

To Whom It May Concern:

We represent a desperate group of families and carers of disabled children and adults in the Southern Grampians Shire Council (SGSC), located in and around Hamilton, Victoria.

We are very aware that there is a distinct lack of available facilities for adequate Respite options – long and short term, and of supported housing options in this area.

We thought that it was time to have our voices heard on a more personal/grass roots level in appealing to you and your political parties regarding these issues. It is obvious that there are gaps in services at present and the issue is going to increase in the years to come.

We are aware that the politicians are aware of the need to remedy these problems and that increased funding has been made available for services such as Case Work, Individual Support Packages (ISP). **BUT** we would like more bricks and mortar and the funds to employ qualified staff to work in these areas.

We (Carers/Parents) are tiring and are very concerned for our children/adults future and for our own future. The disabled people in our care need to have choices and so should we. We acknowledge the shift from institutionalised care has been a positive move and we do not wish to go back down that pathway, but there hasn't been the provision of much in the way of accommodation options for people that weren't already institutionalized, permanent or temporary. It is a problem that is starting to snow ball and is only going to get worse.

We are quite aware of the Victorian Governments' Inquiry into Supported Accommodation for Victorians with a disability and/or mental illness (December 2009), and the Federal Governments' Report on the Inquiry into Better Support for Carers (April 2009). Some of us made submissions to these inquiries.

We are also aware of - Victorian State Disability Plan (2002-2012).
Disability Services Carer Action Plan (2006).
Autism State Plan (May 2009).
Housing Options Unlocked (May 2006).
Disability Act (2006)

BUT **We want to know what is being done, how, and is there anything we can do to assist in the provision of increased services i.e. more respite beds – long and short term and Supported Accommodation Housing.**

We, as a group want you to know how we feel. We have found through using our needs analysis, people have been forthcoming and honest in answers. None of us want to shun our responsibility, but we need more assistance. We have encountered 'brick wall after brick wall' and we want to 'knock this one down' now!

We would like to refresh your minds about where we live and what we have available to us – the carers and families and more so, the disabled people we are caring for.

Hamilton: - is located approx. 300 kms from Melbourne in the Southern Grampians Shire Council – population as at June 30, 2009 was 17,564.

- Number of people with a disability registered @ SGSC – 160 (HACC users with Aged and Disability Services data.
- 20 respite users under 65 years of age
- Number of clients registered with STAY Residential Services – 60 clients
- Clients using short term respite beds in Hamilton (STAY) – 43 *There only 3 beds available on weekends.
- Number of long term respite beds in SGSC 16

- Number of Students attending Hamilton Special Developmental School – 25 families
- Client numbers attending Mulleraterong Centre (Hamilton) – 60
- Barwon Southwest Shared Supported Accommodation Services 57 out of 922 in the State of Victoria (Vic. Govt. Data 2008)

To obtain the information we are presenting to you, we circulated 85 questionnaires to as many locals as we could reach. This procedure was done with the co-operation of-

- : Hamilton Special Development School
- : Mulleraterong Centre Inc.
- : Local appeal through The Hamilton Spectator Newspaper article
- : Southern Grampians Shire Council – Aged & Disability Service Leader

Of the 70 surveys distributed, 41 surveys were forth coming, which was a **48.23% response**. In 4 (four) instances, there was the situation of 2 disabled people living in the one family. Two respondents were already living in Shared Supported Accommodation Housing.

Our survey group did not include the elderly (older than 65) and predominantly pertained to people whose diagnosis was related to an intellectual disability and/or acquired brain injury (ABI).

The following questions and data represent our concerns, feelings, wants and needs to assist in a better and fairer provision of options for our disabled loved ones and our families. **We cannot do this on our own indefinitely.** We need assistance and more concrete answers to our questions. Thank you for your time in listening and reading our plea re: disabilities, and hopefully the information gleaned may help in future planning at all levels of Government (Federal, State & Local).

Sue Hillier
10 College Street,
Hamilton Vic 3300
(03) 5572 3587

Robyn Tonissen
234 H. Mibus Road,
Dunkeld Vic 3294
(03) 5573 3226

SUPPORTED ACCOMODATION AND RESIPTE NEEDS ANALYSIS

1) Disabled Child/Adults' age:

The Average age of respondents was 23.7 years old.

The youngest 5 years old.

The Oldest 59 years old.

Respondents under 18 yrs – 17 answers

Respondents over 18 yrs – 23 answers

The average age of those under 18yrs – 9.15 yrs

The average age over 18 yrs – 30.7 yrs.

2) <u>Gender:</u>	Female – 18	45%
	Male – 22	55%

3) <u>Diagnosis -</u>	Autism Spectrum Disorder	16
	Epilepsy	5
	Down 's syndrome	4
	Cerebral Palsy	3
	Acquired Brain Injury	1
	Growth Disorder	1
	Chromosomal Translocation	1
	Intellectual Disability	6
	Multi Disability	3
	Frontal Lobe Syndrome	1
	Depression	1
	"Cerebellum has died"	1
	"Disabled"	1
	Diabetes Type I	1
	Vision Impaired	1
	"Nerve Touching on brain"	1
	Microcephyl	1
	Cardiac Problems	1

*Note: Some responses included more than 1 diagnosis.

4) <u>Age of Parents/Carers:</u>	The youngest parent/carers – 30 years
	The oldest parent/carer – 79 years x 2
	The average age of parents/carers 54.58 years

5) Present Accommodation Situation:

- a) Living at home with parent/carer - 37 **(92.5%)**
- b) Living in Supported Accommodation Permanently – 2 **(5.12%)**
- c) Living alone with assistance/supports – 1 **(2.56%)**
- d) Other – 0

Questions and responses about respite – short term and long term:

1) How often are you getting Respite?

This section has been divided into children under 18 years and adults 18 years and older.

<i>Time Allocated</i>	Adult	Child
<i>Weekends</i>		
Monthly	2	6
4-6 weekly	5	3
6-12 weekly	2	0
+12 weekly	3	2
<i>Weekdays – overnight</i>	9	0
<i>Do not access respite at all</i>	5	4

*Note 1) Weekday respite is only available for adults unless there are school holidays, as the house is a dual ended house: children one end, adults the other end on double block.

2) Some weekday respite users also access weekend respite.

2) How long is your respite for?

	Adult	Child
Weekend Respite (Usually 2-3 nights)	12	9
Weekdays - 1 night	7	0
- 2 nights	2	0
Short visits (2-4 Hrs)	2	0
Do not access respite at all	5	4
Living in Shared Supported Accommodation	2	

* Note 1: Weekday Respite overnight stay is only available for adults unless there are school holidays.

* Note 2: Some adult users access both weekday and weekend respite.

3) Where is your Respite accessed?

STAY Residential Services Inc. (Hamilton)	-	27	(67.56%)
Community Connections	-	2	(5%)
Southern Way	-	1	(2.5%)
Karingal	-	1	(2.5%)
Southern Grampians Shire Council	-	1	(2.5%)
Mpower	-	1	(2.5%)
Not Answered	-	7	(17.5%)

Note: All agencies except for SGSC are local Community Service organisations within 120 kms of Hamilton.

4) Is this arrangement of Respite suitable for you?

Yes	-	14	(Adult 7 / Child 7)	(35.6%)
No	-	15	(Adult 10 / Child 5)	(37.5%)
Most of the time	-	2		(5%)
Only option in this locality	-	2		(5%)
Not answered	-	6		(15%)
Presently Orientating	-	1		(2.5%)

Note: Child respondents more agreeable to arrangements of respite than adults.

5) If the above arrangements are not suitable, what would be?

More casual/extended respite stays	1	(2.5%)
Change of Management of Service Provider	1	(2.5%)
Gender appropriate respite	1	(2.5%)
One weekend per month	2	(5%)
More Respite time	9	(22.5%)
Overnight respite stay occasionally	2	(5%)
More access to mid-week respite	2	(5%)
Flexibility	4	(10%)
Not answered	18	(45%)

6) Are you getting respite when requested?

Most of the time	16	(40%)
All of the time	1	(2.5%)
Not most of the time	12	(30%)
Accept dates given to me	1	(2.5%)
Sometimes	1	(2.5%)
Not answered	6	(15%)
Have not requested	3	(7.5%)

Note: Often adult respite is granted suitably if requested early ahead of date and if an important reason e.g. Family celebration, holiday.

7) Do you have any special needs/requests for respite e.g. gender/age?

No	7	(17.5%)
Yes	23	(57.5%)
: Gender	9	
: Age	8	
: Similar level of disability	1	
: Similar interests	4	
: Compatible carers	1	
Not Answered	10	(25%)

8) Do you think your local area requires long term respite facilities e.g. 2 weeks, 2 months etc, so as to free up short term respite beds?

Yes	38	(95%)
No	0	
Not answered	2	(5%)

Note: Presently no long term beds available in SGSC area.

Comments regarding Respite in our area:

- 'I have not used respite as I have heard that my child cannot disrupt the other people there.'
- 'Long term respite is probably needed more for adults than the children'.
- 'We desperately need more facilities for respite and residential accommodation'.
- 'Out of home respite has been fantastic for, He has gained the confidence to live independently away from us and have social interaction with others.'
- 'Definitely need at least 1 to 2 long term respite beds e.g. 2 weeks or longer so the clients don't block short term respite beds'.
- 'I wonder where we will be in ten years without help! We need a break too! What happens when we burn out as parents/carers? Who will do the caring then?'
- 'I would like to see it as building relationships with like clients so that in the future possible long term accommodation can be worked out.'
- Managing well presently, but feel restricted for our own needs e.g. ability to travel. Our client is perhaps a little more able than others. In home carer can be provided for one hour or so but can be excessively expensive and not an option long term'.
- 'As aging parents, we all wish to have somewhere we feel completely at ease with to leave our loved special needs person and to know that they are treated with consideration and respect at all times'.
- 'People requiring long term or extended holiday care are taking away the opportunity of regular respite for everyone else. This is creating a great amount of frustration and is unfair!'
- 'Long term respite would prepare clients for living away from home longer with a view to permanent residential living later on'.
- 'Respite is currently biased. The same clients are able to access without any problems'.
- 'We really need at least a 2 week block or respite, twice a year'.
- 'For health reasons, we as parents need more respite'.
- 'I would love a week away!'
- 'I think any availability of housing would be great. As we require fully supported accommodation, we would like to get our daughter in full-time care and it has to be in **HAMILTON!**'
- 'We need more beds! There are over 30 clients for 3 beds on weekends'.
- 'Ideally I would like to see transition into supported accommodation, however I believe more short term respite beds would help a greater number of families'.
- 'Respite options satisfactory, but let it get better – let us have more options. We are tired and have 2 special needs adults in my care. We cannot wait another decade. Action is required now!'

SUPPORTED ACCOMMODATION

1) Would you access Supported Accommodation on a permanent basis if available?

Yes	37	(92.5%)
No	0	
Unsure	1	(2.5%)
Not answered	2	(5%)

2) When would you require to access Supported Accommodation?

Now	4	(10%)
In one year	3	(7.5%)
1-5 years	11	(27.5%)
5-10	13	(32.5%)
Greater than 10 years	4	(10%)
In the future – not determined yet	1	(2.5%)
Not answered	4	(10%)

3) Would you prefer the accommodation to in Hamilton?

Yes	32	(80%)
No	1	(2.5%)
Don't care	3	(7.5%)
Unsure	2	(5%)
Not answered	2	(5%)

4) If not able to be accommodated in Hamilton, where would you choose?

Only 3 respondents gave options out of 100km radius of Hamilton, if necessary, otherwise all were within 100km.

5) Would you prefer mixed or same gender supported accommodation?

Same gender	Female - 12	Male - 9	(52.5%)
Mixed	Female - 2	Male - 12	(35%)
Do not care	0		
Not answered	3		(7.5%)
Unsure	2		(5%)

6) Would you prefer age appropriate supported accommodation? E.g. 18-30 years, 31-50 years, 50+ years

Yes	36	(90%)
No	0	
Don't care	2	(5%)
Not answered	2	(5%)

Comments regarding Supported Accommodation

- 'Need to look at individual interests, personalities and compatibility'.
- 'It is essential that our daughter is given a placement in Hamilton. We have lived here all our lives and our daughter is familiar with the people and places in our community. She feels she belongs here'.
- 'Good luck! More short term accommodation is a must for Hamilton'.
- 'Desperate for Supported Accommodation'.
- 'As you've probably also noted, my needs are not in the respite range, but will be in future planning for permanent placement due to age of parents'.
- 'Additional permanent supported accommodation is absolutely imperative in this area'.
- 'Whilst we are grateful to the STAY staff for their assistance for short term care, we would appreciate the opportunity to have longer breaks each year – around 8 – 10 weeks'.
- 'Caring for someone 24 hours a day, 7 days a week is an impossible job. We need change!'
- 'Desperate for more 'bricks and mortar' and more available options. Desperate, desperate, desperate! Could you do this? We love our children but want to give them more than we can, whilst at the same time have some life of our own'.
- 'I think it is very important for Supported Accommodation and Respite for families. We need more now to make it easier in the future. We can't give up. Keep smiling for our children'.
- 'We have spent all our time trying to assist our son become independent – knowing and believing that he could function with other people besides his family. We would hate to see him regress and stunt his personal growth and development as he gets older, due to the lack of resources available to him'.
- 'We think the Government has badly underestimated the need (growing!!!) for services for the disabled'.
- 'More facilities are obviously needed now and in the future, but they must be staffed by suitable and properly trained people, in appropriately designed accommodation'.

Written resources used:

1. Inquiry into Supported Accommodation for Victorians with a Disability and or Mental Illness – Dec 2009
2. Southern Grampians Shire Council – Website
3. Client Data -
 - STAY Residential Services Inc. – May 2010
 - Southern Grampians Shire Council – Aged and Disability Service – May 2010
 - Mulleraterong Centre Inc. May 2010
 - Hamilton Special Developmental School – May 2010