

The Homes West Experience



Choreographing:

arranging
composing
designing
planning
strategising
directing
organising and
stage-managing
the dance

Choreographing the Future

How succession of authority and responsibility for family business can be planned for in the lives of people with disability in order to continue a good life after parents have gone

This document was an initiative of the Stewardship Group associated with Homes West, with its content facilitated at a Family Day workshop and written by Jan Dyke.

Homes West Association Incorporated (Homes West) is a service in Brisbane, Australia that works with 11 families to support 12 people with a disability to establish and to live in homes of their own and to be included as active and valued members in their local community. However for families, the Homes West experience is much more than having a service supporting the daily life of a loved one. The experience has led to a way of life, one in which many aspects of authority and responsibility have been retained by family members or delegated by design, so that their choices and decisions give direction to their family member's life and safeguard how life is played out, not only now, but also into the future.

This paper follows *Choreographing Life*, an earlier paper on how authority and responsibility can be delegated and shared in right relationship in the lives of people with a disability when they use services that support daily life. In the first paper, families identified elements of life that needed to be maintained as the business of the family and trusted enduring friends. In this second paper, families share their understanding and experience in coming to grips with what needs to be in place in order for these aspects of family authority to continue on in a similar fashion after parents have gone.

The death of parents is always a difficult subject to address and an even harder one when parents are the key decision makers in the life of a son or daughter who has a disability. Many parents do not want to think about how life will continue for their son or daughter with a disability when they are not around – it is often just too emotionally difficult. After all, it embraces our two strongest emotions of love and fear.

Considering what the life of a son or daughter with a disability will look like after the death of parents is always difficult

Sometimes it may be easier to believe that things will somehow fall simply into place, despite this rarely having done so during life, or that family members or good service workers will just step in and fill the gaps. At other times it may be easier to deny the inevitable, hoping that it will never happen, or that things do not need to be addressed just yet, as really the time is a long way off (and, of course, then it always remains so).

The best way to predict a future is to create it.

Despite these feelings, families who are part of the Homes West experience have questioned why their son or daughter shouldn't continue to have a good life and still be supported by other people who have an enduring commitment to them. They have begun to address the succession of family business to the next generation and have sought people who will continue to ensure that the person remains in a home of their own and has good supports that enable them to continue to be a valued member of their community. If there are key things in place to ensure that their vision of a good life continues to be played out after they have gone, they know that their son or daughter will be safer and lead a better life. The families have therefore begun to work on what needs to be in place for planned succession to happen so that they can have a little more peace of mind, knowing that at least some aspects of the future are more assured.

The business of families and trusted enduring friends

In the first paper, these elements were identified as being the business of families and trusted enduring friends:

- Holding the story and understanding of the person's life
- Holding the knowledge and practice of the culture of family life
- Holding knowledge of the person's medical history
- Holding knowledge of the person's skills and abilities, likes and dislikes, gifts and concerns
- Daring to dream the seemingly impossible
- Holding onto the dream about what life could be like
- Imagining what a good life would actually look like with and for the person
- Developing a practical vision of a home of ones own and being an active and valued member of the community
- Deciding where the person lives and with whom
- Thinking lovingly, passionately, intuitively and at times irrationally about the person
- Ensuring that committed people are there now and into the future
- Ensuring that support will be there in the future
- Fostering natural networks in the person's life
- Maintaining a valued role in family life
- Keeping important dates such as birthdays, anniversaries etc
- Celebrating significant rights of passage and important events
- Advocating on the person's behalf
- Giving time and energy freely
- Contributing talents and relationships in pursuit of a good life
- Giving unconditional love and friendship and expecting reciprocity and intimacy
- Planning for a financially secure future in a home of their own
- Considering how the person's future health and well being will be catered for well in later years
- Having a high degree of influence on matters that affect the person's life without having to expend a lot of energy to achieve this
- Having the authority to influence, decide, negotiate, refuse, imagine better, change mind, or counter propose with better ideas
- Naming the nature of supports the person needs
- Allocating supports in ways that reflect the vision for the person's life and well being
- Selecting or approving who comes into the person's life to provide paid support
- Rejecting who comes into the person's life to provide paid support
- Guiding the service to interpret the wants and needs of the person
- Making decisions about health, general nutrition, exercise and well being
- Making decisions about personal finances
- Monitoring to ensure that the expectations of the culture of daily life are maintained
- Monitoring health, well being and quality of life
- Monitoring personal spending.

Key questions that encourage thinking about the future

If these key elements of family business are to be preserved over time, two key questions arise:

- How can these identified aspects of family business be continued when parents are no longer able to take these roles?
- What are things that can begin to happen now, while parents are still alive, that will lead to a more secure and sustainable future for their son or daughter?

In other words, what needs to be in place so that a good life is sustained for their son or daughter, enabling parents to have greater peace of mind as they age?

SUSTAINING A GOOD LIFE

The families involved with the Homes West experience have identified 11 key elements that will help to assure the future for their son or daughter with a disability.

1. **Hold and share a personal vision for the future**
2. **Engage the next generation of family members**
3. **Encourage others to step forward into the person's life**
4. **Enable others to understand the person's story**
5. **Share practical living knowledge of the person**
6. **Work out planned strategies to move the vision forward**
7. **Establish a home of one's own**
8. **Have good service provision working in right relationship**
9. **Seek broader social connections in daily life**
10. **Know what happens in daily life**
11. **Secure decision making and finances in a will and trust.**

1. **Hold and share a personal vision for the future**

Over the years, each family has developed and held a very personal vision about what a good life looks like for and with their son or daughter with a disability. Initially this vision focussed on the life of a young adult in the context of family and community and worked towards the person moving out to live in a home of their own. This thinking has helped to set the **framework and direction** for the way each person is to be seen and treated, as well as very practical things that are worked towards in daily life, including the nature of the paid service that has developed as Homes West.

The vision reflects that there is much more to life than paid services.

However families have also recognised that there is much more to life than the paid service components. In fact it is only one of many important elements. They believe that developing and holding a vision about what a good life will look like needs to be considered outside the confines of service provision, as it is much broader than the paid aspects of a person's life and should not be built around what the service can provide. If the person is to be a valued member of their family, neighbourhood and community, then the vision must also encompass the broader relationships and daily life engagements that make up the overall experiences of the person's life.

The vision can be seen to create a **personalised framework** for the direction of life's journey for the family member with a disability. It is created with and for the family member who remains central to all thinking. Yet, as journeys always head into the future, the future cannot be denied. The vision not only sets out what is wanted and what is to be avoided in the person's life now, but also takes a crystal ball approach to explore what the vision of life will look when parents are no longer there.

Clarify what is not wanted and what is, for now, as well as when parents are no longer there.

Emphasis is put on recruiting and informing the next generation.

When the development of a positive future without parents is embraced and explored, emphasis is put on recruiting and informing the next generation of committed people to take over family business roles. This means that a very different scenario is played out in real life with the focus becoming quite different, questioning who will be around to continue to love the person and take on the anchoring roles that are so essential for the development and continuation of a good life.

Parents begin to look at what they need to preserve and pass on to others, as well as what they want to avoid at all costs. They share their hopes and dreams and what they have been trying to achieve. As part of this process, others learn their family values, history, culture, stories, traditions and expectations that are important to preserve in order for the person to have a good life. The result is that the person begins to have an **intentional community of committed people built around them**. They join the journey alongside the person and are willing and prepared to step in to continue the vital roles of family business long after parents are no longer there.

Others learn about family values, history, culture, stories, traditions and expectations that are important to preserve.

The parents' vision needs to be shared and developed further with other members of the family, as well as trusted and enduring friends. This is especially important with those who are likely to be taking on decision making roles in the life of the person in the future, when the person has limited capacity to do so themselves. Such future roles could be in matters of health, or use of finances, or in lifestyle decisions, such where or with whom the person will live.

The **shared vision** is usually broad, incorporating an understanding of what makes a good life, including:

- having **loving, committed relationships** with the next generation of family and friends who know and understand the person, and who continue to carry on the role of family business
- having a **home of one's own** where life and support are personalised, and where safety and security of tenure are assured
- living a **life as a valued member of the community**, where opportunities, participation and contribution are encouraged
- having **economic security** and the ability to incorporate expectations about life as other family members do.

In order to ensure that the family vision is kept alive and held for posterity, key elements of this vision can be **written down** to help to steer the journey into the future. This might be in the form of a personal letter from the parents that guides the next generation of family and enduring friends or a memorandum of understanding that establishes the scene for a trust, set up for the person upon the death of parents. Some families might choose to do both, or may choose to do this as a recording.

This **message to the future** is very personal and might contain the following:

Life should not be a bread and butter existence. There should be opportunities to have the jam.

Message from a parent to her children

- Why this message is being written
- Hopes about how you would like your son or daughter to continue to be loved and cared about
- Fears about the nightmares that are to be avoided
- What a good life might look like
- Some important things that others need to know.

2. Engage the next generation of family members

The families involved with the Homes West experience know that personal relationships are the key to having a good life. They know that their son or daughter will do better when they have people in their life who love,

Personal relationships are the key to having a good life and keeping a vulnerable person safe.

understand and care about them, who will act in their best interest, overseeing life and taking up issues on their behalf. After all, this has been their personal experience as a parent. They believe that committed family members can continue to share relationships, connections, experiences and aspects of their lives, maintaining a valued family role for the person and enabling greater happiness and safety in the process.

Parents hope that loving family members will be there – but hope is not enough.

Many parents hold the hope of having close relatives from the next generation, often a brother or sister taking an anchoring role in the person's life. Yet they do not want them to have to do what they, as parents, have had to do. What they do want for the future is having committed, loving and anchoring family members who will continue to drive the personal vision of a good life forward for and with the person, and who will maintain and oversee the essential roles of family business in the person's life to safeguard the person's well being.

However they also want to avoid the assumption that other family members will take over responsibilities automatically when parents are gone.

Often a son or daughter, or sometimes all the next generation, will blithely promise to be there for their brother or sister with a disability. This can be a great relief to parents, yet it can also be an easy way for both parties not to have to deal with the reality of what this means. With the heightened mobility of our global world, family members are frequently spread across the city, the nation or overseas. They also may have busy working lives and, with marriage or partnership, and children of their own, their situations bring very different dynamics and lifestyle pressures into play. It is therefore not unusual for the next generation of family members to have lost contact and understanding of what daily life is like and what it takes to support their brother or sister in adult life – after all, they have been busily developing an independent life of their own away from their parents.

It is highly likely that real life will intervene.

This can also mean that many of the lifestyle strategies that parents have developed during the adult life of their son or daughter with a disability are not known. It may also mean that family members have little conception of what it takes to support their sister or brother, or how paid services operate in their life. They may know little about their financial situation, medical history or even about who the key people are in their life. All this information is held by parents, and is often only held by them, leaving great gaps in knowledge after they have gone, as much of the information can die with them if a planned strategy is not thought through as to how information will be passed on.

Parents and their adult sons and daughters need to share their hopes and fears.

Although the involvement of the next generation of family members can never be absolutely guaranteed, it is far more likely that people will be there if they have knowledge and information about what it will take, and can develop an understanding while their parents are still alive. This means that **good relationships between the generations** are important, with parents and their adult children being able to talk with one another, sharing their hopes and fears.

Some parents will have kept information to themselves and not talked about things that have been difficult or painful. They may not have disclosed the personal or medical information about their son or daughter, or shared how difficult their dealings with some services might have been or their need for constant vigilance and advocacy.

Yet such information may be very helpful in understanding why parents are trying to set up **safeguards for the future**. The next generation of family members need to begin to understand more about the journey of their parents and that of their brother or sister with a disability, if they are going to fulfil a commitment in the future.

Parents may need to spell out what they expect of the future and what help they would like from other family members. They may be able to give greater peace of mind to the next generation if they know that they will not be doing it on their own, have a sense of what is expected of them and have some information about what is involved.

Parents can give greater peace of mind to the next generation, if family members know they will not be doing it on their own, have a sense about what is expected and have some information about what is involved.

It is important that the **responsibility is not vested in just one person**. Not only does this cause angst about the size of the task, but also it can create real dilemmas about how life is structured and played out, especially in relation to their own immediate family and their responsibility to them. Having more people involved in the person's life equals greater likelihood of people being around and less likelihood of things falling apart. Consideration can therefore be given to extended family to be involved in a broader personal support network or circle of friends which is set up around the person.

If other family members are all older than the family member with the disability, it **may be important to include a 3rd generation**, if not early in the piece, then in thinking about succession of family members who take on this role.

3. Encourage others to step forward into the person's life

It is all too easy for a person with a disability and their family to become isolated from others, especially when there is not much happening for the person in adulthood. Long after their brothers and sisters have moved into the world of work and out of their parental home, and have forged networks of their own, the family member with the disability typically remains with their parents often socialising with their network, if they still have one. Even when the person has moved to a home of their own, they might still rely on the centrality of the relationship with their parents.

Paid service relationships usually only last while the worker is on the job.

However some may also swap reliance onto paid staff and see them as taking over primary relationship roles. These paid service relationships usually only last while the worker is on the job, with people coming and going in the person's life in sync with their employment opportunities. The families involved with the Homes West experience understand that good services and good workers are essential. Yet they also know that they cannot meet all human needs, especially the fundamental needs for loving relationships, belonging, affection and security. They also know that good services can lose their way and decline over time. They may not adapt to changes, may lose vision, lose good staff, or may not heed feedback and evaluation.

Therefore they see the **creation of friendships outside the service and the family** as important. Just as with anyone else, friendships can allow belonging, companionship and solidarity to flourish, with people being there for one another. Friends can bring shared experiences in playing out parts of life, seeing things from others' points of view, supporting each other, providing assistance and feedback, and celebrating good times, as well as being there in times of crisis.

Genuine friends, in freely given relationships, can become trusted allies and develop an enduring commitment to the person. They can help to plan and implement the vision of a good life and can also step into anchoring roles when needed. They can be there to support family members, as well as be the anchors for the person when, or if, family members are not there.

Trusted, enduring friends can help to plan and implement the vision of a good life.

The families involved with the Homes West experience have come to realise that trusted, enduring friendships can play a very important part in the lives of their family member with a disability both now and into the future. Although parents may have found this to be one of the hardest aspects to acknowledge and take forward, many brothers and sisters have welcomed the move, giving them the security of having a broader support base to continue to do family business when parents are no longer there.

The role of a personal support network or circle of friends

Several families have established a formal support network around the person to continue the business of the family into the future.

Several of the families involved with the Homes West experience have made the decision to formalise the role of family and trusted, enduring friends by establishing a support network around the person to continue the work of family business. The network members have been formally invited in closer and usually are a diverse group who have shown an interest in the person, or have a commitment to them or to the family. They are genuinely interested in the person and not paid to be there in their life.

Many network members are **close family or long term friends and neighbours**, while some are **ex workers** who have chosen to stay on in the person's life as a friend. Many of the networks have both sexes involved and some have particularly sought local people from the surrounding neighbourhood. Sometimes older friends of the parents' generation have also been asked, so they can be **mentors** to the next generation of family members. These people come together regularly to discuss life and how it will pan out in the future, as well as raise the profile of the person in their own life.

Parents have taken the decision to establish a formal support network because they see their son or daughter as a young adult with much of their life still ahead of them. They recognise that there is more to life than Mum and Dad and want to **safeguard the future** by considering how best they spend their time and energies to ensure that some things can be put in place now.

These parents also know that to make things happen for their son or daughter requires deliberate intention and extra effort. They believe their son or daughter needs other people in their life, as well as family members to help them to do this; to be creative and think outside the square, to give new and different perspectives and to consider options and possibilities and how these can happen. They believe that, by having people who care, more creativity will happen and the opportunities for having a good life will be better. The support network therefore acts as an **intentional community around the person**.

Parents want others to help them to be creative, to think outside the square, to give new and different perspectives and to consider options and possibilities and how these can happen.

Each person brings new ideas, personal gifts and talents, as well as their personal networks, **adding to the richness of thinking, creativity and action**. Family and friends can find that this is not a tedious task and that the journey alongside the person and their family can be exciting, creative, ordinary, frustrating and celebratory, especially when surprising and wonderful things happen. However the families involved with the Homes West experience also understand that there are no recipes about how things should work, nor do they see the support network as the panacea for all ills. Life is always a work in progress and can take many turns. Support networks are only as good as the people in them and their ability to sustain themselves and be there over time.

Some families have decided to begin establishing a support network by engaging a **facilitator to help with the process**. This role supports and strengthens the vision of the family and enables the thinking and action to move forward. The facilitator may assist with the difficult process of asking and bringing people together, or may help to clarify issues and focus, encourage ideas and thinking things through, clarify strategic action or keep records of the content and process.

The focus is on the person and their centrality in all thinking and action.

When the network meets the focus is on the person and their centrality in all thinking and action. Network members become clearer about their understanding of who the person is and get to know them well. Together they develop and hold a shared vision for the future and care about how life will pan out. As a group they share the hope for something better than what is on offer, seek options and opportunities that drive the vision forward, build connections so the person does not become isolated, enrich life and organise the resources of the community to work in positive ways. They may bring ideas and create possibilities for a good life with relationships, experiences, and ordinary life expectations such as having a home of one's own, having work and other meaningful activity, having fun and having financial and personal security which are supported and safeguarded over time.

As people in any network will have life intervening, part of the role of the support network is to consider **succession of members and bringing in of new people** so that there are always committed people in the person's life now and into the future.

Most network members consider the invitation and intimate involvement in the person's life to be **a privilege and understand the gravity of what they are doing**. They also understand that they are there to support the person and their family business, to keep information confidential, to be connected with one another and not to pose additional stresses on the family.

Some support networks have been able to look at the succession of some tasks to members while parents are still alive, either by accompanying parents in their advocacy role or by arranging some things by agreed delegation. These might be in relation to monitoring personal spending, accompanying the person and their parent to a specialist appointment, organising celebrations or taking on other aspects that the parents have been responsible for in the past.

Some tasks can be learnt or handed over while parents are still alive.

In order to understand their role more deeply, network members may require information or documentation provided by the family. This might include the following:

- The parents' vision of a good life and their wishes as to how this could be played out in the future
- The tasks of family business and service business and the concept of delegated authority to others
- The giving over of all family business to services and what doing so means
- Important family values, history, culture, stories, traditions and expectations
- Key dates, family rites of passage, birthdays and addresses, celebrations
- The importance of planning and review
- Trustee and Statutory Health Attorney roles
- Advocacy roles and why they could be needed.

Other people will never replace the parents, and nor should they.

Other people, including the next generation of family members, will never replace the parents, and nor should they. They will do things differently, but they can have the knowledge and confidence to **continue to do what needs to be done**. They can remain the heart, head, eyes and ears to move the vision of a good life forward into older age, and ensure that the safety and well being of the person remain paramount.

4. Enable others to understand the person's story

Most parents are the keepers of the personal story of their son or daughter with a disability, especially when the person has difficulty in telling the story themselves. As Homes West acknowledges, parents have known the person the longest and know most about their life and tend to see how everything has summed up in its entirety. Although others have travelled alongside, they may have only looked through keyholes into the person's life, or may have only been there for a while and seen a small portion.

It is therefore **important that the story of the person's life is shared**, otherwise vital information can be lost forever. However, on the other hand, other family members and friends may see very different aspects of the person and their life than their parents do.

The person's story needs to highlight the essence of who the person is.

Any person is likely to act differently when their parents are not there or when they are in different surrounds. The **writing of the person's story** needs to highlight the essence of who the person is. It might include:

- What life has been like, giving the background of childhood, schooling, growing up and adult life
- The person's contributions to family, neighbourhood and community life, their passions, gifts and talents, places they like to go, things they like and don't like, times when they are happiest
- How the person's ideas, feelings and spirituality are communicated and how they make choices and decisions
- The person's struggles and vulnerabilities that need to be monitored and how to know when things aren't going well
- Family beliefs, values, customs and traditions that are seen to be important to preserve
- How the person likes to be treated, a general summary of their support needs and things and that are most important to their well being.

Such information can be **of use to new people coming into the person's life** in both paid and unpaid roles and also means that the information is not lost. Deciding what goes into the person's story may initially be a parent's role or it may be one that is shared with the support network. It can be reviewed down the track with this broader group of people adding their contributions, as the person and their life become more deeply known. Sometimes a photographic history is also included.

5. Share practical living knowledge of the person

If the next generation of family and friends is going to take over the role of family business in life of the person with a disability, then **they will need to understand what it takes** to support the person in ordinary life. As well as sharing information, practical living knowledge of the person can be gained by spending time with them, not just in a social context, but also in their daily life, giving understanding of the person's needs and the support that is required in order for them to have a good life. This may happen by spending time at the person's home or by staying overnight, or by inviting the person to stay or to go away together. In this way others gain a deeper knowledge of the person and their support needs, as well as understanding life from their perspective.

Others need to understand the person's needs and the support that is required in order for them to have a good life.

This direct involvement with the person enables better documenting of the person's needs, strategies that assist them and what needs to be in place to keep them safe.

Some parents have chosen to encourage the succession of responsibility for different tasks while they are still around. In this way they can still be there as a role model or to support the next generation as they take on some responsibilities. For example, in relation to the person's health, specific members of the network might begin to understand what it takes to support the person by accompanying a parent to visit the general practitioner, dentist or specialist in preparation for the Statutory Health Attorney role when parents are no longer around. These people would also need to know the health history of the person, who the key health practitioners are, how to contact them when needed and what support the person is likely to need to put across their ailments.

In order to safeguard the person's well being, some members of a support network might be sought locally so that they are able to **monitor how the person is faring** or to be around if an emergency happens. This is particularly important in the future if the key decision makers in the person's life are family or friends who do not live within driving distance. They can remain in contact with the local person who can give a first hand description of what is happening in the person's life.

Some members of a support network might be sought locally.

6. Work out planned strategies to move the vision forward

By harnessing the passion and getting clearer, goals can be set and reviewed yearly.

In order to move the vision of life forward for and with the person, people who share the dreams can be asked to help with planning for the future. By harnessing their passion and getting clearer about what needs to happen, goals can be set, worked on and realised. Ideally yearly planning is done about the broader aspects of the person's life and what needs to be in place for the future

Plans are also reviewed to see if goals have been achieved.

This planning process is different from setting goals for the provision of paid services, as the **focus here is on family business** rather on what the service can provide, although the plan can have bearing on what roles services will play or how best to use the resources. Any facilitation of the plan is therefore outside the service framework, although it may involve a key service worker invited to input as a participant.

This forward planning **relies on establishing a high degree of trust** in the insights of the members of the support network and their belief in the possibilities for the person with a disability. It also relies on trust that these people will be able to honour the wishes of parents and be prepared to carry out the vision of a good life into the future alongside the person. Even though goals are set, people involved with the Homes West experience are realistic enough to understand that the future is not set in stone. The process acknowledges that this is a journey and, as with any journey, it can move in various directions depending on what life serves up.

Typical areas of focus in planning could include the following considerations:

- Having a good home life
- Having good support
- Being valued and included in community life
- Developing mechanisms for decision making for the future
- Creating financial security for the future
- Monitoring personal safety and security
- Planning what needs to be written down and discussing with interested parties
- Overseeing the diary of day to day events
- Scheduling the yearly calendar with important events, birthdays, anniversaries, holidays etc.

The plan will usually consider **safety nets** that give direction to both the paid and unpaid people in the person's life, for example what to do in emergencies, what to do if paid staff are not available etc. It may also consider the best way that funding can be used to support the person to have a good life. The plan may also set direction about the need to take on advocacy roles that work in the best interests of the person, to promote, protect and defend their personhood and lifestyle when they are required.

Therefore as part of the planning process, the succession of members of the support network needs to be considered regularly so that the group will remain strong for the person into the future.

7. Establish a home of one's own

The families involved with the Homes West experience have been working on the goal of sons' and daughters' establishing a home of their own for a long time. Most have now achieved this and did so, not when a complete funding package became available, but **when the person was ready**. Many began the process with insufficient funds and cobbled together a life for their son or daughter with a mixture of paid and unpaid support. They found that establishing a home was a process, not an event and nor was it simple. Not only did it involve finding and moving out to a suitable place to live, but also it required establishing ongoing support and developing and maintaining an ordinary lifestyle.

Establishing a home is a process, not an event

Moving out was found to be a trial and error process. It took time to consider what type of home would be suitable, where it would be located relative to inclusion in community and relationships, and whether it would be public or private housing, owned or rented.

Families spent time considering what a good home would be like and where the person could develop anchors, such as:¹

- Having a place where they truly feel at home and safe
- Doing some important and routine things each week
- Establishing some personal connections locally who knew the person and would watch out for them
- Having family members and trusted, enduring friends who remained connected and continued to work on the vision of a positive future
- Having social friends who did things with them spontaneously
- Having workers who were trustworthy and respectful and who enjoyed working with and for them.

It also meant having a say over who else lives there and who comes to work there.

Establishing a home of one's own also meant having **a sense of personalisation and ownership** of the place, where one's personality and preferences can be expressed, where hospitality is given and where private life was not made public. It also meant having a say over who else lives there and who comes to work there, as well as having security of tenure.

There was always the opportunity for the person to change address or move back to their parental home if they felt unsettled or unhappy with the arrangements, just as it was with other members of the family.

8. Have good service provision working in right relationship

Part of the early vision of the Homes West service was to support the person in their family home, but with the intent that they would continue their support when the person moved out to live in a home of their own. Families and service together considered what daily life would look like, how support would be negotiated and how the person would best be supported. The Homes West service was built around these ideals.

Much time was spent in clarifying **what families wanted and what they didn't want** from the service.

Families wanted to establish a good service where workers understood the vision for their son or daughter and helped to put it into practice in the paid aspects of the person's life. They wanted to develop clarity about what support was needed as opposed to what the service determined it would provide, and for workers to understand and to value the roles of family business and service business, and how authority is delegated to them for particular tasks in the person's life.

They wanted to develop clarity about what support was needed, as opposed to what the service determined it would provide.

¹ *Family, Community and Service Together: The Homes West Experience, Workshop Handout 1, 2005*

Families have negotiated personalised service agreements with Homes West outlining the ongoing responsibility of each of the parties and clearly stating what is expected, what support is to be given and how the person is to be seen and treated. Workers have learnt about how personal routines are to happen, the importance of positive imagery of the person, the valuing of private life, how meals and shopping are to be arranged, the expectations of working to a personal budget, the carrying on and honouring of family traditions, customs and beliefs, organising daily life around the people, places and times, and a strategies for emergencies. Much of this **information is documented** for workers and remains at the person's home. Family members meet regularly with staff and develop a **monthly calendar**.

Families negotiated personalised service agreements

Ongoing appraisal and supervision of workers is seen to be important, as is a formal **external review** of the service, not just in terms of government funding standards, but also in scrutiny by esteemed disability leadership.

Governance of the vision and values of the service

Boundaries are set which determine what is negotiable, when to compromise, what is possible and what can't be done.

The families supported by Homes West appoint a small board to govern and direct the service business to ensure that the service does the best for the people it serves. This group is informed by the wider group of families who each have a place at the table in setting the vision and values for the policy direction for the organisation. This wider group meets several times a year. In this way, boundaries are set which determine what is negotiable, when to compromise, what is possible and what can't be done by the service.²

The families also **nurture the spirit and culture** of Homes West, in particular, a willingness to work for the common good of the families. In this way the broader group can keep an eye on both the present and the future and pose new ventures which will extend the thinking of the families involved. A **stewardship group** has been formed to continue to face ongoing challenges and to consider ways that will take new ideas forward. A key role is to reach out to the broader community to reflect on and review how things are going and to renew the organisation by finding future supporters and new leadership.

Planned succession therefore is part of the agenda, not only in terms recruiting for the governance board, but also in terms of the next generation of people who will take over the role of family business in the life of each person with a disability who is supported by the service. To this end, Homes West has policy which reflects this ongoing expectation for each family.

Planned succession is on the agenda for service governance and for the next generation of family business.

² Family, Community and Service Together: The Homes West Experience, Workshop Handout 4, 2005

9. Seek broader social connections in daily life

Families know that when people are known and have positive relationships, they are more likely to be safer.

Part of having a good life as a valued member of the community includes having a range of broader social connections and acquaintances made in every day life. The people involved with Homes West put effort into considering this when they established the support service in Sherwood and sought housing in the district. Parents also have chosen to live in the surrounding suburbs. This area has **good public transport and small community hubs** in the local suburbs near to where people live. These western suburbs possess community infrastructure yet remain small and personable.

Each person with a disability goes about their daily life using neighbourhood services such as the local supermarket and smaller businesses such as butcher, fruiterer, hairdresser, suburban bank, club or coffee shop.

The person establishes a regular routine and develops known local connections.

They go on a regular basis, and have become known as valued customers.

Places of interest have been sought locally where the person can participate and **contribute their hospitality and talents** such as in the local church community or the local club. In these places, people have become well known and included in the occasions and celebrations. Some families have put time and effort into developing work options or, if not, meaningful alternatives that engage the person in community life. These can also bring new networks and further possibilities for developing social contacts with the person.

Social connections and acquaintances have proved to be great safeguards.

These social connections and acquaintances have proved to be great safeguards for the person. They are public eyes and ears picking up on how the person is seen and treated. On occasion, families have had casual conversations that have highlighted concerns about a worker, or they have heard about places where the vulnerability of the person has been increased by the inappropriate behaviour of others.

Sometimes closer connections with the person are made intentionally, where people are invited to the person's home to come to have afternoon tea or dinner, or to participate in a particular social event. Some families have developed address contact lists so that people can be called intermittently or on a regular basis. They have also ensured that their son or daughter has these people on their Christmas

Sometimes closer connections are made intentionally.

card list. These connections may take a fair degree of maintenance until they develop a life of their own, but occasionally, some of these are the very people who can be invited closer to the person to **renew or strengthen the support network.**

Finding social connections and places where gifts, talents and passions are able to be expressed can be quite difficult for families. **Often these are yet to be discovered.** In many instances it may be hard to know what or whom the person will like until situations are tried out. Also, having a parent tagging along to places where younger adults hang out does not necessarily engage with the person's generation or attract others to converse. Parents may need to be challenged gently by other family members or people they trust, so that the person has opportunities for an ordinary life as an adult, with interests and connections of their own.

Sometimes new social connections are better developed by support network members through their personal and social networks and by workers who have that explicit role and have the ability to connect and draw others in.

By trying out new places and opportunities, finding ways that the person can participate and contribute, and inviting people closer, some new connections have been made, but families find this one of the more challenging tasks to sustain alone.

10. Know what happens in daily life

One of the major reasons families involved with the Homes West experience have put so much energy into developing relationships is because of necessity to **address the vulnerability** of their son or daughter in the future. Parents have been the main monitors of safety and security of the person and want to ensure this function is not lost once they have gone. By having a range of social contacts across community, as well as having family and trusted, enduring friends in more intimate roles in the person's life, people can make sure they are about in the person's life and being vigilant.

Parents have been the main monitors in the person's life and this function needs to be maintained after they are gone.

Contact in daily life allows for **monitoring of the quality of the person's life** and how they are treated, and gives a sense about their general well being. This most important safeguard assures the person's health and welfare, and picks up and deals with any negative or harmful practices early. This means that some family or friends need the ability to drop in regularly, whilst others who live at a distance need to keep connection by having direct contact with others and invite the person to stay or to come for holidays.

Some family or friends need the ability to drop in whilst others who live at a distance still need to keep connection.

The other key function of people dropping in is to have connection with workers who support the person. Decisions will need to be made about **how paid resources are best used for support, as well as influencing and monitoring who is employed by the service.** People still need to be involved in helping the service to interpret the wants and needs of the person and to ensure that their life is panning out in positive ways.

11. Secure decision making and finances in a will and trust.

People need supported decision making.

As all the people with a disability who are supported by Homes West have some limited decision making capacity, they have needed the support of their parents in their own decision making or have relied on their parents' natural authority to make major decisions on their behalf and in their best interest. Decisions have ranged from health, financial and legal judgments to every lifestyle decisions.

The exception has been for some people who, as youngsters, were swept up into old models of institutional care where the requirement was to hand over major decision making to the state. Despite people exiting these systems years ago and developing new lifestyles, the fight-back on this front still continues for some of these families. What they have found is that the formal systems are quite conservative in their use and management of assets and they involve tedious, regular reporting. Understandably, **families tend to want to avoid these bureaucratic arrangements.**

Part of the future vision of parents is to ensure that their son or daughter is surrounded by family and friends who have gained credence by their caring involvement, trustworthiness and knowledge of the person. Some of these people will be given formal roles in ongoing decision making in the person's life in positions such as trustees, whilst others will do this informally with the person and/or in support of the trustees.

Some people will be given ongoing formal roles in decision making.

In relation to **finances**, preparation for this has happened on a number of different fronts. Parents have considered ways that **use of money in daily life is safeguarded**. Some strategies have included:

- using a local bank where the person becomes known by staff
- going to the bank regularly and establishing a routine
- having a photo identity card or passport
- having automatic payments for rent, health insurance, telephone etc
- having a ceiling in the usable bank account
- having an investment account for savings, home maintenance, special occasions or holidays
- having joint signatories to an account
- having a home-based kitty
- requiring receipts for purchases by workers.

Some families have worked out arrangements whereby the parents have set up an **enduring power of attorney**, so that if they lose capacity whilst still alive, another family member has the continued authority to be a co-signatory on their son's or daughter's bank accounts or other legal documents on the parent's behalf.

Many families have consulted a solicitor who has helped them to write a testamentary trust into their will. This directs the establishment of an ongoing discretionary trust upon the death of the parents with trustees appointed by the parents to use the funds at their discretion, but in line with the vision for the person and wishes of the parents. The **executor of the will is told** about what is likely to happen and some families have begun to set aside specific records of assets, real estate, insurances, shares, savings etc, that will be of use in finding and interpreting important documents.

Some parents have established the setting up of a discretionary trust.

Some parents have also considered what the financial needs of all their children are likely to be following their deaths and have discussed legacy arrangements with family members so that they understand what is happening. These considerations have included whether or not certain parts of the estate would be left to their son or daughter with a disability, for example the family home or certain income producing shares, or how a larger proportion of the estate might be left to the son or daughter with the disability than to the other children.

Some parents choose to leave unequal legacies in recognition of the additional needs of their son or daughter with a disability.

This difficult decision is often taken, as a certain capital may be needed to generate additional income for the person, given the increased need for paid support when the parents are no longer around and for extras that the person cannot afford from their pension. Parents may take into account the person's lifestyle, support arrangements, security of tenure and financial security, as well as the person having assets of their own. Parents have

been known to offset this by writing **how they want the trust to be dispersed** when the son or daughter with the disability dies, often choosing to leave the residual money to their other children or their grandchildren.

When considering **trustees**, families have often begun with a brother or sister of the person, but on further consideration have realised that this is a fragile arrangement. Their availability could change, given global mobility, new partnerships, their own family needs, or health or disabling concerns of their own, meaning they were not contactable easily or unavailable. Therefore, safety in numbers has been the preferred outcome for some, as they have thought about combining a range of skills, as well as availability. This has meant that trusted, enduring friends have

More than one trustee will give better availability and better decision making.

sometimes agreed to become trustees alongside family members. By having more than one trustee and seeking a range of competencies, for example, good understanding of the person's situation and needs, practical money management etc, decision making can be shared and better decisions made on the person's behalf. Parents with trust arrangements in their wills usually **discuss their intent and vision** with future trustees. Although it is preferable for trustees to outlive the person, they will need to mentor potential members from the next generation to move in, in case they retire from the role.

Some parents have made connection with a **financial advisor** who has been given an understanding of the situation and has helped them to consider how money can be invested for the legacy. The trustees may also be introduced to the solicitor and financial advisor, as they are likely to continue to need their services in the future when making decisions about the person's finances. Some parents have established a will and trust a long time ago and have found that it needs to be reviewed, as information grows and situations change. Reviewing the arrangement every few years is advisable.

The will and trust need regular review.

It is a hope that supported **financial decision making**, with the connection between the trustees and other members of the support network, will then happen on two levels:

- Trust decisions which will be about investment and how money is used to support lifestyle decisions or limit expenses, such as approving holidays and extras or setting spending ceilings
- Decisions about daily life involvements such as personal banking, use of credit cards, managing weekly budgets, being signatories, and monitoring.

Depending on capacity, **decision making for health issues** may require supporting the person to have information and guidance in their own decision making, or may require someone one else to make the decisions on the person's behalf. A brother or sister, or trusted friend would have this role naturally under current law, either by being the person's primary carer, but not a paid carer, or by being a close adult friend or relative. This role is referred to as the **Statutory Health Attorney**. This person can consent to most health care issues, including medical and dental treatment and withdrawing or withholding of life sustaining measures. Some parents have considered and put in place ways that will support the person in this Statutory Health Attorney role by:

- naming who that person is likely to be and informing health and allied services
- using local general practitioner and dental services
- having a contact list
- taking the person along to meet medical and dental personnel and giving them an understanding of the role of the person's health advocate
- having a written, up to date medical history about the person
- having a health emergency strategy in place
- considering succession of health care professionals who may have been involved in the person's life since their childhood, but who are now close to retirement
- identifying family health traits that may be of concern for the person in later years
- taking out private health and dental insurance for the person.

Lifestyle decision making requires the understanding of the person's daily life so judgment can be made about the person's quality of life, the support that is required, how support is best used, daily life expenses, home maintenance, and movement around the community, activities, events and holidays. This is where the support network plays a vital role, keeping connection with the person and supporting good decisions with and for them. Trustees are usually members of the support network so that they can remain connected and have access to daily life information if they are not locally based.

The support network plays a vital role in lifestyle decision making.

Conclusion

Even in this latest phase of the Homes West experience, families continue to refer back to the original **four mantras** established many years ago.³

1. Start now, not later, as nothing will happen if families do not plan
2. Believe that it will happen and that the person can achieve a full and valued life, even after parents have gone
3. The next generation of families and trusted friends can continue to know most and do amazing things through their commitment, stick-with-it-ness and knowledge about that person
4. Continue to think outside the square to make it possible.

Despite such considered choreographing of the future, the parents who are part of the Homes West experience will never give up in their quest for a good life for their son or daughter with a disability. As is always pointed out when parents talk about the future they:

***Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.***
(Dylan Thomas)

³ Family, Community and Service Together: The Homes West Experience, Workshop Handout 1, 2005

Choreographing the future

Elements of family business that can be considered and put in place

Family members

Having the next generation of committed, loving and anchoring family members who continue to drive the vision of a good life forward for and with the person, who maintain and oversee the essential roles of family business in the person's life and safeguard the person's well being

Vision for the future

Developing a framework for the future, clearly setting out what is wanted and what is to be avoided in the person's life, as they journey into the future and the next generation of committed people take over roles currently held by parents



Good knowledge of the person

Having practical living knowledge of the person gained by spending time with them, not just in a public social context, but also in the complexities of daily life, giving understanding of the person's needs and the support that is required in order for them to have a good life

Trusted, enduring friendships

Having people who have an unpaid commitment to the person, who help to plan and implement the vision of a good life, who can step into anchoring roles when needed and who can be there to support family members, or if family members are not there



Person's story

Keeping a written story highlighting the essence of who the person is, their contributions, gifts and talents, as well as their vulnerabilities and ways to support, which can be of use to new people coming into the person's life in both paid and unpaid roles

A home of one's own

Establishing a home of one's own with a sense of personalisation and ownership, and a say over who else lives there, as well as security of tenure, in a location that suits relationships and lifestyle



Social connections and acquaintances

Having a range of broader social connections and acquaintances made in every day life, some of whom might be encouraged to move intentionally into closer roles



Planning strategy

Asking others to help with planning for the future by harnessing the passion to get clearer about what needs to happen and determining how things can move forward to achieve set goals, done yearly and reviewed



Decisions, will and trust

Planning for supported decision making and financial security following the death of parents with aspects in place for major decision making by the next generation of committed family and friends

Good service provision

Having good service provision that understands the vision and helps to put it into practice in the paid aspects of the person's life, with an understanding of the importance of valuing and supporting family business, and the succession of good service governance

Knowledge of daily life

Playing out of monitoring roles that take into account the vulnerability of the person and safeguard their well being so that negative and harmful practices do not happen or are dealt with immediately

