COMPASS SA INC.

Submission for the Senate Review of the Commonwealth State / Territory Disability Agreement

'An examination of alternative funding, jurisdiction and Administrative arrangements, including relevant examples from overseas.'

The Commonwealth, State/Territory Disability Agreement's principles were founded on those of the Commonwealth *Disability Services Act 1986* – namely, the right of people with disabilities to have equal access to the same services as other Australians. The Agreement also supported the enactment of State and Territory legislation mirroring the Commonwealth *Disability Services Act 1986*.¹

While the majority of non-disabled citizens in Australia are able to determine their own lives both economically and socially, for people with a disability this is usually not a reality. People with a disability, particularly those with high and complex needs, are greatly affected by their limited choice of services in all areas of their lives. In schools, transport, access to facilities, equipment, employment opportunities and accommodation to name a few, people with disabilities have limited choice and limited access. Complicating these areas of concern is the lack of planning and appropriate funding for people with a disability requiring such services.

Compass SA believes that one way of empowering people with a disability and allowing them greater choices is by way of individualised funding and personalised life planning. We believe that financial independence is the key to achieving equity and empowerment for people with a disability and a mechanism for building inclusive communities.

In discussing this issue it is necessary to mention that Individualised funding is not a new concept or funding mechanism for people with a disability. Individualised funding has been successfully in use as a funding mechanism in many OECD countries for the last 20 years, enabling disabled people with complex and high needs greater freedom and personal choice of services and support (Ministry of Health, New Zealand, 2003:4).

Models of individualised funding can range from a person with a disability having a high degree of self-management of their allocated funds to a model where a broker or trust does the management, control and accountability of the funds on behalf of the individual. The latter still gives the person with disability a great deal of say and hence empowerment and control over decisions that affect their life.

Research in Britain (Riddell et al, 2005:75),² reveals that direct payment to people with disability has the potential to improve not only their economic welfare but also their social status, by transforming their existence from a passive welfare recipient to one of employer *with* the many responsibilities that this role entails. *Additional benefits include including wealth generation for the growing services sector* (Barnes, 1994)³

Other research from Britain indicates that personalized and individual payment schemes are "associated with higher quality support arrangements than direct service provision. In particular, the payments option clearly offers disabled people a greater degree of choice and control and, consequently, leads to higher levels of user satisfaction. Most importantly, support arrangements which are funded through the payments option are almost invariably more reliable (and, therefore, more efficient) than those supported by direct service provision" (Zarb & Nadash, 1994:4)⁴

Justice', Social Policy and Society (2005), 4: 75-85 Cambridge University Press. Barnes C. 1993. 'Making our own choices: Independent Living, Personal Assistance and

¹ Commonwealth State / Territory Disability Agreement (CSTDA) Annual Public Report 2002-03 Commissioned by the National Disability Administrators, Prepared by Australian Healthcare Associates, July 2004. http://facs.gov.au/internet/facsinternet.nsf/vIA/cstda/\$File/cstda annual report 0203.pdf

² Riddell Sheila, Charlotte Pearson, Debbie Jolly, Colin Barnes, Mark Prietsley and Geof Mercer, 'The Development of Direct Payments in the UK: Implications for Social

³ Barnes C, 1993, 'Making our own choices: Independent Living, Personal Assistance and Disabled People, Belper: British Council of Organisations of Disabled People.

http://www.leeds.ac.uk/disability-studiesudies/archiveuk/Zarb/cashing%20in%20on%20indep.pdf
⁴Zarb Jerry & Pamela Nadash, 'Cashing in on Independence, comparing the comparing the

While the States and Territories are responsible for planning, policy setting and management of accommodation, community support, community access, respite and other support services, we would like to recommend the need for appropriate Commonwealth funding, through the CSTDA to, to enable the States and Territories to implement personalized and individual payment schemes on a broad This would assist the chronic waiting lists, unmet needs and lack of services that is a daily reality for people with a disability and their families.

School placements in neighbourhood schools, special classes, accessible transport, equipment, respite, accommodation, therapy services and early intervention are among the major areas needing additional funding for building inclusive communities in South Australia.

The current scheme in England of 'direct payment' used by local governments to fund people with disability, enables them to buy the services or employ people that best meet their requirements⁵. People with a disability are given control to organize their own lives but have the option of a shared arrangement by way of a brokered or Trust situation, should they be unable to fully participate in the process of spending their own funds. Great Britain's Health Department describes the process of individualised funding as:

"Direct payments create more flexibility in the provision of social services. Giving money in place of social care services means people have greater choice and control over their lives, and are able to make their own decisions about how care is delivered" (UK Dept of Health, 2006)⁶.

We recognise that developing such a scheme would involve substantial policy and service change for the Commonwealth, State and Territory Governments. However we believe that such a funding arrangement in a free market would create jobs and opportunities in the services industry that would indirectly assist in the financing of such a scheme. We also believe that if people with a disability were better supported in their daily lives, many would be able to participate in the work force.

Compass SA believes that introducing a direct payment scheme in Australia would be a great move forward in addressing some of the social justice and equity issues that currently face people with a disability, many of whom currently have have little or no control over the services they receive.

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Costs and benefits of cash and services'. http://www.leeds.ac.uk/disabilitystudies/archiveuk/Zarb/cashing%20in%20on%20indep.pdf

⁶ United Kingdom department of Health, 'Direct Payment'

⁵Department of Health, 2006, 'Direct Payment Guidance' England, http://www.carers.gov.uk/pdfs/dpguidance.pdf

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The Aging and Disability Interface with Respect to Health, Aged Care and Other Services.

The are major differences between the needs of people ageing who acquire a disability and those people ageing who have a disability eg, intellectual disability.

People without a disability have very different life experience from those with a disability. Ageing people have mostly worked, have a home and family and a network of friends through social and recreational activities. They plan for retirement and can often be supported by informal networks.

Most people with a disability are locked into the service system at an early age; they do not have the same experiences of work, home, family or social life. They do not plan for retirement and as they are unable to work they need to be supported in a day care situation. As they often live in supported accommodation, they do not have the luxury of choice. The accommodation service they use is not staffed during the day, so they need to go elsewhere.

Much of the Aged Care Policy is dependant on people having an income. However, people with a disability do not have the opportunity to invest in a superannuation fund.

The funding formulae and administration of aged care and disability services seem to assume that a person is disabled or aged, but cannot be both. It is time for the disability sector to face the fact that people with disabilities are living longer and need appropriate support. Presently where the demand exceeds availability, the eligibility criteria are tightened to restrict access to services.

Another issue to consider is the premature ageing associated with some disabilities, eg Down syndrome. Their rate of ageing is often greatly accelerated with early on-set dementia being one example. Being eligible for aged services greatly inhibits their access to disability services (Bigby:3, 2005).⁷ This clearly discriminates against those who age prematurely.

More work needs to be done on improving pathways and linkages between aged and disability sectors. Currently the collaboration between sectors is ineffective.

The issue of health services for people with a disability also needs to be considered. For example people with a disability may need to access speech therapy or physiotherapy, but these services are not generally part of the CSTDA. These services are not available on an ongoing basis without private health care. Clearly the CSTDA needs to consider the needs of ageing people with a disability in relation to health, home, recreation and socialization.

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⁷ Bigby Christine, Associate Professor, 2005, 'Ageing with Intellectual Disability: Program Interfaces', School of Social Work and Social Policy, LaTrobe University, Bundoora, Victoria.