An End to the Silence

The Crisis in Supported Accommodation for People with a Disability in NSW

A collection of families' stories and key statistics compiled by the Coalition for Disability Services

October 2005

Contents

Introduction – The Crisis in Supported Accommodation in NSW

A System in Crisis

There is a crisis in disability services in NSW.

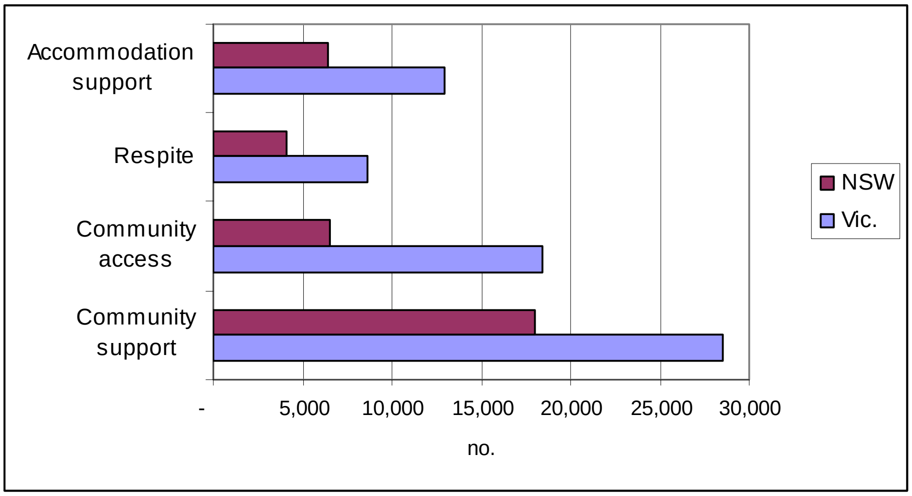
Less people gain access to disability services in NSW than in Victoria, even though NSW has more people needing services.

Recent statistics published by the Australian Institute of Health & Welfare (AIHW) show that in NSW only 6,440 people accessed supported accommodation services in 2003/04. In Victoria, by contrast, more than double the number of people (12,989) accessed supported accommodation services.

> ***Key point: more people with disabilities access supported accommodation services in Victoria than in NSW***

This finding is repeated for other services types. The number of service users was lower in NSW than in Victoria for each of the four State-run service types: supported accommodation, respite, community support and community access. Figure 1 below shows the numbers by service type for both states.

Figure 1: Number of service users by disability service type, NSW and Victoria, 2003/04



source: *Disability Support Services 2003/04* Australian Institute of Health & Welfare, 2005

A moment's thought reveals that both New South Wales' population – and the number of people with disabilities – will be higher than Victoria's. In 2003 there were almost 500,000 people in NSW aged 5 to 64 years with a disability (defined as a 'core activity limitation') while in Victoria the number was 416,000.[1] Thus, the *proportion* of people with disabilities in NSW gaining access to needed services is far less than in Victoria.

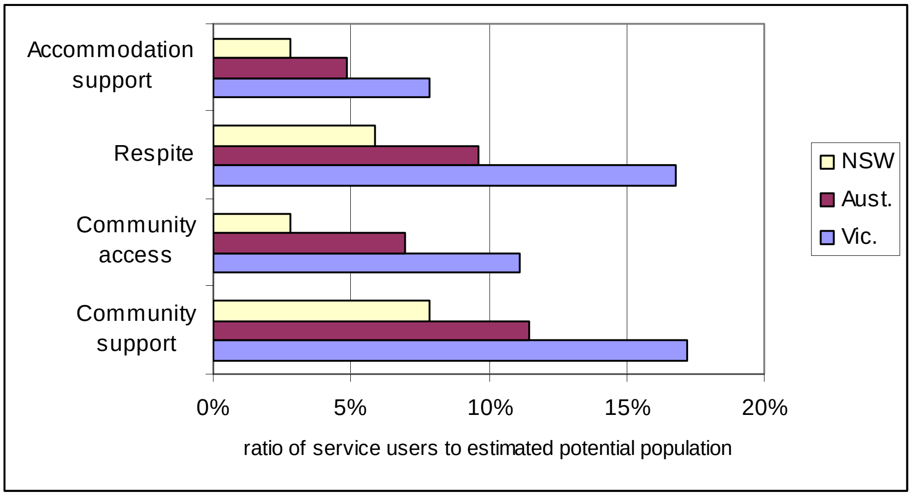
The AIHW in their *Disability Support Services 2003/04* publication produce estimates of the number of potential users of various service types. Comparing the actual number of service users to the potential population gives an indication of how many people who need that service are able to access it – the higher the proportion, the greater the accessibility of the services.

---

[1] Source: Report on Government Services 2005, table 13A.1

Figure 2 shows the results for NSW, Victoria, and Australia as a whole.

Figure 2: Percentage of actual number service users to potential number of service users, NSW, Victoria and Australia, 2003/04



source: *Disability Support Services 2003/04* Australian Institute of Health & Welfare, 2005

Australia as a whole had 4.8% of people requiring supported accommodation services accessing them, while Victoria had a figure of 7.9%. NSW by contrast had only 2.8% of the potential pool of people with disabilities requiring supported accommodation accessing it. The AIHW data showed that NSW had the lowest proportion of any of the states.

Again, the pattern is repeated for all 4 State-run service types (respite, community access etc.).

In fact, NSW was either the worst or second-worst performing state in terms of access to disability services for every state government funded service type. On every measure Victoria had more people accessing state government funded disability services than NSW even though the number of people requiring them in Victoria was less.

> ***Key point: NSW was the worst or second-worst performing state in terms of access to disability services for every state government funded service type***

It is understood that the NSW Department of Ageing Disability & Home Care (DADHC) has between 70 and 150 families in each of its 8 regions urgently requiring a supported accommodation service for a person with a disability, who are not able to access that service.

In other words, at any point in time between 560 and 1,200 families will be on the verge of crisis. Of these, each region has between 1 and 2 families per week actually falling into crisis.

> ***Key point: between 560 and 1,200 families will be on the verge of crisis in NSW at any point in time***

A review of the Western Sydney DADHC Vacancy Management System in July 2004 showed that in the period December 2003 to June 2004 there were 46 applications received for supported accommodation, but only 10 vacancies offered.[2] And in the 18 months to October 2005, only 12 supported accommodation vacancies arose in Western Sydney – and 7 of those were for drop-in support.

---

[2] Includes double-counting of some applicants.

The story is just as grim with respite services. The under-supply of disability services across NSW has driven many families to ‘surrender’ their disabled family member to a respite facility and not pick them up (leading to what some refer to as ‘blocked’ beds) which in turn limits the number of respite places available for other families. Because respite services provide a much-needed circuit-breaker for families under stress, reduced availability places families relying on respite under greater pressure, so increasing the amount of stress already faced by families enduring limited life space and proscribed choices. This then induces some to surrender *their* family members in respite facilities, further reinforcing the trend!

Between 20 to 30% of respite beds in NSW are ‘blocked’ in this way.

> ***Key point: between 20% and 30% of respite beds in NSW are unavailable because a family has surrendered their disabled relative to the facility. This creates added pressure on the service system and on other families who require services***

Some residential institutions provide extra de facto accommodation capacity. These facilities may accept clients into their day programs or provide respite, simply because they want to assist the disabled person and their family and because they know that there are no other services available to these families. However, these institutions fall under the so-called ‘no admissions’ policy, as clients are supposed to be moved to community (as opposed to institutional) living.

The Intention of this Report

This report lifts the lid on the size and impact of the chronic under-provision of supported accommodation services for people with disabilities.

Behind each of the figures cited above lie many thousands of stories of people with a disability, their carers and families doing the best they can under extremely trying circumstances. Sixty of these stories have been collated and are presented in this report.

The intent here is to present – accurately and vividly – the intense reality of this situation.

This report relates stories of families enduring tremendous hardship in the face of circumstances which are strenuous and relentless, and where respite (understood in the broader sense of the term) is sporadic and short-lived.

But these are also stories of endurance, survival and the strength of the human spirit. They are also stories of love and dignity, stories which inspire respect for the nobility and dedication of families who do their best in a situation where the care system has palpably and inexorably let them down.

Stories such as the ones here are rarely, if ever, heard in the public domain. Most are not usually deemed newsworthy, other than the occasional ‘human interest’ story on a current affairs TV program. A family denied essential services who threaten to take their story to the media may be able to secure short-term, ad hoc funding. So the ‘lid’ will remain on the issue of under-supply of supported accommodation services.

This report is the first step in a systematic attempt to lift the lid on the under-provision of supported accommodation services and to register it on the public radar. The silence which has afflicted and exacerbated this crisis will be broken.

The Impacts of the Crisis

The impacts of the shortfall in the supply of disability services are felt in a number of ways. The four recurring and most keenly felt areas of stress from the stories in this report are:

1. <u>ageing carers looking after disabled family members</u> (who are themselves also ageing). These carer(s) are not only denied the right to an enjoyable retirement after an arduous and extended period of caregiving, they also suffer ongoing anxiety over what will happen to their disabled family members when they (the carer) die.

   Take the case of a family on the NSW north coast. A couple aged 81 and 79 are caring for their disabled daughter who is 45. These carers say:

   The way things are the only way a caring parent can die at peace is if they live longer than their child.

2. <u>the limited and declining number of respite beds</u>, exacerbated by the number of 'blocked' beds. As we have seen, respite is a circuit-breaker for many families; without it, quality of life decreases and pressure on the family increases. As one family note in their story:

   We can get usually one night a week respite, this has been cut back even with our high needs position. In November we only have one night for the whole month. It is crippling our family, our marriage is always under huge strain, and my daughter has had emotional problems because of the effects the strain has on her.

3. <u>lack of supported accommodation pushes people into crisis, and the service system is oriented to those who have already entered a severe crisis</u>. This is inhumane insofar as families are forced to endure extremely stressful and painful circumstances which could be avoided in the event that adequate services were delivered. It also makes it more difficult (and expensive) to address the situation.

   The fact that disability services only respond to those in crisis (and even then only in an ad hoc manner) in turn leads to the tragic – and entirely unacceptable – situation where families themselves seriously consider surrendering their disabled family member simply because that is the only option open to them to relieve pressure on the family. One carer notes in her story:

   The Post Schools Options funding has been cut to blazes so (my daughter) will be lucky to get two days per week there. I will therefore have to throw my good job in and go on welfare to care for her. I have a mortgage so how will we live? My only option for the both of us to survive is to surrender my child.

   Another carer notes:

   We have been told there is no waiting list, and that our chances of getting a place when we need it are virtually nil until we both break down and Georgia is considered "at risk".

   And yet another family writes:

   I enquire about a placement and are told we are a priority as I am sure is everyone else. I do not think I can continue in this role for much longer and believe I am going to have to abandon my responsibility in this role or else have a nervous breakdown.

   The situation also militates against people with disabilities who are not in crisis accessing services which would greatly benefit them. For example a person with a disability who has relatively low support needs who would be more easily able to integrate into the community and who is in a relatively stable situation would be unlikely to receive any form of supported accommodation. In the unlikely event that such a person eventually accessed such a service, the person would have waited so long that their living skills would have atrophied, they would be less independent, and the placement would not be as suitable. The service system loses both leverage and traction, and denies those with the potential for quality of life to realise it. As one family noted:

(the service provider) at the request of DADHC carefully devised a comprehensive housing proposal earlier this year. It was specifically planned around five people all requiring a high level of support, including our son, addressing issues of compatibility and individual need, with a very ideal property in mind. Unfortunately funding to support this much-needed facility was not forthcoming. We are finding ourselves on the brink of a crisis and are desperately pleading for immediate assistance.

4. <u>waiting lists for supported accommodation are long, and then abolished or non-existent</u>. Many families have placed their disabled family member on a waiting list (for example, for a group home) in good faith, often for many years, only to find that the waiting list has been abolished and is now non-existent. By even the most minimal standard of competence and due process of administration (not to mention fairness and decency in the treatment of people) such practices are utterly unsatisfactory.

   In one instance, a person with a disability was on a waiting list for 25 years, after which the list was abolished:

   We placed Daniel's name on a DADHC waiting list when he was an infant, after being told that we would wait for decades for a place. We repeated the exercise in the last year (Daniel was then 27) with the regional office after being told that all lists were obsolete with regionalisation.

   Another carer writes:

   Our son has been in a waiting list since he was 6 years of age (he is now 19) and now we have found out that the list is non-existent.

These are the principal (but by no means only) human costs and impacts of the chronic under-provision of disability services in NSW.

Responses to this crisis are sketched in the following section, but the important thing to note here is that the system is in crisis and its impacts are pervasive and concentrated.

This cannot be allowed to continue.

What must be done?

While disability services in NSW are in crisis and the condition of the system is severe, the situation is not however irreparable.

Four clear imperatives for the NSW Government arise from the figures and stories outlined in this report. These imperatives are shown below.

Four Imperatives for Supported Accommodation for People with a Disability in NSW

1. immediately fund and/or provide an additional 1,200 permanent supported accommodation places;

2. immediately unblock all ‘blocked’ respite beds;

3. collect comprehensive data on system capacity and need; quantify the full extent of unmet need for supported accommodation and respite services in NSW (including planning for families with elderly carers) and publish this on a half-yearly basis. Establish an orderly and fully transparent system for the filling of supported accommodation places, and make information about the size of waiting lists public. Enable families to understand and monitor their place in the ‘queue’;

4. increase the capacity of the NSW supported accommodation and respite systems by the amount indicated in the study of unmet need noted above over a 3 to 5 year period, such that waiting times for supported accommodation are progressively eliminated over that time-frame.

Many options are open to the Government in meeting these imperatives, both in respect of the shape of the support provided, and in how it is funded. Investigations of models of supported accommodation are currently being undertaken in NSW.

Possible financing mechanisms include:

- increasing aggregate State Government budget borrowings to finance capital expenditure, freeing up recurrent funds to finance extra supported accommodation and respite services;

- the states could make a joint approach to the Commonwealth to increase funding for supported accommodation under the Commonwealth-State/Territory Disability Services Agreement, or lobby the Commonwealth to reshape the Agreement and take over responsibility for supported accommodation so that its planning and funding could be integrated with that of aged care;

- the service system could be expanded if families who are able to contribute to the cost of supported accommodation provided a co-payment or similar. This could lead to a ‘cocktail approach’ to funding where public and private funds are combined and capacity increased accordingly. If the economic incentives were altered this approach could also foster private investment in supported accommodation facilities (the manner in which investment banks are now investing in aged care facilities is instructive in this regard).

Each of these options require further scoping and analysis. The point remains however, that there are many ways to fund and deliver an expanded supported accommodation system.

The Human Face of the Supported Accommodation Crisis – Stories from the Frontline

The human face of the crisis in supported accommodation for people with disabilities is at the heart of this report.

The stories were collated from people in NSW, who were asked through a letter sent to various agencies and advocacy groups to provide details of their situation. Families were free to express their story as they wished, although contributions were to be limited to one A4 page or less.

Families were invited to include mention of the following in their contributions:

- their name and the name of the person with a disability for whom they care
- how long they have cared for their disabled family member
- how long they have been waiting for supported accommodation
- a typical day in the life of the family
- what the high points – or the challenges and low points – are in their day
- how they cope, and what mechanisms they have in place to deal with their situation.

Families were also invited to include a photo as part of their one page contribution.

Families could provide their story anonymously if they wished.

Sixty stories in all were received, two with photos. Each is reproduced here, expressed in the families' own idiom and expression. Some had to be edited to reduce them to one page, but otherwise only minor edits were made to enhance readability.

Where families have provided their names these have been included, other than where anonymity was requested. Some service providers provided some information about families and clients of whom they were aware, and in these cases client confidentiality had to be maintained (either by identifying the person only by their initials or by their first name). Where a story was provided by an agency this is noted.

The following stories speak for themselves. They are testament to the strain endured by families with a disabled member under a service system in disrepair. They are also an acknowledgement of the contribution made by carers.

The stories break the silence which has shrouded the crisis condition of disability services in NSW.

The silence has ended.

Michael Carman
Convenor, Coalition for Disability Services
mcarman@bigpond.com

The Shields Family

I am Estelle Shields and I, along with my husband, care for Daniel, our 28 year old son who has a moderate to severe intellectual disability. It has been my privilege to raise Daniel and to see him develop into the man he is today. He is the eldest of four boys and we devoted twenty-five years to parenting our sons. Now we find ourselves at the time in life when we are on the brink of retirement and the other boys have left home. Our peers are moving on to the next stage in life, relocating, travelling, pursuing long-held ambitions, but we are stuck and without those options, because we have the day-to-day care of Daniel. It is only in the last two or three years that this has become onerous for us, as it becomes clear that we are not free to enjoy the retirement choices that others take for granted.

We placed Daniel's name on a DADHC waiting list when he was an infant, after being told that we would wait for decades for a place. We repeated the exercise in the last year with the regional office after being told that all lists were obsolete with regionalisation.

A typical day in our lives starts with about an hour of personal care. Either myself or my husband bathe and shave Daniel, pack his lunch and get him breakfast before driving him to the supported employment workshop where he spends the day. At 3.00pm we collect him and bring him home, where he watches television until dinner time, and then more television till bedtime. You can see that we don't have to do much for Daniel - he has no medical or behavioural problems - but one of us just has to be here for him constantly. We would never leave him unattended. My father who was a dairy farmer used to point out that we keep dairy farmer hours - on duty every morning and dropping whatever is it that we are doing about 2.30 in the afternoon.

I have coped through all these years because of three things. Firstly, I have a supportive partner who is equally as much a carer to Daniel as I am. Secondly, and because of my partner, I have been able to enjoy the satisfaction and financial independence of a rewarding career which I have been able to work around Daniel. And thirdly, we have been fortunate to have had a five-day placement for our son, at first at school, then in Post-School-Option and now in support employment. If any one of these factors was not present, my situation would become immediately untenable and I would be in crisis overnight.

We need supported accommodation quite soon for three reasons. The first is for Daniel, who is quite lonely and isolated living with his old and boring parents. He enjoys going to the respite cottage (on rare occasions) because he is with his peers and tells us it is "better than home". He is less adaptable now than he was five years ago, and this makes us realise that the optimum age for leaving home has already passed. The second is for us, so that we may pursue the same retirement choices as other Australians. This we feel is our right having cared for Daniel for nearly three decades and having paid our taxes all our working lives. The third is to avoid the impending crisis, which we see played out over and over again, when the disabled son or daughter loses his/her primary carer and concurrently loses the only home they have ever known. This is a trauma of such great magnitude that they sometimes take years to recover. We want the peace of mind of seeing our son placed in an appropriate residential environment with adequate support to meet his needs. We want to see this preceded by a move away from home that is gradual and sensitively handled.

The Mairs Family

My wife and I, Veronica and Robert Mairs have cared for our daughter Denise for all of her 45 years.

We have been looking at options for her future for about 30 years, but are not anxious to get rid of her so much as to prepare her for the future. Nothing we have seen has given any of us any confidence. We are quite happy to have Denise with us as she is good company and no trouble.

Denise would like to stay with us for ever, unfortunately as we are 81 and 79 respectively that can't last for ever.

The way things are the only way a caring parent can die at peace is if they live longer than their child.

The Grannall Family

I have a son John who has a intellectual Handicap and is not “Down Syndrome” who has resided with me ever since his birth on 31 July 1955. He came home from hospital about 15th October 1955 and has been in my care ever since. He attends Orange Sheltered Workshop 3 day a week, and Wontama Nursing Home day centre 2 days, and spends weekends at home.

I am 78 ½ and becoming a little tired.

The Hodges Family

A day in my life with Emma. I gave birth to Em in 1981 and she was special needs from birth.
Emma is usually awake at daylight but also wakes and seeks me out during each night.
She will need her hair washing, she won't do it as she is hypersensitive to soaps, shampoos etc and won't touch them. So reminders to use soap all through her shower/bath, and the very quick hairwash.

With her autism, each day is repetitive in her actions so I can't hurry her up or change routines. Therefore, speeding up the process due to early appointments or other urgencies means bribing her to do it early them I will do something good like brekky at Maccas.
I must check each day that she has clean appropriate clothes on as this is not her priority-t shirts in winter or heavy jumpers in summer are not unusual. Em can dress herself and feed herself thank god. She is also no longer incontinent (was up till last year) so there are no sheets to wash each day.

Her life pattern is isolating from me and self focussed. I get no interaction from her unles she needs something she cannot do herself. If we are going to town for her living skills program, she will tell me why she doesn't need to go as its boring/ stupid/waste of her time. Either that or she can tell me whose flags are hanging over the town bridge that day-her general knowledge is so vast and amazing. After 6 hours, I collect her after attending an hour of exercises for the mature woman :) , grocery shopping, visiting my dementia affected mum, seeing a friend or two if I can, paying bills.

Em doesn't ever tell me what she has done during the day, that’s her life, she tells me. Her life after town is TV and PC till 9pm. She frequently watches many different programs and, at the same time, reads movie or TV scripts on the PC. If I dare to check my emails or do something else online like pay bills, I get harassed until I get off and leave her to it. She will eat tea in front of both which are side by side anyway.

If I am on the phone in another room, she will often come straight up to me and tell me the dishes need doing/ washing is still in the machine/ her hair needs washing, regardless of who I am talking to.

Em will run a bath in my bathroom not hers, have a bath, then demand that I have one there too (we are on tank water so sharing bathwater is real life) straight away regardless of my activities. She will check on my bathing, drying, getting dressed and sleeping even if I don't want her to. Having a partner is a nightmare and privacy is not OK. I even put a shotbolt on my bedroom which she shouldered hard and broke.

So my nights are as bizarre as my days. If I am in bed sick for a minute or two, she will come and ask me when her lunch is being made/ when I am getting up, etc.

When she has PMT, life everywhere is awful. She is so angry with everyone I can't go shopping, visiting mum, or anything. Even my farm animals and pet dogs are at risk. She will go out and move them, yell at them, hit them etc. She won't take any medications for anything so calming her down is hard.

I have been researching accommodation for about 10 years, thinking if I started early it would be there. Sadly that’s not real in the model I think is human.

I haven't been on a waiting list because none existed for me to get on. I have been looking but found none so thought I better get on and see what I could do.

The Parks Family

My name is Heather-Jane Parks and with the help of my husband, Roger, I have been the main carer of our daughter, Georgia, for 21 years. Georgia was born severely intellectually disabled and soon developed epilepsy. As the years went on she also developed mobility problems which means she can walk only short distances (with a lot of assistance) and often needs a wheelchair.

Georgia has no meaningful communication and needs help in all her activities and functions. She is incontinent, cannot turn over in bed by herself and needs to be fed five times a day. (She weighs 33 kg and is very frail.) All of this means that my husband or I have to be with her every moment she is at home, to feed her, change her, sit her down, stand her up and move her from A to B.

Six ago my husband took early retirement from a senior university management position to help me more with Georgia because my health was starting to suffer. Now we both work part time but cannot vary our strict work hours because one of us has to be on hand every day to see Georgia onto and off the bus which takes her to her Post School Options placement. This makes for a very limited participation in our workplaces. We have found some bosses to be less than understanding about our situation. We do receive a certain amount of respite care, but I would not call it enough.

I am in my late 50s and Roger is 60. We will be looking for residential accommodation for Georgia sometime in the future. We have been told there is no waiting list, and that our chances of getting a place when we need it are virtually nil until we both break down and Georgia is considered “at risk”.

The closest analogy I can think of for our position is being under house arrest. We can leave our home for short periods and even take a nine day holiday once a year, but we wonder if Georgia is to be our responsibility until we can cope no longer.

The Gunning Family

My name is Deirdre Gunning and the person I care for is Leigh Katherine Gunning.

Leigh is sixteen, is autistic and I have cared for her since birth.

I am divorced and Leigh's father doesn't give much support as he finds alcohol more important.

I haven't been waiting for supported accommodation but have been seriously considering giving up my parental rights. The reason for thinking about giving up my parental rights is because Leigh's obsessive, demanding behaviours have become out of control and I am simply not coping as well as I am scared for the future.

As Leigh is sixteen she would have to go into foster care and this scares the hell out of me.

She can only go into supported accommodation when she is 18, and with the present situation we all know that will not happen without me surrendering parental rights. No one on this earth should have to go through that and I feel for the people that have been through it.

A typical day in the life of our family can be good or hell depending on what has happened at school, or out of school or if she has PMT. If everything has been routine, structured and she has had a calm day things aren't so bad.

If things haven't gone along as normal which is most days then the obsessive behaviours start, these include washing all of her clean clothes, stashing anything from her cupboards or draws into any space she can find and punching me.

She doesn't remember where she puts things then becomes violent and anxious when she can't find them. Leigh's school has made some social stories for her which include what she is allowed to get out of her cupboard and what must be left alone, this seems to be working but it is taking time.

Along with trying to keep on top of the loads and loads of washing she creates, I spend a great deal of time trying to find hidden items, control her anxiety and keep the house organised and tidy. I work full time and I am often late, but fortunately I have an understanding boss and Flex time.

The high point of my day is that I get up at 5:30am and ride my horse, I do a little bit of dressage which helps me get my head around the day that is about to start. Leigh stays in bed, she likes to sleep in which is great.

I then come inside and have a shower, sometimes in peace but not always. Leigh then has a shower, while I make beds, then we have breakfast get ready to go then I take her to school and I go onto work. Leigh use to go to school by taxi but was sexually abused at the beginning of the school year, and we can't prove it because of her severe communication problems so now I take her.

I am extremely worried about both Leigh's and my own future. I have been told that Leigh will not get a job in a sheltered work shop because the skills now required are higher than what she has got. This is due to the local factory importing from China. The Post Schools Options funding has been cut to blazes so she will be lucky to get two days per week there.

I will therefore have to throw my good job in and go on welfare to care for her. I have a mortgage so how will we live? My only option for the both of us to survive is to surrender my child. Everyone has a right to life with or without a disability.

John’s Story

This is a glimpse of John's story.

John is nearly six foot tall, very handsome with the most gorgeous personality, sense of humour and generous nature. John would have made a splendid partner and father, but its not to be. John has a moderate intellectual disability, epilepsy, and cerebral palsy. He is unable to look after himself.

He was our first child, really beautiful, a good baby who simply smiled a lot, loved cuddles and played happily by himself. Upon looking back, he was probably too good. Boys are slower, he's o.k., he will catch up were the answers when we expressed concern about his slowness to walk, his wide unsteady gait, his poor motor skills and his slow language development.

For years we did the rounds of early intervention, ensuring the home program was done daily, even twice a day as more therapy might mean quicker catch up of skills. It all helped of course, kept us busy, kept the sorrow at bay, sorrow that our beautiful baby boy was never going to 'catch up'.

Family and friends were sympathetic, offered to baby sit and help out, but we were fearful of leaving him and they were fearful of his epilepsy. We often felt very much alone and very frightened of the future for us all. John's baby sister Mandy came along when he was three and he fell in love with her immediately, she was an excellent role model for him, as she loved and bossed him, he learnt from her and within a few years she became his protector, easily outstripping him in all areas of skill development.

The school years were hard, we shed many tears as John's five years of regular school came to an end as he was transferred to a special school, so he could make his own friends, have a smaller class and be with teachers well skilled in working with 'special needs children'.

John is now 30, we are now sixty, nothing much has changed. We still provide the transport, do his washing, ironing, meal preparation, wipe the bottom, wipe the nose, wipe the face, cut up the food, clean up after and love him very much. But now we are really afraid, afraid of what will happen when we are dead. Who will care if he does not clean his teeth, if he wears old, unmatching clothes and who will cover him up when it’s cold at night.

We never wanted John to live apart from us, but that was before we got this old, before our backs hurt and we got tied, tied of being carers and working full time, so we could make the future safe for him. But now we are not sure of how to make the future safe -- that is unless the Department of Ageing Disability and Home Care will help us make provision for him, help us to get him settled in supported accommodation, near where we live. A small villa type complex, just like Mandy lives in would be ideal. He could come home some week ends, we could go to his place for dinner and he would learn not to miss us so much.

Its been really difficult to write this, its a terrible thing to feel this grief stricken after thirty years, the pain never goes away. Our plans to tour around Australia in retirement have long since been shelved, its hard to make any plans, its hard to feel enthusiastic and its really difficult to cope with the thought that we can't even retire after fifty years of working knowing John will be happy and safe in his own home.

Will we be 80 years of age, still caring for a man who is 60? - it looks that way and it’s just not fair.

The Coburn Family

My Name is Helen Coburn. I am 47 and my husband David is 52, I have a daughter Stephanie who is 14, and my mother Gladys, who is 75, lives with us. We all support my disabled son Adam who has Down Syndrome and Autism, he is 16.

Our situation is probably nowhere near as urgent as some other families we know, but our own burdens are the hardest to bear.

My mother is 75 she has had 2 heart attacks and has had angiplasty, 2 knee replacements and is on a stick, she has osteo-arthritis and osteoporosis; she has diabetes, high blood pressure and stomach ulcers, she is trying to be independent but relies more heavily upon us as time goes by.

My daughter is 14 she has sleep apnoea, ADD, and asthma.

My husband has epilepsy, high blood pressure and arthritis.

I have hyperinsulaemia, I am on Zoloft for depression and anxiety, and suffer from arthritis as well as osteo arthritis in my knees, I have had one operation already, I suffer from neck and back pain from a car accident.

Our son Adam is a lovely boy, he is also non verbal and is a big boy and very strong. He has numerous health issues too long to mention here, he needs constant supervision, as would a 3 or 4 year old. He sometimes has behaviour problems. When he was little it was easier to share the care for him equally, however as he is so strong now, he knows he is stronger than me and will not do things for me to look after him. My husband unfortunately has this bigger burden. We can get usually one night a week respite, this has been cut back even with our high needs position. In November we only have one night for the whole month. It is crippling our family, our marriage is always under huge strain, and my daughter has had emotional problems because of the effects the strain has on her.

Our health issues will only get greater with time, and with my mother's needs are increasing as well – where will it leave us? We would not want to not see Adam each week as we love him so. Even to have a shared arrangement with another family so we both get 3 or 4 nights a week respite would be marvellous: we would be only taking up one bed then.

We have not done anything to deserve the daily suffering which is part of our lives; we are good citizens and deserve better help as does our son.

Over the years all our family members would have paid collectively a few million to the government in taxes, we want some of that money now to help us, just to survive, not to do some thing extra and have a good time, only just to survive.

If we were Panda bears or some other endangered species, there would be funding and media coverage galore, ironically that is just what we are, endangered species, carers of the disabled.

The Hardy Family

Richard was born in 1966. He has Down Syndrome. He has a married sister and married brother.

We (my late husband who has been deceased 13 years) and I were determined to provide the best possible chance for him to live life as normally as possible. He attended a Special School and then Peterborough. He now works with IVS at North Wollongong. We always tried to let Richard live as normal a life as possible. He has never felt the stigma of not belonging. The family, including nieces and nephews, have all treated him as just one of them.

At present we have to get up at 5.30 am to have breakfast, dress etc. and have to walk to the station at 6.30. He starts work at 8 am. He manages very well on the train having to change at Dapto. He loves his work and the companionship there.

Richard is a full member of the Kiama Bowling Club and is the only intellectually disabled person there. The men are wonderful. He goes off in his creams each Saturday, actually getting to the final of the Major/Minor pairs.

I am now 81 and Richard and I live on our own in Kiama. I worry about the future. I would like to know that there was accommodation available for him. A home in Wollongong or surrounds would be ideal. I don’t think his family should be the providers although I know he would always be a part of their lives and have lots of contact with them.

The Bottom Family

I have a 37 year old son Matthew James Bottom – he was diagnosed with epilepsy 25 years ago. He has had brain surgery twice when he was 23. Now he is on a cocktail of medication. 2 x 200 Epilom, 1 x 500 Epilem, 1 x 1000 Kipra, 1 x 100 Lamictal and 1 x 250 Mysoline 3 times a day. That is 18 pills a day and a valium after each seizure. Unfortunately even this does not control his seizures. He works at Glenray Industries (sheltered workshop) and lives at home with me.

His dad, my husband, was killed in a motor car accident 13 years ago. I have 3 older girls, 1 in Canada, I in Perth and 1 in Penrith. All too far away to call on for support in an emergency and there are plenty of them.

He has no warning before his seizures and has had many serious accidents requiring stitches and lots of broken bones, 5 broken bones in his face on 5 different occasions. He has also been scalded 3 times once needing a skin graft.

It is not safe to leave him without some support as his fits are unpredictable. I have to pay someone to stay with him if I have a night away. I went to Dubbo last year with a friend in their car. I was there an hour when the Bathurst Hospital rang to tell me Matthew had been brought in by Ambulance and I would have to pick him up. I told the Doctor I was in Dubbo and couldn’t get home till the next day. He said they could keep him for 2½ hours so my grandchild had to drive me 2½ hours to collect him. The man that was caring for him was too worried to help. As I am 68 we need respite now and full time care later on.

The Knox Family

Toby is a 33-year-old Downs Syndrome man who lives with his parents in Neutral Bay, Sydney.

Toby is an obliging, friendly, affable fellow…. rather charming. He also has a mental age of three years and while he is fit and healthy, he is also quite small. Not a bully, not a bruiser and not able to defend himself at all well. The relevance of the latter will recur below.

Toby’s parents are aged 77 and 74. Nobody else lives in the house. What is Toby’s future?

For a number of years, his parents planned for Toby to live in an institution in outer Sydney. For a time he attended the institution daily ... then on a five-day-a week basis … and finally as a teenager living there full-time.

Apart from the very high costs involved…for example, before attaining an invalid pension, Toby’s annual fees were more than $16,000 in 1988 dollars, his full-time move in to the institution as a 16-year-old brought a sharp decline in Toby’s zest for life. Toby was a walking example of why the NSW Government was on a policy of deinstitutionalisation of people like him.

It was obvious to his parents that if Toby was to survive he must leave the institution. So, at 18, he returned home to live with them.

For some years he spent 365 nights each year with his parents as he recovered his personal confidence and naturally smiling ways. Not least because he was attending a very fine Department of Community Services day centre in North Sydney. It has proved a god-send to Toby and his parents.

In his mid-twenties he began to spend one week-end in eight in a then Department of Community Services respite home. All went well until he returned home with a deal of facial skin missing. While the respite home staff had said nothing about the matter ,a subsequent written complaint and investigation revealed that another resident had attacked the sleeping Toby ’s face with a pot scourer.

Although Toby did not return to that particular house he did go on occasional respite week-ends with a private group and spend time in another departmental respite house. In both situations staff had to intervene to prevent attacks on Toby by much bigger men. So, in the past two years Toby has reverted to spending 365 nights a year with his parents. There he is safe ... and there he is content. And he continues happy at the government-maintained day-care centre….a superb example of how good government service can be.

The critical question for him now is how he is to live in pleasant, safe surroundings. It is not a matter of finding a suitable house and leaving him there….his mental age, to repeat is three years. Nor is it a question of locating an institution where he can be left. As the State of NSW has found, ‘been there done that’.

And neither can he readily access a stand-alone house with suitable protective and caring staff. A number of attempts have been made in that direction … to no avail thus far.

Is he the only one in NSW facing this kind of problem? By no means.

And is Toby the only one, in NSW, dependent for his daily living care on parents in their eighth decade of life? By no means.

Will the situation resolve itself, for Toby and people like him? No…

The Manton/Spooner Family

I am Lynette Manton, and have been caring for my son, Daniel Spooner for the past 20 years.

I have never had supported accommodation in that 20 years.

My days start very early hours in the morning, when most people are still sleeping. My day never finishes in 24 hours. The constant care I provide, mentally is draining, and I do look forward to Dan’s sleep time for a little rest.

I have to keep in mind, he didn’t ask to be that way, and I’m his Mother, and tomorrow, will be a different day, even though it’s the same way.

The Hudson Family

My name is Noelene Hudson and I care for my son, David who is 45 with chronic uncontrolled epilepsy and unable to look after himself.

I have been his carer for the past 5 to 6 years and have made a concerted effort during the past 2 years to obtain supported accommodation for him. He has recently been diagnosed with dementia.

Many letters and ‘phone calls have been made since July 2003 to DADHC and politicians from myself and friend and advocate Douglas Evans without a positive result.

There is no “typical day” as I take one day at a time and hope for the best. The challenge is to remain healthy to maintain my caring role and to cope with the ever changeable nature of my son and to live to see him suitably accommodated.

The mechanism in place to deal with the situation is by attending psychological counselling and physiotherapy.

The Purcell Family

My name is Mark. I am 50 years of age and the sole carer of my 16 year old daughter, Elise. Elise has been diagnosed with an intellectual disability in the moderate–severe range and autism. I have been her sole carer since February this year (2005). I also work full time.

There is no doubt the stresses of care of Elise over the years contributed significantly to my marriage breakdown. Elise’s younger 15 year old sister now lives with their mother. When Elise was younger there were frequent all night tantrums, faecal smearing over her body and her room. She was frequently aggressive towards her sister who tried desperately to have a normal older sister. Adoration and love was responded with by aggressive rejection. This has had a negative impact on my youngest daughter’s self esteem. Any thing she owned was destroyed by Elise. Elise’s mother did have the lion’s share of care for Elise as I have always worked full time and even at times two jobs as her mother had to work part time. For a couple of years I worked nights. Now as full time carer myself I have a greater understanding of the never ending exhausting task it is. But I could not undertake the only means of acquiring full time accommodation for Elise – the “respite dump”: Elise taken to respite house and not picked up. I rely on my respite too much to inflict even greater shortages for other carers.

Currently during school terms with Home Care and her mother I do get to my work each day. I have both my daughters with me each weekend. However school holidays are becoming increasingly a problem. The local non government respite provider who last school holidays provided a total of 6 days between 9 am to 4 pm these school holidays (September/October) are providing only 3 days from 10 am to 3 pm. Three weeks notice was given of this change. As the Disability Department has 4 month bookings system for their respite house and that was all allocated I have to take annual leave.

My biggest fear is when Elise finishes school. At present the post school programmes do not go for 5 days a week and there is no transport to and from.

The Caragher/Lavick Family

My son, Oscar Lavick, will be 16 next month – he has Asperger's Syndrome which was diagnosed 3 years ago. As a toddler and young child, Oscar was diagnosed with ADHD. He displayed hyperactivity, learning and attention difficulties and disruptive and anti-social behaviours.

During this time Oscar attended the local primary school and although his behaviour was very challenging, it never entered my head to have him placed in care.

My daughter Scarlett is 14 months younger than Oscar. We were forced to leave their father due to domestic violence in 1993. I have been a single parent since then.

Oscar's behaviour has changed significantly since he turned 12. He was transferred to Anson Street Special School in Year 7 due to extremely disruptive behaviour and sexualised comments towards a Year 12 girl.

I looked everywhere to find help for Oscar. He attended an assessment at Dalwood, Redbank Family Assessment Centre at Westmead Hospital, and the Brain & Behaviour Centre at Westmead. Locally we were seeing a Child & Adolescent Psychiatrist – we had been seeing a Paediatrician since Oscar was 4 years old. Oscar had several admissions to the local hospital where multiple cocktails of psychotropic drugs were trialled – to no avail.

Meanwhile, Oscar's behaviour was getting worse. He was growing – to 6 feet tall. He was kicking in walls, breaking furniture, displaying sexualised behaviour with the dog, repeating the same phrase up to 200 times, bedwetting, screaming abuse, picking his skin until it bled, absconding … basically it was unbearable.

I literally begged DOCS staff to find placement for him. They fobbed me off to DADHC who could/would not find placement. I now realise that the only way I can get Oscar into care is to leave him in the local respite facility.

Since March this year, Oscar has been living with his father who has similar problems and can be a violent bully. The system is totally inadequate. God knows what will become of my son!

Gareth’s Story

The name of the person with a disability for whom we care is Gareth.

My wife and I have been caring for Gareth since he was born normal. At the age of 4 he stopped talking and went backwards. The Doctor called this “autism”. Gareth is now 24 years old.

From the time we arrived on the Central Coast, when Gareth was 7 we believed his name was put on a list for supported accommodation. We now find this is not so.

Gareth is very pleasant in his nature – is never aggressive. However he has no speech, so needs one-to-one help in everything – dressing, washing etc. He has no sense of danger at all – stranger danger, traffic etc. and does not know his borders.

Gareth has a severe sleeping problem – he may sleep for 2 days and nights, then may stay awake for 2 days and nights. Gareth often wets his bed and cannot be trusted without a “Kylie” in the car.

Gareth still makes a big mess at the table and needs to be prompted to stay seated to finish his meal. Gareth does not speak to indicate his need for toilet – he could run off to the nearest door, pulling down his pants.

We want to keep Gareth at home as long as we possibly can. We do not believe a “Group Home” is the suitable answer for Gareth, because he needs one-to-one help and supervision at all times (day and night) by trained staff.

We need to know that care of this type would be available when it becomes necessary. Gareth is now much more teachable through prayer which we are doing regularly.

Derek’s Story

My son Derek is 23-years-old and he lives at home with me. Until recently both my husband and I cared for him but four months ago my husband had a debilitating stroke and now lives in a nursing home in Richmond. I have another son with an intellectual disability who lives in an institution in Rydalmere. Derek has autism and has a moderate to severe intellectual disability; he is non-verbal and needs assistance in his personal and self-care living skills.

My son he can be very difficult to live with at times. As Derek matured his behaviours have become more aggressive toward the family. He lives by routines and rituals and when these are disturbed or changed he can become extremely agitated and disturbed. At these times he may engage in self-injurious behaviour or hit out at others.

For many years we had been struggling to provide the support that our son needs so in 1999 we put Derek’s name was put on a waiting list at age 18. We heard no more about it and wondered whether that list continued to exist after a period of time. In 1999 and 2002 I gave evidence at Parliament for the Inquiry into Residential and Support Services for People with Disabilities. The chairperson of the committee expressed that our situation was described as “beyond acute”. Yet six years on the only things that have changed is my ability to continue to cope!

Despite the Department’s assurances that Derek is recognised as a person who desperately needs to move into his own home no opportunities and very few possibilities have occurred. Over the years at times new money comes through the state budget and our hopes for accommodation rise. The deck chairs are again reorganised and we sit waiting on these deckchairs until they all crash under the pressure of an under resourced sector. Words cannot express my exasperation at the many meetings and phone calls I have had to get accommodation established for Derek.

Recently when my husband had a stroke the Department provided Derek with emergency accommodation. I have been in this system long enough to know that I could force the Department to provide accommodation to him by leaving him there. I certainly was and am physically and emotionally exhausted. However I want my son to live in a pleasant place that supports his continual growth and development. I feel very confident that if Derek is given a supportive community placement he will thrive in this environment**. It is wrong that the system is so under resourced that families live their lives with this tragic predicament.**

I am not sure of how much more I can cope with. Now I not only support Derek and his brother but I also need to be there for my husband. I hope that whoever reads my story will do whatever they can do to get some resources into the accommodation sector so that Derek and many others in a similar boat can get the support they need.

The Carman Family

My brother, Noel, is a 53 year old man who has Down Syndrome and Alzheimer's Disease. He lived at home in Wollongong with his parents until in 1994 his father died and he came to live in Sydney with his sister, brother-in-law and nephew. His mother had died in 1971, at the age of 57, and a succession of live-in housekeepers enabled Noel's father to continue his shift-working job for a couple more years – although this was quite 'hairy' at times! Noel's father retired early due to ill health but continued to care for his son until his death.

Noel's relocation to Sydney was traumatic for him as his life-long home, peers and familiar surroundings were left behind at the same time as he suffered the grief of the loss of his father. It was also an extremely difficult time for his sister and her family because she needed to leave her employment to care for her brother, grieve for her father, and, with the rest of the family, cope with the adjustments required for all of them. It put huge strains on the marriage as they all came to terms with the changed circumstances. Different rules and expectations applied in this household and behavioural problems and tensions resulted. Noel's nephew has since left home and is married.

Over the ensuing years Noel gained some living skills, which unfortunately have now been lost due to dementia, and as his support needs increase, health problems and ageing are issues for his carers. His dementing behaviour is unpredictable and causes stress and frustration for the family in addition to the usual mood swings and stubbornness which has always been prevalent. Governments claim that ageing carers are a priority when allocating funding for services and accommodation for people with disabilities but what consideration is given to second generation carers? The original primary carers are long deceased and the next generation of sibling carers is now ageing. Noel's brother-in-law is in his 70's. With the increased longevity of people with disabilities this population is rapidly increasing without service provision to accommodate them. Respite provides a life-saving break from the constancy of caring and is greatly appreciated, however blocked beds occupied by permanent residents who have nowhere else to go limits the availability of respite beds. An Adult Day Programme provides activities for Noel which includes companionship, social outings and a variety of recreational activities which family carers are unable to constantly provide. Every carer's greatest fear is, "After me, what?" This is the burning question for us.

The Hill Family

We are Peter & Allison Hill; we are the parents of a 14 year old son Matthew who has autism.

Matthew has had autism all this life and he will need to be supported for the rest of this life.

Currently Matthew goes to a special school run by Aspect. At 16 Matthew will no longer have funding to attend that school.

Our concern is that there is no day program for Matthew to attend. I am very concerned what will happen when we are gone: how will he live?

Matthew never asked to be born and I am sure never asked to have autism. He enjoys going out and will need not only supported accommodation but also good day programs so that he may live a full life. **Not a big ask of a country as rich as Australia!**

A typical day when Matthew is at home starts around 10am. He wakes up and goes to the toilet. Matthew is toilet trained but sill needs assistance and only goes if there is a proper toilet. Meaning if we go out it is important to ensure that there is a toilet. Please note Matthew does not discriminate between the mens or ladies or even if the toilet is plumbed in!

He can feed himself but needs to have food prepared and needs assistance in every area of this life. One of the most challenging areas for both Matthew and us is communications. This for Matthew must be very frustrating not being able to express when he feels sick or needs to go to the toilet or feels sad. How lonely it must be not being able to connect to another human being.

When he does try to communicate it is by taking you to the door or bring you Allison’s hand bag (to go out for a drive) or pulling you into the lounge room (to watch a video) Bath can mean standing naked with the bath plug in his mouth in the hall way with no shame at all. At times it can be quite funny and sad at the same time.

Family outings are always a gamble. We end up taking turns looking after Matthew while the other takes our daughter on the rides or to look at something special. Many a time we have all gone home early.

Highs are seeing him smile when you tickle him or play a silly game with him. Low points are seeing him frustrated or upset and not knowing why. Cleaning out from under his bed piles of toys, partly eaten books, dirty socks, your good tape measure and bits of food!

To help me cope I just remember that Matthew did not ask to be born or to have Autism. To ensure that his life and mine has meaning and to help the 1:100 people affected by Autism I have been raising awareness about Autism and money for Autism research.

The Nisbet Family

Thomas was born 31st October 1987. We had just moved towns to our new farm in the Riverina hundreds of kilometres from service centres. Not that we thought we would need them, pioneer women never needed community health so why should I.

Tom was diagnosed with classic Autism with moderate mental disability at the age of 3 and so started our journey down the difficult road of having a disability in the country. A diagnosis certainly opened doors for us as far as accessing funding but with a disability like Autism where the child looks normal it does little for you socially. Tom would scream and throw tantrums constantly as his environment tortured his senses and humiliated our semblance of control in public.

Our saving grace was that he was born into a small rural community where people knew him and tolerated his progressively disturbing behaviours. Tom would continually pull products off the shelves of the local grocery store and by me replacing them he would hysterically scream, kick, bite himself and headbang. The shopkeepers coming to see what the commotion was would pop their heads around the corner of the shelves and then say “Oh it is ok, it just Roz with Tom”. This acceptance of our journey and trust that we were in control saved my sanity and helped me take the time to teach Tom how to behave in a society where differences are feared and behavioural management is firmly in the hands of the mother.

Tom is now 17 years old, is school captain at his SSP school in Wagga and lives in a group home with other disabled children. Tom wants to live in a house by himself so he can watch his football and talk to himself without being interrupted. It does not have to be just any house but a house preferable planted right on the field of the MCG. Reality and fantasy are difficult to explain to Tom. He does not understand that he won’t be able to live on his own, at the MCG, or anywhere. He promises that he will do whatever he has to do to live on his own but he is unable to remember to turn off electrical appliances, or shower, or eat his dinner.

With a deficit mentality in Mental Health his chances of finding accommodation even within a group home is slight. So why did we go to so much trouble to teach him how to behave? Why did we fight whole departments for integration and the development of skills necessary to live a life of independence with dignity and respect? Why did we spend hundreds of hours and dollars to train him in routines that would help him socialize with people who only marginally understood him? For what? For him now at the end of his school life to come home to a farm and sit in front of a TV and watch Essendon reruns? Funding? Yes funding for work placements 125 kms away. Because supported housing is non existent he can’t work because he can’t live where the work is.

What has integration done for us? It has become his shroud as he is doomed to a life as that weird mental kid out on the farm. Well done State government, you have really brought us into the 21st century!

The Stoyles Family

My name is Kate Stoyles and we have a son, Andrew, who is 38 years old and has an intellectual disability in addition to rather severe epilepsy. At the moment he lives at home with his father and myself and is very happy about that. He lived out of home for 8 years with drop in help and it was definitely not enough for him.

We now have some respite thanks to Eastern Suburbs R & R and Sunnyfield and we are very grateful for this as it has made our lives much easier and less stressful. One of the problems for these people is loneliness and together with the fact that Andrew really only has the reasoning capacity of a child even though he is adult and capable in so many ways, he could not live alone, nor could he move from our area (or comfort zone).

We need more accommodation choices in the Eastern Suburbs urgently. We worry continually about what will happen when we are no longer here or are unable to look after Andrew as my husband is nearly 70 and I'm not far behind.

The Kivits Family

My name is Elsie Kivits and I care for my young son who has Downs Syndrome.

John is 30 years old and during his entire life I have been a single Mum to him. John has four siblings, however as John was a later in life baby, two of his siblings had already established lives of their own by the time he arrived into the family. John and I have both lived in Department of Housing premises and have always struggled financially. As the years have passed I have developed a chronic illness of my own, this has resulted in a decrease in my ability to care for Johns needs.

I have Chronic Airways Disease, Rheumatoid Arthritis and Gout and I am totally dependant on Oxygen and attached to a machine 24 hours a day. I am now in my 70’s and whilst John is a young man of 30, he is mentally an adolescent. I am completely unable to physically keep up to his needs. When things were looking tough I started to investigate the possibility of securing a bed for John in an appropriate facility only to find the rules of entry have changed. There is also a shortage of facilities, especially in the rural area where we live. We have been hoping for supported accommodation for five years; however the added problem of securing a bed is the financial requirement needed to support the person. We do not have any savings that could be used for support. It is also vital to establish how much support John needed to live independently.

On my worst days when I cannot get out of bed I am despairing of where my young son will live when I am gone. I am frequently hospitalised for my condition and John is at the mercy of the service and family when this happens. As John needs assistance for functions of daily living we need services to assist. As he leaves for his daily program I contemplate whether I can get out of bed or not. Some days I am able to sit at the table and some days I am not. Other days I can put together a sandwich without losing my breath but sometimes this can take me up to one hour to complete the task.

When John returns from his program he is often restless and looking for further stimulation – things normal children like to do. We live in a rural area and although there is a bus that stops outside our door it does not accommodate my scooter, which I need to travel around on, and because they move quickly, John when he is with me, also has one. He cannot however travel around on his own.

At night John uses a sleep apnoea mattress and often requires my assistance when things go wrong with it when he is sick and when he cannot sleep. This not only deprives me of sleep but it affects how I function the next day.

As a loving mother and carer I am tormented daily with thoughts of where my son will live when I am gone. One high point is that I have been able to care and provide for my son for the past 30 years. One low point is that John does not have the access to the social stimulation he is entitled to. To deal with the day to day situations I have paid support as well as family back up. I have a strong support network that assist me during working hours but cannot assist at nights and weekends. To deal with the longer term I usually rely on my faith.

As for the future I really do not know.

The Cristia Family

We are Claudio and Cristina Cristia and we have a 19 years old son who has autism.

Our main concern is that we will not be there for Cristobal for the rest of his life. We are getting old and we are getting tired. Living with Cristobal's condition is hard; he is a very demanding autistic young man and cannot be left alone under any circumstance with the situation becoming harder every day. We are finding that we are getting more stressed as each day we are seeing him frustrated or upset and not knowing why.

We have been told that there are no available houses or home groups where Cristobal can live and be part of, mainly because there are no carers that specialize in his type of autism. We believe that we are very much capable in helping to guide new carers wanting to look after Cristobal. We are with him 24 hours a day, so we know exactly how he reacts to different things, different people, different situations, etc. We are willing to go to any extent in order to see our son living in a group home, with a good quality of life and be treated like any other citizen.

We have asked for help, we been involved in many meetings, we are very grateful for the 6 hours a week that Cristobal is looked after. But this has not been enough to ease our struggle. The lack of carers has made our life dealing with Cristobal's autism very hard and we cannot keep up with his demanding life on any more. Our physical health and mental strength are running out. We are very concerned about our mental health; the stress of our situation is hard to handle.

We are trying to do things now so our son can have a good life as he matures and we grow older. If our son Cristóbal had a place to live, with carers looking after him, with activities that will stimulate him, his life and ours would be much easier. If Cristobal lives somewhere else, we would be able to look for a job and integrate ourselves into society.

I can't tell you about to have a rest, because we don't have any. We are Christians and think that God has given us strength all these years to help our son, but it is time to let him go and the only way is to find him a place to live and hope for a door to open to him with specialised carers that will help him to live a happy life.

We are very grateful for the help that we have received, but it hasn't been enough and it is time that we stop blaming ourselves for having a disabled son and try to look for a better life, not only for him but for us as well. Our son has been in a waiting list since he was 6 years of age and now we have found out that the list is non-existent.

We have tried everywhere and we have talked to many people without having a positive response, we now know and believe that it is time for someone to give our son the help that he deserves. Also, I have a beautiful young girl of 21 and I realize, I am never going to have the time to give her a big hug and have a coffee with her like a normal family.

I think I don't have to describe to you a typical day, is hard from the morning to the night. Cristobal never asked to be born and I am sure never asked to have autism. We love him deeply, but we can't live with him any more. We need support!

From A Family In Northern NSW

Once upon a time a boy met a girl and they fell in love and got married. It was their plan to live in their own castle and have lots of lovely princes and princesses and live happily ever after. After all, that's what all their friends did. But no one told them about the wicked witch "gene" who had been waiting silently for the moment to strike! Soon a lovely baby prince was born and all seemed perfect. Two years later another beautiful prince was born, but he had a couple of problems, but the boy and girl didn't worry because these problems could be repaired and the boy had had similar problems and his had been repaired. Very soon though, the first little prince appeared to be in trouble **-** he couldn't talk, though he could do puzzles! People said, "His brain doesn't work properly". Unfortunately his brain couldn't be repaired. Soon though a gorgeous princess arrived to brighten the lives of the boy and girl. She was perfect. All the while the boy was finding more and more problems in his own body that couldn't be repaired. "Gene" was working her wickedness.

One day the girl was very surprised to find that they were to be blessed with another baby and they thought, "Oh well, the boy and the second prince did have some problems but they could be repaired". No-one knew at that time that it was Gene's doing that made the first prince's brain not work properly. Soon another lovely prince was born but oh dear! He had the problems of both the other princes. As time went by the boy and girl managed to look after their princes and princess and to overcome the wicked Gene.

After some time the boy and girl decided to move from the big city to the country where things were quieter and slower. The eldest prince went to a special program every day and his brothers and sister went to school. The boy was finding it more and more difficult to walk and soon had to use a wheelchair and he needed help with so much that the girl was always busy looking after the boy and the princes. The second prince found that he could no longer see very well and had to use a cane to get around. The wicked Gene was working her wiles. Fortunately some magic happened too, and a place was found for the eldest prince to live with some of his friends in a nearby house so that the girl didn't have to look after him any more. That made things a bit easier. The second prince and the princess found their own castles and went to live there.

Meanwhile the third prince kept growing. He finished school and went to a special program, but it was only for three days a week and the girl had look after him for all the other days. He grew bigger and bigger and sometimes would get very angry and hurt the girl. She found that hard to cope with especially as she was getting older and developing arthritis, especially in her knees, making it difficult to walk. The boy was more and more dependent on her. They thought, "Wouldn't it help so much if third prince could go and live in another house, nearby, with friends just like first prince. We've had his name on a list to do this for years and years. Let's ask if there is a place for him now!" The reply came from the rulers of the country "There is no place, and no money to provide one, unless he doesn't have a home now or if unless someone is hurting him".

The boy and girl were totally shocked. They had tried to do the right thing in providing a home full of love and looking after the third prince. They hadn't hurt him, even though he had hurt them. They wondered how would they continue to cope when they had trouble enough looking after themselves. They despaired.

This not a fairy tale. It happened and continues to happen to us. We are pushed to our limit daily with little hope of a solution. Many families are in this situation. We need action to provide supported accommodation for our disabled adult children NOW! A plan for the future needs to be laid out and followed or many, many families will be pushed to the brink as has happened many times already.

From A Family In Sydney’s North-West

My husband & I have three kids, one of whom has autistic disorder & intellectual disability. My 10 & 11 year old girls spend much of their time missing out on things that normal kids should be doing as a result of trying to support their mum & dad with the physical chores of having a child with autism. They don't get much time to do homework, if at all, or have to give up playing with their neighbourhood friends after school in order to help out with their little brother. They also take turns going to friends places and having friends over to play. Our son has broken his 2 front teeth hitting his head on the ground in a temper tantrum and has brought down a glass door with a toy hammer. (Not a safety glass door).

Our house is sectioned off into zones when our 4 year old can & cannot go as he either destroys things or more importantly he hurts himself. Recently he broke a glass snow cone in his sister's room and gave himself a huge gash on the sole of his foot. He was alone for about 10 seconds. He didn't cry but the gash needed treatment due to its depth.

During dinner time most mums put on a video to entertain their 4 year olds so they can go to the bathroom to wash their hands or start preparing the meal but at our house, one of my girls has to stand on guard in front of the oven or griller as our son is fascinated by them and has placed his hand inside the griller blistering 2 of his fingers from the burn.

Our son who is now 4 is mute and has many challenging behaviors from hurling toys done the stair well to listen to them crash against the wall. He is also quite tall for his age and he has a habit of dropping to the ground and going limp when you need him to move from one room or place or activity to another. This often puts my back out, as I have had a broken back as a result of a drunk driver running into my car, and the rest of the family end up looking after both my son & I. My husband works long hours & 2 jobs but we still can't afford the $40,000+, out of pocket expenses per year to pay for the therapy we would like our son to have as there is no government aid for it whatsoever.

If I need to attend a parent training coarse on challenging behaviour or intellectual disability or communication, like learning to sign language, the girls take turn missing out on school in order to watch dog the carer respite service. We can't afford closed circuit TV's in every room in our house but I don't want our son tortured, abused or neglected by strangers who are poorly paid and poorly educated.

We wake up in a cold sweat worrying about the future and the legacy of grief and poverty we will leave our children with if they choose to care for their brother when we no longer can. They also have to make the decision whether or not to have children or to adopt given they have a higher 30% chance that they will also have children with autism.

The Walzak Family

Our daughter Lisa, born in 1974, has a severe intellectual disability as well as a physical disability called Arthrogryphosis and uses a wheelchair for mobility.

We have cared for her for 31 years and she still requires full support in EVERYTHING that she does.

She is unable to walk or even stand to help us to provide the personal care that she needs.

She is unable to communicate effectively enough so that others understand her wants. Although she does have very limited communication, unless you know her well, you would have no idea what she was trying to tell you. Imagine going through life like that! How frustrating it would be!

Her frustration at her inability to communicate is demonstrated by self-injurious behaviour & aggression towards others. Many a time I have been rammed by her wheelchair because she wants something & I am not quick enough to respond.

As Lisa gets older, I see an increase in this behaviour. And as I get older, I'm finding it increasingly stressful & more difficult to cope with her behaviour & her physical needs, as there is a lot of lifting involved in providing her care.

A simple thing like transporting her is hard, as we don't have a wheelchair accessible vehicle. She has to be lifted into our car if we want to go out. Hence we don't go out very much at all….it is too much hard work & I have nearly dropped her at times. So, there again, out comes the self-injurious behaviour, because she is frustrated about being at home…bored!

In September 2002 Lisa was accepted onto the DADHC Accommodation register & now awaits placement in a group home. We were aware that Lisa could wait a long time for placement but it appears to me that the NSW Government sees no urgency in the current situation of there being no accommodation available because I can't see them doing much about it!

OK, so people have been moved out of institutions into the community, but let's not forget that those people were already 'in the system'. So what's happening to those who have been fortunate enough to have lived with their families, but whose families are now breaking under the strain of having to care for their adult children?

I honestly don't know how much longer I will be able to care for my daughter because ours is one of those families!

I know that Lisa would be fine living in a group home, as she is always indicating to me, verbally, that she wants to go to respite. She loves being with her friends. They're not boring, like Mum & Dad!

That's another issue! What's happening to the respite?

Lisa used to get quite regular respite but the beds have been blocked by people whose carers can't take the strain of caring anymore. I feel for these carers because 'there but for the grace of God, go I'. Carers are crying out for support through accommodation services, and they see leaving their son or daughter at respite as their only option, but that doesn't help other carers who are breaking under the strain as well. Now we are under even more pressure because our respite services have been taken away. When will we be allowed to relax & stop worrying about what the future holds for our sons & daughters (& ourselves)?

Please don't force me to do what others have done.

I NEED ACCOMMODATION FOR MY DAUGHTER NOW & if that can't be provided….MORE RESPITE until it can!

Maricarmen And Victoria’s Story

I am Maricarmen Póo ,Victoria Póo is our daughter she is 41 years old. We have applied for her accommodation, but other people who are in a worse situation than we are got it.

My husband is 72 years old waiting for a big operation in his heart. I am 66 years old, with a breakdown years ago and three operations on my breast with cancer in 2003.

Our typical day is very hard to explain, some time to start before the sun rise, cleaning the mess you find in the toilet ,Vicky hide everything, from the comb to the spoon, books, clothes etc....because she can’t speak she screaming and made noises constantly.

Only God knows how hard is to live with our dear girl, some time is to much to cope, we feel privilege to led her go to Temporary Care about one week in a month, but when we needed more, at the time of my operations, the Temporary Care had no room for her.

The McAndrews' Family

I am the second and youngest daughter of two, and now the sole full-time carer of Chris, aged 64. Both parents are deceased and, apart from distant cousins with whom we have little contact, no other family members exist. My care of Chris has been for 31 years, 10 of which were shared with our father who was suffering ill health due to a long history of alcohol abuse. The care was intermittent due to my study/work commitments. Since his death 21 years ago I've had a multi-faceted role as sole carer.

Chris was born normal and at age 10 she contracted measles. Regretfully immunization back in the 1940s was not always recommended and so she was left with an intellectual impairment.

Chris and I live together and, given my commitment, now aged 49 and always engaged in full-time employment, it is clearly apparent that I haven't had an independent life of my own. As the ageing process develops, so the physical needs increase. The psychological, social, emotional, financial demands are ever present, not to forget or minimize the ever present concerns of what will happen to my sister in the future.

About 10 years ago I "uncovered" some limited resources provided by DOCS (now DADHC). Any success in outreaching help/assistance is based on "luck" either by word of mouth, flyers, chance encounters etc. I was at my lowest when my friend, Stuart, engaged the initial contact that led us to Coach House (ADP at North Sydney). This facility has been good to Chris and I, with attendance 4 days per week. Chris feels comfortable, safe, and happy, and over the years I have witnessed a significant growth in her skills, social intervention, confidence and acceptance in society.

Chris has a strong level of dependency on me in her life and the introduction of respite care was a major challenge for Chris mainly because of the separation factor. A loving, reassuring rapport for many years at respite due to professionally committed staff gave Chris respect, friendship and treatment of her as an equal. These folk were regarded like family. Chris grew confident that I wasn't going to disappear and we had a positive return from the placement. No so now! Staff are younger, have a different focus, seem less interested and a hundred other reasons that encourage me to reduce the visits. The negatives outweigh the positives. Through DADHC we had many meetings/discussions for the need for appropriate supportive care accommodation. The department is aware of our needs. Miraculously I have survived some very demanding times over the years – how long can I last and still give my best? I am not accurately able to determine the time frame but our needs are well known. In the course of my job, I witness group home life and know that good ones exist. These sadly have no vacancies or rarely. Those that tear at my heart on the lower end of the scale would naturally be more likely to propose a vacancy for us and so I face an incredible moral/conscience issue of would I be content to have Chris live there or do I continue to give?

As a long term shift worker, my hours are dreadful. My roster rotates and requires me to do night shifts weekly – thus I need to leave Chris alone. She appears to cope in the main. My only goal in life is simply "to prepare today to the fullest to allow tomorrow to run smoothly". High points – when it all goes to plan and Chris is safe, happy, watered and fed.

The low points – well!! Recently Chris was missing for 2 hours with no word. I became frantic, had engaged the services of Police. Finally she came home, in the dark, exhausted, anxious, emotional. Naturally, my life was put on hold and I had to cancel my night shift duty. I wasn't paid for that 14 hour shift due to my sick leave being exhausted so we suffer financially. Just another aspect of being a sole carer.

How do I cope? You just keep going because you have to and there is no other choice. Fortunately I have many friends who give love, support and recognize my need to have some "Julie time" so we share precious time together. Sadly I find myself using my work as an escape from the pressures and demands at home. The irony is as an Ambulance Officer with the Ambulance Service of NSW spanning 17 years, I give at work for either 10, 12 or 14 hour shifts and then I come home and give again 24/7 for 365 days per year.

The Hunter Family

I have cared for my son Aron for 28 years (Downs Syndrome). His father left us when Aron was a baby and was never any help. He has since died from cancer. Without my daughter's support I would not have been able to go to work and we wouldn't have been able to have the comfort we presently enjoy. She cared for Aron each day and took him to therapy etc until he went to a special school in town. None of my daughter's care was ever recognised by the Government in any way.

I haven't needed supported accommodation yet as my daughter and her family live on the same property.

Aron works in a laundry (supported workplace) three days a week. Five days proved too much for him.

As we live 25 kms from town and there is no public bus service to town we rely on lifts from neighbours to get him to and from his work place. This means at times I have to transport him to and from work (petrol cost $13 for the two trips these days). As he only gets paid $11 a day, without the Mobility Allowance (which works out at $11.60 per day) Aron would actually earn nothing if I had to transport him every day. Also to access respite services it costs the same in petrol without any rebate being available.

I transport Aron to and from town three times a week so he can attend respite services which takes two hours out of my day. I do it so he will have a social life and not for my benefit. At present Aron is quite a help at home but as a Downs Syndrome person he will age prematurely. I'm 67 and have a bad back and knees so in time we will have problems with transport. We love living out here. Aron has an ATV which he delights in riding around the property. We have a very comfortable home, the Macquarie River is our back boundary so you can see we would like to stay here as long as possible.

Since Aron was born, the services have improved somewhat but the Government does not recognise the huge amount of money it saves because so many relatives and friends help out.

The Board of the company Aron works for, Glenray Industries, is at present trying to finance a project to build supported housing for the Glenray folk when they are unable any longer to go to work.

Glenray has 30 residents who once they can't go to some activity during the day will not be able to be housed by Glenray. I am on the Board of Directors and it is our dream to provide some place other than the totally unsuitable Aged Care Homes situation for these residents. We have the land and the will, but we will need a lot of help to realise the dream.

Lewis’ Story

I had my second son on the last day of 1994. It was a difficult birth and I knew when I saw him, that my life was as I knew it was over. I had another child waiting at home, who was then 3 years, for me to take his brother home to him. The depth of sadness I felt and have felt since that day has been compounded by the lack of services from the government to support our child and family. I hoped for a career in teaching, but have had to scrounge around for child care for a severely intellectually disabled child, who has been fully tube fed since he was nine months old and seriously ill with pneumonia related problems before then.

Why am I bothering to write to you, is because it may help another family in the future to receive a humane level of help. I don’t think either of us would be here if it weren’t for a kind doctor who managed to pull strings within a struggling hospital system and find some respite for me.

To begin with the effect this situation has had on our first son and our own relationship just burns a deep hole in my chest. I cannot begin to tell you about the pain we have all suffered to keep our son alive and well.

There is no long-term hope for him, as no one will even speak to us about the possibilities of supported accommodation. The government would rather see him buried than have to commit to helping him have a quality-supported accommodation situation for his life.

Regardless of this inhumane approach from the government, we continue to care for our son and love him and appreciate the moments of happiness he gives back to us. He needs to be fed 5 or 6 times in a day and wears nappies continually. He cannot be left as he has no awareness of safety and has serious mobility issues requiring ongoing surgery as he grows, in an attempt to keep him out of a wheelchair permanently.

We have less of social life than in previous years. It’s just easier to stay at home than to take him out. Besides lack of income has greatly reduced holiday and social options.

I’ve been lucky this year, as after three years of my son suffering from chronic bowel problems and weight loss the doctor has been able to find a formula that his body can absorb. It feels like a blessing to get that help.

I wish the government could see that our situation is real and that we deserve to have a better outlook and quality of life. Carers should not be punished because they have had a sick and disabled child. The child they have is a citizen of this so-called lucky country. It’s a matter of looking at our society in a more humane way and offering appropriate supported accommodation to people with disabilities.

How I cope with the future is, I don’t think about it much as I know our son’s chances of survival is low without the level of care we can give to him.

The Doyle Family

I have been caring for my daughter since birth and she is now 21 I have been in the role as a sole parent for 11 years – the most difficult years of our lives. An application was submitted for placement for my daughter when she was 12 years old. I knew I was not going to be able to care for her long term. I was also aware even then that it would be impossible for the level of support needed to be given from our local services providers. In 2001 my daughter was granted placement under 197; this was great, so we thought, but being naive and not realising it did not actually mean there was a placement available so the years just rolled on. My daughter now attends an ATLAS program and as no transport is provided I must take her there and home everyday and maintain my job.

My daughter is just beautiful and such a social butterfly loves to meet people and when she is good she is great. There are days when she is not so good and the house can be trashed in 5 minutes where her bedroom can be rearranged also in 5 minutes flat. This behaviour was manageable when she was 7, 8, 9 or so but as she got older it became harder and harder to control. I have been to all the behaviour analyses and read all the reports and tried to work to the conclusion but I still think they do not have it right. Her behaviour is unpredictable and you could be chatting one minute and bang the next.

My daughter did get an opportunity for placement and I had a sense of relief and a sense of loss but it had to happen so we went forward to follow up. I proceeded to visit the house and was appalled at what I was faced with. The premises was a split level and residents were unable to access the back garden as they needed to go down 14 steps in a narrow staircase with the support of the staff this staircase was locked at all times and access could only be provided by staff. As showering is the preferred way for my daughter it was necessary to have a showering facility and none was available so after a request that an OT assessment be carried out the placement was deemed unsuitable for my daughter.

Although my daughter is getting support thought interim funding they continue to cut back and put me and my daughter under extreme pressure. Policy states that meetings take place every 3 months to review our needs: this is a joke all I ever get told is what is being handed out for the next three months and no stock is taken of what our need may be. I enquire about a placement and are told we are a priority as I am sure is everyone else. I did not think I can continue in this role for much longer and believe I am going to have to abandon my responsibility in this role or else have a nervous breakdown.

The Roe Family

My husband and I have a 30 year old disabled son who we have cared for all of his life through some very difficult times.

Christopher (our disabled son) attends a living skills program five days per week and both myself and husband work full time. Our lives are very busy and require a lot of planning. Christopher needs help with daily living skills eg: bathing, dressing etc.

We are happy to care for Christopher at home and we don't require supported accommodation at this stage, however we are fully aware that we will require accommodation in the future. It would be nice to know that it will be available when it is required.

Our need at this stage is respite care, we are planning to retire at the end of this year and we know how difficult this is going to be due to our lack of freedom. In 2006 we are planning to go over seas for the first time, for us to be able to do this we have had to call on our daughter to take time off work to look after Christopher. We find this very frustrating!!!!

Another frustration is the amount of money that is taken up with administration requirements. It seems to us that in Bathurst alone there would be at least half a dozen different organisations that provide similar types of services. Surely this service could be streamlined. Wouldn't it be lovely if we could use the money to employ people we know to provide a carer service. Think how much further the dollar would go.

The Hayes Family

My name is Clair Hayes. I am mother & full time carer to my 31 year old daughter Kim Baldwin Hayes who has moderate/severe Disability, Epileptic, Autistic, Obsessive Compulsive Disorder, Bipolar Disorder & Schizophrenia.

My day as Kim's primary carer is all encompassing. It is like having a toddler forever, I have to be aware at all times of what she's doing, what she's surrounded by, who she's talking to, what she's wearing, where she is, what she eats & what she drinks.

I rise about 7am take Kim's medications & her daily allowance of $2 down to her. I unlock the door of her quarters with a key for the customised door which had to be made to set up some boundaries to protect us from her pervasive behaviours, when Kim was exited as unsuitable from a 24 hour care house of a Central Coast service provider.

I prepare Kim's breakfast. I check her kettle cord is not twisted around the clothes drier cord, or microwave which sits on the fridge. I place her breakfast on her table & her daily ration of 3 teabags in her canister, I then retrieve all empty bottles & caps & fill them with water & place them in the fridge. I make sure lunch & dinner ingredients are in the fridge, then check the drier & washing machine for tissue residue from uncleared pockets & Kim's nightly laundry attempts (no washing powder), clear away the night before's water bottles, teacups, plates & scraps, gather up the residue of never-ending pamphlets, newspapers & cutouts Kim collects daily & throws in the overflowing waste paper bin & I go in search of the plastic container which she throws from her bedroom in fun. I wait for her to rise to take her meds as she doesn't pick them up if she misses her mouth. I then return upstairs to do Kim's daily notes for the service provider carer if & when they turn up.

I program Kim's daily activities according to her mood swings & energy level. All moneys for petrol, food, coffees, fares, entry fees, insurance medical & dental bills is supposed to come from Kim's disability pension. IMPOSSIBLE. I supplement the money pouch daily & note suggestions for the day, resentful that I cannot work in my chosen careers.

Kim tires rapidly from the daily activities & the medications she is on, so in the afternoons she is even more abusive than in the mornings, & begins chanting: Mum, Mum, as soon as she's left alone for more than 20 mins, or if the carer remembers to switch Kim's phone over for use, she calls me every 5 minutes. I have to go & speak with her despite my home duties. I prepare a separate dinner for Kim & take it down to her with her evening meds, and check to see if her noon tabs were taken, which can be forgotten by some carers.

In 2004 the service provider fell short 3½ months in hours owed, which I have never retrieved because they said they quoted the government incorrectly, & as I write this (September 2005) I'm owed a further 60 hours, because of miscalculations. If I don't record these miscalculations they are totally overlooked. Often I cannot speak with supervisors, I've had to cancel countless appointments, many functions & some accommodation because of unpunctual or unreliable carers. I'm on call no matter where I am: funerals, weddings, church services, meetings, family gatherings, on the toilet or on respite. I had to give up any form of employment because of the unreliable nature of service providers.

As a carer 365 days a year: I feel isolated, unsupported, suffocated, despairing of ever being free again, extremely disappointed in humanity, forgotten, burnt out, frustrated, resentful, misunderstood, envious, cynical, ignored, bored, abused, ripped off, cheated & patronised, but beyond anger & beyond tears.

The Ryan-Baldwin Family

My name is Karen Ryan-Baldwin and my son's name is Matthew Ryan. He is 30yrs old. I have cared for Matt since birth. He has an Intellectual Disability and behaviour problems and chronic Epilespy (Lennox Gastult syndrome) which is hard to control.

I have been on a waiting list in Sydney for the past 10yrs, but the situation has now changed as we moved to Port Stephens in December 2004, and I have had to start all over again. When we first moved Matt got just 4hrs service a week. He has post school options money attached but that did not matter. Back in June Life without Barriers rang to say he could come into the program. He travels all the way into Newcastle 4 days a week. They send a driver for him; he likes the travelling and is more settled now but the past 9 months have been hell.

I refused to go back to Sydney as I had planned for ages to get up here. The services are far & few between. There is no Respite: the DADHC services that have respite have blocked beds (all five units). There is a private one over at Raymond Terrace but she won’t take anyone with behaviours so that leaves me out. I don't have any family backup only when my younger son (24) comes to visit or my niece comes up from Sydney. I sometimes get some relief, I was told that I will be placed on the waiting list for accommodation but not to hold my breath. I do have a caseworker from DADHC as I am not too sure of the system up here yet.

I am trying hard to get some sort of parent group going up here as there are so many people with disabilities up here, especially aging parents. We really need a service in the Nelson Bay area so these people and parents don't have to keep going into Newcastle or Raymond Terrace and Maitland. The public transport system is crap so if you don't drive or have a car (that’s me) you are stranded.

I have had several meetings with services and DADHC about getting programs into the Bay area instead of all this travelling; all the time the money spent on petrol and travel time could be put to better use.

The Starr Family

We lodged an application for supported accommodation for our son Jeremy in June 2001. He is the youngest of three children and is almost 24 years old. He was born with Angelman Syndrome, which means he is severely intellectually disabled, unable to speak, hyperactive and very mobile. He is currently in remission from epilepsy, has a very irregular sleep pattern and has a variety of attention-seeking behaviours. Jeremy requires assistance with all personal care: showering, toileting, feeding, dressing and undressing. He responds well to toilet timing but cannot assume responsibility. For outings to be successful, careful planning and adaptation of the environment is generally necessary. A typical day can start at 5.00am, nearly always after a broken nights sleep. Managing his extensive disability requires full-time, 24-hour care, on a one-to-one basis at minimum.

Since leaving school (35 hours / week) in 2002 Jeremy has attended a day program for 16 hours/week. Having him now at home for the majority of time has taken a dramatic toll on us as a family. The pressure has always been there but the situation has rapidly become unmanageable. His siblings have left home and with most of his time spent here, we find we are dealing with a huge increase in inappropriate, attention seeking behaviour stemming from boredom and frustration. With his increased size and strength, along with our waning energy level, it is very difficult to maintain the level of care that he requires and deserves. His attachment to his mother is noticeably increasing which has led to a reduction of independence and places huge strains on relationships. He demands full attention and monopolises her time. To answer the telephone for instance one has to compete with deliberate loud yelling or emptying shelves/cupboards. Just to use the bathroom or go to the clothesline has to be strategically planned. As parents we find we are locked into an extremely stressful situation with minimal support. Meeting the demands of 24-hour care at such a rigorous pace constantly leaves us feeling exhausted. This is heavily impacting on our health. We are feeling socially isolated even from our other children and extended family. This is emotionally very painful, especially with the arrival of grandchildren and with our ageing/ill parents. We are just unable to make spontaneous decisions. Freedom of choice is dramatically diminished with no visible escape.

Over the years we have utilised various support mechanisms including Cooinda Respite Service (centre based), Commonwealth Carer Respite, Northern Respite Assist (Interim Crisis Funding – daytime hours), Home Care, Taxi Transport Subsidy Scheme and others no longer available. Centre based respite has to be planned in advance and booked in three-month blocks. Jeremy is no longer eligible for any respite during school holidays, which are reserved for school aged children. As his emergency contact we have had to bring him home early or seek medical attention on a few occasions whilst in respite. These services have certainly offered us some minimal relief but we now find that our current Case Management with DADHC is not at all meeting our needs.

We always planned for Jeremy to progress into some form of permanent housing once he left school. Since applying for supported accommodation over four years ago we have made regular contacts with people in head and regional offices of DADHC inquiring of the status of our application. We were constantly reassured that it was moving along and had reached the “top of the ladder”. Repeatedly we were told that Jeremy was the highest priority for this region.

Challenge Armidale at the request of DADHC carefully devised a comprehensive housing proposal earlier this year. It was specifically planned around five people all requiring a high level of support, including our son, addressing issues of compatibility and individual need, with a very ideal property in mind. Unfortunately funding to support this much-needed facility was not forthcoming. We are finding ourselves on the brink of a crisis and are desperately pleading for immediate assistance. Consequently we welcome this opportunity to be part of a collective voice on the glaring lack of supportive accommodation for people with disabilities. Lets put “An End to the Silence”.

The Conn Family

I care for my son who is now aged 34. He has an intellectual disability.

On a daily basis I have to supervise him in every aspect of his life. In the morning, I have to call him to get him out of bed, prepare and supervise his breakfast. Then I have to lay out his clothes, make sure he dresses properly, arrange his money for the day, pack his lunch send him to the bathroom. It is essential that I check his toiletry needs, even to the basic need of checking his “bum”.

He then needs to be got to work. Presently we drive him to work about half an hour’s drive each way. He does return from work by getting two connecting buses. However this does mean either my husband or myself need to be home around the time he gets home. On the odd occasion he does not get the bus connections right and we do have to go looking for him.

Again at night I need to supervise him to shower, prepare his evening meal, and ensure he does perform all his daily duties to taking his tablets, etc. It is essential that I give him his medication morning and night. I have to do all his washing, ironing, cleaning and preparing all his meals.

All his outings with Coastlink I have to arrange and supervise that he attends, or is taken to the pick up points. My son would have no hope of getting himself around without either being taken or trained for that specific task or trip. His reaction to something going wrong would be anger. All the activities that my son has, either my Husband or myself have to drive him to, if we want him to have any outside life, besides living with us. We would travel some where between 200-300 kilometres per week for him.

He does get three separate weeks per year in respite care, which gives us all a wonderful opportunity for us to have a small break.

His work, his Coastlink outings, and the occasional respite care, has given this family some hope to live closer to normal life. Without these three factors, our son’s life would have developed into a social tragedy.

We need the continuing support that we now receive, and we need the governments to accept that we are performing a worthwhile service, even though this is our own family. The means test that now applies for Carer’s is ridiculous. For example we have moved twice, spent many thousands of our own money to try and give our son a life, which as a parent you would call a minimal existence. Governments fail to accept that families who go through the ordeal of having a child with a disability, suffer great financial and emotional loss.

All the parents ask that governments accept more financial responsibility and assist in housing and caring for these people, especially when the parents can no longer, or are too old to help their child.

The Engelbrecht Family

As the parents of severely disabled daughter (Microcephaly) we act as the primary carers of our beautiful but totally dependant girl who recently celebrated her 21st birthday.

In essence, for the past 21 years during a typical day we wake our daughter each morning, change her napkins, dress her, lift her into her wheel chair, give her daily medication, feed her, brush her teeth and fix her hair ready for the day. During the morning period we lift her from her chair and change her napkins again and lift her back into her chair.

At lunch time we prepare a blended meal and feed Renée together with a thickened drink and normally lift her from her chair to allow Renee some ‘free’ time on the lounge or mattress.

During the afternoon we change her napkins and lift her back into her wheel chair for the afternoon period.

At dinner time we prepare a blended meal and give Renée her medication followed by her dinner and a thickened drink and dessert after which we lift Renee onto the special toilet chair in the hope of achieving a motion based upon timing and programme consistency. After toileting, we lift and bathe Renée and prepare her for bed.

Our daily routine is totally governed by our daughter’s needs.

The high points of our day are seeing Renée happy and contented and observing our daughter having fun and laughing or giggling at the family or some unknown funny happening.

The low points of our day are usually at times when Renée is unwell and we struggle desperately to determine the cause as she cannot communicate to us what is bothering her.

We cope as a family by supporting each other as husband and wife however the vast majority of the pressure is sustained by Renée’s mother who constantly gives of herself and her love to maintain the best life for our daughter.

We are greatly disappointed in a Government that ostensibly places greater value on juvenile delinquents, costing around $250,000 each for annual incarceration, than we do to care for our disabled people who are consistently placed at the bottom of the ‘food chain’ of the funding race; and at a time when more funding and support is critically needed the Government has had the gall to REDUCE financial support in the cause of providing a better service???

The funding provided by the Government for Renée and her carer family is grossly insufficient to cover the actual expenses of providing respite, loving accommodation, education and a reasonable lifestyle for Renée.

We have to substantially augment the meagre funds to maintain a decent life for Renée and while we are reluctant to voice our plight publicly we are more determined to END THE SILENCE and demand more caring and more empathetic Government support!

The Wilson Family

My husband and I rely totally on one another for support & respite. Extended family finds it too hard or is unsure so help is never forthcoming, even if concern is shown. Jade's older sister was excellent with Jade when she was younger i.e. 6 – 12 yrs. For a break together we would often go (husband & I) for a walk – our rare time together leaving Jade in the care of Skye. But this burnt her out, we don't burden her with this now and she doesn't offer. We have always coped – but with time we feel we are certainly not handling it as well – our family unit is breaking down with all the hard work and little time to ourselves. And something else we are not proud of, but in the past we have left Jade alone in the house at night while she is sleeping to play tennis (5 minutes) away, sneaking back to check. Care too hard to organize. The added stress is always organizing, paperwork, intrusion and now fighting to try and get services is making us feel like real victims in an uncompassionate world.

We are finding good respite services now – but our needs are now looking towards supported accommodation. But if stress was taken from us with planned respite – we feel we would like semi supported accommodation – 2 weeks in, 2 weeks out for 1 or 2 years – this may work well, and if so if all happy with this, keep it so until our circumstances change due to health etc.

The Caldersmith Family

My husband, Warwick, (aged 68), and I live on the Central Coast, NSW with our 2 beautiful daughters, CASEY (10) and Jaimie (7). At the age of 3, Casey was diagnosed with “global development delay” with moderate to severe intellectual disability, and significant communication problems. She attends “Glenvale School”, a school for children with special needs, in Narara (truly a blessing, and Casey has made tremendous improvement in many of her living skills over the 6 years she has attended). However, as she is unable to make any of her own decisions and is incapable of understanding “Stranger Danger”, living independently in the community, etc., she will need constant monitoring, supervision and ultimately, accommodation and advocacy services for the rest of her life.

Over the years we have received strong support services from various arms of DADHC, the Dept. of Community Services and several private agencies (occupational therapy, physio therapy, etc). Recently, Casey started “Saturday Fun Club” and occasional “Vacation Care” daily outings sponsored by “COASTLINK.” This, most importantly, provides Casey with exposure to environments outside those of her family and school, as well as to enjoy new adventures and more independence, whilst giving us some “time out”.

Following assessments by DADHC approximately 2 years ago, Casey qualified for occasional Respite Services at Reeves Street, Narara late in 2004. Early this year (after only 2 brief visits), the opportunity for Casey to attend was curtailed as one carer (a grandmother of a 10 year old with severe disabilities), “abandoned” her grandson at Reeves Street as he could not be accommodated elsewhere on a full time basis. She couldn’t cope. The child remains there, hence providing less opportunity for other needy kids and carers to benefit from the service. Since then another carer has done the same thing and the respite service has now been “put out of our reach.” Nevertheless, due to the on-going and exacerbated accommodation/full care crisis, we were recently asked to sign a “Declaration/ Disclaimer” form stating if and when Casey next attended, we would not “abandon” her there!!!

We are increasingly concerned about Casey’s future (if we have a tragic accident or illness or eventually are unable to care for her). Basically the future looks very bleak and there appears to be NO ANSWERS for poor Casey. Even DADHC tells us this – no options, “Write to your local Member!” It is very apparent that the parents/carers at these seminars (often still looking after their siblings in their 70’s) are angry, upset, frustrated and extremely worried. To put these parents and carers in this abominable situation is unnecessary and very cruel. How would YOU like to become incapacitated or die before having the peace of mind of where YOUR child will “end up” – and importantly how a sensitive transition, over time, will occur?

We have also been caring for my 81 year old Father on a part-time basis for 2 years – disabled after multiple strokes – and with minimal assistance from DADHC. He has suffered approximately 9 strokes over the past 3 years; is very frail (uses a walker); has lost his speech, interest in life, is deaf in one ear; has all food liquefied; has to have “thickeners” in all his drinks (very expensive and not subsidised), cannot taste, has no teeth, suffers ulcers, but sadly is mentally very alert and a brilliant man.

An Anonymous Family's Story

The lack of supported accommodation for people with Intellectual Disabilities is appalling. Our family discovered this last year when we could no longer care for our 24 year old son with an intellectual disability and needed to apply for supported accommodation through the Department of Ageing Disability & Home Care (DADHC).

The process we went through to secure our son's supported accommodation was long and heartbreaking. I felt that our family was pushed into unnecessary crisis due to this shortage. Initially our son's application was not a priority even though our family was in crisis because he was still being accommodated in our family home. Our son's behaviour continued to escalate as our family's health deteriorated. The crisis intensified and the local police were called for assistance. The police took our son to the mental health ward of our local hospital where he was scheduled. We declared our son homeless, as it was apparent that we could no longer provide him with the care he needed. It was at this point that our son's application for supported accommodation was accepted by DADHC. However, DADHC still had no placement available for him.

My son was left waiting at this inappropriate mental health ward for four long months. During this time he was abused, his health declined further and his needs were not being met. It broke my heart to see my son deteriorate so quickly while waiting for his placement in this unacceptable setting. After four long months at the mental health ward my son was literally thrown out of the hospital because he did not have a mental health problem and because as we were informed, he was unnecessarily taking up a much needed bed. DADHC finally came to the party and blocked a respite bed to offer interim accommodation for my son.

It was one year later that DADHC finally offered my son a supported accommodation placement. My family today are still trying to recover from the trauma this accommodation process created and my son's health has still not fully recovered.

(details supplied by service provider)

David’s Story

David is a twenty year old boy with an intellectual disability and Down Syndrome. David has a history of aggression, assault and violence. David has been expelled from his school due to his challenging behaviours. David’s biological parents have been separated for many years. After their separation, David’s mother and father have been sharing the responsibilities for David’s care. A few years ago, David’s biological father gave up his job and looked after David for several years. However, this was not meant to be a long term solution and David’s father had to re-enter the workforce for financial reasons. David’s father couldn’t manage to care for David and work at the same time. So, David’s father dropped him off to his mother’s residence.

David’s mother is works full time. She tried to continue her support for David in conjunction with the existing disability support services. Despite all support services and medical reviews, David continued to become more violent and aggressive towards his mother. He attacked his mother every week. David’s mother cannot cope with David anymore and she wants supported accommodation for David. Despite letters, phone calls and repeated requests, David was abandoned after being admitted to a local hospital.

(details supplied by service provider)

William’s Story

William is a fifteen year old boy with Aspergers Syndrome and Intellectual Disability. William has a history of domestic violence, assaults and property damage. William is living with his parents. His father works seven days a week. His mother currently cares for him. He continues to assault his mother every day. Despite receiving assistance by way of a Behaviour Management Plan, Family Counselling & Therapy, specialist reviews, William continues his challenging behaviours. DOCS has been notified in a number of occasions, but it is understood have closed William’s file because it is perceived to be a domestic violence issue.

William has been expelled from various schools due to his abusive behaviour. Due to repeated incidents of violence and assaults William has been served several AVOs. He has stayed a number of overnights in the juvenile justice centre as well. William’s mother has had depression for several years. She is desperately looking for supported accommodation for William.

(details supplied by service provider)

The Morgan Family

My name is Frances Morgan and I am the primary carer for my sister Mary.

Mary was born in 1946 and the diagnosis was mild cerebral palsy. This manifests itself as a minor intellectual and physical disability. Mary attended primary school and then did the first ever high school course in Queensland for people with a mild disability. She attended high school to year 10 equivalent. Mary's main disability manifested itself in 1965 with a diagnosis of schizophrenia. Mary lived in Brisbane with our mother until 1993 when mum died. Mary came to live with me at this point.

I am one of the lucky ones, I didn't have to give up my job although I had to change it for one where I did not travel interstate anymore. Mary is reasonably independent and manages a lot of things for herself. Mary was introduced to Coach House in October 1993 for 1 day a week and also to group run by the Uniting Church at Willoughby. She progressed to 4 days a week at Coach House and that is how it remains.

We access respite through DADHC and another organization and both of us enjoy the breaks from each other. Mary also travels on short holidays with a company that caters for people with disabilities.

I suppose I should outline a typical day.

6AM – I get up and have a shower get myself organised
6.45am – I get Mary up and help her with her shower
I help Mary get her lunch and she assists me with getting breakfast.
I go off to work and Mary gets the 202 bus to Coach House
Mary gets herself home from Coach House about 4.30pm
I get home from work about 6pm and we work together to get dinner.
This is a normal day.

There of course are the days when we have toileting accidents and problems with buses but like all carers I cope.

Mary depends on me for transport to all her social events evening and weekends, we don't qualify for taxi subsidy.

I depend for support on a small group of friends; all our relatives are in Brisbane.

Mary needs intensive travel training to learn new bus routes etc. We have applied three times for taxi travel subsidies but as Mary can get from home (Crows Nest) to North Sydney on public transport each day we don't qualify. We need this as it cost a fortune in taxis if Mary has to travel from respite or she has to miss her normal activities when at respite.

What happens to Mary if I have an accident or go forbid pass away.

Also what happens as we get older: Mary is 59 and I am 57 and I become less able to care for her..

There are no accommodation alternatives that I can see. Does she end up holding a place in a respite house while DADHC find somewhere for her or are one of our nieces/nephews supposed to take on an older aunt they hardly know?

The rules change all the time: I have filled in three sets of paperwork to apply for funding for long term accommodation. As I said: the rules change all the time.

The Jones Family

Along with my husband Richard, we care for our disabled son, Robert who is 31 years old.

Robbie was born with Gross Hydrocephalus which at first doctors would not treat so Robbie’s head grew too large and heavy for him to ever sit up or have any form of normal life. At 4 years of age he began a long series of operations which eventually enabled him to sit, walk (with bent knees) and attend a special school. However he still had both physical and intellectual disabilities including epilepsy, severe kypho-scoliosis and looked very different from his peers.

At between 22-24 years of age he had a couple of severe shunt blockages. As a result he is now confined to a wheelchair and is almost blind. His speech has been affected and he has lost the use of his left arm. His level of need is high and he requires assistance with all day to day needs. Surprisingly he has retained his easy going, happy personality and he rarely complains.

About 10 years we put his name on what we thought was a “waiting list” for Supported Accommodation with (then) DOCS but were surprised recently to find that no “waiting list” now exists. About a month ago we went through the procedure of Registering with DADHC for Accommodation but feel this only a formality as we are only too aware of the lack of funding. Along with several other families in a similar situation we have started a support group with the aim of establishing Supported Accommodation (RASAID) in the Ryde area. Robbie does access some respite care which he loves and also gives us an opportunity to do some “normal” things with our 13 year old son. As it is too difficult to go on a holiday, given Robbie’s needs, these times are precious to us. However because many of these beds are now blocked with permanent crisis care residents, this service is now becoming rarer. Robbie believes that one day he will be in his “own home.”

We are finding caring on a daily basis increasingly difficult given our ages and Robbie’s slow deterioration. Our day begins early (5.30am) with Robbie’s toileting needs, dressing, breakfasting etc. and generally preparing him for his day activity. In between this the rest of the family is trying to organize themselves for the day. For me one of the increasing difficulties is lifting his heavy wheelchair into our station wagon – oh for a more adequate vehicle! Maybe one like he would have access to if he was in Supported Accommodation! Both Richard and I require regular Chiropractic care to keep our backs “working”. I can only work part time hours – around Robbie’s hours and medical appointments etc.

Another concern is finding recreational activities on the weekends to occupy his time. Because of his multiple disabilities it is difficult to find or access suitable recreation, but luckily he has a passion for all types of music.

Our day ends much as is starts: feeding, toileting, showering, preparing for bed etc., and dealing with all the extra paperwork that seems to come with a disability. We do receive some services from Home Care who come twice a week to shower Robbie (1 hour per week).

The Rona Family

We are a Jewish family with 6 "children" living at home. Three have Autism and various degrees of developmental delay, Dovid, our oldest at 26, with high-level support needs, Moishy, 18, and Pinchas, the youngest at 14. During the day, Dovid goes to Miroma Centre; Moishy has just graduated from Blackwattle Bay High School, with his programs for the future still up in the air; and Pinchas goes to Vaucluse High. Our other three are at work, uni and starting Year 12 respectively.

We began using short-term supported accommodation within a year of Anglesea St house being opened. We used to be able to rely on getting respite every Tuesday after school till bedtime, first for Dovid, then Dovid and Moishy, then all three. As first Dovid, then Moishy, grew too old, they transferred to Dunningham and later to Doncaster when the centre moved. We also occasionally took a 10-day holiday, with the boys in respite. We provide kosher food for them, plus the houses have a kosher list. There was a time when the houses provided and prepared kosher food on our behalf but that went in a cost-cutting move. The respite was very important, as it was the only chance for other members of the family to have time off.

Moishy and Pinchas are particularly intrusive, with their deafening screaming, nagging, fighting, interminable dissertations on their obsessions, physical harassment, etc. Long-term difficult behaviours have included running away (Pinchas was a master escaper who was hit by a car on one jaunt - the other boys went into respite care while I stayed with him in hospital), setting fires (major fire damage during our other son's HSC year forced us out for 7 months, of which the boys spent most of the first two in Anglesea St and Dunningham.), killing our pet, jumping on people's backs and hanging from their necks, tearing down the pergola (because it was "old"), chiseling holes in the wall, destroying electrical and other household objects by rough handling, etc.

Dovid is withdrawn; his loud tantrums and physical destruction are of the past. No more using freshly washed laundry, toyboxes and walls or sides of cupboards as toilets; no more throwing curtains and clock radios out the window; no more cutting up library books and homework; setting fires; flooding rooms or pulling doors off their hinges. However he does still occasionally empty out the fridge and requires prompting for every task, no matter how simple and routine. His name has been down for long-term accommodation for over ten years.

A few years ago our respite care began to reduce, not by our choice but because of blocked beds. We began missing some Tuesdays. Holiday care went down to 3 or 4 days and sometimes omitted one child. About a year ago, Anglesea St stopped taking Pinchas entirely. When I had a hip replacement this May, DADHC offered little supported accommodation. The boys went to Sunshine for my first 4 days, then Pinchas went to Bexley for the weekend and the other two to Doncaster for a week. This was only finalised the week before I went to hospital and I had to spend the last weekday before my admission making frantic phone calls because the out-of-area care was incompatible with Education Department taxi transport policies. While Pinchas was in Sunshine and Bexley, and Moishy in Sunshine, their drivers weren't allowed to deliver them to and from school.

DADHC had to supplement this with in-home care as I didn't get out of rehab till the following week (and still had a month of recuperation left.) It was quite a strain on my other kids who had to pick up the slack, especially my older daughter, who had to keep in regular touch with services to monitor her brothers' care. It only gets harder.

JP’s Story

JP is a man with an intellectual disability and psychiatric diagnosis who is aged 45 years. JP had always lived at home and his parents acted as full-time caregivers until late 2003. A deterioration in JP’s mental health resulted in admission to the local Psychiatric Unit. His parents determined they could no longer cope: both were unwell & having treatment for cancer.

DADHC was reluctant in the first instance to provide/supply or facilitate alternative supported accommodation. A family advocate negotiated and constructed temporary crisis care and interim funding arrangements. Since late 2003 JP has resided in temporary accommodation in a residential institution which is devolving residents into the community. He was confirmed as eligible for the Vacancy Management Program, but in the 24 months of temporary accommodation not a single suitable option has arisen within Western Sydney.

details supplied by Western Sydney NGO Disability Service Provider

LA's Story

LA, aged 39, has an intellectual disability as well as a psychiatric diagnosis (LA's mental health remains fragile). In 2003 LA suffered a serious mental health deterioration, resulting in admission to the local Psych Unit. Since 1985 LA had been in supported living arrangements (28 hrs support per week) with a non-government service provider. By August 2004 discharge planning with DADHC from the Psych Unit had failed to get started as a dispute arose over LA's predominant condition (intellectual vs. psychiatric disability).

An alternative non-government Disability service provider was requested by the Psych service to assist. Temporary placement for 6 months was offered in a residential institution which is devolving residents into the community. LA was processed as eligible for the Vacancy Management Program. The roll-over to the second 6 month *temporary* placement is due shortly. No suited vacancies have arisen to date. No interim funding was permitted by DADHC.

details supplied by Western Sydney NGO Disability Service Provider

BB's Story

BB is aged 45+ years and lives with his widowed Mother. BB was referred to brokered case management for assistance following the closure of a DADHC work setting (a sheltered workshop) and behavioural disturbances at home. BB is reportedly aggressive to his mother. The family are looking to secure permanent supported accommodation. BB is ineligible for DADHC Vacancy Management Program and was referred for support options to a non-government residential institution which is devolving residents into the community. BB still lives at home and is currently receiving planned respite at the residential institution. No funding assistance has been provided by DADHC.

details supplied by Western Sydney NGO Disability Service Provider

CTA’s Story

CTA is aged 30+ years and lives with his parents. His family are looking to secure supported accommodation for CTA’s future. CTA is not eligible under the Vacancy Management Program. He displays anti-social behaviours in his own neighbourhood, and police intervention has been required in the past. Despite his competencies he is unable to access appropriate support or accommodation. A personal referral to a non-government residential institution which is devolving residents into the community secured planned respite for CTA. No DADHC funding assistance has been provided.

details supplied by Western Sydney NGO Disability Service Provider

VP’s Story

VP, who is aged 48 years, was admitted to a Psych inpatient unit following an assault incident at home. A long-standing Psychiatric disorder accompanies VP’s intellectual disability. Discharge planning advised against VP’s return home to the care of his widowed father (who is aged over 80 and has congestive heart failure). DADHC was unable to assist with alternative accommodation. Brokered case management sought assistance from a non-government residential institution which is devolving residents into the community. VP’s transfer was effected to this non-government institution with full time accommodation trialled and temporary placement provided. The ‘temporary’ placement has lasted for over 24 months. No DADHC funding assistance was received.

details supplied by Western Sydney NGO Disability Service Provider

HP’s Story

HP is aged 30+ years and has been diagnosed with intellectual and psychiatric disabilities. HP lives at home and his family has requested assistance. DADHC registered HP as a client and funded behavioural support but then stopped providing this support. HP remains in bed till 12 noon and then retires at 10pm. He has no work/vocational placement or community support. Planned respite was arranged by a non-government residential institution which is devolving residents into the community. No DADHC funding assistance has been provided.

details supplied by Western Sydney NGO Disability Service Provider

TJ’s Story

TJ is aged 45+ years, has a moderate intellectual disability and lives with his disabled mother and sister (his sister is the main carer for both TJ and his mother).

An urgent request for assistance was received by a non-government residential institution which is devolving residents into the community via the Commonwealth Respite Centre. The institution provided planned respite, which has now been completed. Day support services and transport continue to be provided by the institution to maintain TJ’s links. No DADHC funding assistance has been provided.

details supplied by Western Sydney NGO Disability Service Provider

The Allen Family

My name is Lynette Allen; I am the mother and carer of a 27 year old young man named Dean. I have been caring for Dean since he developed epilepsy at 18 months of age.

Dean has been on a waiting list for accommodation since he was 8 years of age; the point of this was that at this particular time, one had to get in early. Dean’s situation was reviewed from time to time to ascertain if he was still looking to needing care in the future. His name was not on the bottom of the list, that is when there actually was a list. This was the way it was done, DOCS were supposedly aware of the young people with disabilities who were coming through the system and would be in need of accommodation in the future.

Dean went to Cromehurst SSP (High School) and was given some instruction in caring for himself (somewhat). He was given some instruction in becoming independent in the future as this was to be the way, many children were and we were led to believe this would happen. They were taught skills to assist them to be dependant. This has not happened. This is not an option for them or for us. They have lost many of these skills and have no opportunity to have a life. Neither do we as parents. We are to be carers of young adults with intellectual ages of young children, imagine looking after an 8 to 10 year old (with massive behaviour problems who is 6 foot 2 inches tall and weighs over 100 kilos and at times has a short temper) for your whole life! This is devastating and very often frightening to say the least.

High points and challenges include: Not challenging him and trying to let him do things on his own, low points include the fear of waiting to see if & when he comes home and not letting your imagination run away at all the horrid things that can happen to a naive impressionable gentle giant with epilepsy who just wants to have friends and to be independent. A typical day holds fear, anxiety, stress and hope. Dean thinks he is ten foot tall and indestructible. We have to put blinkers on at times, but it hurts a lot. Some of the local ‘gangs’ protect him, this is down to a local bad lad with a heart. Lucky huh?! He has been taken advantage of and both the bus companies and police have been involved both for and against him. How do we cope? We are lucky that we know how some of the systems work within the DADHC network, we have a Behavioural assistance person available to Dean. Yes this is amazing! They have saved Dean’s life many times (Really!) As Dean has walked on railway tracks, played chicken on the Pacific highway, hung over stairwells, lay down in the middle of the road and disappeared on the trains and buses for 20 odd hours at a time, (with no medication) we have had and are lucky enough to still get some assistance. DADHC have tried to stop this, but we are lucky that so far they have not succeeded. We also still have a case manager, but she is unable to do anything at all. I write letters to the government.

We do receive some Respite. The Respite managers & allocation people are very thoughtful of our situation and this is down to Dean’s needs / situation, as well as the staff and our relationship with them and also Dean’s love of being there. We try to be thoughtful of their needs and they of ours (when possible).

On a day to day basis, we try to cope; our stress levels are very high. But we would like to have a life, we would like our son to have a life. We all deserve this. We all pay taxes to assist the people in our community who need assistance: this is not happening. Disability is constantly overlooked. The State Government would like us all to lie down and give up. We can’t do this, our children have the right to a future and so do we, we want the best for them and they are not getting it.

The Weymans Family

My name is Leanne Weymans and I have a son, Jed, who has a profound physical and intellectual disability. Jed was born 3 months premature and survived what only could be described as a horrific 6 months in a Neonatal Intensive Care unit in Canberra Hospital, having to be revived numerous times as the full extent of his severe condition was not understood. Jed will never be able to walk (or even roll), communicate or recognise his family. His conditions include severe cerebral palsy (affecting all limbs and trunk); epilepsy; reflux; vision impairment; profound deafness; right infarct of the brain; 2 brain bleeds; chronic lung disease and very poor bowel function (due to cerebral palsy). What this means practically is Jed must be fed thickened fluids (to prevent aspiration into the lungs) with a bottle and fed pureed solids. He requires at least six medications a day, given up to three or more times a day. He rarely sleeps more than five hours at a time and I am often up at 3 or 4 am trying to put him back to sleep, usually unsuccessfully. During the day he must be re-positioned every 2 hours and fed every 3 to 4 hours. He requires regular enemas (due to poor bowel function) to avoid severe constipation. It is like caring for a 13 kg newborn baby with added extras.

Because Jed does have so many problems, I have no doubt that we could live in a hospital having everything investigated and operated on. It was after one of our first visits to the Sydney Children's Hospital, when the doctors started talking about a gastronomy -even though Jed could feed orally - that I realised enough was enough. He was never going to be a normal kid. We had to accept that. What we really want for Jed is to have him how he is and try and live as normal life as possible. To keep him as happy, comfortable and well and maintain our family life, not live a life of hospital visits, doctors and unrealistic expectations. So we decided to keep seeing the neurologist annually and only have absolutely necessary hospital admissions, no experiments or investigations. On a day to day level we keep up his physio and occupational therapy, which are available locally and visit the local GP when necessary. We make it a priority to put our relationship and family first rather than have Jed's illness define our lives. That may not sound right to some but it works for us.

My parents live close and are very capable and Jed has 2 respite carers (through the local council host family program) who provide occasional care for Jed. One lady takes Jed for 3 hours about 2 weeks of every month and Jed goes to another host family for one weekend a month.

Seeing a light at the end of this tunnel is hard, sometimes life is darker than any place than we could ever have imagined. The constant stress of having a child, with so many complications and conditions and death is never far from our minds, even though Jed may live for years.

Sometimes I feel as if I am living in a time warp of Jed's illness. That everything is going on around me and I just join in occasionally. Things have changed considerably since the birth of our daughter 20 months ago. She is healthy and we are enjoying her immensely. She is our sanity saviour at times. Jed hasn't been having as many seizures and is smiling and laughing which is great for us all. A big change from the 10 to 50 seizures per day he was having 18 months ago.

I now believe that you do not choose life, it chooses you. At times it can unleash a torrent so strong that you wonder if you will be able to cope. You wonder how you will face those that you love and tell the hardest truths you've ever had to face. You wonder how you will survive. The ironic thing is that you do. Somehow you learn to live with the stress, disappointment and grief that this sort of situation brings. We all have our battle scars we just chose to wear them differently.

Lastly, I'd like to say that we love our child. We give thanks for each day we get to share a smile or a cuddle. But our child is not one of those miracle babies that make frontpage news or that fill the feel good pages of women's magazines. His story is one of continuous trauma and battles for life, followed by a slow evolvement of his disabling conditions. I imagine that ours is a story that is occurring in many forms all over Australia, and the world.

Phillip Kearins Story

Hi my name is Phillip Kearins. I live at Junee. I am a disabled person. I have my right arm amputated at the shoulder also my right leg is missing above the knee. My family have suffered as much as I have as I suffer from chronic pain from the stump area of my right arm. I lost my mother last year. I still feel that she died from worrying about me and my pain as much as from her collapsed lung. I was married just after my accident but it only lasted 4 years: I put it down to my attitude from the accident. Apparently I took a long time to get over the accident but I feel if there was more help out there than I would still be married and not now living alone. I had a daughter from my marriage but when me and my wife split up I did not know where they went to. My brothers and my sisters still worry about me but I never tell them that at times I want to take my own life. I get very scared at times. I put that sort of feelings down to my loneliness. There definitely should be more help out there for disabled people. Maybe there is but I just don’t know how to find it.

The Strudwick Family

My 19 year old son Ryan was diagnosed as moderately intellectually delayed when he was a child.

There have been many hurdles to overcome throughout the ensuing yeas. Ryan cannot properly care for himself, he needs constant support in most areas, his social skills are very limited. He is trusting of all people with no concept of “stranger danger”, this coupled with his inability to comprehend the real value of his personal property including little or no understanding of the value of money leaves him open to exploitation by unscrupulous persons.

Due to our strong marriage we have survived these years where lesser relationships would have failed. We have never asked for supported accommodation as both my husband and I have been able to juggle our careers in such a way as to provide for Ryan’s needs, but since he left school last year the situation has deteriorated, the Community Participation Program Service Provider can only offer 3 days a week. Our quality of life has been adversely affected by this transition, our life is completely consumed by work and Ryan’s needs. If there was supported accommodation available to provide respite, our quality of life would be greatly enhanced.

What is to become of Ryan when we are no longer around to take care of him? When that day arrives will there be supported accommodation available for him?

We are more fortunate than some parents with disabled children as we can take care of our son at the present. Our greatest fear is that without supported accommodation who will look after Ryan when we no longer can.

The Schulz Family

Our daughter Cheralyn Anne Schulz was born on 30 November 1984. She suffered sever asphyxia at birth which has caused sever brain damage resulting in cerebral palsy. Cheralyn was born with a congenital left hip dislocation and he been in a wheelchair for the past 18 years with the other hip eventually dislocating itself. She has spastic quadriplegia affecting her right side, visual impairment, epilepsy and chronic asthma.

When Cheralyn was 2 years old I became very ill and desperately needed help. My case worker at the time arranged for Cheralyn to attend Allowah Children's Hospital for respite care. Allowah offered us respite for 3 weeks out of every month and so I was able to work, contribute to the economy and supplement the family income.

However, when Cheralyn turned 15 in 1999, Allowah could no longer provide respite care and so I was forced to give up work and devote myself to become Cheralyn's carer. This has continued up to the present time.

Cheralyn was attending Flintwood Day program 5 days a week which was proving to be highly beneficial to her well being. Cheralyn was a lot happier and content and it was great to see her smiling again which gave us peace of mind and helped to take some pressure off us. However, we have been dealt a traumatic blow by the government – Cheralyn's funding was cut in half and so she has been attending her day program for 5 days a fortnight for the last 5 months until an appeal for high support funding has given her an extra day a fortnight since mid September 2005.

Cheralyn has become very unsettled and frustrated that she is unable to attend her day program 5 days a week.

When Cheralyn turned 18 she was on the waiting list for three years before she received case management in July 2005 and she has been on the waiting list for a group home for the last 6 years.

I have recently had an x-ray which shows that I have arthritis on the right hip which is causing me a great deal of discomfort and a low lumbar tilt which causes me constant lower back pain. This has come about due to the constant lifting of Cheralyn from either the wheelchair or commode, or to and from the bed at night and in the morning. Cheralyn now weighs 45 kilos.

Over the past 20 years I was determined to cope and give Cheralyn the best care that I could give, to the detriment of my own failing health. I used medication to deter the normal course of nature so that I had the ability to care for Cheralyn's high support needs.

The culmination of Cheralyn's demands on me and my husband's failing health and my own has taken its toll and I have become emotionally and physically drained. My doctor has put me on anti-depressant medication.

My husband is 62 years old and has resigned from his full time job in July 2005 to take on the role of carer as well because he fears for my health.

I have probably failed to elicit all the difficulties facing Cheralyn, my husband and myself in the first instance, be that as it may, these represent our plight at present.

The Lawrence Family

We have been requesting supported accommodation for our son Wade for in excess of ten years. Wade is 29 years of age, has a severe intellectual disability and is totally dependant (toileting, feeding, dressing etc).

In the last ten years we have made countless representations to case workers, and various managers within the Newcastle office of DADHC, as well as three meetings with the Regional Director (the last being January this year) and a meeting with our local Member Mr. Mathew Morris (February this year).

We have been categorised by DADHC as a 'family in crisis' for in excess of five years. In addition I have it in writing from the Regional Director that he regards our situation as the highest priority in the Hunter.

In the period 2002-2004 we went through an extensive sequence of meetings and assessments with external consultants, DADHC and the Sunnyfield Association with a view to Sunnyfield setting up a house here (Newcastle) for our son and three other young males. We were under the impression that finalisation of the placement was imminent and then were told early this year it was a no go because of funding or the lack of it.

I am a Vietnam Veteran and am totally and permanently incapacitated as a result of a psychiatric condition. There are times when Wade’s safety is at risk as a result of my condition. All those mentioned in this letter have been made aware of this at least verbally as well as in most cases by supporting documentation from three different psychiatrists. I also have a copy of an email from the Regional Director(Hunter) sent to the two Deputy Directors at DADHC Head Office explaining this situation and expressing his frustration and concern at being unable to provide a solution due to funding.

As a family we cannot continue the way we are for much longer without some form of collapse.

The Carter Family

Our second son Nicholas is now 14 years old, is severely intellectually disabled, cannot speak or effectively communicate his needs, has episodic epilepsy which can strike him down at any time making it difficult to control by medication, he has challenging, aggressive and dangerous behaviours and weighs 70 kg. He is man-sized functioning at the level of a 2 year old. He will not live an independent life but his disability should not preclude him from living a happy one.

He is also delightful, he is healthy, loves to laugh, loves his family and his dog, Stellar. He can be so wonderful and yet so terrifying. The death of our dream of a "normal" family life was slow and inexorable. The future for us is filled with dread for what will happen to our little boy when we can no longer care for him or when we die, whichever comes first. To their great shame Federal and state governments have made no provision for him or for thousands of others like him throughout Australia.

In the aftermath of de-institutionalisation, the accommodation of those with mental illness and disability remains unaddressed and there is no succession plan for provision of care and housing of those with a dependent disability who are under the age of 65. A situation has arisen in which there are parents and family members in their 70s and 80s still caring for a family member with a dependent disability. All they want is to be able to die in peace knowing that their family member will be cared for. We can and must do better than this.

Those with a dependent disability have a right to be protected, care for and valued. Those who drive and make policy must not go down dead-ends. The future must be a collaborative approach. Parents and carers were shut out in the past and the "institutions of old" grew from that. Now’s the time for Australia to do something for those who can’t care for themselves, something that’s world’s best practice, something exciting, clever and innovative where at least in this area Australia can show its humanity and compassion.

The Posa Family

I have disability child, by Syndroma downi. He was born on 19 May 1982. in Croatia. My husband had worked here many, many years.

In my country I worked only for all family, because my husband couldn't because he had to kept our sick son. He had to change him, prepare food for him, fooding him, washed cloth for him etc.etc.

When beginning bad war we have been on the end of existence, because my pid was not inaff for family. My son went Mainsbrigdde scholl, and I couldn't work. We have to wait 10 years, that my child had got pension. When he finished Mainsbridge school, he gone in Carramarr post school options ATLAS 3 time of week. And now is problem that government doesn't like finance this school. My child like others go only 3 day of week there. He is very happy and he indeed enjoy play with another kids. I'm not and cannot be person for play of my son. He has to have his company, but government like doesn't finance this school. It does mean there is not hope for this child. I'm bad surprise, that government can't to give some money for keep this school, that and this disability child be happy one part of their poor life. In the case that they stay in home, this children will became very alone, without friends and happiness all their life. It is not any one chance for them. It is very great pain for parents. My boy is happy like others in this school.

Teacher is very understanding and they make program for this child. What is depends of childs level on intelligence. Everyone of government can ask himself or herself how it will be that they are sicks like this children. Please, in the name of good appel of government that they don't cut money for working this school. I believe, that they will not cut this school.

Another reason is that government save too much money, because we like parents keep this child all time, where they are not in the school. It is one very sorrow and disappointed story.

Please tell the our government this story about our childs. When is this kids I question, government to find money for them, if they cut little money from every-one.

I can tell you, that this case smell by discrimination of disability childs. How will new funding levels effect services to people with disabilities? Will PSO/ATLAS services close? What can parents and care providers do! Will my son or daughters service get cut by 50%?