12.08.2010

To whom it may concern,

Re: Productivity Commission Disability Care and Support Inquiry

My name is Maree Ireland. I have an Arts / Law Degree and I work as a Project Co-ordinator for field – furthering inclusive learning and development. I have competed in a number of Boccia competitions and recently performed in a play at the MTC Theatre called Perfectly Imperfectly around the rights of women with disabilities to motherhood.

Why am I telling you all this?

I have told you all this because without the current disability supports I receive (currently 34 hours) none of the above would have been possible.

However there are hundreds of people with disabilities who are "stuck", yes stuck inappropriately in nursing homes because of lack of funding for the disability support they should be entitled to.

Entitlement to long-term care and support

I have worked as a disability advocate for several years. My work involved advocating for an entitlement system for disability supports for all people with disabilities. Australia has ratified the UN Convention on the rights of people with disabilities. This should mean Australia should "take measures to the maximum of resources" ensure the human rights of people with disabilities are upheld. I realise that governments have limited resources it is still unacceptable that many Australians with disabilities are living without the basic disability supports.

I hope the powers that be realise it is imperative that a disability care and support scheme is funded to cover the real costs of living with a disability and fully participating in society.

Eligibility

5Entitlement should cover all people with disabilities who have a disability, either from birth or acquired from an accident who have on-going needs from their disability. Again acknowledging initial funding limitations, the scheme should eventually and preferably cover people who have disability-related needs regardless of their age.

The scheme should be available across a person's lifespan to promote continuity and on-going independence.

The scheme must not be means-tested. The disincentives to workforce participation inherent in a means-tested scheme would far outweigh any savings to be made.

I fully endorse the following points put forward in the submission by Action for Community Living. These are:

"Assessment

An assessment system has to provide a framework for funders to provide money, however it must also allow for the complexity of people's lives. Universal assessment systems have traditionally used inflexible tools that splits up people's lives. The assessment process should be a holistic process that looks at all aspects of life and takes account of the person's strengths and capacities as well as needs. Needs should be looked at in the context of the person's aspirations and goals.

The process should be assisted by someone who is aware of eligibility/funding issues but independent of both funder/s and service providers. Assessment personnel require an understanding and extensive knowledge of disability and its impacts, not just the medical or clinical aspects of disability.

Flexibility in program and funding guidelines

Discrete programs, with their own strict eligibility/priority criteria and guidelines, create complexities and barriers for people with disabilities with consequent adverse effects on their quality of life. An individualised approach, with flexibility in program and funding guidelines so that individuals' needs can be met in the least disruptive way, will significantly improve the quality of life of people with disabilities.

Power and decision making

People with disabilities (with the assistance of 'supporters' if necessary / desired) should have control over how their funding is used, within agreed parameters. This includes having the flexibility to meet their support needs in the way that best suits them, the choice to directly employ their own support workers or to purchase their support services through an agency of their choice.

Funding administration could be implemented in a variety of ways to suit people's needs. The administration of the funding can be with a maximum of self-management by the person or with the assistance of paid or unpaid supporters (family members, friends, advocates, guardians). Options should include a financial intermediary model, as well as direct payments, where people with disabilities can have maximum control over their own funding and service arrangements.

Additional infrastructure to make the scheme work

A number of supporting structures are required to underpin an individualised funding system. These include:

- Advice and information services to assist people with a disability and/or their support network to manage funds and support services, e.g. nonprofit organisations run by people with disabilities to provide information and referral, peer support, independent living skills training, and possibly other services such as administration of funding.
- Community development and capacity building to make access to informal support and community activities easier.
- Access to independent advocacy support for people with disabilities
 who need assistance to have a strong voice on matters that directly
 affect their well being and their rights. It is our position that funding for
 independent advocacy is separately funded and not required to be
 purchased from individual funding packages."

I hope the Commission fully realises there should be an Entitlement System for the provision of appropriate disability supports. This should be funded through a fully established National Disability Insurance Scheme.

Thank you for your time.

Regards

MAREE J.IRELAND