1 Introduction

Luke is a handsome young man with a pleasant personality. He is fit strong and physically able. He is never mean, says funny things, has funny reactions to things, has a good sense of humour, is forgiving, truthful, honest, remorseful, empathetic, trustworthy, loyal, polite, endearing, determined, engaging. He has four younger siblings.

Luke is autistic and this creates many challenges for him - in every day living. He needs a lot of love, forgiveness and support - in every hour of his life.

On February 26, 2004, at the age of 15, he moved out of his parent's home in Mount Waverley, to spend 12 weeks in "Emergency Respite" at "Greenock" in Wantirna. Eighteen months later, two days before his 18th birthday, he went to live at "The Crescent" in Mount Evelyn.

This was not his choice, and not that of his parents or family. They felt they had no choice. Despite significant setbacks the family continues working towards its dream of finding and building supports that would enable Luke to live in his own home close to home.

This submission was prepared in the hope that it might help people to avoid some of the problems of the past, and to inspire all of us to keep planning for better, and more appropriate supports for all people with a disability or mental illness.
Inquiry in Accommodation and Disability Support

1 Introduction

The authors of this submission would like to thank the following people for their care and support, both recently and over the years in which the information for this submission was created.

Anne Marie Russell
Cat Lancaster
Gary Radler
Jean Graham
Jean Topps
Jeanne Marshall
Jeff Strully
Kevin Stone
Lois Blackwell
Michael Kendrick
Philip Graves
Rebecca Hicks
Rosemary Crossley
Tanya Lowes

Our Family
Many friends

... and all those happy people (carers) who have stepped up to the mark -

In support of Luke
1.1 In memory of Hannah -

Hannah Marie Modra loved her brother Luke. She was one of few people that would visit Luke in the place where he is now living. She didn’t like it; she wanted him to be living in a better place. In February 2005 she wrote a story, somewhat prophetic, called “Monkey 127”. It was a parable of what she hoped would one day come true for Luke.

In January 2008, she went to visit Luke with her father. She witnessed evidence of his unhappiness and the terrible conditions in which he was forced to live. It made her cry. On the way home she insisted on being taught to drive “Luke’s Van”. Several days later, she wrote in her diary -

“God has given me a peace of mind about Luke. In my vision of life with [my husband to be], we go out with Luke, hiking through the bush, to the beach, or cycling”.

Sadly, her dream will never come true. At least not the way she described it here.

But that doesn’t mean we have to give up hope. It doesn’t mean we can’t pursue the dream without her. We must press on. We must continue working, to make real, that which she had hoped for -


We hope and pray that she will see it all come true, from Heaven.

For more information about Hannah (03.11.1990 - 30.01.2008) go to www.hannahmodra.info
1.1.1 “Monkey 127”

Monkey 127 is a story that was written by Hannah Modra in February 2005. It was written about one year after her brother Luke moved out of home to live in “emergency respite” at “Greenock” in Wantlma.

The full text of “MONKEY127” is available in the appendix of this report and on line at - http://www.abc.net.au/austory/content/2007/s2366128.htm

The story ends like this ...

“Monkey 127,” boomed the zookeeper, slowly and steadily. “The conditions you have been put in are shocking. The attention you receive is minimal. But, from this day forth, you will no longer be treated like a rock, and thrown into a hole. Forgotten. “You are a wonderful monkey, I have learned, and you can learn. Also, you will never be called monkey 127 again. From now on, you will be what you always should have been - Jon.”

The zookeepers’ eyes grew heavy, and his legs were weak. He was very tired. So he flopped down inside the dirty little hole and slept.

Who knows if Jon understood that speech. He probably did. But, seeing the zookeeper slumbering made Jon feel at peace. Maybe he would be taken back to his real home soon. With that nice thought in his mind, Jon closed his eyes and dozed off.

The next morning, Jon woke up in a totally new environment. Where were those dusty walls? Where was that little hole up above through which he could see the stars at night?

This was a nice new place. Trees, ropes, flowers, fun things to do. Two monkeys scampering towards him. Mum and Dad! He jumped up and ran towards them. He hugged them tight.

There are no words to describe the joy in his heart. He was home. Jon lived in the big gum tree next to his family’s tree. Medication was a thing of the past. So was boredom. Every day Jon would go off to a fun program with other monkeys that were crazy just like him.

He runs and jumps and plays. He also learns. All living things can learn. Together, Andrew, Helen, Jon, Chris, Marie, Davie and Abbey make up a happy family of monkeys, living in the Sunnyside Zoo of Mount Yelevaw.
Inquiry in Accommodation and Disability Support
1 Introduction

1.2 Purpose & Structure

1.2.1 Purpose

The main purpose of this document is to provide the committee with information that will help it to formulate recommendations for improvements in the planning and provision of accommodation and disability support.

1.2.2 Structure

The main content of this submission is provided in two parts -

1. A personal perspective -

   a. A Short Historical Account of Luke's journey, the places he has lived, and the supports provided, and
   b. Suggestions for planning and provision of accommodation and disability support

2. Specific responses in line with the terms of reference -

   a. Response to the Legislative Assembly
   b. Response to the Legislative Council
   c. Answers to questions posed by the Committee

Supporting information and further details are provided in the appendices.
1.3 Table of Contents

1 Introduction ................................................................. 1
1.1 In memory of Hannah .................................................. 3
1.2 Purpose & Structure .................................................... 5
1.3 Table of Contents ....................................................... 6
1.4 List of Acronyms ......................................................... 6
2 Summary ........................................................................ 7
3 A personal perspective ................................................... 8
3.1 A short historical account of Luke’s Journey ...................... 8
3.2 Planning and provision of accommodation and disability support ..... 18
4 Specific Responses to Inquiry Terms of Reference .................... 19
4.1 Responses for the Legislative Assembly .......................... 20
4.2 Responses for the Legislative Council ............................ 27
4.3 Answers to questions posed by the Committee .................... 43
5 Conclusion ....................................................................... 53
6 Appendices .................................................................... 59
6.1 Terms of Reference ..................................................... 60
6.2 Planning to Live Well (shortened presentation) ................... 63
6.3 SNR Application (extracts) ............................................ 65
6.4 GSP (General Service Plan) ......................................... 67
6.5 A story - Monkey 127 (by Hannah Modra – 2005) ............... 73
6.6 A Home Close to Home (shortened presentation) ............... 81
6.7 Company Profile – Jay Nolan Community Services ............. 83
6.8 Company Profile – Judevine Centre for Autism .................. 87
6.9 Happy People Helping People (shortened presentation) ......... 89

1.4 List of Acronyms

- DHS Department of Human Services
- EMR Eastern Metropolitan Region (part of DHS)
- DAS Disability Accommodation Services (part of DHS)
- SASI Statewide Autistic Services
- UCCO Uniting Care Community Options
- TCME The Crescent Mount Evelyn (CRU operated by DAS)
Inquiry in Accommodation and Disability Support
2 Summary

This is a very long report, but we make no apologies for that. We feel very passionately about the need for improved accommodation and disability supports. We see this inquiry as a rare opportunity to provide information that can be used by others to a) prevent further harm and b) plan for and build better accommodation and disability supports.

What we have tried to do is present a personal perspective as well as specific responses to the questions posed by the committee in its discussion paper and the terms of reference given to it by the Legislative Assembly and the Legislative Council.

We talk about where Luke has lived and the sort of supports he received in each of those places - at home, in respite, emergency respite and long term high dependency and secure accommodation. We also provide some suggestions for planning and provision of services, based on our own experience and what we have seen in operation in various places around the world.

Suggestions for planning and provision of better accommodation and disability come from the personal experience of the family and what it has discovered during its search for better accommodation and supports for Luke. Over the years the family has collected information from all over the world, and compiled its own standards and references with the intention of using such documents in the building of better supports for Luke. These include - a practical guide to person centred planning (“Planning to Live Well”) an exploration of accommodation options (“A Home Close to Home”) and various presentations (e.g. “Happy People Helping People”) aimed at motivating people to imagine what might be possible and how they might be able to contribute and benefit from caring for someone. The family provides suggestions for how services might be improved through better use of industry standards, robust management practices, accountability, market research (polling of service users), and practices that support team building, communication, problem solving, respect and support for families, and people from the wider community who are willing to offer their time and energy.

In terms of specific questions raised by the various terms of reference provided by the Legislative Assembly, the Legislative Council and the committee this submission includes specific responses to each question, and some discussion with facts and examples taken the family’s personal experience and research.
3 A personal perspective

3.1 A short historical account of Luke’s Journey

For this report we decided to give an explanation of -

1. The places where Luke has lived
2. The supports that he has received in each of those places

3.1.1 Places where Luke has lived –

Luke has lived in three (3) places, and we are planning for him to live in a fourth -

1. The Family Home
2. “Greenock” (a CRU run by DAS)
3. “The Crescent” (a CRU run by DAS)
4. A Home Close to Home (the future)

He has also stayed (or been accommodated) at several “respite” houses -

5. “Swonnel House” (a respite house run by SASI)
6. “Sevenoaks” (a children’s respite house run by DAS)
7. “Travis” (an abandoned CRU owned by OOH)
8. “Healesville Home Stay” (a private home adapted to provide weekend respite)
   “Mount Eliza” (a private home used to provide weekend respite)

The following sections provide information on the first four (4) places.
Inquiry in Accommodation and Disability Support
3 A Personal Perspective

3.1.1.1 The Family Home

Luke was born in Mount Waverley and live in his family home, with his family (Mum, Dad, two brothers and two sisters) until he was 15.

It started as a smallish single story house with a cramped kitchen. It had a very large backyard that contained a garage, a cubby house, trampoline, swing, bird cage and other gym equipment. The house was located very close to bushland walking trails, and the primary school that Luke attended - Essex Heights Primary School.

*During these early years family provided Luke with disability support while he was living at home. Other than professional help for diagnosis, special treatments, support for Luke while he was at kinder or school, and the odd holiday or recreational program for children with autism, the family did not seek assistance from outside services.*

From 1996 a small office was built into the back of the garage and used as a miniature classroom and art and craft room.

*The family started to make use of HACC services for in home help. When it was discovered that Luke was able to learn more effectively with the use of an ABA program the funding for “home help” was redirected into providing direct support for learning. Most of which took place in the garage.*

In 2000 the house was modified to provide an open plan kitchen area

*Something happened to Luke in the early part of the year (before the modifications) that caused him to become disturbed. By May of that year he became very unwell and was taken to doctors many times in pursuit of some further medical treatments. This was around the time of the modifications so it seemed pretty clear that the modifications may have exacerbated the underlying problems he was facing. New treatments were tried but only seemed to make things worse. At the peak of his illness DHS agreed to pay for all of the windows in the house to be replaced (or reinforced) and for specialists from PCC (Psychiatric Care Consultants) to be engaged to provide in home help and support for Luke. The family found that the specialist training of the MRNs did not seem to include a good understanding of how to support someone with autism and this service was discontinued fairly quickly (it was also very expensive at about $60/hr cf $18/hr for a HACC worker). The Education Departments response to this crisis was to insist on higher levels of medication. The family had no choice but to accept the advice of the so called experts in autism (i.e. the school) and*
the paediatrician they had recommended. Medication levels were increased to the point where Luke was on what was effectively a double adult dose of major tranquilizers. Even then the school was not able to support him appropriately. While things were often very difficult the family still managed to support Luke at home, with some out of home respite - some weeknights and some weekends.

In the autumn of 2002 a second storey was added to the house to provide upstairs bedroom and separate living area, toilet and bathroom. It was only when the upstairs bedrooms were completed in 2002 that Luke was allowed to have a room to himself. Prior to that he shared it with his two brothers.

Late in 2002 it became clear that high doses of medication were starting to cause permanent damage to Luke's brain. A programmed withdrawal was started early in 2003. We were told that it would take 2 years and that things would get worse before they got better. The family made a formal request for special supports to help Luke and the family to get through this crisis.

A new and detailed General Service Plan was created. It included references to the need for emergency accommodation (including the provision for immediate hospitalization) to be established. While the plan was drawn up with the co-operative participation of all currently active services providers, the Education department refused to co-operate - saying that the medication withdrawal was a mistake and was going to put its staff and students at risk. The Education Department subsequently reduced the time that Luke could attend school to 12 hours per week. The Home First (Day time respite) provider warned that it would have to withdraw its services if we did not continue to keep Luke sedated with medication. The out of home accommodation provider (Children's Respite Services - operated by DHS) was able to arrange for Luke to spend more nights in the local respite house, but this became problematic with its staff wanting Luke to be officially declared as "a dangerous person" so that they could refuse to provide him with support. The family arranged for a private company to have its staff provided 1:1 support while he was staying at that respite facility.

In March 2003 the Home First provider pulled out at short notice (basically called the family during the afternoon to tell them that it would be terminating its services at the end of that shift - a Friday afternoon before the labour day weekend). From July 2003 the family too on the daunting task of organizing all supports under the auspices of a "family governed family support project". This gave them the freedom to choose staff, activities for Luke and venues without having to seek permission or co-operation of a case manager from DHS. This would have worked OK except that but August 2003 Children's Respite services had declared Luke was no longer allowed to stay at their
Inquiry in Accommodation and Disability Support
3 A Personal Perspective

Facility in Burwood. It was discovered that this decision came about because there had been altercations with, and from some accounts, provoked by one of the younger permanent residents at that place, and that during those events, some significant numbers of staff had been injured.

It was around this time, during 2003 the walls and windows in Luke’s room were modified to minimize damage and injury.

With support from a small band of dedicated support workers who continued to provide out of home respite (short outings) the family struggled on with no additional in home supports for Luke.

In January 2004 the family found itself with no-one available to provide support for Luke, at home or on an outing, and no where for him to go for respite.

In February 2004 the school rang Ellen, Luke’s mother to tell her that Luke had been suspended for 3 days and that she must come and pick him up immediately. When they offered her no assistance or support for those three days Ellen took Luke to the offices of DHS and refused to leave until somebody organized some respite for her and her family.

In late February 2004 Luke was moved out of his home to go and spend 12 weeks in “emergency respite”. The place he went to was known as “Greenock”.
3.1.1.2 Greenock – a CRU run by DAS

"Greenock" was a large single storey suburban home on an average house block in Wantirna that had been modified to accommodate four young men with autism and extremely challenging behaviours. It had been left in a state of disrepair after those residents had been moved onto newer accommodation.

Luke was the sole resident and DHS provided a minimum of two staff to be on duty at all times. The family provided toys and other equipment for Luke to use, but staff simply put it all away. One of the staff members commented to the parents (not knowing who they were) something like “I remember working here when it was a CRU - all you had to do was make the meals, unlock the doors to each bedroom shove the meal in close the door and walk away, come back a few hours later to pick up the plates - a real bludge”. Within four weeks of moving in Luke had pushed out some of the plexiglass windows and attempted to run off.

DHS response was to simply board up the windows and replace the large sliding doorway to the backyard with a small wooden door with a window.

One evening, while watching TV with a couple of carers, Luke was startled by his own reflection and went to hit the window that was in the door. It was not made of safety glass and it shattered leaving long shards sticking up and down. Had Luke fallen into it the shards would have cut his throat and he would have died. He did not fall but on standing up he sustained deep lacerations to his upper arm and shoulder. To this day carries a 6 inch Z shaped scar to remind us of his ordeal.

DAS response was to board up the doorway.

While living at Greenock Luke spent most of his time locked in what they called “the back area”, while staff spent most of their time either in the office, the kitchen our out on the “smoking deck” adjacent to the kitchen.
Inquiry in Accommodation and Disability Support
3 A Personal Perspective

The back area comprised:

- a small bedroom - with vinyl floor, no windows (except for 4 portholes) and no furniture but the bed and
- a lounge room with old furniture and no windows (except for two portholes and a skylight)

The doorway between the back area and the rest of the house was self locking (if enabled). When this door was locked, there was no access from the back area to the bathroom or toilet.

*To get attention of staff - who spent most of their time in the kitchen, or outside on the “smoking deck” Luke would have to shout and or bang violently on the door.*

*Luke was abused by DAS employees while he was living at Greenock.*

*When it became clear that we were not able to organise the supports we needed to enable Luke to return home, DHS started looking to find alternative accommodation. DAS said the only option was for Luke to move to the Crescent.*
3.1.1.3 The Crescent – a CRU run by DAS

"The Crescent" is a very large single storey house, situated in the middle of a one acre bush block just east of the township of Mount Evelyn.

There are currently four people living there. Luke and three older people.

The house is usually staffed at a ratio of 1:1. That is, there is usually four staff on duty at any time. The team consists of about 17 full time permanent employees of DAS and about 15 casuals that are called in as needed. There is no facility for sleep overs. Every night is an active night with a minimum of two staff on duty at all times.
Inquiry in Accommodation and Disability Support
3 A Personal Perspective

All exterior doors remain locked most of the time. Most of the internal doors are self locking.

Luke currently spends most of his time locked in what they call “Luke’s Area”. The only time he gets to go into the rest of the house, or the backyard, is if two of the other residents are not in the house.

Luke has no contact with the other residents, other than through the walls, and only limited contact with staff. Most staff will not go into his area for any longer than is necessary to exchange something - e.g. to pass him a meal, or to receive an empty plate.

“Luke’s area” comprises -
- Bedroom
- Bathroom with Toilet
- Living Area - a corridor wide enough to house a TV, couch and table.
3.1.1.4 A Home Close to Home – the future

No one in our family was happy about Luke having to move out of home - least of all it seems - Luke. From before he left we started planning to “organise supports that would enable him to live with us at home”. However as time progressed we had to fact the fact that one day we would be too old to provide direct support and care for him, and that we should start planning for the long term, and seek to establish the supports that would enable him to live in his own home close to home.

In April 2005 we attended a CRU conference in Brisbane and saw how people like our son could be supported to live in their own homes, even after many years of living in an institution. We came home from that conference convinced of the need to “get him out of DHS care” and provide him with “his own home close to home”.

To cut a long story short we bought the house next door and started planning the supports that he would need to live there with “friends”.

Situated quite literally on our back fence it would enable Luke to live in his own space by be free to visit us and our back yard when ever he wanted to. Being so close we (all of our family) would be able to provide direct support without having to walk very far.

We figured that with only about $20,000 we could modify the property to make it safe and ready for Luke to live in. We also figured that if DHS was to pay the wages of direct care support we would be able to provide some support and would end up saving money on the current cost of Luke’s care, but would be enabled to give him a much happier and healthier lifestyle.

Today we lack only two things -

☆ A team of People to provide direct support for Luke
☆ An Organization to provide those people with support they will need.
Inquiry in Accommodation and Disability Support
3 A Personal Perspective

Money shouldn't be a problem - as we know that DHS would already be willing to pay up to 2/3 of the current cost of care, and that would more than adequately cover the cost of wages of the support staff. Of course we would like more - a) to ensure that we have enough funds to cover start-up costs, and b) to ensure long-term viability of the team.
3.2 Planning and provision of accommodation and disability support

Q: “What would I do if I had to provide accommodation and disability support ...?”
A: I would take the lead from Service Providers who are already doing a good job.

Now, while I have not completed a comprehensive search and assessment of all of the companies providing accommodation and disability support to people severely affected by autism around the world, I have found, and been to visit, two (2) that I think are worth looking at, and working with. In fact we were so keen to see one of these companies replicate its services here in Australia we organised a conference that should have enabled interested parties to gauge the feasibility of such action. If we had been successful that company would be setting up already, and I would not have felt the need to make this submission.

My two favourites, and they are by no means perfect, but they are better than anything I have seen or heard of in Australia, are -

**Judevine Centre for Autism** - provides cradle to grave supports - starting with intensive training for parents, from the time they get a diagnosis, through to aged care of people in their own homes. [www.judevine.org](http://www.judevine.org)

**Jay Nolan Community Services** - renowned for its person centred approach to teaching people to communicate, dream and plan for a life that they want to live, followed up with planning and provision of supports that enable people to live in their own homes close to home. [www.jaynolan.org](http://www.jaynolan.org)

These companies and the people that work for them are truly remarkable. We would like to recommend that a visit to these companies or at least a visit to their websites is essential for members of the committee to understand just what is needed, and what is possible without spending inordinate amounts of money.

If you were to ask me what makes the biggest difference - it is leadership and a positive mind set amongst all the people that work there.

In an attempt to motivate people to see for themselves I created a presentation and short video (7 min) called “HAPPY PEOPLE HELPING PEOPLE”. A copy of this presentation will be provided in the appendix, and we can provide the video on request. It is still my hope and dream that we will one day be able to replicate such services here in Australia.
4 Specific Responses to Inquiry Terms of Reference

The following section aims to provide specific responses to the questions posed by the Committee (in its discussion paper) and related to the terms of reference handed to it by both the Legislative Assembly and the Legislative Council.

The responses are provided in three separate sections -

1. Response for The Legislative Council
2. Responses for The Legislative Assembly
3. Answers to questions posed by The Family and Community Development Committee
4.1 Responses for the Legislative Assembly

In this section we provide answers to each of the specific terms of reference listed by the Legislative Assembly.

The terms of reference ask for a comparison of - CURRENT STATE against BEST PRACTICE in the following areas -

a. the standard and range of accommodation currently available;
b. the extent of accommodation and services currently available, including the different models for service delivery and funding;
c. the methods for measuring unmet demand for accommodation and how these can be improved;
d. the process for managing service quality;
e. availability of sufficient accommodation to meet future demand with an appropriate range of services;
f. access and service issues for particular groups, including rural communities, culturally and linguistically diverse communities and indigenous Australians; and
g. the impact on families of the current service provision of accommodation;

4.1.1 Standard and Range of accommodation

In summary the standard of accommodation service that we have experienced has been poor and in some cases abysmal. He has been abused "in care". There are some who believe that the conditions under which our son has been forced to live are in breach of his basic human rights.

For some - there is NO RANGE. Even with the intervention of our local member of parliament we were forced to accept what was currently available or nothing at all. We were told that “there is no alternative”. Such statements were offensive. We could attribute the lack of alternatives to a failure by DHS to plan appropriately. Our son was diagnosed as having autism and being eligible for disability support when he was four years old. It was recognized that his condition was severe and he had high support needs, from very early on. Yet it seemed to come as a surprise to the Department of Human Services that he might need special accommodation when he turned 15. There was no recognition of the need and no planning to suit.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

An additional factor that contributed to this “failure to plan” became obvious to us when we first asked our local member to visit the local respite house (“Sevenoaks”). At that time there were several young boys living in that house on a semi permanent basis. Her visit was delayed, and she was told “there are no permanent residents living in that house”. It was a lie, perpetrated by DHS that only served to delay and deny any opportunity to have appropriate attention (and therefore appropriate funding) being paid to meet the need. Even today we believe that statistics are not being reported honestly by DHS. We believe that the reason for not wanting to reveal the whole truth is the fact that unless the families formally relinquish their responsibilities as parents, there is no legal provision for allowing children under the age of 18 to be living in the care of the state.

4.1.2 Extent of accommodation and services

We were not sure what was meant by the term “extent” but in relation to whole of life supports that should be provided to a person while they are living in supported accommodation we feel we must quote the regional manager of disability Accommodation Services who, when we asked for accommodation staff to provide specialist activity support such as “helping Luke to finish his homework” told us that -

“We are an accommodation only service provider, and as such we cannot expect our staff to provide an ‘educational’ support”.

Perhaps this could explain why from our experience it seems that the “extent of services provided” seems, for some staff (not all) to end at - washing dishes, preparing meals, driving the bus, and cleaning the floor, and sometimes, the toilets.

We would like to contrast this with the sort of services provided by people from overseas organizations such as Jay Nolan Community Services where the support person, even though they are being paid, are highly trained, and are constantly vigilant in their support of the eligible person, becomes almost indistinguishable from a friend, or family member.

4.1.3 Measurement of Unmet demand

How to measure UNMET demand?

Some might argue that the reason we don’t know is because there are many people who do not come forward … this is nonsense - because we have almost 30 years of historical data that should enable accurate extrapolation based on survey.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

I would have thought that we already have years of reasonable statistics - starting with births, numbers of children at school, services being funded.

At a recent forum set up in support of the state autism plan I asked the simple question - how many people are we talking about - none of the departmental or government representatives could answer the question. However, I cannot see why we cannot collect statistics via Medicare on the number of children presenting for diagnosis. Surely we should also be able to obtain and publish figures on actual diagnosis.

Now while that might give us statistics on how many people have a disability what we still need to know is how much support do they need, and then how much of that support can be provided by family and other natural supports. If we knew that, then surely we could estimate the level of need for government funded services. How to estimate “how much support do they need”? How to estimate “how much support can be provided by family and natural supports”? Again, I would have thought that we would have had at least 20 years of statistics to support at least some level of reasonable estimating. For example - when the law was changed to ensure that every eligible person was to be supported with a General Service Plan - we should have started to see the level of need more easily identified. The problem was that those people implementing the plans had no understanding of the links back to resources. Plans became motherhood statements and dreams of things that were never going to be. We lost a great opportunity to learn and develop higher level strategies for meeting the unmet need. Even today, with the introduction of the Disability Bill 2006 we still do not have in place a mechanism for reporting up the need for resources. It should be possible to have every individual plan worked out to the point where the family and natural supports can say - we can do this much - but we need this much more. At that point, DHS should be able to say - well let’s take that need and report it up though management, including parliament, to make sure that they know exactly what we need and can then allocate funds accordingly. I think one of the biggest problems we have today is the fact that DHS is not reporting honestly or accurately the real needs of people in our community. It works from a basis of we have a budget, and we must manage with what we have been given. We would like to see this situation changed so that the planning happens at the grass roots level, that resources are determined at that level, and that the need is reported honestly and efficiently up through the system to enable appropriate planning and budget allocation at the highest level.

Another suggestion would be to simply run an internet poll. Most people have access to the internet. Most can provide an email address to DHS. So why not take advantage of the technology to ensure that every needy person is contacted and asked for their opinion. For those who do not have access to the internet - it would not be that hard or costly to send them an invitation - and then get some of the case management staff
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

to fill in the survey for them. In most cases, it might even be possible to help people fill in such surveys over the phone.

Why has this not happened in the past? It takes a lot of for-thought and planning to design a good survey. It also takes an honest politician to insist on and receive the data that comes back. All too often we have seen public servants within the Department of Human Services and Department of Education wind back the requirements in order to meet the budgetary constraints, or worse they overstate the need in full knowledge that someone higher up will, without any justification other than speculation that the applicants have overstated their need, wind back the results of any such application.

As an example - in an application for out of home accommodation support for our son Luke we ended up declaring only the truth about our situation. The result was a letter saying that our son was not eligible. For your reference I have included a copy of the statements we made in that application. There was no exaggeration, but there was at that time, no recognition of the need.

What is needed is honesty and a transparent process for collection, collation and representation of all data coming in from the field.

Examples of what we wrote in the SNR Application in February 2004 -

Factors For Consideration Of Urgency Status

*Imminent Family Breakdown* - The demands of providing direct care and dealing with multiple incidents and the constant turnover of staff, constant need to make repairs, and the denial of quality time together has left the family at the point of imminent breakdown. It is envisaged that even if the applicant is granted immediate accommodation away from home that the family unit will fracture.

*Living arrangement Risks* - even though we have lived without serious injury for this long, given that we are getting no in home support and less and less out of home respite we are getting weaker and weaker and are now at the point where we cannot guarantee the safety of our other children, or ourselves. During the rage attacks, things get broken, and these objects present significant risk to all.

*Significant Family Stresses* - as above.

Please note - that despite the difficulties listed we still believe that with appropriate supports these risks can be minimized and that Luke can be supported to live happy and safe in our community - in his own home close to home.
4.1.4 Managing Service Quality

During a recent conversation with a senior member of DHS staff it was explained to us that the hierarchy in DHS could be represented not as a pyramid but as a star. A pointy bit at the top, a wide area in the middle - so wide that it looks like two outstretched arms of a star, with a squashed, but still divided, two legs at the bottom, the coal face - where they remained those that really cared and those that were simply in it for the money.

It seems to us that there is a significant lack of good management practice being applied within DHS and this is adversely affecting the quality and quantity of services being delivered to the people that need it.

I could give many examples of where management practice could be improved, but right now I would like to start with -

1. Meeting Management
2. Written Communication
3. Customer Focus (both towards eligible persons and their families)
4. Complaints Handling (at all levels)
5. Planning (identification of goals, supports and resources required to achieve those goals)
6. Project Management (establishment of requirements, obtaining of resources, implementation, and follow up)

Unfortunately a discussion of such things would probably bore most readers of this report so we have chosen to not provide any further detail. We would be happy to provide more details on request.

4.1.5 Future Demand versus Current availability

Future Demand - increasing.

Statistically there are more people like my son born every day and according to statistics from the USA the proportion of people like my son in the population is increasing.

If we were to take no action - the future demand - based simply on our situation - would be the continuation of current level of support - unsatisfactory, possibly illegal, demoralizing and dehumanizing at a cost of ~$300,000 per annum (and at its peak $500,000 p.a.). Of course DHS would like to reduce the cost and will seek to move him
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

to a lower cost situation. However, there is currently no plan to build anything else or provide a service that is any different to the current one.

Current availability of appropriate supports - close to nil.

If we were to be successful in our plans to build community based supports that would enable our son to live in his own home close to home then we would be successful in making a place available in the current situation, building up a team of people who will work not just with my son, but others, and a community that is aware, and sensitive and willing to support the needs of my son, and not just my son, but others like him, and other with a lesser need for support.

We need to do more to build appropriate supports. We must start now, in fact we already have. Not only have we bought the house next door, we have bought a new car to provide him with transport, and we have been working with local services providers and community groups to build resources and a supportive network of helpers.

4.1.6 Access for Particular Groups

Access to services is hard for almost everybody. Some say it is the squeaky wheel that gets the most attention. However I sometimes wonder if it is those of us that press on for better services that actually end up with less. It seems quite clear to us that the harder we try to get better services for Luke, the worse his situation becomes.

It seems that the system, be it by design or otherwise, actually makes it easiest on those the simply choose to GIVE UP EARLY!

I have a friend who's work colleague, on hearing the diagnosis of autism, and knowing a little of the history of support services in Victoria, took immediate action to have his two children placed into care. The oldest one was only four years old. To achieve his aim he simply abdicated his responsibility and rights as a parent guardian and walked away. So, you can see, it can be easy - for some.

For those of us who struggle on - it can be hell - a perpetual nightmare. A nightmare that haunts us every day. A nightmare, that potentially will not, and cannot end until our son dies, or we die, or a miracle takes place and he finally gets the support he needs and deserves. That is the miracle we pray for - every day. It is why we have to keep working. It is why we have taken the time to make this submission.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

4.1.7 Impact on Families

Sadly - this is actually a dangerous question to ask someone who has just lost a child, who suffers constant anxiety and frequent bouts of depression - all because of the pain and grief of having to deal with the issues associated with having a family member living in supported accommodation, which is operated by the Department of Human Services.

I think you would be hard pressed to find one family that is truly happy with the situation they have. The Department says that there are many, but we are not one of them, and we very rarely, if ever, meet such people. When we do - it seems that they are supported not by DHS, but by a close knit small privately run, and often privately funded organization. We are one of those who are not happy with the services provided, or the way in which we are treated by service providers, and in particular - the Department of Human Services.

In summary - the effect of a failure to plan and provide appropriate accommodation and disability supports for an individual can be - devastating.
4.2 Responses for the Legislative Council

In this section we provide answers to each of the specific terms of reference listed by the Legislative Council.

The terms of reference ask for -

1. description of current government funded supported accommodation, including the number and location of places, occupancy, staffing, demand management, methods of funding and oversight;
2. the adequacy of the current number of places and care provided in community residential units, residential institutions, community care units, secure extended care units, prevention and recovery care facilities and other forms of supported accommodation;
3. the adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability or mental illness because of insufficient places in the specialist system, and in particular including supported residential services, boarding houses, public hospitals, nursing homes and SAAP funded services;
4. the impact on Victorian families of insufficient supported accommodation;
5. estimates of future supported accommodation needs and the appropriateness and transparency of the Government's management of demand and placement;
6. the government's response to unmet accommodation needs, including sources of funding, planning and delivery;
7. the ability of country Victorians to access supported accommodation and the appropriateness and quality of care they receive;
8. the ability of members of culturally and linguistically diverse communities to access supported accommodation and the appropriateness and quality of care they receive;
9. the appropriateness of the current mix of service providers, including government, private and community; and
10. alternate approaches addressing unmet needs in supported accommodation in Victoria.
4.2.1 Description of Current Supported Accommodation

From a personal perspective - Our son has experienced four types of supported accommodation in at least 7 specific locations and supports from at least 10 different service providers.

1. In Home Support
   a. Casual, paid by the hour, disability support workers with little or no training, some with no information about our situation, Luke’s diagnosis his support needs, or the risks involved, from companies such as -
      i. UCCO (Uniting Care Community Options)
      ii. Access Unlimited
      iii. MECWA
      iv. MSSA (Melbourne Specialist Support Agency)
      v. EACH (Eastern Access Community Health)
      vi. Monash City Council HACC Services
   b. Professional Nurses from
      i. PCC (Psychiatric Care Consultants)
2. Children’s Respite Services
   a. “Swonnel House” SASI
   b. “Healesville Home Stay” Vicki Colgrave
   c. “Sevenoaks”,
   d. “Mount Eliza Home Stay” DHS-EMR-DAS AU
3. Emergency Respite
   a. “Traverse” DHS-EMR-DAS
   b. “Greenock” DHS-EMR-DAS
4. High Dependency Residential Accommodation

The following sections provide details of including the location of these places, occupancy, staffing, demand management, methods of funding and oversight.

4.2.1.1 In Home Support

Luke’s home was in Mount Waverley and was occupied by his parents and five children, all younger than himself, and their friends.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

Mum, Dad, some family friends, and in later years, his siblings provided Luke with support at home. From 2000 DHS provide funds that enabled the family to have carers take Luke out and away from the family home on short outings, but very rarely were they able to willing to provide supports within the family home.

Demand Management was based largely on getting the most hours of respite for the funding available (e.g. through HACC) and then later through formal assessment in support of an application for HOME FIRST. The family chose to get support for high stress periods such as after school and before dinner, and some weekend outings.

Funding was always based on “packages” with little or not regard for individual need for support. When the need for support increased the funding remained capped and so the hours of support were reduced. For example - the Home First Package - was capped at 36 hours assuming $15/hour. Not only was this unrealistic - assuming base rates of pay - even though the support needs were such that they clearly required professional support (as evidenced by the use of PCC at one stage) - but when it became apparent that Luke needed two people to be present for anything other than very passive activities such as sleeping - the funding was not increased, and the number of hours of support was simply cut in half.

When it came to oversight - a case manager was allocated for a time (typically they are appointed for no longer than 6 months), but his level of expertise meant that poor advice was given to the family and carers, services failed, and communications became overly complicated. None of the case managers were able to provide adequate support - not to the family, the workers, or to Luke. The family has found that the taking on of “case management” for Luke has been less stressful than having to rely on someone else. On this point we would recommend that where a family has the ability to do so, it could save our communities a lot of money if DHS was to invest in helping individuals and families to become good managers of their own supports.

4.2.1.2 Children’s Respite Services

- “Swonnel House”  
  SASI
- “Healesville Home Stay”  
  Vicki Colgrave
- “Sevenoaks”  
  DHS-EMR-DAS
- “Mount Eliza Home Stay”  
  AU
4.2.1.2.1 “Swonnel House”  

Swonnel House was a weatherboard house on a corner block in suburban Moorabbin. It had been refitted with a lockable kitchen, and vinyl flooring throughout. It had a large backyard with playground equipment. While it seemed a little stark, the management and staff we met seemed pleasant.

Typically it seemed that there would be anything from two to five young people with autism staying at any given time. While some attempt was made to match the people who were staying, it didn’t seem to work out that well.

While we met with some nice people on our first interview and visit, on subsequent visits we found ourselves confronted with people who seemed a bit “rough” and one several occasions when I enquired of the level of training they had received I was told “none” and things like “I came here from the UK for a holiday, and to earn a bit of money I applied for job here. When they heard I had some experience as a nanny, they asked me to start straight away.” It seemed to us that the vast majority of carers were short term employees with little or no training.

To get a weekend of respite (i.e. Luke staying there from Friday Night to Sunday afternoon) we had to book through SASI many weeks in advance. At the time we did receive some priority assistance from the case manager at DHS.

Funding was provided by DHS and I think we paid a token amount - something like $10.

It became apparent to us that for the most part - a permanent member of staff was on duty - but not always - and we are aware that there were times when Luke was left in the care of casual employees.

We stopped using that service because we found that Luke was always upset after a weekend away and it often took several days to a week before he would return to a calm state. On one particular occasion he came home in a dreadful state (covered in sores and bruises and obviously distressed about something) and suffered severe waking nightmares for several weeks. It was after one of those visits (in June 2000) that he became seriously ill and was given medication that only made his situation worse. That is, to the point of us thinking that he needed hospitalization.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

4.2.1.2.2 “Healesville Home Stay” Vicki Colgrave

Vicki Colgrave had her home, on a large property set in the forested hills near Healesville, modified to suit the needs of children with autism. She offered to provide 1:1 support for one or two children at a time for overnight and weekends away.

She and her husband provided most of the support with occasional help from friends.

We came to know of the service because Vicki had been a teacher for Luke when he was attending Irabina Early Intervention Program.

Her costs were quite high but mostly covered by Yooralla through Yooralla’s Flexible Respite Program.

Vicki was trained as a teacher of autistic children and worked at the Irabina Early Intervention program so we were comfortable with her ability to plan and supervise Luke’s supports during his stay there. We went for an interview prior to the first overnight stay.

This situation seemed idyllic, but when Luke became upset and went to hit someone during his visit Vicki said that she was not setup to handle such behaviour and we were asked to come back, pick him up and take him home, after just one evening. He didn’t even get to stay overnight.

4.2.1.2.3 “Sevenoaks” DHS-EMR-DAS

“Sevenoaks” was a regular sized four bedroom house on a corner block in East Burwood. It had one shared living space and almost no backyard. The trampoline was small and a swing that had been hung from a rafter in the enclosed carport was so short that anyone other than the smallest of children would bang their head on the roof if they swung on it.

Typically it was meant to have up to five young people staying overnight or over the weekend. Things seemed to work out OK when all of the people staying were roughly the same age and mobility as Luke. However, for several years there were two, sometimes three young boys (around 8 years) living there on a semi permanent basis. When we asked our local member of parliament to visit - her visit was delayed, the place was repainted and she was told that there were no permanent residents living there. However, sometime later it was an incompatibility between the autistic sensitivities of Luke and in particular one of these smaller permanent residents that led to Luke being banned from ever attending that respite facility again.
The house was usually staffed by permanent employees of DAS (DHS - Disability Accommodation Services) with some casual staff. Generally the professionalism and skills of the DHS staff seemed to be OK but limited to mild autism. Similarly for many of the casuals that they ended up employing to provided 1:1 support for Luke. The real problem with this place was that it was very small and with large numbers of staff and young children mixed with rough and tumble teenagers who were full of energy and used to getting out and about, there was always going to be a lot of conflict. Over the years the level of conflict escalated and the situation became quite dangerous for all. DHS response was to simply ban Luke from ever using that service again.

Bookings were made through a case manager at DHS and the house supervisor. We were fortunate in one way in that the case manager at the time was able to convince management that we needed the respite more than most. However, we knew that the demand for services was high and when we sought help from our local member to at least draw attention to the need, managers at DHS chose to deny it.

Respite hours were funded by DHS directly.

DAS maintained oversight of a house supervisor and a small number of permanent staff. Many contractors were used but always seemed to be supervised directly by the house supervisor or at least a permanent employee of DAS. As is typical of DAS the house supervisor reported up through a team leader, and area manager who then reported to the regional manager of DAS. However, it was apparent to us that even DAS staff did not receive much training for the job. We organised for behaviour support and autism specific training to be conducted by Gary Radler and DAS was willing to let its employees join in. However, there was no follow up, and no accountability. It was left up to staff to choose whether or not they followed the professional advice.

**4.2.1.3 Emergency Respite**

Given that DAS had banned Luke from ever making use of “Sevenoaks” we went for a time without anywhere for Luke to go. One service provider offered to look after Luke for a couple of nights, but that situation was not sustainable because they were using their own family home, and with young children, and one other autistic person there, it was never going to work out long term. Eventually DHS offered the use of two houses that had been used as CRUs in the past. The houses had fallen into disrepair and the prior occupants had been moved into newer facilities nearby.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

4.2.1.3.1 “Traverse” DHS-EMR-DAS

“Traverse” was a two story house on an extremely small corner block in East Burwood. There was NO BACKYARD to speak of. It was dark and dilapidated and some of the rooms had clearly been used as timeout rooms - i.e. with deadlocks and what were supposed to be bedroom doors.

We got to use the house for a couple of overnight stays where Luke was the only resident, and then for a couple of weeks during the school holidays, as a base for daytime outings.

Staff were provided by various private agencies - EACH, ACCESS UNLIMITED and UCCO to provide 2:1 on a casual basis.

Demand Management was based on available funds and availability of workers, not on the basis of need. With the need to provide 2:1 support at all times, the number of hours of support was severely limited.

Funding came through a “Family Governed Family Support Package” which was basically the same as a “HOME FIRST PACKAGE” but with the money held in trust by a “HOSTING AGENCY” and spending directed by the family.

While some agencies provided debriefing and some training and coaching of its workers, the nature of the “Family Governance” meant that the family maintained responsibility for training, directing and supervising the workers. This was always problematic because the workers felt that their primary obligation was towards their employer. In some cases the employers were not sympathetic towards the family’s objectives, and part of this came from the fact that they themselves were not capable of providing good supports or of supervising staff that do.

It should be needless to say that this arrangement - the use of this house, and the use of casual staff without professional training and supervision - turned out to be a disaster - for everyone involved.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

4.2.1.3.2 “Greenock”  DHS-EMR-DAS

“Greenock” was a CRU, a house of average size, in suburban Wantirna, that had been used to
house four people who presented with very challenging behaviours. They had been moved into
other houses after it became clear that this situation was not acceptable. We were led to believe
that the CRU had to be closed after one of the residents had died on site. This house had been
offered for our use as a place for “weekend respite” Despite its dilapidated state we did use it,
on at least one occasion for weekend respite, where support was provided by one private company
using funds redirected from an allocation that had been set up to support Luke at “Sevenoaks”.

During January 2004, after several disastrous events arising from our use of “Travers” and a failure
by the education department to provide appropriate supports at school we found ourselves with no
supports at all for Luke. No where to go, no where to stay, no one to look after Luke - at all. It
was one day, after the school had called her to pick up Luke from school and take him home and
keep him there, that Ellen, Luke’s mother took him to the offices of DHS in Box Hill and refused to
leave until they offer her some decent respite and a reliable day placement.

DAS offered to provide 12 weeks of emergency respite to enable the family to get its act together -
and organise properly the support they would need to keep Luke at home. DAS recruited a team
of staff and opened up the abandoned CRU known as “Greenock” and Luke moved out of home in
late February 2004. Within four weeks of him moving in, as the sole resident, he visited hospital
four times - he suffered serious lacerations to his arms and shoulders, and a broken wrist.
Needless to say, as a family we were devastated and we have never really recovered from the
shock of that terrible experience. Subsequently it was reported that Luke had been abused
physically, emotionally, psychologically and almost certainly sexually while living in that place.

We are not sure where the funding came from but a conservative estimate was that it cost about
$500,000 per annum to keep him there. He lived there for 18 months.

As for children’s respite the house was managed by a house supervisor. However, most of the staff
were casuals or permanent staff put there on short term assignment. At one point in time, over a
period of nine months, it was reported that there had been as many as 75 different people working
in that house. Part of the problem we believe was in the way in which management described the
situation to new and potential staff. Another major factor was the appearance and setup of the
house. A close friend who came with me to visit Luke with his son, also autistic, said to me
afterwards - “My first impression when I walked into that place was - what sort of animal is living
in here?” It was a disgusting place and it should never have been allowed to exist. We believe that
if it were not for the fact that the house was shown on a Current Affair that it would still be in use
today.
4.2.1.4 High Dependency Residential Accommodation

“The Crescent” was first described to us as being a SECURE FACILITY and “the only property with the fabric and design to be able to support someone like Luke” It is officially described as a CRU but more recently, as a place meeting the needs for high dependency accommodation.

4.2.1.4.1 “The Crescent” DHS-EMR-DAS

“The Crescent” is a very large single storey house, situated in the middle of a one acre bush block just east of the township of Mount Evelyn.

There are currently four people living there. Luke and three older people.

The house is usually staffed at a ratio of 1:1. That is, there is usually four staff on duty at any time. The team consists of about 17 full time permanent employees of DAS and about 15 casuals that are called in as needed. There is no facility for sleep overs. Every night is an active night with a minimum of two staff on duty at all times.

Demand Management - the house was built as a “staging place” and it was not expected that people would stay there for more than a few years before being moved on to more suitable accommodation back in the suburbs. However the house seems to have become the permanent residence of all four of the current occupants. At least there appears to be no plans by DAS to move anyone to any other place. It took DAS almost 12 months to organise a place for Luke. Since it opened in 2003 there have only been two residents move out, and no new residents are expected in the foreseeable future.

We are not sure where the funding comes from but Luke pays a nominal rent which is based on a percentage of his pension, plus a contribution to household costs (food etc.). We estimate that with the number of staff, the size and cost of the facility and the land which it occupies, the cost of operation must be of the order of $1.5M pa. That is, at least $350,000 per resident per annum.

As for most CRUs the house is managed by a house supervisor who is in turn supervised by a team leader, area manager and regional manager within DAS. DHS provides specialist services through ABC (Adult Behaviour Consultants) - previously known as BIST (Behavioural Intervention Support Team). From time to time we have organised for other professionals to observe and make recommendations, and now more recently DAS has engaged its own specialists to offer technical and team building support to staff. The office of the senior practitioner has just recently commissioned and completed a
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

Quality Systems Audit. We welcome these experts and the work they are doing. We see this as necessary part of improving the service and support that is to be provided to Luke.

Currently we are not happy with the service. We believe that Luke has been neglected and that some of the policies of DAS management, along with the behaviour of some staff have resulted in serious breaches of Luke’s human rights, and if nothing else his right to good quality disability supports, his dignity and denial of any opportunity to live a good life despite his disabilities.

Luke has no planned program in the house. He receives about 8 hours a week of “day program” support from a private company that is funded through the “Futures for Young Adults” program. Other than that he is mostly locked up in his area with little of anything to support him in meaningful activity or taken for long drives through the country side. Despite often having two carers with him on such drives Luke is rarely if ever allowed to get out of the bus on such trips. For example - “a successful trip to the beach” means driving to a carpark and watching the waves from within the bus.

It is an appalling situation and we would invite each and every member of the committee to visit that place to see first hand. The question that any visitor must ask themselves is these - would you be happy to live here - permanently?

If not - what would you change, and how would you go about changing it?
4.2.2 Adequacy of current number of places

Simply - there is not and never have been enough places.

4.2.3 Adequacy and Appropriateness of care and accommodation

We have not yet found accommodation that is suitable. Luke has been living in substandard and degrading conditions since his early teens. In each of the places outside of his home he has been subjected to significant breaches of basic human rights. He has not been well supported in any of those places.

4.2.4 Impact on Families

Devastating.

While I could describe in detail the terrible effect that a failure to provide appropriate accommodation and disability supports has had on our family, I would like to quote a doctor (Neurologist) who wrote in response to the ABC-TV presentation of Hannah’s story -

Yes, [since your story has gone to air] many mental health professionals and others have turned their minds to the issue of adolescent depression, but there’s more to be done. For my part, your terrible experience has heightened my longstanding awareness of the need to be ever mindful of the welfare of the siblings of “children with special needs”.

For more information about Hannah, and a small glimpse at the relationship we have with our son Luke - you can view the ABC-TV documentary by going to the Australian Story website at - http://www.abc.net.au/austory/specials/leastlikely/default.htm

4.2.5 Estimates of Future Needs

Appalling. We have evidence to suggest that the planning process within the Department of Human Services is fundamentally flawed. Unless that process is cleaned up there will never be a proper recognition of the need - and the cost of the failure to meet the needs of individuals and families affected by disability will continue to increase.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

We would like to suggest that planning for future need should not be that difficult. A basic place to start would be the mandatory collection of statistics from all of the diagnosing practitioners. Subsequently it should not be that difficult to obtain basic statistics from the Department of Education, numbers of children needing support as well as an estimate of the level of support required into the future. We have a scientific history of disability, dating back to at least the 1980s, which should be able to tell of the normal progression of need, from diagnosis to the development of intense supports and out of home accommodation.

4.2.6 Government Response to Future Needs

We cannot comment on this, except to suggest that the recent round of so-called public consultations on “autism” was a waste of time and money. We have it on good authority that the process of evaluating public comment was corrupted by parties with vested interests. We have no confidence that this government will be able to respond appropriately to current and future needs unless it implements a more rigorous approach to planning and the collection of real data. For example - the Disability Act 2006 states that every person who seeks a service is eligible for support to conduct planning. However we have established that such planning has no real connection to the budgetary process. This is nonsense and should be changed. Families should be equipped with tools to plan the supports they need, encouraged to muster as much natural support as they can, and when that fails to be provided with a mechanism for feeding information about the supports required back into a statewide planning tool. We need to remove all the politics, layers of middle management and poor business practice that hinder and corrupt the planning process. I believe that with clear process and robust planning mechanisms in place, decision makers will be better placed to make informed choices about the level of funding required. For example - at one of the forums related to the Autism State Plan I asked three simple questions, which none of the government officials could answer. This is nonsense and clear evidence of poor business management practice. My questions were -

1. How many people have autism?
2. How many of them would be considered as having severe autism?
3. How many people with autism are in supported accommodation today?

Unless we can answer questions like this from a factual basis there is no way that any government can be expected to respond appropriately to future needs. This is a problem that arises from poor (and sloppy) management practice within the Department of Human Services.
4.2.7 Access for Country Victorians

We live in the Eastern Suburbs of Melbourne and cannot comment on this except to say that while we would like to move to small country town, because we believe that the environment would be better for our son, we also know that if we did so, we would not have access to a) good quality professional support and b) direct hands on support for our son.

We would like to suggest that there are lessons to be learned from organizations such as the Judevine Centre for Autism in Missouri, USA. In 2002 they came to Australia and talked about how they used to expect people to come from the country to access their service. Some 17 years ago they decided to change their mode of operation and now provide a city based training service complemented by satellite offices which serve small and rural communities. For more information go to - www.judevine.org

4.2.8 Access for culturally and linguistically diverse communities

While we come from distinctly unique cultural backgrounds we are professional people who can speak and write in English with reasonable clarity. However we find it difficult to access services and to maintain appropriate levels of communication with people from the Department of Human Services, and can only marvel at the tenacity of those who struggle with English not being their first language. For such people, as for us, it would help a lot if the Department of Human Services could develop and apply customer friendly disciplines which are based on robust principles of planning, project management and communication. For example - meeting practice - correspondence - reports - forms

4.2.9 Appropriateness of mix of service providers

We were not sure what was meant by this and cannot make any comment at this stage.

If it is in relation to the suggestion that there is a conflict of interest in having DHS provide accommodation and disability support then we would like to agree. We can also provide examples of how DHS can not by virtue of its current structure, culture and dimensions be expected to provide the sorts of services and support needed by people with autism.

We have heard some argue that “the government must maintain its hand in the provision of such services, because when it comes to the really difficult cases, the NGOs cannot handle them and they end up back in the care of DHS”. From our
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

perspective, having involvement with one of those people some might consider “too thought for the NGOs to handle” we have evidence to prove -

1. that DHS does not have the appropriate capability (it is doing a poor job) and
2. that there are plenty of agencies, overseas, demonstrating that successful supports can only be provided where the agency has
   i) strong influential leadership than can actually provide the supports themselves - even to the toughest clients,
   ii) accountability,
   iii) intensive support, close supervision and training for the workers, and
   iv) an appropriate, if only equitable, level of funding.

It is clear to most that the main reason why NGOs in Australia cannot provide support to the most needy is because - a) they are not funded properly and b) they are hindered by simple minded and hypocritical bureaucracy which is maintained by people who gave up caring about the people they are being paid to support. Tough words, I know, but that is the truth.

We would like to see the government invest in free enterprise - enterprise that will enable the community to rise to the challenge with the constraints the inevitably come from a large bureaucracy that is more interested in covering up and maintaining status quo than innovating to achieve real, new and better outcomes for its customers. The fact is, whether they wanted to change or not, the very size and nature of DHS means that it cannot change to meet the needs of the people it has been setup to support. DHS should stick to its core responsibilities as an arm of government and focus on policy, funding, and regulation. It should do everything it can to support the growth and development of high quality supports from community and non government organisations.

4.2.10 Alternative Approaches to meeting unmet need

There is much good work being done by some people within the state of Victoria with respect to the development of alternative approaches to meeting unmet need.

While we would like to comment on such approaches, and I would be willing to talk about better methods for data collection, planning and project management for this submission we would like point out that the proposals listed at the beginning of this document as being viable not just for our son, but for others like him. We would like to think that our proposals provide not only specific information in support of our very
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

difficult situation, but potential solutions and ideas for others who have similar, but perhaps lesser need.

Our aim is to get as many people as we can to see themselves as HAPPY PEOPLE HELPING PEOPLE. If we can do this we can go a long way to meeting a much neglected unmet need. We are motivated to do this because we know that one day we will need to know that there are plenty of good people out there willing and able to provide the support we will need when we find ourselves living in supported accommodation. Chances are so will everyone who reads this submission. I would like to think that we could all work together to bring about a change in society that will benefit us all.

I would be happy to provide more information on this subject.
4.3 Answers to questions posed by the Committee

There were eight (8) separate questions posed by the Committee.

1. Availability, Suitability, Adequacy
2. Access - information, planning and decisions making
3. Other approaches for - funding, planning and delivery
4. Alternatives to Supported Accommodation
5. Comparison of Private, Government, Community Sector
6. Current Approach - Affect on Families and Carers
7. Issues relevant to a persons location, background, culture
8. Other Issues

4.3.1 Availability, Suitability, Adequacy

1. What have been your experiences with supported accommodation in Victoria with regard to availability, suitability, and adequacy of care for people with a mental illness or disability?

In summary - it has been our experience that the stress of having our son living at home was less than the stress created by having to deal with DHS and the almost daily issues created by having him living away from home.

While Luke is living away from home the accommodation is NOT APPROPRIATE and we are told that there are no other options.

The accommodation and supports provided are not suitable. For example - it makes no sense to force four people who have severe autism, and disparate needs and idiosyncrasies to be living in the same space. These are people with high support needs and yet most of the staff have little or no training to suit ensure that they understand and can provide suitable supports, and the environment is not conducive to a happy lifestyle.

The care provided by some staff is adequate, but on the whole, and for the most part, our son is left alone for long periods of time, he is neglected.

For more information please refer to “A PERSONAL PERSPECTIVE” for more details.
4.3.2 Access – information, planning and decisions making

2. What is your experience of trying to access supported accommodation in terms of information, planning and decision making?

Specifically - access has been made very difficult by the lack of professional support provided by people working for the Department of Human Services. It may be that they are without appropriate support, or are without the resources to do a good job and so we don’t think they should take this criticism personally. However, something must be done to ensure that the process is made easier for those who need and are seeking support. Information is often sketchy and poorly presented. Rarely if ever, has information at the ground level been presented in a professional manner. Evidence of any real planning, or planning skills - is almost non existent. Decision making has been at best - underhanded and without robust process or accountability. Many significant decisions have been made without due consultation and more often than not decisions are not properly documented and rarely if ever carried out to the satisfaction of the persons seeking support. I could give multiple examples but it would waste a lot of time right now to do so.

4.3.3 Other approaches for – funding, planning and delivery

3. What other approaches/models should be considered to address supported accommodation funding, planning and delivery?

Please refer to a short paper "PLANNING TO LIVE WELL" that we prepared some time ago. It was a short presentation that we created in order to understand for ourselves the practical implications of the then new legislation and its references to planning. To this day we still think that it is a far better and more comprehensive explanation of the total process than anything we have seen coming out of the Department of Human Services.

4.3.4 Alternatives to Supported Accommodation

4. What are the implications for individuals who need but cannot get supported accommodation? Is the alternate accommodation that is available adequate and care appropriate?

While people are young, they should be supported to remain with their families, in the family home. As they get older they should be encouraged and equipped and supported to live in their own homes.

To this end we created a plan to get our son out of his current “supported accommodation” and enable him to live “in his own home close to home”. This is still
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

our dream, and despite significant setbacks, some of which have come about because of the actions of the Department of Human Services, we are still working towards.

For your information please refer to the appendices for a copy of our proposal “A HOME CLOSE TO HOME”

4.3.5 Comparison of Private, Government, Community Sector

5. What is your view on the provision of accommodation and care in private, government and community sector managed supported accommodation?

I think that the government should make arrangements to ensure that there is free and fair choice for the provision of disability supports for all people regardless of the level of need. That is - the government should provide fair and reasonable funding that would allow non-government agencies to provide all of the services currently provided by the Department of Human Services, particularly those provided by Disability Accommodation Services. Currently we have a situation where managers of DAS can quite proudly say “we end up with all the case that none of the NGOs can handle.” But at the same time they say - “we can pay our staff more”. NGOs similarly will say - we would like to provide support for people with the high support needs, we have the skills, but we are not funded to the level at which the Department funds its own. This is not fair.

We would also like to suggest that DHS could do a lot more to promote the good work that is done by disability support workers in the community. Recognition of work well done is one of the strongest motivators, in any industry, yet we have a situation where in some case DHS will not allow parents to know the identities of individuals who are providing support to their children, let alone allow them to become involved in campaigns aimed at raising public awareness of the need, and the joys of providing good services. The secrecy and issues around privacy that are held up by the Department of Human services are damaging to the cause of building community awareness and support for people with disabilities. It is almost criminal.

Some people are keen to point out that the current services are of high quality and that the government needs to maintain its hand in the industry so that it can continue to provide services to those people that the NGO sector cannot support. We would urge the committee to make its assessment firstly - on the basis of the formal evaluation of performance against standards, and secondly and more importantly, on the feedback from those people receiving services.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

Unfortunately in both cases there are currently no adequate tools to collect such information. Because of this most customers feel frustrated and unheard.

We have in the past used a simple template for assessment of service provision against known standards, but it is still a long way from being useful as a tool for collecting feedback from customers.

The following example is one of ten slides in a simple do it yourself presentation aimed at enabling service users and their families to validate the services they receive -

<table>
<thead>
<tr>
<th>Industry Standards - VDSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service: Working Weekday Supports</td>
</tr>
<tr>
<td>Provider: ABC</td>
</tr>
<tr>
<td>1. Service Access</td>
</tr>
<tr>
<td>2. Individual Needs</td>
</tr>
<tr>
<td>3. Decision-Making and Choice</td>
</tr>
<tr>
<td>4. Privacy, Dignity and Confidentiality</td>
</tr>
<tr>
<td>5. Participation and Integration</td>
</tr>
<tr>
<td>6. Valued Status</td>
</tr>
<tr>
<td>7. Complaints and Disputes</td>
</tr>
<tr>
<td>8. Service Management</td>
</tr>
<tr>
<td>9. Freedom from Abuse and Neglect</td>
</tr>
</tbody>
</table>

We would like to recommend that the Committee makes strong recommendations about enabling the full implementation of good customer feedback tools (such as this one) in line with the Departments commitment to the implementation of ISO10002 -

"Customer Satisfaction - Guidelines for complaints handling in organizations".

From our perspective the Government should NOT be providing disability support services. From our perspective it is not (as some would argue) doing a good job today - it is inefficient and it is structurally incapable of providing the services that most people need. The happiest families seem to be those that have nothing to do with DHS. They get their supports from the NGO. Similarly we would also question the merit of DHS continuing to provide housing stock. While it may seem sensible for the Government to retain ownership of such assets it has a poor track record in the design and maintenance of such assets. For example - why does a house - purpose build to accommodate able bodied people whose only disability have to be built with a bathroom that you could drive a truck into, and a 'living area' which is smaller than a toilet. This is just one of several excesses which stand in contrast to significant and
obvious shortcomings in the design of a "purpose built house". For example the kitchen came with a servery opening and a shutter that could be closed to keep residents from climbing into the kitchen. When one of the younger residents demonstrated his speed, agility and strength by climbing under the shutter as it was being closed during a crisis the department realised that it was actually a safety risk to both residents and staff. A new shutter was installed, but it remains closed and locked for most of the time. This is because it cannot be closed quickly in the event of an emergency requiring evacuation of all personal to the kitchen area, and according to DHS “was not designed for that purpose”.

To the question of accountability - we can prove that Market Forces currently provide good accountability on the quality of services, except where there is no competition - i.e. families have no choice and /or insufficient funds to be able to choose or work with an alternative or better service. Poor services exist because they are under funded and no money if provided to support or encourage new ones (take our example). What would prove this point and lead better quality outcomes overall is the enforcement and accountability against agreed industry standards - starting with ISO10002 and the quality outcomes. We are looking forward to the transparency that will come with the mandatory compliance to and auditing of performance against standards. However, having spent 20 years in the automotive industry where standards, quality systems and auditing is part is a part of day to day business we are also well aware that standard and audits on their own are not enough. What really counts, in all industries, except this one it seems, is the measure of customer satisfaction. Because there are currently no robust processes for assessing and reporting customer satisfaction we would like to see the committee recommend and make proposals for the regular polling of customers. This is in line with DHS existing commitment to ISO10002. So it really a matter of reinforcement and the provision of funds to setup and maintain the "marketing" arm of DHS. That is, an agency that would be responsible for continuous monitoring of performance through customer survey. It works in every industry and I am sure it would if nothing else, help to ease the burden felt by most customers that nobody care what I think - no body cares that I am not happy with the services being provided. I could raise a complaint but it would be better for everyone if I could provide my feedback in a positive way, e.g. as in the form of a regular customer satisfaction survey. We would like to suggest that the committee recommends -

- 1. **A system for continuously monitoring and reporting customer satisfaction, across the board, at all levels, and through to all interested parties - from consumers and their families, to regulatory bodies and members of parliament.**
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

We agree with the view that there is currently conflict of interest in having the Government operating as provider and policy maker, funder, and regulator. First of all we are philosophically opposed to the view that the government can be both regulator and provider. We are led to believe that there is something like a 30% disparity between funds provided to, and wages paid by NGOs and the funds provided to and wages paid by DHS to its own staff working in Disability Accommodation Services. With DHS acting as both funder and provider it has seen fit to apportion greater proportion of funds to support its own. Strong leadership coupled with flexibility and the ability to promote innovation is a critical part of providing personalised supports. As a government organisation DHS is, by definition, unable to allow or promote the sort of innovation that will be required in future, neither can it (because of its sheer size) be flexible enough to change and keep up with new knowledge and best practice.

To support this view I would like to provide snippets of information gleaned from senior executive within DHS. She said “most people in DHS work within a social context, an oral culture, where we prefer to take an organic approach to conduct of meetings”.

It was also explained to me that most people in DHS cannot accept or respond to the notion that there are “problems to be solved” (that can be solved, and should be solved) Years of dealing with a vast and complex array of needs without enough resources to do things properly has resulted in a culture that has left them with the impression that there are, at best, only “conditions to be managed”. Such a view cannot tolerate innovation, let alone promote it. We believe that it is only with a “can do”, “fan fix it” attitude that we will get the innovation required to develop, provide and maintain good quality supports to people with disabilities, and that such attitude is not currently available from within the culture and structures of DHS.

We are confident that the example shown by the Government of Tasmania will be proven to provide satisfaction to the vast majority of service users and providers alike. We urge the committee to not disregard the voice of the service users when considering the outcomes of that example.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

We would also like to draw attention of the committee to the stark difference in services that can be provided by a private versus government run service. We have been told by successive managers from DAS that “we are an accommodation only service provider”. This means that DHS staff cannot and will not do anything related to education or personal development of the person being supported. We would like to contrast this with the work that the people from Integrated Education and Communication (IEC) are able to do. These people, starting from a similar base in terms of qualifications and experience, are through disciplined and innovative leadership are able to be trained and equipped to not just support Luke in everyday activities but are able to teach him and help him grow in confidence and self esteem.

![Image](image_url)

Close, Caring & Creative - typical of the supports provided by IEC.

We would be pleased if the committee was to recommend -

- **2.** **Transparent accounting of funds provided for the provision of disability supports**

- **3.** **Corporatization and privatization of all direct care service provision (with appropriate funding)**

- **4.** **Clearer Standards to assist in the development of services**

- **5.** **Transparent Monitoring of Performance against standards**

- **6.** **Transparent monitoring of Customer Satisfaction via regular surveys**

The main fear put up by some as an argument against privatisation was that keeping government as provider will ensure that vulnerable people are protected from abuse by unscrupulous service providers. However, what we have found is that it transparency of operation, and customer feedback that provides the greatest defence against abuse. For example - The director of Jay Nolan Community Services said to me, in answer to the question “in these situations where you have one care with one person, how do you protect against abuse”, said “if there is abuse, or the customer is not happy, they will tell us, if only by a change in their behaviour, and if that happens we, with the person being supported, seek to find them someone else to provide them with support”.
Inquiry in Accommodation and Disability Support
4 Specific Responses to Terms of Reference

The sad fact is that with everything that DHS has in place today - abuse is still occurring. Its time to try a different approach - one that is person centred, totally transparent, and accountable.

Some people argue that government agencies are more accountable to the public because of their obligations to report through to various other government agencies such as the Disability Services Commissioner, The Office of the Public Advocate, and Ombudsman Victoria. Our experience, and we would be happy to provide examples, is that such mechanisms do not guarantee accountability. They usually hinder it, by taking inordinate amounts of time and resources to process claims that invariably seem to be denied. One only needs to compare this with the public accountability of Corporatised services such as the railways. When the system fails - the CEO is called to account for his actions throughout the media to the general public. If the same had occurred while the railways were under government control - it would have been a junior public relations officer of some obscure department that would have been put up as a representative of the minister. Someone with no accountability or deep knowledge of what really happened, and no authority to make decisions or do anything to fix the problems. We support the privatization (with equitable funding) of all disability support services and encourage DHS to focus on what it, as a government agency can do well.

4.3.6 Current Approach - Affect on Families and Carers

6. What are the positives and/or negatives of the current approach to provision of supported accommodation on families and carers?

Devastating.

If you want specific examples we can give you many. However a simple short explanation is given in a recent edition of Australian Story - “The Girl Least Likely”. While it was not mentioned specifically in this story, the impact of the stresses placed on the family by the failures in the service system, should be obvious to anyone who watches this story. We received responses from several medical professionals who also attested to this fact - “the impact on siblings is significant but rarely acknowledged”

While it is true that “there is no one to blame” we have no doubt that the long term effect of the struggles and abuse that Luke and his family had to endure was a major contributor to the onset of major depression in our daughter Hannah.
4.3.7 Issues relevant to a persons location, background, culture

7. What issues need to be considered in the accessibility and provision of supported accommodation for people from:
   - Rural and regional Victoria
   - Culturally and linguistically diverse backgrounds
   - Indigenous Victorians

We believe that there is a good model for service delivery that was developed by the Judevine Centre for Autism in Missouri, USA. In stead of forcing people to come to the city to receive services, they set up a city based training facility which equipped people - families, individuals and support workers to go back to live in their own, mostly rural communities. In any case the biggest issues I would imagine for people living in rural and regional communities are a) access to appropriate professionals and b) direct support workers. The Judevine model could be used to address both issues. Ahead of providing financial incentives to get people to move to the country, the government should consider providing funds to equip the people where they are at. That is, sing a model like that of the Judevine Centre for Autism, get the local people skilled up to work together in support of each other. If that were to happen, then we too would be enticed to go and live in the country, and we would bring our skill, money and expertise with us.

Not sure that we can make much comment here except to suggest that a more disciplined approach to the conduct of meetings, and the application of good business and communication principles would help people from all cultural and linguistic backgrounds. Even we as proficient communicators in the English language find it difficult to understand and follow the way in which people from DHS discuss and manage information. Some basic meeting practice and discipline would go a long way to help everybody - regardless of their cultural background or language

Even though I am not an indigenous Victoria I do believe that the application of good customer service disciplines, accompanied by good business practice, and a little courtesy, should ensure that all people are treated with dignity and respect.

4.3.8 Other Issues

8. What other issues do you think need to be considered which have not been addressed by the above questions?

I must apologize for not having any more issues to list at this point. There probably are other issues that should be raised but I have run out of time.
5 Conclusion

From a personal perspective the accommodation and disability supports that have been made available to people suffering from severe autism have been inadequate, inappropriate, poorly managed, and harmful to both the individuals being supported and their families.

With respect to the specific questions and terms of reference this submission suggests that there is a need for more accommodation (and not just more beds), the hidden cost of failure to do so has been and continues to be significant, current approaches to planning are inadequate, and that there is still need and opportunity for change in the way in which accommodation and disability supports are managed at all levels.

To summarise the views expressed in those responses -

- There is not enough accommodation
- Supports provided are inadequate
- Impact on families is devastating
- Future need is inevitable and predictable
- Government response is “in the right direction” but needs follow up
- Service providers should be supported to operate according to best practice in business management (and not be hindered by nonsense from DHS) as well as in the provision of direct care and support

We believe that access to appropriate supports can only be improved through a massive change in community attitude, which would lead to agreement that would let Government spend more money (e.g. on training, best practice management, housing, better pay for workers), and a recognition of the fact that everyone can benefit from helping.

We would like to encourage the committee to makes it findings well known and use the media to promote the good work already being done while at the same time encouraging more people to step up to the plate.
Inquiry in Accommodation and Disability Support
5 Conclusion

Our experience has left us deeply saddened and stressed. One of the main stressors has been the lack of respect shown towards us parent guardians. There seems to be little or no recognition of the grief that separation causes, or of the value of taking the latent enthusiasm of families, and supporting them, equipping them to manage their own affairs, and to provide ongoing support for their children. The current government policy which denies legal status for early separation is a good one, but it needs to be backed up with more appropriate supports being provided to families in the early days and in those obviously difficult teenage years.

DHS should spend more of its time and energy supporting families and less time on trying to defend it actions. Our experience has been that we spend more time dealing with issues created with management and its reluctance to respond quickly and honestly to issues, than we do in solving the real problems that are being faced by Luke. Having recognized this problem we have stopped meeting with DAS management and choose only to communicate when there is high likelihood of it having a positive impact on the care and support being provided to Luke. Given the current attitude of DHS which is one of “condition management” this means that our communications have been reduced to almost nothing. Not because we don’t care, or don’t want to help, or don’t have suggestions, but the responses we have had from DHS and direct care staff have only led to people getting upset (unreasonably) and time being wasted in creating defensive responses from management. We need to get past this. To this end we have asked for a professional conciliator to help us sort through the problems in communication - both with direct care staff and with management. Unfortunately DAS management is now reluctant to participate in such activity and has not been helpful in promoting reconciliation with staff. It is quite clear to us that they do not want or appreciate our involvement. Trouble is, they have our son, we want to see him and spend time with him, but right now we can’t - because their behaviour and responses will only cause us to become upset. So we suffer in silence. We would be pleased if the committee would recommend -

- 7. DAS management need to publicly and in practical ways acknowledge the role of parents, and promote the importance of maintaining good relationships an practical supports for the families of those people who are living in supported accommodation.

No person is an island. Every person living in supported accommodation did, once upon a time, live within a family. For those families that choose to maintain contact DHS should be acting to nurture those family relationships. Any action that stands in the way of such relationships should result in countermeasures that heal and restore.
Inquiry in Accommodation and Disability Support
5 Conclusion

We would be pleased to see the committee recommend that -

- 8. Providing resources to build the strength and capability of families will help to reduce the need for early separation and out of home accommodation for teenagers and young adults with disabilities.

Some have argued strongly for the immediate construction of more housing stock. While we support the need for more houses, we see that a simplistic approach to “build more houses” will not solve the bigger problems of a diminishing workforce. Neither does it address the current problems associated with moving people from large institutions into “group homes” or “micro institutions”. It is not a case of “build it and they will come” we need more than just more houses, **we need more people** - happy people who have developed appropriate skills through professional training and supervised experience. We would be pleased to see the committee recommend -

- 9. wide scale promotion of caring as an a noble profession, opportunity to become a better person, part of the productive workforce, something that adds value and purpose to life - every life.

To this end I would like to offer the committee with an opportunity to view a short presentation and 6 minute video called HAPPY PEOPLE HELPING PEOPLE. Transcript of the presentation is provided in the appendix.

Just in case it doesn’t come across anywhere else we have found that DHS has failed over many years to provide adequate **training and supervision** to people providing support to our son. We have even gone to the extent of engaging and paying for professionals so that workers could get the very basic levels of training. Even then DHS was not keen to have people trained, claiming that it was too difficult to organize rosters, too expensive and not effective. To some extent they were right about the waste - but only because of a failure to follow up with close supervision and appropriate monitoring of performance (accountability). We would be pleased if the committee would recommend that -

- 10. any budgetary planning for disability services must include funds for ongoing professional development and refresher training, and

- 11. training should be followed up with close supervision and appropriate accountable performance monitoring - especially in areas of high support need (as we would expect from a high support need situation involving medical care)
Inquiry in Accommodation and Disability Support

5 Conclusion

I would like to draw on the example of certified first aiders - must complete the course every 6 months. In the field of autism the techniques and practices are far more complex, and the new knowledge is growing at a very fast rate. Any worker who has not received autism specific training within the last 6-12 months may be applying principles and practices that are out of date, and possibly harmful.

I would urge the committee to collect detailed information about the specific training that has been provided to all staff working in all houses. If services providers have been behaving responsibly then it should not be hard to collect and collate such information. I am confident that such a review would reveal a significant lack of training, and when correlated to the number and severity of workplace injuries will provide a fiscal incentive to invest in more training for all staff.

I would also like to draw the committee attention to a recent Quality System Audit performed on the place where our son is living - “The Crescent”. That survey that was commissioned by the Senior Practitioner and carried out by Lisa Fahey from QUOVIS.

Particular attention should be paid to the amount of training that is autism specific. Some say that as much as 80% of the people living in supported accommodation provided by DAS have a moderate to severe level of autism. We believe that training in this regard has, until very recently, been almost non existent. For example - a recent survey of staff at The Crescent revealed that NONE of the staff recognized “communication” as having anything to do with residents becoming upset. For us this clearly demonstrates a lack fundamental understanding of not just autism, but basic anger and frustration. Similarly last year we discovered that advice being given to staff by the DHS own Adult Behavioural Consultancy (ABC) clearly lacked an appropriate understanding of autism. We were so upset by this that we raised a complaint with the Disability Services Commissioner. An example we gave was that of the way in which staff had been directed to teach Luke about the house rules -

In this example - not only are the rules inappropriate (i.e. presenting negative instructions - DO NOT ...) but the method of teaching, and the format of the instructions is at odds with common knowledge about the way in which people with autism learn and should be taught.
Inquiry in Accommodation and Disability Support
5 Conclusion

Some have argued that INDIVIDUALISED FUNDING arrangements are likely to undermine the feasibility of many smaller organizations. For a start, it is clear that there is some risk of individuals always choosing not to spend money on training, and to employ worker with less training in order to save money. Two things can be done to offset these concerns - one is to provide training funds to the workers - if they want the training they go for it. If they are any good they will get the work that pays. The other thing to do is make sure that if service users need people with the higher skills and level of training then let their support funds be increased, and monitored accordingly.

Autism is a complex disorder - and a “one size fits all” approach to the provision of services is not appropriate. Some will receive more than they need, and others (as has been our experience) will be left without any supports at all. For people with high and complex support needs there must be a means of ensuring that workers are trained to meet the specific needs of the person - as is the case for children with high support medical needs. Their support staff get training that is tailored to each person.

For example - Staff employed Calvary Silver Circle for “Specialist Children’s Services” receive training that is specific to each child they support. Training is provided as part of the “Family Choice Program” which is managed by the Royal Children’s Hospital. Staff receive training for several weeks before they are left to work alone with a child and that only happens if the worker is happy and confident to do so. Such training is then followed up with on the job examination of all workers and formal exam every 6 months. The workers, the families and the people being supported are very happy with this level of scrutiny and accountability.

Similarly they should be supported to let staff go if they turn out not to have the skills they purported to have. Again regular training and refresher courses coupled with feedback from service users would enable training institutions to a) target their training and b) reinforce their criteria for accreditation. It is our belief that market forces, backed up by appropriate levels of funding for salaries of workers and training providers, will enable good companies, and good workers, to thrive.
Inquiry in Accommodation and Disability Support
5 Conclusion

Finally, and on a more personal note - we make no apologies for the length of this document. As Mark Twain said -

"I didn't have time to write a short letter, so I wrote a long one instead."

This has been a very time consuming, and sometimes painful effort for us. We hope that someone will take the time to read through it all. More importantly we hope that someone will learn from some of what we have presented here, that this information will be used to prevent further suffering and tragedy, and that it will help in the construction of better services.

Whatever the outcomes of this inquiry we have no choice but to press on and work to find and build better supports for our son.

We do hope that anyone who reads this will be inspired to join us, and/or to work together for the benefit of all Victorians.

Yours Sincerely

Mark Modra
November 2008

11 Saint Johns Wood Road
Mount Waverley, Victoria, 3149
Australia

+61 439 605 782 Mobile
6 Appendices

Contents –

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>Terms of Reference</td>
<td>60</td>
</tr>
<tr>
<td>6.2</td>
<td>Planning to Live Well (shortened presentation)</td>
<td>63</td>
</tr>
<tr>
<td>6.3</td>
<td>SNR Application (extracts)</td>
<td>65</td>
</tr>
<tr>
<td>6.4</td>
<td>GSP (General Service Plan)</td>
<td>67</td>
</tr>
<tr>
<td>6.5</td>
<td>A story - Monkey 127 (by Hannah Modra – 2005)</td>
<td>73</td>
</tr>
<tr>
<td>6.6</td>
<td>A Home Close to Home (shortened presentation)</td>
<td>81</td>
</tr>
<tr>
<td>6.7</td>
<td>Company Profile – Jay Nolan Community Services</td>
<td>83</td>
</tr>
<tr>
<td>6.8</td>
<td>Company Profile – Judevine Centre for Autism</td>
<td>87</td>
</tr>
<tr>
<td>6.9</td>
<td>Happy People Helping People (shortened presentation)</td>
<td>89</td>
</tr>
</tbody>
</table>
6.1 Terms of Reference

6.1.1 From the Legislative Assembly

The following reference was received from the Legislative Assembly:

To the Family and Community Development Committee for inquiry, consideration and report no later than 30 June 2009 on the provision of supported accommodation for Victorians with a disability and/or mental illness and, in particular, the Committee is asked to report on the current situation in Victoria and compare it to best practice in other jurisdictions regarding:

1. the standard and range of accommodation currently available;
2. the extent of accommodation and services currently available, including the different models for service delivery and funding;
3. the methods for measuring unmet demand for accommodation and how these can be improved;
4. the process for managing service quality;
5. availability of sufficient accommodation to meet future demand with an appropriate range of services;
6. access and service issues for particular groups, including rural communities, culturally and linguistically diverse communities and indigenous Australians; and
7. the impact on families of the current service provision of accommodation; and

for the purpose of this inquiry supported accommodation means public and private accommodation provided for people with a disability or mental illness who need additional support services but excludes mental health treatment services (SEC, PARC) and the disability forensic program (SFS).
6.1.2 From the legislative Council

The following reference was received from the Legislative Council:

That this house requires the Family and Community Development Committee to inquire, consider and report, no later than 30 June 2009, on the state government’s provision of supported accommodation for Victorians with a disability and/or mental illness with regard to the following:

1. description of current government funded supported accommodation, including the number and location of places, occupancy, staffing, demand management, methods of funding and oversight;
2. the adequacy of the current number of places and care provided in community residential units, residential institutions, community care units, secure extended care units, prevention and recovery care facilities and other forms of supported accommodation;
3. the adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability or mental illness because of insufficient places in the specialist system, and in particular including supported residential services, boarding houses, public hospitals, nursing homes and SAAP funded services;
4. the impact on Victorian families of insufficient supported accommodation;
5. estimates of future supported accommodation needs and the appropriateness and transparency of the Government’s management of demand and placement;
6. the government’s response to unmet accommodation needs, including sources of funding, planning and delivery;
7. the ability of country Victorians to access supported accommodation and the appropriateness and quality of care they receive;
8. the ability of members of culturally and linguistically diverse communities to access supported accommodation and the appropriateness and quality of care they receive;
9. the appropriateness of the current mix of service providers, including government, private and community; and
10. alternate approaches addressing unmet needs in supported accommodation in Victoria.
6.1.3 From the Committee

The following was extracted from the Discussion Paper which was prepared by the Committee -

The following are some questions which may provide a guide to you in framing your submission to the Committee:

1. What have been your experiences with supported accommodation in Victoria with regard to availability, suitability, and adequacy of care for people with a mental illness or disability?
2. What is your experience of trying to access supported accommodation in terms of information, planning and decision making?
3. What other approaches/models should be considered to address supported accommodation funding, planning and delivery?
4. What are the implications for individuals who need but cannot get supported accommodation? Is the alternate accommodation that is available adequate and care appropriate?
5. What is your view on the provision of accommodation and care in private, government and community sector managed supported accommodation?
6. What are the positives and/or negatives of the current approach to provision of supported accommodation on families and carers?
7. What issues need to be considered in the accessibility and provision of supported accommodation for people from:
   • Rural and regional Victoria
   • Culturally and linguistically diverse backgrounds
   • Indigenous Victorians
8. What other issues do you think need to be considered which have not been addressed by the above questions?
6.2 Planning to Live Well (shortened presentation)

In summary - Planning has three steps -

1. where are we now,  
2. where do we want to be, and  
3. how are we going to get there.

We start with someone who has a need.  
We encourage them to dream  
about how they would like things to be.  
We work out how to get there.

We work out what sort of supports the person will need and how they would be applied. The result is something we call a “Life Plan”, for example - “My Life My Plan”.

Conversations help to precipitate the ideas into more formal support plans. The Disability Support Plan (DSP) takes its direction from the requirements listed in the person’s life plan. The support plan will list goals, actions and resources.

We look to the person’s natural supports in order to find out if they can get what they need from there. If a person can’t get all they need from their natural supports then we need to make an application to a wider audience – the community – via the Department of Human Services (and others).
Inquiry in Accommodation and Disability Support
6 Appendices

If the Department of Human Services recognises a person as being "eligible" (someone deserving of their support) we can apply for formal support by getting the person and their needs listed on the Disability Support Register. A person can then take their life plan to any of the appropriate service providers and ask them to respond with a support plan.

The resource requirements derived from the various plans can be reflected back up to the various funding bodies as a quote for approval and inclusion in a budget.

Depending on the complexity of need there may be as little as one support plan, simple and direct. But in some cases, there may be the need to define plans down to the level of Daily Activity Schedules.

The most ‘fantastic’ thing about this model is that if followed it would enable more efficient planning and management of resources. Just imagine if the outputs of all the plans were in a compatible format that would allow the automatic flow of performance and resource requirements!

Even so - while all this planning and the creation of all these documents might help with the preparation of budgets and the allocation of resources - we must never forget - it's all about the person - it's all about - planning to live well.

All of us need it. All of us can do it. All of us can help each other.
6.3 SNR Application (extracts)

The following information was provided in an application for additional supports in February 2004 via Service Needs Register Application which was supported by UCCO and submitted to DHS for approval.

The application was rejected with a letter that stated that Luke was not eligible for additional supports because he was under 18 years of age.

Please note - that despite the difficulties listed we still believe that with appropriate supports these risks can be minimized and that Luke can be supported to live happy and safe in our community - in his own home close to home.

6.3.1 Comments about the services you are receiving

HOME BASED SUPPORT - We have a “Homefirst” package that was meant to be used to employ workers to provide in home support and out of home, community access and recreation. However, it is almost impossible to find suitable workers to do this at the rate that DHS allows for.

CASE MANAGEMENT - UCCO has acted as ‘host agency’ for a Family Governed Family Support Project that was give us greater control over how the homefirst money was spent. It was intended to cover after school care, weekend support and eventually weekend and holiday respite care. However DHS and DET have imposed extra responsibilities on UCCO which have made the situation complex and difficult to manage. Two hours was planned but 10 hours (or more) is actual.

DAY ACTIVITIES - DET claims that it cannot provide any more than 15 hours of support per week, expecting that we will organize supports and an education program for the other 15+ hours of school time. This is despite the fact that we have no place or facilities, limited equipment, and no team of people. While it worked OK for a short time last year it looks like it is not going to be possible to build a consistent team of appropriately skilled workers to support this.

FACILITY BASED RESPITE - Children’s Respite services refuse to provide any overnight or weekend respite care. What we have been able to arrange in recent times (roughly 2 nights per month) is for a few dedicated carers to stay with him 1:1 in an unused CRU. However this CRU is said to be no longer available and willing staff are in short supply.

6.3.2 Services Requested

Constant supervision is required during all waking hours with 2:1 staffing ratio. Waking hours can range from typically 16 hours through to 72 hours straight.
6.3.3 Factors For Consideration Of Urgency Status

Violence leading vulnerability to injury - With little warning the applicant is prone to get to a state of rage in which he will attack anyone who comes near him (e.g. carers) and will often attempt to attack people who are close by (i.e. innocent bystanders). During these attacks he has attempted to punch, pinch, scratch, kick and grab at sensitive parts of the body including the eyes. During such rages he has thrown himself at fixed objects, smashed windows with his fist or head, pinched, punch and otherwise attempted to harm himself, including attempts to poke out his eyes.

Physical Demands - The applicant is stubborn requiring constant supervision during his waking hours. If there is a need for restraint (i.e. to protect others or self) it requires up to 8 people. One person attempting restraint almost invariably receives some sort of injury.

Imminent Family Breakdown - The demands of providing direct care and dealing with multiple incidents and the constant turnover of staff, constant need to make repairs, and the denial of quality time together has left the family at the point of imminent breakdown. It is envisaged that even if the applicant is granted immediate accommodation away from home that the family unit will fracture.

Living arrangement Risks - even though we have lived without serious injury for this long, given that we are getting no in home support and less and less out of home respite we are getting weaker and weaker and are now at the point where we cannot guarantee the safety of our other children, or ourselves. During the rage attacks, things get broken, and these objects present significant risk to all.

Significant Family Stresses - as above.

6.3.4 Self Care/Living Skills That The Applicant Needs Assistance With

Staying happy and occupied to prevent boredom and the subsequent the onset of anger and rage. Needs assistance with all activities while awake.

6.3.5 Summary of the applicant's current situation / needs

Please refer to the GSP.

However because of imminent family breakdown and the fact that we have realized that we have neither the skills, resources, equipment nor facilities to keep him and others safe - we now refuse to take responsibility for keeping him at home. He has to live somewhere else.
6.4 GSP (General Service Plan)

The following GOALS & STRATEGIES were extracted from the General Service Plan that was prepared for Luke in 2006. It was provided here to give the committee an appreciation for how a good plan can lead to the development of good strategies.

What is missing from this plan (and all other plans we have seen created by DHS) is the recognition and planning for the resources required to implement those strategies. Invariably it seems such plans are created and then basically ignored. Most of the strategies listed here have not been used and as a consequence almost none of the goals have been achieved.

What follows are just the GOALS (in blue) and the associated STRATEGIES (in green) that were agreed back in 2006.
6.4.1 Living Situation

Long Term -
- A home close to home that fosters family connections.
- A team of people prepared to support Luke in his home
- An organization that supports those people

Short Term -
- Homely environment at “THE CRESCENT” IN MOUNT EVELYN where Luke’s
effectiveness in meaningful activities and relationships is actively supported
- Appropriate supports at “THE CRESCENT” IN MOUNT EVELYN
  - For the Long Term -
    - Maintain “Luke’s Flat”; Modify when ready
    - Establish suitable Support Organization
    - Recruit, Train and Support the People
  - For the Short Term -
    - Renovation Projects
    - Regular Maintenance & Repairs

6.4.2 Education

Academic
- Maintain and develop practical skills in the areas of Reading, Writing, Counting,
  Timetabling

Life Skills
- Skills required to reduce the need for support both at home and in the
  community (e.g., communication, conflict resolution, planning, co-operation)
  - Generally -
    - Encourage Luke to maintain an interest in reading and writing
    - Provide Luke with opportunities to learn
    - Talk to Luke about things, encourage expression through various
      media and subjects
  - Specifically -
    - Work to IEP
    - Develop and Implement Off Campus Education Program (OCEP)
    - Develop new IEP for 2007
6.4.3 Vocation / Work

Administration
☆ Administration reduced to a minimum, enabling Luke to make decisions that are important to him.

Domestic
☆ Luke able with whatever support he needs and happy to do most of his own domestic chores

Paid / Purposeful / Productive
☆ Luke choosing and being supported to spend a reasonable amount of time (more than 20 hrs/wk) in meaningful, worthwhile, constructive and rewarding work

Short Term
☆ Luke will attend a suitable post school option
  ○ Administration
    ▪ Administration managed by family
    ▪ Setup methods for efficient administration & personal decision making
  ○ Domestic
    ▪ Design domestic duties to suit, plan them into daily life, and provide active support that places Luke at his best advantage in carrying out these activities
  ○ Paid / Purposeful / Productive
    ▪ Career Planning - Explore and plan for opportunities, organize supports, and try them when he's in a good mood.
    ▪ Promote the worth of supported employment
  ○ Short Term
    ▪ FFYA will assist with the facilitation of finding a suitable post school option

6.4.4 Leisure

☆ Luke choosing and able to entertain and occupy himself in a wide range of recreational activities that he can enjoy by himself and with other people with whatever support he needs.
  ○ GENERAL
    ▪ A Recreation Plan that provides and builds regular access to, and support for, a wide range of recreational activities, including joining a club based on shared interests.
  ○ CREATIVE
    ▪ Access to and effective support in craft activities, including drawing, painting, woodwork, clay modelling / pottery
  ○ LEISURE
    ▪ Access to Walking, Swimming, and a place to rest
    ▪ Camping in the bush, by the beach
  ○ SPORT
    ▪ Opportunities to go (with effective support) Cycling, Running, Climbing, Swimming, Hiking
6.4.5 Community Access

☆ Luke able to enjoy the benefits of a supportive community, with family and friends
☆ Comfortable transport
  From "THE CRESCENT" IN MOUNT EVELYN –
☆ Friendly relationships with staff, friendships and connections with other residents, and people in the community close to his residence
  From within the SCHOOL community –
☆ Friendships that last beyond school
  From DAY SERVICE –
☆ Friendships with other members, Connections with local community - shop keepers, police, community groups
  From HOME –
☆ Friendships with siblings, family friends, church community, people of Luke’s choosing
  ● DEVELOP & IMPLEMENT A COMMUNITY CONNECTIONS PLAN
    o From "THE CRESCENT" IN MOUNT EVELYN –
      ● Regular HOME VISITS,
      ● Extended HOME VISITS,
      ● Planned Opportunities to meet and spend time with people in his immediate community
    o From DAY SERVICE –
      ● Planned participation in work, community groups, community events, social outings with other members
    o From HOME –
      ● Regular home visits, Holidays with support

6.4.6 Health

☆ Good Mental and Physical Health
☆ Continue to be Free from medications that have adverse side effects
  ● Good food, exercise, healthy activity, time with family, opportunities for conversation with other people (and not just those paid to provide support)
  ● All health and medical issues to be referred to and managed by Luke’s parents
  ● Regular visits to a doctor specializing in care of people with autism

6.4.7 Finance

☆ Funds enough to provide for normal living expenses (e.g. rent, food and recreational)
☆ Funds enough to provide for the special supports identified in this plan
  ● Develop Personal Income Stream
  ● Disability Pension, Rental Assistance
  ● Support Funding through FFYA, S&C and DOH P, DHS
  ● Parents to manage Luke’s finances
Inquiry in Accommodation and Disability Support
6 Appendices

- Special / Additional funding to be sought as needed

6.4.8 Family Support

☆ Family independent of the need for direct support from DHS.
☆ In home and community supports provided by an appropriately skilled and resourced community service organization.
  - Informal supports provided by Family, Friends & VALID
  - Develop and set standards for professional behaviour, respectful communication and close co-operation
  - Develop in home supports that would allow extension of current home visits
  - Establish or identify a community service organization that is capable of providing in home & community supports for people like Luke and families like ours

6.4.9 Advocacy & Personal

☆ Effective personal advocacy for LUKE that also supports family values and intentions and is independent of DHS or service system constraints.
  - Parents to continue to advocate for Luke with genuine support and respect from all service providers
  - Regular meetings between service providers and family

6.4.10 Communication

☆ Luke able to speak for himself
☆ Luke able to use the most effective communication at all times.
  - Use Visual Communication Strategies recommended by Speech Pathologist
  - Develop tools to assist with daily planning and communication (e.g. daily planner, cards for choices)
  - Keep exploring new ways to develop his communication skills

6.4.11 Human Relations

☆ Successful and healthy friendships
☆ Luke to develop and enjoy the benefits of a long term loving relationship with a partner for life.
☆ Luke able to enjoy and manage his sexual feelings appropriately. That is, no socially inappropriate behaviours
☆ Appropriate coping strategies, communication and conflict resolution skills to support healthy human relationships
  - Implement Sexual Development strategies (e.g. as provided by Jenny Butler)
  - Encourage and develop social communication skills
Inquiry in Accommodation and Disability Support
6 Appendices

- Opportunities to meet and spend time with people who might be willing and able to be his friend, close companion, partner (without resorting to prostitutes or casual and/or promiscuous sexual activities)

6.4.12 Behaviour Management

☆ Luke Happy & Safe
☆ Luke able to engage self control, to communicate, and resolve conflicts without the need to resort to sudden violent actions
☆ No bouts of violent or destructive behaviours
☆ No accidents - a planned approach to crisis management
☆ Effective Anxiety Management Skills
  - Provide an active lifestyle (refer OCEP)
  - Implementation of the Positive Behaviour Support Plan
  - Review and Update PBSP, OCEP, etc.,
  - Specific training for all supporters
  - Specific Anger Management, Communication, Problem Solving, Conflict Resolution, education and training for Luke

6.4.13 Justice

☆ Luke publicly recognized for his honourable behaviour and contribution to promoting safety and honesty in society
  - Continue to talk with Luke about life, rights and responsibilities as a part of his education program
  - Work with Victoria Police in the development of safe work practices and positive community attitudes

6.4.14 Fire Safety

☆ Normal safety training (taking care, evacuation drills)
  - School programs on safety
  - Residential Programs on safety (fire drill etc.)
  - Normal safety training in the home
6.5 A story - Monkey 127 (by Hannah Modra - 2005)

"Andrew!" It's a boy! We have a little boy!"

It was a strangely sunny day in winter on the day Helen and Andrew, of the monkey clan, had their first baby boy. The first time they laid eyes on him, he was so gorgeous, and the sun made his light fur glow. A leaf fell from a tree, fluttered down, and landed on in his mouth. He ate it. "This baby sure is different from the rest!" exclaimed Helen. "Let's call him Jon."

Jon grew up in the "Sunnyside Zoo" of Mount Yelevaw. The enclosure he and his family lived in was huge, but he knew it off by heart. As he grew older he got two new brothers and two new sisters. Chris, Marie, Davie and Abbey.

When he was about five, Jon was swinging by himself on a rope, flipping around and around, again and again. "Jon!" Helen called. "The zoo staff have brought us a meal! Come!" Now Jon loved food, but something made him really angry about the way she talked at him. "Eeeeeel" He squealed angrily.

Picking up a log, he started smashing everything he could. What was that high-pitched sound he could hear? It was his little sister Marie! 'Please could you stop squealing!' He thought, but the words wouldn't come out. "Could I have some fish?" he yelled. But then he slapped himself. That wasn't what he wanted to say!

Without thinking, he went up to Marie and pinched her really hard. She wasn't squealing now. She was crying! 'What have I done?.' Thought Jon. He was so angry at himself, that he went up to the glass window, and smashed it, much to the horror of the spectators, who had just come for a nice day of watching animals at the zoo. Then, Jon ran away. He needed all the bad thoughts to go away.

Chris and Marie were worried. They had just heard an announcement saying, "Could all zoo staff report to the zoo office so we can start a full search for a missing monkey?" It was pretty exciting, though.

"Will Jonie be okay?" said the scared mother to the stressed father.
"Yeah, he'll be fine." replied Andrew. "There really is something different about Jon. Have you noticed he likes to play by himself? We really should ask Old Nick about this."
Inquiry in Accommodation and Disability Support
6 Appendices

Old Nick lived in the same enclosure as Andrew's family. He was very wise. You would only get to speak with him if you had a serious problem. Well, this was serious enough. They decided to meet up with him.

"Yes, Jon is a very special monkey," said the wise Old Nick. "He probably seems crazy to you, but he can't help it. He can't control his anger. No one knows what causes it, even me. But about 1 in 1000 monkeys will get it- it's called "Autism."

"Autism? Jon has Autism?" said Helen, trying to sound calm but having trouble.

"Yes" replied Old Nick.

"But - don't worry about it." interrupted Helen, suddenly realizing the time.

"Yes, we really have to go find our son." said Andrew. Andrew was surprised too, but they really had more important things to think about.

Jon was found, in the seal's pool. He just wanted to have a swim! As soon as he was released back into the enclosure, he ran into his father and mother's open arms.

"I'm sorry, I'm sorry." He muttered. "It's okay, It's okay," said his parents kindly. Their son was found. What more could they want?

After that incident, Old Nick told Andrew and Helen that Jon would be better off on something called 'medication.' "Are you sure it will help?" asked Helen, still a bit worried about the idea.

"Yes, it will make him a lot calmer." answered Old Nick. But the medication didn't help much. It was full of side effects. In fact, you could say it made the little monkey worse.

5 Years Later...

"Let's play piggy!" shouted Marie, scampering down the tree.

"Yeah Jon, chase us!" squealed Davie, running around like crazy. It was always really fun when Jon was 'it!'

"Eeeeeee!" squeaked Abbey, the littlest monkey, as she scampered off to her little hiding place behind the bush.
Inquiry in Accommodation and Disability Support
6 Appendices

Jon went for the easiest target. It was Marie, on the low rope. She screamed in excitement as he came towards her, and tried to scramble up on top of the rope, so he couldn’t reach her. But Jon was a tall monkey.

He grabbed Marie by the legs and pulled her. He couldn’t control his anger—she was screaming! “Mum, help!” she squealed. She was gripping on the rope with all her might, but her fingers were starting to slip.

Luckily, Helen realized what was going on. She scampered over.

“Let go, Marie, I’ll catch you!” said Helen. Marie was already thinking about letting go, so she did. Her mother lowered her safely to the ground.

“I’m sorry,” said Jon, and he started crying. He couldn’t stop himself, and the medication didn’t help. It affected his speech and his brain, making things even worse.

“I don’t know if we can take care of Jon full time any more,” sighed Andrew as he tried to stop Jon from bashing his head against the tree. “We need some help.”

“Yes, it’s very hard,” said Helen. “Especially since they expelled him from little monkey training classes. They say he can’t learn! All monkeys can learn. They just need—”

Suddenly she was interrupted by the zookeeper barging through the glass door.

“Alright—where’s monkey 127?” he boomed.

All the monkeys scattered to their hiding places. The zookeeper only came to deal with very important issues.

“127— that’s Jon!” screamed Helen. “Where is he?” She frantically rushed around searching for him. Behind the big oak? No. On the high rope? No. Where was he? There was only one more place to check. Up the gum tree. She was right. There was Jon, sitting at the top of the gum tree, eating a banana. “Come down Jon!” she whispered. Jon laughed and jumped down. Helen grabbed his arm and pulled him behind a bush. It was too late. They were spotted!

“There you are! Monkey 127.” Said the zookeeper as he grabbed Jon by the scruff of his neck. But Helen was still holding his arm. She wouldn’t let them take him away.

“I bet you’re his mother, aren’t you?” asked the zookeeper, chuckling. Helen held on tighter. The man pulled harder.
Inquiry in Accommodation and Disability Support
6 Appendices

"Let him go- you can’t take care of him anymore!" explained the zookeeper. "We have a better place for him, where you can see him sometimes." Helen started to let go. He was convincing her. Maybe Jon would be happier living in a different enclosure.

Helen looked around. Firstly she saw her husband, tired from looking after Jon even though he secretly liked it. The she saw her four other kids. Although they sometimes got ignored because of Jon, they loved him because he was funny and exciting.

"You can’t take care of him anymore!" The zookeeper’s word echoed in her head. Jon looked puzzled and scared. He didn’t know what was going on. Helen’s grip was loosening. Andrew ran to help her.

The zookeeper pulled hard. Jon’s parents pulled harder. The zookeeper was starting to look annoyed.

"These monkeys are crazy!" He declared, and he yanked Jon so hard that he flew backwards, landing in a pile of monkey poo. No one laughed. The zookeeper stormed out, slamming the door behind him.

"Where am I?" thought poor Jon as he woke up in a totally new world. He looked around and spotted an orangutang staring at him. "Who is that?" he thought.

It was boiling hot. Jon got up and headed towards the pool of water. He jumped in. Ah, that felt good. He swam around. He was so peaceful, and everything was so quiet. But the silence was broken by angry voices.

"What’s he doing in the water?" screamed one orangutang. "I don’t know, I thought Bob was supposed to be looking after him!" said another.

Jon was confused. He scampered out of the lake.

"Jonnie, come have some breakfast." said one big fat orangutang. Now Jon was really confused. "Eeek- can I have fish?" growled Jon. "Why can’t I get the right words out?" he thought, and he started bashing his head on a rock.

"Woah, slow down, Jon." said Bob. "Come have your breakfast."

So Jon grabbed his food and sat down by himself in a corner to eat it. The orangutangs talked among themselves. They didn’t talk to him at all.
"What is this food?" he thought as he bit into his sandwich. "It's definitely missing something".

"Gluten," said Bob to another orangutan. "He's not allowed to have gluten. It's wheat, to put it in simple terms."

"Boy, I wouldn't be able to survive without wheat." said the big fat orangutan.
"By the way, do we have to, you know, do anything with this monkey? You know, like play with him?"

"Nah," said Bob. "We can leave his most of the time. Any way, I can't be bothered." He finished, lying back against a rock.

Jon was bored. Those orangutans wouldn't let him do anything! They'd taken away the water. How he wished he could be home again! Some of those orangutans were fat and lazy - they didn't know how to entertain a crazy monkey.

Jon started to rip up things. I mean, he didn't have anything else to do. One day he ripped a big branch off a tree. It was kind of annoying anyway, because it prevented him from climbing it.

"That's it?" said Bob. "Jon is too hard to handle. Let's dig a hole and put him in there." Most of the other orangutans agreed, so they dug the hole. Sticks and leaves covered it, so the zoo staff never saw it.

Jon hated the hole. At first he banged and screamed on the walls. "Slow down, talk quietly!" they yelled down at him. Then he did, but they didn't listen to him. They didn't understand. So Jon was stuck in the hole, nothing to do, only food to eat sometimes. He wanted adventure! He wanted fun!

Back at the monkey enclosure, Things were not at all peaceful. Up till now, Andrew, Helen and the family had been visiting him as much as they could, and taking him out on adventures. But now that he was stuck in the hole, it was almost impossible to see him!

"We have to take action!" shouted Andrew, climbing up a tree so all the monkeys could hear what he had to say. "There is a monkey in the orangutan enclosure." He boomed.
"He has no fun! Think of your own children, are they stuck in a hole? Look at them playing- that is what Jon deserves! The zoo staff have not acted, so we must do it for ourselves." He paused for effect. All the monkeys were listening intently. "We're going to build a tunnel." Everyone was almost in tears. "To Jon. Who's with me?" There was
no need to ask. Everyone was squealing and screaming. Monkeys work together. With Helen and Andrew in the lead, and their kids following, the monkeys started digging.

Poor Jon was still stuck in the hole. He was drawing on the ground with a stick. Couldn't they give him something to do? Everything was so quiet.

Suddenly the silence was broken by a scratch-scratch-scratch noise on the wall. Then a little hole appeared. Jon looked at it curiously. This was exciting. A hole broke through the wall, and Jon was face to face with his mum and dad. They gave him a big hug.

After that day, Andrew, Helen, and often their kids would take Luke on adventures. Every time Andrew's head popped through the hole, Jon was filled with joy. Unfortunately, they had to take Jon back to the hole after a day of fun. Andrew had to work hard back at the monkey enclosure, and Helen would be teaching and caring for the young monkeys.

The zookeeper was worried. "Have you checked up on monkey 127 lately?" he asked his top employee, Jane.

"Well, no," answered Jane. "The orangutangs are taking care of him fine, I heard. He's not our problem. We shouldn't worry about him."

"Well, if you're sure," replied the zookeeper, sipping his fifth cup of coffee for the day. But he knew there was something wrong. It was like there was a little mouse in the back of his head, scratching, telling him something. He tried to ignore it. "You may go now, Jane." He forced himself to say. She left, but the mouse didn't.

Later that day, the zookeeper had a horrible headache. No Panadol could cure it. Frustrated, he called on Jane, his top employee.

"Please, Jane, could you please check on monkey 127," he begged her, almost in tears. "I'm sure there's something not quite right."

"I'm sorry Harry (that was the zookeepers' name), but I'm not paid to do odd jobs. I'm your top employee, remember? Everything will be fine, I'm sure." "No, everything will NOT be fine!" shouted Harry, slamming his coffee down on the table. The contents splashed everywhere, including Judy's crisp white dress. "That's gonna stain, you know!" squealed Judy, shaking her dress and running around in circles. "Quick, get me a cloth!"
Inquiry in Accommodation and Disability Support
6 Appendices

"I don't CARE if it's gonna stain!" boomed Harry. "And if you're not gonna check on that blasted monkey, well I guess it's up to me!" And he finished but ripping Jane's "top employee" badge off her dress and tossing it out the window. Grabbing a torch, he stomped out the door, slamming it behind him. "Wait, does this mean I'm not your top employee any more?" yelled Jane. "Because if I'm not, I QUIT!" "No need!" answered the zookeeper, slipping on his shoes. "Coz you're fired!" and he ran off into the distance, leaving coffee stained Jane on the doorstep, angry as a bull.

As he approached the orangutang cage, Harry got out his keys so he could make a fast yet silent entry. Slipping the key into the lock, he slowly opened the door. The sight in front of him was normal. Most of the orangutangs were asleep, except one, to look after monkey 127. But where was monkey 127? He was nowhere to be seen.

Harry looked everywhere. Up trees, behind bushes. Behind rocks. But he couldn't find the monkey.

Wait! He heard something. A scraping of some sort. He turned off his torch and closed his eyes, so he could listen better. The noise was very faint. He walked towards it, still closing his eyes.

Suddenly, the ground gave way beneath him. He fell and hit his head on the dusty ground, before slipping backwards and falling through a hole.

"Ouch!" screamed the zookeeper as he hit the bottom. His leg was throbbing with pain. Looking around, he found he was in a hole. And right next to him was monkey 127 scratching something in the dirt.

Harry watched painfully (he was still in shock) as monkey 127 carved a smooth 'J' into the ground. Then a 'O' and an 'N'! JON! "Wow!" exclaimed the zookeeper. "This monkey can learn!"

Harry stood up to make a speech. Immediately his faulty leg gave way, but he leaned against the wall for support.
"Monkey 127," boomed the zookeeper, slowly and steadily. "The conditions you have been put in are shocking. The attention you receive is minimal. But, from this day forth, you will no longer be treated like a rock, and thrown into a hole. Forgotten. You are a wonderful monkey, I have learned, and you can learn. Also, you will never be called monkey 127 again. From now on, you will be what you always should have been - Jon."

The zookeepers' eyes grew heavy, and his legs were weak. He was very tired. So he flopped down inside the dirty little hole and slept.

Who knows if Jon understood that speech. He probably did. But, seeing the zookeeper slumbering made Jon feel at peace. Maybe he would be taken back to his real home soon. With that nice thought in his mind, Jon closed his eyes and dozed off.

The next morning, Jon woke up in a totally new environment. Where were those dusty walls? Where was that little hole up above through which he could see the stars at night?

This was a nice new place. Trees, ropes, flowers, fun things to do. Two monkeys scampering towards him. Mum and Dad! He jumped up and ran towards them. He hugged them tight. There are no words to describe the joy in his heart. He was home.

Jon lived in the big gum tree next to his family's tree. Medication was a thing of the past. So was boredom. Every day Jon would go off to a fun program with other monkeys that were crazy just like him.

He runs and jumps and plays. He also learns. All living things can learn. Together, Andrew, Helen, Jon, Chris, Marie, Davie and Abbey make up a happy family of monkeys, living in the Sunnyside Zoo of Mount Yelevaw.
6.6 A Home Close to Home (shortened presentation)

In order to enable Luke to live in his own home close to home we bought - “the house next door”. It was a two bedroom unit, with study -
The UNIT is one of six, in a small cul-de-sac, quite literally, with its driveway entrance, right next door. Our house is at Number 11. "Luke's flat" is Unit 6, Number 13.

Situated quite literally on our back fence it would enable Luke to live in his own space by be free to visit us and our back yard when ever he wanted to. Similarly being so close we (all of our family) would be able to provide direct support without having to walk very far.

We figured that with only about $20,000 we could modify the property to make it safe and ready for Luke to live in. What is needed is a lead tenant and team of up to 8 people to provide him with support, AND, an organization to provide those people with training and support that they will need.
6.7 Company Profile - Jay Nolan Community Services

From their website - www.jaynolan.org -

6.7.1 Our Mission

The Mission of Jay Nolan Community Services, Inc. (JNCS) is to enable individuals with Autism Spectrum Disorder and other Developmental Disabilities to live fulfilling lives as members of the community by providing support services customized to their individual needs.

6.7.2 Our Vision is...

Every Person living a quality life. Empowered, Included, Embraced
Our agency living our mission. Strong, Respected, Visionary

6.7.3 History ...

Jay Nolan Community Services, Inc. a non-profit 501(c)(3) organization, was established in 1975 by members of the Autism Society of LA. Initially named Programs for the Developmentally Handicapped, Inc., JNCS operated a social and recreational Saturday program, group homes, and day programs.

In 1992, JNCS began changing the way it provided services. The organization closed its group homes and began providing supports to people to enable them to live in their own homes, have jobs, and participate in other valued activities during the day. Today, JNCS provides an array of support services in Los Angeles and its surrounding counties and in Santa Clara County, offering individualized planning guided by the needs and wishes of the person receiving services and his or her circle of support.

6.7.4 JNCS believes that:

• All people have capacities and gifts.
• All people need a sense of belonging to a community.
• All people contribute to a community.
• Relationships and trust are equally fundamental for inclusion to happen.
• All people can live in their own home with the right support.
• All people should be treated with dignity and respect and have a right to privacy.
• For all persons, self-advocacy and empowerment should be promoted.
• All people have the right to be free from pain, coercion, and cruelty.
• All people have the right to be heard and their ideas acknowledged.
Inquiry in Accommodation and Disability Support
6 Appendices

JNCS' philosophy is based on the belief that with the right kinds of support and assistance, individuals with disabilities can pursue their hopes and dreams and live to their full potential within the community. It is an ideal of inclusion rather than exclusion and segregation.

6.7.5 Board of Directors

July 2007 - June 2008 Officers:
Allen Brody - President
Vicki J. Johnson- Vice President
Robert McBride - CFO
Ann Laferty Snowhook - Secretary

6.7.6 Locations:

Because of the nature of our business, the majority of our work happens right in your community - Every Day. However, our administrative work is performed in our offices by our very dedicated administrative staff. Our office locations and contact information are listed below. Feel free to contact us. We love hearing from you!

Corporate Office -
MAIN OFFICE
15501 San Fernando Mission Blvd., Suite 200
PO Box 9604
Mission Hills, CA 91346-9604
Phone: 818/361-6400
Fax: 818/365-0522
Email: Info@jaynolan.org

Los Angeles Office
4607 Prospect Avenue
Los Angeles, CA 90027
Phone: 323/805-0207
Fax: 323/805-0208

San Jose Office
1190 S. Bascom Avenue, Suite 240
San Jose, CA 95128
Phone: 408/293-5002
Fax: 408/293-5015
6.7.7 CONTACT US

Jeffrey L. Strully, Executive Director, Jeff@jaynolan.org
Rebecca Burkhardt, Director- Supported Living - Mission Hills, Rebecca@jaynolan.org
Joseph Nacario, Director of Day Services and Supported Employment, Jnacario@jaynolan.org
Jennifer Lengyel, Director-Supported Living/San Jose, Jenny@jaynolan.org
Charlotte Mazzeo-Comelione, Director - Training, Charlotte@jaynolan.org
Jessica Morrow, Director - Supported Living/Mission Hills, Jessica@jaynolan.org
Christa McAloney, Senior Director-Human Resources, Christa@jaynolan.org
Al Sommerville, Director of Finance, Al@jaynolan.org
Cindy Strully, Director-Family Services, Cindy@jaynolan.org

6.7.8 Did you know – “Everyone deserves to live a valued life”

The odds of having a child with autism are 1 in 150. The number of students with autism receiving special education services has increased 1,354%. The number of persons diagnosed with autism in California increased 253%; the number of persons with mental retardation increased 36%, epilepsy 28%, and cerebral palsy 27% between December 1994 and December 2002. Over 31% were diagnosed with more than one type of developmental disability.

At Jay Nolan Community Services, we know that children diagnosed with a developmental disability fare much better with early intervention services and with in-home supports so they can remain with their families instead of being placed in institutional settings. We know that adults with developmental disabilities live happier, healthier, more productive lives when they have options, are treated with dignity, and have control of their own destiny. We know that the key to minimizing the affects of developmental disabilities is to offer persons with disabilities and their families services based on individual needs. Jay Nolan Community Services has valued lives for 30 years. We work every day - 24 hours a day - to provide the specialized supports people with disabilities need to live enriched lives within our communities.
Inquiry in Accommodation and Disability Support
6 Appendices
6.8 Company Profile - Judevine Centre for Autism

From their website – www.judevine.org -

6.8.1 History

Back in 1970, funding for the Social Exchange Lab at Washington University was cut. So Lois J. Blackwell, then assistant director of the Lab, with the help of a parent whose child had “graduated” to regular schools, moved the Lab out into the community. Seventeen families took to the streets to raise $9,000 on a “toll road” that allowed Judevine Center for Autistic Children to open its doors in the old St. Patrick’s in University City.

In his book, 'Reaching the Autistic Child-A Parent Training Program' (published 1998, pg xi), Martin A. Kozloff writes “I remain indebted to Lois J. Blackwell, former Assistant Director of the Instructional Systems Program and head teacher of the Laboratory-school; currently Executive Director of the Judevine Center for Autistic Children, St. Louis, Missouri. Through Ms. Blackwell I received much of my training in the application of applied behavior analysis to the education of autistic children. Her ideas, encouragement, and help were invaluable.”

Judevine's first program had an enrollment of 17 children. Today, on an average week, the Center directly touches the lives of literally hundreds of children and adults with autism spectrum disorders (ASD). And because no one is prepared to be the parent of a child with autism, we also work with families, helping them learn the special skills they will need each and every day.

Although much has changed over the years, Judevine Center is still based on its founding, client-centred philosophy that offers progress towards as much personal freedom and fulfillment as each person with ASD can achieve.

Autism puts up a wall between the individual affected and the world around him or her. At Judevine, we help to break through that wall, brick by brick. We focus on building bridges between the person with ASD, the family, the school, the program, the neighborhood, the community.
6.8.2 Services

Judevine Center for Autism offers a full range of services and supports to children and adults with autism and their families. Our broad range of services includes:

- Evaluations and Assessments
- Specialized Parent Training
- Specialized Training for Professionals
- Training and Consultation
- Workshops and Seminars
- Family Support
- Clinical Therapies
- Transitional Treatment
- Adult Programs and Support, including Supported Employment
- Residential Services
- Autism Projects in Out-State Missouri

6.8.3 Contact Us

Main Office:
1101 Olivette Executive Pkwy.
St. Louis, MO 63132
314.432.6200
Fax: 314.849.2721

E-mail: judevine@judevine.org
6.9 Happy People Helping People (shortened presentation)

The following is a short story prepared by Mark Modra for presentation at the "Who is challenging who" forum at "HAVING A SAY" Conference, in GEELONG, on FEBRUARY 8, 2007. The conference was organized by the Victorian Advocacy League for individuals with a disability (VALID).

The pictures were to be presented to the audience via an overhead projector, with changes made at points indicated in the text.

<PICTURES HAVE BEEN DELETED FROM THIS VERSION TO SAVE SPACE>

Hi, my name is Mark Modra, and this is just a picture of "A HAPPY PLACE". I use it to remind me of the dream that we have for our family, for my eldest son in particular.

This place is real, and its not that far away. Is not mine and I don’t have the money to buy it. But what I can do is talk about it and I can use it remind me of the dream. I can also use it to inspire others to imagine something better for themselves as well, and that is what I hope to do with you today.

Ellen and I have been married for 20 years now, and we have five children.

Our eldest son is Luke. He is a handsome young man - handsome, fit strong and physically able. He is autistic and this brings with many challenges for every day living. However this diagnosis pales into insignificance when compared to the disability that has been imposed on him by others.

He has been - medicated and sedated to the point of stupor, restrained with overwhelming force, and imprisoned and kept separate and isolated from his peers for years.

The scars he bears are permanent - Brain damage caused by the excessive use of sedating medication, traumatized by the abuse, and crippled by institutionalized neglect and isolation.

However, I do not want to focus on the negatives. Besides, It would take me all day, and it may not be helpful.
Inquiry in Accommodation and Disability Support

6 Appendices

A good friend encouraged me to “tell the alternative story”. He told me to “paint a picture of where it is you want to go”. He suggested that “if you do that well then people are more likely to come alongside and help you to achieve your dream.”

As I said before this is just a picture of “a happy place” - a nice place. Its a place I go to in my mind when things are not so good. It is actually a part of my dream for the future, our future. If I had the money, I would like to buy this property (or one like it) and set it up as a place where families could go for a bit of comfort, encouragement and enthusiasm. It would be a place where they can go and rest, and learn and become strong. It would be a place providing support for families like mine, and training for those who would like to help out.

Unfortunately, I don’t have the money to do that ... yet ... but I am working on it.

Even if I never get there - I can still talk about it. Hopefully, you can share my dream, and talk about it too, and maybe one day, just maybe ... our dream will come true.

Now, part of the problem we face today, in trying to make this dream come true, is that most people, particularly those in government, actually believe that we already have all the services we need.

Several years ago we wrote to the minister for community services with a desperate plea for help and a proposal for establishment of special services for people like my son. She wrote back to us saying that there were more than enough services already established and available to provide support for my son.

Yes we do have some very good services here in Victoria, but for some, like my son, the supports provided are just not enough.

Several months after receiving this letter from the Minister for Community Services, we found ourselves with NO SERVICES - no respite, no in home support, no community support and limited access to school.

That is, less than 12 hours a week - 9 - 12 and that not withstanding the fact that the school continued to suspend him for three days at time, with out warning, and no support being provided to my wife who had four smaller children at home at the same time.

Our family went into crisis. Ellen locked herself in the offices of the Department of Human Services (DHS) and refused to leave until they promised some support.
DHS offered us 12 weeks of “emergency respite”. It opened up an old abandoned CRU, pulled together a team of workers, and our son moved out of home and into “care”.

This is a picture of Luke standing at what they called his bedroom window.

Here are some views from the outside.

This was supposed to be his “living area”

He stayed there for 18 months, and during that time he was wounded, abused and neglected. He and we will the carry the scars of that experience forever.

Fortunately he now resides in a different place. It’s a big new CRU, nestled amongst the trees of the Dandenong Ranges. It is a secure facility which is about an hours drive from our home, and it has a big back yard ...

People from DHS tell us that he is happy and that “he chooses” to spend most of his time alone in his room. So I wonder - Why do the doors have deadlocks, with electronic release?

You might wonder also - Why are the windows frosted?

The reason for the frosting is this - Left alone in his room for hours on end (with most staff afraid to enter his area) he becomes bored and rips at his clothes. The windows are frosted because of “privacy concerns”.

Well, I don’t believe that he is happy. I don’t like that place at all.

It makes me feel sick.

In 2006 I went to the United States of America and I saw that my son didn’t have to live this way.

I visited organizations that were providing cradle to grave, 24/7 support, for people like my son.

I was reminded of the lifestyle that we used to live. The things we used to do as father and son. I realized that the best place for him was with his family, with the people that love him the most.

We decided that if he couldn’t live in our family home (because DHS wouldn’t put its workers there), then the next best thing would be for him to be living in his own home
Inquiry in Accommodation and Disability Support
6 Appendices

close to home. An opportunity arose, and believing it to be the will of God - We bought the house next door. A beautiful home, close to home.

So we had a place for him to live, but we were still lacking two things -

- PEOPLE to provide direct care and support, and an
- ORGANIZATION to provide support to those people.

When I went to America I saw the type of organization that we needed, and met the type of people that would be prepared to live with and provide support to my son.

I came back from America determined that we were going to succeed. I called a few friends together and that is how this new support group called PALS was started.

Now what did I see in America that was so inspirational?

I saw people like my son, living in beautiful homes ...

... service providers with magnificent facilities ...

... and fantastic programs.

All the things you would want and need to support a person with an Autism Spectrum Disorder (ASD).

But what impressed me most, was not these things - the beautiful homes, the magnificent facilities and fantastic programs. What impressed me the most was the PEOPLE I met.

Happy People - People like Bob, Jean and Jim, Cathy, Shaun and Amy.

People severely affected by autism and elderly parents, relaxed in retirement resting assured that their children were happy, living in their own homes, support by friends (some of whom were paid).

I saw these people - Jean and Bob, and I said to myself - “I know what I want”. “I want what they have got.” “I want to make it happen here in Australia.” “When I am 75 I want to be relaxed and happy like them.”

But of course it was not just these people that impressed me. I was impressed by the people who had chosen to support them.

The Helping People ...
Inquiry in Accommodation and Disability Support
6  Appendices

It amazed me that all of these people were happy to be interviewed, on camera. They enjoyed their work and they were proud of it. Disability was hardly mentioned and no one talked of clients. Most saw themselves, not as workers, but as friends. Friends of the people they had chosen to serve.

In America I visited two companies -

1. Jay Nolan Community Services (Los Angeles, California) and
2. Judevine Centre for Autism, (St. Louis, Missouri)

They operate under different models of service, but both provide high quality, family friendly services - lifestyle and educational supports for people affected by autism.

You can look them up on the web. You can even send them an email.


For me they have always been keen to assist and quick to respond. In fact I can get better advice from them, quicker than I can from anyone in Australia.

Of course these organization do not operate in isolation. They operate with support from government, business, community groups and individuals.

- Laws that support the people and the work they do
- Businesses prepared to employ people with special supports
- Groups willing to make a space and lend a hand
- Individuals deriving benefit from simply choosing to become somebody's friend

We can do the same, we can do even better. All we need to do is muster the same sort of support from the same sort of people who live here in Australia. By working together, we can make the dream come true.

We too can be happy people helping people.

Everyone of the people in these photographs agreed to be interviewed on video. I have compiled a selection of those interviews for presentation. Anyone wanting to see this 8 minute video can contact me via email - maemodra@ozemail.com.au.

Just about every person who has watched this video, is amazed by what these people say and do. It is truly inspirational.
6.9.1 Postscript to the presentation

In the original presentation of this story, there was no “call to action” or conclusion. The reason being that I did not want to burden people with any expectations. I simply wanted people to DREAM, and that is what they did.

At the end of the presentation I simply left the image of the HAPPY PLACE on the screen. It stayed there for about an hour while people sat and talked about the possibilities.

Since that day I have talked with many people about the presentation, they say it’s a great story, and well presented. However most people also ask the question “So what is it that you are asking for?” It was this question that prompted me to expand the postscript to include a listing of things that might hopefully give people a clearer picture of what it is, that they could do to help.

6.9.1.1 What is that we are looking for?

The answer to this question depends on who you (the reader) are. Not wanting to be prescriptive or pushy I was reluctant to answer the question. I had hoped that in reading the story, that you would see what it is that we are looking for, and that somehow, perhaps miraculously you would simply understand and be prompted to do whatever came to mind.

Nevertheless, I decided to make the following suggestions and grouped them according to the various groups of people identified in the original presentation -

1. Happy People (families and the individuals needing support)
2. Helping People (people who chose to provide direct support)
3. Supportive Community
   a. Government
   b. Business
   c. Community Groups
   d. Individuals
6.9.1.1.1 *Happy People*
For families to band together in support of each other and those that choose to provide support.

6.9.1.1.2 *Helping People*
For people to become inspired to volunteer, apply for work as a disability support worker to get training, or simply find away to spend time with someone, spend time to become a friend.

6.9.1.1.3 *Supportive Community*
To welcome people with autism, and not be afraid. To welcome and commend anyone who chooses to provide support to another person - particularly those with a disability.

6.9.1.1.3.1 *Government*
To support people who band together to organize supports - both with legislation and money. To make that those who choose to do the more difficult tasks are recognized and rewarded appropriately.

6.9.1.1.3.2 *Business*
To make space that would enable and support people with disabilities to be engaged in meaningful work - that is work that make a significant contribution - that is worthwhile. People helping People is worthwhile - it makes people happy.

6.9.1.1.3.3 *Community Groups*
Making space and lending a hand wherever possible. Raising money, for sure, but more importantly providing encouragement through team efforts.

6.9.1.1.3.4 *Individuals*
Every one can play a part, even those who might not have the skills to provide direct support. If nothing else I would like to think that every person would be keen to help - in whatever way they can. After all - as my father said - The purpose of life is to help other people.

Happy people helping people.