



young people in nursing homes
family & friends association



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

The Committee Secretariat
Family and Community Development Committee
Parliament House, Spring Street
East Melbourne VIC 3002

Wednesday October 29, 2008

RE: SUBMISSION

Dear Sir/Madam

Please find enclosed Inability Possability's submission to the Victorian Government Family and Community Development Committee Inquiry on the Provision of Support Accommodation for Victorians with a Disability or Mental Illness.

Thank you for the extension we received to present our submission.

Please contact me if you have any queries.

Yours Sincerely

Megan Atkins
Secretary
Inability Possability



**INABILITY
POSSABILITY**

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

**Submission to the
Victorian Government Family and Community
Development Committee
Inquiry on the Provision of Support Accommodation for
Victorians with a Disability or Mental Illness**

October 2008

This submission was authorised by Eileen McCormack, President, and written on behalf of
Inability Possability Inc (IP) ABN: 15 114 313 739, by Megan Atkins, Secretary

For further information regarding this submission, please contact Megan Atkins, Secretary
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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 fifty people, including twenty 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 Family and Community and Development Senate Committee Inquiry into the provision of Support Accommodation for Victorians with a Disability or Mental Illness. We see this as an opportunity to give further serious consideration to the provision of accommodation for young people with an Acquired Brain Injury requiring high levels of care.

Inability Possability has provided a response to all 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.

RESPONSE

- I. What have been your experiences with supported accommodation in Victoria with regard to availability, suitability and adequacy of care for people with a mental illness or disability?

Availability

- a. Young people with a severe Acquired Brain Injury (ABI), particularly those who are non-speaking, have unique and changing medical, social and rehabilitation needs. Currently, the only option available for this group is an aged care facility, or to be cared for at home by family members. There is no other option for people who acquire a severe brain injury and need nursing care.
- b. We welcome the development so far of a specialised building by Villa Maria and the Department of Human Services in Alphington to provide appropriate accommodation for 10 young people with severe ABI. We hope that, once operational, this can be replicated to accommodate the other young people with severe ABI currently living in nursing homes or acute care in Victoria. Adequate funding and the implementation of a social medical model remain as challenges.

Suitability

- c. Aged care services and facilities are, appropriately, designed for people over 65 years of age. Despite this, an increasing number of people aged under 65 are placed in such facilities. This is a result of there currently being no other sustainable alternative accommodation option.
- d. Aged Care services and facilities are designed for an 'end of life' approach, and are not structured to provide age appropriate accommodation and care for young people who are living life. Given the appropriate environment and care, these young people can make gains over a lifetime and with appropriate support and live life. Young people with an ABI, particularly those who are non-speaking, have unique and changing medical, social and rehabilitation needs, which cannot be currently met in a system designed for the elderly. Further, young people with ABI, like all of us, experience different stages of life, which require appropriate changes in their social environment. What is appropriate now will not be so in five or ten years' time. Aged Care facilities are not designed for individual care that will extend into decades.

- e. Young people with ABI have a normal life expectancy, which under the current accommodation situation, means that they will be living in an aged care facility for the next 40 to 50 years.
- f. Due to the confronting nature of ABI, most friendship groups reduce or disappear after injury. The environment of an aged care facility is not an appropriate place for young people to meet together and is a further hindrance for young people with an ABI to maintain and develop their social connections. Social interaction is vital for any person, and especially so for the rehabilitation of a young person after their brain injury. Aged care facilities do not provide for the needs of young people living in such an environment because they are not designed or structured to do so.
- g. While some families are either initially or long term willing and able to care for their loved ones at home, funding is often inadequate. There is no respite, and it is difficult to recruit and retain carers. Carers live in constant fear of funding cuts and the fear of 'what will happen to my son/daughter if something happens to me?'
- h. In our experience, people in the ABI: Slow to Recover program reported high to extreme levels of stress among all carers of young people whether their family member was in aged care or at home.
- i. We are at a new frontier with latest brain research overturning the old view of brain recovery. It is now realised that the brain has plasticity, and can make new connections given appropriate enriched environment and care. This fact is not understood or recognised on operational levels for this group – if a person is non verbal, they are mostly regarded as 'not there', not cognitive and treated as such. The effect of this attitude on the young person their and carers is profound. Many experience 'learned helplessness' and hopelessness, which can lead to depression.

Adequacy

- j. The health issues experienced by young people with sever ABI are not adequately addressed in an aged care setting. Medical staff who work in nursing homes are, appropriately, trained to care for the elderly, not younger people with different and complex physical and social needs, particularly those who are non-speaking. Medical staff possess the skills, but require additional specialised training.
- k. There is limited training and understanding in the general medical profession of the particular needs of young people with an ABI. From our experience, the needs of this group require the provision of nursing care due to the narrow margin of health, alongside boarder social care. If appropriate care is not given, this group's health status is compromised. This potentially increases the occurrence of acute health episodes, which lead to non-elective admission to hospital. Emergency admissions to hospital often lead to further issues for the young person with severe ABI and are costly. Health can be better maintained with proactive and preventative care where problems are identified early, and addressed by trained professionals. This in turn negatively impacts on quality of life and rehabilitation.
- l. Aged care facilities do not have the appropriate physical and social rehabilitation facilities required for this age group. Young people with ABI require access to specialised equipment and therapists, which cannot always be accommodated in an Aged Care facility.
- m. When a family member is in an aged care facility, many family members do not stop caring and advocating for their relative. This is especially common, as young

people with an ABI are often non-speaking and rely on their advocate(s). The family advocate is often responsible, and called upon, for informing medical and nursing staff regarding all aspects of their care. The nature of the staff in an aged care facility, including case managers, is one of constant change, requiring regular education especially in relation to care for a non speaking young person with ABI with high care needs. This places an unfair burden on the young persons advocate and also negatively impacts on the quality of their care.

- n. Funding is an issue that affects adequacy of care. The ABI:Slow to Recover Program is a unique and positive initiative (1996-2008) to assist young people who are non-compensable to have the opportunity of rehabilitation. Many young people with severe ABI are on the waiting list for the program. Many miss out on optimum outcomes as they become contracted and develop other problems because they do not have early intervention. Some wait years while others never get on to the program, because of the high demand and the fact that a place is lost if you are on the waiting list for more than two years.
 - o. The workforce in the area of accommodation and care are major issues. Multiple awards, lack of skills, carers refusing to work for lower wages with no weekend penalty rates affect the quality of care.
2. What is your experience of trying to access supported accommodation in terms of information, planning and decision-making?
- a. Members of our Family and Friends Association find the uncertainty and absence of appropriate accommodation and care their main concern. In our experience, families are often so busy caring for their family member that they have limited resources or energy to either actively play a part in, or challenge decisions made. Others find the constant questioning and responding to changing staff exhausting. From our experience professionals frequently put up barriers and do not always welcome the active involvement of family members, friends or advocates.
3. What other approaches/models should be considered to address supported accommodation funding, planning and delivery?
- a. Inability Possability has provided secretarial and design support to a group called 'What Does Chris Want', who this year published *'Acquired Brain Injury (ABI) – A socio-medical model for the care of young people with severe acquired brain injury'* (see Appendix B). This is a social-medical model of partnership that has been developed from eleven years' experience of caring for Chris Nolan, and eight other young people with ABI, accommodated in an aged care facility. We believe this to be a world-first approach to the care and accommodation of this particular group of people, and should be considered in this inquiry.

The aged care facility had no experience in caring for a young person with severe ABI and there was no 'road map'. With the assistance of ABI: STR (Slow to Recover)¹ funding for therapy and attendant care, together with the commitment of a primary nursing team, a core group of specialists developed a new approach. This approach evolved into an unprecedented model of care, grounded in the philosophy of partnership. This model's successful adaptation to the needs of Chris, and eight other young people with similar needs, is described in Appendix B.

¹ Acquired Brain Injury Slow to Recover Program, Department of Human Services (Victoria).

Eleven years post injury, Chris is living evidence of the model in practice. While trapped in a profoundly disabled body—Chris has no sight or speech and very little independent movement—he still hears and understands. He is now beginning to vocalise, and say a few words, indicating the small but significant gains from the ‘slow to recover’ rehabilitation process. He has a strong social network and is well, despite a narrow margin of health². This is in direct contrast to most young people with ABI living in nursing homes, many of whom have deteriorated due to complex physical conditions and a lack of appropriate expertise to respond to their needs.

- b. This model is supported by the World Health Organisation 2001 International Classification of Function, Disability and Health (ICF) calling for social medical models of care.
 - c. The gap between Disability and Health philosophically and practically is like a chasm on every level including language and at systemic levels. As one Minister said, it is greater than the gap between Commonwealth and State regarding young people in nursing homes (see WHO ICF reference above). It is tragic and a human rights issue that young people who acquire a catastrophic ABI and disability and require nursing care are denied that level of care and accommodation. This gap must be addressed at all levels including listening to the experiences of families who have to live it.
 - d. We recognise that we still face challenges in implementation of the social medical model including skills set of work force, funding and the disability/health interface.
4. What are the implications for individuals who need but cannot get supported accommodation? Is the alternate accommodation that is available adequate and care appropriate?
- a. For young people with severe ABI who cannot get supported accommodation, many are cared for at home, often by ageing parents. This places excessive demands on parents, impacting on their own health and wellbeing and on their relationship.
 - b. We are aware of one couple in their 70’s who care for their daughter at home for over 10 years, with another couple in their 80’s looking after their daughter for 20 years. The parents are exhausted and in fear of how their children will be cared for after they have gone. Parents having the sole responsibility is also unsustainable because of the age of the parents of these young people, many of whom are in their 60s, 70s and 80s.
 - c. As a result on inappropriate care and accommodation, young people with severe ABI can end up in acute care, which is inappropriate and ineffective use of government resources.
 - d. For young people with severe ABI, this inadequacy results in premature death for some, unaddressed pain and suffering, for most, contractures and bodies becoming so twisted that in 2 cases we know of, they are unable to get out of bed, with pressure sores, inadequate nutrition, depression, isolation and hopelessness resulting.

² ‘Narrow margin of health’ refers to the high levels of risk experienced by young people with severe physical and cognitive impairment as a result of ABI. It means that even a relatively simple chest infection, for example, could be life-threatening for the individual concerned.

5. What is your view on the provision of accommodation and care in private, government and community sector managed supported accommodation?
 - a. Please refer to Appendix B: '*Acquired Brain Injury (ABI) – A socio-medical model for the care of young people with severe acquired brain injury*'

6. What are the positives and/or negatives of the current approach to the provision of supported accommodation for people from Rural and regional Victoria and from culturally and linguistically diverse backgrounds?
 - a. Rural and regional Victoria – The best outcome for a young person with severe ABI is to remain in their community and so accommodation options should be developed to enable this to happen. A key negative is the general limited access to appropriately trained staff as outlined in Point 1.

 - b. Culturally and linguistically diverse backgrounds – In our experience, families whose second language is English, frequently experience difficulties in accessing new programs and developments and in understanding funding decisions. They frequently do not have the confidence or knowledge to question or challenge these decisions. Some families will refuse to place their daughter or son in an aged care facility as they want to keep them at home. In this instance, funding and services need to be structured in different ways, so as to better support and enable this option.

RECOMMENDATIONS

Inability Possability puts forward the following recommendations to the Victorian Government Family and Community Development Committee Inquiry on the Provision of Support Accommodation for Victorians with a Disability or Mental Illness

1. Specific accommodation for young people with severe ABI that addresses their social and medical needs and provides age appropriate support, and is staffed by professionals with additional specialised training.

2. An evaluation and expansion of the partnership model '*Acquired Brain Injury (ABI) – A socio-medical model for the care of young people with severe acquired brain injury*' to better meet the accommodation and care needs of young people with severe ABI across Victoria.

3. That the gap between health and disability be addressed from the bottom up that is listening to the actual experiences of young people with severe ABI and families and that solutions be tailored to their needs, as well as systemic issues. This must be addressed on a philosophical and practical levels, as well and include adequate and sustainable funding packages.

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.