Inquiry into Supported Accommodation for Victorians with a Disability or Mental Illness
Family and Community Development Committee
Re: Luke Modra

Introduction

Luke Modra is a handsome, pleasant young man who is fit, strong and physically able. Luke is never mean, has a good sense of humour, is forgiving, truthful, remorseful, empathetic, trustworthy, loyal, polite, endearing, determined and engaging. He has four younger siblings. Luke is autistic and this creates many challenges in everyday living. He needs a lot of love, forgiveness and support - in every hour of his life**.**

It was not Luke or his family's choice when Luke had had to leave his family home. On February 26, 2004, aged 15, Luke was moved out of his parent's home in Mount Waverley, spending time at various respite houses, "Greenock" in Wantirna, and then "The Crescent" in Mount Evelyn. As you will read, Luke's living conditions and treatment at these accommodations have been appalling.

This is Luke's sister, Hannah Marie Modra, who really loved her brother.

Some people believe, and it is not hard to see why[1], that Hannah's witnessing of Luke's appalling treatment was a major contributing factor in her depression and resulting suicide.

Despite such monumental setbacks, the Modra family continues working towards building supports that would enable Luke to live in his own unit close to the family home. This report recommends improvements in the provision of accommodation and disability support for Luke and for all people with autism.

This report is presented in three sections:

1. **Luke's living situations and respite support over the last five years.**
2. **Specific Responses to Inquiry Terms of Reference**
3. **Suggested planning and provision of accommodation and disability support**

---

[1] Refer Hannah's Story and some of her thoughts about Luke at www.abc.net.au/austory/content/2007/s2366128.htm

Table of Contents

Special Note:

This is a shortened version of the original submission that was provided on 17-Nov-2008.

Section One: Luke's living situations and respite support over the last three years

When Luke was young, the Modra Family Home in Mount Waverley was modified with specialized play equipment and a separate, outside ABA therapy room was used to meet his autistic needs. When Luke's condition deteriorated, internal fittings in the house were reinforced including a second storey with locked rooms. Specialist home help such as from PCC (Psychiatric Care Consultants) was engaged but proved very expensive and ineffective.

To assist the family, Luke was accommodated outside of the family home. Luke intermittently and briefly stayed at several "respite" houses such as "Swonnel House", "Healesville Home Stay" and "Sevenoaks". When these were not suitable, Luke spent time in called "emergency" accomodation – older, abandonded, CRU houses; "Traverse" and "Greenock" before being sent to "The Crescent" where he is today.

"Swonnel House" SASI

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 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 well. While we met with some nice people on our first interview, on subsequent visits we were confronted with people who seemed a bit "rough"; and it appeared that the vast majority of carers were short term employees with little or no training.

To get a weekend of respite, we had to book through SASI many weeks in advance. We did receive some priority assistance from the case manager at DHS and funding was provided. For the most part, a permanent member of staff was on duty but 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. Luke 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, to the point of us thinking that he needed hospitalization.

"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. 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 at once.

"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. There was a small trampoline and even smaller swing. Typically it was meant to have up to five young people staying overnight or over the weekend. Things seemed to work out when all of the people staying were roughly the same age and mobility as Luke.

For several years, however, there were two or three young boys (around 8 years) living there on a semi permanent basis. With young children and Sevenoaks being very small, Luke's energy led to conflict situations emerging to the point of danger for all. DHS' response was to simply ban Luke from that service. For a time, there was nowhere for Luke to go. Eventually DHS offered the use of "Traverse" and "Greenock", two houses used as CRUs in the past which had fallen into disrepair.

"Traverse" DHS-EMR-DAS

"Traverse" was a two story house on an extremely small corner block in East Burwood. There was effectively no backyard. The house was dark and dilapidated with some rooms deadlocked. We used the house for several 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), 2:1 and on a casual basis. Demand management was based on available funds and availability of workers, so that needing to provide 2:1 support at all times, meant support hours were 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 with spending directed by the family.

While only some agencies provided debriefing and training of its workers, the nature of the "Family Governance" meant that the family maintained responsibility for training, and supervising the workers. This was problematic because the workers felt that their primary obligation was towards their employer. In some cases the employer was not sympathetic to our family's objectives; and sometimes good supervising staff were just not available. The use of "Traverse" and casual staff without professional training and supervision was a disaster for everyone.

"Greenock"

After the disasters at "Traverse" in January 2004, the Modra family found they had nowhere else to go. The Education Department said it was not able to support Luke for more than 12 hours a week, and continued to suspend Luke for 3 days at a time whenver he wen to strike at a teacher, the provider of day time supports (funded through Home First) pulled out at short notice, and so did the Children's Respite Services (operated by DHS). In desperation, Ellen, Luke's mother, took him to the DHS offices in Box Hill and refused to leave until they offered some decent respite and reliable daytime support. DAS offered 12 weeks of emergency respite at "Greenock" to enable the family to organise the support they would need to keep Luke at home. DAS recruited a team of staff and opened up the abandoned CRU "Greenock"; 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. Luke suffered serious lacerations to his arms and shoulders, and a broken wrist. Subsequently it was reported that Luke had been abused physically, emotionally, psychologically and almost certainly sexually, while living in "Greenock". The family were devastated and have never really recovered from the shock of that terrible experience.

As a conservative estimate, it cost about $500,000 per annum to keep Luke at Greenock; he was there for 18 months. The house was managed by a house supervisor but most of the staff were casuals. Over a period of nine months, as many as 75 different people worked at Greenock. Not only were management and staffing practices unprofessional but the appearance and set-up of Greenock was described as "not fit for an animal" as was shown on "A Current Affair" when it broadcasted Luke's situation in September of 2005. In July 2006 - Luke moved on to "The Crescent" because the Modra family were not able to organize the supports to enable Luke to return to his family home.

"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. Luke is living at "The Crescent" now, along with three other older people. The house is usually staffed with four people. 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. 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" consisting of a bedroom, bathroom with a toilet and living area being a corridor wide enough to house a TV, couch and table.

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 such as to pass him a meal, or to receive an empty plate.

The future alternative: Luke moves to the home next to the family home

The Modra family have brought the house next door to their home in the hope that Luke can live there. Luke could live in his own space, and be free to visit the home and back yard. His family could provide direct support. For this to happen, the family need a team of people to directly support Luke as well as an organization to provide this team with support. Financial assistance would be required to modify the property to make it safe for Luke (approximately $20, 000) plus assistance with wages for direct care support. This would be considerably more cost-effective than previous alternatives. Most importantly, Luke would live in a happy, healthy environment.

Section Two: Specific Responses to Inquiry Terms of Reference

Firstly, there are the responses for The **Legislative Assembly** and **Legislative Council**'s terms of reference, and then the responses to questions posed by The **Family and Community Development Committee**.

Responses for the Legislative Assembly and Council

The terms of reference listed by the Legislative Assembly and Council invite comparisons between "current state" against "best practice" in the following areas – the standard and range of accommodation and services currently available, the different models for service delivery and funding currently offered; the methods for measuring unmet demand for accommodation and how these can be improved; the process for managing service quality; availability of sufficient accommodation to meet future demand with an appropriate range of services; access and service issues for particular groups, including rural communities, culturally and linguistically diverse communities and indigenous Australians; and the impact on families of the current service provision of accommodation.

Standard and Range of accommodation with Description of Current Supported Accommodation

Luke has experienced 4 types of supported accommodation in at least 7 specific locations and supports from at least 10 different service providers.

1. In Home support, mainly 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 (UCCO (Uniting Care Community Options), Access Unlimited, MECWA, MSSA (Melbourne Specialist Support Agency), EACH (Eastern Access Community Health) and Monash City Council HACC Services) and some support from professional PCC (Psychiatric Care Consultants) nurses.
2. Children's Respite Services ("Swonnel House" SASI; "Healesville Home Stay" Vicki Colgrave; Sevenoaks DHS-EMR-DAS; "Mount Eliza Home Stay" AU)
3. Emergency Respite "Traverse" DHS-EMR-DAS; "Greenock" DHS-EMR-DAS)
4. High Dependency Residential Accommodation ("The Crescent" DHS-EMR-DAS)

The following information is in addition to the specific details of Luke's home and accommodation support given in Section One.

Previous In Home Support

Luke's home in Mount Waverley was occupied by his parents and five children, all younger than himself, and their friends. Mum, Dad, some family friends, and in later years, his siblings, provided Luke with support at home. From 2000, DHS provided 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 no 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. This was unrealistic given base rates of pay and Luke's requirement of professional support. 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.

A case manager was allocated for a time (typically 6 months) but his level of expertise meant that poor advice was given to the family and carers; services and communication failed. None of the case managers were able to provide adequate support to the family, the workers, or to Luke. We found that taking on "case management" for Luke ourselves was less stressful than relying on someone else. Our recommendation is that where a family has the ability to do so, funds should be invested in helping families become good managers of their own supports.

Current Support; "The Crescent" DHS-EMR-DAS

Luke is now living at "The Crescent", a "secure facility" for high dependency accommodation; "the only property with the fabric and design to be able to support someone like Luke". It took DAS almost twelve months to organize a place for Luke and there are no current plans for him to move elsewhere. "The Crescent", a large single storey house on a bush block near Mount Evelyn, is home to Luke and three older people. The house is usually staffed at a ratio of 1:1; i.e. 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. Every night is an active night with a minimum of two staff on duty at all times. The Crescent was built as a "staging place" but it seems to have become the permanent residence of all four of the current occupants. Luke pays a nominal rent based on a percentage of his pension, plus a contribution to household costs such as food. The cost of operation must be of the order of $1.5M pa.; at least, $350,000 per resident per annum.

Like 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 Quality Systems Audit. We welcome these experts and the work they are doing as necessary parts of improving the support for Luke.

Despite these interventions, we are not happy with the service. Luke has been neglected and some policies of DAS management, along with the behaviour of some staff, have resulted in serious breaches of Luke's human rights, his right to good quality disability supports and his dignity. Luke is being denied any opportunity to live a good life despite his disabilities.

Luke receives about 12 hours a week of "day program" support from a private company that is funded through the "Futures for Young Adults" (FFYA) program. Other than that he is mostly locked up in his area with little to support him in meaningful activity. Sometimes he is taken for long drives through the country side. Despite often having two carers with him on such drives, Luke is rarely allowed to get out of the bus on such trips. "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 anyone to visit that place to see first hand. Any visitor would not want to live here permanently.

In summary of Luke's experiences, the standard of accommodation service has ranged from poor to abysmal. Luke has been abused "in care"; his enforced living conditions have, at times, been in breach of basic human rights. There is no "range of accommodation". Even with the intervention of our local Member of Parliament, we were forced to accept what was currently available or nothing at all; "there is no alternative". How can the DHS not have planned appropriately? Our son was diagnosed as having autism and being eligible for disability support when he was four years old. From then, it was recognized that his condition was severe and he had high support needs. There was no recognition of the need and no planning to suit special accommodation for Luke when he turned 15. Our experiences at other respite houses have alerted us to the fact that, even today, 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 supported accomodation outside of the family home.

Extent of accommodation and services

The extent of support is limited. When we asked for accommodation staff to provide specialist activity support such as "helping Luke to finish his homework", we were told that support was limited to "accomodation only". 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. By way of contrast, in the USA provider example "Jay Nolan Community Services"[2], support persons are highly trained, and are constantly vigilant in their support of the eligible person, becoming almost indistinguishable from a friend or family member.

Adequacy of current number of places

There is not and never have been enough places.

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 the places outside of his home, he has been subjected to significant breaches of basic human rights.

Measurement of Unmet demand

Measuring demand has not been done. At a recent forum set up in support of the state autism plan, I asked "how many people are we talking about?" None of the departmental or government representatives could, or would, answer the question. Statistics could be readily collected via Medicare on the number of children presenting for diagnosis.

How much support do disabled people need and how much can be provided by friends and family, and then how can the government assist? What is needed a transparent process for collection, collation and representation of all data coming in from the field. We have at least 20 years of statistics indicating the effects of family and government support to answer this question. When the law was changed to ensure that every eligible person was to be supported with a General Service Plan, the level of need should have become plain. The problem was that those people implementing the plans did not understand the links back to resources. Plans became motherhood statements and dreams 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 the need for resources. It should be possible to have every individual plan set such that natural supports (family, friends, community) can indicate their capacity to help and the DHS can respond with meeting further need, including taking shortfalls to Parliament for further financial assistance.

Another suggestion would be to run an internet poll. Most people have access to the internet and 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 to send them an invitation and have case management staff help them complete it. It might even be possible to help people fill in such surveys over the phone.

The DHS is not reporting honestly or accurately the real needs of people in our community. It works from a basis of managing within budget restraints. We would like to see this situation changed so that the planning happens at the grass roots level, so that resources are determined at that level, and that need is reported honestly and efficiently through the system to enable appropriate planning and budget allocation at the highest level.

We have seen public servants within the Department of Human Services and Department of Education wind back Luke's requirements in order to meet the budgetary constraints. Or, as in the past, they have overstated the family's need knowing that higher bureaucracy will wind back the result anyway. In our application for out of home accommodation support for our son Luke, we declared only the truth about our situation. The result was a letter saying that our son was not eligible; there was no recognition of our desperate need.

---

[2] www.jaynolan.org

Appropriateness of mix of service providers

As shown by current practice, the DHS in its current structure and culture cannot provide the support needed by people with autism. World-wide best practice examples show that success comes with strong leadership from management who are willing and able to provide direct support, even to the toughest clients. Success includes accountability, close supervision and training for the workers, and an appropriate level of funding. The unwieldy size and nature of DHS makes it unable to meet individual needs effectively. The DHS should stick to its core responsibilities as a government arm and focus on policy, funding, and regulation, doing everything it can to back high quality supports from community and non government organizations (NGOs) for people with a disability. Currently NGOs in Australia cannot provide support to the most needy because they are not funded properly and they are hindered by bureaucratic practices which do not care about the people they are being paid to support.

Alternative Approaches to meeting unmet need

In Victoria, there is much good work being done privately with alternative approaches to meeting unmet need. Our own methods of data collection, planning and project management are available to share with others who deal with people with special needs of varying degrees of difficulty. For our own future support, when Luke is living close to home, and for all who need support to work with disability, our aim is to motivate people to work together. Anyone wanting more information can contact us and ask for a copy of a presentation called “HAPPY PEOPLE HELPING PEOPLE”.

Managing Service Quality

There is a significant lack of good management practice being applied within DHS and this adversely affects the quality and quantity of services being delivered to needy people. A senior member of DHS staff recently explained that the hierarchy in DHS is like a star; pointy bit at the top, a wide area in the middle and with a squashed, but still divided, two legs at the bottom. These two legs are the coal face – one leg, those remaining who really cared and, the other, those that were simply in it for the money – a job. We have many suggestions of improvements to management practice that we would be happy to share. These include strategies for handling meetings, written communication, focusing on the what is important for the client, complaints handling, planning mechanisms, and project management.

Future Demand versus Current availability

The rapid increase of those diagnosed with autism is a world-wide phenomenon. Future demand for support in Australia is increasing rapidly yet current availability of appropriate supports is close to nil. If we take no action, the future support for autistic people will be unsatisfactory, possibly illegal, demoralizing and dehumanizing. It will continue at an cost of anything from ~$200,000 - $500,000 p.a. for people with high support needs.

There is currently no plan to build new faculties or provide different service for Luke. Therefore, we have been taking steps ourselves; buying the house next door, buying a specially modified car and working with local services providers and community groups to build a supportive network of helpers.

Estimates of Future Needs

The cost of the failure to meet the needs of individuals and families affected by disability continues to increase; the Department of Human Services is unprepared to meet these needs.

Planning for future need should start with the collection of statistics from diagnosing practitioners and the Department of Education so that a clear base is established of numbers requiring assistance and their range of needs. 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.

Government Response to Future Needs

Government will be able to respond appropriately to current and future needs once it implements a more rigorous approach to planning and collecting real data and then correlating these needs to budgetary constraints. The 2006 Disability Act states that every person who seeks a service is eligible for "support to conduct planning" but our experiences demonstrate that a family's planning is not connected to the budgetary processes and is hindered by middle management and poor business practices.

Access for Particular Groups

The harder we try to get better services for Luke, the worse his situation becomes.

The system makes it easiest on those the simply choose to "give up early".

A friend's work colleague, on hearing the diagnosis of autism, took immediate action to have his two children placed into permanent 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.

For those of us who struggle on, it is a perpetual nightmare that haunts us every day. This nightmare 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.

Access for Country Victorians

We live in the Eastern Suburbs of Melbourne; we would like to move to small country town, because we believe that environment would be better for Luke. If we did so, we would not have access to good quality professional support or direct, "hands-on" support for our son.

As an example of how rural and regional communities can be properly supported we would suggest a quick look at The Judevine Centre for Autism in Missouri, USA. It provides a city based training service for families and carers, complemented by satellite offices which serve small and rural communities; www.judevine.org

Access for culturally and linguistically diverse communities

The Department of Human Services should develop clear, client-friendly ways to deal with planning and managing projects especially in the language used in meetings, correspondence, forms and report-writing. Despite us being professional people, and with English as our native tongue, we find it difficult to access services and to maintain appropriate levels of communication with DHS people. We can only marvel at the tenacity of those who struggle with English not being their first language as they deal with the DHS.

Impact on Families

The effect of a failure to plan and provide appropriate accommodation and disability supports for an individual can be devastating. We have just lost a child and suffer constant anxiety and frequent bouts of depression because of the pain and grief of having a family member living in appalling DHS supported accommodation.

We have never met a family that is happy with DHS support. Those families who are happy get their support from close knit, small, privately run, and often, privately funded, organizations.

A Neurologist wrote to us, in response to the ABC-TV presentation of Hannah's story[3] -

> "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".

---

[3] "Hannah's story" can be viewed online at - http://www.abc.net.au/austory/specials/leastlikely/default.htm

Answers to questions posed by the Committee

The eight questions posed by the Committee are similar to questions of the Assembly and Legislative Councils, namely Availability, Suitability, Adequacy; Access – information, planning and decisions making; Other approaches for – funding, planning and delivery; Alternatives to Supported Accommodation; Comparison of Private, Government, Community Sector; Current Approach - Affect on Families and Carers and Issues relevant to a persons location, background and culture.

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?*

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; we are told that there are no other options.

The accommodation and supports provided are not suitable; forcing four people with severe autism and disparate needs to be living in the same space is unsuitable. These four people have high support needs yet most of the staff have little or no training to provide supports. The care provided by some staff is adequate but mostly our son is left alone and neglected.

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?*

Access has been made very difficult by the lack of professional support provided by people working for the DHS. Whether or not this lack of support is due to poor DHS resources, something must be done to ensure that the process is made easier for those who need support. Information is often sketchy and poorly presented. Rarely has information at the ground level been presented in a professional manner. Evidence of any real planning is almost non existent. Decision making has been underhanded and without robust process or accountability. Many significant decisions have been made without due consultation, are not properly documented and rarely satisfy the persons seeking support.

Other approaches for – funding, planning and delivery

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

In order to understand the practical implications of the then new legislation and its references to planning we created a short paper – “Planning to Live Well”. Many people say that is is a far better and more comprehensive explanation of the total process than any DHS paper. A summary has been provided as an appendix to this document.

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 have a plan to get our son out of his current “supported accommodation” and organise the supports that would enable him to live “in his own home close to home”. Despite significant setbacks, including DHS actions, we are still working towards this dream.

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?

The government should make arrangements to -

- Give free and fair choice for the provision of disability supports for all people regardless of their level of need. Just because a person has greater needs it shouldn't mean they have to be supported by DHS' own DAS (Disability Accomodation Service). It is currently an unfair situation where DAS managers can say "we end up with all the cases that none of the NGOs can handle" and also "we can pay our staff more". NGOs say they 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".
- 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. In some cases, the DHS will not allow parents to know the identities of individuals who are providing support to their children, let alone allow disability workers to become involved in campaigns aimed at raising public awareness of the need or the joys of providing good services. The DHS issues around privacy are damaging to the building of community awareness and support for people with disabilities.
- develop clearer Standards to assist in the development of services
- make transparent both the Monitoring of Performance against these standards and the use of funds for their provision
- Implement transparent monitoring of Customer Satisfaction via regular surveys.

The Government should facilitate disability support through NGOs which are more effective and efficient. There is a stark difference in government and private services; DAS managers say that "we are an accommodation only service provider" while as an example - Integrated Education and Communication (IEC) people do much more, supporting Luke in everyday activities, teaching him and helping him grow in confidence and self esteem.

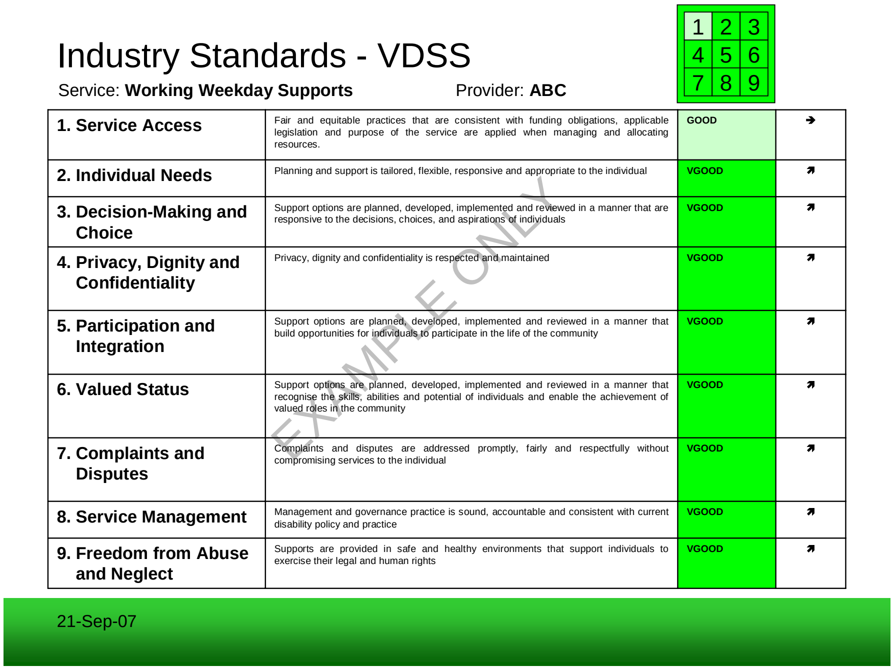
The main argument against privatisation is that the government as provider will protect vulnerable people from abuse by unscrupulous service providers. It is transparency of operation and customer feedback that provide the greatest defence against abuse. With everything that DHS has in place today, abuse is still occurring.

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 but hinder it, by taking inordinate amounts of time and resources to process claims that invariably are denied.

We question the merit of DHS continuing to provide housing stock. It may seem sensible for the Government to retain ownership of such assets, but it has a poor track record in the design and maintenance of them. For example, "purpose-built homes" have huge bathrooms and a "living area" smaller than a toilet cubicle. Another recent example was a kitchen with a servery opening and a shutter that could be closed to keep residents from climbing into the kitchen. One resident demonstrated his ability to climb under the shutter as it was being closed, so the department deemed it a safety risk. A heavy, new shutter was installed, a remains closed and locked for most of the time.

The Committee's assessment should be made on the basis of the formal evaluation of performance against standards and on the feedback from customers. Currently there are no adequate tools to collect such information for a fair assessment; customers feel frustrated and unheard.

In the past, we have used a simple template for assessment of service provision against known standards but it was not useful as a tool for collecting customer feedback. There are alternatives such as this following example, one of ten slides in a "do it yourself" presentation aimed at enabling service users and their families to validate the services they receive –



Industry Standards - VDSS

Service: **Working Weekday Supports** Provider: **ABC**

1	2	3
4	5	6
7	8	9

1. Service Access	Fair and equitable practices that are consistent with funding obligations, applicable legislation and purpose of the service are applied when managing and allocating resources.	GOOD	→
2. Individual Needs	Planning and support is tailored, flexible, responsive and appropriate to the individual	VGOOD	↗
3. Decision-Making and Choice	Support options are planned, developed, implemented and reviewed in a manner that are responsive to the decisions, choices, and aspirations of individuals	VGOOD	↗
4. Privacy, Dignity and Confidentiality	Privacy, dignity and confidentiality is respected and maintained	VGOOD	↗
5. Participation and Integration	Support options are planned, developed, implemented and reviewed in a manner that build opportunities for individuals to participate in the life of the community	VGOOD	↗
6. Valued Status	Support options are planned, developed, implemented and reviewed in a manner that recognise the skills, abilities and potential of individuals and enable the achievement of valued roles in the community	VGOOD	↗
7. Complaints and Disputes	Complaints and disputes are addressed promptly, fairly and respectfully without compromising services to the individual	VGOOD	↗
8. Service Management	Management and governance practice is sound, accountable and consistent with current disability policy and practice	VGOOD	↗
9. Freedom from Abuse and Neglect	Supports are provided in safe and healthy environments that support individuals to exercise their legal and human rights	VGOOD	↗

21-Sep-07

The Committee should make implement good customer feedback tools such as this one, in keeping with **ISO10002** – "Customer Satisfaction - Guidelines for complaints handling in organizations".

As a government organization, DHS is unable to allow or promote the sort of innovation that will be required in future, neither can it be flexible enough to change and keep up with new knowledge and best practice. After years of dealing with a vast and complex array of needs without enough resources, for the DHS, there are, at best, only "conditions to be managed" or "issues to be dealt with". Such a view cannot promote innovation; only with a "can do" attitude will we get the innovation required to develop, provide and maintain good quality supports to people with disabilities. By way of contrast is the recent example shown by the Government of Tasmania to provide satisfaction to the vast majority of service users and providers alike.

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?*

The effects are devastating. 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 (see the edition of the Australian Story called "The Girl Least Likely").

Accessibility Issues for specific people groups

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 there is a good model for service delivery that was developed by the Judevine Centre for Autism in Missouri, USA (www.judevine.org). Instead of forcing people to come to the city to receive services, Judevine 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. The biggest issue for people living in rural and regional communities is access to both appropriate professionals and direct support workers; the Judevine model addresses both issues.

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 help everybody, regardless of their cultural background or language.

Even though I am not an indigenous Victorian, I 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.

Section 3: Suggested planning and provision of accommodation and disability support

The conclusions of this report on disability support are clear. There is not enough accommodation or support, leaving families devastated. Government responses need attention as there are inevitable, growing future needs. Service providers should be supported to operate according to best practice in business management as well as in the provision of direct care and support.

A positive approach to people working with disabled people should be promoted. Access to appropriate supports can only be improved through a massive change in community attitude, leading to agreement that Government spend more money on training, best practice management, housing, better pay for workers, and a recognition of the fact that everyone can benefit from helping. More than building more housing stock or managing group homes, what is needed is more positive people who have developed appropriate skills through professional training and supervised experience to work with disabled people. What is needed is the wide scale promotion of caring as a noble profession, an opportunity to become a better person[4], and lead a purposeful, valuable part in life.

DAS management need to publicly acknowledge the role of parents, and promote the importance of maintaining good relationships and practical supports for the families of those people who are living in supported accommodation. Our experiences as parent guardians has left us deeply saddened and stressed with little recognition shown to us of the grief that separation causes. We want to be valued as an enthusiastic family, to be supported and equipped to manage Luke's situation. The current government policy which denies legal status for early separation of the child and parents is a good one, but more support is needed for the family in the early and teenage years. 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.

Better training and provision of services are urgently needed. Budgetary planning for disability services must include funds for ongoing professional development and refresher training. Training should be followed up with close supervision and appropriate accountable performance monitoring - especially in areas of high support need. In the field of autism, the techniques, practices and new knowledge are growing rapidly so that workers are applying out-of-date practices after six months. A review of current specific training of staff working in houses would reveal a significant lack of training. In a recent Quality System Audit survey of "The Crescent" (commissioned by the Senior Practitioner, carried out by Lisa Fahey from QUOVUS), results showed that none of the staff recognized "communication" as relating to residents becoming upset. A fundamental understanding of autism is that anger is evidence of frustration at their lack of communicative ability. Likewise, the power of supporting good behaviour was not identified in staff procedure; e.g. Teaching Luke house rules was done by a series of "Do not…" commands. Basic teaching methods and instructions for autistic people (and just about everyone else) are done by positive reinforcement of good behaviour. Correlating this lack of sound training to the number and severity of workplace injuries should provide fiscal incentive to invest in more staff training.

Autism is a complex disorder and a "one size fits all" approach to the provision of services is not appropriate. For people with high and complex support needs such as Luke, 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. In those situations support staff get specific training that is tailored to each person. For example, staff employed by Calvary Silver Circle for "Specialist Children's Services" receive training specific to each child they support. This 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 then it only happens if the worker is happy and confident to do so. Such training is followed up with on the job examination of all workers and a formal exam - every 6 months. The workers, the families and the people being supported are very happy with this level of scrutiny and accountability.

---

[4] For more information please ask to see a copy of the short presentation "HAPPY PEOPLE HELPING PEOPLE".

Similarly, in the field of working with autistic people, regular training and refresher courses coupled with feedback from service users would enable training institutions to target their training and reinforce their criteria for accreditation. Market forces, backed up by appropriate levels of funding for salaries of trained workers and training providers, will enable good companies and good workers to thrive.

To plan further accommodation and support for people with autistic disability like Luke, there are many examples of best practice, from current service providers who are already effective. Looking first hand, world-wide for "best practice" models, we can recommend two American examples, "The Judevine Centre for Autism" and "The Jay Nolan Community Services". As can be seen from their websites, key to these remarkable organisations' successes is the leadership and positive mind-set amongst their employees. People from these organizations are interested in supporting Australian adoption of their provision models.

"The Judevine Centre for Autism" provides "cradle to grave" supports, starting with intensive training for parents, from the time they get a diagnosis for their child, through to aged care of people in their own homes. www.judevine.org .

"The Jay Nolan Community Services" is renowned for its person centred approach to teaching people to communicate and plan for a life that they want to live. They follow up with the provision of supports which enable people to live in their own homes close to family home. www.jaynolan.org

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.

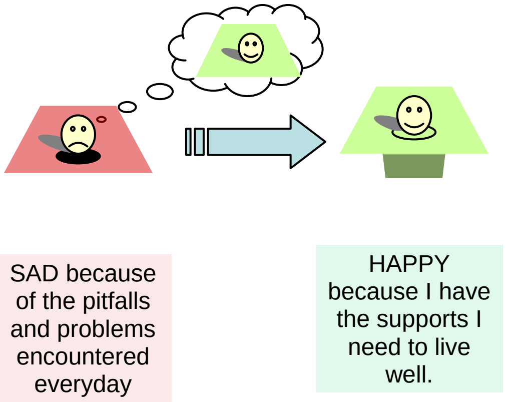
Mark and Ellen Modra
November 2008
11 Saint Johns Wood Road
Mount Waverley, Victoria, 3149
Australia

+61 4 3960 5782 Mobile

Appendices

Planning to Live Well (shortened presentation)

In summary – Planning has three steps –



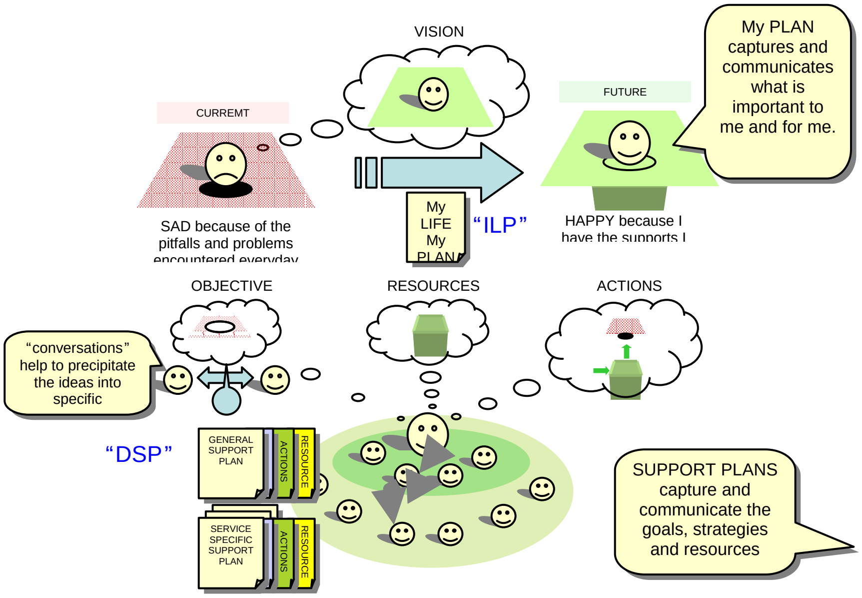
1. where are we now,
2. where do we want to be, and
3. how are we going to get there.

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”.

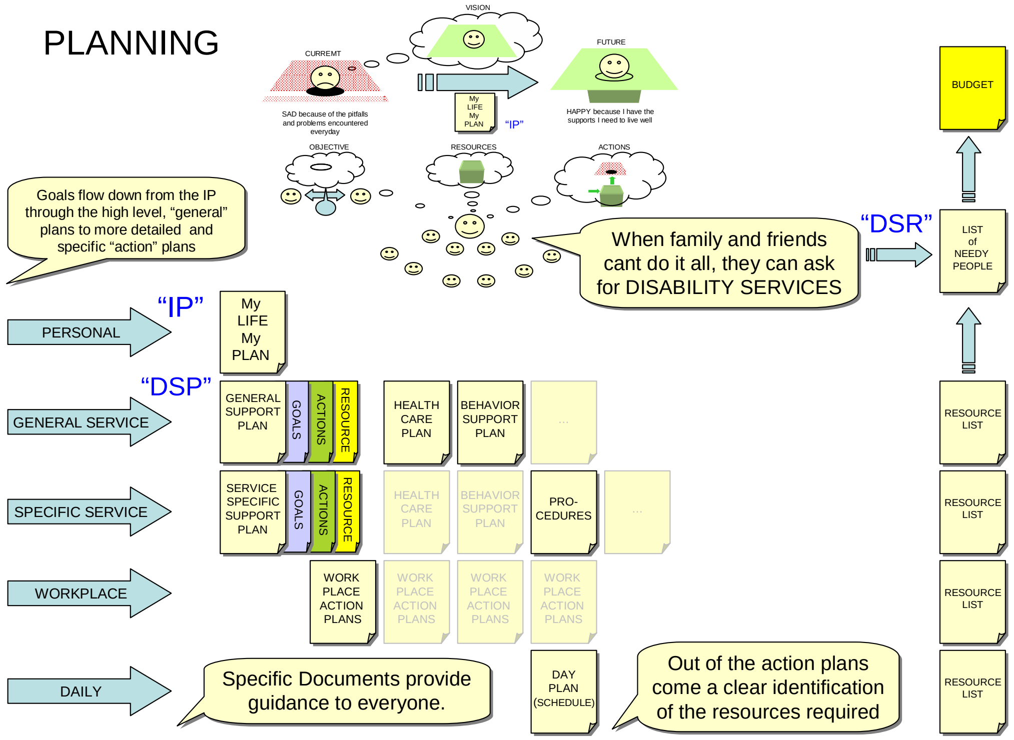


Conversations help to precipitate the ideas into more formal support plans. The Disability Support Plan (DSP) takes its direction from the requirements listed in the person’s life plan. The support plan will list goals, actions and resources.

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 cant 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).

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 – its all about the person - its all about - **planning to live well.**

All of us need it. All of us can do it. All of us can help each other.