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

Submission to the Senate Community Affairs References Committee inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

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

Inability Possability formed an association of Family and Friends of young people with severe ABI. 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 the Funding and Operation of the Commonwealth State/Territory Disability Agreement. We see this as an opportunity to continue to address the effect of the CSTDA.

Inability Possability will not be responding to all the terms of reference in the inquiry. Our response addresses most directly point's b, and c, and will focus on younger people with an acquired brain injury requiring high levels of care.

We welcome the Younger People with Disability in Residential Aged Care Program which includes:

- Offering younger people with disabilities in residential aged care homes a care needs assessment;
- Negotiating and providing appropriate alternative long-term care options, where it can be made available and this is what the clients choose;
- Developing and establishing new services and care options including improved services within nursing homes; and
- Reducing future admission of younger people with disabilities to residential aged are

RESPONSE

Senate Community Affairs References Committee inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement.

(b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;

LEVELS OF UNMET NEED

1. ACCOMODATION SERVICES

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. 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. We support the current proposal, but stress that t is vital that the proposed COAG program has provisions for ongoing support and funding to provide accommodation that will address the needs of this entire group.

We welcome the COAG announcement in February 2006 of the proposed program to provide a care needs assessment. This is of great importance for this group, as their needs can be identified and appropriately provided for in the planning for appropriate accommodation. The current Aged Care Resident Classification Scale assessment tool does not work in identifying need. Inability Possability does not want the development of appropriate accommodation to be hindered while this assessment tool is being developed. We believe that this needs to be done concurrently because many young people have already being living in aged care facilities for ten years and more.

2. SUPPORT SERVICES

Rehabilitation Funding

In Victoria, the *Slow to Recover Program* is a positive initiative to assist young people who are non-compensable to have the opportunity of rehabilitation. The program is open to people who are two years post injury. Many young people are on the waiting list for the program, but often miss out due to the high demand and the two year time frame elapsing before a place is offered. All people requiring rehabilitation should be afforded the right to the program.

Continued allied heath support for young people with severe ABI is vital for them to build on, and not lose any of, the function and skills that were regained and re-learnt in early rehabilitation. In our experience the maintenance level of funding is often inadequate for these young people to live life fully. Often this groups' health needs and status is compromised due the lack of funds for appropriate and informed medical and allied heath care.

Recreation and Social Funding

An important area that is not recognised and supported is the social and recreational needs of this group. It is often attempted for them to fit into the activities of the aged facility in which they live. In our experience, the leads to social isolation and frustration. The limited funding that is provided can make a major difference. Can you imagine having the opportunity to go out of you home for only two or three hours a week and never having a holiday? Often these activities are dependent on funding applications being successful or not.

Family Carers

When a family member is in an aged care facility, family members do not stop caring and advocating for their relative. This is especially common, as this group of young people are often non-speaking and rely on their advocate. 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. The family member is often the only person who is a constant in this young person's life, and is the one who informs and provides continuity for their care and social history.

(c) An exanimation of the ageing/disability interface with respect to heath, aged care and other services, including the problems of jurisdictional overlap and inefficiency;

AGEING/DISABILITY INTERFACE

1. HEALTH AGED CARE AND OTHER SERVICES

The health issues faced by young people 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 possesses the skills, but require additional specialised training.

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. From our experience, the needs of this group require the provision of nursing care due to the narrow margin of health. If appropriate care is not given, this group's health status is compromised. This potentially increases the need for acute health episodes which lead to non-elective admission to hospital. This then impacts on their quality of life and rehabilitation.

RECOMMENDATIONS

Inability Possability puts forward the following recommendations to the Senate Community Affairs References Committee inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

1. Inability Possability welcomes the development of the working party for the Victorian DHS Young People in Residential Aged Care project. We look forward to the outcomes of this project but are concerned that there will not be sufficient funding to provide for the estimated 214 people under 50 currently residing in Victorian aged care facilities (Source: Department of Heath and Ageing)

2. In relation to the provision of accommodation and care for this group of people, it is not to be assumed that disability service providers, nor those with a medical model focus, can accurately address the needs of this particular group. This group requires a respect and co-operation of each area of specialist provision, both disability and medical.

3. There needs to be a model that takes a holistic approach that encompasses aspects of both areas. We stress that any approach needs to strongly focus on the individual's needs and wishes.

4. Our concern is that this small group of mainly non-speaking younger people with high needs will be overlooked because of their need to be intensively resourced, an option that is often unattractive to service providers because of the high recurrent costs.

5. We are aware of work that has been done by a group called 'What Does Chris Want' (WDCW) on a model of care that focus on the socio-medial model and partnership in care philosophy. The model has been developed over 10 years and it appears to be a world first approach to the care of this particular group of people. The focus of the model is YPINH with ABI with high medical and physical needs who are non-verbal and are unable to speak for themselves. The group has made a submission to the National Health and Medical Research Council (NHMRC) Ethics Committee issues paper on the 'Guidelines for the care of people in post coma unresponsive or minimally responsive states' in June 2006.