Office of the Public Advocate

10 August 2010

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT. 2601

Dear Sir/Madam,

The Office of the Public Advocate (OPA) has considered the Productivity Commission's Issues Paper 'Disability Care and Support' and welcomes the opportunity to comment.

The scope of OPA's work is defined by the *Guardianship and Administration Act 1986*. OPA provides advocacy, guardianship and investigation services to people with a decision-making disability. OPA coordinates the Community Guardianship Program and the Private Guardian Support Program as well as the Community Visitors Program and the Independent Third Person Program.

People with a decision-making disability under guardianship include people with an intellectual disability, a mental illness, an acquired brain injury (ABI), dementia and people who are in a coma or otherwise lack the capacity for cognition or communication. Most of these disabilities are non-compensable hence not covered by TAC, work cover or medical indemnity insurance. Guardians see a stark contrast between the services and supports able to be accessed by compensable clients as compared to non-compensable clients as the following example illustrates.

> **The case for a National Disability Insurance Scheme**
> Graham, now in his early 50's, has lived in a neurorehabilitation facility for people with an ABI and mental illness for the past eight years. For ten years prior, he lived in various institutional settings, as a result of an ABI sustained in his early 30's. Graham is listed as 'ready for discharge' and would like to live in his own unit with support but does not have the funding to do so - he is a non-compensable patient without family support or accommodation to go to and is not eligible for the Victorian *My Future My Choice* program because he is over 50 years of age. Unless something changes, he will live out the remainder of his life in this facility, with little contact with the community and few options to enjoy individual pursuits or a reasonable quality of life.

A director of a Melbourne rehabilitation centres surmises that there are three factors, aside from the severity of the ABI, mediating the successful discharge of a person with an acquired brain injury in a rehabilitation setting: housing, support and compensation. People who do not own their own home, do not have strong personal advocacy and support and are non-compensable are far more likely to linger in inappropriate accommodation than people who are in possession of these.

In general, people with disabilities without access to adequate funding or compensation are financially disadvantaged. In 2003, the median gross personal income per week of people of working age with a disability was $255, compared to $501 for those without a disability[i]. The cost of living for people with a disability is generally higher than for the rest of the community due to higher medical costs, and paying for mobility and communication aids, transport and help with attendant care. These costs are not fully covered by Medicare, the PBS and other public subsidies[ii].

Recent Organisation for Economic Cooperation and Development (OECD) research found that Australia has the lowest average personal income for people with a disability, at 44 per cent of the income of people without a disability[iii]. After paying for accommodation, many residents of Supported Residential Service accommodation are left with almost no disposable income.

OPA welcomes the introduction of a scheme that acts as a no-fault social insurance scheme to provide long-term care and support to people with disabilities. We would like to provide the following comments for your consideration:

1. OPA is supportive of the concept of the scheme being a non-fault social insurance scheme that would provide a consistent pool of funds for disability services and support – essential care, therapy, aids, home modifications and access to community, education and training. OPA reserves its position on how the scheme should be funded but we believe the idea of a scheme funded by all taxpayers through general revenue or an extension of the Medical insurance levy warrants consideration.
2. OPA acknowledges that the scheme is not intended to cover all degrees of disability but that the principal beneficiaries would be people whose disability has a significant impact on their daily life – no matter how that disability was acquired. OPA shares the concern of the Commission that the category 'severe and profound' disability may lead to the exclusion of people who would benefit from early intervention or where functional limitations are curtailed by other variables (lack of support/location/ disadvantage). Although not wishing to suggest that eligibility should be based on diagnostic definitions, we submit that the following disability groups are groups whose needs are poorly addressed in the current system: people with autism, Huntington's disease, dual disabilities and complex needs, mental illness and non-compensable ABI.
3. OPA believes that funding should be provided for people of all ages, regardless of when the disability was acquired. For example, if someone acquired an ABI after the age of 65, they should still be eligible for disability funding and support. Similarly, an older person with autism who has ageing parents and needs to make new accommodation and support arrangements and a person over 65 with an intellectual disability living in a disability setting would benefit from the continuity associated with being funded under one scheme.
4. OPA is supportive in principle of people with disabilities and their families/significant others exercising choice over their own funding. However, OPA has concerns about the potential for exploitation and neglect by families or significant others. OPA receives many calls through its telephone advice service about the exploitation of people with disabilities through misuse of Enduring

Powers of Attorneys (see attached OPA submission into Enduring Powers of Attorney). This will require that effective monitoring and accountability mechanisms are put in place.

5. OPA is supportive in principle of individualised funding and the potential for recipients of funding to purchase their own accommodation and support. However, OPA has concerns about the new privatised accommodation and support providers that have come into the market in the context of individualised funding and the lack of scrutiny of these services. While in Victoria, disability services, mental health services and supported residential services are subject to the monitoring of Community Visitors under the various acts of Parliament, many private providers are not. This will also require that effective monitoring and accountability mechanisms are put in place.

6. OPA believes that independent support and advocacy for people with disabilities to ensure that needs are being met will be required if the scheme is introduced. Where assessment and planning is undertaken by an assessor who then leaves only to return twelve months later to review the plan as has been the case in some government funded disability funding pools, people are often left to engage and coordinate services themselves. Within what is a complex and fragmented system that even paid workers find hard to negotiate, this may create an unrealistic expectation of the funding recipient.

7. OPA has concerns about the capacity of people with poor decision-making capacities to manage their own finances. The substitute decision-making provisions of legislation such as Victoria’s Guardianship and Administration Act need to be considered in the new scheme. OPA is keen to ensure that society sees the role played by guardianship not just in terms of rights-restriction but as a protective mechanism where it is needed.[iv]

8. OPA has concerns about replacing the current system of disability services with a scheme that is wholly individually determined. The current community-based disability support system consists of not for profit services established over decades with the benefit of operational, infrastructure and capital funding as well as funding for casework services. A new model will need to consider the sustainability of the current service system as a whole as it will not be beneficial to wholly substitute specialist models with mainstream models of service provision.

9. There is a shortage of professional and appropriately trained disability workers across mental health and disability services in Victoria. Community Visitors Reports identify a lack of skilled workers across Mental Health, Disability Services and in Supported Residential Services. This is a critical issue to be addressed in terms of the quality of services able to be purchased by people with disabilities (see attached Community Visitor Report 2009/10).

10. OPA believes the provision of accommodation is critical to the quality of life of people with disabilities. The failure to provide adequate housing and support for people with a disability and/or mental illness contributes to both increased economic and social costs to the community. There are economic costs to the community associated with ill health, increased use of health services and increased exposure to the criminal justice system. For people with a disability and/or mental illness there are social costs relating to disempowerment, social

> isolation, lack of autonomy, restriction of movement and quality of life.[v] As such, housing is a critical issue that needs to be addressed by the Commission.

Attached to this letter are three recent documents: OPA's submission to the Guardianship and Administration Review, 2010, OPA's submission to the Supported Accommodation Review, 2009 and OPA's submission to the review of Enduring Powers of Attorney, 2009. These submissions outline a number of important issues that have emerged from OPA's experience of guardianship, many of which are pertinent to the terms of reference of the Productivity Commission's Review.

I thank you for the opportunity to comment on your work and look forward to the opportunity to comment further.

Colleen Pearce
**Public Advocate**

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[i] Australian Bureau of Statistics (ABS) 2003 *Persons aged 15-64 years living in households,* cited in Office of the Public Advocate, 2009 *Submission to the Inquiry into Supported Accommodation for Victorians with a disability and/or mental illness:* response to Family and Community Development Committee Discussion Paper, February 2009.

[ii] OPA, 2009 see above.

[iii] OECD 2003, *Transforming Disability into Ability, Policies to Promote Work and Income Security for Disabled People*, cited in OPA 2009 see above.

[iv] Chesterman, 2010 *Submission to the Victorian Law Reform Commission in Response to the Guardianship Information Paper,* Office of the Public Advocate, May 2010.

[v] OPA, 2009 see above.