

SUMMER
FOUNDATION



Productivity Commission **Disability Care and Support**

Submission prepared by
Summer Foundation Ltd | August 2010

Table of Contents

<u>Executive Summary</u>	<u>3</u>
<u>Introduction</u>	<u>5</u>
<u>About the Summer Foundation</u>	<u>8</u>
<u>Submission Overview</u>	<u>9</u>
<u>Part One: About Young People in or at Risk of Entry to Nursing Homes</u>	<u>11</u>
Target Group Characteristics	11
Support Needs	13
Rehabilitation Needs	13
The Social Exclusion Experience of Young People in Nursing Homes and their Families	14
Themes and Issues Arising from Discussions with People with Disability	14
Themes and Issues Arising from Discussions with Families	19
Summary	20
<u>Part Two: Building on What We Know Works</u>	<u>22</u>
Disability Service Provision in Victoria	22
Getting Out: Mid-term Evaluation of the National Younger People in Residential Aged Care Program	28
Mid Term Review, FaHCSIA Younger People in Residential Aged Care (Urbis, 2010)	29
Summary	30
<u>Part Three: A Good Service System</u>	<u>31</u>
The Social Inclusion of People with Disability	31
The Social Inclusion of Families	31
Building on What Works in the Existing Service System	32
Eligibility Assessment	32
Early Intervention	32
Housing and support	33
Information and Advocacy	33
Conclusion	34
<u>References</u>	<u>36</u>

Executive Summary

The Summer Foundation welcomes the commitment of the Australian Government to a National Disability Long Term Care and Support Scheme. This reform has the potential to significantly increase the social inclusion of people with disability in Australian society. This submission provides an evidence base that illustrates the chronic exclusion experienced by young people with disability in or at risk of entry to nursing homes. This group requires targeted intervention to enable them to return to the mainstream of society. In addition this submission proposes a range of strategies to develop a good service system, with a clear and transparent assessment of eligibility and support needs, equitable access to funding for support, improved service coordination and delivery across health, disability and the rehabilitation sectors and a range of housing options.

To achieve this aim a literature review and a series of individual interviews, focus groups and attendance at scheduled meetings were completed. Consultations took place with people with disability and their family members/carers; staff from disability services; members of the Victorian Coalition of ABI Service Providers (VCASP); members of the Victorian Brain Injury Recovery Association (VBIRA); and members of the Young People in Nursing Home Consortium (YPINHC). The theoretical framework, social inclusion and disability legislation policy and practice principles have been utilised throughout this submission to contextualise the evidence provided and solutions generated.

Key learnings from the literature and qualitative and quantitative research undertaken by the Summer Foundation validates the Australian Government commitment to a Long Term Disability Care and Support Scheme. As a consequence it is argued that a Long Term Disability Care and Support Scheme would provide the structural change necessary to build a good service system and resolve the issue of young people in nursing homes. For the group that is young people in nursing homes the scheme would therefore:

- Build capabilities and provide resources which will see people learn, work, engage and have a voice
- Provide security and enable proactive planning with knowledge that funding will be available rather than having people competing for rationed resources and on wait lists
- Be a positive investment in the lives of people with disability which would enable them to realise individual potential and contribute to the development of society
- Enable people with disability to maintain valued life roles such as mothers, fathers, brothers, sisters, daughters and sons
- Have significant cost benefits through maximising abilities and independence and decreasing life time care costs
- Reduce the time, emotional and financial burden on families/carers which can contribute to their social exclusion
- Ensure equity in access to services
- Have significant cost benefits related to long stays in hospital (throughput) or hospital readmissions (due to secondary complications)

- Reduce demand for nursing home beds.

Introduction

The Summer Foundation welcomes the commitment of the Australian Government to a National Disability Long Term Care and Support Scheme. This reform has the potential to significantly increase the social inclusion of people with disability in Australian society. This submission provides an evidence base that illustrates the chronic exclusion experienced by young people with disability in or at risk of entry to nursing homes. This group requires targeted intervention to enable them to return to the mainstream of society. In addition this submission proposes a range of strategies to develop a good service system, with a clear and transparent assessment of eligibility and support needs, equitable access to funding for support, improved service coordination and delivery across health, disability and the rehabilitation sectors and a range of housing options.

In doing this, the Summer Foundation acknowledges the wisdom and input into this submission, of our partners including people with disability and their families/carers and service providers from the ABI compensable and non-compensable, neurological and generic disability service systems. Work on resolving the issue of young people in nursing homes has a long and proud history in Victoria, the introduction of a National Disability Long Term Care and Support Scheme provides the fundamental structural reform essential to resolving this social problem and building a fairer Australia.

The social exclusion effects of being a young person in a nursing home include the comparative absence of and barriers to mainstream housing, education, employment, social participation and access to services. The factors are multiple and overlap (Winkler, Sloan and Callaway, 2007). These descriptors align with the Australian Social Inclusion Boards definition of multiple disadvantage and chronic exclusion.

The Summer Foundation supports the governments approach to mitigating the experience of social exclusion through approaches designed to advance social inclusion. *Social inclusion is about ensuring that everyone is able to participate fully in Australian society. It is about people having the necessary opportunities, capabilities and resources to enable them to both contribute and to share the benefits of Australia's success as a nation. Being socially included means that people have the resources, opportunities and capabilities they need to: learn, work, engage and have a voice* (Social Inclusion Board, 2010:1)

A Long Term Disability Care and Support Scheme would provide the structural change necessary to build a good service system that is a service system designed with social inclusion as its core objective. For the group that is young people in nursing homes the scheme would:

- Build capabilities and provide resources which will see people learn, work, engage and have a voice
- Provide security and enable proactive planning with knowledge that funding will be available rather than having people competing for rationed resources and on wait lists
- Be a positive investment in the lives of people with disability which would enable them to realise individual potential and contribute to the development of society
- Enable people with disability to maintain valued life roles such as mothers, fathers, brothers, sisters, daughters and sons

- Have significant cost benefits through maximising abilities and independence and decreasing life time care costs
- Reduce the time, emotional and financial burden on families/carers which can contribute to their social exclusion
- Ensure equity in access to services
- Have significant cost benefits related to long stays in hospital (throughput) or hospital readmissions (due to secondary complications)
- Reduce demand for nursing home beds.

To inform the construction of a good service system that the Summer Foundation also provides evidence regarding administrative and operative spheres of service delivery which build on:

- What we know is working in Victoria for young people with severe to profound disability including the Department of Human Services (DHS), Disability Services *my future my choice* initiative and the ABI: Slow to Recover Program Southern Health
- Existing infrastructure and the good work undertaken across the Victorian ABI compensable and non-compensable, neurological and generic disability service systems.
- Approaches to service delivery outlined within Victorian Disability Legislation and Industry Standards, A Fairer Victoria and the Victorian Human Rights Charter. It should be noted that Victorian Disability Legislation and Industry Standards have arguably been designed to achieve the social inclusion of people with disability, the extent to which this has been realised for young people in or at risk of entry to nursing homes has been limited because this population, mostly receive services, from providers where disability rights are not understood, mandated or monitored. This situation arguably exacerbates an individual's exclusion experience.
- Qualitative evidence derived from consultation undertaken with people with disability and their families/carers (Summer Foundation Ltd, 2010)
- Outcomes from the Young People in Nursing Homes Summit, Young People in Nursing Home Consortia (July, 2010)
- The Australian Governments definition of social inclusion (Social Inclusion Unit, 2009)
- The Australian Public Service Social Inclusion and Policy Design and Delivery Toolkit (2009) provides a methodology which aims to influence policy design and delivery ensuring better outcomes for disadvantaged individuals and groups.
The methodology developed with the advice of the Australian Social Inclusion Board, includes: *"building partnerships with key stakeholders; developing tailored services;*

giving a high priority to early intervention; building joined-up services; using an evidence-based approach; using local approaches; planning for sustainability and building on individual and community strengths”
(2009, page 1).

About the Summer Foundation

The Summer Foundation is a not-for-profit organisation founded in 2006 that aims to resolve the issue of young people in nursing homes. The Summer Foundation Ltd is not able to implement all these strategies in isolation, but collaborates with other organisations, government, people with disability and their families to achieve this aim. The key aim of the Summer Foundation is to change human service policy and practice related to young people in nursing homes (YPINH). The Summer Foundation utilises a range of strategies to influence health, housing and disability services policy and practice related to the target group:

Creating a movement

Supporting people with disability to provide leadership to existing stakeholders and engage the corporate sector and general public

Empowering

Enabling young people in nursing homes and their families to be informed, make choices and tell their stories.

Providing an evidence base

Conducting and fostering research that provides an evidence base for policy change

Building expertise

Fostering innovation and collaboration to improve the quality of services

Developing integrated supported housing

Increasing the range and number of supported accommodation options

Work to Date

The publication of DVD and Booklet: *From a home to their homes* to enable people with disability and families make an informed choice about housing and support options

The publication of *Younger People in Residential Aged Care: Support needs, preferences and future directions my future my choice*, which aggregates the data of 105 people under 50 living in aged care

Have conducted a series of forums throughout metropolitan and regional Victoria to inform and listen to the families of young people in aged care as the first step in working with families to develop a network

The Summer Foundation leads Building Better Lives[®], a state-wide collaborative campaign that brings a range of disability organisations together under the one banner to resolve the issue of young people in nursing homes in Victoria. www.buildingbetterlives.org.au

The Building Better Lives[®] Ambassador program engages and supports a representative group of young Victorians in nursing homes or at risk of admission to nursing home to get involved in systemic advocacy

The Summer Foundation has been recently engaged by the Department of Human Services to undertake a Quality of Life Evaluation for individuals receiving support services through *my future my choice*.

Submission Overview

This overall aim of this submission is to provide an evidence base that illustrates the chronic exclusion experienced by young people with disability in or at risk of entry to nursing homes. It is argued that this group requires targeted intervention to enable them to return to the mainstream of society. In addition this submission proposes a range of strategies to develop a good service system, with a clear and transparent assessment of eligibility and support needs, equitable access to funding for support, improved service coordination and delivery across health, disability and the rehabilitation sectors and a range of housing options.

Methodology

To achieve this aim a literature review and a series of individual interviews, focus groups and attendance at scheduled meetings were completed. Consultations took place with people with disability and their family members/carers; staff from disability services; members of the Victorian Coalition of ABI Service Providers (VCASP); members of the Victorian Brain Injury Recovery Association (VBIRA); and members of the Young People in Nursing Home Consortium (YPINHC).

The theoretical framework, social inclusion and disability legislation policy and practice principles have been utilised throughout this submission to contextualise the evidence provided and solutions generated. The Australian Governments definition of Social inclusion as *“people have the resources (skills and assets, including good health, opportunities and capabilities they need to: Learn participate in education and training; Work participate in employment, unpaid or voluntary work including family and carer responsibilities; Engage connect with people, use local services and participate in local, cultural, civic and recreational activities; and have a voice influence decisions that affect them”* (Social Inclusion Unit, 2009). Over the last ten years the people with disability and their associates, the Victorian Government and the Disability Sector has made a significant investment in the development and implementation of responses intended to reaffirm the rights people with disability have to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria. There are considerable structural, technical and operational resources available to Victorians to support disability service provision. These include: A Fairer Victoria; The Victorian Charter of Human Rights; The Disability Act, 2006 (principles and practice implications); Quality Framework for Disability Services in Victoria (2007); Standards for Disability Services; Industry Standards for Disability Services; The Disability State Plan 2002- 2012, and the United Nations Convention on the Rights of People with Disabilities (2007). Although we have the legislation, policy and practice guidelines to foster the social inclusion of people with disability in Victoria, there is a significant gap between the aspirations in these documents and the day-to-day reality of people with a disability. The current service system is largely crisis driven and resources are highly rationed.

This submission comprises three parts:

Part One provides evidence of target group characteristics, needs and support requirements. The primary sources used here include: Younger People in Residential Aged Care: Support needs, preferences and future directions (Winkler, Sloan and Callaway, 2007), ABI STR: Therapy Review (Sloan, 2008) and outcomes from consultation undertaken with people with disability, their families and/or carers.

Part Two provides examples of practices that foster the social inclusion of people with severe and profound disability in, or at risk of entry to, nursing homes. The primary sources here are the Victorian Department of Human Services (DHS) Disability Services *my future my choice* initiative, the ABI: Slow to Recover Program Southern Health and Anj's Story. Part Three considers the implications of the evidence provided in part one and two, to envisage a good service system for young people in nursing homes.

Part One: About Young People in or at Risk of Entry to Nursing Homes

The following section provides evidence of target group incidence and prevalence characteristics, needs and support requirements. In addition to consultation the primary sources utilised include: Younger People in Residential Aged Care: Support needs, preferences and future directions (Winkler, Sloan and Callaway, 2007), the ABI STR: Therapy Review (Sloan, 2008) and outcomes from consultation undertaken with people with disability, their families and/or carers.

Target Group Characteristics

1540 young people reside in nursing homes in Victoria of whom 163 are under the age of 50 while 1,377 are aged between 50 and 65 years (DHS, 2009).

At its February 2006 meeting, the Council of Australian Governments (COAG) agreed that the Australian Government, states and territories would, from July 2006, work together to reduce the number of young people with disability in nursing homes. Governments jointly established and funded a five-year program, providing \$244 million, with the initial priority being people aged less than 50 years. The Victorian initiative, *my future my choice*, aims to provide better living options for young people in, or at risk of entry to, nursing homes. As part of the *my future my choice* initiative in Victoria, people less than 50 years of age living in nursing homes were offered an individualised planning and assessment process to assist them and their family or key others to consider their specific healthcare and accommodation needs, aspirations and other important lifestyle factors. It provided an opportunity to explore options and consider models of care to best meet each individual's needs and preferences. The process also provided information about the needs and preferences of this group as a whole. The following is a summary of a larger report. Younger People in Residential Aged Care: Support needs, preferences and future directions (Winkler, Sloan and Callaway, 2007) found that: The majority of the 105 individuals in the sample are 40-50 year age group with only 28 people under 40 years of age. Of the 105 individuals in this population, 61 are male and 44 are female. Fourteen people are from a non-English speaking background. The majority of individuals (66) lived in metropolitan Melbourne while the remainder resided in regional and rural areas.

Information obtained about the factors leading to each person's initial and current nursing home admission revealed a variety of pathways to nursing homes. Preceding their first placement in a nursing home, 58 people had an interim stay in an acute or rehabilitation hospital and, prior to the current nursing home placement, people were living in their own home (36 people), their parents home (8) people, another nursing home (24 people), or other supported accommodation (11 people). Some of these people were in acute care before their transfer to nursing homes and 17 individuals were in hospital for more than six months prior to their placement in the current nursing home.

The people in the sample have a diverse range of disabilities, health issues and support needs with the most common disability type being acquired brain injury (61 people), followed by multiple sclerosis (14 people) and Huntington's disease (9 people). In addition to these disabilities, many people had sensory impairments, symptoms of mental health issues and secondary health conditions. Secondary health conditions commonly experienced by the sample included pressure areas (33 people), contractures (33 people), urinary tract infections (24 people) and chest infections or pneumonia (19 people).

Many people in the sample had periodic admissions to acute health services. In total 44 of the 105 participants had an admission to an acute hospital in the preceding 12 month period, with some people experiencing multiple admissions. Of the total sample, 17 people were reported to have had an elective admission in the preceding 12 months. Reasons for elective admissions included orthopaedic issues (4 people), PEG related issues (3 people), catheter insertions (2 people) and gynaecology related issues (2 people). Thirty-one people were reported to have had a non-elective admission to an acute hospital in the past twelve months resulting from health issues such as PEG management (4 people), chest infections or pneumonia (4 people), seizures (3 people) and psychiatric issues (3 people).

Many people in the sample (63 people) were fully aware of their environment and oriented to time, place and person. Thirty-three people were assessed as partially aware – they were conscious and awake but had profound memory difficulties and significant levels of confusion. Nine people were minimally aware of their environment. Fifty people had difficulty communicating their basic needs and seven people were prone to wandering or getting lost.

Many people were highly physically dependent with 42 people requiring assistance with moving in bed and 49 people needing assistance with mobility inside the nursing home. Seventy people required assistance to get in and out of the place they live and 75 people required assistance to get around their local community. A large proportion of the sample required specialised equipment such as hoists, wheelchairs and pressure care overlays.

Eighty-two people displayed at least one challenging behaviour of varying severity. Challenging behaviour is behaviour causing distress to the person with the disability or is disruptive to other people causing them distress or making them feel uncomfortable. Many people displayed complex combinations of challenging behaviours with 41 people having three or more challenging behaviours. Lack of initiation and verbal aggression were the most common behaviours identified.

Many people in the sample were effectively excluded from participation in community life. Thirty-two people never participated in community-based activities such as shopping, recreation or leisure. Many people did not participate in activities organised by the nursing home either, with 30 people participating in these activities less often than once per month. Many people in the sample had very limited opportunity to make everyday choices such as the time they go to bed or the content of their meal and the majority had lost several valued life roles such as friend, caregiver, worker and home maintainer. One person was working part-time and a few people had maintained roles such as part-time student (4 people), volunteer worker (3 people) or caregiver (6 people). The caregiver role maintained by some people is likely to be related to the fact that people were parents of children under the age of 17 years.

Sixty three percent of this group was receiving one or more additional services from external providers with the most common additional supports being attendant care (39%), case management (37%), occupational therapy (31%) and community based recreation groups (11%). Thirty two percent of participants accessed additional services funded by DHS Disability Services such as Support & Choice or Assisted Community Living packages, and 23% had additional packages funded by the ABI: STR Program.

In addition to information regarding characteristics and life circumstances, data was obtained and analysed specifically to inform service planning and development. Sixty-eight

people and their support networks indicated that they would like to explore alternative accommodation and support options while 27 people indicated that they would prefer to remain living in their current nursing home facility. Of the people who were interested in moving, nine people indicated that they would like to live in a private or family residence, 56 would like to live in shared supported accommodation and three people indicated a preference for other options. Other options included living independently in a unit with individual support and living in a unit attached to a hospital.

Support Needs

The support needs of the group were diverse so rather than describing the average support needs for the whole sample, the sample was divided into three homogenous sub groups: a Very High Care Needs Group (52 people); a High Care Needs group (35 people); and a Moderate Care Needs group (16 people). The Very High Care Needs Group generally required 24-hour supervision, daily nursing support and a high level of physical assistance for basic daily activities, often by more than one staff member. The High Care Needs group also had significant support needs but were overall less complex to manage and most did not require regular nursing care. The moderate care needs group had minimal physical support needs and few medical complications but required assistance with more complex household activities, day to day problem solving and financial management. (Winkler, Sloan and Callaway, 2007)

Rehabilitation Needs

Sue Sloan (2008) undertook a comprehensive review of both national and international research regarding the provision of rehabilitation programs to people with catastrophic brain injuries for the ABI: Slow to Recover Program Southern Health. The author found the following including:

- In order to provide a comprehensive continuum of care, the systematic availability of slow stream rehabilitation across the entire lifetime following catastrophic brain injury is required
- Individuals in minimally conscious or vegetative states may pass through various phases of consciousness at varying points post injury. As such, the timing and nature of rehabilitation intervention will be influenced by an understanding of the level of consciousness of the individual
- Functions and skills can emerge many years after catastrophic brain injury, highlighting the importance of long-term intervention and the importance of minimising secondary complications that may otherwise hinder future progress
- The brain's recovery potential is influenced by the physical and social environment to which the individual is exposed. This points to the need for environmental stimulation, opportunities for learning, minimisation of the experience of pain and stress and early intervention

- Optimal recovery can be promoted by minimising secondary health complications such as neurological, musculoskeletal, skin, respiratory and digestive issues
- Skill development is encouraged by providing consistent and repeated opportunities for contextualised practice of personally meaningful activities
- Disability management plans require that skills and routines which are developed in active rehabilitation phases are maintained over time when therapy input is reduced
- Better health status and functional outcomes are seen following specialist ABI rather than generic programs, indicating that expert knowledge and experience in working with catastrophically brain-injured individuals is crucial to outcome
- Progress towards role participation is an overarching long term goal following catastrophic brain injury and requires a level of resources and rehabilitation input to achieve
- The individual's changing level of insight and readiness to benefit from therapy necessitates monitoring as well as long-term, flexible funding and dynamic intervention
- Given high levels of family and carer distress, provision of education and training and support for caregivers is an essential component of ABI rehabilitation (Sloan, 2008).

The Social Exclusion Experience of Young People in Nursing Homes and their Families

The Summer Foundation has undertaken significant consultation with people with disability, their families and carers. The following is a summary of themes and issues derived from a series of discussions.

On no level is the following a condemnation of nursing homes. It is acknowledged that young people faced with living in nursing homes have high level and complex needs. The following focuses on the 'age inappropriateness' of nursing homes for young people in the context of considering 'next generation' accommodation options for young people.

Themes and Issues Arising from Discussions with People with Disability

Privacy and Respect

Many of the contributions to the discussion centered around the key issues of privacy and respect. For many young people living in nursing homes lack of privacy and respect were significant and constant areas of concern. The significance of this issue varied among participants, and it seemed that the 'institutional' nature of nursing homes by their very nature largely contributed to this issue. Even those participants who felt they were personally treated with respect and dignity craved a higher level of privacy.

A number of participants commented on the fact that they are constantly reminded that their home is an institution. This often manifested in the way the staff regarded the facilities.

The overwhelming notion was that these facilities are not primarily viewed as ‘the home’ of the residents. Nursing homes tend to be viewed and treated as a workplace, a service provider and an accommodation.

“I don’t want to be treated as though I’m in a nursing home...it is my home....”

“the staff at times treat the home as theirs, rather than ours. I would like more privacy and respect....”

An additional issue relating to privacy and respect, which emerged related to carers and support staff. For those who were treated with dignity and respect this aspect was a highlight

“I enjoy the friendships I have with the staff – they are more to me than staff...”

However for others their experiences had not all been as positive, and the need for support staff to respect the dignity and privacy of young people was raised.

“in my ideal home the support workers would understand the needs of young people. They would have the compassion and empathy to care for people with dignity...”

For those who had the experience of sharing bathroom facilities, lack of privacy was a very significant issue. Although this issue seems simple, it was raised by all participants – a strong positive for those who had an ensuite and an even stronger negative for those who did not.

“....there were unpleasant issues with her having to share an ensuite...”

“...I have my own room and my own ensuite – I enjoy being able to escape to my own space...”

Choices

The question of choice was a strong theme throughout the discussion. Choice as it relates to where a person lives, who they live with, who provides their care and support, what their living environment is like (its ambience, how it is furnished and designed etc). Young people are typically placed in nursing homes as a result of disability from acquired brain injury or late onset disability from neurological disorders. Consequently prior to entering nursing homes, the young people participating in this discussion had all experienced or anticipated the freedom of choice their young (non disabled) peers take for granted. To have these choices dramatically and completely removed was devastating

Choice of housemate(s) was a critical issue. Several people contributing to the discussion had experienced difficulties with the people they found themselves living with, while others had positive experiences to recount. Either way the significance of having choice around who you choose to live with was a dominating theme.

“How you feel about where you live has more to do with the people who surround you...”

“If I were to share accommodation, it would be important to me to share with

someone of my choice – not someone independently paired with me...”

“I would change not being the youngest by a third of all the people I live with...”

Several key elements relating to location emerged. Many of the participants felt a strong level of comfort that they were living in close proximity to family, friends and the area they had grown up in. For others, critical aspects of location included ready access to appropriate public transport and other services. Being in a vibrant, central location was also raised by several participants.

“...ideal home would be near public transport and shops, inner city, near young people and support...”

Without exception all participants felt restricted by lack of space. In most cases the only space they could call ‘their own’ was a small bedroom. Even those who had experienced generous sized bedrooms made comment that these were still not sufficient to adequately accommodate their hobbies/interests.

“I would love to be able to have a cat...”

“...need more than just a bedroom. I don’t have the space to pursue my interests. An office would be ideal so I could spread out and set up my computers properly...”

“...more space to pursue my craft interests – if I had a designated space for this I wouldn’t have to pack up whenever I left the activities for a period of time...”

Food was another aspect where the desire for a greater range of choice was expressed. Some participants commented on the lack of control/choice about food, others mentioned the desire to prepare their own meals, while others raised the lack of opportunity to have friends over for a meal.

“in my ideal home the food would be age appropriate and taste good, and suit individual needs...”

“I would love to have my own kitchen facility...I would love to have access to a BBQ...”

“I would love to invite people home for a meal...”

The facilities and possessions available on a daily basis to young people without disabilities are typically not available to young people living in nursing home facilities. Young people in nursing home facilities often do not have individual access to a TV, a computer, internet etc. Agreement was reached by all that having access to the possessions and facilities most other young people take for granted would make an enormous difference.

“The ideal living environment should involve choices, access to all things in a regular home...it needs to be homely...”

Although a couple of the young people involved in this discussion have been able to access external activities, pursuits, rehabilitation and service – largely through the *my future my choice* initiative, the general consensus was there should be a much larger rate of participation in community based activities and groups, but living in a nursing home facility encumbers this.

“I haven’t been socially active, but would like to get back into living a normal life, and live as closely as possible to how I would have...”

“...shouldn’t be forced to live with other people with a disability; this reduces opportunities for socialising....needs to have as many opportunities as possible to mix with people...”

Friendships

Another key theme raised by participants was the how their disability had impacted their friendships and relationships. There were many aspects of this, which directly related to the nursing home environment.

One of the most significant issues for the young people participating in this discussion was the lack of opportunity for social interaction. Most nursing home facilities at best have communal areas for visitors. In addition the lack of a private space or recreation area to spend time with visitors often makes it uncomfortable and discourages younger visitors such as friends and family members.

“There is nothing relevant to young visitors in a nursing home – nothing inviting. Simple things like a pool table/dart board etc would help young visitors feel more at ease and give them a focus....”

“The nursing home environment contributed to the deterioration of my friendships...”

The lack of opportunity for private entertaining was an issue raised by a number of participants.

“I would like more space, more private space – the socialising space where I live is communal...”

“The (lack of) potential for intimacy is a huge issue – I can’t bring anyone home, it like living with my parents again...”

“I would like room to entertain – with some privacy...”

Another common theme was that friends had undergone a ‘grieving’ process, and the nursing home environment did not support or make allowances for this.

“friends go through a grieving process – they grieve the friend and relationship they had. They need support and help to work through this and reconnect with

their friend...

“My friends were very supportive when I was in hospital, visiting regularly. The problem is they were not given information about what to expect and what the implications of my accident were for me. They rarely now make contact. I don’t believe the problem was with them, their support faded because there were insufficient measures in place to support them...”

Security and Support

Security and support emerged as a significant area of consideration. While all participants want to see accommodation options that move significantly away from the ‘institutionalisation’ of nursing homes, combining this with the necessary and appropriate security and support is critical.

An appropriate physical environment – one which accommodates wheelchairs, walking frames and other requirements – is clearly imperative. While the physical environment of nursing home facilities caters for these needs, it would be important for these issues to be addressed in a non-institutional manner in any alternate accommodation.

“Where I live now facilitates my mobility with flat surfaces, supporting rails and room to manipulate my walker...”

Access to appropriately trained support staff is critical in any accommodation model put forward. The key appears to be blending a sufficient level of appropriate support, into a ‘homely’ and typical living environment.

“...need supervision and help...should treated with dignity and respect... this respect should come from everyone...”

“Ideally they should be supported by people who are motivated by care and love...”

“To facilitate young people exploring their needs/interests there needs to be an appropriate ratio of support staff to young people – many activities require one-on-one care...”

“Young people need a balance between support and privacy. The staff can make an enormous difference...”

“...needs to be treated like other young people. Treating her differently makes her feel humiliated...”

Security is a significant area of concern which needs to be addressed when considering alternatives to nursing homes facilities.

“These young people are vulnerable – any accommodation model needs to address this and measures need to be put in place to reduce their vulnerability...”

“I appreciate the security of where I live now...”

Key Messages

The discussions were concluded by asking questions about what the key message would be relating to the issue of young people in nursing homes. A sample of response includes:

“... Give us a go, just because we can’t walk/talk/see or whatever else our disability might be, doesn’t make us any less of a person with hopes, dreams, goals and aspirations. The fact we mightn’t be able to tell or show you something doesn’t just make it go away. It just means we need your love, support and friendship even more. We still have a heart....it’s now even more easily broken....just because something doesn’t work quite the way it used to, doesn’t make us any less an important human being...”

“...Young people just don’t belong here. Some of us had no choice. I would love to see an age appropriate care facility for young people in the future. Somewhere that supports an appreciation of individuality, individual interests and personal tastes...”

“....Should anyone be in nursing homes? Society doesn’t make this issue a high enough priority....”

Themes and Issues Arising from Discussions with Families

Key Messages

The consultations with families concluded by asking questions about what their key message would be relating to the issue of young people in nursing homes. Their responses reflect the emotional turmoil, time and financial burdens experienced.

Family Experience/Reflections

A father expresses his despair and sadness of his son’s future being sent to a nursing home
“.. you just go NO, no, no”

A mother with a son in a nursing home describes this as “devastating” for all the family. She reflects her pain when visiting him “*I still find it confronting, he’s living with people who die...*” and she asks “*why isn’t there a place for young people...?*”

Comments regarding the benefit of meeting other families (through forums) also highlight the family isolation previously experienced

A husband reflects at the conclusion of a rural family forum

“ I feel wonderful today to hear your story, and my story.....”

A sister bravely stated in the many years caring for her brother in a nursing home

“ this is the first time I’ve cried, I’ve spoken to others...that’s why I cried... ”

A mother describes the forum has provided her with information and ideas

“ I have been given the strength to hang in there when it all felt hopeless...”

Insights and ideas for our future community. A wife identifies that family members have so much to offer

“ we talk about wisdom and courage, this where wisdom and courage is, its experienced and reflected...”

Summary

Improved medical technology has increased the survival rates and life expectancy of people who sustain serious brain injuries (Department of Human Services Victoria, 2001). People who would have died at the scene of an accident two decades ago are now surviving with very severe disabilities. People also live longer with degenerative disabilities such as multiple sclerosis. As a consequence there has been a significant increase in the numbers of people with severe disabilities requiring specialist disability services, who find themselves in the only option available, specialist aged care services where arguably the situation is further exacerbated by the dehumanising experience of institutionalisation. Individuals from this group present with factors that are multiple and overlap and include severe to profound disability, trauma and loss and the associated health consequences, barriers to mainstream housing, education, employment, social participation and access to services. These factors are congruent with the Australian Social Inclusion Board (2009) definition of multiple disadvantage and chronic exclusion. Historically, this new population has challenged the disability service system, however the evidence provided increases the depth of our understanding of the social exclusion of young people in nursing homes and the profound and often devastating impact that this has on individuals and families. This, in conjunction with the significant body of evidence, which highlights the potential for positive change, provides critical information central to the formulation of solutions. Clearly, resolution of the young people in nursing home issue requires solutions that incorporate both housing and support. While housing provision therefore is about a process of deinstitutionalisation, (arguably housing is the core to social inclusion), the support component is provided in response to a person's 'capability'. Sen (1999) defines capability as an understanding that development is a process of economic and social growth, which cannot be achieved unless barriers including poverty and social deprivation are removed. Nursing homes are not oriented or resourced to meet the 'capability' requirements of young people with disability, nor should they be. Rather, the solution is to provide community based housing and support that is mandated by disability legislation and policy, and aspires to providing individuals with opportunities to learn, work, engage and have a voice. The implementation of a National Disability Long Term Care and Support Scheme that invests in the lives of people with a disability and maximises their potential is likely to result in significant 'savings' at both the local and state levels of government. These resources could be allocated or reallocated to the development of essential housing infrastructure and/or the provision of a range of services to people with disability who will not be directly covered by the scheme.

The following provides information about two targeted interventions in response to the needs of young people in nursing homes that redress barriers to mainstream housing, education, employment, social participation and access to services thereby mitigating the experience of social exclusion: the ABI: Slow to Recover Program and *my future my choice*. Both qualitative and quantitative research indicates positive outcomes for young

people in nursing homes who have been recipients of these programs. In addition to a brief discussion of the theoretical frameworks, which guide disability service provision in Victoria, Part Two provides information regarding eligibility assessment and the allocation of resources. In addition evidence of practice, which achieves the social inclusion of people with severe and profound disability in or at risk of entry to nursing homes is provided. The Victorian Government Department of Human Services (DHS) Disability Services *my future my choice* initiative the ABI: Slow to Recover Program Southern Health, Getting Out: Mid-term Evaluation of the National Younger People in Residential Aged Care Program (Winkler, D., Farnsworth, L., Sloan, S. and Brown, T, 2010) and a case study, Anj's Story, are the primary sources utilised. It is argued that elements from both of these programs could inform the development and implementation of a National Disability Long Term Care and Support Scheme.

Part Two: Building on What We Know Works

Disability Service Provision in Victoria

Over the last ten years the Victorian Government and more recently, the Federal Government, has made a significant investment in the development and implementation of responses intended to reaffirm the rights of people with disability to live and participate in the life of the community, with the same rights, responsibilities and opportunities as all other citizens. There are considerable structural, technical and operational resources available to Victorians to support disability service provision. These include:

- A Fairer Victoria
- The Victorian Charter of Human Rights
- The Disability Act, 2006 (principles and practice implications)
- Quality Framework for Disability Services in Victoria (2007); Standards for Disability Services; Industry Standards for Disability Services
- The Disability State Plan 2002-2012
- The United Nations Convention on the Rights of People with Disabilities (2007)
- Guardianship and Administration Board Act, 2006
- Social Inclusion: Social Inclusion Board 2009 (definition and practice principles)

It is not within the parameters of this submission to provide an extensive analysis of government disability legislation, policy or practice guidelines. Suffice to say that the implementation of disability legislation, policy and guidelines should ensure a rights-based and inclusive response to the support needs of people with disability and should therefore underpin all services provided to people with disability. As discussed however, the extent to which this has been realised for young people in or at risk of entry to nursing homes has been severely limited because this population, by and large receive services from providers where disability rights are not understood, mandated or monitored. Moreover, the disability sector in Victoria is under-resourced and funding is rationed, which results in young people in nursing homes competing for funding according to Department of Human Services (DHS) Disability Services Priority of Access policy. This policy means that the need for support and alternative accommodation is assessed in competition with, for example, a child with disability who may be at risk of family breakdown and homelessness, or a young person with disability at risk of entry into the youth justice system, or an adult with disability whose primary carer has died. Under these circumstances young people in nursing homes, who at least have some form of accommodation and support are unlikely to meet DHS priority-of-access criteria.

The ABI: Slow to Recover Program Southern Health and the *my future my choice* programs are targeted interventions. However both of these programs are insufficiently resourced to meet demand. This is reflected in wait times and the somewhat arbitrary priority of access criteria applied by both programs, which restricts the provision of services to people under

the age of 50. However, families of young people with severe and profound disabilities who are in receipt of these programs are generally very appreciative. Families identify a number of factors which contribute to an increased sense of wellbeing and security provide by these programs including:

- case management support at the outset, having a key contact person with whom to communicate
- inclusion in all aspects of program development, implementation and review
- speaking with program staff who listen and are willing to accept family opinions and understand what we are going through
- having clear information and being able to ask questions, and knowing what to expect from the service system
- receiving support and advice in their decision-making about the options in the medium to longer term
- staff who are optimistic and respectful and who do what they say they will do and the hope this provides
- responsiveness and flexibility – *I have always been told to ask, sometimes I get knocked back and sometimes I don't*
- opportunities provided by the program to meet with other families and share information and experience
- expertise and experience of staff providing the range of services including case managers, therapists and program managers
- knowledge of the ABI and Disability sectors and referral to appropriate family support options including respite, family counselling/therapy
- knowledge of supports offered by the Commonwealth Government including carer payments.

The ABI: Slow To Recover Program Southern Health

Commencing in 1996, the ABI: Slow to Recover Program was designed to assist those people who experienced a catastrophic brain injury, who were not in receipt of compensation, and required nursing home level of care with long term support. The program has been described as internationally ground breaking in that there were very few, if any, models of service designed to assist this target group. The program has been successful in providing slow-stream rehabilitation and support for noncompensable highly dependent persons with severe ABI and facilitating reintegration into the community for over ten years. The program has improved the quality of life of people in that many are now living in more age-appropriate surroundings and have the opportunity through slow-stream rehabilitation to achieve greater independence and engagement (HDG Consulting, 2004).

How the program works

Funds to purchase services are allocated to each individual. These resources are used to strengthen and enhance the capacity of existing mainstream services to meet the needs of people with acquired brain injury rather than developing a separate service infrastructure. A Case Manager is responsible for developing the Care Plan, which identifies the range of rehabilitation services and supports required. Typically, funds are provided for attendant care (which supports a therapeutic program and provides assistance with activities of daily living), therapy including occupational, health, psychology, speech, physiotherapy and hydrotherapy, aids and equipment, community access and participation, home help and childcare. To be eligible an applicant must:

- have a diagnosis of severe ABI in relation to an acute health episode within the preceding two years
- have a current primary diagnosis of acquired brain injury
- is post acute and medically stable or requiring limited medical intervention
- is at least 5 years of age and less than 50 years. Applications for people over 50-65 years are considered if funds are available
- is non-compensable
- require specific age-appropriate care and support, including individual psycho-social and familiar assistance, which is not available through other programs. There may, for instance, be a need to purchase a specific environment because of the person's youth or because of family commitments and responsibilities, for example a young family and parenting responsibilities
- is not eligible for fast-stream rehabilitation or has not completed sufficient rehabilitation
- has been assessed as needing long-term nursing care and/or is eligible for Commonwealth funded nursing home services.

The ABI: Slow To Recover Program is designed to cater for a small but significant group of young adults with acquired brain injuries who are distinguished by:

- The severity of their acquired brain injury
- Their slow recovery and persisting high dependency requiring prolonged rehabilitation and/or other therapies
- The complexity of their care needs
- Their inability to access, through any other means, services that are appropriate to their age, level of disability and recovery potential.

my future my choice

The Younger People with Disability in Residential Aged Care (YPIRAC) Program is a joint initiative of the Commonwealth, State and Territory Governments to provide accommodation and support to young people with disability living in, or at risk of admission to, residential aged care (RAC). The Program was announced in February 2006 by the Council of Australian Governments (COAG), and represented a joint commitment by the Australian, State and Territory Governments to decrease the number of young people with disability living in residential aged care. In Victoria, the current five-year \$244 million is called *my future my choice*. The program aims to:

- Move young people out of nursing homes
- Divert young people at risk of entry to nursing homes
- Enhance the lives of young people who remain in aged care

As at March 2010 the program had assisted 28 people to move out of nursing homes, allocated 132 enhancement packages and diverted 53 people from nursing homes. Initial program targets included: a net reduction of 71 to 136 people under 50 years living in nursing homes; 140 people to move out of aged care; 60 people to be diverted from admission to nursing homes and 40 people to receive enhancement. It is expected that a revised set of targets will be achieved over the next twelve to eighteen months. Eligibility for the *my future my choice* program is broader than the ABI: Slow to Recover Program and includes people with degenerative neurological, intellectual and physical disabilities. Eligibility criteria for the *my future my choice* program include:

- Has a disability as defined in the Disability Act 2006
- Are aged less than 50 years
- Are living permanently in residential aged care or is at risk of entry to residential aged care

Composition of Support Packages

The composition of support packages in both programs is similar. It is reported that support package costs range from approximately \$5k to \$120k per annum. At the lower end a young person in a nursing home might receive funds for example to go out into the community fortnightly or receive a piece of equipment (an enhancement package). While at the higher end a young person in a nursing home might go home to family, with difference in cost attributed to a greater need for attendant care support to support activities of daily living. A typical support package comprises case management and coordination, aids and equipment, speech, occupation and physio therapies, attendant care support for activities of daily living and social inclusion.

Infrastructure Development/Consolidation

A key strength of both of these programs is that they build on existing infrastructure and expertise in the specialist acquired brain injury compensable, neurological and generic disability service systems. This is evident in partnerships and collaboration across the

service system, resulting in outcomes that minimise the possibility of program drift and duplication and optimise program capacity and sustainability, for example ABI: Slow to Recover Case management positions have been outsourced to other ABI service providers, in turn enabling appropriate mentoring and support to case management staff. In recognition of the lack of appropriate housing the *my future my choice* program has also provided capital in partnership with a range of not-for-profit organisations (who have also contributed capital) to develop accommodation in metropolitan and rural Victoria. Stakeholders believe that the development of accommodation options has been integral to the success of the program. Arguably therefore the efficacy of a National Disability Long Term Care and Support Scheme, will in large be determined by a commitment to, and a parallel investment in, the development of housing infrastructure.

Socially Inclusive Practice

Other examples of socially inclusive practice arising from an examination of the evidence provided include:

- person-centred planning and supported decision-making
- the allocation of resources to people with disability and their families to facilitate access to advocacy services for example *my future my choice* program
- provision of communication technology and other aids and equipment
- participation in training programs for example Leadership Plus
- opportunities to undertake volunteer work
- opportunities to participate in systemic advocacy for example the Building Better Lives[®] Ambassador program
- positions on advisory and reference groups to government.

Reference here, should also be made to practice undertaken in Victoria by our colleagues in the Victorian compensable service system i.e. Workcover and the Transport Accident Commission (TAC). TAC and Workcover, as providers of a social insurance scheme, have significant experience and success in the delivery of housing and support to people with severe to profound disabilities and are well regarded in Victoria.

The following is a narrative that provides a summary of the social problem and the potential for change as experienced by Anj. The narrative was derived from a series of workshops held by the Summer Foundation to support people with disability to tell their stories, engage in systemic advocacy and provide leadership in the disability sector.

Anj Barker was an active 17 year-old when her life changed in a split-second, and she and her family were confronted with the idea of Anj living in a nursing home for the rest of her life. Anj warns us all this could happen to any young person; this could happen to you, to your sister, or to your daughter.

Anj, now 24, looks back and describes herself then as a happy, active, enthusiastic, popular, 16 year-old living in Benalla with her loving family. She

enjoyed sport and was a talented high jumper; played netball, basketball, footy, soccer and more. She loved socialising and enjoyed singing with friends. Anj also used her creative skills in abstract art, leadlight and woodwork. The week Anj had commenced practising for her debutante her life changed forever when she was brutally bashed to near death by a controlling ex-boyfriend.

Anj survived the bashing but suffered a severe brain injury. Initially she was rushed to hospital then urgently transferred to Melbourne. There she lay unconscious for 2 months.

After she woke from the coma she underwent a rehabilitation program for the next 5 months. Then Anj and her family faced the next step - the idea of Anj living in a nursing home. Anj could return to live near her family in Benalla, but this meant living in a nursing home there.

If she stayed in Melbourne she would still be living in a home for elderly people. Neither option appealed to Anj. She chose to live in an aged care facility in Melbourne so that she could receive therapy. Anj describes this not as living but as “hell”. She felt angry, trapped and incredibly sad that this was her life. After living there for two and half years, her parents made the brave move to bring her home. Her parents and carers provide the everyday care and help she needs.

Her determination and strength have enabled Anj to keep moving forward despite the horrific injuries she suffered, and the medical concerns that she would not improve. She describes how “with the help of my family and friends I’ve been able to keep soldering on.”

This ‘soldering on’ kept her alive, helped her survive living in the nursing home, helped her leave the home to return to Benalla.

Anj still needs help every day and night. She uses an electric wheelchair to move around the house and outdoors, she talks slowly and often uses electronic aids to help with her ability to speak.

This life differs greatly to what Anj had imagined. She had dreamed that by 23, she would have finished school, moved to Melbourne to study psychology, would be working in her chosen profession, be in a loving relationship and on her way to being married and having three boys. She planned to be continuing with her love of art and music.

Anj is a determined young woman and is not only a survivor but has chosen to open the hearts and minds of others. She campaigns and educates the public on anti-violence. She gives talks to students, young women, to police and even to politicians. Anj empowers others to say no to violence, and has represented Australia at the United Nations level. She helps educate others to overcome their barrier to see the person not the disability. In addition she advocates, speaks, and writes to help stop young people ending up in nursing homes.

Anj can clearly visualise her ideal home, and she is on her way to making this vision a reality. Anj recently moved to Melbourne, into an apartment that is well located, with transport, entertainment and shopping easily accessible. Her new home is everything Anj dreamed of, but there is one final hurdle in Anj's quest for independence. Currently Anj's parents have moved to Melbourne with her, filling the shortfall between the support Anj's funding provides, and the support Anj needs. When this funding gap has been bridged, Anj will have fully realised her dream – to live as an independent woman, making her own choices, and living her own life.

At the thought of returning to a nursing home Anj says:

“we, young people, still deserve every chance to live a full life, give it our best and not be given a life sentence and be left to live with those who are dying...”

Further evidence of program outcomes are provided by the following reviews of the National Younger People in Residential Aged Care Program.

Getting Out: Mid-term Evaluation of the National Younger People in Residential Aged Care Program

The Summer Foundation and Monash University undertook an evaluation of the current five-year \$244 million National Younger People in Residential Aged Care Program initiative in a study, *Getting Out: Mid-term Evaluation of the National Younger People in Residential Aged Care Program*. This study provided a range of perspectives on the implementation of the national initiative, captured the shared wisdom of a range of stakeholders and provided clear direction of the development of future services for this target group. The study involved 36 recorded telephone interviews with health professionals, disability workers, advocacy organisations and public servants throughout Australia who are actively involved in the implementation of the current national YPIRAC program. The key findings from the study included:

- Some lives have been dramatically transformed by the services received in the first half of the initiative
- This program is poised to make a significant positive difference to the lives of many more people in the target group as new accommodation services open
- The development of new accommodation options has been slow and only seven new services have opened in the first three years of the initiative
- So far the initiative has resulted in few innovative models of accommodation and support, nor has the range of options to enable real choice been developed
- An increased focus on systemic change is required to prevent new admissions
- Not enough alternative accommodation options will be developed to meet the demand identified in the current target group or future demand

- People are less likely to be amenable to leaving the known of a nursing home to the unknown of disability accommodation or go home after a period of time.

In addition the authors found that there are insufficient resources to meet the full range of needs of all current participants of the program (and many people have not had the opportunity to participate). As a result of the initiative, some people's lives will change dramatically: they will move out and be supported to actively participate in everyday activities and the life of the community. Other people, particularly those who have no one to advocate for them, will receive limited assistance and will continue to lead impoverished and restricted lives in nursing homes. At the end of this program, many young people residing in nursing homes are likely to be left disillusioned because they have been asked where they would like to live in the future but not everyone will have the opportunity to move to an age-appropriate setting.

The state and federal governments have committed to recurrent funding for shared supported accommodation services that have been developed as part of this initiative, individualised support packages designed to divert people from the aged care system and enhancement packages for people who remain in nursing homes. However, at present there is no commitment or plan to meet future demand. Accommodation options developed will soon be full to capacity and over 250 people under 50 will continue to be admitted to nursing homes in Australia each year (Winkler, Farnworth, Sloan and Brown, 2010).

FaHCSIA Mid Term Review, Younger People in Residential Aged Care

This report, commissioned by FaHCSIA, analyses the targets, performance-to-date and key issues associated with the Younger People in Residential Aged Care Program (Urbis 2010). Overall, the review has found that the program is having a positive impact on a large number of young people living in or at risk of admission to nursing homes. State and Territory governments have undertaken varying approaches to the Program's implementation reflecting the different local policy and legislative contexts in which they operate.

The review found that jurisdictions have benefited greatly from the flexibility in the Program design. Jurisdictions have been able to prioritise and define target groups and allocate funding to reflect their policy, legislative and service delivery environments. This has allowed for the development of the Program in different ways across jurisdictions – ensuring that Program implementation is efficient and reflective of local contexts. Some jurisdictions have built on existing government structures and service delivery models to implement the Program in genuine 'joined-up' government settings. These approaches reflect the complexity of the Program's operating environment and the necessary overlaps across the health, disability, housing, community services and aged care portfolios. These are good-practice implementation approaches that will support sustainable outcomes for clients beyond the five year cycle of the Program.

Given the complexity of the Program in responding to so many varying individual needs of clients and their families, many jurisdictions have implemented productive partnerships with non-government organisations that have the expertise and service infrastructure to support the client-group. This has produced efficiencies across the Program.

Significant progress has been achieved nationally in providing genuine individualised alternatives to inappropriate accommodation for young people with disability, in a flexible and tailored service environment. This has been achieved through the development of strategic partnerships across/within governments and with the non-government sector, in a complex service interface between health, housing, aged care, disability, and community services.

Jurisdictions have developed strong informal and information sharing networks across the Program nationally, sharing experiences and resources in an environment of cooperation. This is producing efficiencies across the Program nationally, reducing the likelihood of duplication, and ensuring that solutions to common problems are shared (Urbis, 2010).

Summary

The *my future my choice* and the ABI: Slow to Recover programs are targeted interventions which have been responsive to the needs of young people in nursing homes with severe to profound disabilities who have been fortunate enough to receive services. These programs provide opportunities for deinstitutionalisation (by broadening the range of accommodation option possibilities), and social inclusion (by building capabilities). Both of these social programs maintain partnerships with key stakeholders, develop targeted and tailored services, use an evidence base, plan for sustainability, and build on community and individual strengths – key indicators of better outcomes for disadvantaged individuals and groups (Social Inclusion Board, 2009). As discussed there is overwhelming evidence to suggest that with appropriate support and housing young people in nursing homes are able to realise their individual potential, maintain valued life roles such as mothers, fathers, brothers, sisters, daughters and sons, and contribute to the broader community (Winkler, Farnsworth, Sloan and Brown, 2010), while their families and carers benefit directly with a reduction in the time, emotional and financial burden experienced. The Summer Foundation proposes that the Productivity Commission consider the practice experience derived from the ABI: Slow to Recover Program and the *my future my choice* initiative to assist with the formulation of a Disability Long Term Care and Support for people with severe to profound disabilities.

Part Three: A Good Service System

Part Three considers the implications of the evidence provided in part one and two, to envisage a good service system for young people in nursing homes. Please note that the following is not an exhaustive representation of solutions, the Summer Foundation through research and consultation adds to the evidence base and our understanding in an ongoing manner.

A Good Service System

“to invent, concretely, futures other than the one inscribed in the order of things....to think the world as it is and as it could be”

(Wacquant, 2004:1)

The Social Inclusion of People with Disability

All aspects of a good service system should incorporate meaningful opportunities for input from people with disability at the development, implementation and review phases. Central to this idea is the concept of person-centred planning. Person-centred planning was developed to mitigate the potential for services to make a situation worse – that is to further disempower, devalue and exclude people. Person-centred planning is designed specifically to empower people, to directly support their social inclusion and to directly challenge their devaluation. Person-centred planning strives to place the individual at the centre of decision-making, treating family members as partners. The process focuses on discovering the individual’s gifts, skills and capacities, and on listening for what the person considers really important. It is based on the values of human rights, independence, choice and social inclusion, and is designed to enable people to direct their own services and supports, in a personalised way rather than attempting to fit within pre-existing services. Person-centred planning utilises a number of techniques, with the central premise that any methods used must be reflective of the individual’s communication mechanisms and assist them to outline their needs, wishes and goals. There is no differentiation between the process used and the outcomes of the person-centred plan. Instead it pursues social inclusion through inclusive means. A good service system should be lead by people with disability, increase personal self-determination and improve independence.

The Social Inclusion of Families

Family members experience many ongoing emotional responses. The families are reacting to their young family member having a severe disability, (for many the disability is new and acquired), and reacting to a system/society that concludes a nursing home is the only option for their young family members. They are confronted with the lack of clear information, lack of choice of accommodation/ supports, and the lack of ability to create alternatives. This situation creates uncertainly, fear, concern, sadness, guilt and more leading to them experiencing emotional turmoil and ultimately social exclusion. Family members provide incredible insights into how a system could assist, how our system/society could respond to enable choice and to facilitate meaningful options for young people with disability. Family members have an insider’s view on these issues, and an insider’s reflections on how our society could be better equipped to include young

people with severe disabilities. The inclusion of family members is central to addressing the issue of young people in nursing homes.

Building on What Works in the Existing Service System

In Victoria a good service system for people with severe to profound disabilities will build on the existing infrastructure, expertise and the good work undertaken across the Victorian acquired brain injury compensable and non-compensable, neurological and generic disability service systems. There are many examples across the sector of positive practice and innovation to build on. Notably the work here is characterised by collaboration and partnerships, research, the application of evidence and integrated data to inform policy, the sharing of practice wisdom across health, rehabilitation and disability sectors, planning for sustainability and building joined-up services and whole-of-government solutions. This provides significant capacity for expansion and therefore the integration of a Disability Long Term Care and Support Scheme.

Eligibility Assessment

In a good service system assessment would be strengths-based, articulate maintenance of lifestyle and comply with disability legislation, policy and practice. Multiple factors need to be considered regarding the severity of the injury and support needs. Early after an injury, measures of injury severity may be employed to determine access to services such as length of coma; length of post-traumatic amnesia; level of physical disability and diagnostic medical imaging. However these measures alone are inadequate and should be considered in conjunction with a measure of the person's actual support needs, because the outcomes of severe acquired brain injury and other neurological conditions vary tremendously between individuals and over time (Sloan, Callaway, Winkler, McKinley, Zino and Anson, 2009). The Care and Needs Scale (Tate, 2007) is a reliable and valid determinant of the person's level of support following brain injury.

The burden of proof for eligibility would sit with the service system and not with people with disability or their families and the eligibility criteria would be clear and transparent. Finally, there would be an ongoing capacity for review. As an outcome from this process the person with disability and/or their family would feel informed about the process, the outcome and that their opinion had been heard and accepted.

Early Intervention

Early intervention for young people in nursing homes comprises two main goals: the prevention of chronic exclusion and the realisation of potential. To this end people with disability should not enter the aged care system. Alternative accommodation and support services ought to be provided at either the acute level when a person is medically stable (for people who acquire their injuries) or as appropriate for people with neurological disabilities. In a good service system, health, rehabilitation and disability services, people with disability and families/carers would work closely together to formulate and deliver early intervention solutions based on individual need. For some young people in nursing

homes this could include for example time limited access to specialist in house slow stream rehabilitation services, a current service system gap.

Housing and support

Housing is the core to social inclusion

For young people in nursing homes therefore, the Summer Foundation understands the world as it could be is one where young people with disability have a say and choose where and how they live. A world where options would include: going home, living in purpose built accommodation, shared and/or supported accommodation, or in modified accommodation, or apartments or town houses integrated within larger developments. A community where the young person has a place they call home. A world where the built environment would accommodate the person with disability and any equipment they may require, their lifestyle choices and possible life changes, and space to accommodate their children/significant others and support the visits and involvement of families and friends in their day-to-day life. The accommodation/housing provided would be affordable. It would be pedestrian and wheelchair-friendly and have attractive and accessible connections to shopping and services, and be located to accommodate previous life experiences and networks. Accommodation would be designed to make it easier for people to go about their daily business without being unnecessarily dependent on others for help, and would include expandable assistive technology systems to provide a range of alarm communications, and monitoring functions tailored to individual needs and preferences.

Support is about capability, opportunity and potential

Support would be provided in recognition of the unique constellation of cognitive and physical abilities each person with an acquired brain injury or neurological disability has, the person's unique skills and personalities, the unique family situation and family wisdom. Support would therefore be individualised, responsive and flexible, and would be provided according to disability and social inclusion best-practice. The support provided could comprise specialised medical and nursing care, rehabilitation including, speech, occupational and physiotherapy, disability support including case management, person-centred planning, social and skills development, community access, participation and integration. Further, the support provided would be life-long, account for change and transition and commence (though level of support required may vary considerably with individuals) post injury or at disease onset. The system would ensure that a young person and their family have choices and feel included in the process.

In a good service system, given the numbers of people and range of disciplines involved in supporting a young person with a severe to profound disability, there would be universally understood pathways, protocols and processes to ensure individualised responses, complimentary goal setting, seamless transitions and coordinated approaches. In a good service system the roles and responsibilities of all the respective stakeholders would be understood and valued by the whole system.

Information and Advocacy

Information provision in this context is about empowerment, participation and decision-making and is potentially an ongoing need. In a good service system therefore the key aim

of information provision is to enable people to have input into decisions that affect them. Decision-making requires the following: definition and clarification of the issue, the gathering of facts, consideration and comparison of the pros and cons of each option, further consultation as necessary, selection of the best option and explanation to those involved and affected to ensure proper and effective implementation.

In a good service system therefore, people with disability and their families would know where to start and what could be expected, would have access to 'experts' (to get more/explain information) and advocates as necessary, would have time to give due consideration and would have recourse to monitoring and review mechanisms once decisions are made. This process enables the individual and family to have clarity, to have choice and to have a different opinion. The experts or information providers would, at the very least, have knowledge of the family and relationships and an understanding of the issues and burdens being faced. Moreover information providers would have knowledge of the service system and capacity to help the person with disability and their families to navigate the service system and the capacity to provide or refer for advocacy support as necessary. Advocacy would be provided by either advocacy professionals or from peers that is either people with disability or family members.

Information about service providers, services and options needs to be easily available to people and written (or presented) in a form that is easily comprehended (i.e. free of jargon). It also should be provided in a range of formats for example online, print, audio and in various community languages.

Conclusion

In this submission the Summer Foundation has provided overwhelming evidence that a National Disability Lifetime Care and Support Scheme, provides the structural reform essential to resolving the issue of young people in nursing homes. To achieve this, the Summer Foundation has examined the social exclusion experience of young people in nursing homes and their families/carers, highlighted the range of inclusive benefits to people with disability their families and/or carers derived from the implementation of targeted interventions and presented relevant practice and systems wisdom in collaboration with our service provider partners.

The ABI: Slow to Recover program and the *my future my choice* initiative have made significant inroads into the provision of services for people with severe to profound disabilities. The programs are unique and progressive, but given compromises to program integrity arising from insufficient resourcing, will not resolve the issue of young people in nursing homes. Over 250 people under 50 are admitted to nursing homes each year in Australia. Not enough places are being developed to stem the flow of young people being admitted to nursing homes. Young people end up in nursing homes because the existing disability service system has failed them. Without a commitment to increase resources and implement responses to address housing and support needs and systemic change, this group will once again become lost to the system. The Summer Foundation believes that a National Disability Long Term Care and Support Scheme is an essential reform and humbly recommends that the Productivity Commission consider the evidence and practice experience provided to assist with the scheme's formulation.

As Michele Newland, a Building Better Lives[®] Ambassador reflects:

“I have spent 7 long years climbing a mountain”....regaining continence, learning to talk, learning to swallow, learning to read again, dress myself, learning to walk, swim and ride a tricycle.”

Through all this Michele remains positive and focused and justifiably proud of her progress and regards herself as “blessed.” Today Michele continues her rehabilitation, having established a name for herself in her community making greeting and special occasion cards. In addition Michelle spends two days a week volunteering at her local primary school, the same school she attended as a student. Michele continues to advocate for young people in nursing homes...

***“Young people just don’t belong in nursing homes.
It is not the right environment and young people need to be
surrounded by people their own age.”***

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