The Challenges of Change and Choice

Grampians Disability Accommodation Network Project Report

Joanne Richie
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Contents

Contents .......................................................................................................................... i
List of Figures .................................................................................................................. ii
List of Tables .................................................................................................................... iii
Acknowledgements ......................................................................................................... iv

Introduction
  Disability & Disability Support .................................................................................. 1
  With change, come choice ......................................................................................... 2

The Grampians Disability Accommodation Project
  Background .................................................................................................................. 3
  The Grampians - the project research area ................................................................ 3
    Disability Data .......................................................................................................... 5
    Disability Services – Background ........................................................................... 5
  Project Aims ................................................................................................................. 7

Methodology & Processes

Literature Review ......................................................................................................... 8
  Themes:
    Government legislation – Commonwealth & State Responsibilities ...................... 8
    Commonwealth & State Agreements ..................................................................... 9
    Provision of disability services in Victoria ............................................................. 10
    Current government legalisation in Victoria ............................................................ 10
    Conceptualising Supports & Services ...................................................................... 11
    Housing Options ...................................................................................................... 12
    Support Options ....................................................................................................... 16
    Individualised Funding ............................................................................................. 18
    Family Governance .................................................................................................. 19

Community Engagement ............................................................................................ 20
  Exploring housing & support options ....................................................................... 20
  Empowerment ........................................................................................................... 20
  Recruitment ............................................................................................................... 21
  Grampians Disability Accommodation Network .................................................... 22
  Parents – Background ............................................................................................... 22
    Demographics .......................................................................................................... 22
    Functional Impact of the Disabilities ...................................................................... 23
    Considering Future Living Arrangements .............................................................. 23
    Perceived Future Living Arrangements (with permission to dream) ...................... 24
    The findings – In ‘Real’ Terms ................................................................................. 24

GDAN Meetings ......................................................................................................... 25
  Information Delivery & Discussion .......................................................................... 27
  Drawing from ‘Real’ Experiences .............................................................................. 27

Outcome – Being Informed .......................................................................................... 28
Outcome – Being Empowered ...................................................................................... 29
Liaison & Networking ................................................................................................................................. 32
DHS Disability Services ............................................................................................................................ 32
Disability Service Providers ....................................................................................................................... 32
Disability Networks & Networking ........................................................................................................... 32
Community Service Organisations – Accommodation Projects .............................................................. 33
Local Information ........................................................................................................................................ 33
Research ....................................................................................................................................................... 33

Findings & Recommendations
The Collection & Collation of Information .................................................................................................. 34
  Access to Information ................................................................................................................................. 34
  Government Legislation & Policy Developments .................................................................................... 35
Information Content & Delivery .................................................................................................................. 36
  Conceptualising Supports & Services ........................................................................................................ 36
  Informing families ....................................................................................................................................... 37
Empowering Parents ....................................................................................................................................... 37
  Empowering Parents to Envision a Future ................................................................................................. 38
Conclusion ...................................................................................................................................................... 38

References ..................................................................................................................................................... 40

Appendix
Appendix 1: Commonwealth & Victorian Governments’ Legislative Timeline ............................................. 44
Appendix 2: State Disability Plan ................................................................................................................ 48
Appendix 3: Conceptualising Accommodation & Support Services .......................................................... 50
Appendix 4: Accommodation Options (Selection) ..................................................................................... 53
Appendix 5: Support Options (Selection) .................................................................................................... 55
Appendix 6: Individualised Funding ............................................................................................................ 57
Appendix 7: Determining Need & Planning ............................................................................................... 60
Appendix 8: Parent Questionnaire .............................................................................................................. 61
Appendix 9: Parent Questionnaire Data ...................................................................................................... 64
Appendix 10: GDAN Meeting Outline ....................................................................................................... 68
Appendix 11: Project Evaluation Questionnaire – Parents ......................................................................... 70
Appendix 12: Project Evaluation Questionnaire – Service Providers ......................................................... 73
Appendix 13: Questions about Support & Choice ....................................................................................... 76

ii
List of figures

Figure 1: GDAN research area ................................................................. 4
Figure 2: Legislation around the provision of home based support 1969 – 1985 ....... 9
Figure 3: The disability supports and services conceptual framework .................. 12
Figure 4: Examples of accommodation supports/services in the disability services
          & supports conceptual model ............................................................ 12
Figure 5: Public Housing summary ................................................................ 13
Figure 6: Housing/Accommodation options ....................................................... 14
Figure 7: Support options ............................................................................. 17
Figure 8: Supported Living ........................................................................... 18
Figure 9: Types of disabilities reported by parents .......................................... 22
Figure 10: Milestones influencing future accommodation & support needs .......... 23
Figure 11: Introducing Dan ......................................................................... 25
Figure 12: Dan’s place ................................................................................. 27

List of tables

Table 1: Description of housing option .......................................................... 15
Table 2: Application process ......................................................................... 15
Table 3: Disability specific issues ................................................................... 15
Table 4: Contact details ................................................................................ 16
Table 5: Roles of participating organisations/workers ....................................... 21
Table 6: Degree of functional impact upon tasks associated with everyday activities... 23
Table 7: Breakdown of the housing & support parents perceive (hope for) in 5 years... 24
Table 8: Factors influencing empowerment (Buchanan 2003) ............................ 30
Table 9: Empowerment – negative & positive experiences of participating parents ..... 31
Acknowledgements

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Project work is an adventure, and this project was no exception. Without the support and encouragement of many it would not be possible. Thanks particularly Norelle Pearce (Wimmera Uniting Care) and Yaso Nadarajah (RMIT) for their guidance and advice.

Acknowledgement must be made of the many people who unreservedly gave their time and shared their expertise throughout the project. Networking was a crucial part of the research process for this project, and with a few rare exceptions, all enquires were met with valuable information, advice and encouragement.

Finally, thanks must go to the parents whose lived experiences inspired and shaped the project. The everyday challenges of family life combined with the uncertainty and anxieties around their sons/daughters future needs cannot underestimated – some days are tough. My hope is that the project will be of value to them; now, or at later time. My reward was their ongoing support and willingness to share their hopes, dreams and frustrations; with opportunities for laughter along the way.

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16th May 2007

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Introduction

Disability & Disability Support

On the 1st of July 2007, the Victorian government’s most recent legislation governing the provision of services and support to individuals with a disability will come into operation. The Disability Act 2006 strives to promote increasing awareness of individuals with a disability as valuable members of the community, and as such, these individuals are entitled to realise their potential in every aspect of their own lives. These changes represent a major shift in the provision and delivery of disability services. Emerging policies aim to provide access to services that people with a disability want and need, rather than having them fit into the available services.

Individuals with a disability, their families and supporters, have been advocating for changes in the way disability services are delivered for a long time. Families in British Columbia (Canada), first proposed the notion of allowing individuals to choose the supports and services they needed and wanted in the seventies. This is in contrast to traditional expectations, which assumed that people with a disability needed to be cared for by a government approved disability service provider, and that the provider knew best.

The emerging approach in Victoria recognises that individuals with a disability are able to be supported to live and work in the community, in ways that reflect the needs and aspirations of the individual. The Individualised Planning & Support approach first materialized, officially, in Victoria in the year 2000; and its full implementation has been outlined in the state’s ten year plan in 2002.

Until the 1980’s, disability services were strongly influenced by the attitudes that came to Australia with the first settlers. Individuals with a disability required care, often within the confines of a large institutions and benevolent societies. In 1962, legislative change recognised intellectual deficiency; individuals were classified, often as children, in terms of their potential to learn. Those deemed to be educable were eligible for community based education and services. The privilege to live as normal life as possible was extended to individuals with moderate to severe disabilities twenty years later.

The process of deinstitutionalisation commenced in the mid eighties, moving individuals from large institutionalised settings into smaller community based residential units. The emphasis on community residential units (CRU’s) was considered to be a major advancement in disability policy; however, experience has revealed that this type of service also imposes significant restrictions on the lives of many residents.

Recognising these limitations and responding to the views of individuals, their families, carers and advocates, the Victorian government is introducing a more flexible approach to housing and support for individuals with a disability; CRU accommodation will remain an option, particularly for individuals with high support needs (including 24 hour care), however, disability services are developing resources for individuals who seek to live with friends or on their own, with less intensive support.

With Change, Comes ‘Choice’

The current trend in the delivery of disability support challenges, (and to some extent threatens) the traditional delivery of services. Rather than offering a set range of programs that target a select group of individuals; services and supports need to reflect upon what individuals with a disability both want and need.
'Choice’ features strongly in the States Disability Plan; as a guiding principle, the notion of choice is closely aligned with dignity and self-determination:

...dignity and self-determination is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live’ p. 9

However, it isn’t legislative change that stories and anecdotes about innovation and transformation in the lives of individuals reflect, rather the fundamental decision not to accept existing service structures and the creation of one’s own network of support. To a certain extent, the use of the word ‘choice’ underplays the potential that the current legislative change offers. It is not about having more services and programs to select from; rather, it is about creating the opportunity to reflect and build on the needs, goals and aspirations of an individual with a disability.

Research has revealed a number of potential challenges inherent to this process. The stories and anecdotes that initially inspire, also confront readers with notions akin to war; language of battles, persistence, risk and courage, convey both a enduring and taxing process that few families wish to take on. This observation was confirmed by a mother whose years of service contributed to a successful family orientated organisation that focuses upon supporting a small group of individuals, to live their own lives outside of traditional accommodation and support services. The introduction of the Disability Act 2006, sets the groundwork for the process of developing responsive and creative support structures for individuals with a disability. There is little doubt that the changes proposed will offer challenges to individuals, their families, and service providers alike.

The goal of the Grampians Disability Accommodation Network project is to empower families to take an active role within the new and emerging processes of exploring and establishing housing and support options for their sons and daughters.

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The Grampians Disability Accommodation Project

Background

The Grampians Disability Accommodation Network (GDAN) evolved from concerns expressed by parents of young people (teenagers & young adults) that have significant disabilities. Conscious of their son/daughter’s support needs, and the ‘normal’ life experiences commonly with adolescence and early adulthood (gains in independence, moving away from the family home); the parents were becoming increasingly aware of the inappropriateness, if not absence of formal housing and support options available for their sons/daughters in their local areas.

The parents were familiar with the existing structure of residential group homes (shared supported accommodation) but remain unconvinced that this type of accommodation would adequately cater for their son/daughters individual needs and desires. That’s if their son/daughter was able to secure a place; at the 30th June 2006, there were 2,364 individuals registered for shared supported accommodation². The parents were also aware that there are changes occurring within Victoria around the type and nature of service provision, but had little knowledge what these changes meant for their sons/daughters future living arrangements and lifestyle.

The parent’s concerns were heard by Parent Support Co-ordinators. Regionally based, the co-ordinators facilitate Support Groups enabling parents to meet on regular basis to share their experiences and concerns with others that care for and support a son/daughter with special needs. In an effort to address these concerns, the co-ordinators had arranged for guest speakers to discuss the emerging types of housing and support available. These opportunities did not have the desired effect; rather than alleviate the underlying anxieties, each opportunity fuelled the uncertainties. Guest speakers spoke of metropolitan based programs, families armed with support packages/resources and individuals who were able to live independently with minimal supervision & support. The parents could not relate these stories to their own lives and sons/daughters who would always require high levels of supervision and support.

Recognising that these experiences were not isolated examples in remote areas the Parent Support Co-ordinators, together with a Family Respite Worker based in Horsham collaborated to submit a proposal for a regionally based project that would work with parents to investigate existing and evolving models of accommodation and support for young people with a disability. Recruiting the support of Rural Access Co-ordinators in the area, a successful application was made to the Helen & Geoff Handbury Fellowship Program in 2006. The funding supported the employment of a Project Worker to research, collate and share information about housing and support with parents over a six month period.

The Grampians Disability Accommodation Network project not only sought to inform parents and strengthen their understanding of the possibilities for their sons/daughter, but also to strengthen the capacity of the parents, and empower them to take an active part in the process.

The Grampians – Project Research Area

The Grampians National Park is a rugged mountain range that lies 260 km from Melbourne in Western Victoria. Dominating the landscape the park has a rich heritage of timber production, gold-mining and quarrying. Today, the Grampians area is a vital source of water for communities in a large part of north-western Victoria.³

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² DHS Disability Services Website – webpage no longer active
The participants in the GDAN project come from a wide and diverse geographical area extending beyond Local Government Areas (LGA), and the regional boundaries of the Department of Human Services (DHS). As indicated by the shaded area in figure 1, the project involved parents from six local government areas. The most northerly LGA, Buloke is in the Loddon Mallee DHS region. The Hindmarsh Shire, Horsham Rural City, Northern Grampians Shire and Ararat Rural City are in the DHS Grampians region. While the Southern Grampians shire is the most southerly LGA, sits in the DHS Barwon South-West region. The Grampians and the surrounding area is the one geographic feature that connects the range of communities represented in this project.

The scale of this area is difficult to quantify. The Wimmera region covers an area of 23,500 square kilometres and draws a population of 44,000 people from the local government areas of Hindmarsh, Yarriambiack, Northern Grampians, West Wimmera Shires, The Rural City of Horsham and parts of The Rural City of Ararat and the Buloke and Pyrenees shires. The combined population of Ararat Rural City and Southern Grampians Shire increases this figure to 71,600.

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5 Long term strategic planning data overview analysis (2003)
Disability Data

Accurate population statistics reflecting the numbers of individuals living with a disability in the project research area is not available. The ensuring data has been extrapolated from statistical information published in 2006. In a 2003 survey, 20% of the Victorian population reported having a disability. Findings indicated that there a slightly larger proportion of people with a disability live outside of major cities compared to those without disability and that 33% of people with a disability have a profound or severe core activity limitation.

These figures suggest that of the approximate 71,600 people living in the research area:

- More than 14,300 have a limitation, restriction or impairment, which has lasted at least six months and restricts their ability to communicate, mobilize and/or carry out self-care activities, and
- That 4,700 of these individuals are unable to complete any or all this tasks without assistance of one or two people.

Disability Services - Background

White settlement in the research area is traced back to the third expedition of Major Thomas Mitchell in 1836 when he mapped the area including the Grampians which he named the Grampian Mountains. His reports of excellent grazing land attracted squatters and settlers to the southern and northern areas of western Victoria. Squatters, many of wealthy English backgrounds soon established sheep farming in south west Victoria. The wool production in the Hamilton area continues to dominate the local agricultural industry providing approximately 10% of Australian wool exports. In contrast, the Wimmera region attracted experienced farmers from South Australia, many of them of German descent. They came to grow wheat in what was to be very different conditions to those in the south. Pastoralists also settled in the areas of Ararat and Stawell. However, the actual origin of both centers is traced back to the discovery of gold, which drew thousands of people to Pleasant Creek and Ararat within weeks of its discovery in 1853 and 1854 respectively.

Health care was soon identified as an essential need throughout the research area. Between 1858 and 1891 hospitals were established and built in at least six boroughs and towns with funds raised within each community. There is little evidence of government support for the establishment of these services, rather it was 'responsible citizens [who] were setting up institutions of a settled, orderly community’ (p. 165).

Gold in the Ararat area was dwindling in 1863 when it was proclaimed a borough; it survived as service centre and became a major rail junction in 1875. In competition against other boroughs and towns throughout Victoria, Ararat was selected as a site for the construction of one of two lunatic asylums in the 1880’s. Until 1994, Ararat had the legitimate claim of having the oldest mental health institution in regional Victoria; its official opening ceremony in 1887

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7 Partnering for the future (2006)
8 In the survey, a person has a disability if they report that they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts core activities.
9 Core activities – communication, mobility and self-care
10 David Reilly – Australian Explorers, Thomas Livingston Mitchell www.davidreilly.com
11 Southern Grampians Shire – Pastoral History www.sghgrampians.vic.gov.au
14 Walkabout – Ararat www.walkabout.com.au
15 Wimmera: A regional history (1973)
16 Ararat Heritage study (1994)
17 Western District Health Services – A brief history... www.wdhs.net
18 Like the ark (1955)
19 Walkabout – Ararat www.walkabout.com.au
preceded Beechworth’s Mayday Hills by five days. The asylum (later known as Aradale) housed the insane as well as feeble, helpless and epileptic patients who required more than ordinary supervision. At the time the Zox commission recommended that mentally ill patients housed in the penal system should be transferred to the Lunacy department for treatment. The Ararat goal, virtually empty since the goldfields ran out and deemed to ‘suffice as a temporary measure’, was acquired by the Lunacy Department as a ward (J-Ward) of the Ararat Lunatic Asylum housing the most depraved and violent men for 107 years.

Stawell welcomed a second institution to the region in 1934. The Mental Hygiene Department purchased the former Pleasant Creek Hospital to house delinquent, mentally handicapped boys under the age of sixteen. Established to relieve over-crowding in of the Child Welfare Departments in Melbourne, the local paper reported that “... a great institution will be raised in our midst – one which will benefit the town of Stawell to a greater degree than was ever anticipated.” p. 1

Institutional care for the mentally ill (and the intellectually disabled) in south-west Victoria was established in Warrnambool in 1957.

Formal community based services for people with a disability in the research area were first established in 1953. Hamilton was the first to have a formal therapy and activity centre for children and adults with a disability. The Warracknabeal community followed establishing services for retarded children in 1959 and hostel accommodation two years later. Similar services began in Horsham (Karkana), Nhill (Coolinda) and Ararat (McGregor House) during the next two decades. A sheltered workshop, The Wool Factory at Horsham was opened in 1982. In each locality, the establishment of these Voluntary Organisations was driven by members of the community. Managed by a volunteer committee, these organisations responded to the needs of people with a disability living in the local area. Prior to 1973 when the education department took on the role, the organisations provided educational opportunities to children with an intellectual disability; after 1973 the focus was shifted to the needs of adults. Day Training Centres were partially funded by the state government on a 4:1 ratio; consequently fundraising was a significant responsibility of each centre’s management committee.

Government funded community based services were introduced throughout Victoria in the seventies and eighties with the emergence of services such as emergency housing, foster care and HACC programs (including Meals on Wheels and in home personal care assistance). In the nineties respite and advocacy services were established to extended the type services and support available throughout the research area. Community based programs that supported individuals with a disability to live independently were also established during this time.

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20 Grapevine (1980)
21 Report of the Royal Commission on asylums for the insane (1884)
22 Grapevine (1988)
23 J Ward – About J Ward www.jward.ararat.net.au
24 Pleasant Creek Special School: 50th Anniversary celebrations (1987)
25 Mental Health Authority Yearly Report (1957)
26 Hamilton Spectator (newspaper) 6th June 1954
27 Woodbine – Services History www.woodbine.org.au
29 West Wimmera Health Services www.wwhs.net.au
30 History (2005)
31 A story of Horsham (1982)
32 Report of the Victorian Committee on mental retardation (1977)
33 Mental Health Authority Yearly Report (1974)
34 A pillar of the community (2006)
35 A pillar in our community (2006)
36 Grampians disAbility Advocacy Association – Information sheet
37 Southwest Advocacy Association – Information for service providers
38 A pillar in our community (2006)
The introduction of the Intellectual Disability Act in 1987 and the release of a Ten Year plan heralded significant changes in the provision of residential support for people with an intellectual disability throughout the state. The closure of residential Training Centres (including Ararat and Warrnambool Training Centres and Pleasant Creek in Stawell) in the eighties and nineties moved people with a disability from institutional care to group homes (Community Residential Units – CRU’s). Ararat and Stawell have a comparatively large number of CRU’s; however these changes have brought residential services for people into other centres such as Hamilton\textsuperscript{39}, Horsham and Nhill.\textsuperscript{40}

**Project Aims**

The concerns of the parents and the ensuring issues that Parent Support Co-ordinators hoped to address in the project extend beyond the services and supports that already exist in the research area. The parent’s anxieties reflect the availability of residential services, the inherent restrictions that they impose upon the lives of the individuals who use them, and the potential for alternative forms of housing and support that may overcome these issues.

The collection of information about housing and support options for people with a disability was a significant component of this project. Although housing and a support were obvious themes; the current legislative changes governing the provision of housing and support in Victoria also needed to be explored. A second component of the project was to deliver the information gather to individuals and families enabling them to make an informed choice. The experience of Parent Support Co-ordinators was that one-off presentations were not effective; parents need the opportunity to hear about a range of information as well as the opportunity to develop an understanding of how it relates to their own set of circumstances. The life of the project was too short to attempt an in-depth study of how parents heard and interpreted information; however their ongoing participation at regular meetings provided an opportunity to discuss and gauge how information could be best presented to facilitate a real/understanding that inspires parents to actively plan and determine their family’s future.

\textsuperscript{39} Background of Mulleraterong Residential Services

\textsuperscript{40} Review of adult intellectual disability services for Horsham & West Wimmera (1996)
Methodology – Processes

The Grampians Disability Accommodation Network (GDAN) project has drawn information from a range of resources that can be categorised into four distinct sections:
- A review of contemporary (and some historical) literature,
- Engagement with parents of adolescents and young adults with a disability
- Liaison and extensive networking with DHS Disability Services, Community Services Organisations and others that deliver services and support to people with a disability, and
- Current areas of research about the delivery of disability services and support

Literature Review

The purpose of this section is to outline the current trends around the provision of, and the emerging ideas about, accommodation and support. This discussion does not include a thorough discussion of the information researched for the GDAN project. As previously established, the purpose of this project was to deliver the information to individuals and families, enabling them to make an informed choice.

In acknowledgement that the potential audience for this report is a broad one, including individuals with a disability, their families and supporters, service providers, managers and policy developers, the project has been structured to accommodate readers both with and without an extensive understanding of the current policies and trends in disability service provision. The report has an ‘attachment’; a separate publication that contains the information developed about specific themes and issues addressed during the project. The hope is that the attachment will provide readers who are not already familiar with these themes and issues, an opportunity to have, at hand, more extensive information to draw from.

Themes

Government Legislation – Commonwealth & State Responsibilities

There are three levels of government in Australia; commonwealth, state/territory and local levels. Disability service provision in Australia is influenced by both commonwealth and state legislation; however, the resources and funds are generally managed by the state. This demarcation goes back to federation in 1901, where Section 51 of the constitution assigned the responsibility of health care funding and provision to the states.41

The commonwealth government has assumed the responsibility for the provision of some disability services and supports, particularly in the areas of financial support and vocational training (employment). From 1910, they introduced the invalid Pension for “people aged 16 years and more who were not receiving the Aged Pension and were permanently incapacitated for work”.42

In response to the return of soldiers from the first and second world wars (many of them with significant disabilities), the commonwealth established the Repatriation Commission. The commission had the responsibility of repatriating returned soldiers into the community. It was expanded in 1945 to become the Commonwealth Rehabilitation Service (CRS), extending vocational training services to any person of work-force age who had a disability.43

41 Can good intentions ensure good outcomes? (1996)
42 Can good intentions ensure good outcomes? (1996)
43 Can good intentions ensure good outcomes? (1996)
Commonwealth & State Agreements

Aside from its responsibilities for the delivery of vocation (employment) services and support, the commonwealth government provides funding to the states and territories for the provision of disability support and services under a joint agreement.

The first joint agreement between the commonwealth and state governments was the Commonwealth State Housing Agreement (CSHA) in 1945. The CSHA has never made provision for disability specific services, but continues to influence the provision of public and affordable housing by the states/territories.44

Between 1969 and 1985 the commonwealth and state governments introduced legislation agreeing to jointly fund the provision of domestic (Home Help) and allied health services that were delivered in the homes of older adults (Aged Pensioners), people with a disability (Invalid pensioners) and their carers. The main goal of this policy was to prevent premature admissions to long-term residential care (Fig. 2).

<table>
<thead>
<tr>
<th>State Grants (Home Care) 1969</th>
<th>State Grant (Paramedical) 1969</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivered Meals Subsidy Act 1970</td>
<td>Home and Community Care Act 1985</td>
</tr>
</tbody>
</table>

**Figure 2: Legislation around the provision of home based support 1969-1985**

The original Commonwealth State/Territories Disability Agreement (CSTDA) was signed in 1992; clarifying the responsibilities of both levels of government and establishing a common framework for the funding and provision of disability services Australia wide.45

Legislation also permitted the transfer of responsibility for the provision of specific types of disability services between the commonwealth and the state. In 1970 the commonwealth introduced the Handicapped Children’s Assistance Act 1970 assuming responsibility (previously that of the states) for the provision of funds in the form of subsidies to meet the costs of providing training and accommodating children with disabilities.46 The Personal Aids for the Disabled Program (PADP)47 and the Attendant Care Support Scheme48 were established by the commonwealth under the Department of Health & Family Services before being transferred to the responsibility of the states in the eighties and nineties. A time-line mapping the changes of legislations, the timing of Commonwealth State/Territory agreements and their impact on Victorian legislation and policy is in Appendix 1.

The commonwealth government’s most recent initiative is the establishment of information and support mechanisms for the families of individuals with a disability to make private financial provisions for the future care and accommodation needs of their son/daughter. The funding package was announced in October 2005.49

The commonwealth government made legislative changes in 2006 that enable parents and other immediate family members of a person with a severe disability to establish Special Disability Trusts for providing care and accommodation for an individual who has a severe disability50. The Family Relationship Services Program provides services that assist family members to reach agreements over the future arrangements, resolving any emerging conflicts and negotiating a settlement in the best interest of the whole family.51

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44 Victorian Regional Housing Council – History of Public Housing [www.infochange.net.au/rhchome/iurhc/history.htm](http://www.infochange.net.au/rhchome/iurhc/history.htm)
45 Can good intentions ensure good outcomes? (1996)
46 Can good intentions ensure good outcomes? (1996)
47 *Now known as the Aids and Equipment Program (A&EP)*
48 *Later known as In-Home Accommodation Support (IHAS) before being consolidated with Homfirst in 2002*
49 Succession planning for carers (2006)
50 Special Disability Trusts: Getting things sorted
51 Planning for the future (2006)
Provision of Disability Services in Victoria

Influenced by the English health system; disability was considered to be a health care issue. Individuals with an intellectual disability in Victoria were housed in asylums, together with the mentally ill, while the provision of care and support for individuals with physical and sensory disabilities (the blind and the crippled) was delegated to charitable and voluntary organisations.

It wasn’t until 1960, when Victoria’s Mental Health Act 1959 was introduced, that state legislation formally recognised that mental illness and intellectual deficiency were separate entities, and provisions were made for individuals to be trained in basic life skills. Nine years later, additional funds were made available to provide clothing and equipment for children living in residential training centres through the Intellectually Handicapped Children’s Amenities Act in 1969; a responsibility states were relieved of the following year.

In 1987 the Mental Health Act 1986 and the Intellectually Disabled Persons’ Services Act 1986 were introduced, formally legislating two separate entities; mental illness and intellectual disability. Reflecting these legislation changes, disability services remained within the state’s health portfolio until the mid to late eighties. In 1984, disability services moved from the Health Department to Community Services Victoria, to be followed by the Office of Intellectual Disability four years later.

In wasn’t until the establishment of the Commonwealth State/Territory Disability Agreement, that Victoria developed legislation for the provision of services for individuals with a disability, other than an intellectual disability. The Disability Services Act 1991 was introduced to bind Victoria to the principles and objectives for service delivery to those in the Commonwealth Disability Services Act 1986.

Current Government Legislation in Victoria

In Victoria, the body responsible for the provision of disability services and supports is the Department of Human Services (DHS) Disability Services Division. The role of the division is to develop policies and guidelines that reflect current trends in legislation and to put them into practice.

The Victorian government wants disability services to focus on supporting people with a disability in flexible ways, based on their individual needs, so that each person can lead the life they want. This new approach represents a major shift in the way services for people with disabilities are provided. Anticipating the scope of the change for funding bodies, service providers and individuals/their families, a ten year (2002-2012) State Disability Plan has been developed. The State Disability Plan specifies the vision of the Victorian government and the principles that underpin the plan; equity, self-determination, diversity and non-discrimination. A more extensive summary of the plan is in Appendix 2.


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52 Can good intentions ensure good outcomes? (1996)
53 DHS Disability website: Disability Legislation in Victoria http://nps718.dhs.gov.au
54 The living history project (2004)
56 Victorian State Disability Plan (2002)
57 Victorian State Disability Plan (2002)
58 DHS Disability website; Disability Legislation in Victoria http://nps718.dhs.gov.au
The Disability Act 2006 provides the framework for a whole-of-government and whole-of-community approach to enabling people with a disability to actively participate in the life of the community. It also provides for a fairer and more coherent approach to the provision of services for people with a disability in Victoria.\(^{59}\)

The Disability Act 2006 sets out the legislation governing all aspects the provision of disability services and supports, including the rights of the individual with a disability. Broadly, the areas include:\(^{60}\)

- Inclusion in the community
- Access to disability services
- The strengthening of rights in residential services
- The provision of better complaint and review systems
- The provision of high quality services
- The protection of the rights of people subject to restrict interventions & compulsory treatment

Conceptualising supports and services

A central tenant to the Disability Act 2006 is the provision for:

* A stronger whole-of-government, whole-of-community response to the rights and needs of people with a disability

The whole-of-government, whole-of-community approach, represents a shift from the traditional expectation that individuals with a disability need to be cared for by an authority-approved disability service that *knows best*. The current approach recognises that given the skills and resources, individuals with a disability are able to be supported a number of different ways that can enable the realisation of the individual’s dreams and aspirations.

The philosophy driving the whole-of government and whole-of-community approach, is that human needs do not respect organisational barriers, thus the placement of ‘disability specific’ services would be more responsive to individual needs if they were placed “within the broad field of human services for all people.”\(^{61}\) This is not an easy idea to conceptualise, and given the emphasis the Disability Act 2006 places on the whole-of government and whole-of-community approach, an assumption that the approach is a *unique* one, is tenable.

In an attempt to exemplify the concepts of the whole-of government and whole-of-community approaches, a model was sought, that would illustrate the diversity of sources that services and supports for individuals with a disability can, and do draw on.

The adaptation of Disability Services Queensland’s *Disability Supports and Services Model*\(^{62}\) is described in Appendix 3. Essentially the model has five tiers, each one representing a different level of service provision and target group (Figures 3 & 4).

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60 About the Disability Act 2006 (2007)
This model builds on the assumption that generic services and supports would be accessed initially. If (or when) the services/supports represented by the lower levels of provision are insufficient, service and supports represented by the higher levels are then considered.\(^\text{63}\)

It is important to note that each tier is not mutually exclusive; individuals and their families can (and do) utilise several services at any one time. Nor should it be assumed that the use of services at a higher tier (eg Outreach) negates the need for service/supports from a lower tier (eg private rental). What this model does provide, is a visual representation of whole-of-government and whole-of-community approach, that is strongly promoted in the Disability Act 2006.

**Housing Options**

Information about housing and accommodation options was sourced from DHS publications (Disability Services Division and the Office of Housing), the internet, Community Based organisations and in many cases, word of mouth. Once a type of housing/accommodation was identified, information about it was consolidated. An example of the range of information that could be collected for a type of housing is in Figure 5. A wider selection of housing/accommodation options is in Appendix four.

\(^{63}\) Funding reform project: Issues Paper – Demand for disability services (2002)
Public Housing - Director of Housing owned houses
- Eligibility determined by income & assets
- People with a disability are prioritised
- Office of Housing will complete modifications as required

**Waiting-list**

**Grampians Region**
- Ballarat - 104 with priority, 549 not prioritised
- Horsham - 18 with priority, 98 not prioritised

**Barwon South West Region**
- Warrnambool - 33 with priority, 384 not prioritised
- Portland – 6 with priority, 92 not prioritised

*Tip: If 2-3 people apply to live together in Public Housing the chance of being allocated a house is greater than a single application for a one-bedroom house*

**Note:** Waiting list numbers were current at December 2006


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**Figure 5: Public Housing summary**

The conceptual level of each type of housing/accommodation option was not always as ‘clear-cut’ as anticipated. Drawing on the nature of the Disability Housing Trust (DHT), as an example, which is an independent property holder, established to ‘promote and develop new housing options and encourage new investment for people with a disability.’

DHT is a non-government charitable trust working to develop a portfolio of housing assets, specifically for individuals with a disability. The initial injection of state government funds ($10 Million), focus on providing housing for a specific population group (people with a disability) and links to DHS Disability Service indicate that it would be a level 1 option (*disability specific service*). However, the trust is dependant upon financial contributions from commercial, community organisations, philanthropic and individuals. This reliance on finding sources outside of the government, and the potential for the trust to promote accessible housing to property developers and other investors, imply that the DHT could develop sustainable outcomes drawing on Level 1 (*Generic, community supports*) and Level 3 (*private funding*).

DHT was not the only housing option to present this challenge. The range of housing options identified in the project is clustered according to corresponding conceptual levels in fig 6.

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64 Disability Housing limited – Factsheet
Figure 6: Housing/Accommodation Options
The range of different housing/accommodation options identified in the project was too extensive to summarise in one session; GDAN members also recognised that the information made available during the project, would be valuable reference material for use at a later date. To ensure the information would be a valuable resource, an alternative format was produced. A table was developed incorporating:

- A brief description of the housing/accommodation option (Table 1)
- A summary outlining any application processes (Table 2)
- Any disability specific information about the housing/accommodation (Table 3)
- Contact details for housing/accommodation services available in the Grampians and Barwon South-west regions (Table 4)

<table>
<thead>
<tr>
<th>Type of Housing Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Housing</strong>, Office of Housing</td>
</tr>
<tr>
<td>Housing assistance provided &amp; managed directly by the Office of Housing (OoH), DHS. Public Housing focuses on providing suitable, affordable and accessible. Housing is targeted to those in greatest need, delivered cost-effectively and in co-ordination with support services where required.</td>
</tr>
<tr>
<td><strong>Tip</strong></td>
</tr>
<tr>
<td><em>If 2-3 people apply to live together in Public Housing the chance of being allocated a house is greater than a single application for a one-bedroom house</em></td>
</tr>
</tbody>
</table>

Table 1: Description of Housing Option

<table>
<thead>
<tr>
<th>Process of Application</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Housing</strong>, Office of Housing</td>
</tr>
<tr>
<td>To be considered for Public Housing, an applicant must:</td>
</tr>
<tr>
<td>- Not exceed current general income &amp; asset eligibility limits</td>
</tr>
<tr>
<td>- Live in Victoria</td>
</tr>
<tr>
<td>- Not own, or part own a house, unit or flat</td>
</tr>
<tr>
<td>- Have Australian Citizenship</td>
</tr>
<tr>
<td>- Repay any moneys owed from a previous public housing tenancy or Bond loan</td>
</tr>
<tr>
<td>Complete the General Public Housing Application Form OR apply for priority housing via the segmented waiting list system</td>
</tr>
<tr>
<td>Wait-turn Income Eligibility</td>
</tr>
<tr>
<td>- $420 per week, for a single adult OR</td>
</tr>
<tr>
<td>- Centrelink income (Disability Support Pension)</td>
</tr>
<tr>
<td>$30,000 Asset Limit ($60,000 where MAJOR or FULL home modifications are required)</td>
</tr>
</tbody>
</table>

Table 2: Application process

<table>
<thead>
<tr>
<th>Disability Specific Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Housing</strong>, Office of Housing</td>
</tr>
<tr>
<td>Early Housing – Supported Housing</td>
</tr>
<tr>
<td>People with specific issues can be prioritised when waiting for housing</td>
</tr>
<tr>
<td>People who have high support needs or need major disability modifications to their home are given second priority status on application</td>
</tr>
<tr>
<td>Home modifications</td>
</tr>
<tr>
<td>Considered on recommendations by an Occupational Therapist</td>
</tr>
<tr>
<td>Recommendation need to be documented in Special Accommodation Requirements form</td>
</tr>
<tr>
<td><strong>Note:</strong> Tenants in Office of Housing properties are not eligible to receive Commonwealth Rent Assistance</td>
</tr>
</tbody>
</table>

Table 3: Disability specific issues
Table 4: Contact details

This process was completed for each housing option (including the two housing programs) and compiled into a Housing/Accommodation Matrix. The matrix can be viewed in the attachment to this report.

Support Options

The identification of support options mirrored the processes described previously. Information was gathered from a range of sources, and collated into a Support Matrix (available in the attachment). Conceptually, support options are not as easily categorised as the housing and accommodation options were. Actual services, such as case management, flexible support packages, CRU’s and HACC funded programs, were readily identifiable as government funded Level 4 and 5 (disability specific, targeted & whole-of-government).

Others support options, such as shared accommodation, key-ring models and circles of support, could be established by drawing on resources from one level. However, depending on their development they have the potential to draw from one or more additional sources. One example is a circle of support; the establishment of a group of people (friends, family and community members) that meet on a regular basis to help somebody accomplish their goals in life. This type of support certainly has the potential to draw from the wider community. This circle of people may initially involve immediate family members and possibly a few close friends, and then could grow to include other people from the community. This, and other variations are illustrated in Figure 7.

Descriptions of a selection of accommodation supports are in Appendix five. Readers will note a division between specific forms of support and types or models of support. The models of support reflect the emerging concept of supported living (Fig 8) that promotes lifestyles that reflect the aspirations and goals of the individual with a disability.

In 2005, DHS Disability Service launched the Accommodation Innovation Grants. Funding was granted to 15 agencies throughout Victoria to source and establish long-term and sustained housing options for people with a disability. The projects draw from the principles of supported living, working directly with individuals to establish both housing and support within their local community. Each project works with a small number of individuals (10-25) ensuring a unique and responsive service is available for each person.

There are currently no innovation accommodation projects in the Grampians Region. The two projects in Barwon South West Region are based in Geelong66, prohibiting access for families involved in the GDAN project.

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65 Circles of Support - [http://www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)
66 My Own Place (Karingal, Geelong) and Local Accommodation Support Project (CREATE, Geelong)
Supported/Living

Supported living is a concept that operates on the belief that "all people can be supported to live in the community regardless of the level of disability of behavioural considerations." Principles of supported living include:

1. **Separation of housing and support** – the agency coordinating/managing support has no organisational connection with the landowner
2. **Focusing on one person at a time** – identification and responding to what the individual wants
3. **Full user choice & control** - Individuals choose where they live, who they live with (if anyone), who supports them and how
4. **Rejecting no one** – no criteria’s or barriers exist for accessing services, the implicit assumption of supported living is that everyone can live in the community
5. **Focusing on relationships** - making use of informal supports and community resources. The starting point is to build on a person’s existing relationships and connections; people who are in the individual’s support network should promote networking with others who can provide advice or assistance

Figure 8: Supported living

**Individualised Funding**

*Individualised funding* is public (government) funding that is allocated to the individual on the basis of their needs and aspirations. Traditionally, funding was allocated to organisations in *lump sums*, it was the role of the organisation to determine how the money was used to fund the services they provide. Individualised funding promotes a shift in service provision and determination. Rather than organisations having the power to decide who will be served and how; funding is allocated to the individual (according to demonstrated need). They (and their personal network) in turn determine how the funds are used. A more extensive discussion about the development of individualised funding and an outline of the adoption of individualised funding in Australia can be found in Appendix six.

Individualised funding is a key component of the *Individualised Planning and Support (IP&S)* approach that was introduced by DHS Disability Services (Victoria) in 2003. The IP&S approach strongly reflects the principles of *Supported Living* already described. It involves:

- **Individuals directing** the planning process to the greatest extent possible and **making their own choices** about how they wish to live their life
- **Assisting the person to identify** their goals, aspirations and needs, ways that these can be achieved and the supports required
- **Exploration of supports** that are flexible, wide-ranging, and may include, but are not limited to, those that may be available from the existing disability service system
- The **inclusion and participation** of people with disabilities in community life

The resources most influenced by the IP&S approach, are the *Individualised Support Packages*. These packages are designed to enable individuals to exercise choice in meeting the goals associated with pursuing their lifestyle. The funding is allocated upon an agreed support plan, and is attached to the individual rather than a specific service.

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67 Action for more independence & dignity in accommodation report (2000)
68 A life more ordinary (2002)
69 Individualised funding: Emerging policy issues (2004)
70 Enterprise International (2004)
71 Access to ongoing support: DSR registration guidelines (2007)
Obtaining an Individualised Support Package was one of the key questions raised by the GDAN members. The majority of members were familiar with the initial branding of the IP&S approach (Support & Choice) however; none of the families had accessed funds at the time of the project. Unwittingly, the project ran alongside a period of review of the Disability Support Register and the process required for an individual to request long-term (ongoing) support, permitting the project to include the most up-to-date information.73

The Disability Support Register is explained more thoroughly in the Attachment to this report. A key aspect of this process is the type of support required must be clearly articulated and documented prior to registration. Individuals applying for an Individualised Support Package may be required to complete an extensive planning process prior to development of their proposal. A brief discussion describing the requirements of the proposal and the availability of support for planning is in appendix seven.

There are provisions for planning assistance in the Disability Act 2006.74 Individuals are able to request assistance from a Community Service Organisation or DHS Disability Services. There is also a growing number of organisations including the Personalised Lifestyles Assistance (PLA) project and Plan of Action Services that offer independent facilitation/planning. DHS Disability Service’s current Policy & Funding Plan does include a provision for small projects or initiatives that aim to assist individuals (or groups of individuals) to explore personalised arrangements.75

A third type of support is Family Governance where several families may pool a portion of their funds to employ a co-ordinator to support both the planning processes and implementation of these plans once the resources become available.

Anecdotal evidence indicates that there are individuals (and families) who have been able to receive and manage individualised funds, which enable them to establish accommodation and support options to suit them. Some families have contributed funds, or provided housing, while others have been able to access public housing or enter the private rental market. There are also examples of organisations that cultivate the desire of individuals to live and partake in the community without the monetary resources, such as individualised funding. Homewest in Queensland and the Community Living Project in South Australia were established by strong, committed families and supporters who were able to creatively use community based resources, and develop support networks outside of existing disability service structures.

It is beyond the capacity of this report to describe the establishment of individual arrangements; each one is different, reflecting the resources available, and the capacities of people involved. A common thread in many of the stories is the persistence and commitment of the individual and their personal support network.

Family Governance

Family governance is also a formal network of individuals, their families and other supporters, who strive to assist individuals to achieve their goals and aspirations. Rather than ‘receiving’ support from an agency, the network acts a semi-autonomous body, directing operations of the network. Governance groups are generally supported by a co-ordinator who acts as a facilitator, working with the governance group and individual family members. The group addresses issues around administration, and the vision and goals of the governance group, while individuals and their family retain the power to make decisions about their own lives. Family governance can be

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73 Access to ongoing support: DSR registration guidelines (2007)
74 Disability Services planning policy – DRAFT (2007)
a difficult concept to comprehend, a more detailed description can be found in the attachment to this report.

The Accommodation Innovation Grants currently fund two family governance groups in Victoria, Living Distinctive Lives and Yoorooga. The family governance group One by One pre-dated the Accommodation Innovation Grants. Initially supported by a seeding grant, the group now supports the employment of a co-ordinator by pooling a portion of their individualised funds.76

**Community Engagement**

**Exploring Housing & Support Options**

As previously established, the parents from the Hamilton, Ararat & Stawell and Wimmera regions have had sporadic opportunities to learn about different types of housing and support for people with a disability, but were still very confused about the actual possibilities for their sons/daughters. As a network, the project provided a forum for parents across these areas to meet and learn about these issues. Their involvement was fundamental to the project. As participants, they not only received information, but their contributions, feedback and enquiries offered a very real perspective of how information is received, and, to an more limited extent, personalised.

**Empowerment**

Empowerment and the empowerment of people participating in community based programs and projects has grown in prominence since the 1990’s; particularly in the Australian health77 and natural resource/environment 78 sectors. One project that looked at the experiences of individuals with a disability and their families in the two decades since the International Year of the Disabled Person, found that negative experiences including exposure and the loss of privacy, exclusion, powerlessness, emotional turmoil, the need to fight, and the ongoing exhaustion has not changed or lessened over time;79 these experiences reflect feelings of disempowerment. Empowerment does not feature prominently in current policy and planning documents. In the Victorian State Plan which envisions that in 2012;

> Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities80 towards society as all other citizens of Victoria

The word ‘empowerment’ occurs once within the document, suggesting that as a value, it rates considerably less than ‘enabling’ (21 occurrences), ‘individualised’ (28 occurrences) and ‘community’ (151 occurrences). 81

The term empowerment is a complex notion; researchers endeavouring to conceptualise it are developing a consensus recognising three main assumptions that underlie empowerment:82

- Empowerment is not an enduring personality trait, it involves a range of cognitive functions and is influenced by the individual’s environment & circumstances
- It is a continuous variable that can shift along a continuum; “people can be more or less empowered, rather than empowered or not”

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76 One by One website – [www.onebyone.org.au](http://www.onebyone.org.au)
77 Feedback, participation and consumer diversity: A Literature review (2000)
78 Effective community engagement (2004)
79 The living history project (2004)
80 State disability plan (2002)
81 What’s the vision (2006)
82 The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct funding model (2003)
• Empowerment is a subjective process of mastering one’s self and the world around them in order to fulfil human needs.

From a more global perspective, empowerment can be recognised both as an outcome itself, and as an immediate step to a long-term goal.\(^3\)

Again, it is way beyond the capacity of this project to assess or measure the degree to which participants are experiencing empowerment or any other changes they may experience in their feelings of empowerment. However, disclosures made by participants during the course of the project may provide a glimpse into their experiences (both past and present) of being empowered.

**Recruitment**

Parents were recruited through the Hamilton, Ararat and Wimmera Parent Support Groups. Parent Support Co-ordinators made the initial invitation to members. After the appointment of a Project Worker, two of the three groups invited worker, and the Family Respite Worker who initiated the project, to attend a meeting to talk further about the project. Parents that expressed interest in participating provided their contact details to the project worker, and arrangements were made for the first Grampians Disability Accommodation Network (GDAN) in September 2006. Attendance was not crucial; parents who were unable to attend meetings were given the opportunity to receive GDAN correspondence (meeting minutes etc). Four families took this opportunity, and contact was maintained between them and the project worker throughout the project.

**Grampians Disability Accommodation Network**

The first GDAN meeting was held on 18\(^{th}\) September, 2006 at Halls Gap. Eighteen people attended, including nine parents, representatives from the Handsbury Fellowship/RMIT, Parent Support Co-ordinators and Rural Access Co-ordinators. Halls Gap was the chosen venue as geographically, it is the central-most point between Hamilton and Horsham. One family were fortunate enough to live in Halls Gap, making the journey a relatively easy one. Others were required to travel in excess of 300 km to complete the round trip. Support in the form of reimbursement was made to parents that attended the meetings. The initial meeting provided an opportunity for network members to meet and define their various roles (Table 5)

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handsbury Fellowship</td>
<td>• Funding body</td>
</tr>
<tr>
<td></td>
<td>• Handbury Fellowship partner</td>
</tr>
<tr>
<td></td>
<td>• Research advisor – providing support &amp; advice on the projects research methodology so that becomes a valuable &amp; recognised tool of influence in the community</td>
</tr>
<tr>
<td>RMIT</td>
<td>• Auspice the project</td>
</tr>
<tr>
<td></td>
<td>• Receives &amp; manages the funds</td>
</tr>
<tr>
<td>Wimmera Uniting Care</td>
<td>• Support parents to attend the GDAN meetings and disseminate information to other interested parents</td>
</tr>
<tr>
<td>Parent Support Workers</td>
<td>• Promote community inclusion for people with a disability</td>
</tr>
<tr>
<td></td>
<td>• To disseminate information within the regions communities &amp; through existing state-wide networks</td>
</tr>
<tr>
<td>Rural Access</td>
<td>• Contract to work 16 hrs/week over a 6 month period</td>
</tr>
<tr>
<td></td>
<td>• Responsible for collecting, collating and disseminating information to the network members</td>
</tr>
<tr>
<td></td>
<td>• Goal is to empower parents to make informed choices about their son/daughter future housing &amp; support needs</td>
</tr>
</tbody>
</table>

**Table 5: Roles of participating organisations/workers**

\(^3\) What is the evidence on effectiveness of empowerment to improve health? (2006)
As demonstrated in Table 5 the network included a range of individuals that could offer valuable support to the project, and promote its findings throughout extensive networks at local, regional and state levels. The involvement of Parent Support Co-ordinators ensured an additional support mechanism for parents involved in the project. There is little doubt, that on top of their current demands associated with caring for a son/daughter with special needs; the act of considering their future needs, combined with inherent anxieties, had the potential to create some emotional turmoil. The involvement of Parent Support Co-ordinators provided support after, and between meetings to parents who might need the opportunity to debrief, express emotions or just simply talk about any issues that the meetings might raise.

**Parents - Background**

To gain some understanding of the backgrounds and experiences of the parents that participated in the project a questionnaire (Appendix 8) was distributed 6 weeks after the second meeting in October 2006. Ten of the seventeen families involved in the project completed the questionnaire providing valuable information about their circumstances, and the impact of their son/daughter’s disability on their lives. The following discussion describes selected findings; a more detailed description of the questionnaire results (raw data) can be found in Appendix nine.

**Demographics**

As previously established the parents that completed the questionnaire came from a large geographical region that included six LGA’s and crossed three DHS regions. All of the families have more than one child, with an average of two children currently living in the family home. The majority of parents (both mother and father) are currently employed in a diverse range of occupations. Interestingly, only four parents indicated that they were a carer. Eight of the ten families report that they receive a *Carers Allowance* while three families are *Carers Payment* recipients.

Among the ten families, five daughters and six sons aged between 13 and 29 years have a disability. The types of disabilities included intellectual, physical and sensory impairments (Fig. 9). Six of these young peoples have more than one disability or/and a chronic medical condition that has a direct impact upon their functional capacities.

![Disability Types](image)

*Figure 9: Types of disabilities reported by parents*
Functional impact of the disabilities

More pertinent to the experiences of these parents, is an indication of the level of care and support their sons/daughters require. In the questionnaire (Appendix 8) parents were asked to indicate the extent of support or supervision their son/daughter requires to complete tasks associated with everyday activities. The question was adopted from assessment forms designed to collect information from service providers about individual support requirements for the CSTDA National Minimal Data Set. The process used to translate the raw data into the following results is described in Appendix nine.

<table>
<thead>
<tr>
<th>Tasks associated with everyday activities</th>
<th>Functional Impact of the disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carry out everyday activities</td>
<td>Moderate</td>
</tr>
<tr>
<td>Learn new skills &amp; solve problems</td>
<td>Moderate</td>
</tr>
<tr>
<td>Communicate with others</td>
<td>Moderate</td>
</tr>
<tr>
<td>Get around inside &amp; outside the home</td>
<td>Mild</td>
</tr>
<tr>
<td>Complete self care tasks</td>
<td>Moderate</td>
</tr>
<tr>
<td>Participate in domestic activities</td>
<td>Moderate</td>
</tr>
<tr>
<td>Develop &amp; maintain relationships</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

Table 6: Degree of functional impact upon tasks associated with every day activities

As indicated in Table 6, in order to accomplish most tasks associated with everyday activities, the young adults sometimes require help/supervision, indicating the need for someone (often the parent) to be physically present.

Considering Future Living Arrangements

All eleven young people currently live in the family home; however, their future accommodation and support needs have been on the minds of their parents for an average of 10½ years. Parents were asked when they first began to consider these issues; the responses generally relate their initial thoughts to the age or developmental period of their son or daughter at the time.

<table>
<thead>
<tr>
<th>Milestones</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
</tr>
<tr>
<td>Age:</td>
</tr>
</tbody>
</table>

Figure 10: Milestones influencing future accommodation & support needs

Figure 10 illustrates the different life stages (milestones) that their sons/daughters were at when parents began thinking about future accommodation and support needs (as indicated by the arrows). The shaded arrows represent milestones that were defined by an event, rather than the age or developmental stage of their son/daughter. The events described by parents were:

- The diagnosis of their child’s disability
- Senior high school years; it became apparent that their child didn’t have the same life skills as their peers
- When siblings began to leave the family home reducing the level of informal, everyday support for the child with a disability

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84 Applying the ICF to a national disability services data collection (2003)
Perceived Future Living Arrangements (with permission to dream)

Parents were asked in the questionnaire to suspend their concerns and anxieties (given permission to dream) and describe the living arrangements that they perceived having for their son or daughter in five years time. The responses were not outlandish or beyond reasonable expectations, but identified a range of expectations that would permit their son or daughter to remain in the area (or nearest centre) of the family home, and allow the parents to play an active role in their son or daughter’s life, without the burden of full-time care. The services and supports identified by parents (Table 7) indicated an even split between the current model of shared supported accommodation (CRU) and (supported) independent living.

<table>
<thead>
<tr>
<th>Accommodation type</th>
<th>Expectations of service/supports</th>
<th>Other requirements</th>
</tr>
</thead>
</table>
| Shared supported accommodation • CRU | • 24 hour supervision  
• Compatibility with housemates  
• ‘Safe’ environment  
• Responsive to sons/daughters needs & quality of life  
• Staff to have (acquire) good knowledge & understanding about son/daughters disability  
• Staff need to be caring & treat son/daughter as an individual  
• Parent & son/daughter to participate in selection of carers/support staff  
• Parent to contribute to staff training | • Remain in local area  
• Able to visit family home on weekends  
• Parental control over welfare issues  
• Parents relieved & relaxed  
• Son/daughter happy/OK |
| Own Home  
• Home ownership  
• Public Housing  
• Share House  
• Granny flat | • Funding to adequately resource in-home support  
• Some supervision  
• Personal care assistance  
• Domestic assistance (meal preparation, paying bills)  
• Overnight support  
• Accommodation/support shared between family & formal supports  
• Consistency in carers/support people  
• Outreach (back-up) support | • Remain in local area  
• Adjoining/opposite block (granny flat)  
• Independent access to community  
• Opportunities to socialise |

Table 7: Breakdown of the housing & support parents perceive (hope for) in 5 years time

One notable observation was the absence of the young adults’ voices in the questionnaires that were completed; only one of the parents responded to this question from the perspective of their son.

‘[He] wants to live in his own “apartment” on his own...’

It is not possible to determine whether the responses reflect the capacity of the young people to express their desire and plan for the future, or were influenced by the way the question was phrased; such an analysis is beyond the scope of this project. It does raise questions of how individuals can be involved in future plans, and whether the original intention of the project; that is ‘to empower people with a disability and their families’, is a realistic proposal for the participants in this project.

The Findings - In ‘Real’ Terms

Conscious that the majority of participants have little or no research background, and that the potential audience for this report may include people with a similar background, an alternative summary of the findings of the GDAN Parents Questionnaire was developed.
Dan (Fig. 11) is a caricature created from the findings outlined above. Rather than just documenting the averages, issues and other findings; the creation of Dan offers a short narrative that people can relate to, and learn from.

**Introducing Dan...**

Dan is 17 years old. He lives with his family; mum, dad and younger brother on a property 30 km from Stawell. The family are well known in the area, having lived there almost 20 years.

Dan also has an older sister who lives in Melbourne and is studying at university.

As well as running the farm, both Dan’s parents have other jobs. His dad is a wool contractor, while his mum is a registered nurse, and works 3 days a week at the local community health centre.

Dan has an intellectual disability, and reasonably well controlled epilepsy. He can’t communicate all that well, however his family and close support workers know when he wants something. Dan does become very frustrated at times – hitting out, which frightens others who don’t know him so well.

Dan attends the special developmental school in town. It’s his final year and his program includes some work experience at the local gym. Next year he’ll go to the adult training centre.

Physically, Dan can complete most tasks he needs to like showering and getting dressed. He’ll even rake up the leaves and do other things in the garden. Several people have commented that he seems happier and more content when he’s outside. One of Dan’s difficulties is that he has trouble starting a task (and often becomes distracted part-way through). He needs someone with him to regularly remind him to refocus on the task, and occasionally, physically help him out.

If Dan’s in a new place or situation he gets pretty anxious and stays close to people he knows.

Dan’s parents are worried about where he’ll live in the future. He goes to respite and has come to know another family really well through the Interchange program.

They know that his future will be different to other people his age. When his sister finished Year 12, she soon moved to Melbourne. Dan finishes soon, and although his parent love and support him at home – they get tired. Respite is a great help, but it’s a 1 ½ hour round trip just to get him there Saturday morning, and another 1 ½ hour trip to pick him up Sunday afternoon. This doesn’t make for much time to spend together, let alone be able get away.

There are a lot of Community Residential Unit’s in the area, a legacy of the large institution that closed down seven or eight years ago, but Dan’s parents would like to see him have more space to himself than share with 3-4 others. It seems unlikely he’ll get a place in the next 5 years, even if they wanted it. They know other parents who have had their daughter’s name registered for 8 years. They’d also like to be a part of how Dan lives, choose the people who support him and make decisions with Dan.

*Most of all, they want him to be OK – with consistent support from people who have (and will) come to know him well.*

**Figure 11: Introducing Dan**

**GDAN Meetings**

A major assumption underlying this project is that the capacity to make an informed choice is dependent upon provision of accurate information, which individuals with a disability and their families can understand. The GDAN meetings provided a forum for:

- The delivery of information about housing and support to parents (directly and via correspondence)
- The opportunity to raise and discuss issues around housing and support
- The opportunity for parents to influence the development of upcoming agendas
From an initial review of information and literature around accommodation, housing and support for the people with a disability prior to the first meeting, a number of significant issues and themes were identified. These include:

- Changes in legalisation – the introduction of the Disability Act 2006 (Victoria)
- The newly formed Disability Housing Trust in Victoria
- Individualised planning – Support & Choice
- A report of a small, family governed group creating housing opportunities in Queensland around the needs of individuals
- The separation of housing and support – that rumour; that there were no more CRU’s being built in Victoria
- Localised programs in Victoria delivering support to people with disabilities that wanted to live independently in their local community
- The introduction of Special Disability Trusts by the Commonwealth Government

Conscious of the short-term nature of the project, the meeting schedule and the need to present information in a logical and succinct format to participants, the information was divided into more manageable themes and issues:

- Disability legislation and policies
- Changes in the provision of services and support to people with a disability
- Responding to the needs and aspirations of the individual with a disability
- Housing options
- Support options
- Funds and financial planning (Trusts, Guardianship)
- Accommodation projects in Victoria & Australia
- Services providers
- Innovations in accommodation & support

To convey the range and extent of the themes and issues (domains) that could be addressed during the project, a framework was established. Anticipating six GDAN meetings over the course of the project, the initial plan was to address one to two of these domains at each meeting. The framework would need to clearly identify the separate domains, but to also convey that each of the domains was intrinsically connected. Thinking building blocks, networks and connectivity a framework emerged, creating a metaphor around construction, and more suited to the concerns around exploring future accommodation and support; building a home.

The GDAN House or Dan’s Place (Fig. 12) is a construct representing the framework that would determine the initial development of the project. At the centre is the individual, the person with a disability for whom the housing and support options are being explored. Serving as the foundation is government legislation. A review of disability services and supports in the past and present day, revealed that since the 1950’s there have been significant legislative changes, both at commonwealth and state levels that have significantly transformed the provision of disability services and supports in Australia. This is not to say that governments have necessarily initiated these changes; however it does recognise that government policies can and do influence the way in which formal services and supports are delivered.

Continuing the construction theme, once the foundation is laid, the structure of the house emerges; the installation of timber frames, roof trusses, insulation, bricks, mortar and roofing tiles shape the walls and roof to provide shelter for the inhabitants. Finally, the house becomes a home. Interior design: Making it mine recognises that accommodation and support is not just about having a house with appropriate levels of support. It represents the role of the individual’s family and friends, their connections within their community, and the strategies required to sustain it well beyond the immediate future.
Information delivery & discussion

The extent of the information available for the project above was underestimated. The six nominated meetings were insufficient to deliver the extent of information collated; the overview of the six meetings in appendix ten outlines the topics addressed over the course of the projects. The schedule was primarily influenced by the framework already established above (Dan's House).

Equally important were the issues raised by the parent participants. Recognising that it was from their experiences that the project evolved; as participants their contributions and directions continue to shape the project. Unfortunately, the short-term nature of the project did allow it to evolve to a point where meetings could be described as 'participant directed'. Unresolved issues and requests for specific information were respected and brought to the following meeting where possible, but these actions did not constitute true participant direction.

Drawing from ‘real’ experiences

Paper based information has its limitations. Many people find it difficult to relate to short descriptors and conceptual information. Acknowledging this, as well as the diversity of knowledge and experiences among network members (parents, Parent Support Co-ordinators & Rural Access Co-ordinators) small group and other activities were included during the initial meetings to promote discussion among members; by the third meeting, and a degree of trust had been established and the members need for structure and facilitation to promote discussion diminished. Alongside the notes and minutes generated from each meeting, anecdotes written by individuals and/or their families of ‘lived’ experiences were circulated.
There was also the opportunity to invite three guest speakers to the final GDAN meeting in March 2007. Two mums spoke about their experiences of establishing accommodation and support options for their son and daughter. The third speaker was a facilitator who supports families and groups to establish family governance arrangements.

Outcome – Being informed

A large amount of information was generated during the project, the majority of which was presented to the GDAN members, distributed to other interested persons and included in this report. Topics have included the historical context of accommodation and support for people with a disability, legislative development and changes, emerging changes in Victoria (particularly around individualised planning and the revised Disability Support Register within the confines of time, and length of this report. More extensive discussions around individual topic are in the attachment to this report. Information about housing and support options has been presented alternatively; descriptors, specific details about eligibility and application details as well as contact details were tabulated for easy reference. Both matrixes are also included in the attachment.

After the last GDAN meeting (March 2007) questionnaires were distributed to parent and services provider members (Appendices eleven and twelve). The feedback recognised the amount of information generated and presented; however the responses suggest that more (not necessary information) was required before parents would feel confident about their choices and decisions:

- *It made me realise that there is many more options out there and resources available* (Parent)
- *I think I already knew the complexities of this topic & [it] probably just validated the difficulties around accommodation* (Parent)

The questionnaire asked service providers about feedback they had received from other GDAN members. Statements such as the following support the feedback above:

- *People have said they’re much better informed and they’ve had the opportunity to voice their concerns* (Service Provider)

As previously identified, the short-term nature of the project, and the (unanticipated) amount of time required to research and collate information, minimised the opportunity to actively assist parent members reflect upon their own experiences and consider the potential housing and support options that are available. One service provider observed:

- *I don’t think [the project] has addressed individual concerns* (Service Provider)

To some extent, and perhaps much easier to say on reflection; the degree to which the project could have assisted individual families to make decisions about future accommodation needs was limited. Parent feedback suggests that for some parents the project did influence their considerations about the future to some degree:

- *Helped a little – still confused* (Parent)
- *... it was just part of the jigsaw, a base from which to start* (Parent)
- *The project hasn’t change my vision [for my son/daughters future], it has helped form it* (Parent)

The feedback touches upon issues that emerged during the project, and were addressed as part of the findings and recommendations. The provision of paper-based information, and a
limited time to discuss them, was not enough to give these parents the confidence they needed to consider making decisions about their son/daughters future.

There are many factors that would influence the timing of the considerations and decisions made; however, from the initial parent questionnaire, we do know that ten of the families participating in the project had been thinking about their son/daughters future accommodation needs, and had some idea of what they could envision within five years time. The project’s design may have also presented issues that another type of forum would not have raised; the research and collation of information occurred alongside the meetings at which the information was presented. Difficulties arose when the timing between meetings was insufficient, limiting the amount of information that could be found. The experiences of the project worker were shared with the members, and although any information that was later found to be incorrect or superseded was rectified, participants were aware of the difficulties. In response to whether the project met their expectations, one parent wrote:

Yes and no. Yes because it has given me hope that there must be a way forward for us [parents] collectively. No because of the brick walls [the project worker] encountered. (Parent)

A main focus of the project was in Individualised Planning and Support, the current approach introduced by DHS Disability Services in 2003. It is relatively new and recent reviews have addressed issues surrounding attendant care support, (Homefirst) and the application process for the Disability Support Register. Service providers highlighted the potential of this research to document the challenges and difficulties faced by families of individuals with a disability.

Recommendations may be a springboard for change; that there was a need to document the challenges of the project (service provider)

The research meets the gap between DHS and families/people with disability (service provider)

This is a terrific first step towards seeking change for support around accommodation issues (service provider)

Outcome – Being Empowered

The mission of the Grampians Disability Accommodation Network (GDAN) project was to:

Empower people with a disability and their families, to make informed choices about their future accommodation and support options

Framed assertively, the statement pre-empted a positive experience for families that participated in the project. As previously discussed, parents participating in the project were exposed to the limitations and frustrations of finding good quality and reliable information.

The project did provide an opportunity to meet and talk with others who shared similar life experiences associated with caring for a son or daughter with a significant disability, and wanting to know that achieving their future accommodation and support needs was possible, if not assured.

Angus Buchanan has developed a framework to research the predictors of empowerment for parents and carers of people with an intellectual disability. His research was at the time of the introduction of Direct Consumer Funding (Individualised Funding) in Western Australia. This research model identified three groups of influences that predicted the empowerment of parents and carers85 (Table 8).

85 The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct funding model (2003)
<table>
<thead>
<tr>
<th>Influence</th>
<th>Factors</th>
<th>Description of factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person Factors</td>
<td>Locus of control</td>
<td>Extent to which people believe they exercise control over their own lives (internal) or the degree to which they feel their destinies are determined by fate or powerful others</td>
</tr>
<tr>
<td></td>
<td>Level of education</td>
<td>Highest level of education achieved</td>
</tr>
<tr>
<td></td>
<td>Unpaid support</td>
<td>Support provided by family, friends neighbours, volunteers etc</td>
</tr>
<tr>
<td></td>
<td>Experiences with funding</td>
<td>The length of time the parent/carer has been receiving funding</td>
</tr>
<tr>
<td>Program Factors</td>
<td>Availability of paid services</td>
<td>Access to services paid for using individualised funding</td>
</tr>
<tr>
<td></td>
<td>Portability of funding</td>
<td>Ability to move funds between service providers</td>
</tr>
<tr>
<td></td>
<td>Funding availability</td>
<td>Belief that additional funding is available when required</td>
</tr>
<tr>
<td></td>
<td>Control of funding</td>
<td>Belief that a person has a ability to plan when &amp; how they spend their money</td>
</tr>
<tr>
<td>Congruence factors</td>
<td>Values congruence</td>
<td>Abstract ideas, positive or negative, not tied to a specific or situation, representing a persons beliefs about modes, conduct and ideal terminal modes</td>
</tr>
<tr>
<td></td>
<td>Information availability</td>
<td>Extent to which appropriate information is available to support people to use individualised funding</td>
</tr>
<tr>
<td></td>
<td>Sufficiency of funding</td>
<td>Adequacy of funding to meet needs</td>
</tr>
<tr>
<td></td>
<td>Timeliness of funding</td>
<td>The access of allocated funding in a timely manner</td>
</tr>
<tr>
<td></td>
<td>Collaborative planning</td>
<td>Effectiveness of planning between parent/carer &amp; funding organisation</td>
</tr>
</tbody>
</table>

Table 8: Factors influencing empowerment (Buchanan 2003)

As previously stated, any assessment or measurement of empowerment is beyond the scope and capacity of this project. However, this does not devalue the information obtained from participants and collected during the project. At the second meeting (October 2006), three statements were presented to the group for discussion.

I feel that governments make decisions and laws that are good for the way my family lives locally
I feel that experts such as administrators, policy makers and managers of disability services can be trusted with dealing with local issues
I feel that I can influence those figures of authority who are associated with services my family utilises

The statements were adopted from the Community Sustainability Questionnaire for a project investigating both strong and threatened communities. The first two statements generated some discussion recognising the difference between government agencies as a whole, and difficulties faced by individuals working within the bureaucracy of the system. The response to the third statement was strong and poignant, the initial silence was broken by anecdotes from three parents who had been ‘failed’ by the system, and the inadequacy of the delivery of disability services at the time when they were desperately needed. When asked if anyone could share a positive experience around the delivery of disability; the silence conveyed what words could not.

Anecdotes and comments made during the project that represented both empowering and disempowering experiences of parents are recorded in Table 9. The factors influencing empowerment have been adapted from Buchanan’s model. The comments/anecdotes in bold text are directly related to the project.

86 The Globalism institute - Community sustainability  [www.communitysustainability.info/index.html](http://www.communitysustainability.info/index.html)
<table>
<thead>
<tr>
<th>Negative experiences</th>
<th>Factors influencing empowerment</th>
<th>Positive experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception that there is no support of this nature in their communities</td>
<td>Unpaid support</td>
<td>Parents meeting others facing similar challenges &amp; struggling with issues around accommodation &amp; support for their son/daughter</td>
</tr>
<tr>
<td>Absence or delayed response to request for assistance to the past</td>
<td>Experiences with disability</td>
<td>Perception that your concerns are being heard</td>
</tr>
<tr>
<td>The need to fight for services &quot;It's the squeaky wheel that gets a response&quot;</td>
<td>services</td>
<td>Seeing “a light at the end of the tunnel” perceiving that something’s possible</td>
</tr>
<tr>
<td>That statement – there will be no more CRU’s built in Victoria</td>
<td>Availability of services</td>
<td></td>
</tr>
<tr>
<td>Perceived absence of services &amp; support when needed (eg. Behavioural Intervention</td>
<td>Availability of supports</td>
<td></td>
</tr>
<tr>
<td>Support at the time of a crisis)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Daughter continues to live at home…parents are considered too young to [her] to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>receive a placement in a CRU”—parents ages are 51 &amp; 46 years</td>
<td></td>
<td></td>
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<tr>
<td>Current numbers on the Disability Support Register are overwhelming: known other</td>
<td></td>
<td></td>
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<tr>
<td>families who have waited for an accommodation placement for years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents (service providers) unaware of application process for Individualised</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support Packages</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time taken (by project worker) to find information about the application process for Individualised Support Packages</td>
<td>Information availability</td>
<td>Amount of information provided during the project</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Development of a resource; &quot;I’m not going to use is right away, but I will come back to it when I am ready”</td>
</tr>
<tr>
<td>Need for a facilitator to support ongoing forums around housing &amp; support; 6 months</td>
<td>Understanding the information</td>
<td>Potential for the Grampians Disability Accommodation Network to continue as a forum for parents enabling parents to explore issues around housing &amp; support</td>
</tr>
<tr>
<td>not enough</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence of support to develop plans &amp; articulate goals for their son/daughters</td>
<td>Collaborative planning:</td>
<td></td>
</tr>
<tr>
<td>future living arrangements; perceived isolation</td>
<td>developing a proposal for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Individualised Support Packages</td>
<td></td>
</tr>
</tbody>
</table>

**Table 9: Empowerment - Negative & positive experiences of parents**

The project presented opportunities for parents that were considered to be empowering, however, it also raised issues that were, or could be disempowering. Although the need for an ongoing forum in the region that is adequately resourced and supported, has been identified and recommendations have been made to that effect; no proposals had been completed at the time that this report was written. As one parent stated in their evaluation:

*Unfortunately it has to end. ...the support circle has been established & much more was able to be shared than going it alone (Parent)*
Liaison & Networking

Liaison and networking activities - contacting organisations, seeking key players and following leads – were a significant component of the research process in this project. Within the first month of the project the information obtained touched upon a diverse range of areas including:

- The Disability Act 2006 (Victoria)
- The Disability Housing Trust in Victoria
- Individualised planning – Support & Choice
- A report of a small, family governed group creating housing opportunities in Queensland around the needs of individuals
- Localised programs in Victoria delivering support to people with disabilities that wanted to live independently in their local community

DHS Disability Services

Initial contacts were made with DHS Disability Services at the local (Ararat, Hamilton), regional (Grampians and Barwon South-West) and central (Melbourne) offices, depending upon the level of information required. Local DHS personnel were able to discuss locally based services; however, requests for information about policy development and state-wide programs referral were made to management personnel at regional and state offices.

Disability Service Providers

There are five Adult Training & Support Services (ATSS) in the research area, two of which provide accommodation services, as well as day training and supported employment programs. The managers and staff of these services have wealth of knowledge and experiences to share which prove to be invaluable in areas of government legislation and policy from a service provider’s perspective.

Other disability, housing and welfare agencies in the research area were also contacted. Local Community Directories for the Rural City of Ararat, Wimmera region and the South-West proved to be valuable resources.

Disability Networks & Networking

Contact was made with formal disability or community services networks in each area, enabling messages about the project (and requests for information) to be distributed throughout the project area electronically.

For access to disability state-wide news, the Infoexchange website proved to be invaluable. The site has a Disability and Housing News sections, including a weekly electronic bulletin promoting news, upcoming events, publications & research and programs from the disability and housing industries. The bulletins were invaluable in promoting small but innovative projects throughout Victoria that would not have been identified by the project worker otherwise.

Networking, whether locally, state-wide or (in some circumstance) nationally, was a really positive aspect of the project. With very few exceptions, the people contacted were willing to share their knowledge and experiences, offer guidance and learn about the project. As the project progressed, a growing contact database was produced through which the GDAN meetings minutes and notes were distributed. This activity also generated vital feedback, providing additional information and (when necessary) correction of erroneous details.

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Community Service Organisations – Accommodation projects

There are many projects currently being run in Victoria around housing and support, each one with a unique perspective and geographical area. The Accommodation Innovation Grants currently fund thirteen projects in both metropolitan and regional areas. Access to many projects was often through Infochange or word of mouth, very few were detected by search engines on the internet. Conference programs and abstract books were also a good resource, the annual One Person at a Time conference in Victoria draws many speakers from around Australia to talk about their experiences in creating individual lifestyles, including housing and support arrangements. Again the challenge is to find out more about these conferences.

Local Information

The project also required background information on the LGA’s within the research area, information about local disability services and supports, and how they evolved. Ararat and Stawell have a long history of disability service provision as the location of Aradale (Ararat) and Pleasant Creek (Stawell) Training Centres, residential institutions for people with an intellectual disability. Now closed, J-Ward in Ararat is a museum and holds some archival information from its main campus Aradale. Thanks to the committee, access was made available to these documents providing a valuable source of historical material. Likewise, the assistance from the History centres in Hamilton and Horsham also provided local reports and newspaper cuttings that would not be available elsewhere. These documents, coupled with history books available in the local and state libraries, as well as local government and other websites, provided more than enough background information for the project.

Research

In a broader context, research into disability and the impact of different services and supports occurs throughout the world. During the project, contact was with researchers at La Trobe and Melbourne Universities in Victoria. Their area of study was diverse; social work, social policy, architecture and planning with each one complementing the others.

The recent Roundtable on disability policy88 discussed the ramifications of the State Disability plan on the provision of support for individuals with an intellectual disability. Another researcher at La Trobe had completed an initial evaluation on family governance programs in Victoria, a valuable document describing a process not so easily defined. Other academics taught diploma and degree level studies to people wanting to work in the disability industry; again, for these students understanding the implications of current legislations in their future workplaces was vital. Finally, a PhD student from the School of Architecture and Planning found links between this project, and his work into exploring the decisions and choices parents make about their sons/daughters future accommodation needs.

The Grampians Disability Accommodation Network project shares themes and ideas with each of these areas reinforcing its relevance in the current era of disability service provision and research.

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88 Proceedings from the roundtable on intellectual disability policy (2006)
**Findings & Recommendations**

**The Collection & Colation of Information**

**Access to Information**

*I anticipated that this process would be – not easy – but relatively straight forward. I was wrong.*

(Project worker)

One of the assumptions underlying this project was that information about accommodation and support options for individuals with a disability did exist; and that the role of the project worker would be to gather and review this information and direct parents to selected resources. This assumption proved to be incorrect.

Information about disability supports and services does exist; however, access to it is very limited. An immediate difficulty encountered in this project was the absence of an obvious starting point, a resource offering an overview of the range of services and supports. The one exception is the publication appropriately titled *Through the Maze* by the Association of Parents of Children with a Disability. It is a 30 page booklet offering information about services for families of children with a disability. Available online on the association’s website, it can be downloaded or printed, along with contact details for services in the family’s DHS region (geographic area). *Through the Maze* offers summary and contact details of different services. Rather than provide the answers to every possible query, it endeavours to assist families to negotiate the complicated ‘maze’ of support services for children, adolescents and young adults under the age of 25. The existence of a resource that provided an overview of *housing options*, or describing the many possibilities that could be used to establish a *supported living* arrangement, would have been a valuable asset for this project.

**Recommendation 1:** That a comprehensive ‘directory’ be developed mapping the range of accommodation and support options for people with a disability including regional contact details

The research process was both time consuming and exhaustive. The information collected could be broadly categorised into two groups; consumer focused and service specific. Consumer focused information tended to be brief, generally directing the reader to contact the agency for further assistance. The service specific information included documents such as policies and project reports which were written from the perspective of the service rather than the consumer. A significant amount of time was spent drawing information from these types of documents and reinterpreting it from a consumer perspective, before presenting it to GDAN members. An evaluation of the *Individualised Living Project* in 2004 also highlighted the absence of consumer focused information. The evaluators found that parents of children, eligible for flexible support packages, had little understanding of what ‘having a package,’ (including their entitlements) meant. This observation draws on former organisational policies that did not promote the provision of information to clients. Traditionally, individuals and their families were only informed of *what services were available to them*, which at the discretion of their case manager. Both the agency and DHS have acknowledged that such practices do exist. Importantly, both have recognised that such policies need to change to allow individuals and families to take an active role in determining and managing their services and supports.

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89 Association of Parents of Children with a Disability – www.acd.org.au
90 Through the maze (2003)
91 Individualised funding/family governance project: Evaluation of a pilot project conducted by Uniting Care Community Options (2004)
92 Individualised funding/family governance project: Evaluation of a pilot project conducted by Uniting Care Community Options (2004)
Recommendation 2: That Disability services and Community Service Organisations need to ensure that consumer orientated information is available for individuals and families who wish to investigate disability services & supports.

Another valuable source of information was the findings of small and medium size projects in Australia. Projects enable innovative ideas to be trialled, nurtured and developed by like-minded people. There are small groups of families who have established sustainable housing opportunities for their sons and daughters, both in Victoria and interstate. Learning about these initiatives can be difficult; word of mouth and other serendipitous events proved to be the most common way of learning about such projects. However, these methods are certainly not the most effective.

Recommendation 3: That a central register of projects and localised housing and support initiatives be established.

Not only is the development of user friendly information and resources essential, they also must be readily available. The Community Resource Unit (CRU) in Queensland, and Disability Information and Resource Centre in South Australia, house information and resources at state based centre. These organisations provide information about disabilities and disability related issues, for individuals with a disability, their family, agencies and the wider community. This is not to suggest that there is not information available in Victoria. There is a wide range of advocacy and disability specific services that strive to provide information and support. The difficulty is that this information is widely dispersed, obscuring the volume and depth of knowledge that is available.

Recommendation 4: That a state based resource centre be established in Victoria to provide information for individuals and families who want to investigate information about accommodation, service and support options along with other disability related issues.

Government Legislation & Policy Developments

This project has coincided with legislative change, and the recent developments of corresponding policies within DHS Disability Services providing access to current and up-to-date information. However, not all the information sought was ‘easily’ found.

Parents in the GDAN network expressed a strong desire to know about Support & Choice, the branding associated with Individual Planning and Support (IP&S) and individualised funding packages. In particular, the parents wanted to know how they could access this type of support.

*As project worker, what struck me just how unobtainable information was and the growing frustrations experienced while in pursuit of it. The information I did receive were not substantial enough to provide a good understanding of the how the principles of individualised funding (responding to the needs and aspirations of the individual) translated into an application for funding and resulting in the provision of innovative support arrangements.

I was very aware that this was the one issue parents wanted to know about. After 4 months into the 6 month project I was becoming decidedly uncomfortable – I knew for certain I wouldn’t satisfy the questions parents were asking, I was still asking them."

Information was limited, the evaluation of the implementation of Support & Choice\(^93\) described the stages of the application process, but there were still several issues which needed clarification (the list generated is in Appendix 13). At the time, the Disability Services Register (DSR) was under review and new guidelines were being developed. The (now) recently released DRS guidelines\(^94\) addressed the issues identified during the project, including a clear description of the application process.

\(^93\) Evaluation of Support & Choice Implementation (2005)

\(^94\) Accessing ongoing support (2007)
The concern drawn from this experience is the absence of any indication that the guidelines were under review. Over the duration of the project, the DHS Disability Services web page on Individualised Support Packages has not made any reference to a review process or to the new guidelines (released in March 2007). This is in contrast to the DHS Disability Services Homefirst web page, which clearly indicates that the program is currently under review and has links to the Homefirst Review report (including an easy English version) and announces the current development of an action plan.

Recommendation 5: That consumer focused information be developed at times of legislative and policy development (change) and that notification of these changes be made public prior to and during any review processes

**Information Content & Delivery**

**Conceptualising Supports & Services**

As outlined in the State Disability Plan, the current changes in Victoria includes a strong focus on strengthening relationships and developing partnerships across government departments, the non-government sector, business and industry groups, local government and communities. In real terms, the relationship between different levels of government, industry and the local community, and finding somewhere to live while establishing appropriate supports, is not an obvious one to families. The project has attempted to establish a link by including an adaptation of Disability Services Queensland’s (DSQ) Disability Services & Supports Conceptual Model that identified the level or source of different types of services. In the evaluation of the project, six (of eight) families indicated that the topic was useful, suggesting that its inclusion has been valuable.

Recommendation 6: That information about the current disability policy and its impact on the provision of services and supports be developed

**Informing families**

Reviewing the minutes of the GDAN meetings show that the majority of meetings were dominated by the delivery of information about a predetermined domain. The information delivered reflected the progress of the research more than a thorough dissemination of information. The advantage of this, is that members were aware of the challenges associated with gathering information. Conscious that the information may be incomplete (or even erroneous); care has been taken to report and include amendments in the notes distributed after each meeting. Acknowledging that this is a time of change (the Disability Act 2006 will be fully implemented on 1st July 2007), it is important that the parent participants of the project, like other families throughout Victoria, are kept informed of the changes.

Recommendation 7: That families involved in the Grampians Disability Accommodation Network be given the opportunity to receive any further accommodation and support information developed in the Grampians and Barwon South West DHS regions

Ten of the eleven GDAN members, who completed an evaluation questionnaire, indicated that they believed there was potential for the network to continue to meet on a regular basis. Two parents indicated that with the completion of this project, the opportunity to share in the process with others would be lost.

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97 DHS Disability Services Division Homefirst Review (2006)
98 Victorian State Disability Plan (2002)
Parents advocating for the continuation of the network were not suggesting that there was more information about housing and support opportunities to investigate; rather they wanted an opportunity to explore the information that had been presented further. When asked what type of information they wanted to explore, one parent wrote:

_all that was researched in the accommodation network [project], and naturally finding more information out_ [Parent]

This request reflects a need to explore the available information further. As already discussed, network meetings were dominated by the presentation of a large amount of information and very little time was available for parents to explore this during meetings. The opportunity for less structured, participant directed meetings, would give parents an opportunity to further explore the issues around housing and support for their sons/daughters.

Recommendation 8: That the Grampians Disability Accommodation Network be resourced to maintain the network; enabling participants to review, discuss and explore issues of accommodation and support at their own discretion

**Empowering families**

People learn in a variety of different ways. The project was fortunate enough to host three guest speakers who spoke about their experiences in establishing housing and support for individuals with a disability. However this was the exception, most of the sessions were based on paper based information and facts. It was difficult to find articles, written by individuals and family members, of their experiences in developing supportive and sustainable accommodation within their community. The parent GDAN members especially struggled with articles about individuals who were able to live independently with minimal support and supervision. They recognised the achievements, but could not envision their son/daughter achieving that level of independence. Parents spoke about the value of books and films that capture not only the successful outcomes, but also the challenges associated with everyday life as well as planning for the future; not only for them, but to convey their experiences to disability service planners and policy makers.

The Summer Foundation\(^99\) in Melbourne is currently producing a book and DVD of case studies of young people moving from residential aged care to more appropriate settings. Although the young people in nursing homes initiative targets a specific group of individuals, there are strong similarities between them, and the level of support needs of the son/daughters in this project; sharing resources with other initiatives, such as the Summer Foundation’s book and DVD could help parents to see the possibilities for their own son/daughter and reduce unnecessary expenditure on the duplication of resources.

Recommendation 9: That more resources (articles, books & short films) be developed portraying the _lived experiences_ of individuals with high support needs and their families, who have successfully developed and sustained supportive accommodation options

In the evaluation, what parents expressed their appreciation for, was that a project worker had been employed to research the information and facilitate the meetings. Parents were able to receive a significant amount of information without having to stretch their already busy lives. Most of the parents that responded to the evaluation questionnaire felt that if the network was to continue it would need to be resourced, supporting a facilitator who would organise meetings on behalf of the parents. As one parent wrote:

_[We] need a facilitator who can follow-up things, as we as parents are tied up looking after our children_ (Parent)

\(^99\) The Summer Foundation - [www.summerfoundation.org.au](http://www.summerfoundation.org.au)
Parents do want to be able to plan and develop housing and support for their sons/daughters and need the skills and confidence to do so; but, without the support and resources to do this their capacity 'to do' is threatened by the sometimes overwhelming demands of their everyday lives. A paid facilitator would have the time (and energy) to research opportunities for guest speakers, workshops and other activities that could enhance the learning opportunities for parents and their families.

** Recommendation 11:** The GDAN network be funded to support a facilitator and fund activities (host guest speakers, run workshops, attend conferences, visit other groups)

** Empowering families to envision a future**

An important issue for parents participating in the GDAN was the application process for securing individualised funds for their son/daughter. Research revealed that prior to submitting an application for the Disability Support Register, individuals (and their family) needed to be able to articulate their needs and aspirations in a proposal. The guest speakers that attended the last GDAN meeting described the processes they went through before documenting the request. Although empowering, the process was time consuming, and both parents drew on very different resources to achieve it. One parent sought assistance from an independent planner while the other returned to study and completed an associate diploma in disability studies, during which she was able to draw upon the support of teachers, family members and local service providers to write and consolidate a plan.\(^\text{100}\) The stories of both conveyed strong ideas and commitments on behalf of the family and a need for support throughout the process.

Indicators suggest that none of the parents in the network had formulated comprehensive plans at the end of the project; their responses described a need to explore the possibilities further. Actual planning would be a future step. Ideally, support to take the next step will be available within the Grampians and Barwon South-West regions through DHS Disability services, community services organisations or independent planners after June 2007. Should the network be resourced to continue, it would provide a potential forum for parents to meet and establish the beginnings of a working relationship with a planning facilitator.

** Recommendation 12:** That information provision needs to be followed by an opportunity for parents to understand it in the context of their circumstances, and of what’s possible

** Recommendation 14:** That an independent facilitator/planner is recruited to support this process, offering both group and one-to-one support

** Conclusion**

The Grampians Disability Accommodation Network project has revealed many issues that parents of young people with high care needs face when contemplating their son’s/daughter’s future accommodation needs. The current changes in the provision of support and services for individuals with a disability, together with the experiences of families that have successful developed sustainable housing and support options for their son/daughter (brother/sister), offer some hope that the creation of a sustainable housing option is a possibility.

The challenges of this project reflect both systemic failure and personal endeavours; and the need to develop and provide the resources that will address both. While being exposed to these challenges, the parents who participated in the network had the benefit of witnessing how some of the issues were resolved or being able to contribute the development of potential solutions; an experience that (hopefully) will enrich their appreciation of just how complex the

\(^{100}\) A research report on the establishment of a privately owned residence for an intellectually disabled adult with high attendant care needs (1994)
area of housing and support is. But also give them the confidence to take an active role, with their son or daughter, in formulating ideas and plans for their future.

Ideally, the Grampians Disability Accommodation Network will continue, consumer focused information and resources will be developed, and more success stories of innovative housing and support arrangements will be told.
References


Author(s) & Publisher Unknown

Yearly reports:101
- Mental Hygiene Authority 1955 – 1961
- Mental Health Authority 1962 – 1974

Newsletters:
- Mental Health Authority April 1975 (Vol 1 No. 1) - November 1978 (Vol 4 No. 28)102
- Pleasant Creek Redevelopment Project News (Issue 1, May 1997 – Issue 3, January 1999)103

Report:
- Report of the Royal Commission on asylums for the insane (1884)104

Papers presented to Parliament Session 1885 (1886)105

General Profile of clients from Pleasant Creek Centre who continue living in the Stawell Community (2000)106

101 Source: J Ward Archives, Ararat
102 Source: J Ward Archives, Ararat
103 Source: G. McKechnie
104 Source: J Ward Archives, Ararat
105 Source: J Ward Archives, Ararat
106 Source: G. McKechnie
## Appendix 1: Commonwealth & Victorian Government Legislation Timeline

<table>
<thead>
<tr>
<th>Year</th>
<th>Issue/Type of Support</th>
<th>Commonwealth legislation</th>
<th>Victorian Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to 1901</td>
<td>Financial Support</td>
<td>-</td>
<td>Provision of <em>Invalid &amp; Aged Pensions</em></td>
</tr>
<tr>
<td>Federation 1901</td>
<td>Disability Services</td>
<td>Section 51 of the constitution</td>
<td>Allocation of responsibility for provision of health services</td>
</tr>
<tr>
<td>1908</td>
<td>Financial Support</td>
<td>Provision of means tested, non-contributory Aged Pensions</td>
<td>-</td>
</tr>
<tr>
<td>1910</td>
<td>Financial Support</td>
<td>Provision of the <em>Invalid Pension</em></td>
<td>-</td>
</tr>
<tr>
<td>1919</td>
<td>Disability Services</td>
<td>Establishment of the Repatriation Commission</td>
<td>-</td>
</tr>
<tr>
<td>1945</td>
<td>Housing</td>
<td>Signing of the first Commonwealth State Housing Agreement (CSHA)</td>
<td><em>Under the agreement the Commonwealth would provide low cost loans to the state for the purpose of building public housing</em>&lt;sup&gt;107&lt;/sup&gt;</td>
</tr>
<tr>
<td>1948</td>
<td>Disability Services</td>
<td>Commonwealth Rehabilitation Service (CSR) established</td>
<td>-</td>
</tr>
<tr>
<td>1954</td>
<td>Disability Services (Residential)</td>
<td>Provision of subsidies to volunteer/charitable organisations with approved accommodation for aged or disabled people; subsidies available for hostels accommodating residents requiring assistance with personal care</td>
<td>-</td>
</tr>
<tr>
<td>1956</td>
<td>Housing</td>
<td>Second Commonwealth State Housing Agreement (CSHA) signed</td>
<td><em>Designed to encourage home ownership: states able to sell dwellings at concession rates</em>&lt;sup&gt;108&lt;/sup&gt;</td>
</tr>
<tr>
<td>1958</td>
<td>Housing</td>
<td>Provision of Rent Assistance to private renters</td>
<td></td>
</tr>
</tbody>
</table>

<sup>107</sup> Victorian Regional Housing Council – History of Public Housing [www.infoexchange.net.au/rhhome/urhc/history.htm](http://www.infoexchange.net.au/rhhome/urhc/history.htm)

<sup>108</sup> Victorian Regional Housing Council – History of Public Housing [www.infoexchange.net.au/rhhome/urhc/history.htm](http://www.infoexchange.net.au/rhhome/urhc/history.htm)
<table>
<thead>
<tr>
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<th>Issue/Type of Support</th>
<th>Commonwealth legislation</th>
<th>Victorian Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1962</td>
<td>Disability Services</td>
<td>-</td>
<td>Introduction of the Mental Health Act 1959 includes provisions for people with an intellectual disability</td>
</tr>
<tr>
<td>1969</td>
<td>Disability Services</td>
<td>-</td>
<td>Introduction of the Intellectually Handicapped Children’s Amenities Act</td>
</tr>
<tr>
<td>1969</td>
<td>Disability Services (Home based support)</td>
<td>-</td>
<td>Introduction of State Grants (Home Care) 1969 &amp; State Grants (Paramedical) 1969</td>
</tr>
<tr>
<td>1970</td>
<td>Disability Services (Home based support)</td>
<td>Introduction of Delivered Meals Subsidy Act</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Handicapped Children’s Assistance Act</td>
<td>Relieved states of financial responsibilities associated the provision of training &amp; accommodation facilities to children with a disability</td>
</tr>
<tr>
<td>1971</td>
<td>Financial Support</td>
<td>Pension payments extended to Residents of Training Centres (institutions)</td>
<td>-</td>
</tr>
<tr>
<td>1972</td>
<td>Financial Support</td>
<td>Introduction of Handicapped Children’s Benefit</td>
<td>-</td>
</tr>
<tr>
<td>1974</td>
<td>Disability Services</td>
<td>Handicapped Persons Assistance Act 1974 introduced</td>
<td>-</td>
</tr>
<tr>
<td>1980</td>
<td>Housing</td>
<td>Rent Assistance extended to increase the level of assistance &amp; target specific household types</td>
<td>-</td>
</tr>
<tr>
<td>1981</td>
<td>Disability Services</td>
<td>Program of Aids for Disabled Persons (PADP) established</td>
<td>-</td>
</tr>
<tr>
<td>1981</td>
<td>Disability Services (Residential)</td>
<td>-</td>
<td>Development of the Community Residential Unit (CRU) program</td>
</tr>
<tr>
<td>Year</td>
<td>Issue/Type of Support</td>
<td>Commonwealth legislation</td>
<td>Victorian Legislation</td>
</tr>
<tr>
<td>------</td>
<td>-------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1981</td>
<td>Housing</td>
<td>Commonwealth State Housing Agreement (CSHA) signed</td>
<td>As concerns over poverty levels grew; agreement progressively increased resources towards assistance for low-income renters</td>
</tr>
<tr>
<td>1982</td>
<td>Housing</td>
<td>Housing Authority (public housing) residents loose eligibility for Rent Assistance</td>
<td>-</td>
</tr>
<tr>
<td>1984</td>
<td>Housing</td>
<td>Commonwealth State Housing Agreement (CSHA) signed</td>
<td>Introduction of programs the quarantined funds for specific housing needs: Rental Assitances Programs for Aboriginals &amp; Pensioners, Mortgage &amp; Rent Relief, Crisis Accommodation, Local Gov &amp; Community Housing</td>
</tr>
<tr>
<td>1985</td>
<td>Disability Services (Home based support)</td>
<td>Home &amp; Community Care Act (HACC) 1985 signed</td>
<td>Commonwealth funded; state delivered services</td>
</tr>
<tr>
<td>1986</td>
<td>Disability Services</td>
<td>Disability Services Act 1986 introduced</td>
<td>-</td>
</tr>
<tr>
<td>1986</td>
<td>Disability Services (Home based support)</td>
<td>Attendant Care Scheme introduced</td>
<td>-</td>
</tr>
<tr>
<td>1987</td>
<td>Disability Services</td>
<td>-</td>
<td>Intellectually Disabled Person Services Act 1986 introduced</td>
</tr>
<tr>
<td>1987</td>
<td>Disability Services</td>
<td>-</td>
<td>Administration of Program of Aids for Disabled Persons (PADP) transferred state government</td>
</tr>
<tr>
<td>1988</td>
<td>Disability Services</td>
<td>-</td>
<td>Report commissioned; Ten year plan for the Redevelopment of Intellectual Disability Services</td>
</tr>
<tr>
<td>1989</td>
<td>Housing</td>
<td>Commonwealth State Housing Agreement (CSHA) signed</td>
<td>-</td>
</tr>
<tr>
<td>Year</td>
<td>Issue/Type of Support</td>
<td>Commonwealth legislation</td>
<td>Victorian Legislation</td>
</tr>
<tr>
<td>------</td>
<td>----------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1990</td>
<td>Disability Services</td>
<td>Accommodation for People with Disabilities: Report of the Senate Standing Committee on Community Affairs released; also know as the 'Ronald’s Report’</td>
<td>-</td>
</tr>
<tr>
<td>1991</td>
<td>Disability Services</td>
<td>-</td>
<td>Disability Services Act (1991) introduced</td>
</tr>
<tr>
<td>1991-1992</td>
<td>Disability Services</td>
<td>Commonwealth State/Territories Disability Agreement (CSTDA) signed</td>
<td>Complementary legislation to the Disability Services Act 1991 enacted to enable Victoria to be a signatory</td>
</tr>
<tr>
<td>1992</td>
<td>Disability Services</td>
<td>Disability Discrimination Act 1992 introduced</td>
<td>-</td>
</tr>
<tr>
<td>1996</td>
<td>Housing</td>
<td>Housing Assistance Act 1996 introduced</td>
<td>Provision of grants to states/territory’s for Housing Assistance; authorizes Australian Government to enter Into agreements with states &amp; territories</td>
</tr>
<tr>
<td>1996</td>
<td>Disability Services</td>
<td>-</td>
<td>State plan announced for Intellectual Disability Services 1996 - 1999109</td>
</tr>
<tr>
<td>2003</td>
<td>Housing</td>
<td>Commonwealth State Housing Agreement (CSHA) signed</td>
<td>Guiding principle: to assist those whose needs cannot be met by the private market</td>
</tr>
<tr>
<td>2002</td>
<td>Disability Services</td>
<td>-</td>
<td>State Disability Plan released – 10 year plan</td>
</tr>
<tr>
<td>2007</td>
<td>Disability Services</td>
<td>-</td>
<td>Disability Act 2006 introduced</td>
</tr>
<tr>
<td>2007</td>
<td>Disability Services</td>
<td>Commonwealh Senate Committee Report released</td>
<td>Primary Recommendation – 'That Commonwealth, State &amp; territory governments jointly commit as part of the fourth CSTDA agreement to substantial additional funding to address unmet need for specialist disability services, particularly for accommodation services and support”(p ix)110</td>
</tr>
</tbody>
</table>

109 The living history project (2004)
110 Funding and operation of the Commonwealth State/Territory Disability Agreement (2007)
Appendix 2: State Disability Plan

The Victorian Government has a vision for the future:

*By 2012, Victoria will be a stronger and more inclusive community - a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria.*

For Victorians who have a disability, the state government wants disability services to focus on supporting people with a disability in flexible ways, based on their individual needs, so that each person can live the lifestyle that they want.

Some of the changes that will take place between 2002 and 2012 are:

<table>
<thead>
<tr>
<th>In 2002</th>
<th>By 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>People Live in the community</td>
<td>People will be included &amp; participate in the community</td>
</tr>
<tr>
<td>We create lives of dependency</td>
<td>We will enable connectedness with the communities in which people live</td>
</tr>
<tr>
<td>We view people as recipients of services</td>
<td>We will view as partners in developing supports</td>
</tr>
<tr>
<td>We take centralised control of decision making</td>
<td>We will facilitate more personal control of decision making</td>
</tr>
<tr>
<td>Individuals are allocated a services provider</td>
<td>Individuals will have choices about their service providers</td>
</tr>
<tr>
<td>The focus is on health &amp; community services</td>
<td>The focus will be on the full range of services which support people's quality of life</td>
</tr>
<tr>
<td>The focus is on programs</td>
<td>The focus will be on people as individuals.</td>
</tr>
<tr>
<td>We make placements in programs</td>
<td>We will enable people to have lifestyle choices</td>
</tr>
<tr>
<td>There are standard services &amp; programs</td>
<td>There will be more flexible &amp; tailored supports</td>
</tr>
<tr>
<td>We provide reactive, crisis-driven services</td>
<td>We will provide more proactive planning and support</td>
</tr>
<tr>
<td>Government Departments and programs work in isolation</td>
<td>We will create active partnerships and more integrated, whole-of-government approaches</td>
</tr>
</tbody>
</table>

Four **principles** underpin the State Disability Plan. They are:

- **Equality** - people with a disability are citizens who have the right to be respected and the right to have equal opportunities to participate in the social, economic, cultural, political and spiritual life of society.

- **Dignity and Self-Determination (Choice)** is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live.

- **Diversity** is about recognising and valuing individual difference. Inclusive societies are strengthened by the diversity of their populations and by the contribution that each person makes to the social, economic, cultural, political and spiritual life of society.

- **Non-Discrimination** implies that all people have the right to live their lives free from discrimination. This means that society must set right all forms of discrimination – including both active and passive forms of discrimination, and unfair and outdated standards, laws, policies and practices.

**The State Disability Plan & Grampians Disability Accommodation Network**

The first priority of the State Government’s State Disability Plan includes two areas that are pertinent to the Grampians Disability Accommodation Network project;

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• Individualised Planning & Support and
• Having More Choices about Housing

**Individualised Planning & Support** will place the person with a disability at the centre of support delivery working together as equal partners to enable people to exercise choice in getting the support they need to pursue their own lifestyle.

This approach will enable people with a disability to live in the community and receive support within the ordinary structures of education, health, employment and community networks.

**Having More Choices about Housing** will allow people with a disability to exercise more choice. Committed to supporting people with a disability to live in a setting best suited to the person’s needs and wishes; the government will work with people who have a disability, their families and carers as well as the local community.

Housing options will place emphasis on public housing, private rentals, supported accommodation and community care.
Appendix 3: Conceptualising Accommodation & Support Services

There are many types of supports and services that people with a disability and their families utilise. They can include formal accommodation services (shared supported accommodation), informal arrangements (a Granny Flat on the same property as the family home) and individual arrangements that draw on the skills and resources of the individuals, their family and wider support network.

Acknowledging the current whole-of-government and whole-of-community approach to the provision of disability services; the author wanted to demonstrate that families involved in the Grampians Disability Accommodation GDAN project were already drawing on supports beyond those provided by DHS Disability Services.

In response to a questionnaire circulated to GDAN family members, 10 parents responded identifying 15 services/supports they currently use and 22 services/supports that they perceive using in five years time. The services identified were associated with education, respite, home-based support, community activities and accommodation.

The services and supports associated with their son/daughters future accommodation needs include:

- Shared supported accommodation
- Support for domestic duties
- Outreach support
- Sharing flat/unit with friend/partner
- Own accessible house
- Power to make decisions about son/daughters health & welfare
- Role in choice & employment of carers
- Son/daughter living independent of family
- Weekend visits to family home

Determined to demonstrate the potential for these services and supports to embody the whole-of-government and whole-of-community approach a model was sought that would accommodate the structure of formal and informal accommodation services and support, as well as the contributions of parent, family and friends.

![Figure 13: DSQ Disability Supports & Services Diagram](image-url)
Disability Services Queensland\textsuperscript{112} conceptualised the \textit{Disability Supports and Services Model} to develop a framework of service and supports use and provision. The model (Fig. 13) has five tiers, each one representing a different level of service provision and target group.

The lowest tier represents the \textit{generic or mainstream} supports. That is, the types of services and infrastructure available to all members of the community; this might include housing and building design, transport, justice and education systems. Moving up, the hierarchy the second tier encompasses the \textit{familial response}. This represents the support provided by the individuals personal support network of family and friends. The third tier represents the services and supports that are \textit{purchased privately} such as the paying of rent or the purchase of a specific piece of furniture that appeals to the buyer.

Government services make up the topmost tiers. At a lower level, (the fourth tier) are \textit{whole-of-government} services. Services available to a wider population group than just those who have a disability (public housing and health care). This tier includes government services that are \textit{targeted} at more specific populations. For example, the Health & Community Care (HACC) program is targeted to people who may be struggling to live at home independently (people with a disability or the frail aged) and are at risk of premature admission to residential care. The top tier represents \textit{funded disability services}. Services/supports in this category have been established and run in accordance with the Commonwealth States & Territories Disability Agreement (CSTDA).\textsuperscript{113}

The assumption of the model is that people with a disability (and their families) would initially access services and supports (including infrastructure) available in the general community. If (or when) the services/supports represented by the lower levels of provision are insufficient, service and supports provided represented by the higher levels are then considered.\textsuperscript{114}

It is important to note that the layers of the diagram are not mutually exclusive, it is possible that people with disabilities and their families might utilise several services at any one time. Nor should it be assumed that the use of services at a higher level (eg. specialist disability services) negates the need for service/supports from a lower level. A point illustrated in Fig. 14 which categorises the accommodation services and supports that parents participating in GDAN perceive to be using in five years time in an adapted version of the \textit{Disability Supports and Services Diagram}. The actual model depicting the framework for the GDAN has adapted the original triangle into a house-shaped icon (Fig. 15) maintaining the relationship with the focus of the project, housing (and support).

One of the purposes of this project is explore with parents and other members of the working group the options and possibilities for their sons/daughters future accommodation and support needs. This diagram will be used to assist the process of exploring the types of accommodation and support options available by place them in a framework that conceptualises the diversity within whole-of government and whole-of-community approach.

\textsuperscript{112} Funding reform project: Issues Paper – Demand for disability services (2002)
\textsuperscript{113} Funding reform project: Issues Paper – Demand for disability services (2002)
\textsuperscript{114} Funding reform project: Issues Paper – Demand for disability services (2002)
Figure 14: Services/supports identified by GDAN members

Figure 15: Services/supports framework devised for the GDAN project
Appendix 4: Housing Options (Selection)

Housing/Accommodation

Shared Supported Accommodation (CRU’S)

- Provision of low cost, secure and appropriately designed housing to enable people with disabilities to live independently with external support
- Also provides for larger groups of tenants requiring more intensive on-site support in Community Residential Unit Settings

Eligibility – The individual:
- Meets the criteria as determined under the Disability Act (2006)
- Their support needs that are best met in shared housing that provides the required staff resources, and
- Has to change their current living arrangements because they are not longer suitable (for example, the individual’s parents are getting older and finding it harder to keep looking after the individual at home)

Public Housing - Director of Housing owned houses

- Eligibility determined by income & assets
- People with a disability are prioritised
- Office of Housing will complete modifications as required

Waiting-list

Grampians Region
  Ballarat - 104 with priority, 549 not prioritised
  Horsham - 18 with priority, 98 not prioritised

Barwon South West Region
  Warrnambool - 33 with priority, 384 not prioritised
  Portland – 6 with priority, 92 not prioritised

Tip: If 2-3 people apply to live together in Public Housing the chance of being allocated a house is greater than a single application for a one-bedroom house

Note: Waiting list numbers were current at December 2006

Supported Residential Service (SRS)

- Private providers of accommodation & care for people who need support in everyday life
- Providers are registered with the State Government
- They are monitored to ensure they provide a certain standard of care & accommodation
- With the exception of HACC services, residents generally meet the criteria for government funded disability services

The sole SRS in the Grampians area available for younger adults is Golden Lodge in Ararat
Eventide Lutheran Homes (Hamilton) has a SRS facility but is specifically for the aged
Private Rental - open market

- Bond Assistance - Interest free loans from the Office of Housing
- Aids & Equipment Program (A&EP) - DHS Disability Services program that funds the provision of equipment & home modifications
- Commonwealth Rent Assistance (CRA) - non taxable income supplement paid in addition to the pension, allowance or benefit

Housing Support Programs

**Supported Accommodation Assistance Program (SAAP)**
- Office of Housing service for those who are homeless or at risk of homelessness
- Provides short-term case management directed at finding appropriate housing
- Not a disability specific service, case-manager would work in conjunction with disability supports

**Transitional Housing Management Program (THM)**
- Assists individual & families in housing crisis to establish and/or maintain appropriate, secure & sustainable housing through the provision of transitional housing, information & referral services, and support when required

**Housing Establishment Fund (HEF)**
- Grants provided for immediate financial assistance to households by increasing their purchasing power to access private rental or to intervene where private tenancies are at risk due to rental arrears
Appendix 5: Support Options (Selection)

Specific accommodation supports

<table>
<thead>
<tr>
<th>Shared Supported Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Residential Unit, Group Home</td>
</tr>
<tr>
<td>Outreach – Attendant Care</td>
</tr>
<tr>
<td>Flexible Support Packages – HomeFirst,</td>
</tr>
</tbody>
</table>

Home and Community Care (HACC)

- Meals on Wheels - Home Help
- Linkages (case management)
- Personal Care

Supported Living

Live in personal carer

Not common; 89% of primary carers in Australia are an immediate family member

One example of a successful ‘partnership’

- Ongoing arrangement for 18 ½ years (sustainable)
- Financially viable - individuals receive DSP & Carers Payment
- Support services used - respite program, carer support programs
- Office of Housing owned home (Public Housing); Person with a disability is the lead tenant

Shared Accommodation

Not a live-in carer arrangement

- Agreement around shared accommodation rather than provision of care
- Agreement could include reduced share of rent for some personal care assistance with or responsibility for specific chores
- Not disability specific

Shared Accommodation Projects

Independent Accommodation Network (IAN) – state-wide service; includes a registration & matching services for individuals looking for potential housemates

Wesley Homeshare – Formal housemate/boarder matching service for older adults or people with a disability who require domestic/personal care assistance in exchange for a reduced rent
Models of Support

### Cluster Care models
- A number of self-contained units on the same property, and includes one unit that accommodates an on-site manager
- The manager may be responsible for administration and/or some direct-care support

**Advantage** staff can be optimised and therefore provide a better overall service to residents with complex support needs

**Issue** around the congregation of people with a disability and the potential to reinforce stigmatisation and marginalisation from the wider community

### Co-operative Support funding (pooling resources)
A group of families in country Victoria have worked together to design a model of accommodation that includes:
- supported accommodation (2 beds) with provision for overnight support,
- a detached unit on the property for someone who is able to live independently but close enough to receive assistance as required (‘outreach on demand’) and
- separate units for people requiring outreach support

**Financially** - The support funding allocated to each individual will be pooled
- A combination of people with low/high/complex needs should attract sufficient funds to provide the support required for everyone

### Key-ring
- Are networks of 6-12 people living in flats or units are established in close proximity to one another (approx 10 min walk)
- The close proximity enables network members to act as an informal network of support for each other
- A community living worker is attached to each network living in the same area as the network working on a part-time flexible basis
- The community living workers do not provide nursing or personal care; rather they work with network members to develop their own networks & supports

**Key-ring Accommodation Projects**
- *Neighbourhood Connections* (Marrilacc, East Brighton & Rosebud)
- *Alternative Accommodations Option Program* (Northern Support Services, Northcote)

### Circle of Support
Circles of Support are a group of people (friends, family and community members) who meet on a regular basis to help an individual accomplish their goals in life
- Members are not paid to be there
- People are involved because they care enough about the focus person to give their time and energy to helping that person to overcome obstacles and increase their options
- The relationship is not only one way, all members have diverse gifts & interests that can appear with any new possibility and opportunity

**Key-ring Accommodation Projects**
- *Directlife* (E) Tipping Foundation, Oakleigh)
Appendix 6: Individualised Funding

**Individualised funding** - public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in the community as a full citizen.¹¹⁵

*Individualised Funding* was devised by a group of parents in British Columbia, Canada. In the 1970's when Woodlands Institute was closing and community based services were being established, parents of former residents formed a group to advocate on their behalf of their sons and daughters.

Conscious that the specialist community services might (and did) relegate their sons and daughters to an 'institutionalised community life'¹¹⁶ rather than enable them to fully participate in the community. In 1976 the Woodford Parents Group submitted a proposal to for an alternative funding policy to the provincial government.¹¹⁷

*The idea that came to them was a simple but powerful one. What if everyone with a disability was able to choose the supports and services that they needed from the whole range of possibilities that exist in any given community? This would mean that it would not be necessary to have people fit into services. Instead, services could fit people. The Woodlands Parents group envisioned that people with disabilities could present their personal support plan to government and receive the funding for their support needs directly. Then they could use this money to purchase the supports that would help them to meet their goals. People who needed support with decision making could receive it through trusted families and friends who could be legally authorized to help them to manage their funding.*¹¹⁸

The Woodford Parents proposal did not come to fruition until the 1990's when the first Individualised Funding pilot project took place in British Columbia. However; the vision of the Woodford Parents was embraced, Individualized funding as a tool for self-determination began to take on the qualities of a movement and initiatives took root in Great Britain, Europe, the United States and Australia as the British Columbia idea was exported around the world.

**Characteristics of Individualised Funding**

The two fundamental characteristics of Individualised Funding are:¹¹⁹

- The funding amount is determined by direct reference to the individual’s specific needs
- The individual and their personal network determines how funds are spent

There is a distinct shift in the roles of those who provide funding and support. Rather than lump sums (block funding) going to service providers who decide who to serve and how, funding is allocated to individuals (according to demonstrated need) who decide how the funds are used.¹²⁰

Research suggests that Individualised funding is more empowering and more cost-effective than traditional block funding¹²¹.

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¹¹⁵ Individualised Funding: Emerging Policy Issues (1999)  
¹¹⁶ Guide to Individualised Funding (2005)  
¹¹⁷ Seattle Declaration on Self-Determination & Individualised Funding Conference Speakers  
¹¹⁸ http://members.shaw.ca/individualizedfunding/index.htm  
¹¹⁹ Guide to Individualised Funding (2005)  
Individualised Funding in Australia

In Australia, Western Australia was the first state to adopt Individualised funding passing a new disability Act that allowed individuals with a disability to receive funding enabling to purchase their own services.\(^{122}\) The ACT, and Queensland followed suit (Fig. 16). To date, New South Wales and South Australia are the only states/territories who have not introduced individualised funding.

<table>
<thead>
<tr>
<th>State</th>
<th>Name</th>
<th>Year Introduced</th>
<th>Current Demand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victoria</td>
<td>Individualised Support Packages (Support &amp; Choice)</td>
<td>2003</td>
<td>1,317 individuals registered for support to live in the community at 31st December 2006(^{123})</td>
</tr>
<tr>
<td>ACT</td>
<td>Individual Support Packages</td>
<td>1990’s; Evaluated in 2003(^{124})</td>
<td>Information not available</td>
</tr>
<tr>
<td>New South Wales</td>
<td>No provision for individualised funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern Territory</td>
<td>Individual Community Support Package</td>
<td>2000(^{125})</td>
<td>Information not available</td>
</tr>
<tr>
<td>Queensland</td>
<td>Adult Lifestyle Support Program</td>
<td>1994</td>
<td>Information not available</td>
</tr>
<tr>
<td>South Australia</td>
<td>No provision for individualised funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tasmania</td>
<td>Individualised Support Packages</td>
<td>-</td>
<td>260 individuals assessed as requiring a package on waiting list</td>
</tr>
<tr>
<td>Western Australia</td>
<td>Intensive Support Funding (ISF) &amp; Accommodation Support Funding (ASF)</td>
<td>1993</td>
<td>Approx 12% of ASF applications are able to be funded</td>
</tr>
</tbody>
</table>

**Figure 16: Individualised funding programs in Australia**

National data about Individualised funding in Australia was first collected in 2002-2003, in that year around 15% of people accessing specifically funded disability services reported receiving Individualised funding.\(^{126}\) In that year, individuals living in Queensland were also receiving individualised funding.\(^{127}\) This figure is increasing, 17% of people receiving Commonwealth/State funded disability supports reported receiving individualised funding in 2003-2004.\(^{128}\) This increased to 18% in the following 12 month period.\(^{129}\)

**Victoria**

In 2003-2004, the Victorian government’s Disability Services Division implemented an individualised planning and support (IP&S) approach. Rather than the exclusive allocation of funds to specific programs, the state government redirected growth funds to individuals,\(^{130}\) the key component of individualised funding.

In the first year 920 individuals were allocated funds. Individuals targeted participated in a planning process with the support of regionally based facilitator. The role of the facilitator was to assist individuals (and their families) to identify and articulate their aspirations and work with

\(^{122}\) Bostock & Gleeson. 2004  
\(^{124}\) A new approach to individual support packages (2005)  
\(^{125}\) Disability Services in the Northern Territory (2006)  
\(^{130}\) Evaluation of Support & Choice Implementation (2005)
the family to explore the range of potential services and resources that might be accessed to make the dream a reality.

A proposal was developed in this planning process stipulating the resources required to enable an individual to achieve their specified goals. The proposal was then considered for funding by a regional panel. An evaluation of the IP&S process took place in 2005\textsuperscript{131} and was followed by a comprehensive review in 2006.

The most recent development in Victoria is the release of guidelines around the Disability Support Register (DSR)\textsuperscript{132}. These guidelines are not exclusive to Individualised Funding applications, the DSR receives requests both that are individually determined or are specific types of ongoing (long-term) support.

Available figures indicate that Support & Choice is rapidly growing. From the original 920 recipients the DHS Annual Report 2005-2006 indicates that 7,898 people received individual support.\textsuperscript{133}

\textsuperscript{131} Evaluation of Support & Choice Implementation (2005)
\textsuperscript{132} Access to ongoing disability support: DSR registration guidelines (2007)
\textsuperscript{133} This figure is listed under ‘Individual Support’; it is unclear whether this refers to people receiving IP&S, the author recommends that clarification needs to be sought prior to drawing conclusions.
Appendix 7: Determining Need & Planning

The emerging policies around the provision of services to people with a disability aims to deliver the support and resources that people with a disability want and need. This represents a major shift in the way services for people with disabilities are provided. While the shift for funding bodies (State Government) and disability support providers is a large one; there are also fundamental shifts for individuals and families in the way they make a request for supports and services.

The recently reviewed Disability Support Register represents the extent of the change. Rather than registering for a specific type of support (a bed in a CRU or day program placement); the application is made as a proposal for support and/or resources that will enable the individual reach a specified goal. The proposal needs to reflect the needs and aspirations of the individuals and includes:

- The desired goal(s), what the individual wants to achieve
- How the individual can achieve the goal (one or more strategies)
- The resources and support required to make this happen

The development of a proposal can be a much more involved than contacting the Regional Disability Intake and Response Team and lodging an application in consultation with a case manager or service provider.  

Individuals and families who have engaged in a planning process and developed a proposal have reported a greater sense of control and satisfaction.  

‘Before, people didn’t listen to what I wanted and told me what to do. Now I have a plan and goals and someone to support me to achieve these goals who listens and gives advice when needed – I am getting somewhere’. (Participant living independently)  

‘We were encouraged to think ‘outside the box’ and it was wonderful to be able to do that for the first time’. (Parent of autistic child)  

The process itself does take time and energy and the support of a facilitator or planner can be valuable. There are several different ways this support can be accessed. Firstly, individuals and families are entitled to begin (and complete) the proposal independently or they can request assistance through DHS Disability Services, a Community Service Organisation or an independent facilitator. There is an emergence of organisations that offer independent facilitation/planning; including, the Personalised Lifestyles Assistance (PLA) project and Plan of Action Services that offer independent facilitation/planning.

A third type of support is the emergence of Family Governance where several families may pool a portion of their funds to employ a co-ordinator to support both the planning processes and implementation of these plans once the resources become available.

DHS Disability Services are running regional forums for families and individuals to inform them about the planning process prior to July 1st 2007 when the Disability Act 2006 comes into operation.

---

134 Accommodation Planning for people with intellectual disability (1999)  
Appendix 8: Parent Questionnaire

Name(s) ____________________________________________

Town __________________________ Local Government Area __________________________

Your family

Names & ages of family members (including yourself)

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Sex</th>
<th>Does this person live at the above address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Y / N</td>
</tr>
</tbody>
</table>

How long have you lived in your present area or neighbourhood? ___________ Years

How do you and your partner best describe your current occupation(s) or roles?

Are you in receipt of?

- Carer Allowance Y / N
- Carer Payment Y / N

Your son/daughter who has a disability

Name(s) _______________________________________________________________________________

What type of disability does you son/daughter have?

How does this disability impact your son’s/daughter’s ability to?
### Carry out everyday activities (eg. carry out daily routine)

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Learn new skills and solve problems

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Communicate with others

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Get around inside and outside the home

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Complete self-care tasks (eg. shower, dress)

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Participate in domestic activities (prepare a meal, housecleaning, paying bills)

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

### Develop & maintain relationships

<table>
<thead>
<tr>
<th></th>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>
How would you best describe your son’s/daughter’s current occupation(s) and/or roles?

What are your son’s/daughter’s current living arrangements?

What living arrangements do you perceive for your son/daughter in 5 years time?  
* Dare to Dream with this one!

When did you start to think about your son’s/daughter’s future living arrangements?

Outside of your immediate family, have you discussed your son’s/daughter’s future living arrangements with anyone? If yes, who?

What services did your son or daughter use 5 years ago?

What services does your son or daughter currently use?

What type of support or services you envision your son/daughter using during the next 5 years?
Appendix 9: Parent Questionnaire Data

Demographics

• 10 families responded to the questionnaire

• 4–6 family members, average of 4 living in family home

• 2 families – son/daughter with a disability only child living remaining in the family home
  (age of son/daughter - 16 & 29 years)

Address (Local Government Area & DHS Region)

<table>
<thead>
<tr>
<th>DHS Region</th>
<th>Local Government Area</th>
<th>Number of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loddon-Mallee</td>
<td>Buloke</td>
<td>1</td>
</tr>
<tr>
<td>Grampians</td>
<td>Ararat</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Hindmarsh</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Horsham</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Northern Grampians</td>
<td>1</td>
</tr>
<tr>
<td>Barwon South</td>
<td>Southern Grampians</td>
<td>3</td>
</tr>
</tbody>
</table>

Years living in area: 2 - 26 years (mean 16.6 year)

Parent’s occupation

<table>
<thead>
<tr>
<th>Status</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>full-time</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Part-time 0.5 - 0.9</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Part-time 0.1 - 0.4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Not Indicated</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Health</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Homemaker</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Own business</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Primary Producer</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Retail</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Retired</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Trade</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Welfare</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Not Indicated</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Eligibility for financial support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Carers Payment</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
**Sons/daughters with a disability**

11 sons/daughters  6 males/5 females

Age range 13 – 29 years (mean 18 year)

**Disability Type**

6 individuals have more than one disability/significant medical condition

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>Number of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>7</td>
</tr>
<tr>
<td>Sensory (hearing loss)</td>
<td>1</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>2</td>
</tr>
<tr>
<td>Autism</td>
<td>3</td>
</tr>
<tr>
<td>Aspergers syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Chronic medical conditions*</td>
<td>3</td>
</tr>
</tbody>
</table>

* These conditions that has an impact on the individual’s functional abilities

1 male would be ‘classified’ as having a *dual diagnosis* – both a disability and a chronic mental illness

3 individuals had a disability that was attributable to a recognised syndrome

- Downs syndrome
- Rubinstiens Tabyi Syndrome

3 individuals have chronic medical conditions

- Epilepsy
- Osteoporosis

**Functional impact of the disability**

The International Classification of Function, Disability & Health (ICH)\(^{136}\) was developed to collect more meaningful data about the functional impact disabilities and health conditions have on an individual’s life.

Determining the relevant domains/chapter headings for the questionnaire

(Source: activity and participation of component ICF– home based activities)

- Carry out everyday activities (eg. Carry out a routine)
- Learn new skills and solve problems
- Communicate with others
- Get around inside and outside the home
- Complete self care tasks (eg. Shower/dress)
- Participate in domestic activities (prepare a meal, house cleaning, paying bills)
- Develop and maintain relationships

Domains excluded for the purposes of this questionnaire:

- Major life areas (eg. Work & employment)
- Community, social & civic life (eg. Recreation & leisure, religion & spirituality)

---

\(^{136}\) ICF Australian user guide (2003)
Determining individual support needs from responses – scale adopted from CSTDA National Minimum Data Set redevelopment:137

<table>
<thead>
<tr>
<th>Does not need help/supervision in this life area</th>
<th>Does not need help/supervision but uses aids or equipment</th>
<th>Sometimes needs help/supervision in this life area</th>
<th>Unable to do or always needs help/supervision in this life area</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

Mapping support needs categories to ICF performance qualifier:

<table>
<thead>
<tr>
<th>Support need Category</th>
<th>Qualifier</th>
<th>Extent of problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not need help/supervision in this life area</td>
<td>1</td>
<td>NO problem</td>
</tr>
<tr>
<td>Does not need help/supervision in this life area but uses aids or equipment</td>
<td>2</td>
<td>MILD problem</td>
</tr>
<tr>
<td>Sometimes needs help/supervision in this life area</td>
<td>3</td>
<td>MODERATE - problem</td>
</tr>
<tr>
<td>Unable to do or always needs help/supervision in this life area</td>
<td>4</td>
<td>SEVERE problem</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Determining a group (overall) rating of the functional impairment of the sons/daughters disabilities:

<table>
<thead>
<tr>
<th>Domain – Activities &amp; Participation</th>
<th>Qualifier range</th>
<th>Mean/Average</th>
<th>Functional impairment of the disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carry out everyday activities</td>
<td>3 - 4</td>
<td>3.7</td>
<td>Moderate</td>
</tr>
<tr>
<td>Learn new skills &amp; solve problems</td>
<td>3 - 4</td>
<td>3.5</td>
<td>Moderate</td>
</tr>
<tr>
<td>Communicate with others</td>
<td>1 - 4</td>
<td>3.1</td>
<td>Moderate</td>
</tr>
<tr>
<td>Get around inside &amp; outside the home</td>
<td>1 - 4</td>
<td>2.5</td>
<td>Mild</td>
</tr>
<tr>
<td>Complete self care tasks</td>
<td>1 - 4</td>
<td>3.3</td>
<td>Moderate</td>
</tr>
<tr>
<td>Participate in domestic activities</td>
<td>3 - 4</td>
<td>3.8</td>
<td>Moderate</td>
</tr>
<tr>
<td>Develop &amp; maintain relationships</td>
<td>3 - 4*</td>
<td>3.5</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

* One son/daughter was given a N/A rating

**Occupation – roles & activities**

<table>
<thead>
<tr>
<th>Roles</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student</td>
<td>Church</td>
</tr>
<tr>
<td>Student - SDS</td>
<td>Individualised (flexible) activity program</td>
</tr>
<tr>
<td>Unpaid employee - work experience</td>
<td>Living skills development</td>
</tr>
<tr>
<td>Participant - ATSS</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
</tr>
</tbody>
</table>

**Services & Supports**

<table>
<thead>
<tr>
<th>Service/support</th>
<th>5 years ago</th>
<th>Currently</th>
<th>5 years time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite</td>
<td>8</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Respite – out of home</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Respite – in home (HACC)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Holiday Programs</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Accommodation</td>
<td>Community residential Unit</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Permanent Accommodation</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domestic Support</td>
<td>Personal care</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Meals on Wheels</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Help</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

137 Applying the ICF to a national disability services data collection (2003)
Educational

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>School – Integration/support</td>
<td>2</td>
</tr>
<tr>
<td>School – Special developmental School</td>
<td>1</td>
</tr>
</tbody>
</table>

Vocational

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult training Support Service</td>
<td>1</td>
</tr>
<tr>
<td>Sheltered Employment</td>
<td>1</td>
</tr>
</tbody>
</table>

Recreational activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leisure buddy</td>
<td>1</td>
</tr>
<tr>
<td>Community Member</td>
<td>1</td>
</tr>
</tbody>
</table>

Other

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Management</td>
<td>1</td>
</tr>
<tr>
<td>Aids &amp; Equipment Program (A&amp;EP)</td>
<td>1</td>
</tr>
<tr>
<td>A&amp;EP Continence aids</td>
<td>1</td>
</tr>
<tr>
<td>Interchange</td>
<td>2</td>
</tr>
<tr>
<td>Occupational Therapy/Speech Therapy/</td>
<td>2</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td></td>
</tr>
<tr>
<td>Nursing support (medical needs)</td>
<td>1</td>
</tr>
<tr>
<td>Individualised/flexible program</td>
<td>1</td>
</tr>
<tr>
<td>Home &amp; Community Care (HACC) program</td>
<td>1</td>
</tr>
</tbody>
</table>

**Future Living Arrangements**

Time parents have been thinking about their sons/daughters future living arrangements

2 – 24 years (mean 10½ years)

When parents began considering their sons/daughters future living arrangements

<table>
<thead>
<tr>
<th>Age of child when considered living arrangement</th>
<th>Number of years considering future living arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-3 years</td>
<td>2 years</td>
</tr>
<tr>
<td>4 years</td>
<td>3-4 years</td>
</tr>
<tr>
<td>7-8 years</td>
<td>5 years</td>
</tr>
<tr>
<td>9 years</td>
<td>8 years</td>
</tr>
<tr>
<td>- Adolescence</td>
<td>8-10 years</td>
</tr>
<tr>
<td>21 years</td>
<td>12 years</td>
</tr>
<tr>
<td><strong>Events</strong></td>
<td></td>
</tr>
<tr>
<td>Diagnosis - infant</td>
<td>17 years</td>
</tr>
<tr>
<td>Senior years at school - difference observed to peers</td>
<td>Always (24 years)</td>
</tr>
<tr>
<td>Siblings leaving home - loss of informal carers</td>
<td>-</td>
</tr>
</tbody>
</table>

Who parents have discussed accommodation/support issues with

<table>
<thead>
<tr>
<th>Confidant</th>
<th>Number of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>No one</td>
<td>1</td>
</tr>
<tr>
<td>Immediate family</td>
<td>1</td>
</tr>
<tr>
<td>Extended family</td>
<td>2</td>
</tr>
<tr>
<td>Informal network - friends</td>
<td>3</td>
</tr>
<tr>
<td>Informal network - work colleagues</td>
<td>2</td>
</tr>
<tr>
<td>Support group/network</td>
<td>2</td>
</tr>
<tr>
<td>Teachers</td>
<td>1</td>
</tr>
<tr>
<td>Health/Welfare professionals</td>
<td>1</td>
</tr>
<tr>
<td>Disability support services workers</td>
<td>2</td>
</tr>
<tr>
<td>DHS Disability Services</td>
<td>1</td>
</tr>
<tr>
<td>Minister for community affairs</td>
<td>1</td>
</tr>
</tbody>
</table>
## Appendix 10: GDAN Meeting Outline

<table>
<thead>
<tr>
<th>Date</th>
<th>Attendance (Apologies)</th>
<th>Themes/Issues</th>
<th>Handouts/ Further reading</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• Role of project worker</td>
<td>Meeting Mathew (2004)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Role of Rural Access</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Role of Wimmera Uniting Care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Role of Parent Support Coordinators</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Role of Handsbury Fellowship/ RMIT</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Background to disability Services in Australia</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Small Group Activity – Models of accommodation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Proposed GDAN framework</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Future meetings – planning</td>
<td></td>
</tr>
<tr>
<td>October 2006</td>
<td>12 (4)</td>
<td>1. Commonwealth and State government legislation</td>
<td>Parent Questionnaire</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Parent Questionnaire issued</td>
<td></td>
</tr>
<tr>
<td>November 2006</td>
<td>8</td>
<td>1. Introducing DAN – feedback from the parent questionnaires</td>
<td>Housing Matrix</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Conceptualising disability services</td>
<td>Make it happen (2006)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Housing &amp; Accommodation services</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Activity – potential use of different housing/ accommodation services</td>
<td></td>
</tr>
<tr>
<td>December 2006</td>
<td>9 (3)</td>
<td>1. Clarifying housing/ accommodation services</td>
<td>Support Matrix</td>
</tr>
<tr>
<td>Date</td>
<td>Attendance (Apologies)</td>
<td>Themes/Issues</td>
<td>Handouts/ Further reading</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------</td>
</tr>
<tr>
<td>February 2007</td>
<td>10</td>
<td>1. Individualised planning – Support &amp; Choice</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Family Governance</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Next meeting – guest speakers</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Final phase of project:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Report</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Trip to Ballarat to see accommodation options</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Community Forum</td>
<td></td>
</tr>
<tr>
<td>March 2007</td>
<td>17 (15)*</td>
<td>1. Disability Support Register – 2007 guidelines</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Guest speakers:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Two Parents and a facilitator:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Talking about envisioning a future, individualised funding &amp; family governance</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Deb Rouget (PLA)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anita O’Brien</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lesley O’Loughlin-Schultz &amp; Cindy O’Laughlin</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anita and Lesley spoke about their experiences around establishing accommodation and support for their son/daughter Warren and Cindy</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Deb works with the Personalized Lifestyle Assistance Project (PLA) and spoke about her role as a facilitator, assisting individuals and families to envision and plan for their future.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>* Meeting was opened to other parents &amp; service providers not already involved in GDAN</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Presentation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A Dream Becomes a Reality – Developing a 10 year Plan</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>By Lesley O’Loughlin Schulz</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Notes from the meeting</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Disability Support Register – applying for ongoing support</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Including Individualised Support Packages</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Envisioning a future – Determining need &amp; planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Individual planning forum – Ballarat</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Choose Your Own Facilitator – Independent Planner</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Family Governance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Evaluation Questionnaire – Parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Evaluation Questionnaire – Service Providers</td>
</tr>
</tbody>
</table>
Appendix 11: Project Evaluation Questionnaire - Parents

Attendance

Which of the following sentences best describes the way you participated in the Grampians Disability Accommodation Network (GDAN)?

☐ I was able to attended most of the sessions (4-6)
☐ I was able to attend some of the sessions (2-3)
☐ I was able to attend only one session
☐ I was unable to attend any of the sessions

If you were unable to attend more than two sessions, was this because (select the one that best describes your situation):

☐ I was unable to attend due to other family and/or work commitments
☐ I was not able to travel to Halls Gap
☐ I attended one or two sessions before choosing not to attend the sessions

If you choose not to attend the sessions, please indicate why you made this decision:

☐ I did not feel that the information being discussed was relevant to my family
☐ I do not believe I need this type of information at this time
☐ I did not find the information useful
☐ I did not feel comfortable attending the sessions
☐ The information alone was sufficient; I did not need to attend the sessions
☐ Other

________________________________________________________________________
________________________________________________________________________

Information provision

There were several different types of information made available during the project, please indicate if you found each type of information useful or not useful:

<table>
<thead>
<tr>
<th>Useful</th>
<th>Not Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
| ☐      | ☐         | Written information
| ☐      | ☐         | Matrixes – table information
| ☐      | ☐         | Articles
| ☐      | ☐         | Personal stories/scenarios (published)
| ☐      | ☐         | Guest speakers

What changes could be made to the types of information used? (eg. amount, complexity, format)
The following list includes most of the topics/themes addressed during the project; please indicate if you felt that they were useful or not useful:

<table>
<thead>
<tr>
<th>Useful</th>
<th>Not Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
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<tr>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Consider the topics that you did not find useful; if these sessions were delivered for other families, would you exclude them from the program?

☐ Yes ☐ No

The following topics are not directly related to accommodation and support provision and time did not permit them to be included in the available sessions. However, the literature and anecdotal evidence suggest that they can have a significant when considering the long-term needs of your son or daughter.

Please indicate whether you would find them useful or not useful.

<table>
<thead>
<tr>
<th>Not Useful</th>
<th>Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
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<tr>
<td>☐</td>
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</tr>
</tbody>
</table>

_Please note: It is anticipated that the information delivered during the project (including the information listed above) will be included in an attachment to the Project Report._

Is there any other information that you feel should have been included in the in the project?

☐ Yes ☐ No

If yes, please indicate what topics you feel should be included:

________________________________________________________________________

________________________________________________________________________
Expectations of the Project

How did you find out about the Grampians Disability Accommodation Network?

Did the project meet your expectations?

Has the project changed the way in which you visualise the future accommodation and support options for your son or daughter?

Are there any further comments you would like to make about the Grampians Disability Accommodation Network Project?

Future developments

Do you feel there is potential for parents (and supporters) to meet on a regular basis to continue exploring accommodation and support options?

☐ Yes ☐ No

If yes, how would the network need to be supported?

If yes, what type of information would you like explore further?

Would you consider attending workshops, information sessions of trips to visit existing accommodation/support arrangements should they be made available in the future?

☐ Yes ☐ No

Thank-you very much for your time – your thoughts & responses are very much appreciated.
Appendix 12: Project Evaluation Questionnaire - Service Providers

Name: ________________________________

Organisation: ________________________________

Catchment area: ________________________________

Information provision

Did you feel that the information provided was suitable for yourself as a service provider?

In your opinion, do you feel that the details provided were appropriate for parents?

There were several different types of information made available during the project, please indicate if you found each type of information useful or not useful:

<table>
<thead>
<tr>
<th>Useful</th>
<th>Not Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
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<tr>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

What changes could be made to the type of information distributed?
(eg. amount, complexity, format)

________________________________________________________

________________________________________________________

The following list includes most of the topics/themes addressed during the project; please indicate if you felt that they were useful or not useful:

<table>
<thead>
<tr>
<th>Useful</th>
<th>Not Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Consider the topics that you did not find useful; if these sessions were delivered for other families, would you exclude them from the program?

☐ Yes       ☐ No

The following topics are not directly related to accommodation and support provision and time did not permit them to be included in the available sessions. However, the literature and anecdotal evidence suggest that they can have a significant when considering the long-term needs of a family member who has a disability.

Please indicate whether you would consider them to be useful or not useful.

Not Useful  Useful

☐  ☐ Power of Attorney & guardianship
☐  ☐ Special Disability Trusts
☐  ☐ Centrelink payments
☐  ☐ Planning for the future (Commonwealth Initiative)

*Please note: It is anticipated that the information delivered during the project (including the information listed above) will be included in an attachment to the Project Report.*

Is there any other information that you feel should have been included in the project?

☐ Yes       ☐ No

If yes, please indicate what topics you feel should be included:

**Expectations of the Project**

The Grampians Disability Accommodation Network project was conceived in response to the concerns of parents who were concerned about the future accommodation and support options for their sons and daughters. Do you think the project responded to the original concerns?

Have you received any feedback about the project from GDAN members (please respect their confidentiality, do not include names)?

In what ways is your organisation able to respond to enquires about accommodation and support options for people with a disabilities or/and their families?

Has your participation in the Grampians Disability Accommodation Network raised the profile of accommodation and support within your organisation?

Are there any further comments you would like to make about the Grampians Disability Accommodation Network Project?
Future developments

Do you feel there is potential for parents (and supporters) to meet on a regular basis to continue exploring accommodation and support options?

☐ Yes ☐ No

If yes, how would the network need to be supported?

Would your organisation be able to provide ongoing support?

☐ Yes ☐ No

If yes what support could be provided?

Thank-you very much for your time – your thoughts & responses are very much appreciated.
## Appendix 13: Questions About Support & Choice

<table>
<thead>
<tr>
<th>Stage</th>
<th>Questions</th>
</tr>
</thead>
</table>
| **One: Identify, prioritise & target potential applicants** | 1. How are individuals selected from Disability Support Register (DSR) when funding becomes available?  
2. Can individual initiate the facilitation process or do they need to be formally allocated a facilitator?  
3. If an individual has an Individual Plan already written; clearly stating a requirement for disability specific service and brings it to DHS ill this be accepted streamlining their placement on the DSR?  
4. If someone remains on the DSR for more than 12months will they be contacted and their expressed needs reviewed?  
5. How are priorities determined? What's the influence of:  
   - Potential benefits of early intervention?  
   - High need compared with low/medium?  
   - Crisis response?  
   - Ability of individual/family to participate in planning process?  
   - Recurrent need v's non-recurrent funding?  
   - Individuals who have collaborated with others in developing innovative accommodation/support (eg. planning to pool resources with other families for accommodation support OR If housing is available and support is needed to make the option viable) |
| **Two: Planning/identifying the need** | 1. Is this planning process associated with the Planning Policy being developed to implement the Disability Act 2006?  
2. Will facilitators to be more locally based in the future?  
3. Can an individual choose their own facilitator?  
4. Is it possible to see the unit pricing schedule or to obtain some guidance around the funding parameters during the planning process?  
5. Is it feasible to investigate at this point whether a service can be provided for the unit price? |
| **Three: Verification & approval** | 1. How often does panel meet?  
2. Are individuals informed of when their plan is being considered?  
3. What's the time lapse between completing a plan with your facilitator and the plan going to the verification panel?  
4. Does individual need to use funds in specific time frame once it is approved?  
5. If plan not approved, how is individual/family notified?  
6. Is there a written explanation provided?  
7. Is there an appeal process? |
| **Four: Allocation of funding** | 1. What is the role of individual/family?  
2. Is there provision for the individual/family to hold partial accountability for overseeing the activities? |
| **Five: Implementation of the plan** | 1. Who liaises with individual/family around the implementation of plans?  
2. Does the facilitator have an ongoing role?  
3. Who monitors the plan?  
4. Is recurrent funding reviewed, how often?  
5. What capacity is there for variations in the plan over time? |