The Homes West Experience

Choreographing:

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

Choreographing Life

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

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 a home 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, now and into the future. This paper shares families' understanding and experience in grappling with the notion of right relationship and defining what authority and responsibility remains with whom, in their quest for a valued life with and for their family member with a disability.

Why this paper was written

Traditionally, many services that support the lives of people with disabilities have taken an all or nothing approach. People have either lived in their family home where they and their family took all responsibility for their care, or they lived in facilities run by services that took over this responsibility and with it, all authority over the person's life, often to the great detriment of relationships, safety, and decent lives. Even when newer forms of service were established to support people with disabilities, many continued their same way of operating, moving into areas of life that, for other citizens, always remain the personal business of the people themselves and/or of their families and trusted friends.

The families who have formed Homes West have had experience of other services that have taken over this authority and responsibility in relation to their family member's life. Often the results have been devastating. Therefore in the development of the Homes West experience, family members have been keen to ensure that this service would not follow down the same path, but instead would be clear about who would hold authority and responsibility for what.

Families involved with Homes West believe that some very definite roles remain the province of the person, their family and enduring friends (family business), and that others remain the province of the service (service business). This may seem a rather simple notion that is easy to define and to implement. However, there are many aspects that fall between these two poles because of life's complexities. This central part becomes a dynamic dance in support of the person's life where authority is negotiated and delegated, with responsibility shared between the people involved. Working in right relationship therefore can become quite variable and individualistic depending on the understanding, capacity, and efforts of all those involved.

This paper has been written to help to clarify families' expectations and to safeguard these ideals for the future, as well as to share experiences and thoughts with the next generation of family and friends who plan to take up roles to continue life's dance.

About Personal Authority

> Personal authority is the right of a person to determine, judge and settle.
>
> *Macquarie Dictionary*

In a general sense, in everyday life we decide about many things that have an impact on how we live our lives. Some of these decisions we take alone, or we may decide with immediate family, or in conjunction with significant others, or seek the advice of relatives and/or trusted friends, or with those we consider have knowledge or information to help to influence us. However, in many instances the authority to make such decisions about our own personal life and well being continues to reside with each of us. This personal authority is backed up in everyday life and in law, and unless we overstep the legal boundaries of moral and ethical behaviour, it continues to remain with us unless we lose capacity to determine, judge and settle aspects which affect the pattern of our life and how it is played out on a daily basis.

The following are typical areas of life where we retain authority and have the right to determine, judge and settle, even though we may seek information and advice and make decisions interdependently:

- Our general health and well being
  For example, what we eat, how we exercise, what doctor or dentist we go to, any health decisions that affect us personally.
- Our relationships
  For example the people we live with, those we are intimate with, and those we call our friends, as well as people we associate with in community life and in the many service relationships with us.
- Our home life
  For example, where we live, personalising our home, what we do in daily home life, what we build into a home-based routine, and defining our public and private self.
- Our appearance
  For example, our hygiene, what we wear, how we do our hair, how we look overall.
- How we spend our time
  For example, how we organise our daily routines and rhythm of life, in home and out of home, our work and recreation, transport.
- How we use our money
  For example, how money is spent, saved and invested, how much we spend on daily living, what we can afford in our leisure time.
- Our social and moral behaviour
  For example, our code of living, beliefs, roles we take on, responsibilities at home and as part of community life.

About Responsibility

In conjunction with authority to make decisions about aspects of personal life, we take responsibility for their outcomes.

> Responsibility is the act of being answerable for something within one's power, control or management.
>
> *Macquarie Dictionary*

When there is diminished responsibility, as when a person has limited decision making capacity, then authority and also the resultant responsibility are delegated. However we also may choose to delegate authority as much of our life is interdependent with others.

About delegated authority

Personal authority can be delegated to other people.

> Delegated authority is transfer of the powers and functions to another to act and represent as one's agent.
>
> *Macquarie Dictionary*

Personal authority can be delegated in two main ways:

1. By accepted delegation, to those people who are generally recognised and considered able to do this, such as close family members or trusted friends
2. By specific delegation, either to those considered to have been given the specific authority to do so, or as proscribed by law.

About Accepted Delegation and the Natural Authority of Families

In ordinary life we typically delegate authority to make everyday decisions that affect our lifestyle and personal well being, by recognising the natural authority of close family members and trusted friends.

Our parents have already taken this role during our childhood being recognised in law as our legal guardians, unless this right is challenged and they are found wanting. Even as adults this recognition continues with the legitimising of continued decision making in the *Queensland Guardianship and Administration Act, 2000.* Here, for example, there is a declared hierarchy of recognised decision makers in relation to health decisions, which affirms the natural authority of families, including spouses, unpaid carers, family members and also trusted friends.

However society tends to be accepting of this natural authority well beyond the point of law. Michael Kendrick (1995) has pointed out why families hold this natural authority and should be prepared to use it. His statements are strengthened here by how the families involved with Homes West interpret and choreograph this authority.

Choreographing Natural Authority

Arranging

Each family involved with Homes West supports their family member with a disability well beyond the time when adults usually take on the responsibility for themselves, and will revert to a greater role if adversity strikes. They will often put their loved one's needs before their own, to ensure the family member's well being. By doing so, they continue to be there, often supporting the person physically, socially, emotionally and/or economically as part of a shared journey throughout their lives.

Composing

Each family knows their own history, can interpret their needs, has knowledge about how to meet those needs and understands what it takes to do so. Family members know the socialisation that has happened in the family, the culture and rhythms of daily life, the traditions and values that are upheld and the expectations that family members have for what they consider to be a good life. They share information and insights and, in many instances, people rely on their family for advice, and trust in the validity of such advice over time.

Designing

Each family creates or is supported to hold a vision for life with and for their family member. Families typically want their family members to have a home of their own, enriching life experiences and relationships, safety, personal and economic security, not only now, but also into the future. These aspirations are typically held for all family members, including each person who has a disability.

Planning

Each family is there for the long haul, and sees how things add up over time, unlike many paid people in the person's life who move on once they change jobs. They usually know what needs to happen now, so that life can move forward and can contribute to the steps that lead to achieving the vision of a good life over time. Family members also play many work and other valued life roles and can hold a wide range talents and experiences. .These are tapped for knowledge and advice, giving family members additional authority on many matters.

Strategising

Each family is typically concerned about their family member's well being and spends much time and effort in considering and trying to implement their vision about what makes a good life. They have high stakes in the outcomes because they live with the consequences of any actions. The strategies that they and their trusted friends use are usually more relevant, simpler or provide better solutions than stereotyped ones or ones that are devised by people who do not know or understand their family member well.

Directing

Each family determines or is consulted in decision making that affects the life of a family member, and will take a stand on their behalf if they feel that the responses are not in line with meeting their needs or are harmful in any way. Regardless of capacity or skill, families influence the direction of their family member's life as they have remained faithful and committed to the person and their well being. Families are most likely to know when the person is being 'done to' and will to speak up on their family member's behalf to seek solutions that are in line with the vision for life and what the family feels is in the family member's best interest.

Organising

Each family member has emotional linkages, remaining fiercely loyal and continuing their love unconditionally. They are usually available when needed and often will organise to be there when no one else is, frequently remaining the carers of first and of last resort. They therefore have developed and can draw upon intentional support networks around their family member who will continue to play an important role throughout life.

Stage managing the dance

Each family has a monitoring role, and attempts to preserve the vision for life, individuality, safety, preferences and the personhood of their family member. Families see, hear and are part of their journey and therefore are aware of issues and inconsistencies and experience how systems and services impact on the person's life, as well as their own. Family members have a degree of independence of the system highlighting their integrity and motive behind what they do. They are less likely to have the vested interests in the service system that staff may experience. They therefore are placed in a good position to oversee life's "dance".

About Specific Delegated Authority to Others

Specific authority can be seen to be held when a person is the source of information, advice or expertise, or has the capacity to do something on our behalf.

However, we usually still retain the personal authority to make any decisions based on the advice, unless the authority to make these decisions is specifically and formally delegated to that person.

For example we might consult:

- A financial advisor about the best way to invest our money
- A landscaper about which garden shrubs to plant that will be drought tolerant
- A doctor for information and advice about our health care.

In all these situations we can still make the decision and could choose, independently, to use or not use the advice we are given. Alternatively, we could delegate the authority to go ahead to do certain things on our behalf.

Personal authority is delegated to others only when they are seen as having specific skill, reason or capability to do certain tasks or make certain decisions on our behalf.

When any authority is delegated, a high degree of trust is sought, as the responsibility for the expected outcome is also delegated.

This usually happens in a more formal, paid or legal arrangement when we:

- do not have the skills
- do not have the time or capacity
- choose not to do the tasks ourselves
- are unavailable
- are unable or have impaired capacity.

Some typical every day examples of specific delegated authority include formal arrangements such as:

- Employing a mowing contractor and giving the authority to have access to our private property to mow the lawn or employing a cleaner and giving the authority to have access to our house to do the cleaning for an agreed price
- Giving the authority to a landscape gardener to design a garden and select the shrubs for a certain cost, with this agreement being in the form of a service contract
- Getting financial advice and giving signed authority to the financial advisor to invest a certain amount of money on our behalf
- Setting up a temporary power of attorney, giving a nominated person the power to sign a legal contract on our behalf when we are away and unable to do so ourselves
- Setting up an enduring power of attorney which may come into play following a serious accident if we lose competency, giving a previously delegated person the authority to make decisions now on our behalf
- Setting up a formal trust, with trustees who have specified powers to make decisions in relation to those powers to oversee our funds.

Therefore it can be expected that disability services would also operate in a similar way with delegated authority and responsibility for negotiated outcomes.

About the Authority of Government

Authority can also be held in relation to those who are paid to uphold the rules, laws or statutes of the land. Therefore government authority is legislative and regulatory (Kendrick, 2005). This form of authority assumes that there is compliance in relation to the area of intent of law and applies to many aspects of life where social, economic, and moral standards are expected to be played out for the collective good of society.

About Authority and Disability Service Provision

When disability services are funded by government, they are subject to the regulatory requirements for use of public money under the *Queensland Disability Services Act, 2006,* which sets out how services are expected to operate and be accredited. They are also expected to fulfil other legal aspects including incorporation, industrial, privacy, discrimination, health and safety, and tax requirements. These aspects relate to the efficient and effective running of the service and are referred to as service business.

However, disability services are called into people's lives not to do service business, but to meet people's needs. Paid workers are expected to take on very personal and intimate support roles in people's lives, ones that often take them into very private realms. This poses a dilemma. The nature of the work leads to the temptation to move into taking over areas of family business. Yet the typical expectation would be that they would recognise the natural authority of people and their families and be following the same culturally valued norms as for other forms of delegated authority. At the same time, behind the scenes, they would also be attending to the business of service.

In other words, it should be remembered that, just like the mowing contractor, cleaner, landscape gardener and financial advisor, **service workers are given delegated authority to do certain things.** In such instances they would be expected to be helpful or useful within a trusted relationship that negotiates the limit of the authority that is delegated to them, and limited to the responsibility to fulfil that role. This delegation should therefore either come from the person with a disability who has the capacity to do so, or from the natural authority vested in their relationships with committed family members or trusted friends, or if none of these people are involved in the person's life, from an advocate or legally recognised source.

For people involved with Homes West, this natural authority of families and accepted delegation of authority are the keystones of all support, forming an integral part of the relationship between the service and the person and their family. How this happens with Homes West is shown in practical terms in the table which follows. This describes how some aspects clearly remain the business of families and trusted friends and some remain the business of the service, both now and for the future. However there are also many negotiated aspects that are delegated to service workers, as well as other areas where the responsibility for the outcomes is shared. This forms the mutual dance whereby family and service work together in support of the person's life.

The Homes West Experience – Clarity about Authority and Responsibility in Everyday Life

Family Business	The shared dance in between		Service Business
Aspects over which the person, family and trusted friends maintain the authority and responsibility and lead the dance	**Aspects that could be negotiated and delegated to a trusted worker**	**Aspects where responsibility is shared between the person, family and trusted friends and people employed by the service**	**Aspects over which the service maintains the authority and responsibility and leads the dance**
▪ Daring to dream the seemingly impossible ▪ Holding onto the dream about what life could be like ▪ Developing a practical vision of a home of ones own and being an active and valued member of the community ▪ Imagining what a good life would actually look like with and for the person ▪ Ensuring that committed people are there now and into the future ▪ Planning for a financially secure future in a home of their own ▪ Ensuring that support will be there in the future ▪ 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 ▪ Deciding where the person lives and with whom ▪ Naming the nature of supports the person needs ▪ 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 ▪ Allocating supports in ways that reflect the vision for the person's life and well being	▪ Providing aspects of personalised care ▪ Preparing healthy food ▪ Maintaining the person's home, pets and garden ▪ Maintaining personal clothing ▪ Maintaining a fashionable wardrobe ▪ Compiling calendars and diaries ▪ Organising daily activities ▪ Organising daily personal administration, budgeting and travel ▪ Providing transport ▪ Arranging holidays ▪ Supporting other aspects of daily life that are highly relevant to what the person needs the most ▪ Suggesting changes to everyday lifestyle in relation to how supports are arranged	▪ Working in right relationship with one another involving mutual respect, humanness, individuality, honesty, trust, modesty and a sense of 'withness' ▪ Respecting the personal dreams of and for the person as well as their plans, history, values and customs and the vision for their life ▪ Supporting the vision of life as a valued member of the community to become a reality ▪ Ensuring that the person's fundamental needs are met ▪ Ensuring that the person's needs are addressed in a responsive and personally relevant manner ▪ Upholding the customs important to the person's life ▪ Espousing the person's humanity, beauty, talents and gifts ▪ Ensuring positive imagery of the person ▪ Ensuring protection in relation to vulnerabilities ▪ Ensuring safety while carrying out daily tasks ▪ Remaining loyal to the person over time ▪ Defending privacy and integrity	▪ Developing the vision and planning for the organisation and its work through its board ▪ Acknowledging the importance of friends and family in the life of the person ▪ Ensuring processes are family friendly ▪ Working respectfully alongside others building on supports that are already there ▪ Providing the paid support to each person to pursue their unique daily life ▪ Providing support around delegated aspects of daily life so that the person is included in the life of the local community ▪ Knowing each person's situation well and being respectful of their culture of home life ▪ Ensuring relevant and respectful response to each person's aspirations and needs ▪ Thinking creatively about how things can be done rather than putting up barriers to the support of ordinary life ▪ Managing the paid element of a person's life ▪ Managing the work of staff in line with organisational vision and values ▪ Fulfilling expectations that lead to positive outcomes for each person ▪ Maintaining separate individual accounting records of funds received and expended, with allocation to budget available to families or trusted friends ▪ Employing workers ▪ Developing and supporting staff teams ▪ Organising staff development and training ▪ Supervising and appraising staff ▪ Paying wages

▪ Making decisions about health, general nutrition, exercise and well being ▪ Making decisions about personal finances ▪ Having the authority to influence, decide, negotiate, refuse, imagine better, change mind, or counter propose with better ideas ▪ Giving unconditional love and friendship and expecting reciprocity and intimacy ▪ Thinking lovingly, passionately, intuitively and at times irrationally about the person ▪ 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 ▪ Giving time and energy freely ▪ Contributing talents and relationships in pursuit of a good life ▪ 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 events ▪ Advocating on the person's behalf ▪ Guiding the service to interpret the wants and needs of the person ▪ 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	*Family and friends may seek or need support for facilitation of planning external to the service* *The service may become involved in support of family business of:* ▪ *Naming the level of support the person needs* ▪ *Directing resources where they are most wanted and needed* ▪ *Developing a strategy for emergency supports* ▪ *Developing informal relationships and intentional friendships*	▪ Being moral and ethical ▪ Ensuring confidentiality and fidelity ▪ Recruiting support workers ▪ Working as a team ▪ Inducting new support workers ▪ Ensuring that the person is not 'done to' ▪ Supporting living and lifestyle arrangements that are typical and socially inclusive ▪ Ensuring institutional practices are avoided ▪ Encouraging provision of better service ▪ Helping the person to decide what is negotiable and non-negotiable, acceptable and non-acceptable within the culture, beliefs and traditions of family life ▪ Supporting daily life in ways that do not restrict the person to segregated settings with others who have disabilities ▪ Ensuring that no expenses are incurred beyond the capacity to meet payments ▪ Raising issues without fear of retribution ▪ Considering the dismissal of unsuitable support workers ▪ Valuing the involvement of family and friends in the person's life ▪ Supporting hospitality with family and friends ▪ Facilitating connections between formal and informal supports ▪ Understanding that family and friends will at times need to be supported and renewed	▪ Attending to the legal requirements of employing workers ▪ Keeping staff time sheets ▪ Attending to worker entitlements ▪ Maintaining legally required employee records ▪ Paying employer based superannuation contributions ▪ Maintaining public liability and other insurances ▪ Being liable for the actions of employees in accordance with prevailing laws ▪ Receiving public funding as an accredited disability service ▪ Writing organisational policy and procedures ▪ Keeping accurate accounts ▪ Ensuring disability service standards are met ▪ Dealing with bureaucratic expectations of standardised responses, regulations and tedious management processes ▪ Being a buffer between the lives of the people supported and the expectations and demands of funding bureaucracies ▪ Overriding decisions which would place the organisation in breach of its legal obligations ▪ Being efficient and effective ▪ Charging agreed overheads to cover service provision and other bureaucratic and legal requirements ▪ Being accountable for the work done ▪ Ensuring good work ethics and practices ▪ Paying expenses which are specific to meeting the person's support needs ▪ Dealing with complaints ▪ Dealing with dismissal of workers ▪ Arranging formal external evaluation of the service ▪ Participating in government reviews. *The service may write or support families to seek funds via submissions to funding bodies.*

About Working in Right Relationship

People involved with Homes West talk about the need to work in right relationship with one another so that proper authority and responsibility are understood and respected, as well as their delegation. In other words the dance of life is choreographed in partnership with one another with a clear understanding of who leads which parts of the dance and how parts are negotiated and created together.

Michael Kendrick (2005) sees this right relationship as having a shared commitment and ideal, and being achieved only when the following are in place:

- a genuine desire to work together
- an appreciation of each others' strengths and capacity to contribute
- a willingness to have an ethical relationship, both at the level of personal daily interactions, as well as in regards to structures and formal roles.

Families involved with Homes West agree with these ideals.

What families can expect from the service.

Families can expect that the service works in right relationship with them. For right relationship to work they are clear about what they want and do not want from workers:

Wrong relationship is:	Right relationship is:
Absence of ethical relationships: • workers not valuing the person or their family • being neglectful, abusive, or harmful • not ensuring safeguards are in place • divulging private information and breeching confidentiality • being unavailable when needed, not turning up, being inefficient • not doing the work expected of them	**Presence of ethical relationships:** • workers knowing people well • valuing their contribution and remaining loyal to them • taking a genuine interest in the person and understanding their uniqueness • using common sense, being honest and open • applying good work ethics and being reliable and trustworthy
Lack of genuine desire to work together: • workers making decisions alone • making decisions about which they have no authority • using emotional blackmail • promoting self interest or manipulating to get what they want	**A genuine desire to work together:** • workers working respectfully alongside people involved in the person's life • building on the supports, strengths and capacities that are naturally there • having ability to create respectful responses together to meet needs • being willing to work in a team

A lack of appreciation of each others' strengths and capacity to contribute:	**An appreciation of each others' strengths and capacity to contribute:**
• workers overstepping their role and going into areas that are not expected of paid service • being disrespectful, condescending or patronising about the person, their family or their way of life • not listening and ignoring the wishes and concerns of the person and their family • treating people in standardised ways.	• workers supporting no more than the paid service element of a person's life • knowing people well enough to know when to step forward and when to step back • managing service business and protecting people from intrusive bureaucratic processes • supporting and encouraging family members and trusted friends to do their best now and into the future.

What workers can expect from families

In the collaboration process, workers can also expect families to work in right relationship with them. Families therefore are also clear about what workers want and do not want from them:

Wrong relationship is:	**Right relationship is:**
Absence of ethical relationships: • family treating their family member with a disability disrespectfully • putting personal interests first and overriding the welfare of others and the sense of the common good • doing things that could be interpreted as abuse or neglect, eg using the person's finances to serve personal interests, cruelty to the person etc	**Presence of ethical relationships:** • family using common sense, being honest, reliable and trustworthy, and applying good ethics • making the hard decisions about what is non-negotiable, when to compromise, what is possible and what just can't be done • setting negotiated boundaries for authority and its delegation, with a written agreement
Lack of genuine desire to work together: • family imposing personal will without explanation or through intimidation • not being available when greatly needed	**A genuine desire to work together:** • family being reasonable in requests and understanding the consequences of their directions for workers • holding regular meetings with workers and spending time sharing information with them

• giving mixed messages to workers based on family disagreements about what should or shouldn't happen in the person's life • expecting workers to do it all and not be willing to partner in the arrangement • being disrespectful of the worker, not recognising the worker's rights **A lack of appreciation of each others' strengths and capacity to contribute:** • family not giving workers clear information and guidelines about family values, traditions, relationships that are to be preserved • not negotiating about who does what parts of the dance.	• setting the overall values and policy direction of the service to ensure the organisation does the best for people • nurturing organisational spirit and taking a stewardship role, maintaining a willingness to come together to work for the common good of the people and their families • reflecting on how the service is going • reaching out to the broader community to find the next generation of leadership to take over family business and to continue and renew the organisation. • respecting workers' rights **An appreciation of each others' strengths and capacity to contribute:** • family being clear about what is family business and what is service business

These examples of what the people involved with Homes West want and do not want relate to the principles that Michael Kendrick (2000) sets forth about right relationship:

- Relating with people, not at, on or down to them

  By relating with people, both parties are generally viewed as reinforcing the sense of each other as being respected, equal, important, credible and resourceful, and not being involved in an unequal power play.

- Negotiating with people rather than imposing answers upon them

  By negotiating, the person and their family have the chance to respond to and counter the views of others, as well as remind any potential controller of the need to respect their will, personhood and entitlement to determine their own sense of what should be happening with their life.

- Creating mutual and shared ideals of what constitutes right relationship

  The ethos of mutuality sets the expectation that values, goals and priorities are to be developed together. As much of this dance of life with the service is dynamic, expectations can change and need to be worked through and agreed upon.

- Rejecting the theory of ultimate professional or managerial authority over service

  If the service side of the relationship has the final say on important matters affecting life, then it is predictable that the less favoured party, who is the person being assisted, will be subject to domination with the outcome not likely to be in their best interest.

- Relating to each person as unique in how services are designed and operated

  This principle relies on an ethic of supporting one person at a time and permitting ways that give high degrees of flexibility and individualisation at the personal level.

- Leaving the core decisions of a personal nature to the person served or as close as possible to them with people who know them most

  This relates back to the question of personal authority and to matters that are generally recognised as personal and private by most of society. By returning the greatest degree of control of life that may be possible, back to the person and/or those closest to them, this stops the taking over of the business of families which is private or at least very personal.

About the Service as a Buffer against Bureaucracy

As government has moved towards taking greater authority and responsibility for setting and monitoring the quality of community life, its interests and preferences have taken over many matters that have been largely under the control of community, families or citizens (Kendrick, 2002, 2005). Yet, as described earlier, disability services are called into people's lives to meet people's needs, and not to do service business. The core business of supporting life therefore is not about meeting the need of the bureaucracies that organise, govern, regulate and perpetuate the formal service.

The Homes West experience has shown that when the service acts as a buffer between family business and service business, life is focussed on what is needed to live a good life and is much less complicated for all involved. The role of the service as buffer is an integral part of the understanding of right relationship, as it does not allow bureaucratic expectations to regulate how ordinary life is played out, yet the service still fulfils its obligations as a funded, quality assured disability service.

About Areas of Shared Responsibility

The Homes West experience has also mirrored Michael Kendrick's belief (2006) that people who use services to support life can contribute to areas that have often been seen as the realm of service authority in traditional service provision.

These areas have become shared responsibility with Homes West because people and their families:

- are aware of what makes a good workforce
- know whether the service is working well or not
- have a stake in service quality
- can guide the service to what it is or could be
- are able to provide leadership and purpose.

Family members also help to:

- select, supervise and release staff
- induct, train and mentor staff
- clarify what it is that they most need from the service
- build a vision about what is possible and can inspire staff and others to share and implement it
- develop needed innovations.

They also:

- play a key role in evaluating services
- safeguard quality through active advocacy, monitoring and raising awareness
- help to mobilize support for quality service
- are reflective sounding boards for crucial developments
- contribute to family and organisational renewal.

About Right Relationship and Integrity

For right relationship to work, all those involved with the Homes West experience are expected to own the shared responsibility of acting with integrity. This is perhaps the hardest part in working in right relationship, as it involves acting towards one another in ways that demonstrate respect, decency and actual useful service and not be involved in the quest of selfish or narrow self-interest. Such behaviour involves (Kendrick, 2003):

Respect:

- withdrawing from carrying out or supporting any devaluing or degrading practices
- recognising personal shortcomings, ethical lapses, or being a role model for poor or improper practices
- supporting others who are attempting to be good and ethical.

Decency:

- deciding to uphold openness and truthfulness
- remaining loyal to the people being served
- acting as advocates, protectors and champions of the people being served.

Useful service:

- remaining consistently principled
- challenging the organisation to be more faithful to people
- persevering to make a real difference over time.

Maintaining integrity is always complex. As people are people, human frailty will be a constant struggle in the development and provision of personalised service responses.

Such commitment and responsibility may seem quite unattractive to other families who are in search of services that do it all, yet take away all authority and responsibility, often with very detrimental outcomes. For the people involved with Homes West, these principled struggles are worth the effort:

- People with disabilities 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, family members and their trusted, enduring friends have a natural authority and are entitled to influence the direction of a family member'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 personal privacy and security, the development of relationships and intimacy, and 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 to the development of broader networks.
- Families, community and paid support staff 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 together, sharing their skills, experiences and capacities. With collaboration comes a synergy. The whole is greater than the sum of the parts.

To sum up the feeling of the Homes West experience:

> *We feel the costs are more than offset by the satisfaction of putting our efforts into making a real and significant difference to life, rather than having to deal with fighting systems and services that take over and do not come up with the goods.*

References:

People involved with Homes West are indebted to Michael Kendrick who has shared his wisdom with us and many other Queenslanders over many decades.

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