Submission to the Productivity Commission's Inquiry into the Development of a Long-term Disability Care and Support Scheme

1. Recommendations

General

- 1. The Federal Government should introduce a Disability Insurance Scheme which would allow for better participation by people with disabilities in all areas of life, as is their right as citizens, by enabling the provision of appropriate supports and services according to individual needs.
- 2. All Australians have the right to the same level of needs based funding regardless of how the disability was incurred.

Assessment of Eligibility

- 3. Eligibility for the scheme should be automatic for anyone who has a disability, regardless of how the disability was incurred or the age at onset. Assessment of the services and supports should refer to each person's support needs, and not be based on assumptions about a diagnosis.
- 4. Support should be provided according to individual need and should recognise the uniqueness of each person.
- 5. Episodic conditions such as psychiatric/psychosocial disability and chronic illness should be included in the scheme.
- 6. The scheme should use a single application process to reduce inconvenience and increase efficiency and stability, while ensuring that life cycles and transitional periods are taken into account

Scheme Design

- 7. The scheme should promote independence and support people to live a full life, include support where necessary to ensure access to employment, housing, information, education and social participation.
- 8. The Scheme and its benefits should not reduce the responsibility of mainstream services (e.g; to make their services accessible and inclusive to people with disabilities).
- 9. The scheme should take an individualised approach and a whole of life approach for people with a disability, recognising that a person's circumstances may change over time.
- 10. The scheme should support people to make usual life transitions, for example, living independently, having a family and retiring.
- 11. The scheme should be flexible and responsive, and provide timely assistance to meet the range of people's needs. This includes providing intensive support at some stages.

- 12. The scheme should acknowledge and respond to the additional costs of living with a disability in the areas of social interaction, housing, employment and education.
- 13. People who are part of the scheme should receive a concession card (similar to the Pensioner Concession Card) and a companion card.

Administration of Scheme

- 14. The scheme should be administered by a specialist government agency.
- 15. The scheme should be funded via a levy similar to the Medicare Levy or the TAC levy in Victoria.
- 16. One scheme should exist incorporating the needs of all Australians, including those who are injured as the result of motor or workplace accidents.
- 17. Existing funding schemes should be incorporated into one scheme (ie existing TAC and workcover funding)
- 18. Support provided via the scheme should be portable, allowing freedom of movement within Australia

Engagement of people with a disability

- 19. Information about the scheme must be provided to all people with disabilities in a format which will suit their individual needs
- 20. People with disabilities must be able to participate in all aspects of the application and assessment process.

2. Introduction

As a person with a disability, I need some supports to ensure that I have equal access to all areas of Australian Life. However, what support I receive should be based on my individual needs, not on some preconception on what is required according to diagnosis.

Similarly, the level of support I need does not vary according to how I incurred the injury. If I require a wheelchair, I require a wheelchair – the level of funding I receive should not be based on whether I had a car accident, or a workplace accident, or a diving accident, or whether I have had a disability at birth or through illness.

3. Disability and intersection with Human Rights

The Victorian Government has implemented the **State Disability Plan 2002-2012**, which has a number of changes to the way disability services are offered to make sure that people with a disability have a greater say about the planning, funding and type of assistance they receive.

This is in line with Australia's commitment to human rights as outlined in the United Nations Convention on the Rights of Persons with Disabilities (2006) (UN Convention), and with the Victorian Charter of Human Rights and Responsibilities (2006).

The UN Convention includes the following principles:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

4. Discussion of Specific Issues

Australians with disabilities are no different to other Australians. They share the same right to education, meaningful work and social inclusion. They have the same right to independence and freedom of movement. They have the same hopes for the future. However, due to the lack of appropriate funding for the supports they need to ensure their citizenship rights, many Australians are not able to live the life to which they aspire.

4.1. Assessment of Eligibility

Eligibility for the Scheme should not be means-tested in recognition of the high costs of living with a disability that people experience.

Services for Australians with a disability are provided differently across each State and Territory in Australia. This means that people with the same disability, in similar circumstances, can receive different types and levels of support. There are also some Australians with a disability who cannot get as much support as they need.

In Victoria, people with a disability can receive support and assistance in three ways, depending on how they acquired their disability:

- 1. Through a no-fault injury insurance scheme (TAC, WorkSafe)
- 2. Through a compensation payment or
- 3. Through publicly funded disability services (provided by the Department of Human Services).

(See Appendix A)

As a signatory to the UN Convention, it is now time for the Commonwealth Government to introduce a national scheme that will provide appropriate support for all Australians with disabilities, regardless of how the disability was acquired, that is portable, that is based on individual needs, and allows for early intervention, to enable full participation as citizens. The scheme should reflect the principles of the UN convention.

Support for Australians with disabilities should not be dependent upon how the disability is incurred, or the age of onset of the condition, or on where they live. Support should be provided equitably to all Australians with a disability. Any scheme should therefore take into account what an individual needs, rather than being based on a medical diagnosis or assumptions about a diagnosis.

Disability may touch all people at any period of their life, and it would be unwise to provide for an arbitrary age barrier. The provision of aids, supports and assistance will be appropriate to older Australians with disabilities to enable them to live independently. Each person should receive what disability supports they need in order to enable them to participate fully as citizens. Services need to be provided according to the level of need.

It must also be recognised that for some people, their disability is episodic, so that they may require assistance intermittently. For example, someone may have relapsing or remitting Multiple Sclerosis, or a psychiatric/psychosocial disability, which means that they may have times of relative wellness – and then have other periods where more support is needed. Therefore, episodic conditions such as chronic illnesses and psychiatric/psychosocial disability should be included in the scheme.

Australians with disabilities, their family or supporters and service providers all agree that the current method of assessment is onerous, and is largely based on a medical model. There is a continual requirement to attend at doctors to ensure that the disability is verified – yet again. For example, a person who is hemiplegic may be required to attend a doctor's surgery on numerous occasions in order to access services – such as accessible parking, disability support pension, access to education support services, etc- as though the paralysis will have disappeared in the time since the previous examination. While there is a need to ensure that the support provided meet the needs of the individual, there should be a single process which can be used to verify need.

However, it is also important to acknowledge the transitional periods in a person's life, such as from hospital to home and accessing child care kindergarten, primary, secondary and tertiary education, entering the workforce, moving out of home, marriage, family and retirement. The scheme must be able to meet these changing needs.

There is a need to ensure that stereotypes are not a factor when assessment is made – and assumptions are not made as to the needs of individuals. The fact that a person could have multiple disabilities must also be factored into the assessment, and should not be assumed. A person with polio, for example, may also acquire a brain injury, suffer depression or have kidney failure. If support provision is based purely on a diagnosis there is a danger that there may be a failure to meet the needs of individuals and the range of abilities within a particular disability

For example: The range of abilities for persons who contracted Polio in the mid-1950's may differ dramatically from a person who is able to participate fully with the assistance of mobility aids such as a knee and foot orthotic to another person who may require the assistance of a support worker to in order to dress, shower etc. By basing the support on needs, a person with polio is more likely to be able to participate fully in education and employment.

4.2. Scheme Design

The design of the Scheme should be based on the following principles that would promote the human rights and full participation of people with disabilities in community life:

The scheme must promote independence and support people to live a full life, and include support where necessary to ensure access to employment, housing, information, education and social participation. VDAC wishes to emphasise that the Scheme must not provide support as a replacement for services that should be accessible to all members of the community, including people with disabilities. Access to health, justice, education are not disability issues but rather human rights issues, and therefore should be provided equally to all Australians.

For example, all children have a right to high quality education, including children with disabilities. While the Scheme might provide a child with appropriate aids and equipment for personal use and an attendant carer, if necessary, the school the child attends should be accessible and provide educational supports that enable the child with a disability to participate in education. Teachers' aides, note takers or sign language interpreters should be provided by the educational institution not the Scheme.

The right to meaningful work is a necessary component for financial independence. For some people, the lack of funding for the provision of appropriate workplace equipment has impeded employment opportunities. Where equipment funding is available, it is linked to the workplace, which impedes the mobility of Australians with disabilities. Workplaces should be accessible to people with a disability and appropriate supports to enable the employee to access the workplace such as an accessible building, the availability of screen reading software, adaptive furniture and equipment or other workplace modifications should be available through existing schemes such as Job Access and not through this scheme.

Other examples of where a mainstream community service should provide supports include the captioning or audio description in cinemas, accessible recreation facilities, Auslan interpreters and other supports to enable access to Justice, including police and the court system and ensuring access to the health system through the provision of information in appropriate language, access to Auslan interpreters and height adjustable tables. Vulnerable Australians should not be denied access to justice because of a failure of mainstream services to enable the reporting of crime, or the failure to provide appropriate supports such as accessible women's shelters and counselling services.

The more accessible mainstream facilities and services are, the less likely people with disabilities will need disability-specific supports. In effect, an accessible, inclusive community could reduce the need for disability-specific supports. People with disabilities want to participate in mainstream society but are often denied the opportunity to do so because of the lack of access. In effect, the sustainability of any proposed scheme is directly linked to how well mainstream facilities and services meet their obligations to be accessible and inclusive of people with disabilities.

4.3. Governance, Administration and Funding

The introduction of the National Disability Scheme must be legislated and should include the establishment of a national government agency and the appointment of a Disability Commissioner. The office should oversee the administration of the scheme, including initial assessment, review and payments. The disability Commissioner will take responsibility for the scheme, with the ability to hear complaints and appeals and to initiate reviews. The Commissioner should be given the legislative powers to enforce rulings and decisions. The Commissioner should be independent of the administration of the scheme.

In the first instance, an injection of funds would be required to get the program initiated. This would enable the development of a funding pool to meet future needs. The most appropriate funding mechanism would be via a levy similar to the Medicare levy. This method would ensure that the cost is spread across society, and would provide ongoing adequate funding to meet the needs of all Australians with disabilities.

Funding already provided to support people with disabilities through TAC or Workcover should be incorporated into the scheme so that only one scheme exists for all Australians with disabilities.

Assessment must be undertaken in a manner which respects the needs of Australians with disabilities. It must be able to be used across jurisdictions and Australians with disabilities (or their families) must be able to request a review as needed to take into account changes to circumstances or transitional periods. Disability 'experts' should be part of the management, administration and assessment team. The establishment of a national scheme would enable freedom of movement. The long term and/or permanent nature of disability must be taken into account.

Administration would be most appropriately undertaken by a specialist service. The scheme should utilise mechanisms already in place. Where support services are required, they could be purchased utilising existing state mechanisms.

Australians with disabilities and their families must be empowered to make the decisions that affect their lives, so that they are free to choose from whom they obtain or purchase services, and be given the appropriate support to enable them to make informed choices.

4.4 Engagement with Australians with Disabilities

Australians with disabilities have the right to actively participate in all processes which affect their lives, and must be provided with the tools which facilitate that participation. Decisions about how the information is delivered must be made in consultation with people with disabilities, their family or service provider. Australians with disabilities have a range of communication needs which may necessitate the provision of information in a variety of formats, including plain

English, easy English, Braille, audio, face to face with the assistance of an aid, or utilising Auslan interpreters or the National Relay Service.

5. Conclusion

Australians with disabilities are entitled to equitable access to support and services regardless of how the disability was incurred, therefore, one scheme is required. People with disabilities are individuals, and a one size fits all approach is not appropriate. This scheme needs to ensure that assessment is streamlined, and not onerous on Australians with disabilities or their families. The funding must be appropriate to enable people to purchase what they need to participate in all parts of Australian life, whether that is education, work or as social beings.

The scheme must be financially sustainable, and call on the experiences of Medicare as a funding basis. The administration of the scheme must be centralised and call on the expertise of both state and federal bureaucracies.

The scheme must be promoted widely as a positive step forward, with social and economic benefits for the whole community.

Appendix A

Disability Support and Assistance in Victoria

In Victoria, people with a disability can receive support and assistance in three ways, depending on how they acquired their disability:

- 4. Through a no-fault injury insurance scheme (TAC, WorkSafe)
- 5. Through a compensation payment or
- 6. Through publicly funded disability services (provided by the Department of Human Services).

1. No-fault injury insurance schemes

There are two no-fault injury insurance schemes in Victoria: the Transport Accident Commission (TAC) and WorkSafe.

Transport Accident Commission (TAC)

The TAC covers transport accidents directly caused by the driving of a car, motorcycle, bus, train or tram. The organisation pays benefits to people injured in an accident as a:

- driver,
- passenger,
- pedestrian,
- motorcyclist, or
- cyclist.

The TAC can pay for the costs of reasonable medical treatment that a person needs to treat injuries sustained in a transport accident. Services the TAC can pay for include ambulance, hospital, medical, chemist, therapy, dental and nursing services.

The TAC can also pay for the reasonable cost of other, non-medical, services and items a person needs due to injuries from the accident. For example, travel costs to attend treatment, or for special equipment to help overcome accident injuries.

The types of treatment and benefits the TAC pays for will depend on: what can be paid under the legislation; a person's individual circumstances; and what is reasonable in relation to the need for and cost of the service.

Other types of benefits the TAC can pay include income, impairment and common law benefits.

The TAC is committed to delivering these benefits to injured people in a caring, efficient and financially responsible way.1

Workers Compensation Victoria (Worksafe)

WorkSafe provides a range of benefits to injured workers, for life if required, regardless of who was at fault. Benefits can include:

- weekly compensation
- ambulance transport
- hospital treatment
- medical and paramedical treatment
- attendant care and home help
- lump sum payments.

2. Compensation payments

Sometimes people who have been injured in accidents can receive compensation payments, if they can prove that someone else was responsible for the accident.

Compensation payments can underestimate the costs that a person will have over their lifetime as a result of their disability. It can also take many years for people to receive compensation and be stressful and costly to go to court.

3. Public disability services

Accessing disability services is based on the **Disability Act 2006** (the Act). Policy and processes are contained in the Department of Human Services' Access Policy.

The disability service system provides supports for people with a disability that complement supports available to all members of the community through the generic service system. These include hospitals, housing, recreation, leisure and general community supports.

1 http://www.tac.vic.gov.au/

In some circumstances, a person with a disability may have needs that could be better supported in the community through the generic service system.

For people who require services provided by the disability service system, there is often greater demand for supports than resources available.

Aids and Equipment Program

This program provides people with a permanent or long-term disability with subsidised aids, equipment, vehicle and home modifications to enhance independence in their home, facilitate community participation and support families and carers in their role.

Individual Support Packages

Individual Support Packages are Disability Services funds that are allocated to a person to meet their disability related support needs. The funds may be used to buy a range of disability-related supports chosen by the person to assist them to achieve their goals. Disability Services funding may complement existing informal support arrangements from family and friends and/or generally available community services.

People can receive help from a facilitator to bring together the important people in their life, such as family, friends or advocates, to think about and document the supports that are needed and how they should be provided.

Individual Support Packages may assist people with a disability to continue living in the community by providing a range of supports to:

- Maintain independence
- Keep living in their own home
- Move to more independent living arrangements
- Learn new skills
- Participate in the local community.

Outreach support

Outreach support provides up to 15 hours per week of home and community based support so that people with a disability can:

- Live outside staffed residential accommodation
- Remain living in their own homes
- Move to more independent living arrangements.

Outreach supports people with a disability by developing and keeping up their skills to carry out everyday activities. Outreach also involves assisting people with a disability to carry out activities and interactions that they are unable to do without support. This includes assistance with:

- Home living activities such as housekeeping, shopping, cooking, household budgeting
- Using community resources (for example banks, shops, public transport, recreational activities)
- Using aids and equipment for mobility and/or independence
- Decision making, problem solving, conflict resolution
- Managing emotions or personal responses (for example, anger) Building and maintaining community connections and personal relationships
- Using services in the community to enable people to stay in their own homes (for example, home nursing, general health care, dental care).

A person aged between 6 and 64 years, who has an acquired brain injury, an intellectual or physical disability, or a degenerative neurological condition may be able to get Outreach. An assessment of support needs is required.

Priority is given to people when:

- They are homeless or likely to become homeless. Outreach support can assist them with skills to live, or remain living in, non-staffed residential accommodation
- Their primary carer is no longer able to care for them, or care for them as intensely as required. Outreach support can assist in the development of skills to enable them to remain at home
- They are moving to a new home. Outreach support can assist them to develop new skills to enable them to support themselves in their new environment.