INABILITY
POSSABILITY

young people with an acquired brain
injury requiring high levels of care

Submission to the
Australian Government Productivity Commission Inquiry Into Disability Care and Support

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This submission was authorised by Eileen McCormack, President, and written on behalf of
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INABILITY POSSABILITY INCORPORATED

BACKGROUND

Inability Possability is a Melbourne based volunteer organisation, which seeks to address situations of disadvantage experienced by young people with acquired brain injury (ABI) requiring high levels of care. These young people are amongst the most vulnerable people in the community. Due to the nature of their acquired disabilities, they are often powerless to challenge structures that keep them in their position of disadvantage. However, given appropriate environments, resources and care, these young people can continue to make significant improvements for many years, and actively participate as interdependent members their community and broader society.

Following Inability Possability's incorporation in 2001, several projects were undertaken to increase awareness of the isolation and reality experienced by young people with ABI and their families. These led to Inability Possability initiating a meeting of Victorian based young people with ABI, their families, friends and carers in January 2002. The meeting resulted in the formation of a Family and Friends Association. The Association includes young people who live in nursing homes, who are cared for at home, or who are awaiting placement in an acute care facility. Facilitated by Inability Possability, the Association has contact with over eighty people, including thirty young people with severe ABI.

STATEMENT OF PURPOSES

The purposes of Inability Possability Inc. are to work together with young Australians with acquired brain injury who require high levels of care to:

1) increase awareness of the core people’s needs;

2) create and facilitate opportunities for the core people to participate as interdependent members of society. Opportunities may be so created to secure appropriate accommodation and environment, to enhance their social, creative and recreational functions, interactions and possibilities;

3) respect the dignity, uniqueness and choice of the individuals with whom the organisation works;

4) offer a supportive environment to the core people’s families, friends and carers to enhance their ability to identify and meet the needs of the core people;

5) work collaboratively with other appropriate bodies and organisations in achieving the above; and

6) seek funding to support the programs to meet the above purposes.

INTRODUCTION

Inability Possability welcomes the establishment of the Australian Government's Productivity Commission's inquiry into long term disability care and support. We see this as an opportunity to give further serious consideration to the provision of accommodation and appropriate care for young people with an Acquired Brain Injury requiring high levels of care.

Inability Possability's submission has provided a response to most of the suggested questions. Our concerns relate most directly to, and focus on, young people with an Acquired Brain Injury requiring high levels of care, their families, friends and carers. We believe that appropriate and sustainable accommodation is not merely a building, but also encompasses appropriate social and medical care.

Inability Possability assisted the 'What Does Chris Want' group in the production of *'Acquired Brain Injury (ABI) – A socio-medical model for the care of young people with a severe acquired brain injury'* (Appendix B) published in 2008, and will refer to this document as the 'Model of Care' in this submission.

RESPONSE

1. Who should be eligible?

a. Who should be in the new scheme and how could they be practically and reliably identified?

i. In identifying those who should be included in the new scheme we propose a classification instrument be used not unlike the ACFI (the Aged Care Funding Instrument). This classification system determines the level of nursing and allied health needs. This in turn equates to a level of nurse hours and a dollar figure of support. The ACFI system could be drawn upon for ideas.

ii. We propose a similar assessment instrument be developed for a NDIS and could be referred to as the Disability Classification Assessment Instrument (DCAI). It would be expected that it would operate with the understanding and knowledge of current research that indicates that even with the most catastrophic brain injury, recovery is possible if people receive appropriate care and support.

iii. The DCAI would have two phases. Phase one would be early assessment and allocation of an initial amount of funds. Phase two would involve a subsequent assessment to determine the Disability Classification level of the ongoing support needs of the person. It would be anticipated that this group would have the highest classification rating.

iv. The Disability Classification Assessment Instrument Phase 1 would:

1. Occur while the person is still in the acute hospital setting;
2. Be conducted in a timely manner to prevent decline, regression, pain and suffering for the person.
3. Determine the severity of the disability, the level of functional loss and the anticipated level of care and support needs in the immediate and short to medium term.
4. On the outcome of this assessment, provide appropriate funding to the person. It may be that in Phase 1 a set amount of funds are allocated to the person so rehabilitation and other interventions could begin when the person is deemed to be medically ready. (Currently a person without compensation may wait months and years before any rehabilitation begins)

v. NDIS Disability Classification Assessment Instrument Phase 2 would:

    1. Conduct a subsequent assessment in a timely manner to ensure there was no delay in ongoing rehabilitation and support. The time frame would be possibly within 6-12 months of the onset of injury or when deemed appropriate. This assessment would determine the person’s situation at this juncture and their ongoing support needs. A Disability Category on the DCAI scale would be given and ongoing funding would be approved. The Assessment would be comprehensive and would take into account all facets and aspects of the person’s life including medical, nursing, emotional, psychological and social needs.
    2. It would be anticipated that all people involved as part of the person’s care support and rehabilitation team would assist with reports and assessments relevant to their field of expertise. Family members and/or friends would also contribute to the assessment process. This would allow a more comprehensive view of the person to be given in relation to long term care and support needs of the person.
    3. Additional funding could be sought from the NDIS. This is similar to what is now done in the Victorian based ‘Slow to Recover Program’.

vi. The benefit of this two tiered funding system is that it would provide immediate funds to prevent any delay in responding to the person’s care and support needs and it would also provide secondary funds that may be required in life long care. This would be keeping with an approach that is responsive to an individuals needs.

2. Which groups are most in need of additional support and help?

a. People with severe Acquired Brain Injury (ABI) who do not have any form of compensation and who live in nursing homes or who are currently at home being cared for by their parents, who are often elderly.

This group have already been assessed at the highest assessment category under the Aged Care Funding Instrument (ACFI). The majority are still residing in Aged Care facilities. They have limited alternative accommodation options available to them that are able to cater for their high medical and support needs. This group rarely receives adequate funding to fully support their needs because of the high cost of those needs and as a result experience pain and discomfort, isolation, loneliness and despair. This limited funding also impacts on their capacity to receive appropriate allied health supports and the ability to access their local and broader community.

1. Life long funding for those with high support needs would provide some certainty over levels of funding and would alleviate ongoing anxiety when funding rounds are being considered.

2. Intervention and support must be available to people at the time of their brain injury. Timely access to rehabilitation is vital. The cohort we refer to in this submission generally need slow stream rehabilitation such as the Slow to Recover (STR) Rehabilitation model. If people with severe ABI had immediate or timely access to a guaranteed funding source interventions could occur when the person required them. Slow Stream Rehabilitation has allowed more optimum outcomes for people by reducing long term impairments such as muscle wasting and contractures and associated complications and pain. Timely intervention can prevent decline and

regression and despair for the person and be more cost effective in the long term.

3. People should always have the option to care for their family member at home where possible and where they choose to do so. In such cases the person with a disability should receive adequate funding to ensure the parents/family does not have to deplete their financial or emotional resources for this to occur. The person with the disability also needs to be able to secure an alternative accommodation service when they are no longer able to be cared for at home or when respite is needed. It may be with additional funds that the person is able to remain living at home with external carers and support.

We believe a National Disability Insurance Scheme should uphold the principles of the Disability Act 2006 and the Universal Declaration of Human Rights.

3. What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support

a. The development of a The Disability Classification Assessment Instrument as presented in 1.a.ii**.**

b. The term disability is loosely used today and gives the impression that it is a homogeneous state or condition. The term disability should be used exclusively for those who have a diagnosed and registered condition and one that describes a level of physical and cognitive function.

4. How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong?)

a. Power (over finances, medical and social decisions) must be shared between the individual and the service providers. The one service provider should not have control over service provision, finances and accommodation.

b. Access to appropriate funding would allow greater self determination and autonomy by an individual and/or their family or guardian.

c. Individuals or their family should have greater control over their funding or at least part thereof. It would allow greater dignity by way of increased autonomy to make decisions and choices without needing prior approval. For example a certain percentage of funds could be allocated for discretionary expenditure. Periodic auditing could be undertaken like that conducted by the Victorian Civil and Administrative Tribunal where a Guardianship Order is in place.

d. A body could be established that has the power to hear complaints or appeals. This body would be made up of a broad range of professional and include professionals in the area of disability, nursing and medicine with relevant experience and skills.

5. How should the amount of financial support and service entitlements of people be decided (and by whom?)

- **a.** Financial support and service entitlements would be based on an Assessment Tool (as described in 1.a.ii) that determines level of an individual's disability and in turn their level of care and support needs. These support needs should be based on a holistic approach, encompassing the person's health, rehabilitation and psychosocial needs.

- **b.** Inability Possability Inc. recognises the major benefits the Slow to Recover (STR) Rehabilitation Program in Victoria has had for people with catastrophic brain injury. It has been life saving and life changing for many people. Unfortunately it has not been available to everyone who is eligible due to it being under funded and therefore unable to meet demand. It is a program that any National Insurance Scheme could consider as a model for funding and service entitlements.

6. What services are needed and how should they be delivered?

- **a.** Immediate intervention using a model such as the Slow to Recover (STR) rehabilitation program is vital to young people with severe ABI. Funding for such a program needs to be allocated in a timely way.

- **b.** Services including disability, medical, allied health and community services are required to be delivered in an integrated way. We would refer to Page 32 of the 'Model of Care' (Appendix B) '*The Socio-Medical Model in Practice*'.

7. What kinds of services particularly need to be increased or created?

- **a.** Please refer to 6.b above.

8. How could the ways in which services are delivered – including their coordination, costs, timeliness and innovation – be improved?

- **a.** The socio-medical model of care presents an innovative and effective model for service delivery - please refer to pages 33-39 of 'The Model of Care' (Appendix B)

- **b.** Where possible and desired, people could have a choice in the self management of their allocated funds or part of those funds.

- **c.** People with a disability or their family or guardians should have a greater say in choosing paid carers. Where this occurs more satisfactory outcomes for the person are achieved.

- **d.** Where there is greater involvement in the choice of carer there are greater benefits such as: longer tenure of the carer; the carer receives individualised training and education specific to the needs of the person with the disability (when funding is available for this).

- **e.** Consideration could be given to the management of personal care attendants based on a model that some Municipal Councils use in their Aged and Disability Services. A pool of staff provides a variety of home care services including personal care. More specific training would be necessary.

- **f.** The service sector providing staff, including agency services, should have to maintain ongoing and appropriate levels of training and education for staff as they absorb a large proportion of the payment for services.

g. Personal Care Attendants should receive better financial remuneration. They play an integral role in providing care and support to people with disabilities. It is a constant problem for people with a disability to ensure they will have access to reliable and consistent staff.

9. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

a. Please refer to 2.a.2

10. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

a. Adequate funding which is based on a more holistic approach to the health and wellbeing of an individual. For example the people represented in this submission require good nursing and medical oversight to ensure optimum health and it is only then that they are able to more fully participate in their community. This must be factored into funding allocations.

b. Legislation is required so that all community bodies and organisations, workplaces both public and private consider people with disabilities. Allowing people to participate equally in whatever capacity as a player or an observer.

11. How can a new system ensure that any good aspects of current approaches are preserved?

a. Ensuring that decision makers are aware of the current programs that are working such as the Slow to Recover Rehabilitation Program in Victoria.

b. Most services providing long term care and support use models that they know. There are no models of case that adequately meet the need of this group that are currently being used by any service provider**.** A model of care that is appropriate for this group is *'Acquired Brain Injury (ABI) A socia-medical model for the care of young people with acquired brain injury* (See Appendix B). This model was developed over 11 years and is currently being used within an aged care nursing home. It continues to be a success to one particular client and nine others who have been cared for in the past.

12. What should be done in rural and remote areas where it is harder to get services?

a. In Inability Possability's experience with our Family and Friends Association, many members have moved their family member with a severe ABI from a rural area to an urban area to access appropriate services. Specialist training would be required and adopting the model of care *'Acquired Brain Injury (ABI) A socia-medical model for the care of young people with acquired brain injury* (See Appendix B) would be appropriate. Both of these options would require significant funding.

13. How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

a. All people would have a computerized file which would be accessible to the client's care team.
b. The file would be the property of the client.
c. The file would be kept on a database that was accessible to all services involved.
d. The client or guardian/s would give authority for service providers to access information pertinent to their role.
e. Medical and Allied Health Staff would have different access rights to those such as Care Support Workers.
f. The Care Coordination Service would take responsibility to oversee and maintain the file.

g. All people accessing the file would have to adhere to specified guidelines regarding safety of the file; eg. privacy and confidentiality.

14. How should a new scheme be financed?

a. Inability Possability supports the establishment of a National Disability Insurance Scheme to finance the new scheme.

15. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

a. Bodies such as Traffic Accident Commission or Work Cover would be able to inform this part of the discussion. This is not assuming that these two bodies would be part of a new National scheme.

16. Organising and implementing a new Disability Policy

a. The transitions to a new scheme.

i. Current funding systems would run concurrently with a new system until the new system was well established and a transition plan to cross over be implemented.

14. How long would be needed to start a new scheme, and what should happen in the interim?

a. The STR Rehabilitation Program is a successful and well established scheme despite its inadequate funding. It was first introduced and piloted in 1996 by the then Victorian Liberal Government and Mr Rob Knowles was a major instigator. This would be a good example of a successful program to reflect on and gain major insights.

APPENDIX

Appendix A: *‘still the doors are open - writings of life’ (*Publication)
Appendix B: *‘Acquired Brain Injury (ABI) – A socio-medical model for the care of young people with severe acquired brain injury’* (Publication)

Inability Possability are willing to give evidence to the Committee at the Public Hearing, and can provide more copies of Appendix A and Appendix B if required.