



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

**Submission to the Senate Community Affairs
References Committee Inquiry into Aged Care**

July 2004

This submission was authorised by Eileen McCormack, President, and written on behalf of
Inability Possability Inc (IP) by Megan Atkins, Secretary

For further information regarding this submission, contact Megan Atkins PO Box 298
North Carlton 3054 Telephone: 0409 1710 89 Email: secretary@inabilitypossability.org.au

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 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 Senate Community Affairs References Committee Inquiry into Aged Care. We see this as an opportunity to give serious consideration to the issue of young people with an Acquired Brain Injury living in Aged Care facilities.

Inability Possability will not be addressing all the terms of reference in the inquiry. Our concerns relate most directly to point c, and focus on young people with an Acquired Brain Injury requiring high levels of care.

RESPONSE

Senate Community Affairs References Committee Inquiry into Aged Care. Terms of Reference:

- (c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

WHY IT IS NOT APPROPRIATE

1. THE DESIGN OF AGED CARE SERVICES AND FACILITIES

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. Aged Care services and facilities are designed for an 'end of life' approach, and are not structured to cater for young people who are living life. 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.

Young people with an Acquired Brain Injury, 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.

2. SOCIAL ENVIRONMENT

Due to of the confronting nature of ABI, most friendship groups reduce or disappear after injury. The environment of an aged care facility is not the appropriate place for young people to meet together and is a further hindrance for young people to visit their friends in such a facility. 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 unique needs of young people living in such an environment because they are not structured to cater for this.

Young people with ABI had a life and a history pre-injury. Their interests, hopes and desires do not disappear with their injury. Even though communication can be limited and can take time, this does not mean that the person cannot communicate. It is imperative that this history of the person not be lost post- injury, as it is a vital tool in their recovery.

Further, young people with ABI have changing and developing needs and, 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 year's time. Aged Care facilities are not designed for individual care that will extend into decades.

3. REHABILITATION FACILITIES

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. The lack of appropriate rehabilitation facilities negatively impacts on a person's ability to reach their maximum potential. Aged care facilities are designed to provide adequate care for the elderly in their final years of life, not to maximise a person's potential.

4. STAFF TRAINING AND MEDICAL NEEDS

Medical staff 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. There is limited training and understanding in the general medical profession of this issue, as these young people are a new, emerging group with varying needs.

Many young people with ABI are placed on the *ABI: Slow to Recover Program*. This program is unique and frequently is a program that many aged care staff are not familiar with. There is limited nursing home staff trained in this very specific area of care.

5. FUNDING

The current funding situation (or lack of) is not meeting needs of young people with an ABI. The young people who experience the highest level of disadvantage are those with non-compensable injuries, as they have inadequate resources to access effective support services. Because they access residential care in the aged care sector, these young people are unable to access Commonwealth State and Territory Disability Agreement (CSTDA) services, even though they are part of the CSTDA target group. Further, the residential aged care facilities are not set up to cater for the specific requirements of a young person with ABI, which includes appropriate therapy, equipment and trained carers. The current situation is unsustainable, and while the debate over funding responsibility continues, these young people continue to suffer.

6. ASSESSMENT TOOL

The current, and only, assessment tool being used to determine the level of care required and the consequent accommodation facility to be placed in, is the Aged Care Client Record (ACCR, also known as the 3020 form). This assessment tool is flawed, as it does not take into account the person's psychosocial needs which mostly stem from the particular age group they are in. A young person with ABI who is admitted to an Aged Care facility is subject to the same standards of care designed for older people. The history of the young person is vital in understanding needs and assisting in recovery. This can be easily lost in system designed for people staying for only a limited time.

7. RECOMMENDATIONS

Inability Possability puts forward the following recommendations to the Senate Community Affairs References Committee Inquiry into Aged Care:

1. That accommodation options be developed that provide a home in the community, from purpose built facilities, to the modification of existing facilities, which cater for the unique and individual needs of young people with an acquired brain injury. These accommodation options would allow young people with an Acquired Brain Injury to live a 'normal' life as anyone of their age would.
2. That the environment be appropriate to the age and needs of the individual, and accommodate the different stages in their life, and to allow the person to participate in community.
3. That the provision of specialised equipment and access to therapists be ensured for all young people with ABI.
4. That appropriately trained medical staff and allied health staff be accessible to meet the complex needs of young people with ABI.
5. That the input of family and friends into deciding the care needs of the individual be ensured to promote the wellbeing of young people with ABI and ensure improved outcomes for them.
6. That a specific assessment tool for young people with an Acquired Brain Injury be developed.
7. That the State and Federal Governments work cooperatively to ensure that the funding is provided to achieve the above, and that the funding is sustainable and allows for changes in the persons life, including ageing, medical and social elements.

APPENDIX

Hard copy sent by post.

Appendix A: "still the doors are open - writings of life' (Book)

Appendix B: Chronology of Inability Possability Inc. (4 pages)

Inability Possability are willing to give evidence to the Committee at the Public Hearing.