



Making a Move

Produced through a partnership between Montagu Community Living, STAR Tasmania, and the Tasmanian Department of Health and Human Services.

Acknowledgements

Thank you to all of the families who shared their insights, experiences and knowledge to assist others.

The information in this booklet was prepared in April 2013, prior to DisabilityCare Australia coming into effect, for young people aged 15 to 24 from 1 July 2013 in Tasmania.

As DisabilityCare Australia commences, please refer to Montagu's and STAR's websites for updates to this booklet.

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About this Guide

Every individual has their own life to lead, their own potential, goals and dreams to achieve. We grow up, move out of home at different times, we explore, develop, learn and commence our adult life's journey, carving out a role for ourselves in the community. If you have a family member living with disability, you will know that for some people there will always be a need for ongoing support to achieve maximum independence and realise their full potential. Your family may have travelled a different, more difficult path than other families and you may now need to make some major decisions about the future support and accommodation options of your family member.

This Making a Move guide will:

- Provide information and advice from other families who have been through similar situations to yours, through sharing their stories.
- Provide a general overview of accommodation options in Tasmania, and the process to access them, often called referral.

The information in this guide is based on the experiences of families who have a family

member with a disability. You may find there is too much information in this booklet for you right now. You don't have to read it all at once, but you know you have information that you can refer to when the time is right for you.

The information in this booklet was prepared in April 2013, prior to DisabilityCare Australia coming into effect. From 1 July 2013 DisabilityCare Australia will be providing referral and assessment services for young people aged 15 to 25. For people younger or older than this, referral and assessment services are provided through the Gateway Service.

Please note - since the development of this book, and the time you are reading this, changes may have occurred. Please refer to the websites of Montagu Community Living and STAR for updates to this booklet.
www.mcl.org.au www.startas.org

Story one

of Making a Move

Life before supported accommodation

Our daughter moved into supported accommodation in September 2005, after a wait of about 5 ½ years. It had been an arduous journey to reach that point. We first acknowledged to Disability Services that we were not coping when she was 13 years old. For four years prior to this, we had been totally sleep deprived, and I suffered on and off from mild depression and anxiety. Our family life was totally chaotic and dysfunctional. I had given up work when she was 10 because of the sleep deprivation and chronic stress. I missed my work colleagues and the mental stimulation of a career. ***I felt isolated, sad and angry a lot of the time.***

We had been told by Disability Services that the wait for accommodation would probably be about five to six years but we found this hard to believe. However, they were right. During this time we did have our amount of respite increased and so we got used to the wait, knowing




somewhere off in the dim future, there was light at the end of the tunnel.

Preparing for supported accommodation

When I got the phone call from our Disability Service Coordinator, I spoke briefly to him, put down the phone, promptly burst into tears, and cried on and off for days.

For all of us, our other children included, ***it was a difficult, scary time.*** What if it didn't work? What if she hates living there? What if it makes her behaviour worse? How come other families cope? Who will cuddle and kiss and make her laugh at bedtime? Who will sleep with her if she is sick? Are we just weak and slack and need to try harder for longer? Is it too late to change our minds?



Those months were filled with guilt and anxiety. We were on edge constantly, irritable and sad and terrified of the decision we had made. But deep down we knew we had to go through the process and at least give it a try. The thought of the alternative, of not having a plan for her future, of her siblings having to care for her when we died or worse still, her being forced into care when she was much older after the last surviving parent was gone, was much, much worse.

Well-meaning friends and extended family members, trying to help us see the optimistic side of things, repeatedly told us it was just like the other kids leaving home. It was absolutely nothing like that. Unlike when the other kids moved out, we were racked with guilt and anxiety. We were totally convinced it was going to be disastrous.

However, we couldn't have been more wrong.

Making the move

The day of the move went well. There had been some meetings with staff and the other families and these had gone pretty smoothly too. It was a Saturday that she moved in; we had been encouraged to bring her furniture from her room

at home so that her new room would be familiar to her. As we left the house, I suppressed the feelings of sadness at her empty bedroom, the newness of the carpet where the bed had been. I was distracted by her repeated jabbings of the CD player in her efforts to tell me she didn't like that track. Usually I found this behaviour immensely annoying but that day I was glad of the distraction.

We unpacked and sorted clothes and books and CDs. The house manager was familiar to her from Respite and so were two of the staff. The staff member on duty that first night popped in to learn her bedtime routine from me.

She was caring and attentive and very responsive to our daughter and she reassured me she would read the three stories I had picked which would make the bedtime routine familiar. When we left the house at about 4 pm, our daughter was happy and didn't seem to care we were leaving her.

After the move

We rang several times that evening and the next morning and she was fine; how weird, it all seemed too good to be true! And ***she went on coping and being fine for years and years***

Story one

of Making a Move

and still is! We felt on edge for quite some time that it might not work, like we had won, been given some tremendous prize and maybe someone was going to take it away at any moment. But gradually we became more used to the fact that it was working; that we had a plan for her future; that we were going to be able to live a normal life now; that she would benefit from being independent from “us oldies” and that she was very happy and well looked after. We came to gradually accept that she now lived somewhere else and that it was her home and gradually that thought ceased to be sad for us.

Benefits to the family

All our hopes (tentative as they were) have been realised by the move: ***we have the spontaneity, peace and freedom now that we lacked for years.*** We have kept our emotional health intact (mine was teetering on breakage in the lead up to the move) and we have taken steps to plan for a healthier physical future. The move for our daughter, physically, emotionally and socially has been only positive.

None of our fears eventuated: would she be unhappy? Would the staff cope? Would they show irritation toward her? Would her

behaviour deteriorate? Would our guilt last forever? Would we have to bring her home?

Expectations of supported accommodation

We had huge expectations of staff at the outset. However, gradually we have learned to be flexible and realistic with these. We realise no one will ever look after her as we did, but have tried to come around to the thinking that different is not necessarily worse, that the change in support and care may have benefits: independence, increased skills, and more than anything a long-term plan for her future without us.

Staff met some of our expectations, some not. When the latter happened instead of getting on my high horse, I would try to work it out in my own head first by asking myself three questions: was I being realistic or just pig-headed; am I just hating giving up on the control; and, if I let it go, what might be the benefit to her?

Some of our expectations of staff were very realistic and we did not compromise on them. We expected them to give us time to give up on the control of her life. We expected empathy



for our anxiety in the beginning of whether it would work out okay for her long-term. We expected the acknowledgment that apart from people who have worked with her for a long time, we are the best and quickest source of knowledge about the nuances of her behaviour and attempts at communication. We expected that staff will not make assumptions about puzzling problem behaviour, without first discussing it with other staff and with us. We may have the clue from past experience that could solve the riddle.

We expect staff to greet her enthusiastically, stop what they are doing if possible and engage in “conversation” with her about her weekend, when we bring her back after a visit with us. This shows respect for her as an individual.

We expect her privacy to be respected and do not want staff to tittle tattle to us about her unless it is something that by not telling us, she would be at a disadvantage. In other words, don't do it unless it is absolutely necessary for her safety or wellbeing.

I expected to be asked to go to medical and other appointments. Some parents want to go to all of them. I am increasingly happy

to leave some of them. We have expected staff to let us let go gradually at our own pace.

However all of these expectations need to be voiced. Staff are not mind readers. Hopefully their training will cover some of them; but with all of the potential types of parenting and personality, with the variety of disabilities, it would be impossible for staff to know what all parents expect.

So we as parents need to clearly and politely express our expectations, making sure they are realistic and not coming just from a sense of sadness that we are giving up on the control over our child's life.

Benefits to the family member

To sum up, the move to supported accommodation for our daughter is the best decision we ever made. Why? Because now she has a fabulous, enriched, interesting life, there is a long-term, well thought-out plan for her future, and we can, because of the huge weight taken from us, now act as her parents rather than her carers.

Story two

of Making a Move

We are a family of four: me, my husband, and our two sons. When my son was born I thought he was absolutely perfect but we did soon start to wonder if something wasn't right. When I look back on baby photos I can see now he didn't look like a – and I hesitate to say this – “normal” baby; but as they say, “Love is blind”. Finally, after a run around of specialists and eight long, uncertain and stressful months of tests, the doctors had a diagnosis for my son. The Geneticist at the Royal Children's Hospital came in one morning to tell us that our son had an intellectual and physical disability due to a very rare syndrome. At the time, he was about the eighth person in the world diagnosed with this syndrome. ***We were told he would be a 'vegetable'.***

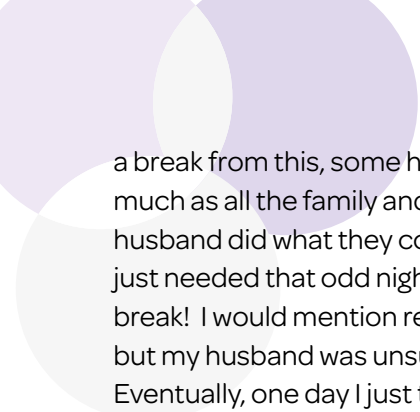
We were devastated.

It took me a while to come to grips with this information, and I think it took my husband a little longer and from then on I went out of my way to prove that doctor wrong!



Life before supported accommodation

Suddenly having someone with a disability in your family, when you have never had to deal with this before, is hard on you, your husband, and everyone else in your immediate family. I took six months maternity leave, and then I went back to work full time and my mum looked after him during the day. This was an incredibly hard time, as of course, when we were doing the circuit of specialists to get a diagnosis, I was also working full time. My husband was finding it a lot harder to come to terms with everything; he helped out if I asked, but I don't think he wanted to admit we had a huge problem here. When my son was around two or three years old I started to say I need



a break from this, some help, as much as all the family and my husband did what they could, I just needed that odd night or two break! I would mention respite but my husband was unsure. Eventually, one day I just turned up at respite and organised it. I went home and told my husband I had just organised our son to go to respite, he's going for the night next week – he didn't say a word. And from then we did send him for a weekend every few weeks.

Our first supported accommodation experience – not quite right

Our son was around 17 when Disability Services suggested to us that we should put his name on the list for supported accommodation. When I said I wasn't ready to do that, I was told I didn't need to be ready yet – this process could take years. I was also told we can also say no to any offer – that we would be able to hold out for the right option. So we did put his name down and it did take years. He was originally offered a placement and moved into a unit with three other men who were much older than him. Our son spent three months

there and the staff and majority of clients were great. However, ***he just wasn't happy; there were issues that I felt were too difficult to resolve.***

Finding the right supported accommodation

Around this time a placement came up with another service provider and we took the opportunity to transfer. It has been three years now and he has been very happy in his new home; whilst the first service were great, this just 'fit' better, particularly as my son is much closer in age to all his housemates. I think it was a great decision to have made.

Once he moved it was a great weight off my mind. I knew he was happy, looked after, and it was more than just a job to the people who cared for him! All the staff knew that they could call on me for anything, it didn't matter how big or small, I would help if I could. I was getting better with this thing of letting go, and knowing that someone else besides me could look after him.

The process of moving into a group home was daunting; there was a lot to take in, but Disability

Story two of Making a Move

Services and the service provider answered most of my questions and queries without me having to ask, and made the process of moving in a smooth one. Before he made the move to the house permanent, he had a couple of day visits, to see how he went. That was our only problem, because when he got there he didn't want to come back home – he wanted to stay! At the time I wasn't sure how to feel about this, to be upset that he didn't need me anymore, or happy that he was happy being there. I have come to realise it was the best thing we ever did.

After the move

For me, the best feeling was to know there were no restrictions on us seeing him when we needed or wanted to or ringing to check how he is. It took a lot for me as a mother to let someone else have the control over his wellbeing and life – but *it does get easier knowing they always have his best interest at heart* and we are informed, involved, and still a big part of his life and what he does. In spite of all that has happened, we wouldn't change a thing. We are a family; things happen, you

have to deal with them, we all love our son for who he is, and he has achieved a lot in his life so far, and now he has gone that next step in growing up and being independent; he has moved out. *He is the happiest he has ever been* and there is a lot less stress on the rest of the family knowing he can come home for a visit, but is just as happy to go back to his house.

Story three

of Making a Move

Life before supported accommodation



I had always thought my daughter would live with me for as long as she wanted to. My daughter's father and I had successfully shared parenting for eight years since our separation, however, once she turned 18 our family's ability to continue that shared parenting arrangement deteriorated. So I recommenced with the respite service in March 2011. We had previously used children's respite eight years earlier but had managed care within the family after that (until the shared parenting arrangement deteriorated). The Gateway [Services] was established about this time and a friend managing a group home told me about it.

I literally called the Gateway in to help – *I was desperate for support and quite burnt out.*

Working with the Gateway

I put my daughter's name on the Gateway accommodation waiting list as I knew I couldn't continue on alone and I was told it could take years to find her a place. My experience with the Gateway was positive. I worked with two Gateway Local Area Coordinators at different times, both of whom were supportive and empathetic without being judgemental. There were times when I felt I just couldn't cope and would call my Local Area Coordinator who usually had a plan of action or if not, at least I felt I had been heard. I found the Gateway very helpful in providing the information I needed, when I needed it. My daughter was on the waiting list for approximately one year, however, we had been accessing respite services for longer. I was absolutely blown away when I got the call to say she had been offered a place; I thought it would take years. I cannot stress strongly enough it was the best thing that could have happened in our lives right

Story three

of Making a Move

now, and I say that for us both. I believe ***the people involved in the placement meeting took great time and care*** to ensure that the individual personalities and needs of the residents at the house would be compatible.

Preparing to move

The transition to supported accommodation was quite straightforward. The house manager and staff seemed to understand what I was going through and arranged for us to meet the families of the other residents in the house. The staff seemed concerned that I may find it hard (I guess they have been through it before!). We started off with an introductory visit, then a meal, then an overnight, then a week's stay prior to the eventual move. At each step of the way I asked my daughter if it was what she wanted and explained in a way she could understand why we were going through this process. I had some initial feelings that I was abandoning her and that I was bowing to pressure put on me by others. I asked her dad to decorate the new room. I kept out of the way as I thought it would be

too emotional. ***On "the day" we kept it low key and just took a few things to the house*** – the thought of packed bags and boxes felt too final. My daughter can walk between the share house and my home.

After the move

Since April 2012 my daughter has started living in supported accommodation with three others. It is still early days for us but already my daughter is happy and revelling in her new-found independence. She is not as lonely. I have realised that my daughter needs to spread her wings too and have experiences in a different setting. As for me, I no longer refer to myself as a "carer". ***I no longer feel as depressed. I have booked a holiday. I have peace of mind*** that there is now a team (the support workers, the house manager and the organisation) who are learning about my daughter's rare medical condition and the requirements that go with it and that it is not just solely up to me anymore.

She is learning to ask for what she needs, do her own washing and other chores at the share house.



Advice to families

If I was giving advice to a family starting out on this journey I would tell them to remember that they are not 'giving up' or 'closing the door'. For me, the absolute best piece of advice I was given during this whole process was that ***I can stay involved; that my daughter could have "two homes" and that she could spend as much time with me as we both wanted. I could be her mum, not her carer.***

We are now about eight weeks after the move and my daughter and I have just returned from a long weekend away together. My daughter is proudly telling people that she has three homes (the share house, my house and her dad's). She said that everyone likes her spending time with them. She feels wanted and cared about. How great is that?

Story four of Making a Move

We started planning for our son's long term future when he was 13. ***It was always part of our plan for him to become more independent*** by the time he was 19 or 20. The process took seven years from 1998 to 2005. We joined a group of parents of children at Hazelwood. As a parent group, we actively sought out as much information as we could including information on all the service providers of accommodation at the time and decided one particular service met our needs more than others. We collaborated with this service provider to develop a business plan and as a group we approached the government for funding. We were successful in securing funding for staff, however, our parent group along with the service provider had to raise funds to build a semi-permanent respite centre. This came at a time when James was finishing up at Hobart College and his future day program options were very limited. One of us would have to give up work, which my husband did for a year. A

Story four of Making a Move



response. I wasn't sure we were ready for our son to go into full-time care; we were both fairly happy with how the semi-permanent respite was working for us as a family.

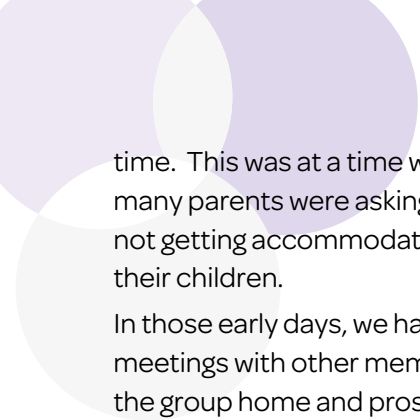
house was rented whilst a dream home was built and auctioned to raise money to build the respite centre. Our original parent group of four families extended to eight, which meant that our children would reside at the respite centre one week on and one week at home. This was the process we embarked on, but wasn't the one on which we settled. Whilst we were waiting for the semi-permanent respite centre to be built, our son was offered a placement in another supported accommodation service.

Before the move

When the permanent option was first offered to us, my husband and I differed in our initial

My husband was very keen to go one step further as he could see ***our son would have wider opportunities to develop his independence***. Our son was by now at the age when you would normally expect your children to be making a push for independence. I suppose I found it difficult to make the decision to allow other people have more responsibility for his care; I was just getting used to the semi-permanent arrangement!

After discussion between ourselves and with Disability Services we felt we had to take up the offer as we knew if we put it off we wouldn't be offered another place for quite some



time. This was at a time when many parents were asking for but not getting accommodation for their children.

In those early days, we had many meetings with other members of the group home and prospective residents' parents to discuss and work out how the model was going to operate. We were involved in decisions about his new home, what modifications had to be made and choices of furniture, curtains and decorations for his bedroom.

Challenges with supported accommodation

We have always felt welcome to be a part of our son's transition into full-time care, but things haven't always gone smoothly.

His behaviour was often 'unsettled' as he became used to his different circumstances. He had inter-related issues with his epilepsy, which gradually became more manageable after a lengthy trial of new medications over several years. This has involved a lot of communication and sharing of the responsibility of his health with his group home key worker and the service provider as a

whole. We wanted to remain in touch with his complex medical issues and we are still active in getting him to many of his appointments.

It was up to us how often he came home for visits. Every second weekend has worked well for the last six years, in addition to longer stays in holiday periods. I still like to have the responsibility of looking after him when he is really unwell or recovering from operations, for example wisdom teeth removal – I just can't stop being a mother!

There is a need to keep the communication channels open between the residential service provider, his day program providers and us as parents. Sometimes I think this is hard to maintain as it involves so many people and changes of staff often means there is breakdown in communication.

Our positive experience with supported accommodation

We think the process of our son living in supported accommodation has been generally a positive one for him. He still loves coming home of

Story four

of Making a Move

course but **he has broadened his social opportunities** more by living away from his parents. Our son is displaying small developments in his ability to do things for himself, especially *wanting* to do things for himself. He is also more willing to go out and about, whereas a few years ago he was extremely hard to get out the door. He has now enjoyed the opportunity to travel interstate with other housemates.

He has a slightly better understanding of what money, shopping and budgeting means and has developed his 'likes and dislikes'. He seems more assertive in some ways.

Family life after the move

Since he moved into supported accommodation, **our life is more settled and certain** knowing his future is guaranteed. We have been able to devote more time and energy to our other two boys as well as allowing us to go out more, develop our block of land and develop our own interests. The relationship between his brothers has been enhanced and his behaviour is easier to cope with when we know he is with us for shorter periods of time.

Advice to other families

Our advice to other families would be: don't sit back; **become active in finding all the necessary information**. Try and get together with other parents who have similar expectations of an accommodation service. Communicate your wishes to the service provider clearly and ask as many questions as you can about everything.

The Planning

Planning for the future support and accommodation needs of your family member with disability can be a difficult, confusing and emotional time. There are many reasons why families begin this journey, some of which may be similar to your own:

- Health issues for parents or carers
- The family member wants to live more independently
- The complexity and care needs associated with the family member's disability impacts on the ability to provide continuous care into the future
- Parents or carers are no longer able to provide for the family member's support needs
- Planning for the family member's future security
- Possible breakdown in marriage
- The needs of other siblings within the family are not being met
- Parents or carers want to give their family member the same opportunities as their peers

Finding the right support services for your family takes time, planning and persistence. Each

individual has their own unique support needs and the needs of families as a whole vary greatly, so there will be no one solution for all situations. The process can take time and so the earlier you can start to think about the future and start planning, the better.

Where to start?

It is important to make contact with either DisabilityCare Australia or the Gateway Service.

At the time of developing this booklet DisabilityCare Australia is for young people aged 15 to 24.

Gateway Service is for all other age groups.

DisabilityCare Australia

From 1 July 2013 DisabilityCare Australia will provide a fundamentally new approach to accessing supports and services for 15 to 24 year olds in Tasmania.

DisabilityCare Australia will be a wide entry gateway to disability supports and services and will operate from three offices – Hobart, Launceston & Devonport. DisabilityCare Australia will also have Local Area Coordinators outposted to all Gateway Services. A web site and 1800 number will be available for contact and will be widely advertised from June 2013.

Young people, their families or

carers who believe they may be eligible for DisabilityCare Australia services can use the 'My Access Checker' – a simple on-line eligibility check.

If you currently receive services, are waiting for services (on a Needs Register) or preparing to leave school then DisabilityCare Australia will be in touch with you. You may not be contacted immediately. There is a process, with people in the highest priority groups being contacted first (for example people in the Needs Register and school leavers).

Young people entering the scheme will develop a plan that details the reasonable and necessary supports and services that will help them to achieve their goals. Family members and/or carers play an important part in the planning process. The Planner will support young people coming into the scheme, their families and/or carers to exercise choice and control. Local Area Coordinators will be available to help connect eligible participants with the supports and providers of services to meet their plan. Participants in the scheme can choose how their plan is managed and who manages the plan.

Gateway Service

The Gateway Service is the single entry point to all family and specialist disability service programmes in each area of Tasmania – South East, South West, North and North West, apart from young people aged 15 – 24 from July 13.

A Gateway Intake Worker will guide you through a process to determine your eligibility. At this point, you may be assigned a Local Area Coordinator who will work with you and your family member towards securing the best accommodation option available. The Local Area Coordinator will assist you in making sense of all the information, options and service funding eligibility criteria you will be faced with.

If your family member has been assigned a Local Area Coordinator, maintain regular contact with them as they are your first point of contact in getting the support you require. Don't wait for someone to see if you are still waiting for an accommodation option or if your circumstances have changed. Your local Area Coordinator will be following processes in place to minimise the amount of times you are required to tell your story to various people.



Accommodation options

There are different types of accommodation options, some more appropriate to your family member's needs than others.

To assist in determining what accommodation option may best suit your family member, you may need to explore the following:

- Would they like to live with housemates, or do they want or need to live on their own?
- What level of support does your family member need on an ongoing basis?
- Do they need particular modifications in a home environment?
- Where are their personal networks – their family and friends?
- Where are their support networks – school, work, community access option, health professionals?
- What are the things that are important to continue in their life – for example, participation in a particular sport, hobby, church or club?

DisabilityCare Australia and the Gateway Service can assist you

to work through the options that would be most suitable. These options could include:

- **A group home**, which may be shared with other people with similar support needs. The support that a person requires is provided by a specialist disability service. On average there are between three and five people supported in the house.
- **Cluster units and hostels** tend to be more suitable for people with lower support needs as the staffing ratios (number of staff to number of clients) are lower and are aimed at providing more informal support arrangements.
- **A tenancy support model** provides services to individuals who wish to live independently in the community. This may be in a Housing Tasmania property or private rental accommodation.

How long is the process to get accommodation?

Finding the right accommodation is going to take time. At the time of going to print there are more families requiring support

than there are vacancies or funding available. Applications for funding and support are assessed by priority and allocated as funds become available.

However for young people aged 15 to 25 DisabilityCare Australia will not be restrained by priority allocation of funds, but initially at least may still be restrained by the number of supported accommodation providers and places. DisabilityCare Australia will start to do things in a new and different way and people may choose different options to those that have traditionally been available.

Seek as much information as you can from:

- **Gateway Service** – Your point of contact may be an Intake Worker or a Local Area Coordinator.
- **DisabilityCare Australia** – your point of contact will be the Planner who helps you to develop your plan and, if you choose to have one, the Local Area Coordinator who helps to link you with the supports and services identified in your plan.
- **Disability Accommodation services** – call them or check out their websites to learn as

much as you can about what is out there and what model of accommodation support may best suit your family member. Remember though, that at this point these organisations will only be able to tell you about themselves and not offer you support directly; all residential vacancies are filled by either the Gateway Service or DisabilityCare Australia using a formal vacancy filling process.

- **Families** who have experienced similar situations as yours – this can be an amazing source of information and support.
- **Disability Support services** that you have developed a relationship with such as Respite and Community Access Services.

A very important point to consider at this time is guardianship. Don't assume you are the legal guardian for a family member who is over the age of 18 years. Contact the Guardianship Board for information and advice to avoid difficulties down the track.

The Move

What to expect?

When the time comes and your family member is offered an accommodation option, you will need to get as much information as you can to help you make a decision as to whether this is the right opportunity for your family member. Take ownership of this process and don't be afraid to ask questions. You know your family member better than anyone else and you know what they will cope with best, but you also need to think about how the decision will affect you. Some questions you might like to ask:

- How long do I have to make a decision?
- Can I visit the accommodation option before I make a decision?
- Is this a permanent accommodation option?

About their staff:

- Who are the staff and what are their qualifications and experience?
- What are the staff/client ratios?

About their service:

- What social activities will my family member participate in?
- What does the service provider expect from me as a

family member?

- Who else will my family member live with?
- Will female staff look after my female family member for personal care?
- Will male staff look after my male family member for personal care?
- Will I be able to visit anytime I like?
- Will my family member be able to come home for visits?
- How will I know the service is addressing my family member's needs?
- How will I be involved in decisions about my family member?
- What is it going to cost my family member and me?
- Will I be able to attend medical appointments, or other meetings relevant to my family member?
- Can I choose the level of involvement I have in my family members life?
- How will my family member's money be managed?
- What do I need to put in place for my family member during the weekdays?

- Will my family member need a Community Access placement?

About the transition:

- Will there be a transition period, and if so, how long is the transition?
- Can the transition period be shortened or lengthened according to the needs of my family member?
- What will the transition period involve?
- What will happen if the transition period is not successful?
- What will happen if I do not like the option that is offered?

About the organisation:

- What is the service provider's background?
- Can the service provider provide me with policies and procedures particularly for Privacy and Confidentiality, Finances, Medication?
- What are the service provider's vision, mission and values?
- Who do I talk to within the organisation?
- What is the complaints/grievance procedure?

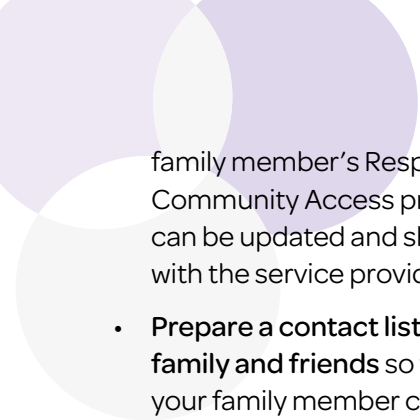
Going ahead with the decision

There will usually be a transition process leading up to a move into supported accommodation.

Transition processes will be planned according to the needs of your family member. The transition may involve meeting other residents, being invited to a social activity or to familiarise yourself with your new community.

The length of this transition period differs for each individual and can vary from days to months – so use this time to document and pass on as much information as you can to the service provider and to prepare for the move as much as you can. Here are some ideas:

- **Prepare written information about your family member** that will assist staff to understand who your family member is and what is important to them, for example, their likes, dislikes and their care and support needs. The more information you can provide the easier the transition will be. It will take time for the service provider to get to know your family member. It may be that your



family member's Respite or Community Access profile can be updated and shared with the service provider.

- **Prepare a contact list of family and friends** so that your family member can remain in contact. You might like to include birthdays and special occasions to be remembered so that the service provider can support your family member to remain as engaged with their family and friends as they have always been.
- **Make decisions about how you want to be involved** with your family member's life after they have moved, and discuss this with the service provider.
- **Talk with family and friends** who you know will be supportive – it is important to look after yourself as well as your family member. Don't underestimate the level of emotion and grief that comes with this very major life decision for your family.
- **Make a photo album for your family member to take with them**, or start writing a history supplemented with photos. This reinforces that your family member is an individual and has a valued role to play within your family. If this is shared with the service provider it helps to build up communication and relationships.
- **Find out the financial policy of your service provider** and what you can do to prepare for this.
- **Advise Centrelink** of all the changes to your family member's circumstances, including address and bank details to ensure they are receiving all the financial support they are entitled to.
- **Ensure your family member has a Companion Card** and their own Medicare Card, and if applicable, a Private Health Insurance Card, or Transport Access Card.
- Discuss with your service provider exactly **what personal furniture is required** and consider what furniture and personal items you will need to keep at home for when your family member comes to stay.

Life After the Move

- **Inform of any Manual Handling Equipment and Assistive Technology** – Your family member may require different equipment in a different environment.
- **Inform your family member's health professionals** about the upcoming move and their future involvement, for example their doctor, dentist and other health or service providers.
- **Consider respite as a transition option** for those family members that are not used to staying away from home.
- **Do something for yourself.** Think about activities you have not been able to do and make a commitment to give at least one of them a try in the future, and feel good about it.
- **Going to any activities** organised by your service provider to meet other families and staff. Ask for support if you feel uncomfortable going alone.
- **Familiarising yourself with the service provider's policies, procedures and guidelines.** This will help you understand how the staff are expected to work and it will also help you to communicate with them and give you some insight into what the service provider's informal expectations are of you.
- Discussing with the service provider what **Standards, Legislation and Regulations** the service provider must comply with. Having some insight into this will assist you in understanding how decisions are made and how support is provided.

When your family member settles into their new home there is still a long journey ahead. From now on your service provider will be a significant part of your life and your family member's life.

Your family's relationship with the service provider

To assist in developing a positive relationship you might like to consider:

- Discussing with the service provider **how much you want to be involved.** Sometimes a service provider may not want to stress you with problems, so communicate your expectations in a clear way.

Grief and Loss

Remember that even though you may have taken some time to make the decision and you may confidently believe it is the right decision, ***you may have an intense emotional response at any time*** that may take you by surprise.

A quote from a family member adds insight to this point:

"We knew about things like denial and anger but it took us many years to realise that the grieving process may start at any time and happen over and over each time something happened. It has a different impact depending on what has happened but the same process could start tomorrow if something happened at the group home over which we had no control."

Grief is a natural emotional reaction to any significant change and is not necessarily associated with the death of a loved one. The transition for your family member to supported accommodation may well trigger similar emotions due to:

- Your concern about the long term future of your family member.

- The sense of loss of the care and protection role that has been such an integral part of your relationship with your family member.
- The loss of the constant companionship that you have experienced during your family member's lifetime.
- The need to re-establish your identity, which has been linked to your family member with a disability for so many years. You may find that you have a large 'hole' in your life, and may need some help to find ways to fill the emptiness that you feel.
- The anticipation of a loss of involvement in your family member's life.

Don't try to ignore any feeling of grief and loss; seek support from your family and friends and professional help if needed.

Services and Contributors to this Guide

Montagu Community Living

Montagu Community Living is a community based organisation that provides Supported Accommodation and Individual Support Programmes for people with intellectual disabilities including multiple disabilities.

Phone 6278 7599

Email montagu@mcl.org.au

Web www.mcl.org.au

STAR Tasmania

STAR Tasmania is a specialised, community based organisation providing accommodation, in home and respite services for people with disabilities in Tasmania.

Phone 6244 9444

Email admin@startas.org

Web www.startas.org

Gateway Service

Gateway Service is funded by the Tasmanian Government to provide information and advice to individuals and families about disability services and other support services in Tasmania. Contacting Gateway Services can be the first step in accessing a number of Government

funded services such as respite, accommodation and individual funding. Gateway Services is hosted by Mission Australia or Bapcare, depending on which region of Tasmania you live.

Phone 1800 171 233

South East

Mission Australia

South West

Bapcare

North

Bapcare

North West

Mission Australia

