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## **Response to Disability Services in the ACT Consultation Paper September 2007**

People With Disabilities (PWD) ACT is a systemic advocacy organization whose goal is to advance, uphold and protect the human rights of all citizens with a disability.

In preparing our submission we note that the Department of Disability, Housing and Community Services have produced a public document titled “Service Delivery Platform” that clearly explains how, what and to whom it delivers services. Although this document is not generally known to many people, PWD ACT feels strongly that not only should it have been mentioned in the Consultation Paper, it should have been provided to everyone to give a clearer understanding of the Department’s delivery platform.

Whilst this Consultation is being undertaken by the ACT Government there is no corresponding timely and independent survey of disability clients or service users in this process.

In addition, PWD ACT is strongly of the view that this consultation outcome meets the following extracted from page 1 of a paper entitled Next Generation in Human Services and the Emerging Challenges for Case Management. A keynote presentation to the Case management Society of Australian’s 7th Annual Conference Entitled “Case Management: Fad or Future”, 19 February 2004, Melbourne, Australia by Michael J. Kendrick, Ph.D.

*“Perhaps the most significant observation that can be made would be that human services quite commonly meet some of the needs and provide benefits to all manner of vested interests other than those of clients. These include staff, professionals, consultants, unions, board members, public servants, agencies, families, politicians, evaluators, academics, funders, managers and so on. In this regard, human services are invariably awash in vested interests, and these interests exert their own independent influence on how service is rendered. These interests are often in conflict with each other and with those of service users, and they vary considerably as to their comparative strength and ability to project their influence on events. At any given moment, these interests may compete for domination, with the net result being the momentary architecture of human sciences.*

*These vested interests are often quite valid, as opposed to being solely sinister, but that does not mean that the rhetorical assertion that services only exist to benefit clients should be adopted uncritically. A more measured conclusion would be to recognise that human services are essentially in the then, when in fact it is quite*

*common in many systems that the people who exert the least influence on services are actually the people who are in the client role. Their comparative powerlessness in the face of the power of professionals and managers makes assertions that their needs will always inexorably prevail over that of better positioned parties an exercise in naïve social and political fantasy. The truth of the matter is that the needs, priorities and interests of service users often must struggle to be heard and noted in the face of much about powerful voices. Consequently, if other parties genuinely align themselves with service users, the prospects for services to be of benefit increases substantially.”*

It is PWD ACT’s view that with any service delivery system there must be an overall leadership responsibility taken by one organisation that is consumer focused, has high ideals, meets standards, is accountable, innovative, flexible and the others working in this same area tries to copy and exceed disability service. Unless this concept is in place, can be monitored and measured with the view to ongoing improvement we believe improvements will not eventuate.

Also PWD ACT fully supports the United Nations Convention on the Rights of People with Disabilities signed on 30 March 2007 by the Australian Government and whose definition of persons with disabilities is “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. The stated purpose of the Convention is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” In Article 3 of the UN Convention the general principles spell out the guiding philosophy for all levels of society.

PWD ACT would like to point out to Disability ACT, Article 21 of the UN Convention about **“the provision of information intended for the general public to be in accessible formats and technologies appropriate to different kinds of disabilities”**. In particular, a plain English and large font version of the Consultation paper about Disability Services in the ACT for people with reading and vision impairments would have been of assistance.

PWD ACT want to address all the issues that have been highlighted in the Consultation Paper about Disability services in the ACT and would like to make recommendations that PWD ACT believe could improve that quality of life for people with disabilities.

PWD ACT acknowledges the ACT Government is committed to ensuring that services and supports for people with disabilities focus on assisting individuals to live in the community and participate in the activities of their choice in ways that are meaningful to them. The guiding vision of Future Directions: A Framework for the ACT 2004-2008 for disability is:

*‘All people with disabilities achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community’.*

We are aware that the ACT government had Michael Kendrick Review Future Directions earlier this year. Although the Review's Report is not yet released publicly we would be concerned if the Report's findings failed to identify if the Vision had enabled Disability ACT to achieve the improvements in disability services as was expected following the 2001 Board of Inquiry into Disability Services found that the rights and interests of people with disability had not been effectively protected by the policies and systems operating in the ACT.

Again, this guiding vision is in line with Article 19 of the UN Convention about Living independently and being included in the community. But it needs to be remembered that also in Article 19 is the clause that states "that people with disabilities not be isolated or segregated from the community".

However, PWD ACT believes that this approach to the provision of services to people with disabilities is limited to only one area of government i.e. Disability ACT. We strongly believe it would benefit ACT people with disabilities if Disability ACT (DACT) was able to take a whole-of-government and whole-of-community approach to addressing the needs of people with a range of disabilities and looking at all aspects of life for people with disabilities.

While it is appreciated that the DACT current and intended activities are clearly articulated in *Disability ACT Future Directions – A Framework for the ACT 2004-2008*, the Consultation Paper and Background Information Paper read as though DACT only sees its responsibility as external to the ACT Government and we fail to identify an approach to whole-of-government for people with disabilities.

Far too often the disability community are left to continually monitor disability aspects of policies and practices in other ACT government departments and where these are found to be detrimental to good outcomes or fail to address disability they lobby for change. PWD ACT contend that such a fragmented approach is detrimental to DACT ever achieving any increase in social, economic and cultural participation of all people with disabilities in the ACT community as is the platform that DACT is endeavouring to be achieve.

Any rewards people with disabilities achieve through service improvement by DACT we suggest are detrimentally offset for this group if they can't use public transport, get aids and appliances, move about a barrier free environment, are accepted by the wider community, be employed and have a level of income greater than that as a result of the welfare level they experience and live under.

The focus needs to be on improving access to mainstream services and increasing participation and employment opportunities for all people with disabilities.

**To promote inclusive principles within each government department, and agency and in line with its Strategy Direction 1, DACT needs to have each government department and agency prepare a Disability Action Plan with a means of measuring improvement (that would be included and reported against in their annual Business Plan) by the next budget date and as a performance measure.**

## FUNDING

If there are in the ACT, 14.2% of the population (45,200 people) who report having a disability, that would mean that 14.2% of the population is missing out on mainstream services that are supposedly being funded by the ACT government for the whole population. When each government department developed their Business Plan and their Disability Action Plan, they would be able to indicate an amount of funding needed to make their services more accessible and inclusive of this 14.2% of the population.

It is incumbent upon PWD ACT to ask about the Reporting System used in the compilation of the Background Information Paper that has the following statistics: Why is it only 14.2% of the ACT population whereas in all other States there is 20% of the population?

Why does NSW only report 2.9% of the population with a core disability?

The Commonwealth State and Territory Disability Agreement (CSTDA) should have its funding boosted generally to allow for more community based organisations to provide services and allow the States and Territories to have more of a role as a regulator and less of the role as a service provider.

With the welfare to work policy of the Federal Government it would seem that the CSTDA has had its basic philosophy changed and the funding of employment services by the Federal Government seems out of step with the provision of employment support by Department of Employment and Work Relations (DEWR) rather than the Department of Families, Community Services and Indigenous Affairs (FaCSIA).

Also with the introduction of the Commonwealth Government's Disability Assistance Package that will be for accommodation support, the whole CSTDA would seem to be out-of-date in its structure for providing support to people with disability.

**PWD ACT believes that the Erebus International Review of the CSTDA be considered and that the CSTDA be renegotiated in the light of the changes to Welfare to Work, accommodation services and FaCSIA's role.**

The greater amount of funding given by the Commonwealth Government is not for people with disabilities but for the carers so it makes it harder for self caring people with disabilities to improve the level of services that they need or for people with disabilities to have their choices considered.

If more funding were made available for PWD ACT, a Self-Advocacy Resource Kit could be developed. With all this emphasis on extra funding to assist carers it will become more difficult for people with disabilities to find and secure services. They will need to become better able to advocate for themselves.

Not only will self advocacy be needed but more advocacy will be needed to assist people with disabilities to have their needs met solely, rather than the needs of the carer. In other States a Disability Advocacy Resource Unit has been developed by community organisations.

For many years people with disabilities have lobbied for recognition of the “Cost of Disability” as an additional cost not met by ANY government service or program. While there have been some programmes like the Continence Aids Assistance Scheme that help offset some of these costs, they are not at a sufficient level (even though they are indexed) to cover all those costs and are not a consideration that people without a disability need to fund or address.

It is also important to mention while on funding the situation that PWD ACT refers to as cost shifting as practiced by the ACT Equipment Scheme (ACTES). It has come to PWD ACT’s notice that the ACTES has not increased its contribution of \$1,800 toward a made-to-measure manual wheelchair for many years. Originally ACTES paid the \$1,800 and the client paid the balance above that figure. Now, if a client meets the criteria for ACTES funding for a made-to-measure manual wheelchair they are expected to pay 10% of the \$1,800 plus the difference between the \$1,800 and the full price of the wheelchair. Thereby the ACTES contribution has now been reduced to \$1,620 while these wheelchairs have increased significantly.

### **Role of DACT as a Service Provider.**

The ACT Government’s role as ‘care provider of the last resort’ makes it particularly difficult for a government department to be an administrator, a carer, a regulator of human rights abuse and an employer while the department is still involved with a day to day organisation of a service.

To develop a more objective assessment of service provision, in an ideal world there would be more funding, so that services could be contracted out to private, voluntary or statutory authorities and then the ACT Government could become “enablers” rather than direct service providers.

Unfortunately the more levels of administration that occur in service provision, the more funds are spent on the administration and the fewer funds remain available for people with disabilities. This situation can clearly be seen with the employment services with Commonwealth funding.

The best method of promoting innovative and inclusive practices is to ask people with disabilities about their choices for their life and being given a greater control of their lives. When people with disabilities are included in the planning processes for their services they may need to be supported by advocates.

It is encouraging to note that in this review of the role of government as a service provider DACT is considering the aspect of creating partnerships in the field of disability. To create an equal partnership for all stakeholders is important for people with disabilities that providing control also moves more toward the end user.

Unfortunately, young people in nursing homes is a reflection of one of the shortcomings of the available funding for service provision for people with disabilities not keeping pace with demand. It also reflects the lack of public housing stocks not adjusted to meet the needs of people with disabilities who with appropriate supports could live in the wider community. This is another indicator of the limitations in choices by people with a disability on how they can choose to live.

## **ACCESS to SERVICES**

History has shown that most services for people with disabilities are based on needs and have evolved through the service provider model based on funding limitations. This approach has not always been a true reflection of real needs, but evolved in many cases on assumptions made by service providers assuming they know what's best for the client, hence the clients receiving substandard services that restrict choice by clients on how they would choose to live.

This practice has been further exacerbated in recent years and also restricts access to services we believe with the introduction of the Occupational Health and Safety policies for care workers. Whilst PWD ACT is not against safety in the work place for care workers this policy leads to a more restricted life for many people with disabilities.

Most stakeholders have found that access to adequate knowledge of the service system and its resources poses some challenges.

In general the access framework is too bureaucratic, rigid and complicated. It does not allow the opportunity for people who are in most need of services to have access to the system. The access framework is based on the medical model and not the social model of service delivery.

Another model of service delivery that is known to PWD ACT is the brokerage system for families that was promoted by a family member from Vancouver Canada in Australia during the 1990's. The Commonwealth government is proposing a third party service which is similar to this brokerage model but all these extra authorities use funds to support their administration that could be used for services.

**In Article 9 of the UN Convention it is a timely reminder about the requirements for Accessibility for people with disabilities. It states:**

- a. 1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

The proposed accommodation models from the Commonwealth Government situation are:

- large residential
- group homes
- independent living with in-home support
- cluster housing
- shared care residential

- paid host family options
- adult foster option
- co-residency
- self-managed funding, and
- family units in residential aged care.

Whether the Commonwealth Government will be able to meet the rhetoric of their Disability Assistance Package is unlikely however it does give accommodation services an idea of alternative models.

The most suitable accommodation service is the situation that best provides for the person with a disability's needs.

## **AWARENESS RAISING**

Under Article 8 of the UN Convention which outlines the extent of Awareness Raising, it is essential that governments be responsible for developing policies that raise awareness throughout society, combat stereotypes and promote the capabilities and contribution of people with disabilities.

**As a beginning PWD ACT suggest that DACT provide an awareness training package that could be delivered to all ACT government departments and preferably be delivered by people with disabilities in the presentation.**

In SA there has been a disability plan developed by a person with a disability who is in the disability policy area of government, that each government department can develop and implement.

## **INFORMATION SERVICES**

An independent service from government and providers is required. "Ideas" is the best example of an information service that was developed and organised by a person with a disability. She had an extensive knowledge of services and the possible sources of funding as well as an intimate experience of living with a disability.

The Citizen's Advice Bureau places information in a community setting but does not allow for any monitoring of the information being provided. It also only delivers information without any intimate experience of disability.

With the introduction of the Commonwealth Government's Supported Accommodation place there will need to be an independent information service who can give advice to people with disabilities and their families that will cover all the services from all funding sources.

In the provision of information it is vital that the following articles from the UN Convention are remembered:

Article 4

- a. To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
- b. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

#### Article 9. Accessibility

- c. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities
- b. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- c. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost..

#### **Respite:**

All respite services should be considered as a service to allow the person with a disability to have the opportunity for have respite and relaxation from their everyday situation as well as the carers having the same opportunity.

#### **Accommodation Support Services-**

The most important aspect of provision of services is the quality of carers who deliver the services. To this end it is a priority to have the following article from the UN Convention included in all training.

#### Article 4 General Obligations

- c. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

### **Accountability and Transparency.**

One of the Government's particular strengths in providing services to people with disabilities are its ability to facilitate cross-government and inter-agency responses to case management of clients with very high and complex needs. Government is also able to collect objective data that requires good infrastructure and resources to undertake baseline assessment, analyse service effectiveness and outcomes and manage external evaluation.

It is unconvincing for DACT who is the service provider to suggest that they are able to collect "objective data". A more rigorous system will need to be put in place when there is competition from the Commonwealth Government's accommodation places.

### **AFFIRM- services for children with disabilities should encompass UN Convention.**

PWD ACT have been informed that there are not enough professionals to work with children and that the professionals have overloaded case allocations. Much of the work of professionals is distorted by the the demands of "autistic" children's parents.

## **Executive Summary.**

PWD ACT is unable to provide the detailed information that is sought in the Key Questions for Consideration from the Consultation paper about Disability Services in the ACT. These Key Questions could only be effectively answered by service providers who had had a great depth of experience within the provision of service to people with disability at an international, national and local level.

PWD ACT can provide information into the most vital aspect of the service provision for people with disabilities and that is the the people themselves. PWD ACT is composed of people who have had many years of experience with the issues of disability and believe it is important that people with disabilities are represented in all levels of service provision i.e. planning, implementing and assessing.

All services delivered to people with disabilities either by the community or by the government, have to be as flexible as possible to cater for the individual needs of people with disabilities.

All services delivered to people with disabilities have to be person focused and be in line with the UN Convention on the Rights of people with disabilities. The Kendrick Report also has an insight into the relationship between service providers and people with disabilities.

PWD ACT 's Recommendations are:

**More funding is needed to cater for a greater percentage of the population than the present 40% of population of people with disabilities. CSTDA could be renegotiated in the light of the Commonwealth Government also providing accommodation support. CSTDA should provide for cost of disability that is incurred when a person with a disability enters the workforce.**

**More evidence that Disability ACT has a whole of government approach by promoting inclusive principles within each government department, and agency and in line with its Strategy Direction 1, DACT needs to have each government department and agency prepare a Disability Action Plan with a means of measuring improvement (that would be included and reported against in their annual Business Plan) by the next budget date and as a performance measure.**

As a beginning PWD ACT suggest that DACT provide an awareness training package that could be delivered to all ACT government departments and preferably be delivered. people with disabilities in the presentation.

An independent information service is needed.

Development of a self advocacy kit by people with disabilities and a monitoring role developed.

Better training of carers

A Visitor scheme like that in Victoria which has a monitoring role in accommodation service provision.