The
Homes West
Experience

Steps to Independent Living for Adults with a Disability

Compiled by Jill Hole from contributions made by Homes West families

homes west
ASSOCIATION INC.

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Acknowledgments

To Disability Services Queensland (DSQ)

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To the Community Resource Unit (CRU)

Homes West Association Inc thanks our colleagues at CRU for the ground-breaking work they did with the original families of Homes West to establish a new service. CRU continues to support Homes West to this day.

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Foreword

How Homes West began

Sixteen years ago, Homes West was no more than a dream in the minds of a few. Joan Hailstone and I were both parents of young people with a disability and deeply concerned about their futures. Joan had been my mentor and colleague for about six years prior to the establishment of Homes West. We formed a partnership to explore and conserve the knowledge and practices we had seen working effectively.

In the past, we had accepted traditional therapy, accommodation and respite services. We both accepted what was the norm in terms of services as we believed that something was better than nothing. By the end of the 1980s, Joan came to the realisation that enough was enough and if she wanted something better than nothing for her daughter Susan, she had to rally the support of like-minded people and do more. She decided to actively support her daughter Susan to create a lifestyle that was closely aligned in quality to that of Susan's three siblings. She knew that what Susan wanted was an ordinary quality life.

Joan knew from first-hand research that there were better options available than the local large service providers were offering. She was highly motivated to make change in terms of service provision for our own offspring and a small number of other local people with disabilities. She envisioned a small service in the western suburbs of Brisbane that would feature:

- support systems that reflected individual needs
- an accommodation model that reflected the preferred choices of consumers
- safeguards for the rights of each individual.

In 1990 Joan presented a submission of intent to the Community Resource Unit (CRU). This submission was accepted by CRU and a plan of action was developed in conjunction with CRU to present an alternate type of accommodation to a larger group of people and their families and friends. At the same time, Joan started networking and contacted me to discuss her plans and to seek my support in establishing a service in the western suburbs. I was immediately interested and keen to take on an active role.

Joan then called the first public meeting in the local school library. Her name was prominently highlighted on the posters we pinned up around the local shops and service centres. As Joan was a well-known local advocate for people with a disability, we were fairly sure that local parents of people with disabilities would recognise her name and if they were interested they would come to the meeting to hear what she had to say.

Deciding to hold a public meeting to share our ideas, hopes and dreams was very significant as neither of us had done this before. Right up until the evening of the meeting, we were unsure about the level of interest in creating a new and different service in the local community. The evening was a great success in that 40 people including people with a disability, parents, friends, community workers and professionals who had an interest in the area attended that night and from there the rest is history. I was proud to be Chair of the first steering committee and ultimately became Chairperson of Homes West for the first 11 years. Together this small group of family and community members worked hard to become incorporated and then to develop the vision of what Homes West would look like in the short and long term. Turning the vision into a reality is a story in itself but is the not the key focus of this book at this time. It is the story of the individuals linked to Homes West that is the key focus. However, many of the lifestyles may not have been of the calibre they are today without the Homes West vision and what that means in real terms.

The mission statement of Homes West Association Incorporated (Homes West) is to work with families to support people with a disability to establish and to live in a home of their own and to be included as active and valued members in their local community.

This statement is powerful in that it means that each person expects that they will live in a home of their own as opposed to a home shared with others, a bed in a house or hostel or living in the family home. It means that each person leads a unique, individualistic life focused on achieving their own hopes and dreams in the community of their choice.

So that it can remain personal, the service itself will always remain small and limited to 10 or 11 families with one coordinator overseeing the service to each individual.

The processes and expectations of achieving a home are closely aligned to what is usually achieved by our non-disabled sons and daughters. When they leave school, they expect they will eventually have meaningful work, a social life and interests around their specific likes and dislikes in their own community. They expect that they will eventually have a home that is of their choosing, friends and relationships that they choose and support from Mum and Dad when required.

To meet these expectations, Homes West adopted objectives. These were that Homes West would provide:

- The support needed for each individual with a disability to achieve a home of their own (this includes providing planning and coordination support, advocating for paid as well as unpaid support).
- A service that arranges this support and seeks out the best possible options for each person (this includes following up opportunities as defined by the person with a disability and their networks).
- A service that will support the person long term (because lifestyles change as people grow, develop and age).

- A service that consults with and involves families and friends who are seen as key players in the life of each person. They are expected to be key decision-makers and supporters in that person's life.

We have chosen to write this book to share our journey because we believe we have something to share that is still relevant. Joan and Margaret Ward (another Homes West family member and well-known advocate) continue to travel around the country talking to parents and service providers about Homes West. Last year Joan, Margaret and Jan Dyke (a freelance consultant and long-term supporter of Homes West) presented a series of workshops to parents interested in establishing an ordinary life for their adult son or daughter. As access to these workshops was limited, we devised this book to be an introduction to parents and carers of young adults with a disability who are about to leave school and enter the brave new world we call 'a quality adult life'.

Jill Hole

Founding Chairperson of Homes West Association Inc.

Why we wrote this book

We believe parents and carers are looking for an imaginative and constructive approach to the difficulties they face when their son or daughter firstly leaves school and then home. By writing this book, based on real life experiences, we hope to engender discussion between families and professionals about better service delivery in the future and maybe, if necessary, encourage other families to get together and establish a group that may eventuate in the birth of a new and innovative service suited to their time and their son's or daughter's circumstances and needs.

The content of this book originated from a time when a small group of parents started sharing their experiences with other parents who were also looking for quality services. They started by sharing ideas and options for action about service delivery with each other. They knew that there had to be a pathway to an inclusive lifestyle for their son or daughter and wanted to start exploring options. In the end, they decided to reject traditional services and joined together to establish a service to support their offspring for the long term. The service is known as Homes West. Homes West is a small community-based service established in the western suburbs of Brisbane. Today Homes West supports 12 individuals with a disability to live in homes of their own. Eleven of the people live in Housing Queensland units or homes.

The book aims to address three key points in times where a quality service is pivotal in an adult's life. They are:

- getting started
- living in the community - moving into a home of your own
- the next generation - when parents are no longer around.

The three sections provide information gained from real life experiences. We hope that by sharing our journey, we will contribute to the next generation's journey by smoothing the pathways in some small way.

CONTENTS

Foreword

Part One – Getting Started

Part Two – Living in the Community

Part Three – The Next Generation

Attachments

Part One:

Getting Started

Introduction

This section is an acknowledgment of the influential role that parents play in the adult lives of their sons and daughters with a disability. For many parents the reality remains that they are often the primary support for their son or daughter and their only advocates.

When a young person with a disability approaches adulthood or prepares to leave school, family members start searching for ideas and mechanisms for creating an exciting future for their son or daughter. The challenge is to align the ideas and available services to the needs and interests of that family member.

It is at this time that families can become very frustrated as they feel they must compromise the dreams and hopes they hold for their loved one's future. The main reason usually centres on the availability of services and paid support at that time. This comes as a great disappointment as they have fought many battles and worked hard to get their child through the education system only to find that it is time to start all over again now that this new journey into adulthood is about to begin.

To achieve the goal of a quality life, each family has had to change from the belief that the best life for their son or daughter is a safe life, best achieved by either keeping them at home each day (full-time family support) or accessing a large traditional service (with full-time paid support). They changed their way of thinking and supported their son or daughter to achieve a life that is as closely aligned to normal as possible. The families in Homes West, like all parents, want their son or daughter to lead interesting, contributing and meaningful lives. They acknowledge that there are risks associated with this and that each person will always be reliant on family support, friends and community networks to act as safeguards.

When asked to reflect on this time in their lives, each family related how when their son or daughter first left school they experienced triumphs, disappointments, a fear that things would not go well and adversities they did not plan for. However, every single family in Homes West agrees that their efforts in supporting their son or daughter to achieve an ordinary life have been worthwhile.

Something is not better than nothing

Parents of people with a disability are themselves at high risk of being marginalised and isolated from their community and the ordinary aspects of life whatever their age or background or the disability of their child. This exclusion can flow on to the child who in turn becomes an adult isolated from their community and an ordinary life. Parents carry the extra responsibility of care and finances way beyond what is expected of other families and it is these responsibilities that can be the initial contributing factors to marginalisation and isolation of both parent and the person with a disability.

Traditional options

Projecting into the future, a person with a disability can live a range of lifestyles. One option is a lifestyle whereby something *IS* better than nothing. When people with a disability have had no support or services and something finally becomes available, no matter how inappropriate, it is usually accepted. The user of the service tries to fit in with what is on offer.

The user of the service can:

- live at home with ageing parents
- live in institutional care
- live a group life in a residential care facility
- become a fringe dweller living alongside others in a home of their own or sharing with others sometimes in a hostel setting. They are most often unsupported in the community.

Another option is a lifestyle whereby a person with a disability can live in a home of their own and be an active participant in their own community

Each adult person has his or her personal vision of a desirable future and nobody really wants a lifestyle that is merely better than nothing. This is regardless of whether they have a disability or not. The key to the realisation of a vision of an ordinary life for a person with a disability and high support needs is for significant others to look for ways to discover each person's desirable future. They need the mechanisms to make that vision a reality so that they can be an active contributing member of our society, eventually live in a home of their own and be respected participants in their community.

What parents in Homes West have found is that by focusing initially on one goal (namely that their son or daughter has as much right to community experiences and acceptance as their brothers and sisters), they have been able to accept each family member as a young adult rather than as a 'forever child' whose disability requires them to be sheltered within the family throughout their adulthood. By accepting that each person has a right to and a need for a place in the community, they have personally gained the strength and determination to speak out for those rights and needs and to question why they are not yet fulfilled and to positively seek ways to achieve a more ordinary lifestyle.

As we know, time waits for no man, so the time for families and friends to plan for their loved one is now!! This is particularly important when the person with a disability is about to change their lifestyle. A good time to start is when a young person makes the change from being a student to becoming a young adult ready to experience life outside the school yard. However, the general feeling is that it is never too late to start.

Parents know in their hearts that it is not a good idea to accept mediocrity. Many parents have previously fought long and hard to access inclusive, quality education programs. However, when a young person with high support needs leaves school, many families are once again faced with:

- poor alternatives for service support
- minimum information about inclusion in the community.

Parents are faced with some interesting alternatives. These include accepting that their child may become institutionalised, become part of what appears to be a circus act; another is to go it alone and become a one-man show; or they can choose the inclusive person-centred model that many Homes West families have adopted.

A circus act

To this day, parents of people with disabilities often see themselves as the passive receivers of helping services. They are often in the situation of having to plot a path through a maze of services including respite, supported employment, recreation and voluntary work. Different services provide a number of hours a week but the support is defined by the service. The remaining hours in the week are usually picked up by the parents. This means that the support overall is not well coordinated and is not tailored to suit individual needs. Parents are constantly juggling the mismatch of services with the needs of their son or daughter. They become parents who are also part time jugglers and agitators.

Or:

A one-man show

Many families find the whole situation too difficult to manage and choose to go it alone and provide the service to support their family member themselves. They may choose just one support agency to work with for a limited number of hours per week. They in turn become parent and service provider – a one-man show.

Or:

A new way

The families at Homes West see themselves firstly as parents, then vision-makers, networkers, advocates and supporters of their son or daughter. As each family's situation is unique, they know that there are no role models. As in all situations, some families cope better than others, sometimes they are overwhelmed by their situation, sometimes they are drawn together and at other times they are split apart around a decision. They all try to find their way through as best they can. It is important to know that not all families in Homes West chose the Homes West alternative initially when their son or daughter left school, and they acknowledge that the path towards a quality life was more difficult to achieve as a result. However, no matter at what point in time the families got started, they all have been through this process in many different ways.

The Homes West Alternative

Seeking information
Defining the vision
Stepping Stones to achieve the vision
Examining what it means for you
Developing and implementing the plan
Stepping Stones to implementation
Seeking funding
Stepping Stones to funding
What Matt achieved

The Homes West Alternative

Seeking Information

There are many difficulties in trying to find out what young people really want in life. Families do know, however, that their son or daughter has a right to be included in their community. The dilemma is how to achieve an inclusive life.

What many parents in Homes West looked for was an overview of what a current inclusive adult life looked like. Remember, most parents were young adults a long time ago and time passes. Many families looked to their older children and cousins for ideas; others looked at scenarios of what life is like for young people today. Information held by a person with a disability and the family of that person is vital to developing a vision for a quality life and combined with ideas gathered from others' experiences can be useful. The following extract is just one piece of information accessed as a starting point by some Homes West families.

In April 2001, Queensland Parents of People with a Disability (QPPD) held a workshop to discuss Politics Partnerships and Personalised Responses. At this workshop, family members and people with a disability identified what an adult life is about and reaffirmed the need for adults with disabilities to get a real life. They acknowledged the need to support their aspirations as adults and to develop their own identity and sense of wellbeing. They highlighted where adults with disabilities were seen to belong: at home, in local neighbourhoods and in the goings on of wider community life. The relationships and commitments of significant people such as family and friends were identified as being of great importance to having a decent life, because it is from these people that the person with a disability acquires their sense of who they are, gains enjoyment and develops intimacy. It was also acknowledged that being known and having significant relationships with others was one of the greatest safeguards for minimising the vulnerability of people who had very high support needs.

The opportunity to play out typical roles that are valued in adulthood was stressed with opportunities to participate and contribute in a variety of contexts, at home, work and leisure and in other community pursuits. Meeting everyday personal support needs, personal mobility, housing and economic security were agreed as fundamental entitlements of any citizen.

The families in Homes West know that relationships, friendships and lifestyle interests, work opportunities and living arrangements will NOT be automatically produced. They know that it is a lifelong process evolving over time. They know that creating an ordinary life with a person with a disability means seizing opportunities whenever and wherever they occur.

Joan's Story

(Joan is Susan's mother and is one of the founding members of Homes West.)

We have no problem using the word 'struggle' for struggle we still do, especially in the area of finding and identifying with our daughter those experiences and opportunities that are meaningful and worthwhile to her life. I agree with the statement 'there are no shortcuts to a typical, ordinary real life.' As a child, Susan lived in the community and yet her adult life, unlike the lives of her sister and brothers, was not opening out but closing in on her. As our other adult children developed many casual acquaintances, some close friendships and relationships and networks with other members of the community, married and had children of their own, Susan's life was becoming more isolated. We knew it, Susan lived it, but nothing began to change until we decided the most valuable contribution that we could make (besides loving her) was to mobilise ourselves and others to help her make real changes to her lifestyle. We had to look realistically at the risks this process might bring for Susan, but we also knew that she didn't want to go on as a fringe dweller, watching others fulfil their everyday expectations but never really belonging to a wider group of society.

What is the community that most of us are a part of? What's good about it, what's bad about it, is it some place where nothing goes wrong, no one ever makes mistakes and has to start again, where there is no pain and suffering or struggle? Of course not, but with all its failings, it's still where most ordinary people choose to live and they live with the known and the unknowns of society where sometimes we think everybody else, except a few of us, are in pretty bad shape. For Susan and with Susan we took the risks, put in place all the safeguards we could and then took every opportunity that came along to keep her everyday life going.

Defining the vision

While opinions vary on how a person with a disability should live, families usually have an innate sense of what will be the best for their son or daughter. This comes from their extensive knowledge of the person and how day-to-day life works for that person compared with their other children. Often, a family's vision for the future is deflated by constant rejection and the limitations of services. This leads to justifiable frustration, anger and grief.

A useful place to start is for the family to identify what they *don't* want. This information acts as a springboard into a better understanding of what they *do* want. And when families are given the chance to see people with a disability leading a full and ordinary life, they can rediscover their original expectations, hopes and vision.

Every family will take a different way forward. Families and the person with the disability need to take their own time. Outsiders will never understand the complexity of relationships, history and unresolved issues that need to be confronted. Families learn in different ways. Some read, while others need to visit and experience things first-hand. Whatever way, families need to find their original hope and plan for their son or daughter and believe that it will happen.

Sometimes a mantra or mission statement is helpful to keep focused. One family said they wanted their daughter to be a 'valued citizen in her local community'. This aim kept them on the path for 20 years. Now an adult, she has her own home, a job and is well-known and accepted by the local community.

Having a vision for what is possible is not enough. This would reduce it to a wish or a hope. A vision is a clear-sighted, person-centred and determined statement of purpose that requires hard work. It can be buffeted by derision from those who are comfortable with the status quo and a realisation that the role of the family - and those who take up your role when you are gone - is never ending. Two keys to success when developing a clear vision include:

Be clear about what you believe

Most families want their son or daughter to have an enriched and full life. However, they may have reached the conclusion that his or her current limited existence is all that can be expected.

This is understandable as most of the general community have limited expectations as well. Not all families want to challenge the status quo.

For a person with a disability to have a rich and full life surrounded by friends and family, everyone involved has to have an unswerving belief that it can happen. If families don't really believe it is possible, this is the time to admit it and not deter others who do believe that such a future is possible.

Be clear about any conflict of interest

Families do well to be sure about what drives them. They need to be sure that their plan is designed truly to meet the needs of their son or daughter – i.e. a full and active life - and not their own needs i.e. 'I need him or her to be safe for ever so I don't have to worry any more.'

Family members may need to be challenged and encouraged by people they trust so they can overcome their personal fears and confusion to focus on a good future for their son or daughter.

Stepping Stones to achieve the vision

Having no available established service can be helpful

Many people complain about the lack of services. The traditional services that do exist are unlikely to meet the individual needs of your family member and efforts to change such services are likely to be unsuccessful. Many families have wasted years waiting for services to improve, meanwhile accepting poor treatment. Having no service available (while not the best option) gives you a 'clean slate'.

Start with the individual

Whether you are alone or with others, it is critical to start at the beginning – with the person. For example, parents may be offered a place in a service in another location. Although tempting if you are tired and desperate, these decisions will compromise your family members hopes and dreams for a life that is truly his or hers.

Gather like minds around you

There is power and safety in numbers and plans are likely to be more robust and lasting if there are a number of you to take them forward. If you must do it alone, keep in touch with others who have gone ahead of you.

There is significant generosity amongst the smaller service organisations and others will be willing to share their expertise and experience. There is little advantage in re-inventing the wheel where the work has been done before.

Take the time to clarify what you believe and want

What you cannot copy is a commitment to a common set of principles and ideals. Other people can share theirs with you but the group around the person with a disability will benefit from coming to their own position and understanding fully how and why they got there.

This understanding will be tested as the group is asked to change and compromise to meet other people's agendas and funding guidelines. The pressures are immense and the best intentions can be corrupted by thoughtless decisions. Homes West families have benefited by not succumbing to pressures to compromise their vision.

Get the best advice available

Families need no longer be isolated from gaining the best advice in the world. Phone calls, the Internet, written materials and even overseas travel is very accessible. There is little excuse not to find out where people in similar circumstances have taken good action over a considerable period of time. Usually they are very willing to assist.

Ask existing traditional services to change

To ask a traditional service to respond to individual need, work closely with families and informal networks and to change with the person is a very big challenge. The larger the service, the more difficult it appears to be. When asked by families to change, traditional services are likely to respond by:

- telling you they are already delivering a 'family-governed, person-centred service'
- asking you to join a committee or advisory group to assist them to consider your request
- ignoring you
- labelling you as a trouble-maker.

These responses can divert you from your real purpose and waste your time. However, occasionally a traditional service will release funds from established programs to try something more flexible to meet the needs of an individual and his or her family. Even if new monies are available, the pressures to revert to existing service practices are considerable, particularly if the existing bureaucracy is required to administer it. Nevertheless, traditional services have been known to support a 'demonstration' or 'pilot' service. This can be a good opportunity, especially if it can become independently managed at a later date.

Examining what it means for you

Be aware that good intentions need to be followed by action. The responsibility for this action commonly falls on a few shoulders and often on the people whose situation is the most difficult and urgent. This is why they are more willing to step out and take action, regardless of the consequences.

Commitment to be there for the 'long haul' is essential. You will need to have such commitment to your vision that you are able to pick yourself up time and time again. The few of you who are the stayers will remain a few until you have some visible success, and then you will be popular and others will want to join you.

Never-ending work

The horizon that you strive for will disappear as soon as you get there. There will be another horizon in its place. Initially, some Homes West families focused on 'a home of your own' others focused on 'moving ahead' after school was finished. It all depended on the age of the person with a disability. However, once whatever they set out to achieve was achieved, it was obvious that that was the starting point not the finish. This is never-ending work. It required a change in thinking for those families who thought their work was done once they found a good arrangement for their son or daughter.

Celebrate and lighten up

This is why it is important to celebrate the achievements, no matter how small and insignificant they are in the big vision. If you don't, nobody else will. Besides, change is hard work and everyone needs to lighten up occasionally.

What you can do now

Be clear about your natural authority as a loving family member – stick Michael Kendrick's article 'The Natural Authority of Families' on your fridge.

Clarify what you believe constitutes a good life for your son or daughter. This may take some time and effort to break away from the limits you presently have been given.

Share your thoughts and concerns with your partner. If he or she isn't ready to take action, check that he/she will support you and won't undermine you.

Tell the service (if you have one) how you feel and what changes you want. You may be blessed with a commitment to change, however be prepared for a lukewarm and even negative response.

Be clear and confident that your request is reasonable. Be tenacious. It is likely you will have to persevere over a considerable length of time.

Talk to everyone who is interested in your ideas – this is how you will find people who can guide and help you.

Be ready for hard work. However, it will be less than the energy wasted on fear and anger you are likely to be expending now.

Join with other like-minded people (maybe at your child's school) to share ideas and get started.

Developing and implementing the plan

Once the vision is established, each person with a disability, with the support of their family and friends, can develop plans on a regular basis. Reflection and review are key components of this process. Each family in Homes West gathers information, knowledge and skills and then plans with the family member with a disability. They believe that alongside friends and community members, they are best empowered to support their son or daughter to achieve their vision for a desirable future. The person with a disability and/or the family identifies like minds and invites them to participate in planning sessions.

In the initial stages at Homes West, most of the planning sessions were facilitated by a paid consultant. The families paid for the facilitation or if they knew a facilitator they asked that person to volunteer their services. Many of the initial visioning group members have gone on to become members of a wider network that supports the person with a disability for the long term.

From this plan, the person with a disability and/or their family and to a lesser degree, the group, then identified the type of service the person needed in the initial stages. This initial plan set the scene for future planning and review. Homes West families are now clear about what they want for their sons and daughters with a disability as far as a service provision is concerned. The hallmarks of their vision for a good service are:

- family governed
- person centred
- respectful relationships
- personal consequences.

The key challenges that families continue to highlight are that problems keep arising and that new challenges present themselves. They also state that satisfaction is often fleeting and that the work never ends. One of the most valuable supports in the implementation phase is to have a group made up of family, friends and maybe a member of the community ready and willing to participate in the process.

Jill's story

(Jill is Matt's mother and the founding Chairperson of Homes West.)

Our first planning session was facilitated by Matt's caseworker at Disability Services Queensland. The family and the caseworker pre-planned the day together and the meeting was held at our home. We took the time to clarify with the facilitator what we wanted to achieve by the end of the day and we spent considerable time identifying the participants' strengths. We invited people who had worked with or had seen Matt in a variety of different settings and we also invited family and friends. The initial planning group consisted of Matt's teacher, a young student teacher (not much older than Matt), his work experience partner, two family friends who knew Matt well, my parents and our family. By the end of the day, we had some good ideas about what Matt's life could look like in the future as well as suggestions to follow up as a starting point to enacting the vision. When I think back to that original plan, we did a really good job that day! The hard work was enacting the plan and making the dream a reality.

Stepping Stones to implementation

Call on your friends

Having friends in a person's life who can give support, advice and friendship without payment because they are interested in his or her welfare, or simply enjoy his or her company is a great asset when considering a young person's future. Friends can be people the family have known for years and are interested in his or her wellbeing or they can be recent acquaintances. A family's son or daughter with a disability is likely to have a few friendships although they are more often limited - particularly if the person spends a lot of time in segregated service settings i.e. a Special School in another suburb.

Sharing the vision and plans for the future with friends can assist them to understand what your challenges are. Many families find calling on friends difficult as it goes against a strong desire for independence and self-reliance. However, when more people are involved, more ideas are available to solve problems and find a way forward. 'Four or six minds are better than one or two!'

The more people, who are freely willing to become involved, knowledgeable and useful throughout a person's life the more support you have around you when it comes to problem solving and spending time with the young person.

Sally's Story

(Sally is Sarah's mother and works for a parent advocacy organisation.)

One day, a day that will be forever burned in my mind, I was fortunate enough to attend a forum where a woman spoke about the life of her daughter who had severe disabilities. She had her own home, she had people around her who liked her and wanted to be in her life. How easy was that?

I thought about it for a while. There were no people, to my knowledge, with Sarah's complex needs living in their own home. Sarah needed 24-hour care.

Two years later there was a Criminal Justice Commission Inquiry into the abuses at the Basil Stafford Institution where Sarah lived and I knew I had to do something. That's when my circle of friends started and we began planning for Sarah to move into her own home. Eventually Sarah got her own circle of friends and they are more than happy to spend time with Sarah, problem solve on her behalf and make useful suggestions to family and workers.

Some common indicators of friendship and who will make good friends include whether they:

- are honest, reliable and have a strong sense of right and wrong
- know the family well and support the vision the family has for their family member
- have worked for the person and on leaving the paid position maintain ongoing contact
- have grown up with the person and remember him/her as a child and have a shared history
- initially make contact because it is the right thing to do and then find the person has much to offer them

- are settled and confident of their position in the community.

Rarely do friendships last if people offer friendship:

- in a hurry
- from a sense of duty
- as a means to an end (say, to get employment, to make money or as part of their studies)
- when they have no community network or good friendships themselves.

Seeking funding

Having some funding support before your son or daughter leaves school is always an advantage. Many of the people with a disability who access Homes West have high level needs and as a result their families had access to some respite care hours. It was these hours that were most often used to support the implementation of the early plans developed with and for most of the members of Homes West. The younger adults in Homes West were fortunate in that they could access Moving Ahead funds and in recent times some have also gone on to access Family Support funding. However, most families at one time or another have saved or accessed funds from a variety of other different sources (pension, other services, family funds, Community Benefits funding, non-recurrent funding) to achieve a certain goal.

It is interesting to note that the reason why Homes West was established in the first place was because there were no services flexible enough to allow families to support their son or daughter to achieve an ordinary life of their own choosing. More importantly, this included moving into a home of their own in the community of their choice. Established services were limited in their ability to set up networks, supports and opportunities that would enable the person with a disability to experience a lifestyle of their own choosing, even before it was time to leave the family home. The outcome was that Homes West was established to fill a gap in services. It did not receive any recurrent funding for the first four years, but it was a vehicle for parents to use to lobby for one-off funding and project work so that they could get started.

Stepping Stones to funding

Have a written plan that includes a vision statement and a business plan

In those instances where accessing the workforce was a distinct possibility, Homes West families found it was a good idea to write a plan and present it to the various agencies that support young people with disabilities. The plan is helpful when seeking paid support so that attending TAFE can become a possibility. It is also helpful so that sport and recreational services can see the need and then work out mechanisms to provide a service. Always include statements about what qualities you are seeking in a support worker.

Identify a service that will advocate for funding with you or on your behalf

In the initial period it may be that the school, local community services, respite care services will be in the best position to identify funding sources and opportunities. However, Disability Services Queensland staff have been most helpful in supporting Homes West families to access funding over the years. It is up to parents/families to make their case known to funding bodies and services.

Approach a known service

It is often surprising how one individual can make a difference. Many service providers enjoy a challenge and are receptive to promoting new and innovative ideas. Remember! If you do not ask, no one will even know what it is you require and as a result you will have no chance of getting the support you need for your son or daughter.

Establish a new service

This is not as difficult as you think. One person in Homes West had an idea and she shared it with a few others. Once the group was formed, it was then a matter of forming a committee and generating the necessary expertise or knowledge. All this had been done before and other small organisations shared their paperwork and past experiences and incorporation was relatively easy to achieve. We did it – you can too! For the purposes of accountability and issues around personal liability it is advantageous to become an incorporated body as soon as possible.

What Matt achieved by getting started as soon as possible

Introducing Matt

Matt is 27 years old and up until this year he lived with his family. He has always loved being driven in motor vehicles. Matt has a photographic memory for road routes. He also enjoys moving objects from one place to another. He cannot speak and therefore he has limited means of communicating with others. This is a constant source of frustration for him. Matt has always had very high support needs.

Matt's story about leaving school as told by Jill

Matt was 18 when he left school and he was ready for a change. For the two years prior to his leaving school and leading up to 'moving ahead' we worked hard with teachers and friends to identify and/or establish what work options, recreational/fitness activities, social opportunities, friendships, church, community services, paid and unpaid support were best suited to Matt's vision.

By the time Matt left school he had been through a work experience program where he 'worked' alongside couriers as their off-sider. I set up this program through the school in his final year. I spent some of Matt's pension employing a young woman a few hours a week to arrange the two work experience opportunities. She also visited all the stakeholders - school, family and friends - to gather more ideas and opinions about what Matt's life could look like in the near future. Her visits to their homes and workplaces were also instrumental in giving our friends and family members an opportunity to volunteer with the work at hand. This was something they told her they had always wanted to do, but had hesitated because we seemed to manage so well.

As a result these friends went on to help us to identify social activities that Matt might like to pursue and some of them even took him to test them out. These friends have continued to take Matt out bushwalking, visiting, celebrating and socialising for the past nine years.

It was about this time that we also realised Matt had a few young friends he had grown close to over the years. We developed a visiting plan with their parents to ensure these friendships did not fall by the wayside. It was difficult in the beginning but I am pleased I persevered as Matt still visits one friend every Friday night and he has lunch with another once a month. He sees another mate at birthdays, Christmas and celebrations.

As far as Matt's spiritual life is concerned we are fortunate in that two of our best friends are dedicated church-goers. They were extremely committed to Matt making his First Communion and when they achieved this it was a day of great celebration. Mary, one of Matt's staunchest supporters, continues to take Matt to church every Saturday night. He is also the longest surviving member of the healing group at our local church – the power of prayer!!

As we had lived in the same suburb for nearly 20 years at the time when Matt left school, it was relatively easy for us to identify and consolidate on the community connections we had made at the local shops, barber, bank, doctors and dentists. They all remembered Matt from when he was a baby. We made a point of letting all these good folk know that Matt was leaving school and that they were now Matt's service providers as well as ours. Most were extremely pleased to hear that Matt was about to leave school and understood that Matt would sometimes be accompanied by people other than us and that if he were at the shops he was there as a customer in his own right.

When Matt first left school, we were fortunate he received funding from a variety of sources. As a result we were able to have a paid worker for some of the week. That worker eventually became Matt's driver when he first set out to do deliveries in his new van. The van was partly funded through a government grant and partly funded by donations. It is owned by Homes West.

Today Matt helps out delivering organic fruit and vegetables part time. This is his third job in nine years as a courier's off-sider. His support worker is the driver of the van. Despite an array of disabilities and complex medical conditions, Matt enjoys life to the full and lives in his own unit in a suburb close to home. He has support workers and volunteers to support him at his home and in the community. He is so busy that we sometimes feel we need to make an appointment to see him – typical of many young folk today!

Part Two:

Living in the Community

Introduction

This section contains a story that is not finished and we sincerely hope that it never is finished – that it will continue to be a 'voyage of discovery'. The story is about how 12 young people with disabilities have come to live in homes of their own in their own community supported by family, friends, volunteers and a flexible support service.

In the main these people and their families had some experience of traditional services and rejected what was on offer. Broadly speaking, they are a group of people who came together and set up a small service that would meet their diverse needs and enable them to direct their own support arrangements with and for their sons or daughters. What they wanted was the opportunity to choose the most appropriate support arrangements for themselves or their family members.

A bed in a house is not a home

When a child grows into an adult, very few parents seriously question whether or not their son or daughter will move away from the parental home. They believe that one day (eventually) the time will come and their child or children will move out. When their children do finally move out, it is considered part of the usual process of growing up. However, when that adult has a disability, the option to move into a home of their own is often not there at all.

Even when an adult with a disability moves away from their parental home, their options can still be severely limited. Of those adults with disabilities who do move from their parental home, many move into institutions, homes or hostels specifically for people with disabilities. In this group are the people most likely to be in need of some form of support in the form of paid workers. When an adult with a disability has need for support to live in a home of their own, their options for community-based housing and support are very limited. Traditional services catering for housing and accommodation support have segregated people from their families and communities rather than support the family to maintain the links and include them as neighbours and citizens. People who have services dominating their lives are in danger of losing connections with family, friends and others who would give freely their time, energy and commitment. The larger and more traditional the service the more likely it is that this will happen.

What is needed is a flexible service willing to work alongside families to support their son or daughter to live in a home of their own in their own community. Finding a service willing to work alongside a family means that each person wanting to move into a home of their own is more likely to move into typical housing and have the assistance they need to move in, to be involved in daily home life and to become part of the community of their choice. Parents know that each person needs assistance to be connected within their community so that they can develop friendships and possibilities for widening their life experiences. They want their own son or daughter to lead a respected and valued life. However they know from past experience that they need a service flexible enough to provide individualised supports.

As there was no service of that nature when the families of Homes West were looking for support, they joined together to form a group and Homes West was established in 1990. It continues to be a family driven, non-profit organisation that provides accommodation support to 12 adults with significant disabilities from the ages of 26 to 55.

The families of Homes West Association Incorporated know that their sons and daughters want a home that is much more than just a bed in a house. They are convinced that:

- People with disability are entitled to a lifestyle which is based on the same rights and opportunities as other citizens, regardless of type or degree of disability.
- Regardless of capacity or skill, families have a natural authority and are entitled to influence the direction of their son's or daughter's life, if they have remained faithful and committed to that person's development and wellbeing.
- A home is much more than 'bricks and mortar'. It should enhance a person's privacy and security, the development of relationships and intimacy, and the expression of individuality through flexibility and choice.
- Community inclusion is more than just living in a house in the suburbs. It gives rise to active and meaningful participation in community life and the development of broader networks.
- Families, community and paid service providers can work together in a respectful ('right') relationship to support a person with a disability to live his or her life well.
- Families do best when they work cooperatively, sharing their skills, experiences and capacities. With collaboration comes a synergy. The whole is greater than the sum of the parts.

Homes West families assume:

- Families want continuing involvement and relationship with the person with a disability.
- Families already have some established networks on which they can build.
- A person with a disability will continue to grow, learn and change throughout his or her life.
- Parents are likely to die before their children.
- Little that is worthwhile happens without planning and thought.
- Funding will not necessarily be available to meet every person's support needs.

To many people this may sound very ordinary. Everyone knows that having a home is a basis for a good life. When Homes West was established, this was seen as very optimistic for people with a disability, even though adults with disabilities have the same rights as others to live in and be supported in a home of their own. The families who gathered together saw the need to find and work with a service willing to:

- support each of their sons or daughters to find a home of their own
- promote the image, capacities and relationships of each person in their community
- work respectfully with family and friends towards these goals
- support their son or daughter for the long term
- help make funding applications
- assume insurance risks (public and professional liability).

Homes West has no standard model of service, but rather, there are common elements that have been agreed to by the families. Its paid employees are clear about what is family business and what is the service business of Homes West. These distinct functions are described in the following way:

The business of each family is to:

- develop a positive vision for their family member and themselves and to plan for the future
- establish the values and standards for their family member's future life and to safeguard his or her privacy, culture and integrity
- direct the level and type of service the person needs
- participate in the recruitment, selection and training of the workers for each family member
- plan for when the parents die.

The business of the service is to:

- build on and support existing natural networks
- protect the person and their family from intrusive bureaucratic processes
- be accountable for the expenditure of funds
- employ, train and support staff well
- support and encourage the person and the family to reach for the stars.

In supporting a person to achieve a home of their own, Homes West supports families through three phases:

- Phase 1 - planning a lifestyle
- Phase 2 - establishing a home
- Phase 3 - anchoring in their community.

At the moment every one of the individuals Homes West supports lives in a home of their own. Some are more established than others – this is their story about how they initially moved into a home of their own and became established in their community. Each individual's life looks different as a result of the age and the individual's chosen lifestyle.

Phase 1: Planning a Lifestyle

A home of their own
Stepping Stones to a home of their own
The Coordinator's role
Stepping Stones from the talking to the doing
Decision making (trial and error)
Stepping Stones to a decision
Establishing networks of support
Stepping Stones to support networks
What Leisa achieved

Phase One: Planning a Lifestyle

It is important to note that this small group of families knew what they didn't want because each and every parent had experienced traditional service provision in one form or another. They drew from those collective experiences to define the service they expected Homes West to provide. What they weren't sure about was how to transform the knowledge gained from those experiences into positive actions. They sought guidance from the Community Resource Unit (CRU) to shape what was possible for their sons and daughters. Below is a summary of some of the earliest work completed by the families of Homes West in consultation with CRU.

A home of their own

The families found that they wanted:

- Their son or daughter to have a real home, like their brothers and sisters in their local community and near people who care about them. Some of the people had experienced living in group situations, where their home was nothing more than a bed in a house or institution.
- Flexible supports in the home of their choice. They did not want the housing to be part of the support service. Issues around one impinged on the other.
- A service that assists the person to have an ordinary life, with all the ups and downs of an ordinary life. They did not want a service that focused on 'care and control'.
- A focus on the life of each individual through learning to understand each person's situation, vision, hopes and plans. They did not want a service where the one model fits all.
- The service to adapt as the person changes and grows. They did not want the rigidity of an unchanging service.
- The person and their family to plan and call on the service as needed. They did not want the service to replace or diminish family involvement.
- The service to acknowledge the person for who he or she is, and to support the person through natural opportunities for change and growth. They did not want a program to 'fix' or train the person before entering the real world.

In short, the families wanted their sons and daughters to have a home of their own and an ordinary life like their brothers and sisters. This might seem self-evident. After all, it seems to be such a simple, unblemished hope. Like most families, the Homes West families have a sense of what's best for their son or daughter, born of their deep knowledge of that person and how ordinary life works for them and their other children. However, Homes West families constantly check that their vision is full of possibilities for their son or daughter. They expect that each person will experience a full and active life - and not the safe option that quells their parental anxieties ('I need him/her kept safe for ever so I don't have to worry any more.')

This takes considerable 'soul searching'. The families have had to face their fears and be prepared to venture into the unknown; that is, truly follow the paths their sons and daughters want to take. Homes West families strive to understand why society treats people with a disability as it does and what strategies work best to improve their sons' and daughters' lives. Here are the stepping stones to clarifying the vision as they see them.

Stepping stones to a home of their own

Start now, not later

Each person in Homes West was not prepared to sit back and wait – they knew that nothing would happen if there were no plans in place. Not one family felt they could wait for adequate funding. They knew IT WOULD NEVER HAPPEN IF THEY SAT BACK AND WAITED. However, most people had some funding to get started. The preparation did not cost a lot of money – the cost was in time.

Introducing Mena

Mena is a very sociable young woman in her twenties. She has a wide circle of friends who visit regularly. She has the steely determination to succeed and achieve her goals. She has a wheelchair to get around. She needs 24-hour support from workers, family and friends.

Mena's story as told by Margaret, Mena's mother

Mena knew she wanted to move out of home. She named the date - her 19th birthday. The message was loud and clear – 'Mum, make it happen!' The family started with nothing but their enthusiasm. Mena had a few young friends who urged her on – blissfully unaware of all the pitfalls, costs and organisation required. This preparation time was very important, not only for Mena but also for her extended family who were trying to catch up with the idea.

Believe it and it will happen

Each family believed that their family member could have a home of their own and a full and fruitful life in their community. This belief was steadfast regardless of the vagaries of government policy or people's attitudes at the time.

Introducing Susan

Susan is in her late thirties and has lived in her own home for over twelve years. She has high support needs in all areas of her life. Nevertheless she enjoys a social life and is mostly a happy person with a loud infectious laugh.

Susan went to boarding school when she was 16 and lived in a residential care facility for a year before her parents moved her back to the family home when she was 20. She has a younger brother in Brisbane and an older sister and brother in Perth and Melbourne with their own families.

Susan's Story as told by Joan, Susan's mother

Between the ages of 20 to 27, Susan saw her younger brother move into a home of his own just as his older sister and brother had. She knew that her family was involved in setting up Homes West and she came to understand that she would also move into a home of her own. A mobile of her home was hanging in her bedroom to remind her. When she moved out it went with her and has been with her for the last 12 years.

Families know the most

No-one knows the person with a disability better than a loving supportive family and they have the greatest commitment, staying power and knowledge about that person. With support, encouragement and guidance, all families have done amazing things for their son or daughter.

Introducing Jane B

Jane had moved into a large institution when she was 19. She appeared to be happy and her family had regular close contact with her over many years. However, when she was 32, she started losing weight and her behaviour patterns became more and more erratic. Her mother, Marg, knew that she was unhappy and that she had no alternative but to bring Jane home and rebuild her life so that she could achieve a home of her own.

Jane B's Story as told by Marg, Jane's mother

When I brought Jane home to live, we realised how she had changed. She did not sleep for five days or nights. When we investigated what had happened to Jane we discovered she had been badly mistreated. Jane lived with us for four years before she was finally up to moving into a home of her own. The path was very rocky at first and Jane was forced to move from the first place because the neighbours complained. However, she finally moved into a purpose-built home of her own six and a half years after we brought her home.

Think outside the box to make it possible

There are as many different ways of doing things as there are people to find them. Each person has a unique family, situation and life. Each person has significantly different challenges. Most do not have what is seen as adequate funding. Creativity and lateral thinking can go a long way to fill the gaps.

Introducing Julia

Julia is a 34 year old woman. Julia is a friendly outgoing person who enjoys being part of the local community. Julia celebrates life. Julia requires constant support, supervision and physical assistance with daily living tasks.

Introducing Peter

Peter's communication skills are limited. His disability presents those who support him with unique challenges. He is a friendly man with high support needs.

Julia and Peter's story

Julia and Peter are brother and sister and they had been living in two separate country town residential care facilities for five years prior to moving into homes of their own. Kathy and Basil, their parents, lived in the same area. The family had always maintained close contact with Julia and Peter as they came home regularly for weekends and family gatherings. When Kathy and Basil found out that Julia's residential facility was to close down, they took the opportunity to make some significant changes in both their offspring's lives. The closure of the residential facility was an opportunity for Julia and Peter to move their funding package to the city. The family got together to discuss future plans and the decision for everyone to move to Brisbane was made. Today, Julia lives in her home and Peter lives in his. Basil and Kathy are still in the process of relocating to Brisbane - not an easy task in itself. However, all agree that thinking outside the box was right for them as the quality of Julia and Peter's lifestyle has improved remarkably and the family feel confident that their future is now more secure.

The Coordinator's role

The Coordinator at Homes West was pivotal to the whole process. She guided the families to do the doing - to make the decisions that had to be made and take the actions that had to be taken. The power of this strength and sharing capacity can be seen in the results – the expanded lives of Homes West families' sons and daughters.

The Homes West Coordinator initially:

- Built on what was already there and identified opportunities as they presented themselves. These were often done diagrammatically.

- Facilitated and supported the person with a disability, their family, friends and networks to explore ideas and possibilities so that they were able to make decisions about where each person wanted to live, what that choice would look like, what supports were required and how it all would happen.
- Made a long-term commitment to each person and their family on behalf of the organisation.
- Clarified, through 'Family Agreements' what each family wanted and expected from the service.

It is important to note that these activities are ongoing and the Coordinator continues to undertake these duties.

Stepping Stones from the talking to the doing

This is a time for establishing what is needed for a person to move from the family to a 'home of their own'.

It involves planning and careful preparation. Some families take years to move through this step while for others it is a short interlude. It depends on where the person is in his or her life at this time, the connections that person already has and the energy and preparedness of the family to take risks in terms of a new venture.

Each person with a disability, their family and networks need to follow the pattern outlined below. Each person moves forward with the support of their family, friends and networks.

Revisit what is already in place

Take time collecting information about what work or day activities the person wants or has, and what leisure and recreational activities they do or might enjoy and whose company they like best.

Examine housing options

Housing options need to be examined. Families need to plan for a home to be available in the future either by investing in a property or listing their family member for public housing. In the meantime, families could investigate possibilities in the local private rental market or modify their own home to allow for more independent living.

Homes West does not own or manage housing; rather, it assists in finding the right place to live.

Establish links

Links to the community where the person with a disability plans to live need to be identified.

Decision making (trial and error)

Each family in Homes West had to think about what their son's or daughter's life might look like in the future, where and with whom that person wanted to live, and what formal and informal supports they would need. Every family held planning sessions to make decisions about all these elements. This was a time for checking assumptions and testing possible strategies to help with decisions. It was particularly helpful for each person to try a few different arrangements on a short-term basis.

Stepping Stones to a decision

Try different options

It may be helpful to explore or try a few different housing arrangements on a short-term basis, for example:

- visit other people with similar disabilities living successfully in their own homes
- try a few different living arrangements, such as living in a unit for a few weeks with family support and some one-off paid support; sharing with another person; going on holidays without the family; house sitting; or living in a granny flat.

Identify unpaid supports

At this time, friends can provide freely-given support by:

- having a person on their own over for dinner
- taking him or her out to new and interesting activities
- asking him or her to care for their home while they go on holidays
- assisting the person and their family to clarify their vision – and dream what is possible (several minds are better than one!)
- doing research on options for housing, work and leisure – using their networks to find opportunities in the local community.

Find some funding for trials

Funding for paid support during the trials can come from a variety of sources, for example in Homes West:

- Some of the individuals had considerable savings from their pensions and the families used some of that money for a 'living away experience'.
- The Community Benefits Fund provided one-off funding in some situations.
- Families funded the experience themselves.

Introducing John

John is 32 years old and has Down's syndrome. He is articulate and confident and very settled in his own home, workplace and community. He is relatively independent and manages with about 20 hours of support a week from Homes West. He has a warm loving family who acknowledges his vulnerability and have addressed this by putting in effective safeguards.

John's Story as told by his mother

On leaving school and obtaining a job at Sizzler, John decided that he was going to move out of home and live in his own unit. He said to his father and me that he now had a job and his older brother and sisters were living away from home. I must say it was a shock to me. I was thinking that I was going to shelter him forever in the family home. Seeing how determined he was, I put his name down with the Department of Housing for a unit and, looking for a service to support him, I felt very fortunate to find Homes West, being a service that includes family and friends who are the key decision-makers in the person's life. We then bought a family home that had a separate living area downstairs which John set up with his own furniture and belongings and we lived upstairs. John loved it, but it was not quite what he had in mind. He lived there for two years before a Department of Housing unit a couple of suburbs away was offered to him. He couldn't move there fast enough.

John by this stage was not funded except for a number of hours the service kindly gave to us which enabled me to employ a support worker to come in and help John prepare his evening meal a few days a week and the family filled in the rest that was needed. Within the year John received recurrent funding from the Department of Disability Services. Even though it is not a large sum of hours, it suits John and us at the present time. He wants to be as independent as possible without being in any apparent danger. Even though I'll always be worried about his vulnerability, all I can do is put safeguards in place and accept that life is about managing risk.

It was hard work, especially at the beginning, keeping John's home and the family home running smoothly. Was it worth it? You bet. Now I see before me a happy, confidant, sociable and independent young man, who, despite his disability, manages life well living in his own very colourful unit.

Establishing networks of support

Homes West families believe that the chances of success substantially increase if networks of support within the community are established (to some degree) before anyone moves out from their current home situation. The coordinator and the family clarified who would be the organiser and contact for the service, who would visit regularly and who was to provide support – paid and unpaid. The coordinator also introduced new activities to the person, such as becoming a member of a local club or church group. A parent recalls the importance of decision-making and assigning roles during this stage.

Margaret's story

Margaret is Mena's mother. Margaret is a well-known advocate for people with a disability and is a presenter and organiser at the Homes West Workshops.

As Mena's mother, I was very clear about who would be the organiser and contact for the service. It was going to be me. I wasn't going to let go very easily. I was going to maintain a tight hold on the day-to-day management of my daughter's life. This was non-negotiable until I could truly trust those involved. This was fine with everyone. They knew me well and acknowledged my fears.

Natural networks are the people in a person's life who give support, advice and friendship. They can help to develop a good life. You can build your natural networks by sharing your experience.

Whatever networks families have are important as they will be the basis of a network for their son or daughter. Some families have small networks (one or two friends) while others have large networks. The size is irrelevant as it is the quality of the input that is paramount.

Stepping Stones to support networks

Find natural networks

Natural networks are the people in a person's life who give support, advice and friendship without payment because they are interested in their welfare, or simply enjoy his or her company. They are also the people a person meets on a day-to-day basis and are interested in their wellbeing. Most families used their own networks as a starting point.

Networks can be expanded or contracted intentionally. A family's son or daughter with a disability is likely to have a natural network as well although often much more limited - particularly if the person spends a lot of time in segregated service settings.

Share experiences with your natural network

A potent strategy to intentionally build your networks is to share your experience. A good starting point is to find someone (with experience) to help you identify the best intentional strategy for your family. The basis of a network may already be in place, such as a supportive extended family or a church group. This is a good place to start.

- *It is helpful to have a clear vision* and some achievable tasks before you start. The group may assist you with this or you may want to clarify what you believe before the group forms around you. It is important that everyone supports the vision and is 'with you' in your endeavours.
- *People do best when they know the limits of their commitment.* It is useful to outline exactly what you expect of them *e.g. 'I need you to come to a two hour monthly meeting for one year.'* Individuals often become intrigued by the process and want to continue on after their initial involvement. This 'contract' permits people who are not able to remain involved to leave without jeopardising the friendship. Think of this as a long-term strategy. People who might not be available now may be in the future. The children and teenagers you know now will be responsible adults in a decade.
- *Gatherings where you share information, search for ideas and plan action should be fun and satisfying.* People do best when they are having a good time. Good food and wine helps. People will want to come again. Have one person who can guide the group to keep the focus on the family member with a disability. It is also helpful to keep a record of the discussion to reflect on later and to see how you are 'travelling'. Amongst the hard tasks should be some easy ones that are very achievable.
- *Some consideration of ground rules is important*. Discussion on some subjects may be too difficult for the person and the family at some point. It is helpful to think this through beforehand. Perhaps the person and the family need an acknowledged 'right of veto' so that everyone feels more confident and comfortable about these 'no-go' areas. Another ground rule can be that a member of the network accompanies the person or the family when there is a difficult meeting or appointment to go to. There is no better way for others to understand what is going on than to 'share the action'.
- *It is also helpful to remind people they are there to support and advise only.* People will have a plethora of ideas and suggestions and only some will be realistic. If for some reason the family does not take their advice, no one should be offended if they know they are there to support and advise - not take over.

Invite the network to provide regular and spontaneous assistance

- *Natural networks can provide practical and regular support to the person or the family.* A grandfather can spend a few hours each week helping with reading, a nephew can mow the lawn, a neighbour can have dinner with your son or daughter every second Sunday. Just spending time with the person allows for friends and family to understand better his or her daily challenges. It takes courage to ask and energy to organise. Then it is important to provide a regular 'thank you'. Some Homes West families have relied strongly on this informal support. They have been gratified by the willingness of others to help.
- *People who make regular visits will pick up changes in the household and in the person's behaviour.* Sometimes these are too subtle for workers and family to recognise on a day-to-day basis. Visitors also come with fresh eyes and may see different ways of doing things.

- *Spontaneous visits are important.* Staff will be more diligent if they know that people who care drop in unannounced. If friends and family feel free to act spontaneously and are encouraged to do so, a person's life can be enhanced considerably. Workers can be encouraged to make spontaneous visits more likely to happen, by readily offering hospitality and being willing to change the routine to welcome and help entertain the visitor. Create opportunities for these important members of your natural network so they can share any ideas or concerns freely with the family. You may need to organise the occasional barbecue or brunch so they can get together, relax and talk.

Create opportunities

- *Build on your existing networks.* Homes West families have created opportunities for their sons and daughters most successfully by asking their own natural networks to extend their influence to make an opportunity possible.
- *Be on the lookout for opportunities to connect with people.* Families and workers become skilled at recognising opportunities which will allow for the person to make his or her own connections. Church groups, choirs, sporting teams and clubs are some options.
- *Never say no to offers of help.* If someone offers to help, always find something for them to do. It may be a very simple task once a month. This becomes an opportunity for that person to connect with your son or daughter slowly and comfortably. You may be able to build on that connection later.

What you can do now

Identify who is interested currently in your son or daughter and include them in a series of circles: the core is for the young adult, the inner circle is for the family, the next for close friends and relatives who already spend time with your son or daughter, the next is for those people who know the person and who ask after that person and so on. The last circle is reserved for the professionals who are in the life of the person with a disability and have demonstrated a high level of commitment.

Ask to share information and ideas with these people – email a newsletter to them on a regular basis with updates about what you are trying to achieve. Ask for feedback.

Develop a circle around your son or daughter as more and more of these good folk offer assistance.

What Leisa achieved with a plan in place for a quality life

Introducing Leisa

Leisa is a cheerful, fun-loving woman with Down's syndrome. She is 32 years old and has recently moved into her own unit. She needs (and receives) encouragement and guidance from 'drop in' support workers and a loving family. Leisa relies on funding for her support from a variety of sources as she does not have recurrent funding yet.

Leisa's story

I wanted to be independent. I explained to my parents that I had lived with them for 30 years and that I had had enough. I wanted a home of my own 'with a lot of support – not just Mum and Dad.'

My parents heard what I said and set about making it a reality. In the meantime I had been observing my friend, John in his own home and I was learning as much as I could from him.

Leisa's story as told by Leisa and her parents, Bevan and Chris

For a number of years Leisa had expressed her wish to live independently. As a family, we wanted this for her and explored as many possibilities as we could. Clearly Leisa needed 'carer' support to achieve her goal. Homes West provided us with the means for Leisa to move forward. We wanted her move to work on a long-term basis and as a family we would play an overseer role. We wanted Leisa to feel that her new apartment would be 'her home'. During the early 1990s Leisa had tried living out of home in a shared arrangement, but a number of issues developed and the move did not survive. We all learnt from the experience, and Leisa continued to convey her desire to live independently in the future. We all felt that Leisa living on her own would work.

Leisa's determination to achieve her goal never fluctuated. When her opportunity eventually arose, after a wait of four and a half years for public housing, we all took it up enthusiastically. Initial teething problems were soon overcome. Homes West assisted with rostered dinner guests and some vital support from a support worker. Leisa surprised us all with her adaptability to her new environment.

The Homes West neighbourhood provided Leisa with a sense of being part of a community which embraced her needs. She has friends and family close by which gives her a genuine feeling of personal security. In the space of six months, Leisa has succeeded in living on her own. Her ongoing needs of carer support, friendship and family involvement are easily defined. Her proudest achievement has been in making her apartment 'her home'. As parents, it is with a great sense of pride, relief and commitment that we can identify Leisa's place in her community as a tangible and permanent lifestyle for her. Homes West has been instrumental in making all this happen and for that we are most grateful.

Phase 2 – Establishing a Home

Moving out
Establishing support
An inclusive lifestyle
Understanding the vulnerability of the person
Safeguarding the person
Stepping Stones to safeguarding the person
Maximising paid and unpaid support
Stepping Stones to maximising support
Mena's support network

Phase 2 - Establishing a home

The majority of the people in Homes West moved out and established their home when they were ready – not when they had funding available. However, most had some limited funding to start with.

Establishing a home is a complex task. Apart from buying furniture and household items, setting up gardens and moving in, there are many agendas to be addressed. The key elements are:

- moving out and establishing a home of one's own
- establishing ongoing support to live in a home of one's own – both paid and freely given
- developing and maintaining an ordinary lifestyle.

Moving out

Homes West families have found that, like other families, helping their son or daughter to establish their first home was not straight forward. They found that moving out is a trial and error process and that the best options take time to find and that the first living arrangement will most likely not be the last. Each family has found that the person with a disability also needs to be able to come home from time to time – not to stay – just regroup. They need to have their parents close at hand in the early stages – some even wanted their parents to sleep over for a while!

Introducing Philip

Philip is now 40 and has always lived at home. He was injured in a motor vehicle accident when he was eight and sustained a brain stem injury. This has left him severely physically disabled and in a wheelchair. He has little use of his left arm and leg, has a tremor in his right hand and his speech is slow and difficult to understand. Although mentally unaffected, years of special schooling, living at home with his parents and a sheltered workshop environment have resulted in him having few non-disabled friends and limited experience of making his own decisions.

Chris and Julia's story: Philip's parents

When Philip first moved out, for us all it was a dream come true. However there were little problems that we had not foreseen. We had to learn how to live in two homes. I really missed just living in my own home. In the first eight months we slept over three nights a week at Philip's house and Philip was home at our place every weekend. In September this year we went overseas and two of our sons stepped in to help out. As well, we paid for Philip to have another carer while we were away. By the time we returned home, Philip had made the decision with his brothers to try sleeping without support for two nights a week with an Alert system as a safeguard if Philip got into trouble during the night. It gave Philip confidence when an old family friend who now worked for the company that installed the Alert system arrived on his doorstep to set up the service. We couldn't believe the difference in Philip as his confidence had risen. We are so grateful that our other sons could make such a difference not only to our lives but also more importantly to Philip's life.

Philip's story as told at the Homes West Christmas party

Philip moved out in November 2005. At the Homes West Christmas party, Phil outlined to the group the advantages and disadvantages of moving out. He had nothing in the disadvantages column. The advantages he listed:

- *Everything was arranged the way he wanted it*
- *He was the boss and he could do what he wanted (within reason)*
- *He got home from work earlier*
- *He had the opportunity for new experiences and to meet more people*
- *His folks had a lot more freedom.*

As far as Phillip is concerned the whole experience is very positive.

Establishing support

At this time, the role of the family begins to change very subtly as paid support comes online and the families step back. At first the family usually provides the majority of the support. They are the key day-to-day organisers, the planners, the main hands-on carers with some support from workers and the coordinator.

The family works in tandem with the support workers for a while. This allows:

- Family members to develop trust in the workers' ability to provide the same standard of care as they do.
- Family values, practices and standards to be clarified, understood and then upheld and entrenched by all those involved in the life of that individual.

Developing and maintaining an inclusive lifestyle

Support workers are required to follow the activities established before and during the 'getting ready' period. These activities are usually organised by the family and displayed on a monthly calendar drawn up by a family member or a designated person. Staff members are encouraged to put forward suggestions for activities and events of interest to the supported person.

Problems are inevitable, but most can be solved locally, immediately and creatively. Over time, families, workers and the person become more confident and trusting of each other.

The key issues and challenges faced (in the opinion of all families) include:

- understanding the vulnerability of each person in their own community
- safeguarding that person
- organising paid support
- maintaining networks.

Understanding the vulnerability of the person

Love and good intentions are not enough to keep people with a disability safe from harm.

All families know that their son or daughter is vulnerable. Inevitably bad things happen. When they do, families know that it takes longer and a greater effort for a person with a disability to recover from the loss, grief and hurt.

Even if families do not fully understand why bad things happen, they have a sense about their sons and daughters and, over the years, develop strategies to make life safer for them. Families also know that without due attention, the good things in a person's life will dissipate. Any 'wins' need to be protected.

Bad things can happen for the following reasons:

- *Our society devalues people with a disability*. Regardless of our love, vision and hard work, Homes West families continue to witness discrimination, fear and disregard for their offspring. Further, this devaluation of people with a disability can turn what seems an ordinary situation into an unsafe one very quickly.
- *In ordinary life bad things happen.* Just because a person with a disability is living a full life in the community, it does not mean they are impervious to the day-to-day dangers of an ordinary life. Tragedies can happen to anyone.
- *The consequences of bad things happening are likely to be more severe.* Due to the nature of the disability, our son or daughter is more likely to suffer more than normal from negative experiences, accidents or poor service. It is also likely to take longer for those who care to understand that something is wrong, for the situation to be rectified and for the person to be assisted.

- *The consequences of these negative experiences (or wounding) are cumulative*. Each time a person is hurt, neglected or betrayed, the damage to the person will be cumulative unless an extraordinary effort to support the person is in place.

The more segregated a person is, the more likely bad things will happen to him or her.

Safeguarding the person

Many attempts to establish good home lives begin with the best of intentions but can be sidetracked by service needs and systems taking over. Good home lives need to be safeguarded so that people can live in ways that continue to respect their (or where appropriate their families' and advocates') wishes to live an inclusive lifestyle.

Safeguards should include:

- having housing separate from accommodation support
- establishing a process mirroring the way people are to be treated
- developing quality management of the service and keeping the decisions close to the person
- involving the person themselves and where appropriate their family and/or advocate in decisions which affect home life
- having good selection procedures and induction for staff
- continually reviewing the process of support to people so that it remains flexible and meets the person's changing needs
- recognising the importance of significant others and having their open involvement in home life activities
- having tenancy and ownership rights clearly understood and respected
- having working complaints mechanisms where open discussion is encouraged and issues followed up
- having open access to people who will take up issues on behalf of the person if required and also external mechanisms which allow others to scrutinize possible violation of rights.

Safeguards are strategies to:

- *build* on what is good
- *protect* the person and
- *fix* the situation when things go wrong.

When a person is segregated from ordinary daily life, abnormal behaviour and treatment is less likely to be questioned. This is a real danger for vulnerable people who are the most likely to be abused or neglected because of these abnormal circumstances.

Homes West families have understood this and assume the following:

- Regardless of how good the service is, it will not be enough to keep their loved one safe.

- Everyone has the capacity to allow a person to be hurt, neglected or betrayed. That includes the family themselves.
- Because of their continuity and commitment, families have the best overall understanding of the person.
- Those who give their time, love and care freely are often the first to identify if something is not right.
- Support workers also can identify dangers and negative changes, and they are more likely to act on these if they are confident, trusted and respected.
- Regardless of how diligent services, family and friends are, the person very likely will be 'wounded' by everyday life.
- Everyone must be vigilant and this vigilance must be never-ending.

Stepping Stones to safeguarding the person

Build - How to build on what is good in a person's life

Homes West families suggest building the following safeguards:

- Promote, review and extend your vision for your son's or daughter's life in a way that is uplifting and morally sound.
- Employ workers who share the same values and vision.
- Continually shape and change the service to meet your son's or daughter's needs.
- Encourage and support the ongoing involvement of friends and neighbours.
- Plan for the long-term personal, economic and legal security for the person.
- Intentionally build on the competencies gained.
- Inform the coordinator of the safeguards and the action to be taken if the family is not available.

Protect - How to protect against bad things happening

Homes West families use the following protective safeguards:

- Make sure your son or daughter becomes well-known in the neighbourhood.
- Keep clear and separate what is service business and what is family business.
- Regularly monitor what is happening in the home by spontaneous visits by family and friends.
- Remove workers who do not work respectfully with the person or the family.
- Put in place processes for workers to account for money, time and type of activities.
- Meet regularly with workers to review, plan and problem-solve service issues in a person's life.
- Be available to act quickly, locally and creatively when a problem arises.
- Expect the coordinator to be aware of the safeguards and inform staff.

Fix - When things go wrong, how to make things better and learn the lessons

Safeguards identified by Homes West families are:

- Promptly identify and admit that things have gone wrong.
- Be available to act quickly and decisively on remedial action.
- Plan for financial, emotional and physical capacity to buffer the person with a disability against unexpected difficult situations.
- Spend time to analyse what happened and develop strategies to avoid a repeat situation.
- Share with the Homes West committee and broader group of families so that any policy or procedures can be remedied and that others may learn from your experience.
- Expect the coordinator to be aware of the safeguards and act if the family is not available.

Leisa's story (cont'd)

At first my parents insisted on Mum sleeping over every night. I wanted it too - just until I got used to being on my own. It all came to a head when my parents went away for a holiday and Anna the support worker slept over instead. Within a fortnight, I learnt so much about living on my own that when my parents returned from holidays I told them they didn't have to sleep over anymore as I wanted to give it a try on my own. The reasons I gave them included:

I'm feeling confident in my own home
I'm feeling safe in my own home
I know that Mum and Dad are close by.

It's good to have Mum and Dad close by as they really care about me and they watch out for me but I like living on my own.

Maximising paid and unpaid support

Within this service, when each person moves into a home of their own, they have individual support arrangements (paid and unpaid) where and when they are needed and where possible, provided in collaboration with family, friends and community. The service is accountable to the people who use the service. It maintains a low profile in the person's life, while remaining aware of vulnerabilities. It is conscientious in building safeguards and time is spent planning so that crises do not develop.

The people involved are not living perfect lives but they (with the support of their families and friends) take responsibility for the decisions that affect their own lives. They and/or their families (on their behalf) deal daily with the intricacies of directing not only their own support arrangements but also with guiding the services established to provide this support. Not so long ago this kind of self-governance by people with disabilities or their families was unimaginable. People with disabilities themselves have been the leaders of what can be achieved. The change came through people with disabilities and families who believed in themselves and in their own ability to create what was needed.

Each story is different: the 'how' of getting there will depend on the individual's unique situation, history, life experience and the support they have had to do it. The role of service provider is to work alongside the person, in partnership, taking direction from the person. The coordinator takes the time to understand the person and his or her needs and works on a one-to-one basis to help establish the community connections and informal supports that enrich a person's life and reduce his or her reliance on formal support systems.

Stepping Stones to maximising support

Employ your own team of workers

Each individual in Homes West has their own team of support workers who work exclusively for that individual. By employing their own workers, the person or their family establishes very clear authority over their own support arrangement. The role of the Service Coordinator will then be dependent on the requirements of the individual being supported. At times, the coordinator might act more in a trouble-shooting role and at other times assist with more deliberate proactive strategies. Responsibilities of the coordinator includes assisting with staff reviews, ensuring that workers understand their role and helping resolve any staffing issues. The person or the family has the ultimate authority over who works within their home, while the service takes responsibility to deal with any industrial issues that may arise.

Introducing Jane G

Jane is a lady in her fifties. She is a very outgoing friendly person with lots of friends and an active social life. She has very close family ties and stays in regular contact with her mother, nieces, nephews, brother and sisters.

Jane G's Story

Jane was a timid shy person when she and her family were first introduced to the families at Homes West. Her mother used to worry about her lack of confidence. Once Jane moved into her own home her confidence increased at an alarming rate. Jane and the coordinator have worked closely together to establish just what Jane needs from a support worker. This week, Jane was overjoyed to announce that she no longer felt she needed to have a family member present when she interviews for support workers! She knows exactly what to do and who she wants to support her. She has made it clear to the coordinator that she only wants young students who are interesting and involved in a busy life – others need not apply! The coordinator is there as a facilitator only if Jane requests that assistance.

Ensure respectful relationships

Having respectful relationships is a major feature of self-directed support arrangements. People with disabilities and their families have to learn about being fair employers and how to hire, train and manage workers. In the past people did not have the opportunity for this kind of decision-making related to service provision.

Homes West constantly strives to ensure that the impact of 'service' in the life of a person with disabilities is as relevant as possible. Considerations such as employing the right workers, planning and implementing support arrangements and rostering workers are tailored to the needs, skills and the self-direction of the person.

There is another dimension to having authority over one's own support. It is one that many families struggle with when they have a key role in shaping the direction of support arrangements on behalf of a family member. This struggle is about the future and raises the question: who will take on this role when they no longer can? This question raises issues such as vulnerability, vigilance and safeguards and one of the most important legacies that families can leave their family member is a group of people who have strong relationships with their son or daughter and a strong commitment to that person.

Convey Family Expectations

Each person and their family in Homes West expect that their vision for their family member and themselves will be respected and adhered to. Where the person has very high support needs, the family takes on a high level role in most of the decision-making. Some of the families have their current plans and ideals written clearly in the documentation that is handed to workers and volunteers when they first meet the householder. It is a major topic for discussion at induction time; it is addressed at staff meetings and reviewed at network meetings on a regular basis. It is the coordinators role to ensure that the key messages are clearly conveyed to all stakeholders and that the vision and plans for the future are implemented.

The values and standards for their family member's future life are outlined to workers and all interested people in that person's life. Safeguards to ensure that his or her privacy, culture and integrity are maintained are clearly outlined to staff and volunteers.

As the family knows their son or daughter better than anyone else, they have a high degree of input into the level and type of service the person needs. Lengthy discussions are held with the coordinator around this topic. Each month (following lengthy consultation), a calendar of activities is produced by the householder or a family member or a delegated person who has communicated with the family. The purpose of the calendar is to ensure that the person's life is focussed on their interests and commitments to family and friends are met.

The person with the disability and the family expect to participate in the recruitment, selection and training of the workers for each family member. The person who requires the support always attends the recruitment sessions.

Set up communication systems that work

There are a variety of communication systems in use in the various households. The systems vary depending on the ability of the householder to communicate directly with others and the purpose of the communication. Some useful tools have included:

- face to face
- email and texting
- notice boards
- letters
- regular meetings with staff and network members
- regular phone calls between the parents home, coordinator, support workers, network members, guests etc.

Mena's support network

When Mena wanted to move out, we had very little funding. We would not be able to cover all the time or pay for support ourselves. We had to call on our network of friends and family for assistance.

The Coordinator of Homes West suggested asking people for dinner on a regular basis. This met two needs - first to keep Mena connected with people after she left home, and second, to provide support during the evening meal.

We set up a dinner roster of people who would be willing to spend two hours with Mena once a month. The paid staff prepared the meal, set the table, helped Mena welcome the guest and then left. Mena had time alone with her friends and family in her own home learning to be a hostess.

At first the roster required a lot of work. Every two months, I would call the dinner guests, then send them a card with a reminder and finally call them again closer to the date.

The staff knew that 'dinner guests could do no wrong'. If they didn't eat the dinner prepared, spilt wine on the carpet or forgot to come – that was OK – they were friends and friends sometimes do that. We needed to manage this with grace and no blame.

Eight years later, there are just as many people who come for dinner. Often they take Mena out instead. They feel comfortable calling in any time and also expect to be invited to her birthday party. They do not require as much reminding and often call to find out when they are coming next.

They have alerted us when Mena has been off-colour, when staff members have not been up to scratch or if something is not right in the household. They have taught Mena how to be a confident hostess, to give as well as take and to enjoy her food and wine.

One long-term friend says, 'The regular dinner date reminds me of my commitment to Mena. It is easy to be her friend. I wish my other friends would call me regularly and ask me for dinner!'

One strategy to meet Mena's support needs when we had no funding was to invite someone to live with her.

We first invited Shevaune – a lovely young worker who wanted to return to study and was in need of a place to stay. She jumped at the chance. She understood the way Mena's household worked and that there would be many staff, family and friends calling in. She knew Mena well and we trusted her.

Mena and Shevaune were comfortable housemates – each getting on with their own lives. It was the added extras that made the difference for Mena. Shevaune would sometimes take Mena out with her on the weekend, they would groove around to loud music when everyone had gone for the day, and they would sometimes curl up together to watch a late night movie.

Mena learnt a lot from this time. She learnt to give not just to 'be served'. She discovered what it was like to just hang out with friends – the first step to a true reciprocal relationship.

Shevaune eventually finished her studies and lost her heart to a man. She left and Mena was very sad. Shevaune, however, still calls in regularly. She is part of our family now.

However, we had to find someone else. Was there someone out there as suitable as Shevaune? We could not think of anybody. Shevaune and a couple of other young women decided to advertise on the university accommodation website. Within two hours of posting the ad for a new flatmate, Mary replied.

Mary was an Indian student who needed inexpensive accommodation where she felt safe and able to study in peace. Sharing with other students had not worked for her. Mary knew nothing about disability or support, however she was keen to try.

Mary's mother in India was initially very concerned about the arrangement and emailed me with lots of questions. 'Would there be wild parties or bad men visiting?' I assured her this was unlikely to happen (though Mena would have loved this!)

There was a lot of adjustment for both Mary and Mena. Mary had to become accustomed to the many workers, family and friends who came through the house. We, in turn, learnt about the Indian way of doing things. The end result was lots of fun and a wonderful flatmate for Mena. Mary graduated with flying colours and considered her time with Mena a privilege.

Each flatmate has brought new life and meaning for Mena. Each relationship requires a lot of support to start and then it takes a life of its own.

What you can do now

Think through when your son or daughter is most vulnerable and why that is so.

Identify what strategies you presently use to keep him or her safe.

Think of other strategies you could use to encourage more good things to happen, to keep what you have achieved and to prevent bad situations from occurring.

Think about how you are going. Can you do anything to help you 'last the distance'?

Phase 3 – Feeling Anchored in the Community

Routines and Relationships – Susan's story
Catching the interest of the broader community
Making the most of life's opportunities
Stepping Stones to opportunities
How anchoring in the community helped Sarah

Phase 3 - Feeling anchored in the community

It is not until people begin to organise themselves around the person with a disability that that person can say they are 'anchored in their community'. To do this, it takes other younger family members, friends and organisations joining together to create a desirable future with the person. These networks can be called upon to clarify, strengthen and sustain the person with a disability once the parents can no longer care for them. The key elements to anchoring in the community are routines and relationships and maintaining what has been achieved.

Routines and Relationships – Susan's story

The reality of establishing routines and relationships takes time. Most of the people supported by Homes West who have moved into their own homes now have some anchorage in their own community.

The first 'Homes West' person to move into a home of her own was Susan, who moved into her first home 12 years ago. Today, her mother, Joan, is proud of Susan's achievements, which include:

- *The security of living in her own home.*
- *Processes that guide her life and allow her to make her own decisions.*
- *Workers who understand and respect how she communicates her needs, desires and dissatisfactions.*
- *A presence in her community – local people know her and say hello.*
- *Community activities – she attends church regularly, shops locally, visits her gym weekly and heads off to the RSL every Tuesday night with friends – all supported by workers who have a similar interest.*
- *Friends who come to dinner or just call in to visit.*
- *The time and capacity to visit her parents regularly.*
- *A cohesive team of family members, friends and workers who come together to support her to plan a lifestyle of her own choosing.*

Susan has anchors in her life, such as:

- *A home where she truly feels at home and safe.*
- *Important and regular things to do each week.*
- *People in the community who know and are watching out for her.*
- *Friends who do things with her spontaneously.*
- *Family members who have a vision and are positive about the future.*
- *Support workers who are trustworthy and respectful and who enjoy working for her.*

These anchors are important for when things do not go according to plan. They help to avoid crises. What the person has in place is unlikely to break down to the point where he or she is totally dependent once again on family members or requires a crisis response.

As people become more anchored, their family members are now able to be just that - family members. They are not the primary hands-on caregivers although they still take an active role in the day-to-day activities of their family member. Their role has become more aligned to what it should have been – Mum, Dad, brother or sister.

Susan's family have established a network of family members, friends and community members who meet monthly and understand that they must remain vigilant to ensure:

- *The work that needs to be done is done - from day-to-day routines to capitalising on every opportunity that comes along to enhance Susan's life.*
- *Susan's home is well maintained, efficiently managed and welcoming to all family and friends who are now an integral part of her life.*
- *Support is of superior quality.*

Catching the interest of the broader community (and holding on to it)

This is a key challenge for families. Community building needs to be thought of as a long-term strategy. It is easier if:

- a sense of community already exists
- the physical environment is safe and accessible
- good public transport is available
- easy access is available to services such as library, bank, doctor, church, supermarket, restaurants and coffee shops
- the person moves to their own home from the family home in the same area
- the person and their family are committed to stay long term.

All the same, community building is hard work and is anathema to many modern families. Often, both parents feel they must work and their work requires frequent moves from place to place.

Some people in your network may not agree with your vision of community inclusion, particularly if your son or daughter is very vulnerable or has challenging behaviour. They may confront or undermine you but, more likely, they will just withdraw support.

These are all legitimate excuses for not taking action. However this does not solve the problem. The reality remains that communities need to be intentionally built around the person with the disability and this is hard work. Attention also must be given to what natural networks exist and to their expansion and maintenance.

Many families of people with a disability have to reassess their priorities. To assist their family member to become accepted and connected in their community may require families to stay put in one place, become connected and involved themselves. They will need to put in the intentional effort to find good people who are interested.

Some practical day-to-day strategies to catch community interest include:

- *Take a valued role and be reliable*. Your son or daughter may have a stall in the local market or become a member of the local church. People will appreciate the contributions by your son or daughter and particularly if they are reliable and consistent.
- *Look good*. It is important that your family member is presented as positively as possible. There are risks in going out with food-stained clothing or unruly hair after a sleep. People judge harshly and hold on to first impressions.
- *Speak in a positive light.* Family members and workers can enhance (or detract from) a person's image by how they speak to and about the person.
- *Frequent local facilities*. People get to know them over time and can expect them to arrive. If communicating takes greater effort, the community person has the opportunity to become familiar to the person.
- *Use local services such as the bank, hairdresser, library.* The people who work there may also use other facilities and may stop to chat to your family member, say, in the supermarket.

John's story (cont'd) as told by his mother Joan

My son John has worked part-time at Pizza Hut for the past ten years. Whenever I meet up with John, I am constantly impressed by the number of people who know him. The shop assistants call him by name, his work mates have a joke with him and the workers at the railway station greet him cheerfully. It gives me pride and reassurance watching him out in the community. I know that these are people who will look out for him because they like him and care for him.

- *Avoid situations where a person's vulnerability is exposed.* Where it can be predicted that a person may not do well or may cause offence, the situation should be avoided. If it can't be predicted, it is important to get the person out of the situation promptly and with dignity.
- *Avoid dangerous environments and behaviour.* There are many risks people take on a day-to-day basis, such as crossing busy roads against the lights and running to catch buses. The consequences of an accident for a person with a disability are commonly more serious and disruptive than for others. Unnecessary risks are just not worth it.

What you cannot expect from ordinary people:

- *You cannot expect more from people than their role determines*. You can expect assistance with courtesy from, say, the librarian; however, the librarian may never show any more interest in getting to know your family member better.

- *You cannot expect people to have a strong value base because of their profession* or *role*. For example, the local minister of religion may have great personal difficulty accepting people with a disability; or the local school principal may have no interest in supporting children with a disability in the school. Expectations that values automatically come with the job can leave a family very disillusioned. People, not positions, have values.
- *You cannot expect all family members, friends or neighbours to be interested in your family member's welfare.* Just because they are related, live nearby or know you well does not mean they will be interested in your son's or daughter's welfare. For a whole host of reasons, they may not want to become involved in your life. Nevertheless, regular positive contact can interest the most insular and uninterested person and most families have found neighbours, friends and family are the foundation of their networks.

In summary, shattered expectations can be very debilitating. It is worthwhile to try to understand your expectations and check whether they are realistic. It is the occasional individual who steps forward to offer friendship that becomes an important building block for broader community interest and inclusion. For others, regular, persistent and positive contact over an extended period of time (sometimes years) will influence even the most uninterested people to accept the presence of a person who is seen as different.

Making the most of life's opportunities (and reducing a person's vulnerability in community life)

For people with a disability, meaningful community involvement requires planning and thought. Very little happens spontaneously without a lot of effort beforehand. The image of the iceberg is often cited to illustrate this: a comparatively small iceberg above the water is supported by a huge amount of ice under the water.

Stepping Stones to opportunities

Consciously observe relationship development

Those supporting the person need to be particularly conscious of the dynamics which are developing in any relationship, minimising the negative ones and building carefully on the positive ones.

Be ready for spontaneity when it happens

When spontaneous opportunities arise, those supporting the person will need to act quickly and decisively to take advantage of that opportunity. This may require a change in support arrangements, extra petty cash, or immediate communication with the family. Preparation can be made to support spontaneous opportunities such as:

- ensuring that staff understand the importance of maximising opportunities and the need to change routines sometimes at short notice
- money being readily available for this purpose
- clear, immediate and reliable communication strategies with family and service coordination
- a clear understanding by all beforehand about what is an appropriate activity and what is not.

Traditional services find this spontaneity more difficult to manage and as a result tend to avoid these opportunities. Capacity to act on spontaneous or unexpected opportunities is a good test of the flexibility and person-centred capacity of the service.

Manage risk

In taking opportunities, there is always a risk of disappointment or hurt. Families will have the best history and understanding of past disappointments and can best assess the risk and the possible damage.

When the risk is high, greater care needs to be taken in supporting the person and providing the best preparation possible. Even then hurt and disappointments happen.

To learn the lessons and to avoid hurt upon hurt, all those supporting the individual will do best coming together without blame, to review what happened and consider strategies to minimise the person's vulnerability in the future.

How anchoring in the community helped Sarah

Introducing Sarah

Sarah is a young woman in her late twenties. Sarah cannot speak or sign to communicate. She requires a high level of support because of her complex needs. Sarah spent many years living in Basil Stafford - an institution in Brisbane. However, as a result of the government's decision to reform institutional care, her mother and father decided to take the opportunity and move Sarah into a home of her own. Sarah received funding to move. Sarah now has a small group of friends and family who support her and call by regularly. She has people around her who are deeply committed and involved in her life once again. It has taken a number of years and seemingly never-ending hard work but Sarah now has interesting things to do and places to go to everyday – if she chooses to take them up on that particular day. Sarah has lived in her own home for ten years.

Sarah's story as told by her mother Sally

We were very fortunate that the Coordinator of Homes West approached us and asked if we would like them to coordinate Sarah's support. We jumped at this, as it was the type of organisation we wanted, where everyone involved was part of a community. The organisation respected Sarah and our family, expected decisions to be made by us, and treated the people they served as the most important members of that community.

Sarah, my husband Dom and I interview every prospective support worker. Sarah can't speak and communication is very difficult for her. We have to make decisions on her behalf, but we make sure that they like Sarah and Sarah likes them before they are taken on permanently. We have regular meetings with Sarah, staff, family and the coordinator where we can be talk about anything. Our support workers are very much a team and are expected to think about Sarah's life and how it could be better. We have had some great help from therapists employed by Disability Services Queensland, but all decisions are made by us. In the early days, departmental people kept asking the organisation to make decisions and found it very confusing when they were told that it was up to Sarah and her family to make decisions, not them.

Sarah (with support from her staff) now pays her own bills, does her own shopping, and makes decisions about what she wants to do. I do her budgeting and Sarah is able to live quite well on her pension. Because she lives alone her funding doesn't cover 24-hour support so we have to provide some extra help. We sort out how we will do this with the help of the organisation. Even Sarah's roster is different; no eight hour rigid, immovable shifts. The roster is built around what Sarah is doing at the time, not what suits somebody else. This experience has left me wondering: why can't bureaucrats work hand-in-hand with families and small organisations to ensure the best outcomes for everybody?

As Dom and I get older our thoughts often turn to what will happen when we can't do it any more. Our dream is a network of like-minded people around Sarah who are there because they have a commitment to her and value and respect her. Whether it be socially or in a monitoring role, people will be there to make the decisions when we can't. What we need is a 'friendly' bureaucracy: one that respects family and friends; that will see the value of networks; and that will assist people to facilitate this by providing resources, financial or human - anything to prevent Sarah being re-institutionalised as she ages. If people with disabilities and their families are to have a decent life, bureaucrats must recognise who are the decision-makers, and that they are there primarily to serve.

What you can do now

Identify who is interested in your son or daughter and what practical things you could do to maintain their interest.

Ask other families how they built their networks.

Develop a circle around your son or daughter.

Identify where your son or daughter would be most happy to live in the long term. Start building connections there.

If you don't have the time for this – find the time. You may have to change your priorities to do it.

Part Three:

The Next Generation

Introduction - Planning for now, tomorrow and the future

‘People keep people safe.’ Families have a pivotal role in working towards a fully-rounded life for their son or daughter with a disability.

But how do we reconcile this belief with the reality that our children will outlive us? Families’ greatest fear is: ‘What will happen when I’m gone?’ What steps, beyond getting the legal matters sorted, do they need to take to safeguard the quality of life for their son or daughter in the future?

Homes West Families believe that it will most likely require three generations of family members – parents, siblings and nieces or nephews working within a network to support a person with a disability long term. It must be noted that all 12 members of Homes West have either one or two parents still actively involved in their lives. While many siblings are actively involved in the life of their brother or sister, no brother or sister has (as yet) the direct responsibility for the wellbeing of that person. What the parents are all considering are the plans each one will have to put into place in preparation for the time when they can no longer physically support their son or daughter. Plans and ideas have yet to be tested.

Homes West has actively provided support for families by:

- Providing consultancy support for exploring ideas and planning purposes.
- Establishing a siblings support group that meets occasionally to discuss issues about the future and to learn more about Homes West and how it operates.
- Shoring up the viability of the organisation by welcoming siblings onto the Committee of Management – two siblings are now currently members of the committee.

As a result of these proactive measures, all families have started thinking about the future. Some families have started a circle of support around their son or daughter and the siblings are members of that network. Others have not got that far. Some may make different choices and go without such a formal mechanism. They may choose a different arrangement. This is all in the future!

Circles of Support

A person with a disability has gifts and strengths just as any other person does. People with severe disabilities are often trapped by the assumption that their ability to live as they choose depends on how close they come to being able to do everything for themselves without help. Reflection shows that the assumption that independence requires a solo performance is false. What is essential to independence is directing one's own life, in relationship with others one chooses, towards goals of one's own. Those people who are most successful are those most likely to receive or command assistance of many forms from many people. Experience shows that people with severe disabilities can live with dignity and autonomy when other people receive their gifts, invest in them and assist them.

Stepping Stones to Circles of Support

The circle of support was originally developed from ideas and proposals put forward in John and Connie O'Brien's article: Commitments That Promote the Well Being of People with Severe Disabilities (Responsive Systems Inc 1992). The work of the O'Briens has been studied closely by some of the families over the years and their work (although it is not new) continues to provide a basis for innovations from time to time. The Circle as we see it will most likely include the following as members:

- Innermost Circle: the person with a disability
- Inner Circle: the Anchors
  - Executor of Will and trustees
  - Close family members including brothers, sisters, nieces and nephews
  - Identified close friends and active supporters
  - Trusted former support workers
- Second Circle: The Allies and Associations
  - Friends
  - Involved members of the local community: neighbours and local identities
  - Community groups
- Outer Circle: Assistance and Agendas
  - Services: supported accommodation, employment agencies, sport and recreation services, government case workers etc
  - Medical Specialists and health care professionals
  - Financial advisors

The reality for many people with a disability is that they develop few friendships in natural ways. For many people with disabilities, the only other people in their lives are close family members and/or paid workers. Consequently, we have to be deliberate and intentional in our ambitions to develop a network of unpaid people to provide long-term commitment and support to family members with disabilities.

John O’Brien and Connie Lyle O’Brien developed a diagram which identifies five different types of commitments that promote wellbeing in the lives of people with disabilities:

- Anchor people, who love the person and are a source of continuity and strength over time.
- Allies, who develop personal relationships with the person, help them work towards a desirable future and share knowledge, contacts, time, activities, conflicts and fun.
- Assistance, either voluntary or in the form of money and service supports (such as personal assistance, assistive technology, learning opportunities, advice representation).
- Associations, formal and informal community groups that are organised around the member’s common interests.
- Agendas, political action to ensure just and effective public policies.

Until people organise themselves around the person with the disability and the family, there are limited opportunities for maintaining a desirable future. When the people are committed, the person can realise a better dream.

Both authors go on to state that when ideas and actions toward a desirable future attract these five commitments a person can move into their future with more assurance and personal power, deal better with setbacks and failures and feel more safe and secure.

That’s why it’s important to start developing personal networks now. The focus on personal networks is based on the belief that people keep people safe in the long term - not legal mechanisms, funding, services or government.

However, there is also a need to get the legal issues right – the wills, trusts, guardianship and administration mechanisms. In resolving the legal issues, clear vision and a plan can assist in determining whether formal appointments of guardians or administrators will be necessary and what provisions to make in a will.

We know that getting legal issues right will not necessarily be enough to keep family members with a disability safe when immediate family members are no longer around. Many of the practical issues which arise when considering the legal issues can also be addressed through personal networks such as support circles. Practical concerns might include: who will continue to provide informal decision-making support to avoid formal guardianship or administration; who will be appointed as trustees in wills; who will ensure that trustees follow the family’s vision, plan and wishes expressed in wills. Committed networks such as support circles provide a potential source of people to fulfil these formal and informal roles.

Stepping Stones for parents – the story so far

Homes West families currently have varying levels of involvement in their family member's life. This depends on the abilities of the person, and the capacity and culture of the family. The risk of the person's needs not being met increases the more 'family business' is taken over by the service.

Features of family business:

- develop a positive vision for their family member and themselves and to plan for the future
- establish the values and standards for their family member's future life, and to safeguard his or her privacy and integrity
- help the person to decide what is negotiable and acceptable within the family's culture, beliefs and traditions
- direct the level and type of service the person needs.

To prepare and support the next generation, it is expected that the parents of the person with a disability (while they are still active and able to be involved) will initially lead the circle of support with the intention of delegating responsibilities in their own time.

They will most likely invest in the future by:

- giving parental love, involvement and care
- planning, planning and planning!
- gathering and documenting clear and concise information and then sharing that information with key stakeholders. Parents need to consider writing a journal that clearly explains what they have done, what worked, what didn't, who has been involved, what support and contacts have been established etc. and importantly what the parents' wishes and intentions for the future of their offspring might be.
- discussing plans and ideas about the future with siblings
- developing a clear written agreement about the boundaries between the service (service business) and family business. Each family differs in their approach and therefore a written agreement is negotiated between the family and Homes West which outlines the responsibility of each party.
- continuing with hands-on support and high level involvement in the day-to-day life of the family member for as long as they are able
- anchoring the person in the community – making connections, establishing the networks of support
- putting safeguards into place
- providing additional financial support when required
- developing long-term financial plans via their Will arrangements.

Possible Stepping Stones for siblings

Many Homes West families believe that ensuring continuity of care for our sons and daughters is most likely to result from involving the members of the next generation of each family – brothers and sisters and in turn their children, the nephews and nieces of the disabled person.

Homes West families find themselves fortunate in the support they can already rely upon from their other children. The current Chairman of Homes West is the brother of one of our supported people and he coordinates meetings and activities for and around the younger members of other families.

Many of our younger children now have young families of their own and limited time available. In the future as their families grow up, our hope is to be able to look to them to take over the supervising, coordinating role presently performed by us, the parents. In time some of our grandchildren may feel that they want to participate.

By the time our grandchildren are young adults there will, we hope, be many other organisations like Homes West; and being part of the support for people with a disability living in their own homes will be seen as an option for altruistic young people wanting to contribute to the community.

If the person's anchors and allies are strong and able to accomplish links to other community people and groups, the siblings of the person will most likely have a less responsible role to play in that they may not have to provide the same level of day-to-day care of that person. They will however, most likely have a major role to play within the circle of support around the person in terms of:

- guardianship and executor responsibilities
- decision-making about the health and wellbeing of their brother or sister
- ensuring the safeguards are working effectively
- liaising with the service providers who support their brother or sister
- maintaining the links with other family members and friends
- seeking out family supporters for the next generation of support.

Philip's story (cont'd) as told by Chris and Julia, Philip's parents

Our younger children come up with plans that we would not have thought of. When we returned from our overseas trip, we found a large barbecue in Philip's back yard. 'We went out and bought it,' said son Mathew. 'Every bachelor pad has to have a barbecue!

'

Stepping Stones for Homes West – the story so far

The governance of Homes West remains with the people being served and their families

Homes West must have a majority of family members or people who receive services on the Committee of Management. The committee also tries to attract community representatives who can offer essential expertise. The next generation already has two representatives on the Committee of Management.

Work collaboratively with a person's family and natural network

Homes West acknowledges that the natural networks in a person's life are crucial for the person's safety and wellbeing. The results are that the support workers do a better job, the family is more accountable and life is generally more interesting for the person with the disability.

Typically it is the family and friends who hold the history and knowledge about the person. Homes West is simply unable to provide a good service without their direction and collaboration. Family members are currently preparing documentation relevant to the person with a disability to hand on to the next generation.

Gain the trust of the people and their families

Homes West has to gain the trust of the people and their families, regardless of their previous experience with services. This can only be done by efficient and effective service and moral and trustworthy behaviour. It is expected that Homes West will continue to set up Family Agreements in the future.

Keep small, knowing what is going on in each person's life

Homes West families want the coordinator to end each day knowing how each person is going and to have a fair idea of the 'state of play' for each family. Contact needs to be regular and the detail of the service thoroughly understood.

Keep separate staff arrangements for each person

The management of Homes West is of a cooperative nature and information and knowledge is shared. However, privacy needs to be maintained. A good safeguard has been not to share support workers across households. If someone works for one person he or she cannot work for anyone else in Homes West.

Understand limitations

Services governed by families are still services with all the responsibilities and limitations that services have. It is therefore important for Homes West to be clear about its purview. The Homes West committee understands what service business is and how to keep this clear and separate from each person's family business.

The notion of service business and family business has been outlined previously. Families have an equal responsibility to clarify what is their family business.

As families age, they can be seduced into trying to hand over to Homes West more and more of their family business. The dangers of this have been examined already. It will be clarity of purview by both parties which will ensure that the person continues to receive the right type of service in the right place at the right time.

Make a commitment never to cover-up or ignore poor service

Homes West cannot afford to cover-up or ignore poor service. Rather, it seeks to promptly redress the situation and immediately review policy and procedures for workers and families.

Commit to regular review

Homes West, like any other service, is at risk when it thinks that it 'knows it all' and the committee and or the coordinator have become complacent and less open to challenge. Regular reviews and evaluations should generate new ideas that are worth investigating as trial projects. If successful, such trial projects could be considered for acceptance into formal policies.

Homes West is committed to regular external scrutiny through evaluation and review.

A checklist for the future

The vision of the family and the person is shared and understood

When the vision is clear and well understood by the person, the family, the community and the support workers, the small achievements can boost the enthusiasm for everyone. Homes West families work hard to acknowledge them and share the success with everyone, for good reasons. Nothing succeeds like success.

Each person is valued and understands their part in 'making a good life for a person'

It takes very little to thank people and to acknowledge their contribution and value. Homes West families have found that staff become engaged and excited about the achievements of the person they are working for; and when their contribution is sincerely acknowledged, they enjoy greater work satisfaction. A significant time within staff meetings may be taken up acknowledging the achievements and each person's contribution towards them.

Clarity of roles and a commitment to teamwork

When people are clear about their role and their boundaries, they feel more confident in taking action and asking for assistance when they need it. If support workers have strategies to solve problems (and they succeed), then the small issues will not become big ones.

Homes West families aim to work alongside support workers, shoulder to shoulder. This is when 'doing what it takes' becomes a reality. If each person is clear about the vision, their value and their role, they are more willing to 'bend over backwards' and to use their creativity to make things happen.

Problems are solved locally, immediately and creatively

A tiny problem for the family may be large for support workers, and vice versa. Prompt resolution of problems or requests has proven to be a good strategy to assure both families and support workers that they are taken seriously and are being looked after. There are often a number of ways to resolve something. If everyone is trusting and confident, they will be willing to try simple, creative and less intrusive strategies first.

Successes, anniversaries and opportunities are celebrated

The daily struggle to create a worthwhile life for a person can overshadow the achievements. Homes West families try to celebrate each success, anniversary and opportunity that has presented itself. Even ‘not going backwards’ is worth celebrating if that has been the challenge.

A continuing commitment to try new ideas and opportunities

Homes West families can tire of new support workers coming with bright suggestions after knowing the person for only a short while. It takes an open mind and a level of generosity to listen to these new ideas and try new opportunities.

It may be the enthusiastic young support worker or friend who challenges the family to try again or allow someone else to try a good idea. This, of course, is tempered with family’s sound judgment about setting a person up to fail.

Clear and known strategies to resolve grievances

Homes West families have seen the inevitable communication breakdowns, poor service and betrayals. For families, the most empowering policy decision has been that if there is an irretrievable breakdown in communication with either the person or the family, the support worker must leave. Homes West families know they do not have to tolerate support workers whom they do not trust.

Similarly, Homes West families know that their behaviour may not always be reasonable. They may be unfair in their requests or criticism. Support workers know they can go to the coordinator to try to resolve this situation. This strategy has saved Homes West losing good support workers because of a stressful time or a misunderstanding.

Recapping what we've learnt as we prepare for the next generation to take over

This work has only begun in Homes West. However, it is worth recapping the strategies used by Homes West families now. It is hoped that these strategies will stand the test of time and be relevant for the next generation.

Review assumptions

Homes West families need to regularly review their assumptions and to reassess their vision for their son or daughter. As each person changes and grows the picture changes and the old assumptions may no longer be accurate. Not to do this will inevitably limit a person's life opportunities.

Be prepared to be challenged

Families are human. They can develop unhelpful behaviour and be blind to issues. Families need to be challenged to do better, like everyone else. How this is done is important. Most families are already very hard on themselves and it will take someone whom they trust to assist them to look at themselves.

If positive and loving guidance leads to a better life for their son or daughter, families are usually grateful for the assistance.

Prepare for when they are gone

Actively preparing for a life for their son or daughter after they have gone is a most important strategy for families.

Remain robust in the meanwhile

Homes West families know they are not dead yet and there is still lots to do. Keeping robust in the meanwhile can be helped if you:

- *Don't go it alone.* It is best to have other people with you. These people need to love you and share your vision for your family member. These friends will care enough to notice how you are travelling and will come to assist, if you allow them.
- *Learn to pace yourself.* Don't try to do it all at once. Allow for regular breaks for both you and your partner.
- *Hang out with hopeful people.* Seek out like minds. Avoid people who drag you down or undermine your vision.

- *Celebrate the milestones.* Often, milestones creep up and are missed. You can concentrate on doing, doing, doing and forget what you or your son or daughter has achieved. Anniversaries are also important to celebrate. Often just doing the same thing for a year is an achievement in itself.
- *Accept that your life is different.* Your role as a parent of a person with a disability is extraordinary and never-ending. Your life, therefore, will be different from your friends and colleagues and there will be few people who will understand. The sooner you accept this and cease railing against it, the sooner you can get on with the job.
- *Acknowledge your sadness, tiredness or anger.* There are times when we all feel down and find it difficult to get up again. You are no use if you are living half a life, becoming dysfunctional and dragging your feet.
- *Pay attention to your health and wellbeing.* You may need to make some life changes in order to manage better. The important thing is not to wallow or remain stuck. Then you become part of the problem.
- *Use your energy wisely.* Assertive families are often roped into broader disability issues, sitting on committees or working in the disability field. This is admirable and a good way to become more skilled and informed.

Check that you are not getting angry and frustrated by trying to change large systems or to influence people who will soon move on to another job. Use your energy wisely by keeping your son's or daughter's future as your main priority.

It is also helpful to do something completely different and rewarding. You will return to your daily challenges with renewed energy and perhaps another perspective.

Conclusion: thoughts from the Chairperson of Homes West, a member of the Next Generation

John G's story

My involvement with Homes West began when I attended Homes West Family Days at the request of my mother. My mother is the oldest parent in Homes West and my sister the oldest person cared for by Homes West so I felt it was time I took an interest.

Subsequently I was asked to serve on the Management Committee and during my second year on the Management Committee took over as Chairperson midway through the year.

Therefore my education about the philosophy of Homes West and its workings has been somewhat rushed and I do not pretend to know the answers about the future.

However I will offer some observations and suggestions from the perspective of a brother of a service user gleaned from the experience I have mentioned.

'I want my children to become involved in caring for their sibling in the future but they are busy and I don't like to ask.'

When I first attended Family Days it was apparent that the most serious and abiding concern parents had was for the future. Discussions would centre on support circles but tended to be repetitive and vague. The parents were worried but what were their worries? Parents hoped their children would attend but were reluctant to ask them because 'they are busy and I don't like to ask' or else were fearful that they might say no. Occasionally a son or daughter would attend but not regularly because I think they found the experience unproductive, failing to engage them or deal with specifics.

As Chairperson I took the step of calling a meeting of brothers, sisters and friends but excluding parents. To my great relief the meeting was well-attended and the message was very clear; that they too worry about the future of their siblings and feel responsible for supporting their brother or sister. They also said that being shielded by their parents only adds to their concerns rather than allaying them because of their uncertainty of what will be required of them in the future.

The Future of the Organisation

Before I acted on the Management Committee I did not realise what a unique organisation Homes West is in the quality and type of service it provides. Should Homes West fold or be taken over, few other services exist which embrace Homes West's philosophy or standards.

Maintaining this service comes at a high cost. Each family needs to make a commitment to not only support their loved one but also to support the Association *as a whole. Until recently this commitment came almost exclusively from parents. However in the future brothers, sisters and friends will need to fill this role.*

As one of the members of the Next Generation, I have undertaken to make this commitment because I want to see my sister Jane maintain her quality of life. Secondly, from a purely selfish viewpoint I worry about the work that would be required to get Jane another service. I feel a little commitment over a long time is far preferable to the trauma should the organisation no longer be viable.

Sustainable Futures

Homes West believes each family should work towards developing a support circle and has taken the step of engaging facilitators to work through this process with families. For most families the children will form the core of the circle.

As part of this process I would like to see parents work with their support circles to develop a hand-over plan that is specific about their concerns for the future. This would allow the circles (in particular, the siblings) to have input into future planning. After all they will be the ones providing the support in the future.

Also I would like to see parents talk to their circle about Homes West as an organisation and what roles they might play in the future maintaining its viability and integrity.

Attachment 1

The Natural Authority of Families

Michael Kendrick (CRUcial Times, Issue 6, July, 1996)

With great regularity, consumers of services and their families will find themselves having to confront professionals, bureaucrats and others in roles of authority. Not uncommonly the authority of these persons tends to overshadow the authority of "small people". It can sometimes help to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power and authority. In order for this to happen, however, families need to appreciate this natural authority and be willing to act on it. What follows is brief description of some of the common sources of authority that families can call on when they are acting in the interests of a family member.

1. The public generally recognise the primacy of families in terms of their responsibility for a person's wellbeing. In this way, families have the authority to be highly engaged because they also tend to have greater responsibility for the wellbeing of their gamily members.
2. Families have authority (normal) arising from knowing their family member the most fully and over the longest period of time. In this way they have the authority that arises from long term observation, insight and personal relationship.
3. Families typically care about or love their relative more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.
4. Families have a stake in outcomes. For example, they have to live with the long-term consequences of service failures to a greater extent than any other party, except the person themselves.
5. Families are expected to advocate for their own members. Not uncommonly, they are granted considerable presence in the decision-making processes affecting their family members, even where legal formalities do not require it.
6. The family is an authoritative witness to the performance of professionals and systems and may have special (though not necessarily exclusive) insight into events that take place.
7. Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an expert educator.
8. Families are often best positioned to see how everything in its entirely, adds up in a person's life. For this reason they can often see the incongruencies of different interventions.
9. Family members are often free of the vested interests which call into question the credibility of other parties. Frequently family members are granted a degree of independence which highlights their credibility and purity of motive.

While these common sources of authority do not, in the end, resolve the question of ultimate authority, they do offer families some measure of security that their views should matter as much as, or more than, others who also claim authority in deciding what will happen to a person. Because it is very difficult for a person to advocate if they hold some doubt about the legitimacy of taking on the role, these points may help to strengthen the resolve to hang-in-there and advocate for your family member.

Attachment 2

Social Role Valorization (SRV)

Social Role Valorization is the name given to a concept for negotiating human relationships and human services, formulated in 1983 by Wolf Wolfensberger, PhD.

The major goal of SRV is to create or support socially valued roles for people in their society. If a person holds valued roles, then the person is highly likely to receive from society those good things in life that are available to that society or at least the opportunities for obtaining these. In other words, all sorts of good things that other people are able to convey are almost automatically accorded to a person who holds socially valued roles, at least within the resources and norms of his/her society.

A high degree of consensus exists about what the good things in life are. A few major examples include home and family, friendship, being accorded dignity, respect, acceptance, a sense of belonging, an education, and the development and exercise of one's capacities, a voice in the affairs of one's community and society, opportunities to participate, a decent material standard of living, an at least normative place to live, and opportunities for work and self support.

Attachment 3

People business: mutual expectations, energisers and respectful clues

Paid service can have an important role in people's lives. However, we all need much more than this. Unconditional friendship and love are essential for us to have a good life… and cannot be bought.

The defining process will start with a clearer understanding about the place of paid service in a person's life.

We will then establish the expectations of families, workers and Homes West, before moving on to a better understanding of the importance of spontaneity, energy and creativity in a person's life – and how these elements can be woven into the business of, and relationships between, families, services and communities.

How paid service fits in a person's life

In paid service, strangers are interviewed, hired and given money to assist a person. Workers are directed to carry out tasks within agreed boundaries in the expectation that they will be done. Workers can be dismissed if they do not do as they are directed or if they do anything illegal, dangerous or immoral. In return, workers can expect to be paid fairly and given reasonable working conditions.

Usually, support workers do not make a long-term commitment to your family. They will have personal goals and issues which will be more important than those of your family member. They need time to understand the family culture and customs as these are unique to each family. In any dispute they may choose to be loyal to other people, and not the family or the person with the disability.

Occasionally, a support worker finds great satisfaction in his or her work and will make a long-term commitment. It helps if the family has the capacity to increase the support worker's responsibility, skill development and salary over time.

Paid service can have an important role in people's lives. Many tasks can be done which will improve a person's life, for example:

- personal attendant care
- preparation of food and housework
- assistance with travel and daily personal administration
- assistance, protection and safety while carrying out daily living tasks
- organisation of daily activities and facilitation of connections in the community.

However, all of us – including our family member with disability - need much more than this. Unconditional friendship and love, an expectation of reciprocity and intimacy are essential for a person to have a good life. These cannot be bought.

Most people look for these from their family and friends first, and then from people who want to be with them and are freely able to give their time and energy. Any long-term, life-choice planning with a person must unequivocally understand that paid service is only *part* of the big picture.

Mutual expectations: What families expect . . .

1: From a worker

Typically, Homes West does not employ workers who have long histories in traditional services. More often, workers are students or local community members who have common sense, good work ethics and a genuine interest in the person they are employed to serve. There is an extraordinary and endless reservoir of able and talented people who can become excellent workers with the guidance of the family.

Acceptance of the person and the family

Families expect workers to accept the person and his or her family unconditionally. Clearly this does not include illegal, unsafe or immoral behaviour.

The family often assists employing and training the person. From the start, the worker understands the importance of the family and friends in the person's life and works alongside them. If this relationship breaks down, that is reason enough to discontinue employment.

Honesty, reliability and integrity

Families invest a high level of trust in workers and expect honesty, reliability and integrity. If this trust is betrayed, workers are asked to leave. Workers typically rise to this challenge; workers who know they are trusted for their honesty, integrity and reliability are proud of it and will rarely, if ever, take it for granted.

Willingness to work in a team

Each person has his or her own team and its success is dependent on the workers pulling together. Homes West spends considerable resources on team-building to assist this happening. Families also spend time with each worker encouraging a culture of give and take and thinking as a team.

Capacity for creative problem solving

Each worker comes with his or her own capacities and talents. Families encourage them to contribute in creative ways. People have talents in cooking, shopping, singing, gardening and housekeeping. The team works best when people are able to do what they like the best and make a positive difference.

Workers are also encouraged to problem-solve creatively. There is a risk here. However, once a team understands the family culture and is trusted, they will be well-equipped to deal with an unexpected situation.

2: From the Coordinator of Homes West

Homes West's business:

- brings families together to govern and direct the business of Homes West to ensure the service does the best for people
- allows families to make the hard decisions – what is non-negotiable, when to compromise, what is possible and what just can't be done
- nurtures the spirit, and maintains a willingness to come together to work for the common good of the families and
- reaches out to the broader community to place Homes West as an organisation and to find supporters and future leadership.

The relationship between the families and the Coordinator is also critical to the quality of the service to the person. The Homes West committee, in consultation with the Homes West families, employs the Coordinator so all families have an opportunity to ensure they have the right person for the job.

Homes West families expect fidelity with the person and the family

Homes West families expect the Coordinator not to make judgements about the person or their family, to speak positively about them at all times and to defend their good name in any conflict or external review. Clearly, the Coordinator is not expected to support illegal, unsafe or immoral behaviour.

The Coordinator understands the uniqueness of each person and their family and responds to their individual needs

Each Homes West family will communicate differently with the Coordinator and expect different levels of support. They expect this level of flexibility and the capacity to 'do what it takes' to ensure the best possible service is provided.

Service business:

- builds on and supports what networks are naturally there
- protects the person and their family from intrusive bureaucratic processes
- provides accountability for the expenditure of funds
- employs, trains and supports staff
- supports and encourages the families for the long term to do their best.

Homes West Committee is the formal employer of the workers and the Coordinator manages their employment (and dismissal) procedures

With the authority of the committee, the Coordinator manages the workers and the employment (and dismissal) procedures with regard to the wishes of the person and his or her family. The person and his or her family can ask for a person to be dismissed if their trust is betrayed or they can no longer sustain a relationship with them. This is not questioned. The Coordinator supports the family and manages the formal processes.

The Coordinator, with the committee, protects the person and the family from intrusive bureaucratic processes

As much as possible the Coordinator relieves the families from the intrusion and stress of formal accountability and review processes. This does not mean that families resile from their responsibility in assisting that the service to be well run and within budget.

Each family has a service agreement and an individual budget for the service. The Coordinator assists the family to work out how the funds can best be spent and works to find more funds if they are needed.

The Coordinator facilitates only the paid service element of a person's life

With such a close involvement in the person's life, there is a temptation for the Coordinator to step into territory beyond that of paid service. This territory is not well defined especially when creative strategies for support involve people who are giving their time freely. The conversation about how and when Homes West becomes involved is ongoing.

Nevertheless, it is understood that if the Coordinator facilitates too many aspects of a person's life there is a danger of Homes West taking control. If a family begins to hand over the 'family business' or the service assumes too much responsibility it is up to everyone to raise the alarm.

The Coordinator will make a long-term commitment to Homes West

Homes West needs a Coordinator who will invest time and energy to know the people and the families well and to develop a robust and trusting relationship. This job is not a stepping stone for a 'bright young thing' to greater and more prestigious employment. It is for someone who makes a long-term commitment to the Homes West families. For this to work, the families are expected to reciprocate their commitment to work through any issues from time to time.

Homes West has had only two Coordinators in its 10 years of service. The commitment of the two women has had very positive outcomes for everyone in Homes West. This pattern is reflected in most small services that have had similar priorities.

3: From the funding body

The main funding source, at present, is government. The departments involved currently have clear expectations of families to support their family member with a disability. In turn, Homes West families have expectations of these departments.

Staff who are knowledgeable and experienced

A responsible funding body ensures that its representatives are knowledgeable and experienced in the field. Further, they have a good understanding of how community organisations work and the character of the region where they work. Homes West therefore encourages the staff to stay in their jobs so that there is some continuity and history maintained.

Homes West families prefer to work with officers who respect the current leadership in the community and who understand what could be possible with constructive partnerships.

Respect for the natural authority of families

Homes West families expect officers to understand the natural authority of families and the comparatively transient nature of service workers. Officers would seek to work collaboratively with families towards the most effective and cost-efficient outcomes for their family member.

Simple actions evidence this respect. When correspondence is answered promptly, meetings are held at the least cost to the person with the disability and the family and communication is helpful, direct and relevant, families co-operate.

Reasonable accountability processes

Accountability is important for everyone. Families who govern services need to be accountable for their actions around their sons and daughters as much as any other service.

These processes have become more complex and time-consuming. Families expect departments to tailor their accountability requirements to the nature of the service and its capacity to respond.

Mutual expectations: What Homes West workers expect from families

A clear written agreement

Homes West families are asked to be clear about the boundaries of service business and family business. Each family differs in their approach; therefore a written agreement is negotiated between the family and Homes West which outlines the responsibility of each party.

Respect for workers' rights

Families are obliged to respect the rights of workers as outlined in the Award. This is complex and both the workers and Homes West have a responsibility to ensure that these conditions are fulfilled. The workers have their union for support and advice and Homes West does receive advice from an employer advisory service for a fee.

Requests are reasonable and consequences are understood

The day-to-day involvement by each Homes West family differs. Homes West families have clear authority to change workers' arrangements and household routines to meet the changing needs of the person. This is a very important strategy to respond quickly to need and to take advantage of opportunities as they arise. Workers need to understand this arrangement from the start. In turn, families are expected to be reasonable in their requests and to understand the consequences of their directions for workers.

Regular meetings with staff and sharing information

Homes West families are guided to have regular meetings with staff, where open and honest discussion can be had on how the service is going. As the families expect workers to understand, support and respect the family culture and history, they need to spend the time sharing information with them.

Occasionally, difficulties arise between the families and the workers. This may stem from the emotional involvement of families and workers' more detached understanding of the situation. The Coordinator has found that meetings without the family allow for staff to express their feelings and to clear the air. With the trust of the family, the Coordinator can affirm the family's authority and at the same time find a way forward without further acrimony.

Attachment 4

Practical strategies for respectful relationships

The family does some of the support work

Homes West families vary on this strategy according to their capacity and their funding situation. When families sleep over, cook the dinner or clean the house for their son or daughter, they find out first-hand what they expect of their workers.

Families discover small issues which can be fixed easily (a better broom, warmer bedding, a different cleaning product) as well as how well the work is being done. Families can then contribute with greater understanding of the day-to-day issues of the household. Families also find this is an excellent way to maintain their relationship with the workers while instilling the family culture and values.

Families are readily available and willing to problem-solve at short notice

Although the Coordinator is expected to be available at short notice and can deal with many issues, it does not take much these days for families also to be available. Mobile phones are excellent for this.

This requires a level of intrusion and personal discipline. The outcomes are well worth it. Families can rest easy knowing that ‘no news is good news’ and that there is no excuse for not taking action when and if it is needed.

Directions, customs and routines are clearly documented

What can be in writing should be in writing and readily available. Documentation of daily routines does not have to be onerous or intrusive. It can be a small ‘how to’ book in a drawer. It avoids the difficult conversations of ‘But, you never told me.’

It is also a good measure of how things change in a person’s life. Details which may have been important may decrease as a person develops and grows. It becomes a training tool and a good way to hand over detailed information to a newcomer.

Develop a culture where it is OK to admit you were wrong, or you forgot to do something

To err is human. Everyone does it and saying ‘sorry’ saves wasteful bitterness and resentment. If you can show you are fallible, then workers are more likely to own up to their mistakes.

This is an important practice if you are expecting real teamwork and trust.

What you can do now

Talk to other families about who have been good workers and why.

Analyse when you worked well in a team and what made it successful.

Develop some skills, if you don't have them already, in team-building and working with people.

Identify what you see as 'family business' and what tasks you are willing to hand over to a service. What is the situation now?

If you have handed over too much to a service, identify what you want to take back and do it.

Begin documenting how you would like your son or daughter to be supported. Both general ideas and detailed information are important. You can build on this over time as your ideas become clearer.

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