People With Disabilities ACT Inc

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Introduction

This submission is made by People With Disabilities ACT (PWD ACT) the peak consumer organisation for people with disabilities in the ACT.

In preparing this submission PWD ACT has consulted with the following ACT consumer and advocacy organisations: Advocacy for Inclusion (AFI) an ACT organisation which provides individual and systemic advocacy for people with disabilities, Women With Disabilities ACT WWD ACT), a consumer organisation of women with disabilities in the Act, Aged and Disabled and carers Advocacy Service (ADACAS) an ACT advocacy organisation and the ACT Mental Health Consumer Network (ACTMHCN) a network of consumer groups for people with psycho-social disability. These organisations referred us to the information they had previously provided to the Australian Federation of disability Organisations (AFDO) and the Disability Advocacy Network of Australia (DANA), as part of the National consultations which led to those submissions and they advised us that they substantially relied on the information provided for those National consultations. Accordingly, PWD ACT have also drawn on material from the AFDO and DANA submissions to this inquiry. Accordingly, this submission, although incorporating views expressed to National bodies by organisations with which we have consulted is substantially the submission of PWD ACT.

This submission does not deal comprehensively with all aspects of the Commission’s draft Report. Rather it deals with those issues which PWD ACT believes need to be emphasized. In dealing with these matters, this submission draws together the views of PWD ACT and the organisations with which we have consulted to give a perspective from the main consumer and advocacy organisations in the ACT.

General Comments

PWD ACT welcomes the Commission’s report in three respects:-

- The recognition that support services for people with disabilities are inadequately funded;
- The endorsement of the principles of self-directed funding and the funding of the individual person; and
- The Support for the principle of access to services on an entitlements basis.

However, aspects of the Commission’s proposals relating to:

Scheme coverage;

Eligibility and assessment;

The role of advocates and advocacy organizations; and

Interaction with the education, employment and aged care sectors require considerable improvement and clarification.

PWD ACT makes the following comments and suggestions with a view to achieving a system of disability care and supports which includes people with disabilities in the community, upholds their human rights and implements Australia's obligations under the United Nations Convention on the Rights of People With Disabilities.

Coverage of Scheme and eligibility Criteria

The Commission correctly recognizes that the lack of funding of disability services is a significant problem and calls for a doubling of the available resources. However, we believe that the final Report needs to contain more clarity on how the figures for both funding and persons covered have been reached and an evidence based assurance that the recommended additional funding will be sufficient to meet the projected need.

The Commission should in designing a disability service and support system, should not place boundaries on access to service and support which are based on boundaries which are arbitrary, because they are based on medical diagnosis or involve a rigid assessment of notions of 'severe' and 'profound'. Such an approach violates the human rights and citizens rights of people with disabilities. Disability support should be an area of universal coverage just as Medicare provides universal coverage of the Australian population for health services.

The report refers to Tier three of the Commission's proposed Scheme as covering the estimated 360,000 people who are determined to have a disability which is severe or profound. However, there are approximately 800,000 people who receive the Disability Support Pension (DSP)and according to the FAHCSIA Discussion Paper for the Australian Disability Strategy, there are nearly four million Australians who experience long term impairment and that number is growing. These figures demonstrate that there is a lack of clarity as to who is included in tier three and who is excluded. This uncertainty is undermining public support for the Commission's proposals, which support is necessary if they are to attract political favour and become a reality.

The Commission's focus on people with severe and profound disabilities locks out from its Scheme many people who need support. PWD ACT is aware of many people who have a severe disability but whose disability may not be assessed as severe or profound under the proposed assessment criteria. These people may have a condition which is episodic or which does not fit neatly into a medical diagnosis and do not continuously access disability support or other social services. these people are significant in number and are equally subject to unemployment, social isolation, ill health and poverty as are people with a severe or profound disability. PWD Act is also aware that for many of these people, the provision of low to medium levels of support at the right times can make a critical difference. In many cases, people in these situations provided with the right support at the right time can transition from social isolation, unemployment, ill health and pension induced poverty to productively employed healthy people who participate in their community and who earn a modest income.

The Commission's proposals need to include these people and ensure that they too have access to the services and supports which will enable them to participate in and contribute to the community. The submission to this Inquiry by the Act Mental Health Consumer Network contains some case studies which excellently demonstrate this point.

Early intervention

The eligibility criteria need to be both informed and flexible to allow people to access early intervention services and supports which may both limit the severity of any future disability and provide the person with skills and coping strategies to manage their disability as it develops. In these situations, there must be fluid boundaries between early intervention and long term support. Also the concept of early intervention should be stretched beyond the medical or therapeutic eg a person may need to move closer to family support or community facilities to ensure a better life in the long term.

Women With Disabilities

The Report's recommendations will not address the issues of gender inequality in access to disability services. We refer the Commission to the submission by Women With Disabilities Australia, which includes input from Women With Disabilities ACT. This submission sets out the circumstances which give rise to disadvantage experienced by women and girls in access to disabilities and the structural factors in the current disability service system which entrench their disadvantaged position. In the ACT as in other jurisdictions, a significantly higher percentage of the funding for people with disabilities is spent on boys and men than is spent on women and girls. In the ACT the gender inequity in service dollars spent on men and boys as compared with women and girls is exacerbated by structural factors such as the focus in ACT on intellectual disability services and the provision of those services by a Government service provider. The WWDA submission contains strategies to address this gender inequity and we refer the Commission to these strategies. Refer: www.wwda.org.au

In addition to gender equity, an equity based disability support service system must take into account the additional costs and support needs that arise from Aboriginal and Torres Strait Islander background, cultural diversity, geographic isolation and the specific needs of children, migrants and refugees.

People Living with Mental Illness

PWD ACT supports the comments made in the submission by the Act Mental Health Consumer Network ACTMHCN in relation to people who live with mental illness. The Commission's attention is drawn to the following aspects of the ACTMHCN submission:-support for a personalized approach which allows a person to access care when they need it and in a way which suits their needs;

- The nature of mental illness and the importance of adopting a social and functional approach to assessment and service delivery as opposed to a medical and diagnostic approach;
- The use of the term psycho-social disability in preference to mental illness; and
- The need to include people with psycho-social disability in the Commission's proposed scheme.

Assessment

The emphasis on assessment processes gives an impression of a Scheme which is trying to exclude people and not to include and support them. There are real risks that in a service support system such as that proposed by the Commission, assessment tools will be inadequate or will be misused in ways which do not measure an individual's real needs and lock him or her out of supports they need to live in the community. In particular we refer to the comments made by the Australian Federation of Disability Organisations (AFDO) in relation to the limitations of current assessment tools and the particular limitations of the WHODAS 2 Assessment Tool, the one recommended by the Commission.

The final report should address this problem by emphatically endorsing assessment in accordance with a social and functional model of disability. PWD ACT refers the Commission to page 14 of UN Guidance Notes which contains a good example of an assessment process based on a social model of disability. A copy of this document was provided to the Commission during PWD ACT's presentation to its public hearings and another copy is enclosed with submission for the Commission's convenience. An alternative assessment tool which also uses a social and functional approach is that used in the German Long Term Care and Support Scheme. This is referred to and described in the ACTMHCN submission. It is noted that the PWC Report to FAHCSIA on a National Disability Insurance Scheme also recommends the use of assessment tool based on a social and functional model of disability

The assessment process also needs to be conducted in a way which supports the person with a disability to participate and to make decisions about his or her support. One way in which this can be most effectively done is to include in the assessment process recognition of the role of advocacy and provision for a person to be supported by an advocate if they request this support. See our comments about advocacy below.

The assessment process should include substantial reliance on self-assessment. Our experience is that people with disabilities are the ones which best know their needs and the services and supports which will most benefit them.

The proposed $500 assessment fee should be rejected. Such a fee would impose substantial hardship on people with disabilities many of whom are on low incomes or solely reliant on income support payments.

Principles of Individual Funding and Self-Directed Funding

PWD ACT welcomes the Commission’s support for the principles of funding of individuals and self-directed funding. It is important that new arrangements for disability support services involve a clean break from historical funding models which focus on funding of service providers and the service provider deciding what a person needs and gets.

PWD ACT would support a funding model which had two tiers. The first and substantially larger tier would provide self-directed funds for individuals. The second and substantially smaller tier would provide establishment and maintenance funding for service provider organizations which provide services purchased by individuals. This approach would use a combination of individual control and competition to drive service quality and improvement. Such a model should also include an annual monitoring and reporting framework with performance measures based on individual outcomes and a Standard such as either the current Disability Service Standards or the proposed new quality framework for Disability Services. This performance monitoring and reporting framework should be administered by an independent auditing agency similar to that used in the aged care sector. These arrangements would require specific transitional funding, including funding for consumer education, and a transition period for service provider organisations.

Advocacy

PWD ACT is pleased that the Commission is to reconsider its approach to advocacy as a result of submissions made to it by advocacy organisations at its public hearings.

PWD ACT considers that the draft Report demonstrated a misunderstanding of advocacy, its role in the disability service system and its importance to the individual service recipient. ‘Advocacy’, is not just another kind of service or disability support. ‘Advocacy’ involves an advocate who stands beside an individual to assist him or her to give voice to their concerns and interests and to obtain an outcome which meets their needs. For an advocate to perform this role effectively, the individual and the organisation for which they work must be independent and have no conflict of interest which prevents him or her from advocating for their client. In particular, in the context of disability services, advocates and advocacy organisations must be independent of family members and carers, service providers and funding bodies.

People with disabilities are more likely than the general population to experience abuse, homelessness, institutionalization, poverty and social isolation. Many rely on paid carers or family members for their basic needs making them extremely vulnerable to the actions and other people. Without advocacy support, many people with disabilities do not have the knowledge, skills or personal resources to engage with the service system or to convince their families associates or the community that they are entitled to live an ordinary life involving meaningful activity, friends and social interaction.

Advocacy also needs to be independent of service provision agencies and funding bodies. Advocacy support for people with disabilities comes from many sources: family, friends and public minded individuals, Government officials, service providers and advocacy organisations. All possible sources of advocacy support will from time to time have interests that differ from the people with disabilities being supported. Independent advocacy organisations are vital additions to the advocacy support available to people with disabilities because they focus on minimizing any potential conflicts of interest and on developing their advocacy skills and expertise to achieve the outcomes desired by people with disabilities.

Independent advocacy organisations also carry out the ‘systemic’ advocacy function. Systemic advocacy is directed to correcting defects in the systems by which services are provided, administered, regulated and funded. Much of this systemic advocacy is informed by information gained from repetitive or cumulative incidents of individual advocacy.

Our experience as ACT advocacy and consumer organisations indicates to us that the availability of independent, professional and accessible advocacy support for people with disabilities will be critical to the success of a disability service system based on a more flexible and individualized approach to funding and service delivery, as envisaged in the Commission’s Report. In the context of flexible and individual service delivery and funding arrangements, it is necessary to provide independent support to decision-making by those people with disabilities who do not have the experience, knowledge and skills to operate as empowered consumers in a more open marketplace model. This means that advocacy support needs to be available for people in tier two of the Commission’s proposed system as well as to people in tier 3. In particular advocacy needs to be available to people as part of the assessment process. Advocacy agencies will need to be properly funded and supported to ensure that the individual person with a disability is informed, empowered and assisted to realize the full benefit of reformed funding and service delivery arrangements.

In the context of the Commission’s suggested approach to funding and delivering disability support independent advocacy would:

- Assist people with disabilities to be informed about the support choices available to them;

- Assist people with disabilities, particularly those with limited capacity to communicate their wishes and desires and to participate in the decision-making and implementation processes;
- Where required, directly represent the person with a disability to protect their interests and rights;
- Assist service providers and system level decision-makers such as funding and policy bodies to better understand the needs of people with disabilities; and
- Identify issues of common concern to people with disabilities and seek reform to address those issues.

PWD ACT agrees with what is said in the DANA submission about the nature and role of advocacy, the need for strong, effective and independent advocacy in the particular context of the Commission's proposals and the design of an advocacy system. They also strongly support DANA's recommendations that funding for advocacy services should be discreetly quarantined and separately administered in a way which safeguards the effectiveness and independence of advocacy services and the independence of individual advocates.

Complaints

There is concern that people with disabilities can only complain about matters of merit to either an internal body or to an overly formal Tribunal or Court. People who require support but who miss out due to arbitrary assessment of need must have an external independent and impartial mechanism of recourse. In the ACT, the ACT Commissioner for Disability Services offers a complaints hearing and resolution process. However, because the ACT Government is itself so heavily involved in service provision in the ACT, some people may feel that this process may not be sufficiently independent of the ACT Government. We would recommend that review of merits complaints of refusal of support be conducted by an Ombudsman established for this purpose.

Interaction with Education, Employment, Health and Aged Care Sectors

The Commission's Report makes assumptions that the disability related needs of people will be met by these sectors. This is not the case. Indeed the Commission's parallel inquiry and report on the aged care sector contains no recommendations for increased funding of that sector to meet the disability related needs of older persons. The focus on defining boundaries between the disability sector and other sectors, results in ineffective supports and exclusion of people with disabilities from community life. An example is that a person with disabilities may obtain employment in the ACT public Service but be unable to take up that employment because he or she cannot get the support to get out of bed and ready for work or access the transport system to get to work or access. Instead of an approach based on jurisdictional and financial boundaries, people with disabilities need an approach in which the disability support service system works with the education, employment health care and aged care systems to enable people with disabilities to live quality lives.

Governance

The governance bodies for the disability support service system need to include people with a mix of skills including fiscal, legal and business management. There are many lawyers, financial experts and business managers who also have a lived experience of disability. The governing body for the new service support arrangements should proactively approach, motor and appoint people with disabilities who have relevant qualifications and experience to governance roles. Further, the governance arrangements should include processes for persons in governance positions to hear and act on the voices of people with a lived experience of disability. Too often the voice of people with disabilities is lost in the mire of expertise in other areas or the dominant priorities of saving money or avoiding risk rather than obtaining equal rights.

Conclusion

PWD ACT welcomes the Commission's report. We believe that if the Commission addresses the matters mentioned in our submission, in particular:

Scheme coverage;

Eligibility and assessment;

The role of advocates and advocacy organizations; and

Interaction with the education, employment and aged care sectors

The Commission's final Report will provide a blueprint for a system of care and support for people with disabilities which are flexible and focused on the individual, which meets their needs and upholds their rights and which supports and enables people with disabilities to participate in the life of the community.