or group's diagnostic label, and very often deterministic.

For example, historically people with intellectual disability, people with cerebral palsy and people with sensory disability, amongst others, were almost as a matter of course educated away from the rest of society by schools that often offered therapies in the place of education. When older, again almost as a matter of course, people so labeled often never received the training or support that people with no disability were eligible for in order to study, or to gain entry to the labour market.

The *problem* to be addressed was perceived to be a problem inherent in the individual or the group bearing a particular label, and was perceived to have nothing to do with society itself, except perhaps as an issue calling for a charitable response, or for the expenditure of taxpayer funds to provide health or welfare services. Thus, people with such labels were perceived as natural recipients of *special treatment*, charity or welfare, rather than as individuals with equal rights to participate fully in society.

A much more holistic and less deterministic approach to disability began to emerge in part as a response to the many injured defence personnel who returned home after the conclusion of World War II. Many of these men and women found it difficult to accept that their new status as a person with disability necessarily precluded them from enjoying the full benefits of the society that they had fought to protect. A new battle for understanding and for rights emerged over the ensuing decades.

The new approach focused on identifying the social and environmental barriers that prevent or limit a person with disability's participation within society, or that prevent or limit their needs and aspirations from being met, and on then breaking those barriers down. To view the experience of disability as a call to identify and break down the barriers that exist within society to a person with disability's fullest participation, and equalization of their rights and opportunities, is to use what is today referred to as the social model of disability.

As a call to action, the social model of disability inextricably entwined with that other means of breaking down barriers that was emerging at the same time - advocacy for human rights. To be an advocate of the social model of disability is therefore to be an advocate for the human rights of people with disability, and to recognise that the *problems* that must be addressed do not inhere in a person with disability or people with disability generally, but exist within the environment and a society that has established and maintains institutional, social, attitudinal and physical barriers to access, inclusion and participation for its citizens with disability. In short it is to understand that disability is a rights issue.

Both the United Nations (UN) and World Health Organisation (WHO) have endorsed the shift towards a human rights and social model of disability. At the UN this is best exemplified by the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (General Assembly Resolution 48/96, 20 December 1993) which integrates the social model of disability within a human rights framework, and the developing

Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Further, the *International Classification of Functioning, Disability and Health* (WHO, 2002), the major internationally endorsed framework relating to disability, attempts an integration of the medical and social models of disability that fits well within human rights-based approaches to disability.

3. International human rights obligations of the Commonwealth, States and Territories

It is trite, yet necessary for present purposes to say, that the Commonwealth and the states and territories are bound by international law to obey those international legal obligations pertaining to human rights to which Australia is a signatory. Accordingly, all people with disability in all states and territories of Australia are entitled to enjoy the same human rights and fundamental freedoms as are enjoyed by all other Australians.

For example, Australia is a party to the International Convention on Economic, Social and Cultural Rights (ICESCR) and the International Convention on Civil and Political Rights (ICCPR) which entered into force for Australia on 10 March 1976 and 13 November 1980 respectively, and which apply without discrimination to all Australians including Australians with disability.

In general terms, therefore, Australians with disability are entitled to enjoy the same human rights and fundamental freedoms as all Australians, including those human rights pertaining to:

- Equality and freedom from discrimination;
- Liberty and security of the person;
- Freedom from torture or cruel, inhuman or degrading treatment or punishment;
- Freedom from violence, exploitation and abuse;
- Freedom from interference with privacy;
- Liberty of movement;
- Living independently and inclusion in the community;
- Personal mobility;
- Health;
- Habilitation and Rehabilitation;
- Work and employment;
- An adequate standard of living and social protection;
- Participation in cultural life, recreation, leisure and sport; and
- Accessibility.

Clearly, the Commonwealth, states and territories must ensure that the human rights of people with disability are respected and met in the implementation of their programmes, policies, legislation and services pertaining to people with disability if these international legal obligations are to be fulfilled. Put conversely, the Commonwealth, states and territories are not permitted to authorise breaches of human rights in the provision of services to people with disability.

This proposition has been expressly recognised within the Commonwealth, the states' and the territories' various Acts of parliament pertaining to disability services insofar as each of these Acts incorporates a set of human rights principles having their origins in

the Principles and Objectives created under the *Disability Services Act, 1986* (Cth) and clause 3 of the first Commonwealth / State Disability Agreement.

In summary, therefore, all disability services provided under Commonwealth, state or territory disability services legislation are obliged to conform to international human rights norms and standards, and the Commonwealth, states and territories are bound by international law to ensure that they do.

While the obligation to honour human rights norms and standards in the implementation of disability services and programmes is relatively clear although seldom recognised or monitored, much less clear is the human rights status of such programmes and services themselves. For this reason we comment briefly below in order to clarify the nature and scope of these measures so clearly aimed at improving the life situations of people with disability.

Disability services are what are called “special measures” in international human rights law and are grounded in a State’s (Australia’s) obligation to eliminate disadvantage caused to people with disability by past and current discriminatory laws, traditions and practices. As such, disability services as a form of special measure authorised under international law represent a means to accelerate the achievement of equality between people with disability as a group and the rest of society.

Ordinarily, services that elect to target a specific group of the population and thereby exclude others will be found to be discriminatory and to so offend the international prohibitions against discrimination. ‘Special measures’, however, do not constitute a violation of the general prohibition against discrimination at international law because they are:

- Aimed at correcting conditions which prevent or impair the enjoyment of human rights;
- Based on reasonable and objective criteria; and
- Limited in time.

The first two bullet points above are relatively self-explanatory. As to the third, special measures must be limited in time, which means that they are essentially to be thought of as having a temporary character, implying that they must be discontinued as a programme, or as against individuals, once their objectives have been achieved. Otherwise their continuation beyond that point would necessarily entail as a consequence the maintenance of unequal and separate standards for individuals belonging to the target group, in this case people with disability, and would thereby offend the general prohibition against discrimination.

Clearly, special measures cannot themselves be permitted to breach human rights and fundamental freedoms when their rationale for existence is so clearly to address past and ongoing human rights breaches.

For these reasons and those cited above it can be seen that human rights concerns are at the very core of disability service provision, and therefore of the CSTDA. This means that:

- Human rights outcomes for people with disability is perhaps the key measure of service provision success;

- Disability services, and policies, agreements and programmes relating to them should be framed clearly as the provision of services necessary to overcome barriers experienced by people with disability to the equal enjoyment of their human rights and fundamental freedoms; and
- Disability services should clearly be held accountable for any breaches of human rights and should state clearly which barriers they will address and be monitored and their quality judged (at least in large part) against such outcomes.

PWD believes that such an approach would allow for more targeted interventions, the provision of clear service provision rationales, and clearer entry and exit requirements (e.g. upon all relevant barriers being identified, relative need being assessed, and relevant barriers overcome where possible). Consistent with the putatively temporary nature of special measures, at least as against individuals, disability services would have a clear role, once all barriers had been overcome (where possible) of transitioning people with disability successfully into generic service provision or the general community.

4. Conclusion and recommendations

The concept 'disability' is premised on the existence of barriers to access to, or participation in, the ordinary activities of life. This conceptualisation stems from the 'social model' of disability. The social model recognises that the *problems* to be addressed by society do not inhere in a person with disability or people with disability generally, but exist within the environment and a society that has established and maintains institutional, social, attitudinal and physical barriers to access, inclusion and participation for its citizens with disability.

The social model therefore frames disability as a call for action to identify and break down the barriers that exist within society to a person with disability's fullest participation, and equalisation of their rights and opportunities. Through the social model and its broad acceptance both internationally and domestically, disability has become an important human rights issue.

Disability services, or more accurately services *for* people with disability are premised on overcoming the barriers to an individual's full access to or participation in activities of life, and thereby addressing the disadvantage experienced by individuals with disability when compared to the broader community. Disability services are therefore inextricably engaged in a human rights project, although this is rarely recognised. It follows that human rights concerns are also at the very heart of the CSTDAs.

To the extent that a significant number of people with disability are not receiving the services they require, disability service provision and the CSTDA are failing to fulfill this premise and their human rights project.

To the extent that programmes and services for people with disability fail to overcome barriers or erect new barriers to access and participation for people with disability using those services, disability service provision and the CSTDA are again failing to fulfill this premise and their human rights project. Indeed, human rights outcomes for people with disability are perhaps the key measure of service provision success or quality. Notwithstanding this, a recent review of the CSTDA by the Australian National Audit Office found that the CSTDA contains " no indicators of the quality of life of people with disabilities, their participation in the community, their value in the community or any

related parameters”, clearly suggesting that the means to monitor the success of the CSTDA and disability services in fulfilling their human rights project are totally absent.

All disability services provided under Commonwealth, state or territory disability services legislation are obliged to conform to international human rights norms and standards, and the Commonwealth, states and territories are bound by international law to ensure that they do.

PWD therefore recommends:

1. Disability services, and policies, agreements and programmes relating to them should be framed clearly as the provision of services necessary to overcome barriers experienced by people with disability to the equal enjoyment of their human rights and fundamental freedoms;
2. Disability services should clearly be held accountable for any breaches of human rights and should state clearly which barriers they will address and be monitored and their quality judged (at least in large part) against such outcomes;
3. The fourth CSTDA should contain a provision in identical terms to clause 3 of the first CSTDA. That clause should be expanded to include an obligation on each of the Commonwealth, states and territories to include/ continue to include principles and objectives in accordance with clause 3 within the disability services Act operating within each jurisdiction; and
4. The Commonwealth, states and territories must agree to implement a monitoring framework that places the human rights outcomes of service users with disability at its centre. In this regard we refer the Committee to the work being undertaken by Queensland Advocacy Incorporated to develop a range of ‘human rights indicators’ for people with disability. Human rights indicators or measures for people with disability could be readily developed and internalised within service administration in areas such as individual planning and service self assessments.

We thank you for this opportunity to have input into your inquiry, and look forward to participating further within your public hearing processes and beyond. PWD would be happy to work with the Committee on the terms of any clauses that the Committee wishes to recommend be included in the fourth CSTDA, flowing from or related to our submissions.

Should you have any queries, please do not hesitate to call Matthew Keeley, Senior Legal Officer, (02) 9370 3100 or matthewk@pwd.org.au

Yours sincerely,

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Senior Legal Officer

Matthew Bowden
A/- Dep. Director, Advocacy