

COAG NURSING HOME PROJECT

“THINK TANK”

Facilitated by Jim Kennan, QC

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INTRODUCTION

Victorian Brain Injury Recovery Association convened a “Think Tank” in response to the new funding initiative from COAG, to address the issue of people under 65 currently, or at risk of, residing in Residential Aged Care (RAC). Invited participants were Clinicians, Educators and Professionals working in neurological rehabilitation and care.

The “Think Tank” was held 2nd December 2006. Acceptees are listed in Appendix 1.

The Desired Outcomes of the Think Tank were:

- To better resource those planning DHS actions for implementation of the COAG decision to move people younger than 65 out of aged care residential facilities;
- To maximise capability of any new system to address a wide range of support, rehabilitation and accommodation needs;
- To explore and expand accommodation options for young people in nursing homes;
- To establish a voice for professionals to pass on their knowledge and insight from experience gained working in this field.

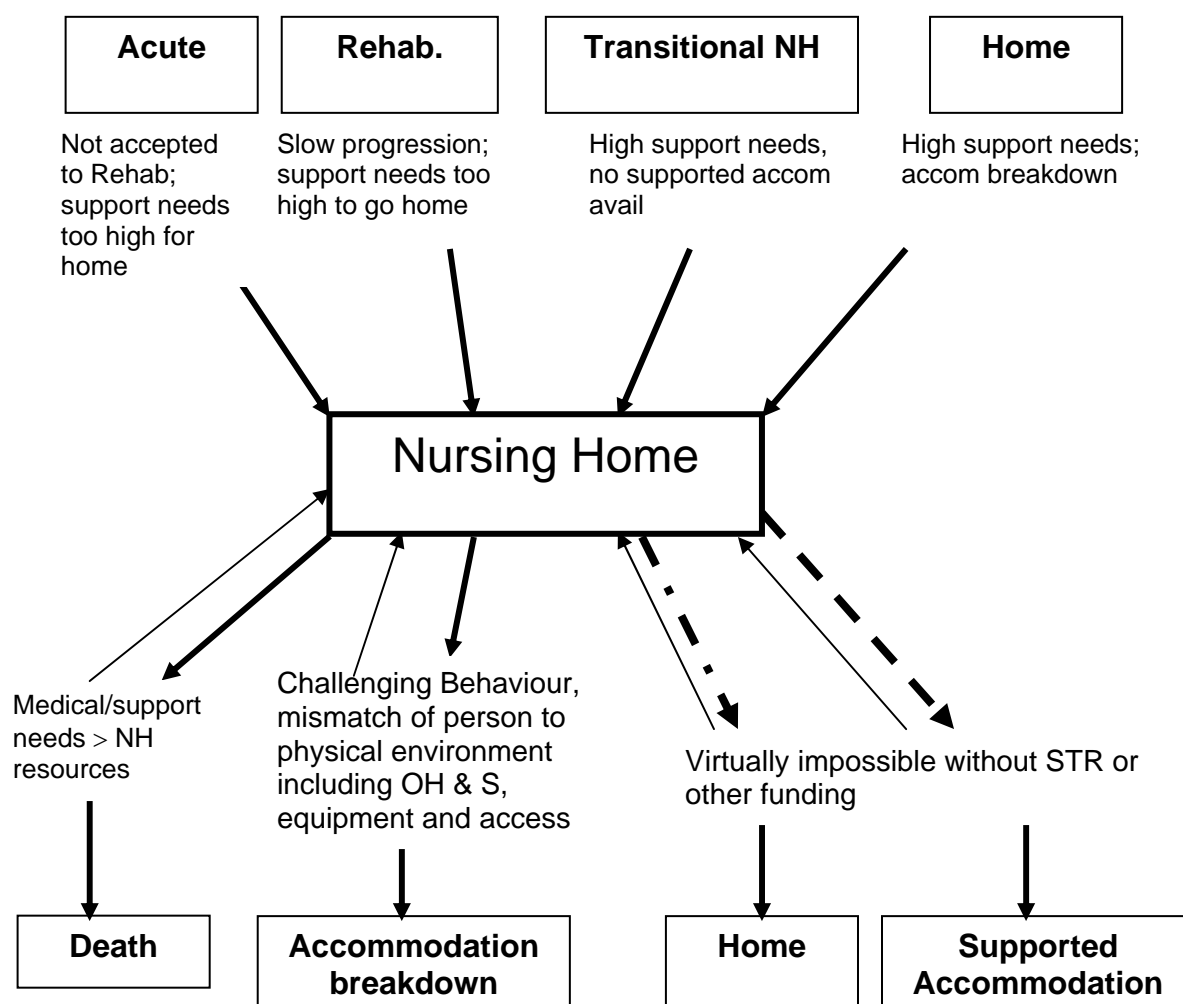
The writers and participants would welcome comment, response and opportunity for further dialogue with DHS around the issues identified and summarised below.

THE CURRENT SYSTEM: WE KNOW.....

1. ***That there are a large number of people in nursing homes with a variety of diagnoses.*** Currently amongst NH residents under 60 in Victoria, 70% suffer neurological disease or injury, of which the largest groups are ABI (37%), MS (17%), Huntingtons Disease (7%). (see Appendix 2) (Ref. Australian Health Review, Feb. 2006, Vol. 30 No. 1)
2. ***That the complexity of needs in this population means they cannot be treated as a single group.*** Deficits include: behavioural, cognitive, physical, communication & functional impairments. In addition, data presented (Sloan) indicated that people younger than 60 had the following complicating factors:
 - 76% challenging behaviour,
 - 55% pressure sore management & prevention,
 - 35% PEG feeds,
 - 21% epilepsy,
 - 12% diabetes.
3. ***That limiting DHS funding to those under 50 years of age at 30/06/06 fails to address a large proportion of the younger than 65 population.*** Limiting the number of eligible residents to 220 – 240:
 - ignores the severity / complexity of disability,
 - excludes people in their early 50s who have been awaiting accommodation for 10 years or more,
 - only results in opening of places for more young people to enter nursing homes due to the waiting list,
 - ignores need as a priority for attention; and goes against the trend of DHS figures.
4. ***That consideration of the whole person, in their environment, is central to determining the accommodation needs of that person:*** Each person has a unique set of needs. In order to provide a physical structure of accommodation suited to the individual, there needs to be: an understanding of the person's unique medical, allied health and personal care / nursing needs; along with the individuals cultural; social, recreational, life and living needs, choices and priorities. This includes not only viewing the individual in context but also the families needs. Examples were given of targeted OT input after placement reducing care needs (Sloan).
5. ***That family damage occurs as a result of isolation,*** frequent for young residents of RACs (Sloane, Wittaker & Winkler);

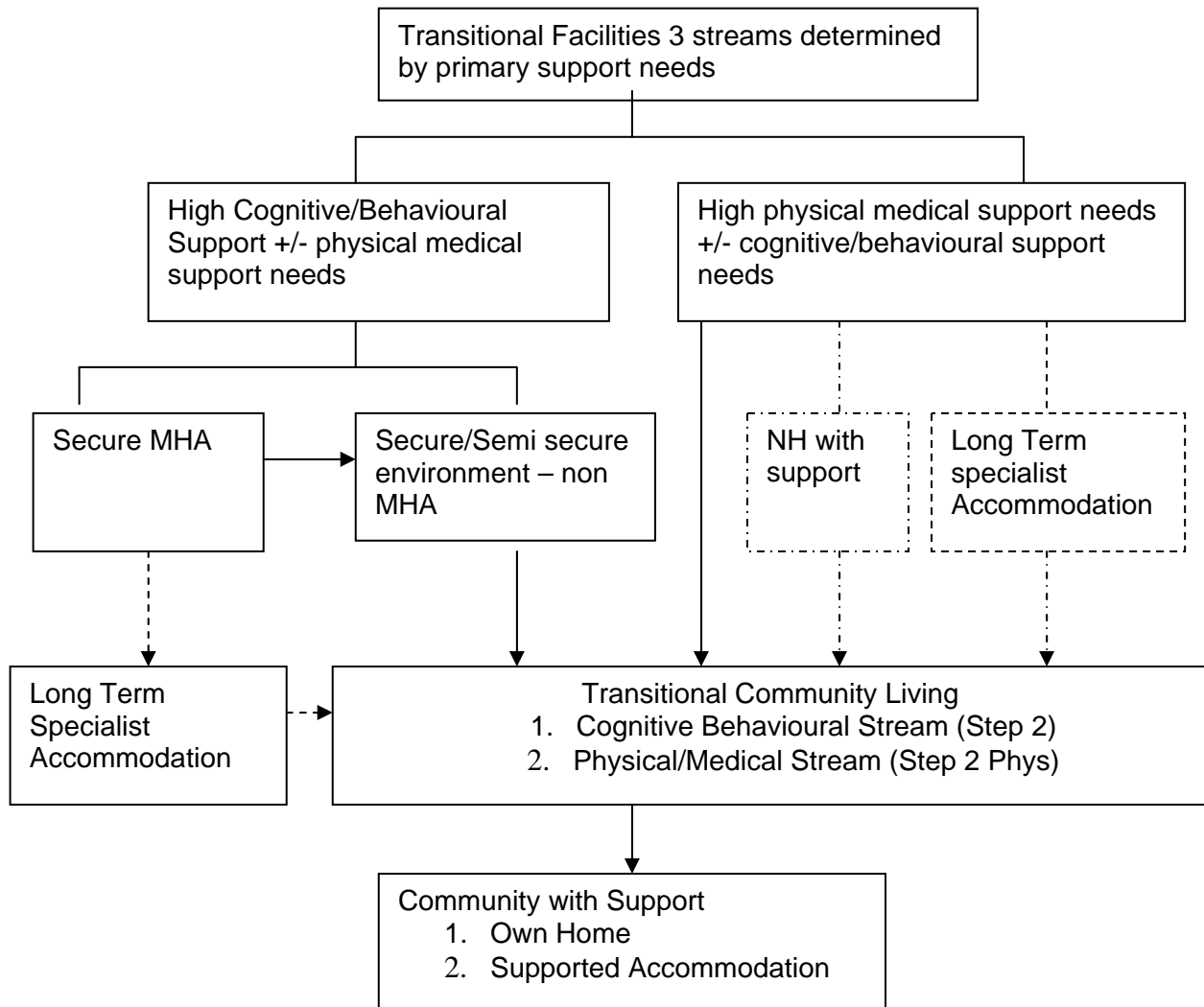
6. ***That there are inequities in the system:*** For example, the Senate Committee demonstrated that some people receive priority access and generous assistance over others with equal needs, or in some instances those who are more severely disabled and with higher needs;

7. ***That the current system functions in this way:***



8. ***That further current options*** include the Acquired Brain Injury – Slow to Recover Program and the Step Down Unit at Southern Health. ABI-STR has >10 yrs experience in addressing the supply of additional services to severely and profoundly younger non-compensable people, living in both RAC and the community. ABI-STR has successfully moved people from RAC to the community, and currently has 139 active participants, with 60 on the waiting list (frequently closed). The Step down unit currently has 4 beds, and provides an alternative early RAC placement, allowing maximisation of slow recovery.

9. ***That the current transitional pathways could function in this way:***



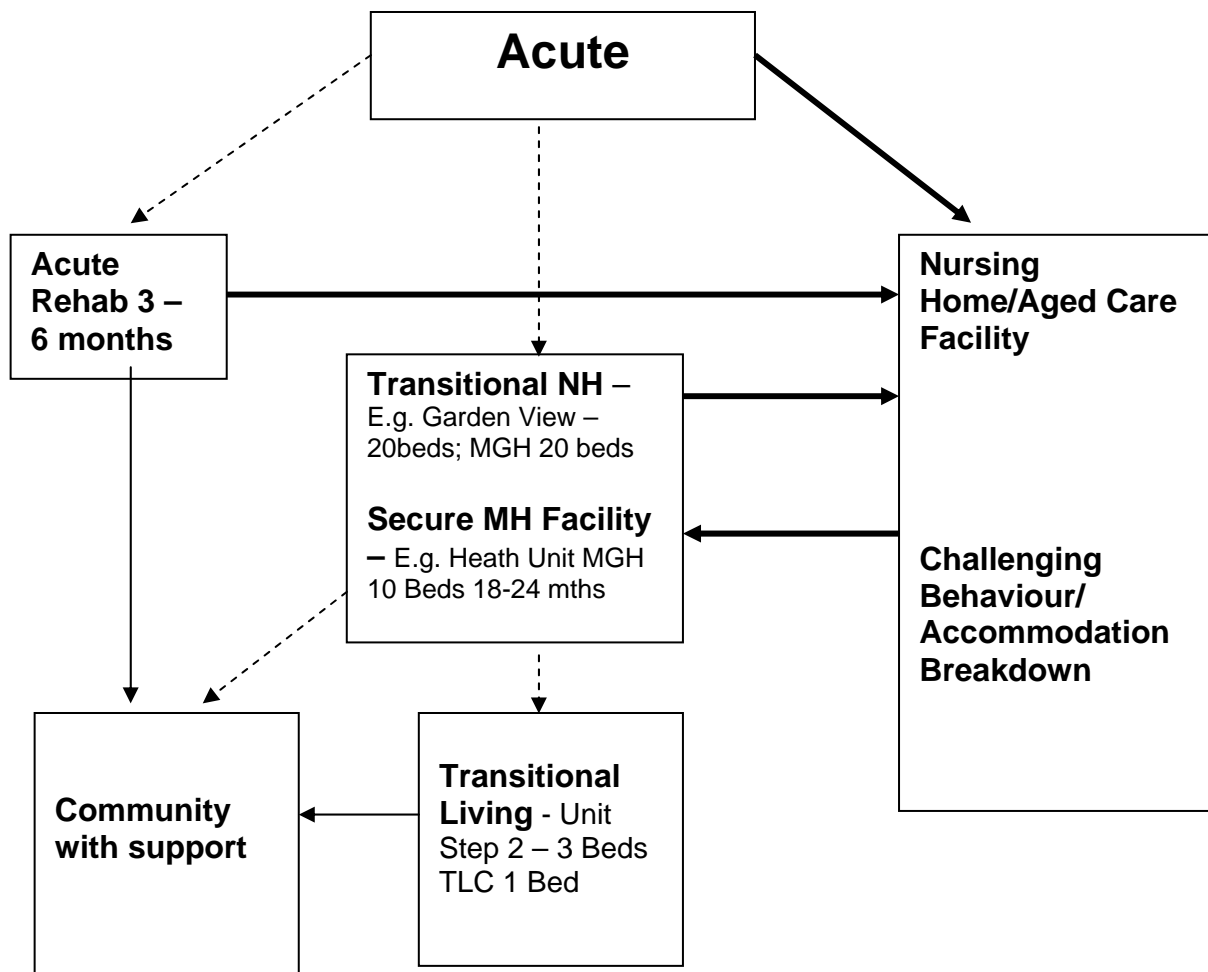
10. ***That the current alternatives to Residential Aged Care*** present a wide variety of support models. Often the difficulty is matching the needs of the client to the support system available. Not infrequently, clients are placed with inappropriate support and / or accommodation because that is what is available at the time of their placement.

Examples of current community accommodation options are:

Alfred St; Brighton House; Cahill Drive; Harper St; Healthscope.

Level of support at these houses:

24/7 active night; 24/7 inactive night; pooled individual packages; 1:1 community access support; case management; therapy support; other specialist support; aids and equipment support.

11. *Example of current pathways to the community (ABI example):*

MGH = Mary Guthrie House

MH = Mental Health

TLC = Transitional Living Centre

SYSTEM BLOCKAGES

Support Workers: effective support workers are scarce due to:

- poor pay structure,
- inadequate training,
- lack of ongoing support
- poor career structure.

These factors impact on the quality and quantity of available workers, particularly in the presence of challenging behaviours. Consistent and effective support workers enhance clients' abilities and quality of life.

Inflexibility in responding to individual needs: failure to provide the optimal blend of accommodation, therapies and support services at appropriate times.

Lack of access to services:

- there is a stark inequality of access to therapy between funded and non-compensable clients;
- lack of recurrent access to specialist support throughout life;
- lack of transitional services from acute / rehab / RAC into the community;
- duration of support packages not based upon needs.

Lack of beds:

- lack of slow stream rehabilitation / dedicated disability beds;
- lack of community beds, resulting in transitional beds becoming as good as permanent;
- inability to access available beds already allocated to another service;
- lack of timely access, inability of system to respond to urgency of need;

Lack of transparency:

- lack of disclosure of reasons behind decisions, and of decisions made;
- the community at large currently believes that disabled people are adequately cared for, and are shocked when faced with the system as it stands.

Lack of understanding of policy makers: particularly regarding the long-term rehabilitation needs of this population and the changing needs of this population over time.

Lack of funding for longitudinal research in this area.

DISCUSSION OF SOLUTIONS

The final session was a brainstorm around the needs, solutions, models and ideas. The participants drew on a varied and specialised knowledge base, from their collective and considerable experience in working in the area.

1. Policy Change

- Introduce support services to enable clients to exit RACs;
- Allow presently denied services into Nursing Homes;
- Structure the workforce to support and foster the client's abilities.
- Create an equitable system.
- Adopt policy of disclosure of decisions and reasons.
- Implement the following fundamental needs of residents:
 - basic clinical care needs,
 - participation in the community,
 - access to the community,
 - the "need to articulate their hopes and needs" (Hudson)
 - taking responsibility for own future,
 - right to choose how they live,
 - quality of life needs,
 - person centred planning, therefore capturing what is
 - important to that person,
 - access to rehabilitation and medical service at appropriate
 - times and places,
 - provision of flexible, dynamic and non-linear services,
 - consideration of immediate, short term and long term needs

2. Funding Focus

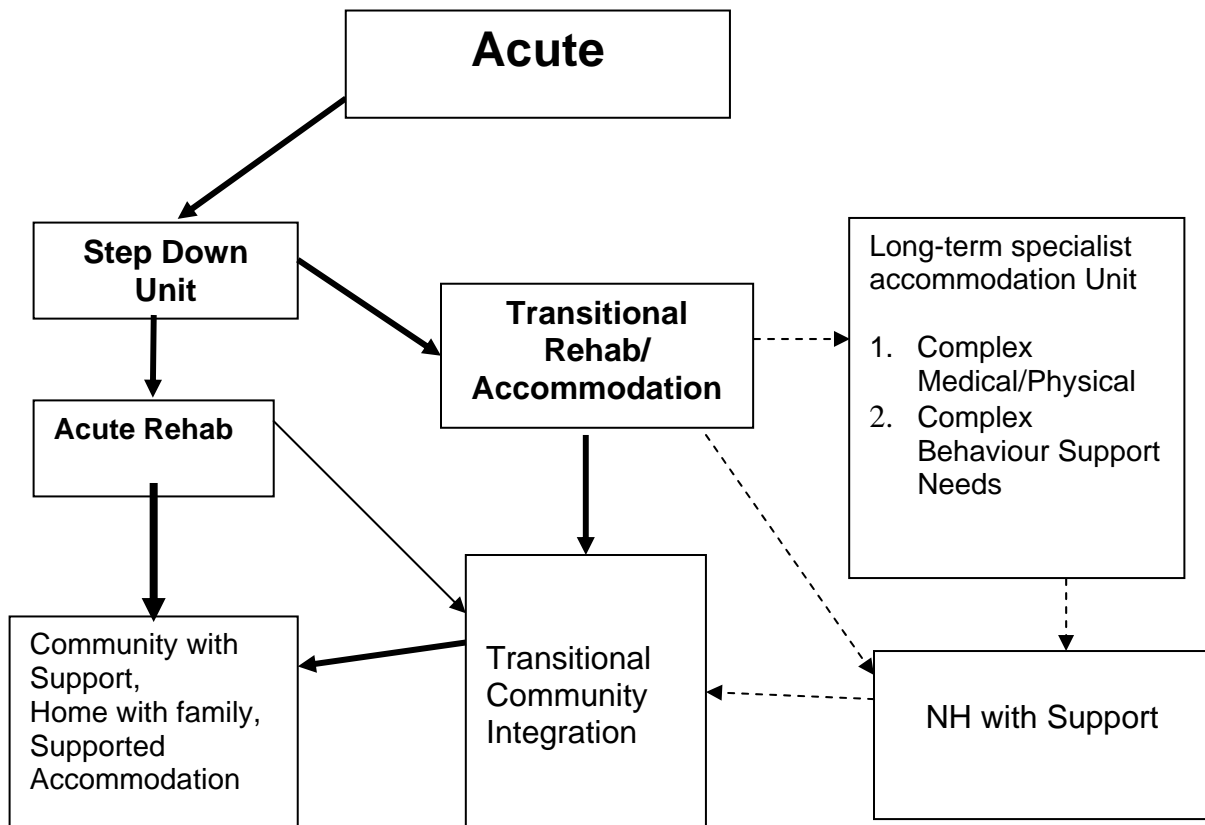
- To train workers – initially and on an ongoing basis as required, and in response to need;
- To support workers and families – again ongoing;
- Service specific training;
- Therapy specific input in training;
- Flexibility in the use of therapy; input to be responsive – high input when there is change or a need, less or no input when appropriate.
- *Provide* funding that is individualised: underpinned by a philosophy that embraces the individual and unique needs having regard to the potential and possibilities of each patient – responsive to the immediate, short term and long term needs of the individual;

NB: The provision of this type of support is to maintain the accommodation placement successfully, thus avoiding nursing home placement. In this respect it has the advantage of being more cost effective.

3. Forum for Communication

- **Between clinicians who have been given an unrealistic plan, and funders** who are charged with decision making around the provision of services. Particularly, in addition to creating greater understanding of the long term needs of people with acquired brain injury, and in relation to the lack of knowledge intermediate agencies often have of client needs.

4. One alternative: a better transitional pathway (complex needs)



This model:

- ***is applicable to anyone*** with complex medical / physical or behavioural support needs.
- ***uses Step Down beds***, which are already tried and tested for ABI; possibly 3 or 4, 4 bed units throughout the metropolitan area, plus 1 x 4 bed unit in each regional DHS area.
- ***avoids the Nursing Home as the end point destination.***
- ***is supported by subjective/qualitative measures*** – the person with a severe disability experiences meaningful life, and families are involved in the process of recovery / integration, in line with WHO definitions of Health and Well being.
- ***avoids damaging isolation.***
- ***has the potential for significant reduction in costs*** as an initial and continuing high cost outlay is avoided.

5. Shared Supported Community Living should have the following

design elements:

- *Where the primary need is Physical Support:*
Home-like, Wheelchair accessible, Specialised aids and equipment available; Space for personnel to meet; OH&S issues addressed; Communal, Outdoor and Quiet Spaces; Community Accessibility.
- *Where the Primary Need is Cognitive/Behavioural Support:*
Home Like environment, Embedded in the Community; Safe and Secure with clever design rather than locked doors; Low Stimulus environment; Environmental Cues; designed to "Progress in Place"; ideally 4-5 residents.

6. Centres of Excellence:

- **Develop** an evidence based centre for each disability;
- **Develop** a trained workforce, including carers, by creating career pathways and providing adequate and ongoing training opportunities;
- **Support** all workers in the field.

7. Transition from hospital to home:

- **Guarantee** of hospital beds (i.e. 'Step – Down unit or beds), metropolitan and rural – with recruitment and retention of specially trained staff. These beds need to be in each DHS region with a minimum of four (4) dedicated beds. Such a Unit exists at Monash Medical Centre (MMC).
- **Ensure** Flexibility in accommodation reflective of the individual needs at that time to prevent NH admission or re-admission due to accommodation break down or unavailability.
- **Create** Flexibility in decision making within the health system hierarchies – the client being central with consideration of the broader influence and effect of the individuals family, social networks, support workers and community networks – aiming for the greatest cohesion and 'fit';

8. Provision of accommodation:

- **Recognise**, underpinned by a philosophy of person centred practice that accommodation needs are varied and will change over time for reasons beyond the ageing process. Transition pathways will need to reflect this recognition and understanding to best meet the long term needs of the individual;
- **Provide** accommodation that is individualised and flexible: Again, underpinned by a philosophy that embraces the unique needs of each client, it is essential that the accommodation is appropriate for the client – in terms of co-residents, choices and preferences, 'progressing in place', community, family and social network and support needs – that is, having regard to the whole person;

9. Respite:

- **Acknowledge** the respite needs for families and support to avoid accommodation breakdown/ family integration breakdown.

SUMMARY AND PROPOSAL

The “Think Tank” enabled clinicians to give their own experiences as examples of what “works” and what “doesn’t work”, as well as suggestions for improvement. Many of these ideas merit further exploration and development.

The aim of these Proceedings is to articulate current issues, and create an opportunity for dialogue about how to enact change to meet the needs of many young people in nursing homes in Victoria who do not have appropriate accommodation and services.

Proposal:
that the collective resources of local experienced health professionals should be used in the planning of Victoria’s response to the COAG initiatives.

APPENDIX 1: ACCEPTEES

Ann	BOOTH
Jenny	BOULTON
David	BURKE
Merrilee	COX
Jacinta	DOUGLAS
Louise	FARNWORTH
Deborah	FARRELL
Michelle	FRENCH
Jayne	GALLOW
Helen	HARRINGTON
Marianne	HUBBARD
Rosalie	HUDSON
John	KENWRIGHT
Katie	KIRBY
Allen	MARTIN
Bronwyn	MORKHAM
Dorothy	PATRICK
Kate	PHILLIPS
Barry	RAWICKI
Sue	SLOAN
Joan	TIERNEY
Sue	VINCENT
Tom	WORSNOP

Also attending: Francene McCartin

APPENDIX 2: DISABILITY TYPE TABLE

The following table details the differing diagnosis of people less than 60 years of age in Nursing Homes in Victoria. The data is based on a survey of 800 nursing homes in Victoria of which 626 responded. 478 residents were under 60 years of age of whom 451 required nursing home care in Categories 1 -4.

Disability type *	<i>f</i>	%
Cancer	1	0.3
Muscular dystrophy/atrophy	2	1
Quadriplegia	2	1
Motor Neurone disease	4	1
Paraplegia	4	1
Cerebral palsy	5	2
Deafness/hearing impairment	5	2
Other	6	2
Psychiatric disability	8	2
Parkinson's disease	9	3
Dementia	16	5
Blindness/vision impairment	17	5
Huntington's disease	22	7
Intellectual disability	48	15
Multiple Sclerosis	55	17
Acquired brain injury	122	37

* Each resident may have more than one disability