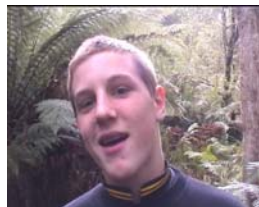


Inquiry into Supported Accommodation for Victorians with a Disability or Mental Illness

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 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 and went to live in "emergency respite" at a place called "Greenock" and then into share supported accommodation at "The Crescent" in Mount Evelyn.

Despite 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.

The 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

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. When Luke's condition deteriorated dramatically in 2000 some specialist home help was engaged but proved very expensive and ineffective. Various respite options were tried. "Swonnel House" was a weatherboard house on a corner block in suburban Moorabbin. "Healesville Home Stay" was a private home, on a large property set in the forested hills near Healesville, modified to suit the needs of children with autism. "Sevenoaks" was a regular sized four bedroom house on a corner block in East Burwood. "Traverse" was a two story house on an extremely small corner block in East Burwood.

"Greenock" was an abandoned secure CRU in Wantirna that DHS allow Luke to use for short term (eg weekend) and eventually longer term "emergency respite" Within four weeks of moving in, as the sole resident, Luke visited hospital four times, suffering 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.

"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.

For the future - 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.

Section Two: Specific Responses to Inquiry Terms of Reference

Responses for the Legislative Assembly and Council

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.

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".

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 “accommodation only”.

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.

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. We believe that relevant data should already be available from medicare and education department records.

Appropriateness of mix of service providers

The DHS in its current structure and culture cannot provide the support needed by people with autism. While they might be willing and able - NGOs in Australia are unable to provide support to the most needy because they are not funded properly.

Alternative Approaches to meeting unmet need

In Victoria, there is much good work being done privately with alternative approaches to meeting unmet need. Some of these are targeted at strengthening the abilities of families while others aim to build community based supports by encouraging people to see themselves as benefiting from becoming someone’s carer and friend¹.

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.

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 a 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

¹ Refer - presentation called “Happy People Helping People”

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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

It seems for us that 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”.

Access for Country Victorians

Regional communities can be properly supported if we were to adopt a model like that implemented by the Judevine Centre for Autism in Missouri, USA. www.judevine.org

Access for culturally and linguistically diverse communities

Despite 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 people from DHS people. Much could be done to improve basic business and communication practice within 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 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.

Answers to questions posed by the Committee

Availability, Suitability, Adequacy

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 still not appropriate but we are told that there are no other options.

Access – information, planning and decisions making

Access has been made very difficult by the lack of professional support provided by people working for the DHS.

Other approaches for – 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”.

Alternatives to Supported Accommodation

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.

Comparison of Private, Government, Community Sector

The government should make arrangements to -

- Enable free and fair choice of provider by funding service providers according to client need.
- Promote the good work that is done by disability support workers in the community.
- Develop clearer Standards to assist in the development of services
- Make transparent both the Monitoring of Performance against these standards
- Implement transparent monitoring of Customer Satisfaction via regular surveys.

Current Approach - Affect 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

To address many of the issues we face today the Judevine Centre for Autism in Missouri set up a city-based training facility which equipped people - families, individuals and support workers- to live and support people in their own, mostly rural communities.

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.

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

There is not enough accommodation or support, leaving many families devastated.

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.

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. 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.

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.

There are many examples of world's best practice that could be used in planning better supports for people in Victoria -

"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
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