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# Submission

## An Innovative Disability Accommodation Support Service

### My Life My Choice My Right

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August 2010

Submitted by –

Mrs Marie Hell

On behalf of families from

Frankston, Casey and Mornington Peninsula

### Background

#### 1.1 Who we are

This submission is made by a group of families living in the Frankston, Casey and Mornington Peninsula area of Victoria who have beloved sons and daughters with a disability. These sons and daughters require accommodation and support outside the family home. The greatest fear of group members is, "What will happen to my son or daughter when I can no longer provide care and support?"

Currently the group has more than 50 members representing 33 families. Membership continues to increase as the aims of the group become better known and families who face the same crisis in their lives seek to become part of a progressive group whose only motivation is the future wellbeing and security of their dependent sons and daughters.

The motivating concern for this group is the need to establish long-term housing and support for people with dependent disabilities, to enable these individuals to live without being required to depend on their parents for accommodation and support.

The issue of accommodation for people with intellectual disability who need care and support has long been ignored or only given token consideration by Federal and State governments. The need is urgent, not only for these people but for their ageing parent carers, who have provided accommodation, care and support for decades.

These same carers, personified by the members of this group, are now in their 60s, 70s and some in their 80s, and are struggling physically, mentally and financially. We have a finite capacity to care and this can no longer be ignored as our mortality is foreseeable. This submission therefore seeks to put the spotlight on this pressing need and the urgency for direct support to be given now.

#### 1.2 Time is of the essence

The Australian Government has recognised that many Australians with disabilities, along with their families, friends and carers, are experiencing systemic disadvantage.

As a consequence, the Government is developing a National Disability Strategy (NDS) which it hopes will provide solutions to the struggle people with disabilities too often face to access the necessities of life and to have the same opportunities as other Australians. A draft 2010-2020 Strategy as an initiative of the Council of Australian Governments has recently been released.

One of the prime concerns relates to the crisis in accommodation, particularly as it affects the nation's aged carers who in many cases suffer from more debilitating health issues than the person for whom they care. Not only do these carers live with the stress of caring, but they also live in fear of not seeing their sons and daughters living in appropriate accommodation before they die.

The Australian Government has asked the Productivity Commission to conduct an inquiry to look at a new system to improve long-term care and support for people with a disability and their carers and families. As carers are ageing and in need of support themselves, planning for the ageing of people with an intellectual disability is also imperative.

The Commission is to include an examination of a social insurance model to replace the existing system funding. Of course, any disability funding scheme has to be sustainable for the future. While the Commission is to report to the government by end July 2011, if

a new funding scheme is accepted by the Australian Government it is likely to be many years before it meets the needs of all those with a severe or profound dependent disability.

Time, however, is a luxury that aged carers cannot afford. This was made clear by Rhonda Galbally, AO, Chair, National People with Disabilities and Carer Council, in her closing statement in the National Disability Strategy Consultation Report entitled "Shut Out" in which she said, *"Australians with disabilities have been waiting for many years for change. They cannot and will not wait any longer."* Consequently, any proposed services that require "time" to implement or introduce or which require further inquiries and/or reports to be initiated will prove to be of no benefit to people who require help now.

It is almost impossible to believe and therefore indefensible that the only apparent option for a person with intellectual disability who cannot live without care and support is to remain in the parental home for the rest of their parents' lives, while being parked on a waiting list with a bleak hope of 'something' becoming available.

The unspoken solution of a place in a nursing home or some other form of residential aged care, although recognised by politicians and bureaucrats alike as needing to stop, is still part of the systemic disadvantage confronting people with disabilities and their families.

### 1.3 Providing choice and solutions now

This group bring to the table an innovative idea to relieve our housing distress through the provision of an accommodation facility that supports our sons and daughters to gain greater independence and provides services that will meet the individual needs of our loved ones in a planned and caring way.

Most importantly, it will provide them with a home of their own, giving them the same rights and opportunities as other residents in Australia, to live their lives to the fullest as valued members of the community. We envisage that our proposed supported accommodation model may be used as a precedent, and considered an enviable model, a new pathway to assist people and families through the coming years.

Because people with a disability differ widely in their respective capabilities, independent living is possible for some with minimal support, while others need 24-hour support and care. This vast difference in abilities demonstrates the need for a range of accommodation styles and options, just as there is a need for a range in education facilities, work opportunities and social integration.

Choice does not equate to more expense. Rather choice equates to equal opportunity. In fact, community life-style supported accommodation, such as this submission proposes, must be provided for people with intellectual disability who seek and prefer this type of accommodation over other options. Indeed, as pointed out in the Victorian Auditor General's report of March 2008, relating to Accommodation for People with a Disability other models are not necessarily providing a satisfactory service to their clients.

Lack of choice was one of the main issues addressed by most submissions in the National Disability Strategy Consultation Report released in 2009. Under the heading of "Proposed Solutions" the suggested focus was on the development of alternative innovative models, more responsive to individual needs and lifestyle.

In excess of \$6 billion has been allocated to affordable housing from the Intergovernmental Agreement on Federal Financial Relations via the National Affordable Housing Agreement. The inspirational objective of this Agreement is that all Australians

have access to affordable, safe and sustainable housing that contributes to social and economic participation. This is an objective we fully endorse.

Whilst recognizing the Commonwealth Government is in the process of examining a host of issues to assist those living with disability, the reality is that the implementation of proposals, including any new funding or social insurance scheme and any proposals that might be generated through this process, are likely to be at least a decade away.

The ability to plan for the future underpins the aspirations of all Australians, and people with intellectual disabilities must not continue to be excluded simply because they need support to make their plans a reality.

This submission provides a way to rectify this exclusion and thereby address the pressing requirement to assist people with disability to live as independently as possible by helping them to establish stable and sustainable living arrangements, increasing their choices and improving their health and wellbeing.

## **2. Critical Unmet Need**

### **2.1 Government Initiatives**

In October 2009, a joint ministerial press release stated that the Rudd government would construct over 20,000 new social housing dwellings providing a key element of the government's \$42 billion Nation Building and Jobs Plan which would include 802 new Defence Force houses. It was proposed that the vast majority of houses be built by December 2010, and provide much needed accommodation for low income Australians who are homeless or struggling in the private rental market, an apt description of any person with a disability surviving on a Disability Support Pension.

In July 2008, the Australian Government signed the United Nations Convention on the Rights of Persons with Disabilities and thus recognised the right of persons with disabilities to enjoy an adequate standard of living for themselves and their families, including adequate housing and to the continuous improvement of living conditions. This very aspect was mentioned in the Disability Investment Group Report released in November 2009. These new schemes have the potential to contribute to meeting the housing needs of people with disability.

Despite the release of the well intentioned 2002-2012 State Disability Plan by the Victorian Government, together with subsequent implementation plans calling for action to provide stable accommodation options for people with an intellectual disability throughout Victoria, it is a simple fact that there is a significant shortfall in the amount of accommodation, care and support for people with an intellectual disability. There are as well instances of services not providing an acceptable quality standard of living.

### **2.2 Victoria's Unmet Need**

#### **2.2.1 Waiting List**

The Disability Support Register (DSR) managed by the Department of Human Services provides an indication of the service needs of people with a disability throughout the State. It indicates those who have registered they require the service now i.e. people cannot register future needs. The number of people recorded on the DSR as at December 2009 is shown in the following table.

**Disability support register as at December 2009**

| <b>DSR Category</b>              | <b>Statewide</b> | <b>Southern Metropolitan Region</b> |
|----------------------------------|------------------|-------------------------------------|
| Supported Accommodation options  | 1291             | 339                                 |
| Support to live in the community | 1234             | 326                                 |
| Daytime activities               | 139              | 52                                  |

*Source: Legislative Council Hansard, 25 May 2010, answer to questions on notice 11 751 and 11 759*

**2.2.2 Regional Comparison**

Approximately 24% of Victoria's population resides within the Southern Metropolitan Region, which incorporates both the Peninsula and City of Casey.

The tables below set out the availability of shared supported accommodation in Victoria using the most recent figures (August 2008) provided by the Department of Human Services. These figures demonstrate that Southern Region has the greatest variation (4%) from the percentage share it could expect based on its population. There would be an extra 209 beds in Southern Region if shared supported accommodation were available on a population basis.

| REGION            | % Population | SSA CRU beds | % rounded | % difference |
|-------------------|--------------|--------------|-----------|--------------|
| Southern          | 24%          | 939          | 20        | -4           |
| Eastern           | 19%          | 1259         | 26        | +7           |
| North West        | 30%          | 1280         | 27        | -3           |
| <i>Metro</i>      | <i>73%</i>   | <i>3478</i>  | <i>73</i> | -            |
| Barwon South West | 7%           | 278          | 6         | -1           |
| Gippsland         | 5%           | 201          | 4         | -1           |
| Grampians         | 4%           | 347          | 7         | +3           |
| Hume              | 5%           | 270          | 6         | +1           |
| Loddon Mallee     | 6%           | 210          | 4         | -2           |
| <i>Rural</i>      | <i>27%</i>   | <i>1306</i>  | <i>27</i> | -            |
| TOTAL             | 100%         | 4784         | 100%      | 100%         |

### **Population Based Comparison**

| REGION        | % Population | No beds if 4784 population based | Change      |
|---------------|--------------|----------------------------------|-------------|
| Southern      | 24%          | 1148                             | +209        |
| Eastern       | 19%          | 909                              | -350        |
| North West    | 30%          | 1435                             | +155        |
| Metro         | 73%          | 3492                             | +14 (0.29%) |
| Barwon SW     | 7%           | 335                              | -57         |
| Gippsland     | 5%           | 239                              | +38         |
| Grampians     | 4%           | 191                              | -156        |
| Hume          | 5%           | 239                              | -31         |
| Loddon Mallee | 6%           | 287                              | +77         |
| Rural         | 27%          | 1292                             | -14         |
| TOTAL         | 100%         | 4784                             | -           |

*Source: Compiled from Legislative Council Hansard. Answers to Questions on Notice, 11 August 2009, Nos 9227, 9244, 9245 9246, 9247, 9248, 9249, 9250*

### **2.2.3 Facts and figures**

Government announcements indicate that 70 places are to be provided in Victoria for supported accommodation as part of the 2008 announcements on funding associated with the Intergovernmental Agreement on Federal Financial Relations- National Disability Agreement. The shortfall of supply to demand is obvious – 70 places when there are 1,291 people on the waiting list.

Indications are that 24 places will be provided in the Victorian Southern Metropolitan Region from Dec 2010-April 2013 for group supported housing.

It is also of note 93 per cent of people with a disability are still living at home. Parents/ carers do not live forever and innovative options in housing need to be considered as a matter of urgency.

Our proposal will result in an increase in the number of places available for the benefit of people with an intellectual disability.

Employment opportunities will also be provided for the local area, which will have a positive socio-economic impact to the local community.

## **3 The Proposal**

### **3.1 Community Lifestyle Supported Accommodation**

The group is proposing a model driven and supported by parents and individuals and is thus actively seeking support from the Federal Government to enable the establishment of a partnership involving the government, families and the non-government and corporate sectors.

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## **Proposal for an Innovative Disability Accommodation Support Service**

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It responds to the lack of options currently available to families of adults with an intellectual disability in the local community with an emphasis on supporting ageing carers.

The selection and mix of residents for each of the programs will be determined by formally established procedures and a transparent process.

Policies including complaints procedures will be based on the Disability Act 2006 principles, specifically that services should: -

- assist people with a disability to be included and take part in activities in the community
- maximize choice and independence for people with a disability
- recognize that people with different types of disability may need different sorts of supports
- consider and respect the role of families and other people who are important to a person with a disability
- be aware of any extra disadvantage a person may have because of their culture, language or where they live
- ensure that people with a disability have support to make decisions as required
- be of high quality and protect the rights of people using the service
- choose the least restrictive option possible, if a person's rights or opportunities need to be restricted
- carers and clients will be engaged in decision making about the built environment and ongoing nature of service delivery

This facility will involve an innovative, flexible, holistic approach to provide best value outcomes for adults with varying abilities together with carer support. It is our aim to provide a combination of individualized services, to meet the needs, goals and aspirations of individuals with an intellectual disability. Accommodation options will provide for individual needs, shared support, respite and a community hub.

The end result will provide a balance between community living principles and the logistics of building suitable accommodation options which are accessible, affordable, safe, secure housing to meet the changing needs of individuals.

People with disabilities are as diverse as any other group of people. Some can live independently with no support or minimal assistance and others need 24 hour care. For people with acquired brain injury supports will be provided to maximize their independence and control over their lives within a community setting.

All accommodation will be carefully planned to ensure long-term sustainability using universal design principles.

A person centred planning (PCP) approach will be implemented to work with the individual to identify the support needed from the perspective of the person and people significant in their lives.

Buildings will be designed to provide a tranquil, peaceful place with minimum environmental impact. A landscaped garden that will provide disability access through out, with paths and board walks allowing residents to move freely and enjoy their surroundings. Residents can enjoy their own space or join in communal activities, such as gardening, cooking, men's group, outings, BBQs, etc.

The development will be centrally located to the community, transport, recreation facilities and other amenities. The ease of access to these amenities will add to the philosophy of social integration in the community as a whole a vital ingredient in enabling all residents to reach their full potential.

### 3.2 Service Principles

The following principles underpin the proposal:

- Innovative, flexible, holistic approach to cater for people with an intellectual disability
- Accessible, safe, secure housing using universal design principals tailored to suit individual needs
- Model driven by parents and other concerned individuals
- Supporting adults with varying abilities who have an intellectual disability to live a positive lifestyle within their own community environment
- Giving people choice, but evaluating the risks that may occur
- Involving and supporting families and tenants in all planning and decision making
- Understanding that resident compatibility and vulnerability as well as their needs, wishes, aspirations and abilities, is central to all planning to ensuring quality of life and quality of care
- Employment of appropriately trained staff who are committed and compassionate about enabling the best quality of life outcomes for all residents
- Providing adequate support to enable integration and community inclusion; to further develop independent living skills, appropriate behaviour, communication skills, personal interests, recreation and supported employment
- Housing includes the relationships within the home and neighbourhood

### 3.3 Proposed Permanent Accommodation

Three types of accommodation are proposed:

- Six semi/ independent one bedroom living units for residents who require (minimal support) with the choice of one's own support worker, or residents may choose to combine their individual financial support and choice packages. Residents will attend a day activity or supported employment in the day time. A lead tenant would reside on the premises and be available to residents in the event of emergency as well as providing guidance and mentoring to the residents as and when required. Facilitated activities, leisure options barbeques, and celebrations will all assist individuals to form friendships and contribute in their own way to the wider community.
- An appropriately designed complex for eight people with low to medium support needs comprising of eight independent studio units each with a well-designed bedroom/sitting room and en suite bathroom together with a shared kitchen , living/dining, laundry and an outdoor recreational area. The complex would be designed to include four units at each end with a central communal area and housekeeper unit. The housekeeper would be required to provide main meals, manage the household budget and provide guidance and assistance to residents in developing their independent living skills. This environment would then provide an option for residents to have their own living space, encourage independence as well as providing companionship, support and security.
- Two houses, one for four adults with high support/complex needs requiring both staff supervision and active night support and one for six adults split into 2x3 bedroom units together with a bedroom for sleep-over support.



### 3.4 Services and Supports

The following services and supports will apply:

- Interaction will be encouraged as everyone will share the communal areas of the house such as the kitchen, dining, living rooms and laundry and outdoor areas.
- Individual care plans will be established for each person with input from the individual and people significant in their lives. This will maximize the potential for each resident to enjoy a positive lifestyle including their local community. Care plans will be regularly updated to include development of each resident's competencies, promotion of choice, independent living skills and personal interests.
- Staff will support and encourage residents in development of skills to promote achievement, positive behaviour, community inclusion and a happy and safe housing environment.
- Spacious areas to accommodate wheel chairs, hoists etc. Incorporation of landscaped areas to stimulate sensory response, maximize and involve the resident's abilities to enjoy both their garden and home environment.

### 4. Outcomes of the Proposal

This proposal offers:

- A practical solution to achieving the best outcome for the person with an intellectual disability to live independently of their parents in a home of their own
- Ageing parents better support by their being relieved from day-to-day care
- A blueprint solution to the crisis in accommodation that could be replicated across Australia to support hundreds of other families facing the same crisis of care.
- A response to the request made to the Productivity Commission by the government in that it re-thinks how to support people with disabilities so that they can engage with their community and live happy and inclusive life " (Sherry, Macklin, and Shorten, p3, 2010)
- Long-term essential care in an inspiring living environment.
- An infrastructure which will manage the costs of long-term care.
- A range of support options for accommodation and community participation.
- For some residents, as the individual's capacity grows and their networks are strengthened the opportunity to move into more independent community accommodation.
- A community hub which will include administration, accessible meeting and recreation room and thus encourage community inclusion
- Co-ordinated supports and services for clients and families

- Co-located supports and services which will be a cost effective way of supporting people with intellectual disability and their families
- Opportunities for residents to live with friends in a vibrant and diverse community
- People with a disability a sense of achievements within their own home

### **5 Funding Required**

This proposal requires the assistance of the Federal Government for a funding grant to allow this group to develop residences to cater for the needs of people with an intellectual disability

#### **5.1 Land Purchase**

One million dollars estimated (at current market value) for the purchase of five acres of land within the areas of Cranbourne and the Mornington Peninsula with ready access to built infrastructure.

#### **5.2 Capital Building Costs**

Five million dollars to meet the cost of the buildings, site-works and fit-out.

## **Appendix**

Community Support: **Local article in Hastings Independent 1<sup>st</sup> June 2010**

For this group of retirees, planning where to holiday over winter is an unthinkable luxury, they are still busy caring for their adult children and worrying about who will look after them when they are gone.

Many of them are single women – the stress of caring for a disabled child often tears families apart – who, limited by their caring duties, have earned relatively little over their lifetimes and amassed even less superannuation. Some have not had a day off, let alone a holiday, for decades.

Mrs Hell said: "An 81-year-old parent of a disabled child said to me, 'I cannot even die in peace'.

"I was in tears and I thought, 'That could be us'. Every forum we go to there are carers in tears."

Most of the group have given up going to forums and are tired of endless inquiries and studies resulting in report after report but no action.

"I was going to bring along all the reports, but I couldn't fit them in the car," joked Graeme, the father of a 40-year-old daughter with intellectual disabilities.

Bureaucratic intransigence and poor policy had resulted in a lack of options for adult people with disabilities, the group claims.

Several families in the group have had disastrous experiences with community residential units, the prevailing model of care in which several people are placed in a unit or house together, with a revolving cast of paid carers.

This group of families wants to build appropriate accommodation with varied levels of care made available to people with different needs and a range of services and recreational opportunities on site.

This doc has been compiled with the assistance of Jackson Ryan Partners  
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